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Exploring the impact of user involvement on health and social care services for cancer in the UK

Final Report

An independent study commissioned by Macmillan Cancer Support

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UNIVERSITY

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Contents

Executive summary

This report presents the findings from a study of cancer network partnership groups in the UK. Cancer network partnership groups are regional organisations set up to enable joint working between people affected by cancer and health professionals, with the aim of improving cancer care.

Background

User involvement in health and social care has become a key policy driver in the UK in recent decades. The primary aim is to ensure that services are patient-centred and take account of patients' and carers' views and preferences. NHS cancer networks, which are partnerships of health service commissioners and providers, the voluntary sector and local authorities, provide the organisational model for delivering cancer services in the UK. Part of their remit is to promote collaborative working between people affected by cancer and health professionals through setting up cancer network partnership groups. Despite the high priority given to the promotion of user involvement in health and social care, however, research has found little direct evidence of its effectiveness.

Aims

The aim of this study was to provide evidence of the impact of user involvement on cancer care, through an evaluation of the activities of cancer network partnership groups in the UK.

Methods

The study employed a mixed-method design, drawing on two main sources of evidence: documentary data produced by the partnership groups, and in-depth case studies of a sample of groups. Lay involvement was central to the conduct of the research.

Key findings

Partnership group aims and priorities

- Cancer network partnership groups aim to improve cancer care by drawing on the experience and knowledge of those affected by the disease, in collaboration with health and social care professionals.

- Although progress has been made towards genuine partnership working between users and health professionals, group priorities are not always driven by people affected by cancer.

The influence of user involvement

- Partnership groups have firmly established a place in the cancer networks for the involvement of people affected by cancer.

- One of the cancer network partnership groups' core functions is to act as a reference group on cancer care issues.

- Networking activities, both formal and informal, are crucial to strengthening the groups' influence on policy and practice.

- The identification of user involvement 'champions' is an essential ingredient of success.

- Increasing user membership in different decision-making forums in the cancer networks is in itself seen as a measure of success.

Improving cancer care

The evidence suggests that cancer network partnership groups have influenced cancer care in a number of ways, including:
- Improving information available to people affected by cancer;

- Enhancing access to care;

- Contributing to health professional training and education;

- Influencing professional attitudes towards user involvement;

- Improving service organisation and delivery, in particular through changes to care environments;

- Monitoring service quality;

- Providing feedback on local, regional and national policy initiatives; and

- Sharing good practice.

There is little evidence, however, of effective user involvement in planning and commissioning cancer care, or of their influence on primary or social care services.

Challenges faced by partnership groups

Cancer network partnership groups face the following challenges:
- User recruitment.

- User representation and inclusion, to represent the diversity of people affected by cancer.

- The provision of effective support for those users who get involved.

- Identifying sustainable funding resources.

- Convincing certain professional groups of the value of user involvement.

- Improving the level of user involvement (that is, moving beyond consultation).

- Widening their influence.

- Monitoring and evaluating user involvement activities.

Recommendations

User recruitment, inclusion and support

- Recruitment campaigns for cancer network partnership groups should use a diversity of strategies including, for example, leaflets, posters in public places, web-based approaches, and personal contacts. It is suggested that facilitators draw on ideas from high profile user groups in other domains, such as mental health, in developing recruitment strategies. Collaboration with non-cancer regional organizations, such as stroke networks, may also be advantageous.

- Recruitment strategies should aim to increase the membership of people affected by cancer not only in the partnership groups but across the network as a whole, for example in site-specific, cross-cutting and locality groups.

- The recruitment of patients currently undergoing or having recently completed treatment has been identified as a problem. It is suggested that frontline health professionals, such as lead cancer nurses or clinical nurse specialists, could play a greater role in recruiting patients as locality user group or partnership group members.

- Particular efforts should be made to recruit members of 'seldom heard' groups, such as members of black and minority ethnic (BME) communities, those living in remote rural areas, and patients who are undergoing or have recently completed treatment. It is important to include people with a range of different cancers wherever possible.

- Different models of involvement will be needed to recruit members of 'seldom heard' communities, such as informal approaches via community organizations. It is important to ensure that interpreters are available where necessary to underpin recruitment efforts.

- Involvement methods should be designed reach a wide constituency, be diverse, and go beyond the traditional patient surveys. It is recommended that they include web-based methods (e mail, web forums, internet chat rooms), post and telephone contacts (for those people without access to the internet), and face-to-face approaches, such as focus groups and open days.

- Additional training and support should be provided for users and professionals involved in partnership groups (over and above Macmillan CancerVOICES

training). User involvement should continue to be an essential component of professional development initiatives.

Monitoring and evaluation

- It is essential that users are provided with feedback about how their input makes a difference to cancer patients and services. It is recommended, therefore, that clear and consistent evaluation methods be put into place across the cancer network partnership groups[1]. This may require additional resources to implement.

Increasing the impact of partnership groups' activities

- It is recommended that partnership groups raise their profile, celebrate their achievements, and share good practice through a variety of promotional and publicity initiatives. These should be designed to target different groups, both lay and professional.

- There is a need to identify reliable sources of funding to strengthen user involvement activities in the cancer networks, and sustain the momentum built up in recent years, in particular to provide training and financial support for users and to fund a dedicated user partnership facilitator wherever possible.

- It is essential to identify user involvement 'champions' amongst health and social care professionals in the cancer networks, in order to drive the groups' agenda forward.

- Partnership groups should aim to broaden their influence on health and social care services for people with cancer – particularly on primary care and social care services - and on the planning and commissioning of cancer care (for example, through increased co-ordination with and representation on network locality groups).

- It is recommended that systems be set up to increase co-ordination between locality user groups (or local patient and carer groups in Scotland and Wales) and regional partnership groups, in order to ensure that group priorities are driven by people affected by cancer. Formal communication systems across all groups within the cancer network should also be established or streamlined.

- It is recommended that partnership groups focus their efforts on a limited number of projects, where they can 'make a difference' and demonstrate that change has occurred. Topics could include, for example:
    - Information resources for cancer survivors;
    - Information prescriptions (providing the local context);
    - Survivorship and post treatment care; and/or
    - Equity of care.

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[1] See the accompanying paper to this report: Cancer network partnership groups: a template for collecting impact data.

1 Introduction

1.1 Introduction and aims

This report summarises the findings of a study of the cancer network partnership groups in the UK, which aimed to provide evidence of their impact on cancer care, and to suggest ways of routinely measuring their contribution to service planning and development.

1.2 Structure of the report

The report is structured as follows:

Section 2: the background and aims of the study.

Section 3: the study methods.

Section 4: the main findings.

Section 5: conclusions and recommendations.

Section 6: key references and appendices.

1.3 Terms used in this report

The term **user involvement** in this study refers to the involvement of people affected by cancer in the planning, organisation and delivery of cancer services. People affected by cancer include patients with cancer, ex-patients, and their informal carers and families, any of whom may wish to contribute their views and experiences to improve cancer care.

Cancer networks are partnerships of health service commissioners and providers, the voluntary sector and local authorities. Typically serving a population of between one and two million people, they provide the organisational model for delivering cancer care policies in the UK.

The **cancer network board** (in Scotland, the regional cancer advisory group) is the body which decides overall strategy for cancer services in the region. Group membership includes key influencers in cancer services, such as commissioners, oncologists, lead consultants, and NHS chief executives.

Cancer network partnership groups are regional organisations set up to enable joint working between people affected by cancer and health professionals, whose aim is to develop more effective patient-centred cancer care. The model is based on the successful Cancer Partnership Project, funded by Macmillan Cancer Support.

Cancer network site-specific groups (also known as tumour-specific groups, disease oriented groups, or managed clinical networks) are bodies which develop clinical and referral guidelines and care pathways, share good practice, implement national guidelines, and carry out network audits of cancer services.

Cancer network cross-cutting groups (also known as regional speciality networks) are set up to develop a specific area of cancer care practice (such as palliative care, oncology, nursing or primary care), to share ideas, and suggest appropriate improvements.

Macmillan Cancer Support is a UK charity working to improve the lives of people affected by cancer by providing practical, medical, emotional and financial support. A core part of Macmillan's work is to support and take part in patient and public involvement. By providing funding and support for cancer network partnership groups and self help and support groups, Macmillan encourages partnership between users of healthcare services, healthcare professionals and carers, to improve cancer care.

2 Background and aims

2.1 *The policy context*

> The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. (Department of Health/Welsh Office, 1995, p6)

The purpose of user involvement in health and social care services is to ensure that they are responsive to patients' needs and wants. Across the UK there is a wide range of policy initiatives that have a direct impact on service development in cancer care and which emphasise the involvement of those affected by cancer. For example, guidance for improving cancer services produced by the National Institute for Health and Clinical Excellence (NICE) recommends that 'mechanisms should be in place to ensure the views of patients and carers are taken into account in developing and evaluating cancer and palliative care services' (NICE, 2004, p7).

The principle of user involvement in health services is now firmly established in UK government policy, placing a statutory obligation on all NHS organisations to involve patients and the public in:

- Planning the services they are responsible for;
- Developing and considering proposals for changes in the way those services are provided; and
- The decisions that will affect the operation of those services (Department of Health, 2003).

In 2006, the Department of Health's consultation document 'A stronger local voice' set out a new framework for consulting and involving patients and the public, the responsibility for which rests with NHS trusts (Department of Health, 2006).

Parallel reforms introduced in Wales and Scotland incorporate a range of public involvement mechanisms, health service planning, and service review exercises (National Assembly for Wales, 2001; Scottish Executive Health Department, 2001).

New local involvement networks (LINks), whose membership includes user-led organisations, local voluntary and community sector organisations and individuals, have been introduced to replace the existing Patient and Public Involvement Forums in NHS trusts. LINks have a range of powers to inform service development; part of their role is to encourage and support users and the public to participate in commissioning health and social care services.

Department of Health policies such as the 'NHS Improvement Plan' emphasise the role that local communities can play in service commissioning (Department of Health, 2004), while the new commissioning framework in the NHS restates the government's intention to develop mechanisms for patients and service users, as well as the general public, to get

involved in shaping commissioning priorities and services (Department of Health, 2007a).

Looking at cancer care in particular, user involvement is also central to service planning and development in the UK. The 'NHS Cancer Plan', a ten year strategy to reorganise cancer services in England (mirrored by similar models in Scotland, Wales and Northern Ireland), includes a framework for involving service users, to ensure that the design of health care respects the diverse needs of patients, their carers and families (Department of Health, 2000). The recent 'Cancer Reform Strategy', which set out plans for cancer services in England for the next five years, also proposes a central role for service users in shaping cancer care (Department of Health, 2007b).

NHS cancer networks, which are partnerships of health service commissioners and providers, the voluntary sector and local authorities, provide the organisational model for delivering cancer services in the UK. Part of their remit is to establish network partnership groups to promote collaborative working between service users and health professionals, and so ensure that service planning takes account of the views of people affected by cancer.

2.2   Review of the literature on user involvement

2.2.1   User involvement in health and social care services

Patient and public involvement in health and social care services has been the subject of a number of research reviews. Viewed overall, however, the evidence on the outcomes of involvement is inconclusive. A Canadian review, for example, examined the international literature linking public involvement and quality health care (Simces et al, 2003). The authors found some evidence of short-term impacts on services, where values identified by the public had been incorporated into recommendations for health care systems. Longer-term impacts were not reported, however, nor were there any objective measures to determine whether lay participation improved the effectiveness or quality of care.

In the UK, a literature review examined the effects of involving patients in the planning and development of health care (Crawford et al, 2002). The review concluded that, while there was evidence that changes to services were made following consultation with service users, the impact of these changes was not evaluated. A later review by the same authors reached similar conclusions (Crawford et al, 2003). While considerable information about the *process* of involvement was obtained through the research, in the main the outcomes of user involvement were unclear or unknown.

An evaluation of the 'Health in Partnership' research programme was more positive in its conclusions (Farrell, 2004). Based on the findings of four studies of primary care trusts, the report states that, from stakeholders' perspectives, public engagement influenced the policies, plans and services of the trusts, and resulted in a better understanding of health care needs and improved health services. One of the main purposes of the research, however, was to explore *methods* of involving service users and the public in decision-

making related to service development; gauging the impact of involvement was less significant.

User involvement in social care services was also the subject of a synthesis of reviews, carried out by the Social Care Institute for Excellence (Carr, 2004). This study explored the impact of the involvement of different groups – such as children and young people, older people, people with learning difficulties, disabled people, and people with mental health problems - on decision-making in social care services. The report concluded that 'there is a lack of research and evaluation on the impact and outcomes of service user participation' (page vi).

Cochrane systematic reviews are internationally recognised as robust and reliable in their assessment of research evidence. In 2006, Nilsen and colleagues carried out a systematic review of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Nilsen et al, 2006). They found moderate quality evidence of its effectiveness in one of those domains – involving consumers in the development of patient information material. The evidence suggests that user involvement produces leaflets that are more relevant to patients, and more readable and understandable.

A recent review examined the literature on the impact of patient and public involvement initiatives on UK health services (Daykin et al, 2007). Little evidence was found of any direct impact on services, although the review suggests there could be social benefits for individuals who get involved. Similarly, a UK review of research on initiatives involving consumers in training and education of health care workers found few studies reporting on the outcomes of user involvement, and no research was unearthed that investigated the effect of consumer engagement on practice (Repper & Breeze, 2007). Only two studies included in the review measured the effect of user involvement on student learning; these found that those students who had user input into their training displayed more empathic understanding of patients and better communication skills.

Overall, therefore, the evidence on the influence of patient and public involvement on the quality of health and social care services is thin; the majority of studies describe the *process* of user involvement, to the neglect of outcomes. While the literature suggests that involving users can contribute to service changes, the precise effects are largely uncharted.

There is some limited evidence, however, that involving users in the design of patient information materials and in professional development initiatives may have beneficial outcomes.

2.2.2   User involvement in cancer services

The perceived benefits of engaging people affected by cancer in the planning, delivery and evaluation of cancer care are wide ranging. Service users are seen as bringing a unique perspective to the task, grounded in their personal experience of the disease (Gray

et al, 1995; Gott et al, 2000). For example, a health care provider in one study explained that:

> …most of the people involved in delivering services don't know what it feels like to be a patient so there's an awful lot you can learn in terms of improving services and making the experiences better, things we wouldn't be able to learn by just thinking about it. (Gott et al, 2000, p8)

Services designed with user input are seen as more responsive, accessible and acceptable to patients, and consequently more efficient (Crawford et al, 2002).

The evidence base underpinning involving people affected by cancer in service redesign and improvement is relatively small, however. In 2007 the Picker Institute carried out an overview of research evidence on the effectiveness of strategies to improve patients' experiences of cancer care (Coulter, 2007). The report concluded that the evidence base for public involvement in service development is relatively weak. None of the studies identified, for example, looked specifically at the impact on the quality of care, while little data were provided on the benefits or costs of involvement.

The Cancer Care Research Centre in Scotland recently completed a major programme of research on the involvement of people affected by cancer in service organisation and delivery (Kearney et al, 2007). A review of the literature categorised most initiatives as 'one-off' involvement exercises, such as focus groups, questionnaires and interviews (Hubbard et al, 2005, 2007). The authors found only a handful of examples of the involvement of people affected by cancer in partnerships with health professionals, outside the structures of the cancer networks. While a number of studies reported a *perception* that the involvement of people affected by cancer had impacted on services, in the main the outcomes evidence is seen as 'anecdotal'. The Research Centre's own studies found that there had been limited progress in establishing partnership working in Scotland, and numerous barriers were identified. The authors concluded that the policy rhetoric of involving and engaging people with cancer in service redesign and improvement was rarely carried through in practice, and that care could be significantly improved if cancer services focused on the overall experience of patients, as well as their disease (Kearney et al, 2007).

With few exceptions, primary studies which address the topic of user involvement in cancer services predominantly focus on the *process* of involvement or its effect on the individuals taking part, rather than its impact on care practice. One study which did evaluate impact looked at the effects of patient participation on the attitudes and skills of undergraduate medical students undergoing interview skills training (Klein et al, 1999). The research found that the group who were taught by cancer patients was better at responding empathetically to patients, showing regard and concern for the patient, and assessing the impact of symptoms on patients' lives.

Two further studies provide evidence of the effects of service users' involvement in training health professionals (Flanagan, 1999; Langton et al, 2003). Flanagan's (1999)

study, which focused on user involvement in the design of educational programmes for cancer nurses, described positive outcomes for all concerned (although these are not specified). Health professionals participating in a similar study described working alongside service users as 'liberating and empowering' and claimed that it 'gave rise to change in individual practice' (Langton et al, 2003, p250). However, such changes are not explored in detail.

A number of studies describe patients' involvement in developing care pathways for specific cancers. For example, in two acute NHS Trusts, focus groups and interviews were conducted with patients, to develop an integrated care pathway for colorectal cancer (Hughes, 2002). A patient perspective sub-group was convened to guide the process. In a similar study, patients were invited to give their opinions on professionally derived standards of care for head and neck cancers (Birchall et al, 2002). As a result, patients' and carers' views were incorporated into regional and national care standards.

More generally, one of the UK's cancer networks was the site of a study of best practice in developing and evaluating user involvement (Tritter et al, 2003, 2004). This included a mapping exercise of the mechanisms of user involvement, the development of a consensus statement on the role and extent of user involvement in cancer services, and case studies in three hospital NHS Trusts. The study also documented users' experiences of involvement and their satisfaction with the process. The results included a 'toolkit' for user involvement, targeted at organisations interested in promoting lay participation in cancer services.

Other research provides evidence of service users working in partnership with health professionals, for example through reference groups. For example, Donaldson and colleagues carried out an evaluation study of the Cancer Genetics Pilots Programme, which included a National User Reference Group (Donaldson et al, 2007). The study describes ways in which users helped to shape local services, for example by improving written information for cancer patients, such as questionnaires and letters. However, the evidence is primarily descriptive in nature, which makes it difficult to assess the extent of users' influence on decision-making.

