Formative Evaluation of the Cancer Partnership Project

Final Report
(May 2004)

An independent evaluation commissioned by
Macmillan Cancer Relief and the Department of Health

John Sitzia, Phil Cotterell
Patient and Public Involvement Research Unit
Worthing and Southlands Hospitals NHS Trust
Worthing Hospital, Lyndhurst Road, Worthing, West Sussex BN11 2DH, UK

Professor Alison Richardson
Florence Nightingale School of Nursing and Midwifery
King’s College London
5TH Floor, Waterloo Bridge Wing
Franklin Wilkins Building
150 Stanford Street, London, SE1 9NN
This report was commissioned by Macmillan Cancer Relief and the Department of Health (Cancer Action Team).


March 2004 © Macmillan Cancer Relief
Acknowledgements

The evidence for the report has been gathered from many service users, group facilitators, and NHS staff across England. Without exception, these participants gave their time and shared their knowledge and experiences with warmth and generosity. Thank you especially to all those service users who welcomed the research team into their own homes for interviews, and shared their personal experiences of NHS cancer services.

We are most grateful to the project Reference Group, a group predominantly of service users and carers who provided invaluable enthusiasm, support and ideas, and helped us work through some difficult decisions. The group met formally three times. A list of Reference Group members can be found as section 6.1 of this report.

Jane Bradburn (User Involvement Adviser) and Siobhan Peattie (User Involvement Coordinator) at Macmillan Cancer Relief made a substantial contribution to this work, informing the work through their extensive knowledge of user involvement in NHS cancer services, and providing friendly and accessible guidance and support throughout the project. The assistance of Juliet Lushington (User Involvement Administrator, Macmillan Cancer Relief) in accessing documentary evidence and in co-ordinating the Reference Group was very much appreciated. We would also like to thank Judith McNeill (Head of Community Links, Macmillan Cancer Relief) and Cheryl Cavanagh (Department of Health) for their interest and contributions.

Thank you to staff at the Demography and Geography Statistics section of the Department of Health for provision of census data (Section 4.3.2).

Finally, we would like to thank several colleagues in the research community for their help: Ann Richardson for her input to the literature review, and Viv Brown, Belinda Clark and Kate Kelley for assistance with data analysis.
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>5</td>
</tr>
<tr>
<td>1 Introduction and Aims</td>
<td>12</td>
</tr>
<tr>
<td>2 Background</td>
<td></td>
</tr>
<tr>
<td>2.1 Review of the literature on user involvement in NHS cancer services</td>
<td>14</td>
</tr>
<tr>
<td>2.2 The Cancer Partnership Project</td>
<td>20</td>
</tr>
<tr>
<td>2.3 The ‘history’ of the Cancer Partnership Project</td>
<td>20</td>
</tr>
<tr>
<td>3 Methods</td>
<td></td>
</tr>
<tr>
<td>3.1 Mapping exercise</td>
<td>25</td>
</tr>
<tr>
<td>3.2 In-depth case studies</td>
<td>29</td>
</tr>
<tr>
<td>3.3 User involvement in this evaluation</td>
<td>32</td>
</tr>
<tr>
<td>3.4 Research ethics and governance</td>
<td>32</td>
</tr>
<tr>
<td>3.5 Some reflections on methodological aspects</td>
<td>34</td>
</tr>
<tr>
<td>4 Findings</td>
<td></td>
</tr>
<tr>
<td>4.1 Working arrangements of Partnership Groups</td>
<td>35</td>
</tr>
<tr>
<td>4.2 Leading the group: the Chairperson and the Facilitator</td>
<td>45</td>
</tr>
<tr>
<td>4.3 Membership of the group</td>
<td>49</td>
</tr>
<tr>
<td>4.4 The dynamics of partnership</td>
<td>55</td>
</tr>
<tr>
<td>4.5 Motivation and commitment of group members</td>
<td>63</td>
</tr>
<tr>
<td>4.6 Views on the ‘influence’ of the group</td>
<td>69</td>
</tr>
<tr>
<td>4.7 Activities and achievements</td>
<td>73</td>
</tr>
<tr>
<td>4.8 Financial aspects</td>
<td>77</td>
</tr>
<tr>
<td>4.9 Strategies for development</td>
<td>80</td>
</tr>
<tr>
<td>5 Conclusions and Recommendations</td>
<td></td>
</tr>
<tr>
<td>5.1 Summary evaluation</td>
<td>84</td>
</tr>
<tr>
<td>5.2 Attainment of stated objectives</td>
<td>85</td>
</tr>
<tr>
<td>5.3 Key themes</td>
<td>87</td>
</tr>
<tr>
<td>5.4 Recommendations</td>
<td>99</td>
</tr>
<tr>
<td>6 Further Information</td>
<td></td>
</tr>
<tr>
<td>6.1 Reference Group membership</td>
<td>101</td>
</tr>
<tr>
<td>6.2 A list of the 30 groups in the study</td>
<td>102</td>
</tr>
<tr>
<td>6.3 References and further reading</td>
<td>104</td>
</tr>
<tr>
<td>6.4 The interview questionnaires</td>
<td>108</td>
</tr>
</tbody>
</table>
Executive Summary