Few research projects about user involvement in services attempt to follow up on changes in practice. One exception is a study by Rees (2003), which examined lay influence on the services provided by NHS radiotherapy departments. The Clinical Oncology Patient Liaison Group established by the Faculty of Clinical Oncology of the Royal College of Radiologists designed a questionnaire entitled, 'Is your radiotherapy department patient-friendly?' This was circulated to radiology departments across the UK and the results were incorporated into a booklet entitled, 'Making your radiotherapy service more patient friendly'. The booklet was distributed to clinical directors and superintendent radiographers in 57 NHS trusts, who were subsequently asked about changes in practice. It was found that the service areas most affected were waiting facilities for patients; information about treatment; maintaining dignity and privacy; and surveys of patients' views. However, only a minority of trusts attributed such changes to receiving the booklet, and it is likely that there were other influences on practice.

A study by Bate and Robert (2007) examined the involvement of head and neck cancer patients in improving services in a hospital in England. The authors used an NHS cancer clinic to test 'user-centric' organisational development methods. The aim was to demonstrate how efforts to improve services actually bring about change. However, the study found that:

> …staff had for many years been fully aware of the many and long-standing weaknesses and shortcomings of the cancer service and the negative effects these were having on patients' – and their own – experiences. They were even committed (they told us) to doing something about the problems. And yet despite this, they never quite managed to turn the motivation or desire into positive action. Here, it is important to distinguish between commitment, engagement, and mobilization. The first is the equivalent to being committed to climb on the change 'bus', the second to putting it into gear, and the third to actually moving it down the road – the issue of practical action. (Bate & Robert, 2007, p62)

On the basis of current evidence it appears that in only a very few cases has the involvement of people affected by cancer in service redesign and improvement resulted in practical, measurable, action.

2.2.3   Conclusions

Despite the increase in interest and activity in patient and public involvement in health services, and the volume of policy documents devoted to the topic, little evidence of its effectiveness and impact has been produced to date. Researchers comment on the lack of a 'benchmark' from which to measure progress as a result of user involvement in initiatives (Sweeney et al, 2005); moreover, a common theme in the literature is the difficulty in attributing changes to user involvement because services are influenced in many different ways. This is true of health and social services in general, and cancer care in particular.

2.3   The cancer network partnership groups

Cancer network partnership groups aim to promote collaborative working between service users and health professionals, and to ensure that service planning takes account of the views of people affected by cancer.

These aims link closely with one of Macmillan Cancer Support's key strategic objectives, to promote and embed user involvement in Macmillan and its partner organisations, and support partnerships with people affected by cancer. From 2002 to 2004 Macmillan Cancer Support and the Department of Health jointly funded a Cancer Partnership Project to promote user involvement in cancer services, which provided funding to each cancer network to support facilitator posts, together with running costs and support for network partnership groups.

A formal evaluation of the Cancer Partnership Project was carried out in 2004 (Sitzia et al, 2004, 2006; Richardson et al, 2005). This study provided evidence about the value of

user and partnership groups as a mechanism for effective and meaningful user involvement in cancer networks and local cancer services, including their impact on service development. The evaluation found that the majority of people involved felt strongly that the groups were 'making a difference' to local NHS cancer services, for example in designing patient leaflets, 'breaking bad news' policies, improving access to services, and training NHS staff in communication skills. However, the study also illuminated some of the complexities and tensions inherent in the partnership model and suggested that making changes to NHS systems and culture would be a long term undertaking (Sitzia et al, 2006). It was timely therefore to return to the cancer network partnership groups to explore their longer-term impact on cancer services, and to identity ways of monitoring and evaluating their influence.

2.4   Aims of the study

The aim of this study was to provide evidence of the impact of user involvement activities on health and social care services for people with cancer, and to suggest effective and acceptable ways of routinely measuring the contribution of user involvement activities to service improvement. This was carried out through an evaluation of the activities of the cancer network partnership groups in the UK.

2.4.1   Research questions

The study sought to address the following research questions:

What evidence is there for the impact of user involvement activity on health and social care services for cancer across the UK?
- o   What can be defined as an 'impact'?
- o   What can be counted as evidence of impact?

Do user involvement activities influence service improvements?
- o   What might be the direct and indirect mechanisms by which user involvement may exert an influence on services?
- o   Through which organisational routes might user involvement exert an influence on outcomes?

How can the contribution and impact of involvement be routinely captured?
- o   What ways of gathering routine data would be effective?
- o   What ways of gathering routine data would be acceptable?

2.5   Evaluating and monitoring user involvement activities

Evaluating the impact of user involvement activities is not a simple task. User involvement varies according to its purpose, the people involved, the degree of involvement, the methods employed to support this involvement, and the context. The outcomes of involvement can be wide-ranging, from meeting policy targets to improving life chances and opportunities for service users. Time factors also play a part. There can be rapid change, or in contrast, there may be a long time lag before users' views are brought to a decision-making agenda (Brown et al, 2006). Many outcomes will have a 'long horizon', making measurement more challenging (Doel et al, 2007).

The effects of an activity are usually multi-faceted – for example, on participants, on the quality of services, on policy makers or on others involved – and are heavily influenced by context. Simple 'cause and effect' models are unlikely to reflect the complex reality of an activity, and to 'capture' the value and impact of user involvement we believe it is necessary to take a wider perspective.

Much of the discussion in the literature on user involvement looks at what makes for an effective *process*, rather than measuring the outcomes of involvement activities (Rowe & Frewer, 2000). Although process issues are important and cannot be entirely separated out, for the purposes of this study we needed to focus on outcomes and impact. Earl and colleagues (2001) suggest that we should consider 'impact' as a developmental process and aim to capture this through systematic story collection and focused discussion. Rather than thinking about 'impact' they focus on spheres of 'interest, influence and control', identifying those people, groups, and organisations that a strategy or project is aiming to influence. We drew on this approach in designing the methods for this study.

3   Methods

This section of the report describes the study methods.

3.1   Study design

3.1.1   Research methods

A mixed methods design was adopted in this study, focusing on two main sources of evidence. In Phase 1, documentary data produced by the cancer network partnership groups was collated and analysed, and in Phase 2 in-depth case studies were carried out.

For the in-depth case studies the research team visited the sites on two occasions, firstly to carry out face to face interviews with a range of 'core' partnership group members, both lay and professional, and secondly to interview key people involved in cancer care, such as senior clinicians, NHS service managers and voluntary sector managers.

3.1.2   Lay involvement in the study

We were keen to encourage lay involvement in the study. In planning the research, therefore, we carried out informal consultations with the North West Users Research Advisory Group (NWURAG) and a local cancer network partnership group. The research team included lay people, as did the Research Advisory Group convened by Macmillan Cancer Support. The project also drew upon the wider networks of user involvement (described as Research Partners) established within the Cancer Experiences Collaborative (CECo) programme (http://www.ceco.org.uk).

3.1.3   Research ethics

Ethical approval for this study was received from the North West Research Ethics Committee (reference number 08/H1010/38). It was designated as exempt from site-specific assessment. Managerial permission at NHS sites was obtained from the relevant care organisations hosting the partnership groups, in accordance with NHS research governance arrangements.

Because this project involved collaboration with lay people, both as members of the research team and in connection with the partnership groups, it was essential to attend to issues of respect, confidentiality and facilitate access to involvement. In this we followed the principles of good practice set out in INVOLVE's publications (http://www.invo.org.uk/Publications.asp).

In order to preserve the anonymity of study participants as far as possible, case study sites are identified in this report by region. Participants are identified by number, and job titles are used only where it is considered that this will not identify particular individuals.

3.2 Phase 1: documentary sources of evidence

3.2.1 Documentary mapping exercise

An initial mapping exercise was undertaken, in which cancer network partnership group documents available in the public domain were collected. Documents from three groups selected at random were then examined by members of the research team in order to begin developing analytical categories.

3.2.2 Identifying the sample

Five cancer network partnership groups were purposively selected as case studies from five of the six Macmillan regions across the UK (see Figure 1 below), with the exception of Northern Ireland.[2] The aim was to ensure representativeness across the following dimensions:

-Length of time group had been operating (years: 0-2, 2-4, 4+)
-Urban or rural location (geographical factors)
-Population diversity (inclusion of BME populations)

Five further groups were selected from each of the five Macmillan regions (following the exclusion of the case study sites) using a stratified random sampling technique. The random number generator can be found at http://www.randomizer.org/. Documents were therefore collected from 10 partnership groups in all, two from each of the five Macmillan regions studied.

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[2] At the time this study was carried out the Patient and Public Involvement Forum in Northern Ireland was in its early stages of development. It was therefore decided not to include it in the case study sample.

Figure 1: Cancer network partnership groups in the UK by Macmillan region

3.2.3 Data collection strategy

Partnership group documents were collected from a variety of sources, including NHS or cancer network websites, group facilitators and Macmillan information workers. User partnership facilitators were contacted first by e mail, followed up with two telephone calls requesting information. In order to avoid repetition with other studies (e.g. Sitzia et al, 2004; Staley, 2007a) the decision was taken to limit the collection to documents from the year 2005 onwards. It was also decided to include only documents that were produced, or collated and distributed directly by the partnership groups. Documents were collected between February 1st and May 1st 2008.

3.2.4 Documentary evidence

In total 92 documents were gathered from 10 partnership groups, detailed in Figure 2 below. The number of documents collected from each group ranged from none to twenty and the types of documents varied, with minutes of meetings being the most frequent. 'Documents' included workshop and network site specific group meeting feedback forms, job specifications, 'Questions group would like on the patient questionnaire', and a draft user partnership strategy. Documents categorised as 'other' included an online patient experience questionnaire and a communications audit tool.

Figure 2: Documents collected by type
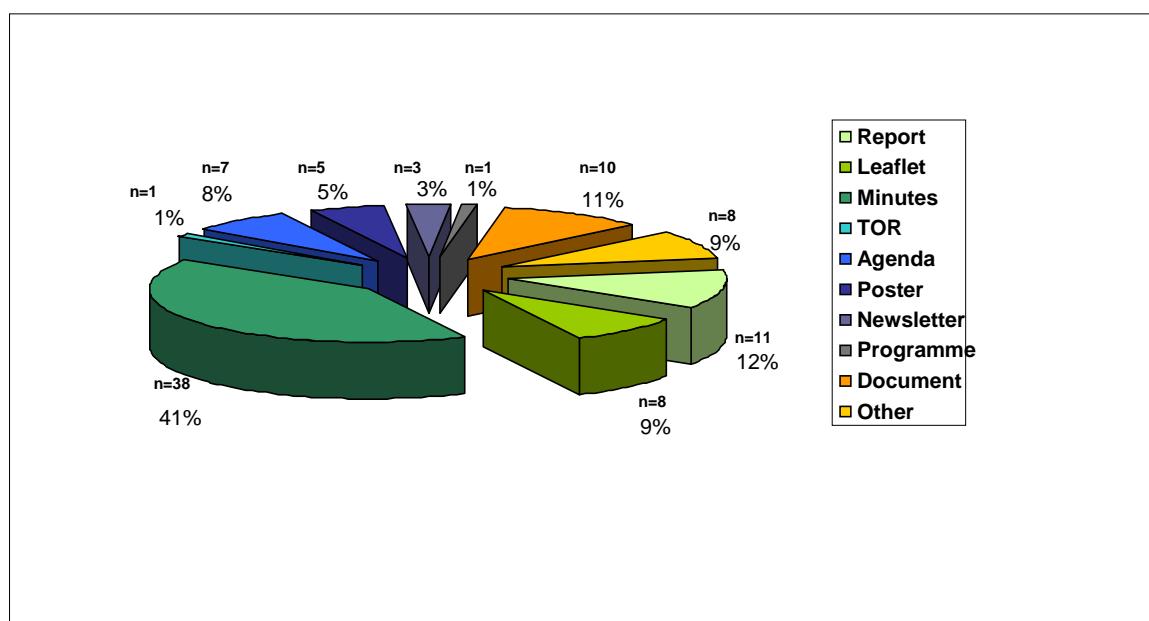
The documents collected were created between 2005 and 2008, with the majority produced in 2007 (n=38, 41%). 12 documents had no clear date of origination; it was decided that these would be collected for analysis as this group included information leaflets and contact lists that appear to be currently in use.

3.2.5 Limitations of documentary evidence

As anticipated, the information available in the public domain was highly variable across the sampled groups. Despite efforts to obtain documents in a variety of ways, the limitations of collecting data remotely also increase the likelihood that documents may have been missed.

It was not only the availability of documents that was an issue for the research team; the *nature* of the written evidence was also problematic. Documents are produced by partnership groups for a variety of purposes, for example to publicise particular events or simply as a record of meetings. They are rarely written for evaluation purposes. As might be anticipated the level of detail varies considerably across sources, and some documents

contain only general statements about groups' activities. As 'stand alone' sources of evidence, therefore, they are inadequate. In the five case study sites, therefore, the evidence provided by the documents was followed up and elaborated upon.

3.2.6   Documentary analysis

Documents were analysed iteratively using standard thematic analysis techniques to identify common issues and themes (Miles & Huberman, 1994). This task was undertaken independently by two researchers; then differences of opinion were discussed by the research team to ensure consistency and rigour.

3.3   *Phase 2: the in-depth case studies*

One case study was drawn from each of the five Macmillan regions; that is Central and South West England, the East Midlands and Northern England, London, Anglia and the South East, Scotland and Wales.

3.3.1   Recruitment of interviewees

We planned to carry out between six and eight interviews in each case study site, firstly with 'core' partnership group members such as the user partnership facilitator and chair person, and secondly with key people involved in cancer care in a position to comment on the impact of the groups on cancer services and/or policy.

Firstly, user partnership facilitators identified by Macmillan Cancer Support were contacted by a member of the research team and provided with an outline of the study (see section 6.2.1 of this report). Arrangements were then made to interview the facilitators, who also negotiated access to the group chairs on the research team's behalf. At the end of this first round of interviews, participants were asked to identify key contacts who could comment on the group's influence on cancer care in their geographical area.

Secondly, potential interviewees involved in cancer care were sent an introductory letter (6.2.2), followed up by a telephone call, to make interview arrangements. Efforts were made to include participants from both primary and secondary care services, together with the voluntary sector (such as hospice staff). It was difficult, however, to identify respondents from primary care who were in a position to comment on the partnership groups' influence, and in a number of cases those who were identified were not readily available for interview. The majority of interviewees in this second round were therefore from secondary, acute cancer services.

3.3.2   The interviews

Interviews took place between 23rd July 2008 and 14th November 2008, and were conducted by the two lay co-researchers and a research associate. All interviewees were provided with an information form about the study (6.2.3) and asked to complete a consent form (6.2.4), in accordance with agreed ethical procedures. Participants were informed that taking part in the research was voluntary, and that any information they provided would be anonymised. They were told that only the research team would have

access to interview transcriptions, which would be password protected and, in accordance with university policy, stored for five years.

Study participants were asked to provide basic demographic details (6.2.5). Checklists were used to guide the interviews and ensure that the most important topics were covered (6.2.6 and 6.2.7). All interviews were tape recorded; permission for this was sought prior to the interview commencing.

Thirteen interviews were carried out with core members of partnership groups, involving 16 people (see Table 1); joint interviews were conducted in two instances (one involving three co-chairs, and one where the facilitator was new in post and accompanied by the lead nurse director).

Table 1: Interviews with core members of partnership groups

Case study site: Macmillan region	**Interviewees**
Central and South West England	User partnership facilitator
	Chair person (service user)
	Ex chair person (service user)
	New lay member (service user)
East Midlands and Northern England	User partnership facilitator
	2 co-chairs (service users)
London, Anglia and South East	User partnership facilitator (new in post)
	Nurse director with lead on user involvement
	3 co-chairs (service users)
Scotland	User partnership facilitator
	Lay representative (service user)
Wales	User partnership facilitator
	Chair person (service user)

The user partnership facilitator was interviewed in all case study locations. A lay chair person alone was interviewed in one site, but in three others more than one lay member was interviewed, mainly because there were co-chairs, or a recent ex-chair person. In one location the chair person was unavailable so a lay representative was interviewed. All 'core' group interviews were conducted face to face.

One person described their ethnicity as African, but all other participants were white. Eight interviewees were female and eight male. The average age of the interviewees was 58 (range: 37-75). The lay interviewees were on average older (61) than the professionals (52).

Following interviews with user partnership facilitators, follow-up questionnaires were issued to record details of the partnership groups' structure and membership (6.2.8). In addition participants were invited to complete a mapping form, in the form of a simple diagram, to identify organizations that they felt that their group had influenced, together with an assessment of the *level* of influence brought to bear (categorized as *strong*

influence, some influence, or no influence). The main purpose of the mapping form was to facilitate the interviews and chart the partnership groups' main areas of influence.

Interviews were then carried out with 24 key stakeholders in cancer care who were in a position to comment on the groups' influence (see Table 2). Of the 24 key stakeholder interviews, 14 were carried out face to face and 10 were conducted by telephone.

Participants were invited to provide any further useful contacts at the end of interviews, in a 'snowball' effect.

Table 2: Interviews with key stakeholders in cancer services

Case study site: Macmillan region	**Interviewees**
Central and South West England	Clinical nurse specialist
	Research associate
	Voluntary services manager
	National Patient Safety Agency representative
East Midlands and Northern England	Cancer Peer Review coordinator
	Oncologist
	Lead cancer nurse
	General practitioner/clinical commissioner
London, Anglia and South East	Citizens' advice bureau manager
	Macmillan development manager
	Two lead cancer nurses
	Macmillan community network development coordinator
Scotland	Senior research fellow
	Cancer information nurse
	General practitioner
	Clinical services manager
	Nurse consultant for cancer/palliative care
	Regional cancer coordinator
Wales	Macmillan development coordinator
	Network director
	Consultant in palliative medicine
	Cancer services manager
	General practitioner and Macmillan GP facilitator

One person described their ethnicity as Asian/Asian British, but all other participants were white. The average age of interviewees in this group was 47 (range: 26-63).

3.3.3   Data analysis

Qualitative evidence from the interviews was thematically analysed in an iterative approach to interpreting data both within and across case study sites. The case studies were analysed individually as well as collectively; however in this report we focus primarily on themes arising across the study sites.

Atlas Ti specialist qualitative analysis software was used to code and categorise the data in ways that allowed for cross referencing. At all stages of analysis care was taken to incorporate lay perspectives and insights.

4   Findings

4.1   *Partnership group models*

4.1.1   Partnership group structures

Cancer networks are large regional organisations, typically serving a population of one to two million people. Partnership groups operate within complex organisational structures, therefore. One case study site, for example, includes two strategic health authorities, six primary care trusts and seven NHS trusts.

User partnership facilitators in the five case study areas were asked to identify the model which best described the organisation of their partnership group, from those outlined in the follow up questionnaire (section 6.2.8). The results are presented in Table 3 below.

Table 3: Partnership group models

Partnership group model	Case study by Macmillan region
Linked, Network locality groups with co-ordinated representation on Cancer Network Board level, or equivalent, Groups	East Midlands and Northern England London, Anglia and South East Scotland
Single Network-level Partnership Group with representation on Cancer Network Board level, or equivalent, Groups	Central and South West England Wales

Although the case study sites in Central and South West England and Wales were described by their user facilitators as 'single network-level partnership groups' it should be noted that they do have a number of linked locality user groups (Central and South West England) or local user groups (Wales) in their areas. Moreover although the cancer networks in Scotland do not have locality groups as such, the partnership groups has links and shared membership with a number of local user groups.

All partnership groups included in the sample had formal terms of reference (for an example see section 6.2.9 of this report). The frequency of group meetings ranged from every six weeks to three months.

4.1.2   Partnership group membership

Lay members of partnership groups include service users (past and present), carers, and family members of people affected by cancer. Health professional representation is multidisciplinary; group members typically include the cancer network director, the nurse director, service improvement leads, cancer service managers, clinical nurse specialists, information officers, lead cancer nurses, charity and voluntary sector representatives, and allied health professionals.

The ratio of service users to health professionals in the groups ranged from one network where service users in the partnership group outnumbered health professionals by a ratio of four to one, to another where there were five professionals for every user member (this case study site had recently lost several user representatives).

4.1.3 Leadership

It is usual for an elected chairperson (typically a service user) to lead the partnership group, with assistance from a user partnership facilitator, or alternatively the role of chair can be shared. In one network the task of chair was shared between three locality user group chairs (all service users), supported by the user partnership facilitator.

It is the user partnership facilitator's role to develop lay involvement across the cancer networks, to work with health professionals, patients and carers to support user involvement at locality and network level. In Central and South West England, for example, in the twelve month period immediately before this study was carried out, the facilitator successfully doubled the membership of one locality user group, set up a new group, and established a young people's group.

Not all case study areas have a dedicated user partnership facilitator, however. In Scotland, for example, the facilitator also manages two clinical networks. Allocating sufficient time to encourage user involvement, over what is a wide geographical area, is challenging therefore.

4.2 Partnership group aims and priorities

4.2.1 Aims of the partnership groups

The actual role is to encourage user involvement with cancer patients, their carers, their families. To actually learn from their experience of cancer as to where service improvements can be made. So it's about influencing change, suggesting ideas for change. (Participant 04)

Partnership groups share common aims; firstly to improve cancer services through drawing on the experience and knowledge of those affected by cancer; and secondly, to increase and widen user engagement in the cancer networks[3]. A lay chairperson explained, for example:

I think it's working with understanding that improvements need to be made. Services aren't necessarily bad, but improvements can be made. And it's working with the healthcare professionals to improve the services for the local area, and the local people, patients, who are being treated there. And it's certainly, I believe, making sure that the sort of patient voice is actually heard. And by patient I do mean carers as well – people who have been affected, or are directly affected

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[3] While this is an expressed aim of the partnership groups as reflected in their terms of reference, it was not the aim of the present study to explore this aspect of their activities. Our primary objective was to examine evidence of the impact of user involvement on health and social care services.

by cancer. So it's very much bringing home to the healthcare professionals that you know they'll be experts in the medical sense, we're experts in terms of having received the treatment and the services. So I see it very much as sort of empowerment to get change. (Participant 13)

Their aims of the cancer network partnership groups can be summarised as follows:

- To embed user partnership working in policy development, service planning and delivery of high quality, patient-centred cancer care across the cancer networks;

- To learn from users' experiences and knowledge of cancer where service improvements can be made, and influence care accordingly;

- To seek active engagement with all organisations involved in delivering care across all aspects of the patients' cancer journey;

- To provide a resource and contact point for health and social care professionals seeking advice from a users' perspective;

- To promote user involvement in all the network groups (for example, tumour-specific or locality user groups); and

- To ensure equality and diversity of membership, encouraging representation from all sectors of the community.

The role of the partnership group is seen as giving clinicians involved in cancer care 'the bigger picture', from users' differing perspectives. A lay chairperson explained the added value of user involvement for health care professionals:

> The way I try to explain it to them is if somebody was asked to take a photograph of the situation, they would all arrive, all dressed identically, and they'd all line up in the same spot to take the photograph. And they would all come out with exactly identical photographs because they are the product of the system. The users are all different. We'd all turn up dressed individually, and we would all stand in different positions, we would take our snapshots, none of them would be exactly the same. (Participant 01)

Whether group priorities should be primarily strategic or operational was often the subject of discussion amongst study participants. A senior health professional in Scotland, for example, emphasised the need for the partnership group to shape cancer care developments at a strategic level regionally, rather than deal with 'small issues on the frontline'. At the same time it was recognised that user members often need 'quick wins', where they can see that they have made a difference for patients, in order to maintain their interest and enthusiasm. In response, some partnership groups have set up implementation groups to take forward specific areas of work, such as patient information or hospital transport.

4.2.2 Deciding on group priorities

How cancer network partnership group priorities are decided is obviously important. The majority of sites in this study produced a yearly action plan or work programme to guide their activities. Opinions were divided, however, about whether priorities for action were driven by professionals or service users. In Scotland, a cancer information nurse said that priorities emerged from the 'wealth of knowledge' held by those affected by cancer – which helped to shape the group's work plans. From this perspective, partnership groups provide users with a platform for getting their views, experiences and opinions across to professionals. It is also common for groups to be approached by health professionals seeking a user perspective on aspects of cancer care or policy. A number of service users in the partnership groups are also members of cancer network site-specific groups, cross-cutting groups and locality user groups, so there is some cross-pollination of ideas.

Participants from Central and South West England, East Midlands and Northern England, and London, Anglia and the South East regions argued, however, that the process of deciding what groups get involved in tends to be driven from the 'top-down', with the overall direction prescribed by official policies such as the 'Cancer Reform Strategy' (Department of Health, 2007b). From this perspective users are able only to 'tamper at the edges' of group policy, rather than initiating it; as a user partnership facilitator based in Wales said:

> … if I'm honest I think it [the partnership group] is primarily responding to the [network's] agenda, yes. We would like it to be… you know the balance to be a bit more level and probably would like to be creating the agenda a little bit more. But if I'm honest at the moment I would say we're… the main role is consultative really I think - people coming to us for our views on proposed developments and changes. (Participant 20)

However, a user partnership facilitator from the Central and South West England region claimed that within-group decision-making is a more even-handed process in that area.

> Well generally speaking the priorities are decided… basically it's a round table decision. It's a very democratic process. It's not one person saying, 'I want something done about this.' It's about saying, 'Well okay what can we do about it? How can we, you know, sort of take this to the right people so that you know things can be influenced?' So generally speaking it's at the meetings that things are decided. (Participant 04)

Similarly, in the London, Anglia and the South East region, there was evidence of a two-way dialogue between users and health professionals.

> I think you know my perspective is that our partnership groups are there for us to work together. It's not sort of the users and the health professionals – we're working as a body with some of the agenda coming from us, and some of the agenda coming from the users in the group in terms of the direction that those groups are going to go. We will bring… health professionals … we'll bring either

national or local issues that we have, you know that we're sort of trying to work around, to the groups to see if they can help us with some of that. Some of that might be around workforce, some of that might be around services that we are either wanting to expand or redesign. And from the users' perspective they may want to bring things back to us that they feel as health professionals we need to be focusing on. And some of that might be local, or it may be quite generic. (Participant 16)

While in a number of instances partnership groups were seen to be responding to the network's agenda, and policies which are 'set nationally', a cancer manager in Wales reported that there were signs of change.

(Interviewer) Do you see them [partnership group] as having had a primarily agenda setting role or mainly reacting to the agenda that the trust and service providers set?

(Interviewee) Probably reactive, but I think their role is slightly changing now to be more kind of… more decision making at the beginning, so that they will inform policy making rather than just respond to the policies that have been directed. So I see that changing. (Participant 22)

This was not a view held by everyone taking part in the study, however. Providing an alternative perspective, a cancer network director stated:

I think where the user group is most influential is where they have been given a topic by the health service, rather than one they have created. Where we work well is where the topics are hotter, mutually hot. (Participant 24)

From the evidence of this study, therefore, the extent to which partnership group priorities are currently driven by service users remains open to question.

4.2.3 Drawing on patient experience

Engaging with people affected by cancer to draw on their experiences when setting priorities and developing local services is a key element of a partnership approach to service improvement. (Kearney et al, 2007, p16)

Patient experience is central to the work of the partnership groups. Emphasising not only the practical but also the social and emotional issues around cancer care, it is seen as a valuable asset for the development of patient-centred services. A cancer service manager, for example, explained the importance of capturing patients' views on how it feels to be on the receiving end of services.

I mean one area I'm quite keen on in the longer term is having, not an expert patient… but what tends to happen when we've talked to patients is they want to talk to other patients and get a view about… because we can say chemotherapy will do this, this, and this, but we can't actually say what it feels like. So I think

that one area that they can do is give that 'I know what it's like because…' and sharing that. (Participant 22)

Patients' knowledge and experience of cancer can be used to inform health professionals about the impact of the disease on their lives. An example provided by a cancer information nurse based in Scotland illustrates this point.

I was doing some work for Scotland's 'Health at Work' and it was for employers and it was round melanoma and sun protection and things like that. And a patient came along and spoke and gave his…what it was like for him being diagnosed with melanoma and how it affected his life, and it was great and it was so well evaluated and it was so interesting. But it wasn't a gripe; do you know what I mean? It was just saying how things affected him, how not being able to get life insurance, no longer being able to play football; it just made it very human, and I think there's a big place for that. (Participant 29)

As well as drawing on the personal experiences of their lay members, partnership groups use different ways of capturing patients' views, such as surveys, conferences, website forums, and diaries. In the East Midlands and Northern England region, for example, a sub group has been set up to help devise a patient experience survey, with the aim of contributing to a national survey currently under development by the Cancer Action Team (as a requirement of the UK government's 'Cancer Reform Strategy'). It is common for group members to be approached by health professionals for advice on the design of patient surveys, as a consultant in Wales explained:

…we've used them as a group to sort of test out what they feel about patient satisfaction surveys. And they've given us feedback and comment on how we can improve them or get the most out of them, so that when they have gone out to patients and we've had them returned, they've actually made a positive impact on services. (Participant 21)

There are a number of user partnership initiatives that have a wider influence, with the potential for adoption on a national scale. For example, a group from the Central and South West England region designed a patient diary, which originated from listening to cancer patients. This was described by the user partnership facilitator as:

…a journal almost, so that they can put in appointment times, they can put in their feelings, they can put in questions that they may want to ask at their next appointment… it's full of really useful, practical information. Lots of contact details for all sorts of different advisory bodies…where they can get information. (Participant 04)

The patient diary has been piloted across the network, and received positive feedback from patients and their families.

4.3 Views on the influence of the partnership groups

This section of the report details the organisations and people involved in cancer care that partnership groups feel they have influenced, and traces the main pathways through which this influence is brought about. To set the scene, we first discuss some of the problems inherent in evaluating the impact of the groups' activities.

4.3.1 Evaluating impact

Participants identified certain problems in evaluating the impact of user involvement on cancer services. A user partnership facilitator in Wales stated, for example:

> … it's quite difficult to evaluate what we've done, because…the main role of the group is one of consultation really. So it's very difficult to come out with specific things and say, well this is what we've done. (Participant 20)

The facilitator explained that feedback to the partnership group about changes resulting from their activities is often poor. When users work on patient information leaflets, for example, their contribution is not always clear. This point was echoed by a lead cancer nurse from the case study site in the London, Anglia and South East region.

Service delivery is a complex issue and change can occur over a long period of time, adding to the difficulty of evaluation. Furthermore, some group outcomes, such as changes in professional attitudes, are subtle and intangible, and not easily monitored. A lay co-chair in the London, Anglia and South East region, for example, said of the group's activities, 'I don't know that there's been any obvious outcome so far that one can measure.'

One of the problems in identifying successful outcomes is that groups do not operate in isolation – they are part and parcel of a complex system of user involvement across the cancer networks. Moreover, individual patients or carers are often engaged in different capacities (for example, in site-specific or locality user groups) and do not distinguish between their different activities, subsuming everything under the general heading of 'user involvement'. This 'blurring of the boundaries' makes identifying outcomes difficult; thus study participants frequently struggled to provide specific examples of impact.

The evidence from this study suggests that there is little consistency in the partnership groups' methods of monitoring their activities. While a number of groups produce annual reports and/or funding applications which highlight their successes, no standard reporting format currently exists.

4.3.2 Organisations and people influenced by the partnership groups

Partnership group 'core' members, such as user partnership facilitators and group chairs, were asked to map the organisations and people which they felt their activities had impacted on, and to assign a level of influence as 'strong', 'some' or 'none'(see Appendix 6.2.10 for a sample mapping form). This exercise provided the research team with a sense of the main networking activities of the groups which facilitated their

influence on cancer services. The following organisations and people are those which group members consider they have a 'strong' or 'some' influence upon.

Local level
- Acute sector/local hospital trusts
- Locality user groups/local patient and public involvement groups
- Network locality groups
- Specialist cancer and palliative care centres
- Lead cancer clinicians, managers and nurses
- Higher education institutions
- Voluntary or 'third' sector organisations (Citizens' advice bureau, Macmillan Cancer Support, Cancer Backup (a charity now merged with Macmillan), Help the Aged, Age Concern)
- Patient and carer support groups
- Hospice staff
- Allied health professionals
- Information officers
- Patient Advice and Liaison Service (PALS) and Local Involvement Networks (LINks)
- Community Health Councils (Wales)
- Patients and the public (through open meetings)

Network and regional level
- Cancer network board
- Network site-specific groups
- Network cross-cutting groups
- Macmillan development co-ordinator
- Regional cancer advisory group and cancer co-ordinator (Scotland)
- Cancer care research centre (Scotland)

National level
- National Cancer Peer Review (England)
- Cancer Services Coordinating Group (Wales)
- Scottish Cancer Group (Scottish Executive)
- NHS Quality Improvement Scotland
- Cancer Action Team (England)
- Cancer policies/strategies
- Continuing professional development

Organisations which were categorised as difficult to influence included the Royal Colleges, the Department of Health, the British Medical Association, and commissioning bodies.

Evidence on the partnership groups' influence on primary care is mixed. Although primary care organisations featured on the majority of mapping forms completed by core group members categorised as 'strong' or 'some' influence, few concrete examples were provided of the groups' impact. A number of participants said that their current engagement with primary care services was limited, but that it was planned to develop it in the future. A lead cancer nurse from the London, Anglia and South East region explained, for example:

> … I think that's around the PCTs as well. They [partnership group] need to work with them, because it's not just about the acute trusts doing all of the work in this. I think the PCTs, you know that's where patients spend most of their time. We're only there for the very acute sort of episodes now. And I think that's probably where it needs much more of a drive. That it's not seen as something that is driven by the acute sector, it's something that's… you know user partnership is across the whole locality. And I think that – maybe again I'm maybe speaking just for our locality more than others – but I think the PCTs need to be… that's a big area of influence there. (Participant 16)

In Wales, a senior health professional argued that cancer care is primarily the concern of acute services, suggesting that influencing primary care is not a priority for the group. However, another respondent, who is employed as a Macmillan GP facilitator, was more optimistic about the potential of the partnership groups to impact on GPs' practice, particularly in the field of palliative care.

The situation in Scotland is slightly different, because direct links with the cross-cutting primary care network, coupled with community health partnerships (which include primary care and social services), provide a conduit for the exchange of ideas about cancer care. The partnership group recently invited the primary care network to identify specific work strands for them to take forward, so some progress is being made in this area. Even so, there is a perception amongst stakeholders that primary care is difficult to influence, as the regional cancer co-ordinator for the Scottish case study site pointed out:

> …interestingly a lot of the things that came up through the world café event and a lot of the things the group members have expressed an interest in sit very comfortably in primary care, yet of all the groups that when we were looking for people to get involved with different things, that was the one group that they didn't think that would actually have the influence to make it happen. (Participant 27)

It was also observed that the sheer size and complexity of regional cancer networks (which can include as many as five hundred GP practices) can make it very difficult to impact on primary care.

In the main, the evidence suggests that social care organisations are currently outside the partnership groups' sphere of influence, although some participants saw this as presenting an opportunity for the future.

> I think the greatest opportunity, and possibly one of the greatest challenges as well, is working with the social sector, through the LINks organisations, because that's going to be the way to go for user involvement. It's not going to be disease specific anymore; it's going to be user involvement where service users have a voice throughout the whole of the NHS and social care services. (Participant 04)

Other commentators, argued, however, that influencing NHS services should remain the groups' key priority.

4.3.3   Pathways of influence

The pathways through which user partnerships can influence cancer care are complex, as group members network with a host of different committees and other bodies, both formal and informal. Within the cancer networks, for example, the majority of cancer planning groups, such as site-specific groups, cross-cutting groups and the cancer network board, have patient representation. Ideally, user involvement in different parts of the networks can help to encourage cross-fertilisation of ideas, and strengthen users' influence on service development.