This report presents the findings from a formative evaluation of the Cancer Partnership Project (CPP). The CPP was a three-year initiative to support the development of service user involvement in the 34 cancer networks in England. Both the CPP and this evaluation were commissioned jointly by Macmillan Cancer Relief and the Department of Health.

Background

The 1995 Calman-Hine report (Expert Advisory Group on Cancer 1995) stressed not only the need for NHS cancer services to be patient-centred but also the requirement that NHS decision makers at all levels take account of patients’ views and preferences. This policy direction was reinforced by the National Cancer Plan (Department of Health 2000), which noted the need to empower patients to improve services. Work on furthering service users’ involvement in cancer care developed alongside changes in NHS structures, with the intention that service users play a meaningful role in shaping policy, practice and provision within the wider NHS (NHS Executive 1996; Department of Health 1999, 2001, 2003; Secretary of State for Health 2001).

However, in the late 1990s there was a lack of an evidence base to inform policy makers of the structures and processes best suited to the engagement of service users in the planning and monitoring of cancer services. Following preliminary work, a report to the National Cancer Taskforce (Bradburn 2001) proposed that a structure of Cancer Partnership Groups be set up in the 34 cancer networks and made suggestions about how this might be achieved. With the support of the National Cancer Taskforce, and in light of this progressive NHS service user involvement agenda, the CPP was established in January 2002. The end date for the CPP was April 2004.

Aims of the Cancer Partnership Project

The CPP recognised the need for support, training and adequate resourcing if user involvement in NHS cancer services was to be effective. The project aimed to support the development of user involvement by:

- Working together with the 34 cancer networks in England to establish cancer partnership and user groups.

- Supporting the recruitment and training of user involvement facilitators in cancer networks.
• Monitoring the development of user involvement in cancer networks.

• Supporting user representatives to inform the development of cancer services and research at both network and national levels.

• Linking effectively with other Department of Health initiatives and organisations.

Aims of the evaluation

The purpose of the evaluation was to provide robust information to the CPP Steering Group about the value of user and partnership groups as a mechanism for effective and meaningful user involvement in cancer networks and local cancer services. Specifically the evaluation aimed:

• To assess the level of involvement that service users had in cancer service networks over the CPP period, including an assessment of the range of diversity of representation achieved.

• To evaluate the impact that user and partnership groups had on local cancer services and to assess the likelihood that positive changes would be sustained.

• To explore the effects of involvement in service user and partnership groups upon individual members, both service users and health professionals.

• To identify supportive factors for, and barriers to, effective user and health professional involvement in partnership groups.

Methods

The evaluation consisted of two different activities, with a total of four separate ‘sets’ of participants providing data. The first activity was a ‘mapping exercise’ to collect factual information on Service User / Partnership Group activity from each of the 34 cancer networks in England. This included information on the composition and structure of groups, support and training, activities and achievements, and barriers and challenges. This information was collected via a telephone interview with a representative, normally the Chairperson, of each partnership group.

For the second activity, we made visits to six selected cancer networks in order to talk in person with a range of service users and NHS staff about various aspects of their involvement in the partnership group, and to ascertain their
views of the group, particularly in regard to its effectiveness and its influence on local NHS services. We interviewed 29 people in this second part of the evaluation, including service users and NHS professionals involved in partnership groups, and also a small number of professionals within each network who were not members of partnership groups. The service users we interviewed drew upon a wide range of experiences, including experience of many different types of cancer. The professionals were an equally varied group, including clinicians and managers from different specialities and service levels.