4.3.3.1 Formal networks

In the majority of case study sites there are clear links between locality user groups and the cancer network partnership group, including shared membership (in Scotland and Wales although there are no locality groups as such, local user groups serve a similar purpose). In the East Midlands and Northern England case study site, locality and partnership group members share an annual 'away day' to discuss priorities for cancer care. Issues identified at a local level by people affected by cancer can therefore be fed directly into the partnership groups' agenda. For example:

> … one of the local groups carried out a survey in the local hospital about what they thought of the local service and of the support they received at the hospital. Now I haven't seen the final findings of that, but that's an example of where they might be able to identify gaps or deficiencies in the service, as well as you know good practice as well. And they're just piloting what seems like a bigger version of that across the network to work with…Participant 15)

In the case study site in London, Anglia and the South East region, for example, three locality user group chairs share the role of chair in the partnership group. However, coordinated working between the regional partnership groups and local groups is more developed in some cancer networks than others. In the Scottish case study site, for example, although each health board has a local user partnership group, links between local and regional user forums are not yet fully established.

User representation on key cancer network bodies, such as site-specific and cross-cutting groups, is seen as of strategic importance. The role of network site-specific groups is to develop clinical and referral guidelines and care pathways, to share good practice, to implement 'Improving Outcomes Guidance' and carry out network audits. Cross-cutting groups are set up to develop a specific area of cancer care practice, to share ideas and suggest appropriate improvements. In some areas users are also represented on network locality groups (distinct from locality *user* groups), in which senior professionals from primary care, local hospital trusts and the voluntary sector meet to strategically plan service development and review performance in their sector.

Representation on local and network-level groups is therefore seen as an important way for patients to improve cancer care, particularly where there is shared membership with the partnership group. From this viewpoint, increasing user membership of the network site-specific, cross-cutting and locality groups is in itself a measure of success.

In addition, a number of partnership groups have set up sub-groups to take forward specific work streams, such as patient experience, information, training and recruitment. In Wales a 'core group' has been formed to provide a forum for debate on hot topics – an arrangement that seems to work well.

Partnership groups work across the health care sector, particularly with service improvement organisations. Professional members of the group, including for example the network director, the nurse director, and the service improvement lead, provide a direct link for communicating users' views to other organisations involved in cancer care. Lead cancer nurses and user partnership facilitators are seen as providing continuity and support, both for partnership groups and locality user groups. Respondents stress the importance of professional commitment to the user involvement agenda in driving it forward and increasing the groups' influence.

Partnership groups therefore provide a forum for productive relationships with key people in the cancer networks. Importantly, they fulfil a consultative function for health professionals who need a 'user perspective', for example on improving patient information. For example a user partnership facilitator explained:

> …they [health professionals] may actually come to us and say, 'Well you know we need help with improving outcomes guidance on skin cancer', and they will call for volunteers for that. Or they may say as a network we have to get involved more strongly with 'End of Life' strategy, because that's their remit from on high. But again they have to get the user involvement around that as well, so they will call for volunteers. So it's really give and take. (Participant 04)

Going beyond consultation, in some cases professionals are now seen as actively seeking user input into decision-making. A regional cancer co-ordinator argued that:

> …even if I just look back to where our own clinicians within our tumour specific networks started, and it was kind of, 'Um yes, user involvement, we'll have

somebody sat in the group.' I would say that's changed quite markedly from them now saying, 'Well we need to be thinking about, and we need to be going to the partnership group.' (Participant 27)

The cancer network board (or, in Scotland, the regional cancer advisory group) is the body which decides overall strategy for cancer services. Group membership includes key influencers in cancer services, such as commissioners, oncologists, lead consultants, and chief executives. User involvement in this group is therefore of great consequence. In the East Midlands and Northern England network, for example, two partnership group members attend board meetings (a typical arrangement). This provides them with perspectives from other parts of the network, which one respondent suggested, 'ties up the great kind of spider's web of where people belong in a network structure. You know suddenly you're doing joined up healthcare.' In some areas users feel they have become a recognised and valued part of the network board; as a lay chairperson explained:

> … there's one area we have had, the network board. We [user members] started to attend the network board as… more or less as observers, because we were all beginners and didn't know what was going on. And finally after… oh after about four meetings I got them to give us our own spot. So we have an agenda item which is the user group, and we tell them what we've been achieving … and I say that's a recognised part of the agenda now. So we've had some success there. (Participant 03)

Of course, having a spot on the agenda at meetings does not necessarily translate into involvement in decision-making about services. A group co-chair said, for example:

> I feel that I'm very well listened to most of the time, in most of the groups... But I certainly think... I think I'm quite… I don't know whether powerful is the right word to say… yes, a powerful member of the group. People listen to and respond to what I say. Whether that gets translated for me more than for other people in terms of the outcomes, like the decisions that are made or the actions that's taken, it's very difficult…(Participant 35)

Partnership groups also network with patient organisations and the voluntary sector, in order to broaden their sphere of influence, The Central and South West England case study group works closely with PALS, for example, so, although the group do not see themselves as providing a complaints service, if a problem repeatedly arises for patients it will be taken up with the local cancer service improvement team. The same group is involved in setting up the LINks in their area, with a view to influencing social care. Approaches for help from cancer support groups and other patient support organisations are also common. For example, a user partnership facilitator said:

> … I think word is getting out, even beyond cancer services. For instance last week I was approached by the Asbestos Support Group, because they had put together some information which they wanted obviously to go out to the general public, to raise awareness of this particular support group. And they'd heard … that we

actually were good at reviewing information and would I therefore have a look at their information leaflet and make suggestion and comment. (Participant 04)

In London, Anglia and the South East, the partnership group has worked closely with the Citizen's Advice Bureau in a Macmillan funded project (described later in this report).

At a national level, partnership groups aim to influence cancer policy and healthcare workforce development. In Wales, user members of the partnership group are represented on the Cancer Services Co-ordinating Group Patient Forum, which is an advisory body to the Welsh Assembly. In Scotland the case study group has links with the Scottish Cancer Group, and a member sits on the National Education Scotland Advisory Group, which develops educational programmes for the health care workforce. A number of lay members in the English partnership groups take part in the National Cancer Peer Review programme.

Figure 3 below describes some of the partnership groups' main pathways of influence, in a somewhat simplified format.

Figure 3: Partnership groups' pathways of influence
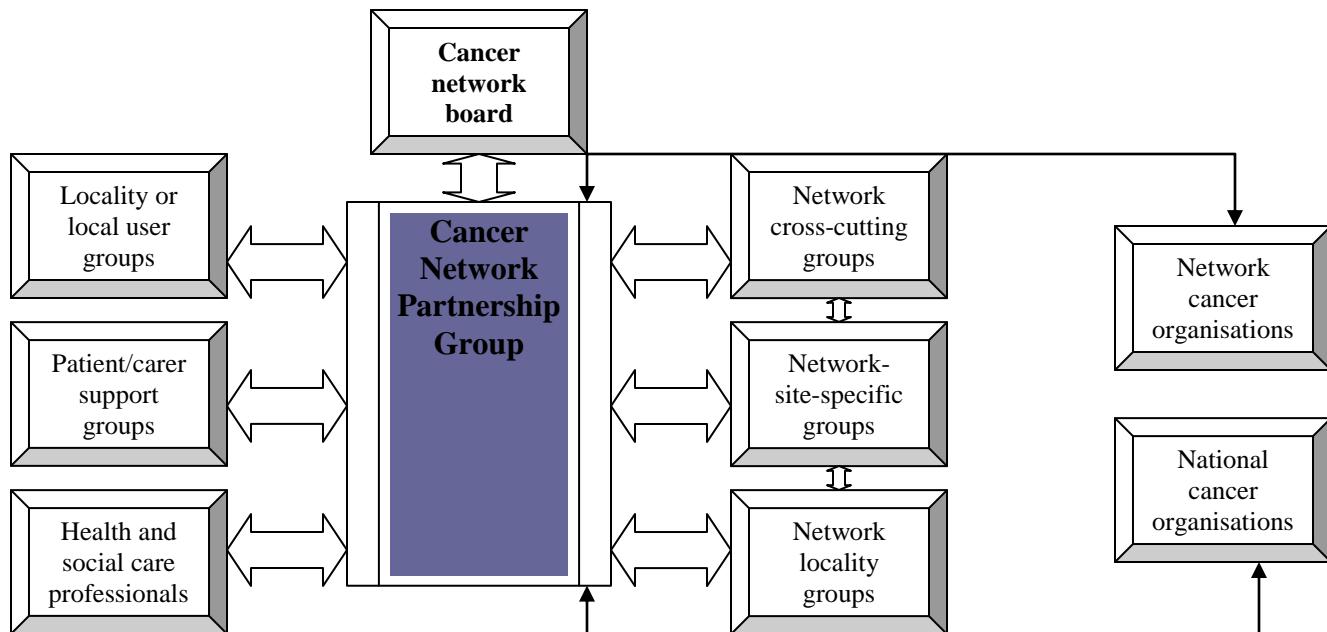
4.3.3.2 Informal networks

Partnership groups are also nurturing less formal connections with patients and the public. For example, in Scotland the group held a world café event to explore people's perceptions of good quality cancer services. A lay chairperson from the Central and South West England region stressed the value of such approaches to 'seldom heard' or 'emerging' communities (such as BME or Eastern European groups):

…we have made contact with an Asian women's group. And they said they'd like us to go in at some point. Now if a nurse goes in and starts talking to them about breast cancer, and breast checks, and cervical screening, and so on, it's not going to have the same effect as us sitting there having a cup of tea and a chat and talking about these things. Because we're not talking as professionals, we're talking as women to women. And it's going to have more of an impact on them. (Participant 01)

Through links with a local further education college, the same case study site has recently set up a group for young people, who have had cancer themselves or experienced a member of their family with cancer. An immediate aim is to produce a carers' guide written in language that is meaningful to young people, while in the longer term it is hoped to set up similar groups across the network.

The evidence from this study suggests that informal networking has potential benefits for partnership groups in three main areas. Firstly, community networking initiatives provide a wider public perspective on which to base group priorities. Secondly, they serve a public health purpose, informing people about cancer risks. Informal approaches to minority ethnic communities, for example, may be useful to overcome social and cultural barriers to health screening.

Finally, building community links helps to raise the profile of the partnership groups and encourage new people to get actively involved.

4.4 Improving cancer care

Improving cancer care through partnership working is central to the groups' aims. Users' contributions can range from improving patient information leaflets to training a new generation of health professionals. In this section of the report we examine the range of activities carried out by the partnership groups, and focus on those areas where the evidence suggests they may be making an impact.

4.4.1 The impact on patients

4.4.1.1 Patient information

The 'Cancer Reform Strategy' identified the issue of patient information as the highest priority, as good information is a prerequisite for patients to be able to participate in decision-making about their care (Department of Health, 2007b). Improving the type and quality of information available to cancer patients is a domain where partnership groups can have a visible impact. Groups typically contribute to new information resources for patients and carers (including web-based sources), and identify gaps in information pathways. For example:

> We do sit down and look at the cancer pathway. And some of us are involved in different teams, and we can say 'Hang on a minute, don't we need a piece of information at this juncture of this patient's journey? Are you going to let the

patient leave this hospital without them knowing what happens next in their treatment?' 'Oh', says somebody, 'Of course, never thought about it like that.' So we have the power to fill the gaps of saying, 'Hang on a minute, I'm the patient.' (Participant 34)

A lay representative from the Central and South West England region explained the importance of this issue for patients.

> I think from the patients' point of view most people would say that it's the provision of information in a timely and logical fashion that people cry out for. And it's not… it's an easy request … I'm not criticising the delivery particularly, but it's obviously a cri de coeur. (Participant 02)

Requests for help with leaflet design, for example, come from both health professionals and patient support groups; moreover partnership group members work closely with cancer network information officers. Because the case studies and documentary sources describe numerous instances of this type of initiative, this report provides just a few examples.

In Wales the partnership group was involved in designing a cancer information centre in a specialist cancer unit. A consultant in palliative medicine explained that:

> …one of the pieces of information that we were fed back to as a senior management team at this hospital was that actually patients had difficulty accessing information. We thought we had… we'd got it wrapped up. We'd got lots of leaflets, but they were all in sort of odd places. It's all a bit higgledy-piggledy. And then patients sometimes when they pick up a leaflet, well they might actually want to check something out with somebody rather than just be left holding a leaflet. And that's driven the development of our… you know a cancer information centre that's been built on site. (Participant 21)

Members of this group also helped to design a booklet for patients finishing a course of treatment, signposting them to sources of information and support. This was then shared with other trusts in the network, as the facilitator noted:

> As a particular example there was the X trust actually worked with some of the members of the group to develop a booklet for people that were finishing a course of treatment, sort of signposting them to sources of information and support. And I think the group, some members of the group, felt you know that was a very nice bit of information that should be being used in other areas as well. So we've now tried to make sure that the other trusts are using that piece of information. (Participant 20)

Helping people to meet the costs of cancer was identified as a priority in the 'Cancer Reform Strategy', as research has indicated that the majority are not aware of the help available (Department of Health, 2007b). A key initiative in the London, Anglia and South East region was a joint venture between the Citizen's Advice Bureau (CAB) and

Macmillan. A 'cost of cancer' event hosted by the user partnership identified the provision of financial advice, such as entitlement to welfare benefits, as a major concern for cancer patients. As a result, Macmillan Cancer Support agreed to fund CAB advisors and support workers to provide outreach welfare rights services at hospital-based clinics, to help people claim their full entitlement to benefits to offset the costs of cancer. Service users are involved in a steering group which periodically reviews the service, and to date the feedback from patients has been very positive.

In the same region, the partnership group has developed patient hand-held records, which hold contact details of key staff and services, treatment records, and space for recording when, how, and where information has been offered to a patient. There is also room for patients to add personal information as they wish.

In Scotland, group members were involved in a review of tumour-specific patient information booklets, in collaboration with Cancer Backup (a cancer charity). This type of project is seen by health professionals as important to group morale, because users can see they have 'made a difference' to patients in a tangible way.

> …patient information materials…tumour-specific materials…we're at a period where we're reviewing them just now, and through the partnership group that was one thing…because they're keen to be involved in…the tangible bits of work you know… because the strategy work can take a long time to actually make a difference. So they're keen to be involved in project pieces of work where they can actually, they do see a difference. (Participant 27)

In the East Midlands and Northern England region, a sub group was recently set up to check new patient information for content, jargon, comprehension levels and plain English. Members also contribute to ensuring that patients, in the words of their co-chair, have 'enough information for them to cope with living with their disease and their treatment' at each stage, from initial screening through to end of life and palliative care. The group developed a document called 'Questions patients ask', used by health professionals to develop information pathways for patients at different stages of their cancer journey.

Group members view this aspect of their work as a significant success, in terms of improvements in the type and quality of information available to people affected by cancer. It may be, however, that the focus on this type of 'easy win' is at the expense of the wider, more strategic role of the partnership groups.

4.4.1.2 Improving access to services

Improving access to cancer services plays a key role in the partnership groups' activities, particularly in networks with large rural populations, such as Scotland, Wales, and the East Midlands and Northern England regions. Transport is a key concern for patients, and one on which groups have led successful campaigns. A group in Wales, for example, lobbied the Health Commission to protest at the need for patients to travel long distances for PET-CT scanning, and were successful in negotiating access to treatment closer to

home. When a new gastrointestinal cancer service was planned the group again highlighted patients' concerns, as a cancer manager described:

> What was interesting is you could say, yes we've got the surgeons, the HDU beds, the pre-op assessment, but they [service users] came from a different perspective and said, 'Right, what's the bus service like?' And that is… you know you may think we've got this wonderful service, but if actually relatives can't visit their loved ones then is that a quality service, even if you can provide everything else? So they came from that perspective and asked difficult questions. (Participant 22)

Similarly, in the East Midlands and Northern England region, a partnership group was involved in the reconfiguration of medical oncology services, ensuring that patients' priorities were at the forefront of planning.

> …this was a commissioning issue where we wanted to, from the affordability point of view we needed to reduce provision at two hospitals… to one hospital and how we were going to do that was going to be very difficult. At the end of the day, the user, the lobby from the user group stopped the pendulum swinging too far the other way to there being no service at all. (Participant 40)

The question of whether care should be provided in local communities or in large, centralised facilities is not a straightforward one, however. It was argued that patients value the *quality* of the treatment on offer, as well as its accessibility, so closeness to home was not the only important consideration in service planning.

> I think the other agenda that they [partnership group]… certainly from the cancer services perspective they've pushed forward, is around correcting misperceptions of what the patient view might be. Because some… I've been in board meetings where the patient view has been put along the lines of, 'Well we know that patients all want services to be provided at their local hospital, and they don't want services to be moved elsewhere'. When in fact what the patient group had said to us, well… particularly when we were looking at reconfiguring surgical services, was that the patients were actually quite prepared to travel for treatment so long as they knew the treatment that they were getting at the end of their journey was of a very high quality. (Participant 21)

Good access to care for cancer patients is not only about improving transport facilities or campaigning for local services. Importantly, user partnerships have worked to enhance access to 'out of hours' care for patients. For example, a consultant in palliative medicine detailed the impact of one partnership group initiative:

> … [the group members] were around improving hands on care at home, but also ensuring that patients and carers had access to advice and support 24 hours a day. Because whilst they appreciated the role of specialist services, I think they… you know they raised the profile of the fact that the majority of the working week is outside normal working hours. So the sorts of services that they didn't find

effective or helpful were ones where there was a sense of the drawbridge coming down at nine o'clock in the morning and then being pulled up tight shut at five o'clock. So I think they were quite proactive in pushing that agenda forward. (Participant 21)

4.4.1.3 Improving patient/professional communication

…communication is always a problem. If you ask any patient it's about you know, 'Well he [health professional] didn't tell me', or 'They didn't do it this way', or 'We didn't think he was particularly sympathetic', or 'She said this instead of that'. And it's always a huge, huge issue. (Participant 04)

The problem of ineffective face-to-face communication between health professionals and patients was raised by a number of study participants (and was also identified as a priority in the 'Cancer Reform Strategy'). For example, one service user said of some hospital consultants that they were 'very good with a knife, but not very good with a person', while another respondent claimed that clinicians have 'stumbling blocks in their minds' when it comes to listening to patients.

Some changes in care practice are relatively small scale, but can make a big difference to patients' perceptions. For example:

Some professionals are very empathic; they know… they can read the individual. Some of them are so distant that they put their foot in it left, right, and centre. A case in point that was raised recently, now that they've moved the palliative care and end of life care together, on one of the wards apparently there were some nurses walking round with palliative care badges, and some that said 'end of life care'. (Participant 01)

One of the partnership group members pointed out to the service managers that seeing nurses wearing 'end of life care' badges could be distressing to patients and the practice was discontinued.

While there is little direct evidence that partnership group activities have impacted on communication between patients and health professionals, there are a number of examples of user involvement in professional development initiatives (described below), which might be expected to have an indirect effect.

4.4.2   The impact on cancer care professionals

4.4.2.1 Professional development

The literature on user involvement in cancer services contains a number of examples of positive outcomes of lay participation in the training and education of health professionals (Flanagan, 1999; Langton et al, 2003; Repper & Breeze, 2007). Our study provides a number of instances of partnership group engagement with education for health care staff, at both undergraduate and postgraduate levels, including communication skills training. The case study group in the Central and South West England region, for

example, describe themselves as at the 'forefront of training' in medical curriculum development and delivery. Lay members described their practical input into teaching modules, where they talk to students about their experiences. Examples of this type of initiative include:

- Communication skills and 'breaking bad news' training for health professionals; and
- Lay membership of medical curriculum boards.

The London, Anglia and South East case study group has also contributed to health professional education initiatives. In addition to working closely with local universities, the group produced a DVD entitled 'Communicating significant news about cancer – the patients' perspective'. This has been used to support the communication of significant news between health professionals, patients and carers in a variety of ways, for example in hospital development days, in road shows and open days, in GP training, and as an online learning resource for nurses. The DVD is seen as an important collective piece of work with a message relevant to other cancer networks and to health services more generally. A health professional explained the wider impact of the project.

> …it's been a really powerful message. These are real people in your locality who have been told within the last two/three years life changing information, and this is how what we [health professionals] said impacted – both good and bad. So that I think has been one really, really big piece of work that our groups have done. And that is sustainable; it's something that you know is ongoing. And it goes way beyond cancer. (Participant 16)

The partnership group plan to build on this success by producing a further educational DVD, highlighting issues of importance to cancer patients attending outpatient follow-up appointments, to be distributed within the cancer network and across other network partnerships. This will be based on an observational study of an oncology outpatient service, carried out by users. As well as identifying areas for improvement, this exercise was also helpful in identifying good practice amongst staff.

4.4.2.2 Changing professional attitudes

Evidence from this study suggests that partnership working may be changing professionals' attitudes to user involvement, in a process described by a lead cancer nurse as 'evolution rather than revolution'. From this perspective, cancer network partnership groups are seen as carrying out 'pioneering work' in promoting acceptance of 'patient voices' in cancer care. Service users are now invited onto network site-specific groups, for example, and health professionals approach patients to join cancer steering groups – both relatively recent developments. A user partnership facilitator noted that:

> …initially, particularly the clinicians and the consultants, they felt as if it [user involvement] was a bit of an infringement on them and they weren't happy with it. But over the course of time it has been a hearts and minds exercise with these people, and you know I think now we're proving the value of user involvement. And they're seeing it first hand for themselves. So instead of us approaching them

saying, well we think we should be involved in this, they're now approaching us saying, well we think you should be involved in this. So the tables have turned - ever so slowly but nevertheless they have turned. (Participant 04)

An example from the Welsh case study site demonstrates the value of user representatives working in partnership with professionals, essentially in holding them to account for their actions.

> …we had representation at board level by a patient… a user, who really was very skilled in seeing… he'd had personal experience with oesophageal cancer through a relative, but he was very skilled in seeing that sort of broader picture beyond his own experience, and applying that to the planning at quite a high level – at board level. And he was extremely effective at calling senior NHS managers to account on how things were progressing against a timescale, and extremely effective in very gently reminding people about the original terms of reference and project plan. And it got to the stage where some senior NHS executives I know would actually put a lot of work in between meetings because they didn't want to be in a situation where the user representative was embarrassing them in front of… because I think he was very effective in doing that. And extremely gently… a very sort of calm and gentle way, but saying, you know you said you'd do this at the last meeting, you said you'd do it by this date, have you done it? Now if the answer is no, it is can you explain why, and can you tell me when you are going to do it by? (Participant 21)

A lead cancer nurse in the East Midlands and Northern England region described how a degree of persuasion about the added value of involving users could be needed when setting up a new group.

> …we have a locality group in X and because of the changes in the PCT that's sort of reformed recently, because obviously people have moved jobs etc and jobs have changed. And we've had a discussion about having [user] representation on that group, and I was very for that. And there were one or two people there who clearly have not got experience of working with patients, carers, whatever, and were a bit more skeptical about that I think. And I, you know was fairly forceful in trying to persuade them, and clearly we have, we've agreed to do that. I think that…it was like, 'Well they won't understand the sort of business of what we're doing'. Well you know that's up to us and my response to that is well that's up to us to make sure they do understand that. (Participant 39)

The evidence from this study suggests that an essential ingredient for success is identifying user involvement 'champions'; that is people in positions of authority in the cancer networks, such as network directors, service improvement leads, cancer managers and nurse specialists, who are supportive of partnership initiatives and willing to promote users' views. It was also stressed that professionals need training and support to facilitate the engagement of people affected by cancer in planning and developing care services.

4.4.3 The impact on service organisation and delivery

4.4.3.1 Service improvement

Service improvement refers to sustained changes in the delivery of cancer services and pathways brought about by partnership between people affected by cancer and professionals, with the aim of improving outcomes (Kearney et al, 2007, p16). Service improvement is central to the partnership groups' priorities. This study found some evidence of change attributable to the groups' activities – examples of which are provided in this report. However, a Macmillan development manager said of user involvement: 'It runs as a thread through some service developments, rather than it being a very powerful driver' (Participant 15).

User partners in the East Midlands and Northern England region have helped to shape the development of site-specific cancer pathways, so there is a clear view of what happens to a patient at different stages of the cancer 'journey'. One group member, for example, drew on his own experience of prostate cancer to make suggestions for changes to practice, while others developed a new social care pathway. Through consultation with patients, the group identified a lack of an orthodontic service for head and neck cancer patients; this has now become part of the clinical pathway. The partnership group was also influential in introducing complementary therapies such as head massage at a cancer care centre, in the face of some resistance on the part of clinicians. Overall, the group's activities are seen as contributing to more 'joined up' care for patients, as an oncologist explained:

> I think the partnership group has been very effective in trying to fill holes in services and make sure that the services are more joined up, because I think quite often medically we think in our own little box of what we do, what we can do. And I think the patients have been quite good about trying to make sure that the care is joined up between different places and different specialties as well. (Participant 38)

Service users in Wales were described as having had a 'huge influence' on the assessment, implementation and review of services at an upper gastro-intestinal surgical centre. The partnership group's annual report stated that:

> The involvement of patient representatives in the development, implementation and review of the surgical centre has been recognised as one of its key strengths, and they remain pivotal to the success of the service. Patient representatives have, and will continue to influence the service at both Board and service level.

A subsequent peer review exercise praised patient involvement in this programme of work.

In the Scottish case study site, members provided input into the 'Cancer Services Improvement Programme', which aims to improve cancer pathways and access to treatment (Scottish Executive, 2006). Moreover, the group worked on developing a

protocol for the care of catheters at home. However, a cancer information nurse in the Scottish network questioned the group's impact on service development. This participant argued that although there are people in the network who take patients' views seriously, except in certain specific areas (such as patient information) their influence was slight.

4.4.3.2 Environmental changes to services

This study suggests that an area where user partnerships have made their presence felt is on environmental improvements to services, both in enhancing existing provision, and planning the layout and design of new services. The following example, drawn from the Central and South West England region, illustrates the importance of partnership group involvement in pinpointing issues important to patients that might otherwise be overlooked:

> We recently had a new cancer centre built at our main hospital…and our users were very involved with, not obviously the building of it, but the design once it had been built of inside of it, you know the cosmetic stuff and this sort of thing. And that was a huge piece of work for them, because I mean that went on for about five years. But silly things like when you go for radiotherapy you obviously are gowned up, and there's changing rooms where you take your clothes off and put your gown on. Well there were no mirrors in the changing rooms. And [it's] such a simple, simple thing. So we were instrumental in making sure that mirrors were put into the changing rooms. But you know just something so small can make such a huge difference. (Participant 04)

Similarly, the East Midlands and Northern England group was consulted about the design of a new hospital wing, including the layout of the wards, the colour schemes, and art work displays. The user partnership facilitator explained the cancer network partnership group's role in the development:

> There was a big emphasis on the decorations within the hospital. And there was a separate sort of arts steering group. So a lot of [user] influence around what type of art was going to be on the walls, what colours were going to be around on the walls, and how they would use spaces within the building as well. If you ever go, it's not like a typical hospital at all. It's more like walking into a hotel - a big hotel foyer. It's huge when you walk in. And there's big spaces, and you know really nice seating areas. It just doesn't look like a hospital at all. And I'm 100% sure that that is the influence of service users, you know definitely. (Participant 36)

A lead cancer nurse involved with the same partnership group reiterated the importance of relatively minor changes to service environments that can make a substantial difference to patients' experience of cancer care.

> I think we've got a lot of positive things that we [partnership group] can say that we've achieved and I think that, as I say, you have to remember what it's like

working in an organisation like this and … it's really small things that actually make a big difference to patients and that's a great achievement.(Participant 39)

A further example was provided about the design of a new hospital cancer wing. Lay members of the partnership group asked the architects to redesign the four-bed wards so that the entrance to the patients' bathroom facilities was external to the ward itself, and therefore less public.

4.4.3.3 Monitoring and evaluating the quality of cancer care

Partnership groups have a role in monitoring and evaluating the quality of cancer care. In Scotland, for example, a service user was part of the NHS 'Quality Improvement Scotland' team, whose role is to visit health boards to review cancer care. Lay participants from all three English case study sites had taken part in the National Cancer Peer Review Programme. This involves peers and user reviewers from one cancer network reviewing the design and delivery of cancer services within another network, assessing teams against the measures set out in the Manual for Cancer Services 2004 (Kent & Seiger, 2007). The impact of the programme on service quality has been questioned, however. An independent evaluation of the National Cancer Peer Review Programme made a number of recommendations for improvement, for example to ensure that the process does not rely entirely on self assessment, and that peer review findings about service improvements are fully implemented (National Cancer Action Team, 2008). The evaluation also suggested that more work was needed to develop ways of using patients' and carers' expertise to best effect.

Members across the UK were also involved in service audits within their own networks. A cancer services manager, for example, stressed the importance of users' input in monitoring service quality.

> What we've recognised, both in both reports that have been done – one was the six month review, and one was a year review – is the influence and how pivotal they've [service users] been to the successful development and evaluation of the service. And that will continue. I mean we have two users on our… what we call our Quality Group, which now oversees the service. And they will continue to take us to task if they feel that at any point, you know something that has been brought up hasn't been taken forward. (Participant 22)

The Scottish case study group has a formal relationship with a cancer care research centre. Lay members help to develop strategy, prioritise research topics, and provide advice on research design (such as patient information sheets and consent forms). A senior researcher from the centre outlined the benefits of involving people affected by cancer in research for the process itself and subsequently, for cancer care:

> … I mean the rationale and the logic behind it is, if you don't involve people with direct experience of cancer then… you're going to be doing research projects that they're not interested in, that they'll just think, 'Why bother?' …and also I don't think the quality will be as effective either because they're going to be helping

you really tune it. So there's that sort of rationale which is that there's something about the unique and direct experience that having that experience is so important that it will improve the quality of your research project and will improve the quality of your services…(Participant 28)

4.5 *Strategic and policy initiatives*

In addition to working on operational issues, partnership groups are consulted at a strategic level; for example on planning and commissioning new services, and on policy initiatives at a local, regional and national level.

4.5.1 Planning and commissioning cancer care

Current UK government policy highlights the importance of patient and public engagement and working with community partners in achieving world class commissioning for cancer services (Department of Health, 2007a). Commentators suggest, however, that the process of commissioning is currently largely uninfluenced by users (Fisher, 2006). Evidence from our study confirms that realising the aim of engaging people affected by cancer in commissioning care remains a work in progress.

A lay chair person suggested, for example, that despite group members' involvement in cancer network board meetings, where they 'rub shoulders' with service commissioners, there is a reluctance to make direct approaches to decision-makers with ideas for prioritising resources. This respondent explained that:

> … there's always commissioners at the [network] board meeting. And we make comments there, but to actually contact them and sort of say, why don't you involve us, no I don't… we haven't made… well I haven't been involved in making that approach. But well I know they're very busy and they probably don't… wouldn't welcome it anyway.' (Participant 03)

In contrast, and more optimistically, a user partnership facilitator suggested that service user participation in network board meetings serves an educative purpose, and is useful preparation for future involvement in commissioning decisions. The following comment from a user partnership facilitator illustrates the symbolic importance of users 'having a place at the table' where funding decisions are taken.

> We know that the government want to get more user involvement in the commissioning processes. And we're hoping that you know sort of sitting in at the board meetings will actually stand us in good stead for that, because obviously being part of the board of those meetings means that we can hear the tough decisions that these commissioners have to make sometimes. Whereas a lot of people who aren't involved just think that you know the PCT are not parting with their money for this particular cancer drug, they don't realise that you know there isn't a finite pot there. Whereas now our users do, because they have been involved in these meetings at that level, and the word comes back you know. Because they don't just sit there and keep it all to themselves, it then comes back to the partnership meeting about what's happening, or not happening as the case may be,

and why, and … good, valid reasons are given for it. So it's a good education for all concerned I think. (Participant 04)

One of the difficulties in involving people affected by cancer in commissioning services is that it is seen as a complex task requiring specialist expertise and knowledge (Staley, 2007b). Initiatives which improve users' understanding of the issues involved can help to overcome this perceived barrier. One partnership group recently carried out an exercise to prepare users to take an active role in commissioning decisions, for example. Similarly, in Scotland, members took part in a regional meeting about funding priorities for patient information materials. So getting to grips with commissioning issues is very much a learning process at present, as a lay co-chair explained:

> …we haven't got a handle on commissioning for the network yet, because it's… because the network commissions big stuff like the new oncology wing… So we haven't got a handle on the big commissioning stuff yet. But we're learning about the process. We need education like they [health professionals] do I'm afraid, about commissioning. But we can actually say, you know, can we think about where this service might be? (Participant 34)

The Welsh case study site provided a rare example of a user partnership influencing the allocation of resources. Through the network board, members lobbied for NHS funding for 'out of hours' care for cancer patients. Their views were fed back into the decision-making process, and as a result £200,000 of new funding was allocated to palliative care services.

4.5.2   Local and regional policies

The study found evidence of partnership group input into the development of local cancer policies or codes of practice. Examples include:
- guidelines for health staff
- outcomes guidance for cancer services
- local standards for an information system
- key worker policies
- high level supportive care pathways

4.5.3   National policies

Partnership groups are frequently consulted about national policies and guidelines for cancer care, including, for example:
- Gold Standard Framework (community palliative care for people reaching the end of their lives)
- End of Life Strategy
- Cancer Reform Strategy
- National policy for colorectal screening
- NICE guidance for palliative care
- National guidelines for sarcoma
- All Wales palliative care review

- National consultation about NHS reorganization in Wales
- 'Better cancer care' – Scottish consultation document

Partnership groups can also be involved in the interpretation of national guidelines to suit local conditions. Opinions were divided amongst study participants, however, about whether such consultations represent genuine opportunities for users to influence national strategies for cancer care, or are simply tokenistic 'tick-box' exercises.

4.5.4   Sharing good practice

The study found numerous instances of sharing good practice in cancer care, both within cancer networks and across them, through members' attendance at conferences, workshops and other local, regional and national events. Examples include:
- Attendance at the annual Macmillan 'Have your say' conference;
- Presentations at network site-specific and cross-cutting groups;
- Newsletters and annual reports;
- Representation at the National Development Programme meeting; and
- Representation on Macmillan Cancer Support's strategy group.

There is also some evidence of members' awareness of the importance of using different methods to publicise the groups' aims and achievements. One case study site, for example, appointed three dedicated media representatives 'to ensure that key messages reflect user partnership group consensus and reflect positively on the development of cancer services across the network. Other approaches included publishing 'success stories' in Macmillan's newsletter, the Cancer Action Team newsletter, the local press and networks' websites. One site created a PR steering group from interested members. Some participants raised questions, however, about the extent to which good practice is shared effectively, suggesting that there is room for improvement.

4.6   Challenges of user involvement in cancer services

A key aim of this study was to explore the perceived challenges and barriers that partnership groups face in developing cancer services that are more effective in meeting the needs of patients and their families. In this section of the report we explore some of those challenges, but also highlight positive signs of change.