Key Findings

Working arrangements of Partnership Groups

Groups had been established in 30 of the 34 cancer networks. 29 of the 30 had opted for a ‘partnership’ as opposed to ‘service user only’ group. Five partnership group models had evolved. The most common model was one in which a single, network-wide group acted as the hub for user involvement activities, with direct representation on the cancer network Board; however, there was an emerging trend to develop more ‘locality’ groups which are closer to people’s homes and focus on local services. Partnership groups had been active for an average of 21 months. Most groups worked to a list of objectives with some having detailed two- or three-year plans. Most groups met every one or two months. There was some tension concerning the timing of meetings with service users preferring weekends and professionals preferring weekday daytime meetings.

CPP funding for groups was mainly used to pay for the group's facilitator and for administrative support. Other expenditure consisted of payment for meeting rooms, members’ expenses, training and conference fees, and printing costs. Only 23% of groups had any future funding in place at the end of the CPP funding period. Over 50% of groups expressed concern over future funding.

Leadership

The Chairperson and Facilitator provided leadership for a group, and on the whole members were very happy with their leaders. Service users chaired 92% of groups, and having a service user as chair was generally considered to be the preferred option. 25 groups had paid facilitators, typically salaried NHS staff for 21 of whom service user involvement was their ‘core’ role. Training for Chairpersons was identified as an unmet need. Key to the leadership roles of chairperson and facilitator was the ability to share a vision of the group’s work and role. A good relationship between the Chairperson and the Facilitator was central to the successful functioning of the group. Succession planning was identified as a concern requiring serious consideration.
Membership

The average attendance at meetings was 20 people, two-thirds of whom were service users and one-third NHS staff. Most group members were women, and most members were middle-aged. Service users had experienced a wide range of cancers, and some were receiving active treatment. Group members identified poor recruitment of new members as a significant concern, together with long-term retention of existing members. Strategies for recruitment of new service user members, whilst entered into with enthusiasm and imagination, invariably reaped small reward. Respondents also were concerned about a widespread lack of representation of certain groups: younger people, men, the rural poor, those from socially deprived areas, people whose disease was at an advanced stage, and, in particular, people from black and minority ethnic communities. The involvement of such ‘under-represented’ groups represented an ongoing and difficult challenge.

The dynamics of partnership

Service users were enthusiastic about working in partnership with professionals. Partnership working generally was seen as a strongly positive development and vital in enabling service users to influence services. A wide range of professional disciplines was represented in the groups and these individuals were seen as a source of support, information and advice. Generally the groups functioned harmoniously. There were however some tensions in this partnership. One was the feeling among service users that a minority of professional members lacked real commitment to the group. A second concerned the issue of service user disclosure of personal experience, which was frowned upon by NHS members in particular. A third tension concerned emotional attachment to the group; whilst service users expressed their ‘passion’ for user involvement, for example, NHS staff remained more – ‘professionally’ – detached.

Motivation and commitment

Most service users had altruistic motivation for their involvement. Over 80% of service users we spoke with told us that their personal experience of NHS cancer services had been positive; and that participation in partnership groups allowed them to ‘give something back’ or to contribute to NHS service development in some positive way. Less than one in five service users reported having had a poor care experience. It is puzzling therefore that the professionals we interviewed thought that service users on the whole were motivated by having a bad experience of NHS care.

Groups typically had a ‘core’ of service users who were involved in and conducted much of a group’s work. This core group expressed disappointment in a perceived lack of interest from the general population of service users. There also was a degree of tension within groups in that service users considered
some professional members to lack real commitment to user involvement, and indeed some – but not all – professionals concurred that they attended as part of their job rather than through personal conviction. Moreover, the commitment of the local and wider NHS to both the group and the wider user involvement agenda was widely challenged by both service users and NHS staff.

Activities and achievements

Groups’ aims typically were framed around influencing local cancer policy and services for the benefit of patients, and ensuring that the service user perspective was integral to service developments, through working in partnership with professionals. Many people spoke of the enormous challenge of working with the NHS and of the complexities of change processes. It was acknowledged that both culture shift and systems change were required in order for service users to influence service policy and delivery, and it was accepted that such changes take considerable time and effort. Respondents generally were of the opinion that ‘embedded’, system-wide involvement was a long-term goal.

Nevertheless, respondents strongly felt that partnership groups already were ‘making a difference’ to local NHS cancer services. Factors that enabled effective influencing were the successful functioning of the group itself, strategic thinking and working, and having the support of senior NHS managers and clinicians. Factors that hindered a group’s ability to influence included group leadership problems, the large geographical size of a network, and concerns regarding funding and sustainability.

The range and depth of activities accomplished by groups was impressive. They had achieved a significant amount in terms of projects completed and their visibility in the network. The establishment and early development work was widely considered a great achievement. The fact that the groups were thriving and, for the most part, were active at network board level were also considered significant achievements. Groups acted in a consultative capacity for a spiralling list of people in their own localities and further a field. Group members ‘networked’ well and were active in an enormous range of other initiatives and projects. The partnership groups appeared to act as a nucleus for much user involvement work within their network areas. An achievement they often felt to be very important was their planning and development of initiatives focused on furthering access to sources of patient information as well as involvement in policies regarding communication skills for staff.

Evolution

It was clear that groups were evolving organically over time. The gaining of confidence, experience and expertise by members was supported by training, particularly CancerVoices training which was regarded as important. Evolution of
partnership working was dependent equally on the development of a receptive and supportive local NHS climate. The Commission for Health Improvement recently reported that NHS organisations routinely gather feedback from service users, but that very few are doing anything that allows service users directly to influence policy and practice (CHI 2004). Cancer Partnership Groups have provided a mechanism through which patient and public involvement has taken one sizeable step beyond this level of ‘consumer feedback’.

Nevertheless, increasingly groups were looking to work towards the next stage of Patient and Public Involvement, in which PPI activities are integrated with other efforts to improve services and in which PPI is regarded as a core activity for the NHS organisation: that is, PPI becomes part of everyday practice across an organisation. For longer-term success, groups need to be secure in the knowledge that they are valued, perceived as important and relevant by local NHS clinicians and managers, and that over time both sides are working towards service users being at the core – rather than the periphery – of corporate decision making.

Recommendations

Recommendations for the Department of Health and NHS organisations

1. Service commissioners, working through cancer networks, need to identify and secure resources required to ensure sustainability of Partnership Groups. This needs to be a flexible, long-term commitment. As a priority and as a minimum, service commissioners should make a commitment to meet the costs of a paid User Involvement Facilitator and of regular Partnership Group meetings.

2. Service commissioners working through cancer networks should make a policy commitment to place equal value upon the priorities for service change identified by service users via Partnership Groups as upon those identified by NHS staff.

3. NHS organisations and professionals should note the clear value of user involvement activities documented in this report. NHS organisations should engage in education and awareness raising within their organisations about the importance of service user involvement, the high significance of patients’ priorities, and the central role of user involvement in the shift towards patient-centred care.

Recommendations for Macmillan Cancer Relief

4. There is a clear need for a better understanding of issues around diversity and inclusion in the context of Partnership Groups, particularly related to Black and Minority Ethnic groups, men, children and young people, and
very sick people. We recommend that Macmillan commission work to collect perspectives on inclusion/exclusion and to further explore barriers to user involvement for these and other less included groups.

5. There is a clear need for dedicated training for group Chairpersons to support their role, with an emphasis upon chairing skills. We recommend that Macmillan make arrangements for provision of this training on an ongoing basis.

6. It is clear that the long-term success of user involvement depends upon genuine collaboration between users and NHS cancer professionals. The attitudes of NHS staff are therefore critical to the viability of user involvement. We recommend that Macmillan commission research to gain a better understanding of NHS cancer professionals’ attitudes to user involvement.

7. Macmillan should work with the Department of Health and cancer networks to develop training in service user involvement for NHS professionals.

8. Macmillan should develop a strategy for the long-term support of groups, embracing evolution and development and cognisant of the wider Public and Patient Involvement (PPI) agenda.
1 Introduction and Aims

1.1 Introduction to this report

The need for greater patient and public involvement is a major theme in current discussions about health policy and practice. This can be seen in the recent establishment of the Commission for Patient and Public Involvement in Health (CIPPIH) and its local patient forums, together with policy guidance and papers issued by the Department of Health. Macmillan Cancer Relief has taken a particular interest in encouraging the involvement of people with cancer in broader policy decisions affecting them. Together with the Department of Health, it has supported the establishment of local user and partnership groups, comprising users of cancer services and local professionals, to work within cancer networks to facilitate user involvement. As part of the brief, it commissioned an evaluation of these groups. This is a report of that evaluation.