4.6.1   User recruitment, representation and inclusion

Recruitment is an enduring problem for all cancer network partnership groups. As participants pointed out, membership can be demanding in terms of the time and commitment required, while the nature of cancer as an illness means that sustained participation can be difficult. There is a danger that as membership begins to fall partnership groups can lose their effectiveness. The majority of case study sites reported losing members through illness or death, or infrequent attendance on the part of some users, with negative consequences for the sustainability of the groups' initiatives. In some cases partnership groups in this study were dependent on the dynamism and enthusiasm of a few lay people, or even one particular chair person. In these circumstances the role of professionals, particularly user partnership facilitators and lead cancer nurses, is vital in

maintaining continuity for the group. In some areas, however the engagement of health care professionals, beyond a 'core' group of committed people, was difficult to sustain. A Macmillan development manager said that:

> The meetings are… the network user partnership groups are I think I'm right in saying – certainly when I've been – are not very well attended by healthcare professionals at senior level. They tend to be people from the network and users, and then there's some representation usually from Macmillan. And then, as and when, other people are sort of brought in to speak on particular topics. But a regular attendance from healthcare professionals, a sense of it being a partnership, I think is somewhat diluted. And hence the impact it makes I think is affected by that and the value it's given by people who are, you know naturally very busy and perhaps don't give it the priority that one might want. So that sort of participation, or the quality of that participation I think must have an effect on the impact. (Participant 15)

It is not only recruitment *per se* that is a problem; the representativeness of membership is also seen as an issue. For example 'seldom heard' groups such as people with learning disabilities, young people, deaf people, BME communities, and those from lower-income neighbourhoods and isolated rural areas are under-represented in partnership groups. Health professionals would also like to engage patients currently undergoing treatment or having recently been discharged from medical care. Gaining access to these groups is seen as difficult, as one of the chairs of the case study site in London, Anglia and the South East explained.

> …the difficulty for the user side of the partnership is that we don't have direct access to the patients that the healthcare professionals are seeing, to be able to get them into our sort of groups. So that we're getting the most recent experiences, you know through to help with the change. And I see that as one of the challenges in terms of the partnership, because there's obviously patient confidentiality, and whatever. And there's this big sort of void, and there should be a bridge there that, you know how do we get the most recent patients actually in and participating? (Participant 13)

Widening participation and engaging people beyond the 'usual suspects' is seen as a particular challenge by user partnership facilitators and Macmillan development coordinators.

> … I think part of the issue is around sort of credibility of not having just the usual suspects. If there was a way of increasing the number of people involved in these groups, so that you know they become a sort of critical mass, it would be hard to ignore them - or harder to ignore them. Given the number of people that use the service versus the number of professionals that help to run the services, you know if some more of those of could be mobilised it would become much more reflective, and as I say harder to ignore, and more credible in a sense. So I think that's a barrier, both for the people who are currently involved, the users, because

you know it falls to them. And naturally they are going to be drawing upon their own experiences. So it makes it more difficult for them I think, but also for the professionals involved, commissioners and things to take it… to treat it with the value that it needs. (Participant 15)

It can be particularly challenging to reach some population groups, such as certain BME communities, in which cancer is a stigmatized topic that is not openly discussed. It was suggested that informal approaches through community groups might be the most fruitful strategy in cases where formal approaches have failed, as a lay person who had previously served as group chair explained:

> … when I was chairman I wrote to all… well not all, but a lot of the mosques in X asking if they would be interested in having someone, you know to go along and talk to them about cancer, and didn't get a single reply. But I have since… I live in X, and I've since, through playing skittles for my local pub, got to know the Indian Association quite well, because they've got a skittle team. And I'm waiting… I've asked them if I can go along and talk to their committee with a view to getting… to be able to discuss [bowel cancer screening]. (Participant 03)

Questions were also raised about the range of cancers represented in partnership groups or other user involvement initiatives in the networks. Lung cancer, for example, affects greater numbers of people from lower socio-economic groups who, according to evidence from this study, are less likely to get involved in decision-making. A similar point was made by an oncologist about people with head and neck cancers.

Importantly, involving people affected by cancer in other network groups (such as site-specific and cross-cutting groups) is seen as key to influencing the clinical management of patients, and as a means of enhancing the credibility of user involvement overall.

> I think a priority I suppose in … broad terms is about I think strengthening what they're working on now, which is about getting members on the network site specific groups, because I think that's a good way of influencing a range of professionals. And I suppose in terms of the priority that's about… it's representing, user representation in a good light if you like so that people are seeing that a user representative is an advantage in your group, and it's somebody who is constructive and not necessarily threatening but somebody who might be challenging. (Participant 39)

A future priority for the majority of partnership groups involved in the study, therefore, is to consolidate and sustain their existing level of user involvement and build capacity to respond to new ways of working in the NHS. It is acknowledged that group membership is not appropriate for all service users, and that there need to be other ways of tapping into patients' and carers' experiences, which are flexible and arranged around people's lifestyles and needs. User partnership is seen as having a wider meaning beyond committee work, as a lead cancer nurse explained:

So I think what we're looking at is that user partnership is not just about pitching up to a meeting, user partnership can be done in many other ways. And that's kind of where our direction is going at the minute. But the groups themselves have a very, very important role to play. There are very significant pieces of work that they've been involved in, that they continue to be involved in…But I think we've got people who are – you know just due to the nature of the way cancer treatment has changed – we've got people who are living a much more normal life at the end of treatment, for whom they're going back to work and spending all of a Saturday morning is not their bag. (Participant 16)

Suggestions for future initiatives included holding open days, setting up smaller tumour-specific focus groups and work groups, and promoting patient feedback via network websites.

Examples of this type of initiative include engaging patients experiencing chemotherapy in reshaping the content of patient information leaflets, and holding focus groups with patients currently undergoing treatment.

4.6.2   Support for users who get involved

The evidence from this study underlines the importance of providing training and support for people affected by cancer who are actively engaged in developing services. Although the majority of lay members of partnership groups have undergone CancerVOICES training (provided by Macmillan Cancer Support), respondents argued that there is a need for additional preparation to provide users with sufficient confidence and knowledge to work effectively within complex NHS structures.

> …sometimes we have patients that literally have had a patient experience, we've given them two days training and then we want them to talk at board level. So it's about an evolving process, and it's getting them, the patients, to understand the agenda. But actually I think change management, the scale takes probably ten plus years, so it's much more engrained. The culture, the organisation, the culture of meetings, but actually we almost like get users then that are trained and developed. And I think over time we will have education and training that supports that for users, as opposed to a two day workshop, or a half day workshop. (Participant 10)

Appropriate training could also help to ensure that users are not simply pursuing their own agendas, which was seen as a problem by a number of participants. A consultant in palliative medicine made the point that:

> … some barriers come from within the group in terms of the… perhaps the expectations of individuals joining the group, but also in terms of level of training. Now I know that's improving, and I know that we've had some extremely effective patient representatives. I've also encountered maybe some who were less effective, and when one has an impression that they've come with a lot of distress, feeling that actually this may be an outlet for their distress, or

maybe very specific personal concerns. And that can be a challenge really, because I think that the group - not that those are not valid - but I think the members of the group function most effectively when they're seeing the bigger picture rather than the, 'and this is what happened to me'. (Participant 21)

Further training could help people affected by cancer to become fully involved in decision-making, where they currently lack knowledge or confidence, and ensure that they are up to date with developments in the NHS. For example, a GP and clinical commissioner said that:

> I think that there are still problems with keeping users up to date because users often get to the level of representation on a district wide or a regional group, like the X user group, have often experienced cancer services several years previously. So their own motivation for being on that group isn't always, is usually because they've not experienced the service they felt they should do, and they want to do something to improve it. And some of them don't reach the realisation that services are changing all the time, so there's a real need for them to be properly trained and for us only to keep the ones who are able to change. (Participant 40)

A lead cancer nurse from the London, Anglia and South East region described an instance where lack of training meant that lay members felt unable or unwilling to comment on strategies for developing the role of clinical nurse specialists (CNSs).

> I wanted to see how we developed the CNS role further from the users' perspective and the CNSs'. And I got the two groups in the room, and all the users in the room were users who had previously done Macmillan Cancer Voice training…but when it came to the crunch of making a decision around…I said to them, 'Okay, so what else would you like to see from the CNSs? You know, do you think CNSs should have a development programme, or, you know, what are your thoughts on that?' And the phrases were coming back like, 'Oh, we couldn't possibly make that decision, I'm only a user.' And so I just felt we haven't empowered them enough. (Participant 17)

This participant suggested that one way to overcome the problem would be for a designated health professional to meet users in advance of meetings, and prepare them to take a full part in discussions.

A further, not inconsiderable, barrier to involvement is the financial cost; paying fees for attendance at national events, for example, and meeting 'hidden' costs such as internet access. While some funding is available for this purpose this was not always considered to be sufficient. Partnership group meetings often involve users travelling long distances, especially in networks such as Wales and Scotland which cover large rural areas. In some cases methods for claiming user expenses were described as overly complicated and cumbersome.

4.6.3   Resources and sustainable funding

Cancer networks are seen as 'early innovators' in promoting the engagement of people affected by cancer in service planning and development; however the evidence from this study highlights the need for reliable sources of funding to strengthen user involvement activities, and to sustain the momentum built up in recent years. The need for adequate funding to provide training and financial support for people affected by cancer, and to support posts such as user partnership facilitators, was a point that emerged strongly from this study. This was seen as an issue at both network and locality-level; some locality user groups had paid facilitators but other did not. It was also argued by respondents that the UK government's policy rhetoric about the value of patient's experiences in service planning and development should be underpinned by the provision of dedicated resources.

The findings from this study about the need for reliable sources of funding to develop user engagement in cancer care reflect those of earlier research, which stressed that user involvement in cancer care needs to be given the same attention and resources as service efficacy, reliability and governance (Sitzia et al, 2004; Kearney et al, 2007).

4.6.4   Professional attitudes towards user involvement

Professional attitudes towards user involvement can be one of the greatest barriers to meaningful engagement in service development, as previous research has found (see, for example, Kearney et al, 2007). A network director claimed, for example, that some clinicians rarely speak to patients 'when they are not wearing pajamas'. Similarly, a lay chair person in Wales explained the nature of the challenge facing service users:

> …it was quite daunting for most of us when we first went on these DONs [disease oriented networks], because you were sitting there with consultants, some of whom had never been used to dealing with patients directly. And I always remember the first one… and this consultant who was coming up to retirement said, 'It's the first time I've ever had this experience of dealing with a patient.' And I happened to say, 'Well you wouldn't be here if it wasn't for us because you know that's…' [laughs] …you know so in a way it's been a sort of gradual… I mean some have been very, very supportive, but I still have the feeling that some of the, you know perhaps older ones are still a bit remote… (Participant 19)

While there has been some progress in acknowledging people affected by cancer as equal partners in planning and developing cancer care, it appears from the evidence of this study that some professional groups are more open to partnership working than others. Barriers to collaborative working are associated with the hierarchical nature of the medical profession and traditional practices, which can make meaningful change hard to achieve. In Scotland, for example, a cancer information nurse argued that:

> I think attitudes [about user involvement] are changing in the nursing profession. I think it's a bit slower in the medical profession. There's quite a lot of paternalism there. (Participant 29)

Similarly, a co-chair of a partnership group said:

> I think another barrier is that for some of the older… I certainly get the impression that there a group of more traditional clinicians than health service professionals, who cannot see…do not recognise the movement towards a, you know user led health service, or a user participative health service… the old more paternalistic… And I suppose that would be another indicator of how I think… you know how I'd know things are changed, when I see them according value to what the patient perspective is and what people say about it. (Participant 35)

The evidence from this study suggests that, in certain circumstances, health professionals may experience difficulties in working collaboratively with service users. For example, a number of users had used partnership group meetings as a forum for asking questions about their treatment, or to pursue personal complaints. According to one senior professional, at meetings where patients or carers were seen as having an 'axe to grind', service providers and commissioners 'switched off' from taking their concerns seriously.

Going beyond individual attitudes and practices, the culture of the NHS generally is seen as a barrier to the effective engagement of people affected by cancer. Respondents expressed a degree of skepticism, for example, about the extent to user involvement is tokenistic, rather than a genuine attempt at power sharing. A network director explained that from his viewpoint:

> I think there's a few barriers. I think the Health Service…part of the whole user involvement agenda is actually paying lip service I think. And I think the whole idea about consulting with customers is actually rather just…it's a political acuteness rather than actually being true. You know it's like the restaurant who says 'leave your comments on this card'; they get them all and they just put them in the bin. At face value it looks as if you're consulting people, but the reality is actually either you're not really interested, or you actually just can't do what they want you to do, because the Health Service doesn't work like that. (Participant 24)

In contrast, another respondent, a GP and clinical commissioner, stressed the symbolic significance of users' presence in groups and committees, and the growing respect that they command amongst professionals.

> That's why I think they [partnership groups] have a role because I think it's easier to be tokenistic about focus group work but only do it when you want to do it. Unless there is some sort of permanent lobby as well in addition, who represent the users and remind people physically by the fact that they turn up to things and it's even better. We're very lucky locally with some of the professional users that we've got if you like, because…they've achieved credibility and respect and that is crucial…(Participant 40)

5   Conclusions and recommendations

In this section of the report, we first provide an overview of the findings of the study, second, we examine the level of user involvement in the cancer network partnership groups, third, we look at widening the influence of the groups, fourth, we examine the issue of monitoring and evaluation of group activities, and fifth, we suggest some potential future priorities for the groups. Finally, we provide a number of recommendations for future practice.

5.1   Overview of findings

Partnership groups have now firmly established a place for the involvement of people affected by cancer in the cancer networks; importantly users are now seen as a 'legitimate presence' in planning and service development forums.

This report has described the significant achievements that partnership groups have made across a broad spectrum of activities, impacting on patients' experience of services, professional development, and service organization and delivery. There is also some evidence that groups are consulted about strategic and policy developments, both locally and nationally.

The evidence suggests that the cancer network partnership groups have influenced cancer care in a number of ways, including:

- Improving information available to people affected by cancer;

- Enhancing access to care;

- Contributing to health professional training and education;

- Improving service organisation and delivery, in particular through changes to care environments;

- Monitoring service quality;

- Providing feedback on local, regional and national policy initiatives; and

- Sharing good practice.

Partnership groups have also had less tangible impacts, for example in influencing professional attitudes towards involving users in decision-making.

As the authors of the earlier evaluation of the Cancer Partnership Project predicted, the partnership groups have evolved from establishing their place in the cancer networks, through a reactive phase, and are now moving towards a more proactive model of working (Sitzia et al, 2004). However, not all the case study areas were seen to be

proactive in their methods of involving users in decision-making. A senior professional from the London, Anglia and South East region argued, for example, that:

> I would say that the ideas [for activities] haven't initially come from them [partnership group], but they've been willing to support a particular development that others have perhaps suggested. Yes, the initial suggestion may have come from a comment from somebody, or one or two users of a particular local service, who may or may not be involved with the partnership. But then as the particular proposal or development has been worked up and taken forward, then the partnership group may be asked for their opinion, or probably more directly you know would they support it rather than even, 'What are your thoughts on this?'. Because it tends to be quite late in the day, and you wouldn't want that… those developing the service wouldn't want at that stage for it to be undermined or sort of taken away as it were. So it's put in terms of, 'Would you mind supporting this?' And so it's a measure of how – I hesitate at the word genuine – but how meaningful that is. I don't know that they've ever said, 'Well we don't actually agree with this development.' (Participant 15)

The extent to which the partnership groups' priorities are driven by service users is still open to question, therefore, although the consensus amongst participants is that progress has been made towards genuine partnership working.

One of the partnership groups' core functions is as a reference group for those seeking a 'user view' on cancer care issues. Group members also act as a pool of representatives for other groups and committees, ensuring that 'patient voices' are firmly on the agenda. The networking aspect of the groups' activities, both formal and informal, is seen as a crucial way to strengthen their influence on cancer care policy and practice, and to raise their profile as a focus for user involvement in the networks.

The identification of user involvement 'champions', that is people in positions of authority in the cancer networks who are supportive of partnership initiatives, was also seen as an essential ingredient of success.

5.2 Level of user involvement

A number of models have been developed to describe the different dimensions of user participation in health care decision making, the most well known being Arnstein (1969). In this report we draw on a simplified version of Arnstein's framework developed by Charles and DeMaio (1993), as a basis for examining the level of user involvement in decision-making about cancer care in the cancer network partnership groups. As the authors point out, there is a difference between simply listening to users' views and lay people gaining control over the decision-making process. This framework describes three levels of lay participation – consultation, partnership and lay control (Charles & DeMaio, 1993, p889).

Consultation represents the lowest form of participation in decision-making. It provides people affected by cancer with an opportunity to express their views on care.

Partnership represents a higher rung of the ladder in which decision-making is shared between lay people and professionals, often in committee settings.

Lay control, the highest rung of the ladder, occurs when lay people are in full control of decision-making. This involves a transfer of power from traditional decision-makers to service users.

The framework also describes three **decision-making domains** in which users can participate, which are as follows:

1. Treatments, services or resources provided to patients.

2. Service delivery resource allocation decisions – that is, what services are delivered, how, where and by whom.

3. Macro-level health care allocation and policy decisions at regional or national level.

If we examine the data from the partnership groups in the light of this framework (see table 4 below), it can be seen that the further we move up the ladder of lay participation, and the higher the level of decision-making domain, the less evidence there is that partnership groups are making an impact. There is little evidence of effective user involvement in planning and commissioning cancer care, for example. While it is not surprising that evidence of full lay control is absent, as these are after all cancer *partnership* groups, the framework does demonstrate the limitations of current methods of involving users in decisions about cancer services.

The earlier evaluation of the Cancer Partnership Project suggested that the next stage of development for the partnership groups would be for established groups to become integrated with other efforts to improve services, and become part of everyday practice across organizations (Sitzia et al, 2004). While cancer network partnership groups have made progress in this direction, evidence from this study suggests that this goal has only been partially achieved.

Table 4: Level of user involvement in different domains of cancer care

Decision-making domain	Level of involvement		
	Consultation	Partnership	Lay control
Treatments, resources and services provided to patients	Members act as a reference group for health professionals. They also liaise with local user groups and collate information on patients' experiences concerning the accessibility, configuration and quality of cancer treatments, resources and services.	User representatives contribute to the development of new services and reconfiguration of existing services, through engagement with service providers, groups and organizations involved in cancer care (NHS and non NHS), and taking part in training for health care professionals. Members make recommendations and directly contribute to the cancer network management board.	No evidence
Service delivery resource allocation decisions (e.g. network or local level)	User representatives attend the cancer network board, site–specific and cross-cutting groups.	User representatives attend the cancer network board, site–specific and cross-cutting groups. At local-level, users are represented on network locality groups.	No evidence
Macro-level health care allocation and policy decisions (e.g. regional or national)	User representatives have input into local and national policy initiatives (e.g. Department of Health consultations on cancer care policies).	No evidence	No evidence

The evidence from the study has identified a number of challenges faced by partnership groups in bringing about sustainable changes in cancer care practice. Predictably, our findings reflect those of other similar studies of patient and public involvement in health care. Challenges include increasing user representation and inclusion in the groups, providing support for those users who get involved (and securing the resources to do this effectively), and convincing health professionals of the value of involving users in decision-making.

As this report goes on to discuss, there are also issues around widening the influence of the groups, and effectively monitoring their activities. This evidence suggests that while partnership groups have achieved a great deal in the last four years, there is room for improvement if user involvement is to be at the core of service planning and development in the cancer networks, rather than at the periphery.

5.3   Widening the influence of partnership groups

The evidence suggests that the profile of cancer network partnership groups is not as high as it might be, except amongst an 'inner circle' of professionals. Across the case study sites, participants were keen to increase the impact of their activities. It was seen as important to ensure that partnership groups are 'on the radar' of both lay people and professionals, through promotional and publicity initiatives targeting different groups.

Two main areas of practice were identified where partnership groups could engage more effectively in the future – primary care and social care. One suggestion was that group members could play a greater role in GP training, on topics such as cancer survivorship and the importance of supporting patients in the immediate aftermath of cancer treatment. Collaboration with the social care sector, for example through LINks, was also seen as a priority area for development (although some participants felt that this was of lesser importance).

This study suggests that one obstacle to increasing the profile of partnership groups is the sheer complexity of the organisational structures in the cancer networks and in the NHS. For example, a voluntary services manager commented that:

> I suppose the only thing I would say is I find it's quite a complicated organisation to get your head around. Do you know what I mean, there's user involvement, user partnership, there's this, this, this and this, the … cancer network and there's this bit and there's this bit. That's one thing I find difficult with it, to actually get your head round what each little bit is for and what it represents and what it means… (Participant 07)

Such confusion about the role and function of different user involvement groups within cancer networks was not uncommon amongst study participants.

In some cases there was criticism of the existing systems of communication between the various strands of the network, for example between local user groups and the partnership

group. This is an important point because while it is often at 'grass-roots', local level that problems with cancer care are identified, the solutions may lie at a strategic level. For the partnership groups to work effectively it is essential to establish strong lines of communication with local groups, firstly to avoid duplication of effort, and secondly to ensure that patients' concerns are heard at network level.

Broadening their strategic-level influence is one of the partnership groups' priorities for the future, through continued engagement with national, regional, and local decision-making forums. While many stakeholders view the groups' primary role as consultative, it was argued that to have a real and sustained impact they need to be engaged in service commissioning. Commissioning is a process which underpins the development of NHS services and an area where user involvement could potentially make a significant difference to patient care (Fisher, 2006). At the same time it is acknowledged that involving service users in effecting meaningful change is difficult, time consuming, and demanding.

> …it's not something to say, 'Oh we're involving patients.' It's real, you know you've got to change your systems so that patients have a bigger say, and that's hard you know. It's easier for us to sit here in a room and talk philosophically but the real front line troops, making that time is difficult and patients are demanding you know and they're relentless and it's really hard work…and we need to have systems to help managers manage that, because it's you know time consuming, hard work, and they need to see the rewards in it, it will come. And I think we're going along that path where we're getting there, but we're not going to change the world in a day. (Participant 37)

The pace of change in the NHS can be frustratingly slow for people affected by cancer who get involved in service development. A carer representative in a partnership group explained his feelings on the subject.

> I think we have to accept that these kinds of things are not going to change. It [service improvement] is not like a new drug that you can say, 'Great there's the new one, lets scrap the old one and we'll all use it'. It's not as simple as that and I sometimes get a wee bit frustrated because I don't see progress being made, but maybe it's just because progress is going to be so slow and that's just the way of it. (Participant 30)

5.4 Monitoring and evaluating partnership group activities

Previous research has shown that users are willing to get involved in service planning and development as long as there are:
- clear aims and objectives;
- their contributions are valued; and
- activities are geared towards improving services.

Above all, people affected by cancer want to know that their involvement has the desired effect on services and care practice (Kearney et al, 2007)**.** But this can be difficult to establish, as one respondent pointed out:

> … I think that's part of the problem, how do you evaluate what difference this group's making? Because they're all very committed people obviously. Plus the professionals that go, sometimes used to take maybe two, three hours out of what is a very busy day, and what is it achieving? But I think it's like everything else now, you've just got to keep chipping away at it and maybe this time next year things will be very different. (Participant 29)

Evidence from this study suggests that, while many partnership groups do record their achievements in various formats, monitoring is not carried out consistently. For example:

> I think they've got to move on from the sort of going through the motions of having patient engagement to being a true partnership between the service and patients and monitoring the improvement. How many patient partnerships groups look at the actual improvements that's been made and monitor how they've achieved that, and how do they share it? (Participant 37)

Evaluating the outcomes of partnership groups, both tangible and intangible, was therefore identified as a future priority. It was also suggested that dedicated funding should be allocated for evaluation purposes.

Firstly, it was argued that meaningful service improvement should be based on patients' experiences and priorities, identified by carrying out regular needs assessments (ideally going beyond survey data), and/or adapting existing methods of monitoring patients' experiences of care to ensure that they reflect their priorities. (For example, in Scotland it was suggested that every health board could carry out a 'snapshot' of patients' experiences at regular intervals.)

Secondly, this evidence could be used to prioritise issues for a clear work programme, specifying people, systems and funding to take activities forward, and timelines for completion of specific activities. This programme would be signed up to by all group members, lay and professional.

Thirdly, at the end of an agreed time period, the outcomes of the work programme would be evaluated.

Finally, on an annual basis, again drawing on patients' experiences wherever possible, findings would be fed back to group members and into the work programme for the following year.

Figure 4: Monitoring partnership group activities

Identify patients' priorities and experiences of cancer care

Identify priorities for annual work programme

Identify people, systems for change and funding and set goals for completion

Monitor outcomes of work programme at regular intervals
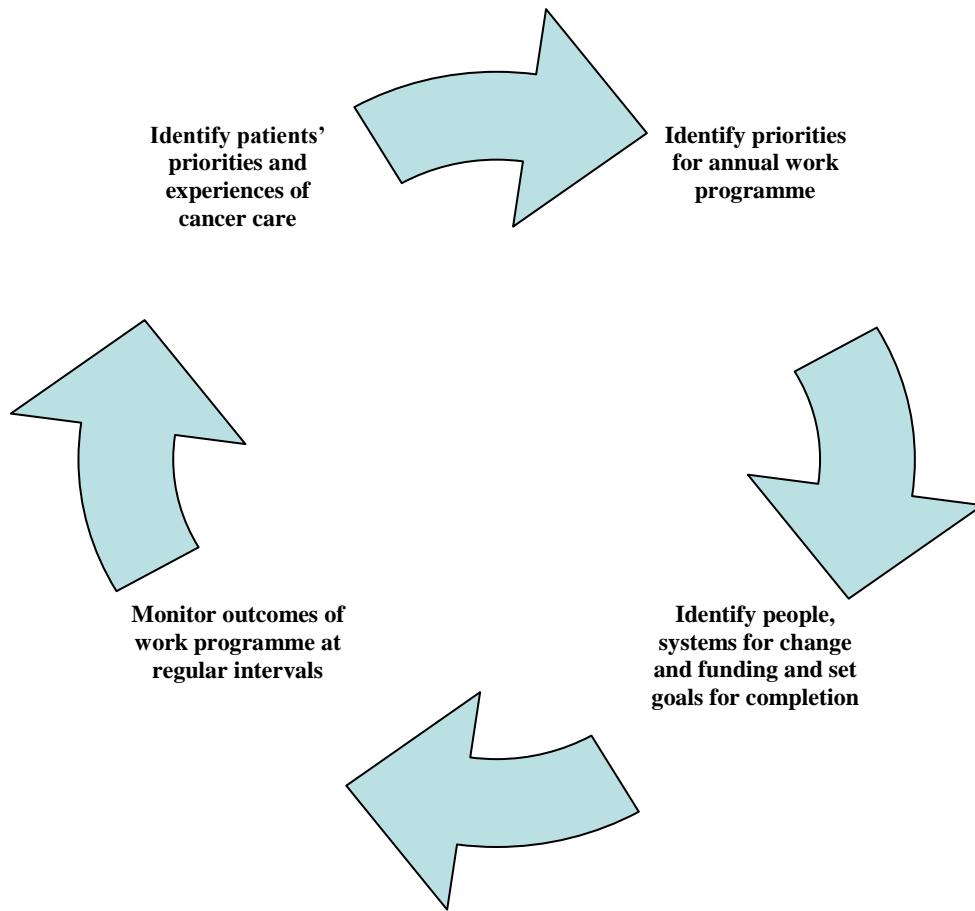
Although implementing an evaluation and monitoring system might appear onerous on the face of it, our study suggests that it is important for it to be designed as 'light touch' to avoid overburdening user partnership facilitators and group chairs with paperwork. The aim is to identify key areas of practice which could be regularly monitored for improvement. Where sub groups or core groups are in place which take on specific projects, this should help to simplify the task of evaluation by breaking it down into smaller, more manageable 'chunks'. As a lead cancer nurse pointed out, service improvements need not be huge to count; small changes can be equally as important to people affected by cancer.

> …you know if there's a mountain to climb you don't have to always have to look at the top and think, 'Oh I'm never going to get there.' (Participant 39)

In an accompanying paper to this report we propose a template for collecting impact data, to facilitate evaluation of the cancer network partnership groups' activities.

5.5   *Future priorities*

While it is important to balance local and national priorities in the partnership groups' work programmes, it was suggested that it could be helpful to focus on specific short-term projects identified by users and professionals in partnership, to try to bring about changes in practice. One suggestion, for example, was that groups could usefully work on issues around cancer survivorship, in particular post-treatment care.

> …we're beginning to look at… now that cancer is really… you know for many patients with cancer it's almost turning into a sort of chronic disease. I think what we're looking to understand more is around issues of survivorship and how we can support people post treatment. .. I think one of the things the group is going to look at in coming years is the idea of you know when we finish a sort of a very long intense period of chemotherapy, and we say, well that's your last dose, off you go into the sunset, how do we best support people? So issues of sort of survivorship**,** post-treatment care is something that we're interested in.
> (Participant 21)

One of the aims of the 'Cancer Reform Strategy' is to ensure that more is done to support patients through their survivorship. This is important because survival rates in the UK are improving and the total number of people living longer with cancer is growing (Department of Health, 2007b). Macmillan Cancer support defines a cancer survivor as:

> …someone who has completed initial treatment and has no apparent evidence of active disease, or is living with progressive disease but is not in the terminal stage of illness, or someone who has had cancer in the past. (Department of Health, 2007b, Section 5.59)

The National Cancer Survivorship Initiative, which was set up in March 2008 and is co-chaired by the Department of Health and Macmillan Cancer Support, aims to consider a range of approaches to survivorship care and how these can best be tailored to meet individual patients' needs (http://www.improvement.nhs.uk/cancer). Partnership groups' established links across the cancer networks, with site-specific groups and key health and social care professionals for example, would facilitate their contribution to this programme.

A further concern highlighted by this study was the question of equity of care throughout the different geographical areas that make up a cancer network. It was suggested that monitoring equality of access to services and consistency of service quality might be a useful task for the partnership groups to undertake.

> I think there is still a lack of equity of service delivery across the area, so often…the level of service, the quality of the service varies according to either the investment in it or the motivation of the people that are delivering the service, and as a consequence of that patients throughout the whole of X don't get the same service and the same patient experience. I think it's the role of this group to be scrutinising that and to be working on where they think the gaps are. (Participant 40)

Initiatives to improve patient information (such as information prescriptions – see OPM, 2008), access to services (for example, for patients living in remote rural areas or disadvantaged urban districts), and patient/professional communication, all issues highlighted in the 'Cancer Reform Strategy' (Department of Health, 2007b), are likely to be areas where partnership groups can have an ongoing impact. Information for cancer survivors has been identified as a gap in provision which partnership groups could help to address (Department of Health, 2007b). It is also desirable that people affected by cancer continue to have an input into professional development initiatives, in particular the national programme for advanced communication skills training for senior health professionals (Department of Health, 2007b).

5.6 Recommendations

5.6.1 User recruitment, inclusion and support

- Recruitment campaigns for cancer network partnership groups should use a diversity of strategies including, for example, leaflets, posters in public places, web-based approaches, and personal contacts. It is suggested that facilitators draw on ideas from high profile user groups in other domains, such as mental health, in developing recruitment strategies. Collaboration with non-cancer regional organizations, such as stroke networks, may also be advantageous.

- Recruitment strategies should aim to increase the membership of people affected by cancer not only in the partnership groups but across the network as a whole, for example in site-specific, cross-cutting and locality groups.

- The recruitment of patients currently undergoing or having recently completed treatment has been identified as a problem. It is suggested that frontline health professionals, such as lead cancer nurses or clinical nurse specialists, could play a greater role in recruiting patients as locality user group or partnership group members.

- Particular efforts should be made to recruit members of 'seldom heard' groups, such as members of black and minority ethnic (BME) communities, those living in remote rural areas, and patients who are undergoing or have recently completed treatment. It is important to include people with a range of different cancers wherever possible.

- Different models of involvement will be needed to recruit members of 'seldom heard' communities, such as informal approaches via community organizations. It is important to ensure that interpreters are available where necessary to underpin recruitment efforts.

- Involvement methods should be designed reach a wide constituency, be diverse, and go beyond the traditional patient surveys. It is recommended that they include web-based methods (e mail, web forums, internet chat rooms), post and telephone

contacts (for those people without access to the internet), and face-to-face approaches, such as focus groups and open days.

- Additional training and support should be provided for users and professionals involved in partnership groups (over and above Macmillan CancerVOICES training). User involvement should continue to be an essential component of professional development initiatives.

5.6.2 Monitoring and evaluation

- It is essential that users are provided with feedback about how their input makes a difference to cancer patients and services. It is recommended, therefore, that clear and consistent evaluation methods be put into place across the cancer network partnership groups[4]. This may require additional resources to implement.

5.6.3 Increasing the impact of partnership groups' activities

- It is recommended that partnership groups raise their profile, celebrate their achievements, and share good practice through a variety of promotional and publicity initiatives. These should be designed to target different groups, both lay and professional.

- There is a need to identify reliable sources of funding to strengthen user involvement activities in the cancer networks, and sustain the momentum built up in recent years, in particular to provide training and financial support for users and to fund a dedicated user partnership facilitator wherever possible.

- It is essential to identify user involvement 'champions' amongst health and social care professionals in the cancer networks, in order to drive the groups' agenda forward.

- Partnership groups should aim to broaden their influence on health and social care services for people with cancer – particularly on primary care and social care services - and on the planning and commissioning of cancer care (for example, through increased co-ordination with and representation on network locality groups).

- It is recommended that systems be set up to increase co-ordination between locality user groups (or local patient and carer groups in Scotland and Wales) and regional partnership groups, in order to ensure that group priorities are driven by people affected by cancer. Formal communication systems across all groups within the cancer network should also be established or streamlined.

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[4] See the accompanying paper to this report: Cancer network partnership groups: a template for collecting impact data.

- It is recommended that partnership groups focus their efforts on a limited number of projects, where they can 'make a difference' and demonstrate that change has occurred. Topics could include, for example:
  - Information resources for cancer survivors;
  - Information prescriptions (providing the local context);
  - Survivorship and post treatment care; and/or
  - Equity of care.

6 References and appendices

6.1 References

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6.2 Appendices

6.2.1 Study outline

Background
For the last five years Macmillan Cancer Support has been active in supporting the development of user involvement in NHS cancer networks through partnership groups. The main aim of the groups, which include both service users and NHS staff as members, is to contribute to improvements in local cancer services.

Research aims
- To provide evidence of the difference that user involvement makes to health and social care services for people with cancer
- To suggest ways of routinely capturing such differences

Research Questions
- What evidence is there for the impact of user involvement on health and social services for cancer across the UK?
- Do user involvement activities influence service improvements?
- How can the contribution and impact of involvement be routinely captured?

Research methods
- We will analyse written evidence (such as annual reports) from the partnership groups
- We will conduct case studies of several partnership groups
- The case studies will focus on the way the groups connect with key people outside the groups.

Lay involvement
- Two lay co-researchers on research team
- Research Steering Group has lay members

Funded by

Macmillan Cancer Support

Research Team at Lancaster University
Dr Sara Morris & Dr Pam Attree
    Health RDS NoW
Sue Hinder & Maggie Clifton
    Lay co-researchers
Prof Sheila Payne, Prof Carol Thomas, Suzanne Vaughan
    Division of Health Research

6.2.2   Information letter for key stakeholders in cancer services

Dear <name>

We would like to invite you to help us with our research study, ***Exploring the impact of user involvement on health and social care services for cancer in the UK.***

This study is funded by Macmillan Cancer Support. As you may know, Macmillan supports the development of public involvement in NHS cancer networks through cancer network partnership groups. The main aim of the study is to provide evidence of the difference that user involvement may make to health and social care services for people with cancer, and to suggest ways of routinely capturing such differences. Page 2 of this letter provides an outline of the study.

We are seeking to conduct interviews with people involved in cancer services in the UK. The interviews will take between 30 and 60 minutes and will be face-to-face at a time and place of your convenience. Where it is difficult to arrange a meeting we would be happy to conduct the interview over the phone. We would be very grateful if you would consider taking part in an interview, although this is entirely voluntary.

One of our researchers will be contacting you soon to tell you more and to ask if you would be willing to consider participating. The full information sheet and consent form will be sent to you if you express an interest. Meanwhile, please do not hesitate to contact me if you have any comments or questions.