1.2 Aim of the evaluation

The aims of the evaluation have been to assess the level of user involvement in cancer networks, to evaluate the impact of user and partnership groups on local cancer services and to explore the effect of being involved on users and health professionals. In addition, it has attempted to call attention to examples where user and partnership groups have contributed to local initiatives for public and patient involvement within trusts and their impact on the quality of cancer services. In short, it is about both the process and the outcomes of these groups.

1.3 Terms used in this report

This report uses a number of terms that might be unfamiliar to the reader. It may be useful to start with some definitions. ‘Partnership Groups’ are groups of NHS cancer service users and, usually, NHS staff that exist to promote and develop ‘partnership’ between local NHS service providers and service users in the shaping and delivery of local cancer services, the ultimate aim being to improve cancer services. The term ‘service users’ is intended to cover those who use health and other services, including family or other carers as well as patients themselves. The term ‘NHS professionals’ covers a range of both clinical and managerial staff within Cancer networks, who work with users within the partnership groups. The ‘involvement’ of interest is in discussions and decision-making about broad policy or practice, rather than in discussions about patients’ own health care. Such involvement may range from major issues concerning what is provided or to more minor decisions about day-to-day practice within service provision.
1.4 Confidentiality

The findings in this report draw heavily upon information provided by service users and NHS staff active in Partnership Groups. To encourage respondents to speak freely, we gave an assurance that, when using comments and quotes, the report would reveal the identity neither of the individual participant nor of the group/network to which the individual was affiliated. Participants are therefore in this report identified only by a ‘Participant Identification Number’, for example ‘Participant 23’.

We also have made efforts to ‘anonymise’ groups or networks where appropriate, and always when the material is sensitive; nevertheless, in some cases the identity might become apparent to an individual reader through his/her prior knowledge of the group/network. It is strictly not our intention to name and shame. By contrast, it has been our policy in this report to highlight successful practice wherever possible, and to identify groups/networks in this context.
2 Background

2.1 Review of the literature on user involvement in NHS cancer services

2.1.1 Themes in user involvement: some general comments

User involvement is by no means a new idea. It has permeated discussions within the NHS and beyond over many years. It was given its first major thrust in the early 1970s, along with interest in consumer participation in a number of other fields, most visibly demonstrated in the health arena by the introduction of Community Health Councils. Over the intervening period, there has been a regular flow of academic and other writings on the subject, which help to shed light on some issues key to the analysis in this report.

A number of themes underlie these discussions. First, there is the question of appropriate mechanisms for user involvement. Arrangements for direct involvement entail the participation of users in decision-making bodies or, at a minimum, in bodies that can feed into the decision-making process. This may be involvement in local committees or working parties or in organisations that are regularly consulted by those who make decisions. In contrast, indirect involvement entails a range of mechanisms for eliciting user views, subsequently used by professionals or managers to influence policy. These mechanisms can be seen to comprise the various forms of research by which users’ opinions can be obtained, such as postal surveys, interviews and focus groups. Over the years, many guides and manuals have been produced intended for those who wish to set up systems for user consultation in the NHS (Sykes et al 1992; Kelson 1997; Barker et al 1999; National Assembly for Wales and Office for Public Management 2001).

Patient support (or self-help) groups are sometimes seen as a means of user involvement, but this will vary with the particular nature of a group’s activities. Such groups can have a range of functions. Often set up primarily to offer mutual support among members, some develop into major service providing organisations and/or serve as pressure groups on behalf of their members (Richardson 1983a; Wilson 1999). In this last capacity, they can prove another mechanism for user involvement in decision-making, although not all groups wish to engage directly with policy-makers. There are many support groups in the cancer field. Some are national in scope, while others are active solely in one local area; in addition, some are generic, with an interest in all kinds of cancer, while others take a particular interest in one form.
A second major theme in writings on user involvement pertains to the attitudes and experiences of users in the course of becoming involved. Some argue that there can be particular difficulties for people from other walks of life in working closely with professionals, including coping with jargon or feeling unable to articulate their views in the time available. On the other hand, it is evident that some users are more than capable of making their views heard. Some research has taken a particular interest in motivations for involvement and in the impact of such involvement for the people concerned (Small & Rhodes 2000; Gallini 2003). Other studies have examined training needs of patients, for instance for communication and representation skills and to understand the NHS and voluntary sector (Brotchie & Wann 1993).