Yours sincerely,

Sara Morris
Chief Investigator
s.m.morris@lancaster.ac.uk
01524 592656

6.2.3 Information form

<div style="border:1px solid black; background:#b0b0b0; text-align:center">

Information about the research
Exploring the impact of user involvement on health and social care services for cancer in the UK

</div>

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear, or if you would like more information.

Background
Macmillan Cancer Support supports the development of user involvement in NHS cancer networks through cancer network partnership groups. The main aim of the groups, which include both service users and NHS staff as members, is to contribute to improvements in local cancer services.

What is the aim of the study?

<div style="border:1px solid black; text-align:center">

The aim of this study is to provide evidence of the difference that user involvement makes to health and social care services for people with cancer, and to suggest ways of routinely capturing such differences.

</div>

Why have I been invited to take part?
We are contacting people involved in cancer network partnership groups in England, Scotland and Wales to ask if they are happy to participate in this study.
We are also contacting people involved in cancer services generally, who have been identified as having contact with a Cancer Network partnership group.

Do I have to take part?
Taking part in the research is entirely voluntary. It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What does taking part entail?
If you decide to take part, you will be contacted by a member of the research team to set up an interview, either in person or over the telephone, at a time and date convenient for you. We do not anticipate that these interviews will last any longer than one hour. Interviews will be audio recorded with your permission. If you incur any out-of-pocket expenses related to taking part in the interview, such as travel or childcare, you will be reimbursed.

What questions will I be asked?
The interviewer will ask you about the following topics:
- Your role with regard to the Cancer Network Partnership Group
- What you consider to be an impact or influence on services
- The people and organisations that the Cancer Network Partnership Group is seeking to influence
- The aims of the Cancer Network Partnership Group
- The ways in which the Cancer Network Partnership Group may influence services
- Specific examples of the ways the Cancer Network Partnership Group may have influenced services
- The Cancer Network Partnership Group's priorities for the future

Will my taking part in this study be kept confidential?
We will anonymise the information we obtain from you, so that your name will not appear in any publically available documents. The audio recordings of the interviews will be assigned a code to ensure anonymity. Interview transcriptions will be password protected; only the research team will have access to codes and passwords. In accordance with university policy all data will be stored for five years.

It is not anticipated that the interviews would lead to unexpected disclosure of information by participants that could require notification or other follow-up action by the researcher, but should this happen, the researcher may be duty bound to inform the relevant people.

What will happen to the results of the research study?
A report will be written and the research team will collaborate with Macmillan and the NHS Centre for Involvement to publicise the results of the project in a variety of formats.

What will happen if I change my mind about taking part?
You can withdraw or change your mind about participating at any stage without giving a reason; however if you have already taken part in an interview, your data may be retained.

Who is organising and funding the research?
The research is funded by Macmillan Cancer Support.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the North West Research Ethics Committee [Project reference number: 08/H1010/38]

Who is conducting the study?
The research team comprises Dr Sara Morris, Dr Pam Attree, Sue Hinder, Maggie Clifton and Suzanne Vaughan.

What if there is a problem?
If you have a concern about any aspect of this study you should ask to speak to Dr Sara Morris (01524 592656) or Dr Pam Attree (01524 594103), the lead researchers, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through Lancaster University's official complaints procedure. Contact Fiona Aiken, University Secretary (01524 592021 or f.aiken@lancaster.ac.uk)

Although the research deals mainly with organisational aspects of the cancer experience, it is still important to acknowledge there may be sensitive issues to deal with and so support will be provided for any emotional issues that involvement in the project brings up. If you feel that you have been affected in this way, please contact a member of the research team.

Contact for Further Information
If you require further information about this study or other aspects of this research please contact:

Sara Morris
Division of Health Research
Lancaster University

Tel: 01524 592656   Email: s.m.morris@lancaster.ac.uk

6.2.4 Consent form

Participant Identification Number:

CONSENT FORM **Exploring the impact of user involvement on health and social care services for cancer in the UK**

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated 3rd June 2008 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.　　☐

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

3. I understand that any information given by me may be used in future reports, articles or presentations by the research team.　　☐

4. I understand that my name will not appear in any reports, articles or presentations.　　☐

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

Name of Participant　　　　　　　Date　　　　　　　Signature

Researcher　　　　　　　　　　　Date　　　　　　　Signature

When completed, please return in the envelope provided (if applicable). One copy will be given to the participant and the original to be kept in the file of the research team at Lancaster University

6.2.5   Contextual data form

PARTICIPANT NAME: _____

NETWORK: _____

LOCATION OF INTERVIEW: _____

1. Are you?   Male   ☐   Female ☐

2. In what year were you born? ☐☐☐☐

3. Do you consider yourself to be?
White   ☐
Black or Black British   ☐
Asian or Asian British   ☐
Chinese   ☐
Mixed   ☐
Other ethnic group (*please describe*) _____

4. What is your role/job title?
_____

5. Where do you work [if applicable]? _____

Date:
Interviewer name:
Face-to-face   ☐   or   **Telephone** ☐

6.2.6 Interview checklist: core members of partnership groups

Interview topics

Topic	Discretionary prompts
About the interviewee	
Please tell us more about your role	What is your role/job description? How did you come to be doing this job/role?
About the CNPG	
Aims of the group	What kinds of impact is the group aiming for? How are the group's priorities decided? (explore local user group input) How are the group approached to get involved (e.g. in service reviews/evaluation)? In the main would you say the Partnership Group is *shaping* the agenda of the Cancer Network or *responding* to it?
Who is the group trying to influence? (*See checklist of organisations and roles and use mapping form*)	Relationship with those who deliver/commission services? Main channels of communication? Formal/informal contacts?
	Checklist of organisations: • Acute sector – hospitals, specialist centres • Primary care – GP practices, community services • Social Services • Voluntary sector – charities, hospices **Checklist of roles:** • Doctors • Nurses • Social workers • Managers • Allied Health Professionals – dieticians, physiotherapists, occupational therapists • Counsellors • Alternative therapists • Journalists – the public at large
What do you see as evidence of	What difference has the Partnership Group made to cancer

success?	services locally?
	
	Who or what has the group impacted on?
	   o patients/public
	   o organisations/services
	   o nursing staff/other health professionals
	
	How has this come about?
	
	I would know things were changing when I noticed that…
	
	Barriers to success?

Specific examples of change?	Tell us a success story How do you document/publicise your activities? Is there any written evidence of impact (e.g. patient feedback)? (*record on finishing up form*)
Partnership Group's priorities for the future	What do you see as the main opportunities for the future? What (if anything) could prevent that happening?
Directions for further interviews	
	Identify key people/organisations that the group has influenced. (*record on finishing up form*)

6.2.7 Interview checklist: key stakeholders in cancer services

Interview topics

Topic	Discretionary prompts
About the interviewee	
Please tell us more about your role in relation to cancer services	What is your role/job description?
About the CNPG	
Relationship with the CNPG	What is your connection to the CNPG? How do you understand the CNPG's aims?

Impact of the CNPG	In your opinion has the CNPG made a difference to cancer services in your area?
	
	Who or what has the group impacted on?
	   o patients/public
	   o organisations/services
	   o nursing staff/other health professionals
	
	How has this come about?
	
	Barriers to success?

Specific examples of change?	In your opinion what is the CNPG's most effective way of bringing about change? A good example of changing attitudes was… Do you have any written evidence of the influence of the CNPG in your area (e.g. patient feedback)? (*record on finishing up form*)
CNPG's priorities for the future	What do you feel the CNPG's priorities for the future should be in your area? Who are the key people/organisations that the CNPG needs to influence? What (if anything) could prevent that happening?
Directions for further interviews	
	People in the organisation who might have information on the impact of the CNPG (*record on finishing up form*)

6.2.8   Follow-up questionnaire

Dear Facilitator,

We would like to thank you for your contribution to our study so far. There are just a few remaining questions which we would like you to answer, to allow us to build up a fuller picture of user involvement in cancer services in your Cancer Network. It would be very helpful to our study if you could complete the brief questionnaire enclosed and return it to Dr. Sara Morris at s.m.morris@lancaster.ac.uk

If you would like to enclose additional information, such as diagrams of the Cancer Network organizational structure or copies of the Partnership Group terms of reference, we will be happy to receive them.

Thank you

Sara

Using the categories in the table following - Which model best describes the organisation of Cancer Partnership Groups in your Network? (If none of these apply please describe)	
What year was the Partnership Group(s) set up?	
Does the Partnership Group(s) have formal terms of reference?	
How frequently does the Partnership Group(s) meet?	
What organisations/individuals are represented in the Partnership Group(s)? (e.g. service user; carer; lead nurse; cancer service manager; consultant)	
What is the ratio of service users to NHS professionals in the Partnership Group(s)?	
Who is responsible for leading the Partnership Group(s)? (e.g. service user, NHS professional; shared responsibility)	

Partnership Group Models[1]	
Model	**Summary characteristics**
Model A	Stand-alone, non-network locality group with no representation on Cancer Network Board level, or equivalent, Groups
Model B	Locality groups each with separate representation on Cancer Network Board level, or equivalent, Groups
Model C	Non-network locality groups represented on Cancer Network Board level, or equivalent; Groups through an intermediary network "Chairs' Group"
Model D	Linked, network locality groups with co-ordinated representation on Cancer Network Board level, or equivalent, Groups
Model E	Single network-level Partnership Group with representation on Cancer Network Board level, or equivalent, Groups

[1]Drawn from Sitzia, J. Cotterrell, P & Richardson, A. (2004). Formative evaluation of the Cancer Partnership Project. London: Macmillan Cancer Relief, page 38.

6.2.9 Cancer network partnership group: sample terms of reference

Introduction

The Cancer Network and the User Partnership Group believe that user involvement is central to cancer service developments and support the principles and aims of all National Cancer Strategy documents including the series of Improving Outcomes Guidance, Cancer Plan 2000, and the Cancer Reform Strategy 2007.

The User Partnership Group is an alliance between service users and health care professionals and is led by service users.

Purpose

The role of the User Partnership Group is to influence cancer policy and services and to ensure the user and carer perspective is integral to all aspects of cancer service developments throughout the Cancer Network area. It is the main source of advice to the Cancer Network Management Board on all matters relating to user involvement.

Membership

Membership includes users (ex patients, patients, carers or family members); health care professionals; representatives of community and voluntary organizations; self help and support group representatives. Wherever possible, different cancer experiences and tumour sites should be represented. Other groups or individuals will be co-opted onto the group as required. Membership should be reviewed regularly and plans developed for recruiting new members. An induction pack is provided for new members.

Consideration will be given to limiting the length of group membership. Members of the group are able to give up their membership at any time, or alter their level of involvement.

Objectives/how the group works

1. To raise awareness about the importance of user involvement and what it can achieve.

2. To seek active engagement with all organizations involved in delivering care across all aspects of the 'cancer journey'.

3. To be inclusive and to find ways of engaging under represented groups within the population (defined by age, social group, disability and ethnic background)

4. To affect change and innovation in cancer care through partnership working, engaging the talents of all.

5. To take an active lobbying and influencing role

6. To provide a resource and contact point for health and social care professionals wanting advice and engagement of users within cancer care

7. To develop and strengthen links and joint working with a range of user involvement groups to build upon the good elements of user involvement, ensure collaboration and avoid duplication.

8. To develop individuals' knowledge and confidence through CancerVOICES training and exposure to events encompassing cancer care issues. The group will not be a support group.

9. To influence and assist organizations to implement the Cancer Plan and the 'Supportive & Palliative Care' guidance.

10. To influence research on cancer to look at (environmental) causes and prevention, recognizing our responsibility to the following generations.

11. Key personnel will be invited to meet with the group to present key issues, service developments and changes to ensure there are effective strategies incorporated for user involvement and input.

12. The Group will not endorse specific products or therapies, nor is it able to recommend specific support groups.

Areas of work
These could include involvement in policy development, peer review, planning and supporting local services, campaigning and lobbying. Group priorities identified to date include information, communication and staff training.

It will also include representation on the Network management Board and other relevant Network groups and events (Site-specific groups etc.). This will be through direct attendance by the co chairs of the UPG at the Management Board meetings. Members of the UPG where possible will attend the Network Site Specific Groups and/or the Network Cross Cutting Groups. In the event of service users not being able to represent in person the User Partnership Group has agreed a formal process with the Network Site Specific Groups for obtaining user advice and involvement. This will be done by exchange of minutes and/or correspondence and direct discussion between the chairs of the Network Groups and/or the NHS person responsible for the user involvement and in the first instance, the co-chairs of the User Partnership Group. This will be facilitated by the Network User Involvement Facilitator.

Meetings
The frequency of meetings will be dependent on the work programme. This may include a fixed number of meetings and additional working groups to take specific work streams forward to meet deadlines. Sub groups or work groups will meet as and when necessary. Meetings currently take place during the day, but evening meetings could be considered.

The frequency, place and timings of meetings will be reviewed annually by the membership. Minutes of the meetings will be considered public documents, circulated to members and made available on the Cancer Network website. Administrative support is provided by the Cancer Network.

Roles of members:
The chair
The chair will be a user or carer, elected by group members for a minimum of one year and a maximum of three and cannot be re-elected for a further year. If no user or carer is available then a temporary chair from a Trust or service provider can be elected on a short-term basis. The chairs responsibilities include: preparing the agenda for the main group meetings, advising on issues relating to the meetings, follow up of issues arising from meetings, and represent the User Partnership Meeting at relevant meetings including attending the Network Management Board meeting.

Vice chair
There will be two vice chairs. Their role will be to assist with decisions on the agenda for the main group meetings, advise on issues arising from the meetings, assist with chairing one of the sub groups and attend the Management Board meetings as representatives of the User Partnership Group.

Alternative structure
In the event of there being a tie for the election of chair there may be two co-chairs, each of whom will be either a user or carer, elected by group members for a minimum of one year and a maximum of three and who cannot be re-elected for a further year. The co-chairs' responsibilities will combine those given above for the chair and vice-chair and the co-chairs will share responsibility equally.

Users and carers
Users and carers group members bring experience, knowledge, skills and direct experience of cancer services and care.

Health care professionals
Professionals are a resource for the group and provide a feedback mechanism to health care providers and organisations.

The terms of reference will be reviewed annually.

6.2.10 Sample mapping form

Who do you aim to influence?
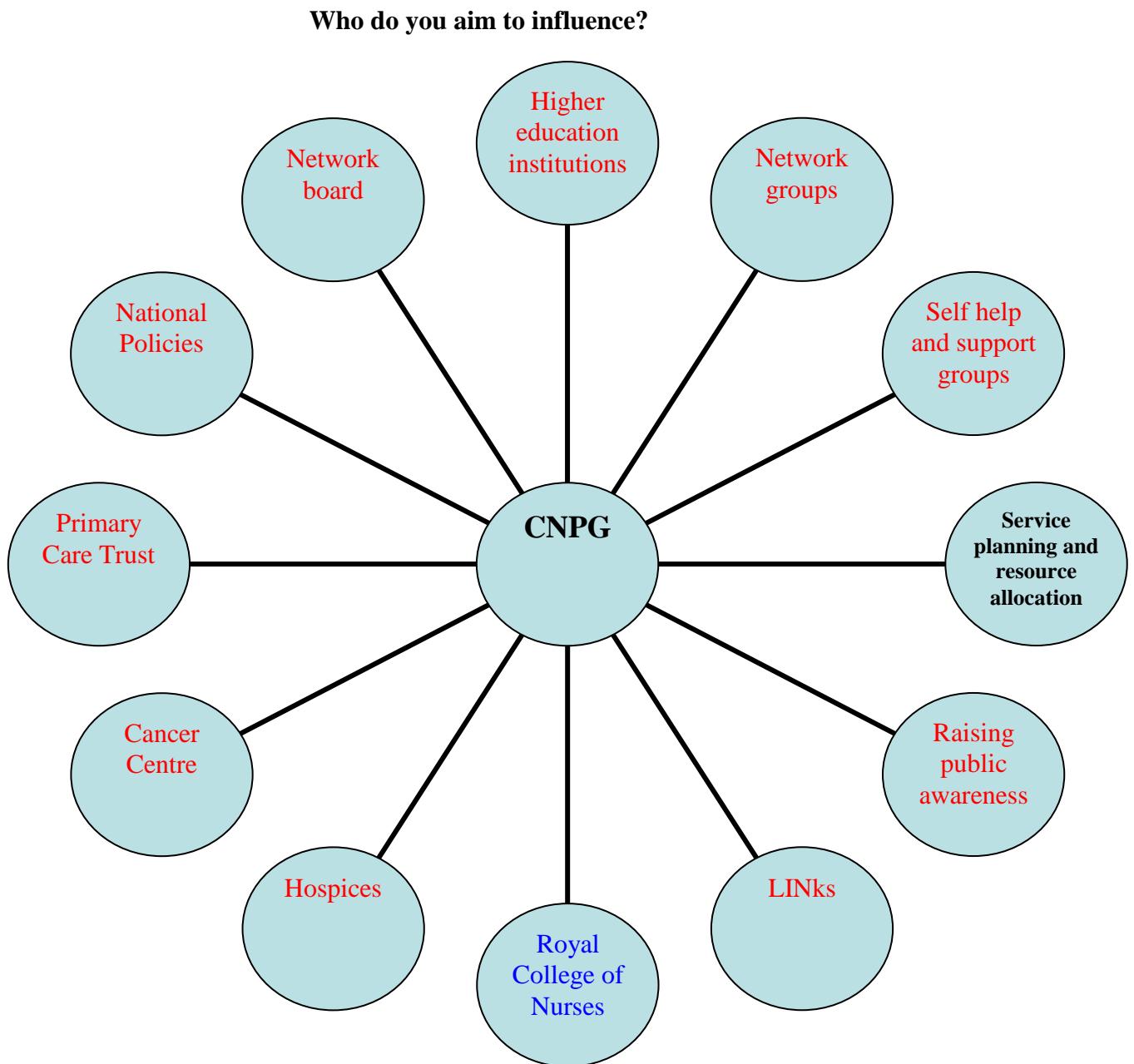
Key: Strong influence – red
Some influence – blue
No influence - **black**