A third theme is the issue of representativeness, that is whether a small group of users can and do adequately reflect the views of the wider body of patients. It is only a small proportion of any set of users who wish to be active in wider discussions and these may not be typical of the wider group or have means of listening to them. This becomes particularly critical where the views of certain types of groups, such as ethnic minority groups or elderly people, are insufficiently represented. In the area of cancer services, it may be that people with less common forms of cancer (or for whom there are fewer user groups) are less well represented. This issue is intertwined with that of the particular system for involvement: the smaller number of users involved, the less likely that they can speak for a wider population.

Fourth, and of particular importance, there is the question of the impact of user involvement, i.e. the extent to which decisions concerning policy or practice are changed. There has been surprisingly little research on this topic. This may be partly because it is very difficult to identify the effects of such involvement: issues can change rapidly, or conversely take a long time before they are brought to fruition, so that there may be a sizeable time lag between seeking users’ views and bringing them to a decision-making agenda. But possibly more problematic, it is not easy to demonstrate that a decision is appropriately attributed to a particular source. Many different constituencies may favour the same course of action. Politic managers may call on users’ views to legitimise decisions they were likely to take in any case. Moreover, it can often be difficult for those actually involved in a decision to know the reason for their views: a strongly held position may arise from discussions with users, but it may also stem from discussions with other stakeholders or from a persuasive article. A cultural climate of taking users’ views seriously may lead an organisation to take decisions in the spirit of their concerns, without even asking them directly.

Finally, some writers have sought to assume a direction of influence according to the intentions of those designing systems for involvement. Perhaps the most widely recognised framework is that first published by Arnstein (1969), which describes a ‘hierarchy’ of motivations, from ‘manipulation’ and ‘therapy’ at one
end of the scale to ‘partnership’, ‘delegated power’ and ‘citizen control’ at the other.

A major review of research on user involvement (Crawford et al 2003) notes that much of the literature consists of case studies prepared by those directly involved and may therefore be subject to bias. Nonetheless, there is some evidence that patient involvement has led to some changes in service provision. Such changes pertain primarily to the preparation of patient information or systems to make services more accessible, but occasionally new services have been provided. The authors note that some research also suggests that patient involvement has had a wider impact on the organisations involved, altering staff attitudes and the general organisational culture. The factors seen to promote user involvement in health care include clarity about its aims and scope, organisational commitment to act on users’ views, and adequate time and resources.

A key research team in this field argues that user consultation in the health arena is growing, but its impact is fairly limited (Harrison et al 2002). Its most recent research found that although most primary care groups and trusts studied had a strategy to involve patients or the public and had set up initiatives to this end, the effect of such activity was fairly modest. There was a growing culture of enthusiasm for the idea of public and patient involvement, responding to expressed needs and being accountable to their communities, including the views of more marginalized groups, such as ethnic minorities, poor or older people. But while they found evidence of additional services (such as additional physiotherapy sessions), changes in the configuration of services (such as the siting of practices), or changes to local plans or procedures as a result of public or user involvement, this was in a minority of areas.

The view that user (and public) involvement has had a limited impact on service provision is reiterated in a very recent report by the Commission for Health Improvement (CHI 2004). It argues that while the NHS is improving its systems for obtaining feedback from users, it is less active in ensuring that this information influences decision-making.

Moreover, activities for public and user involvement are not well integrated into other efforts to improve services and good practice is not being shared across organisations. Impressive strategies on paper were often not rooted in operational priorities or had not become part of the corporate mainstream.

A clear message underlying these findings is the necessity to be sensitive to the many hidden processes by which organisational decisions are taken. This is the message of one recent report, concerned with the processes of organisational change (Anderson et al 2002). Instead of an emphasis on formal decision-making mechanisms, the authors propose that it is important to look more
broadly at the ‘messy political process’ through which organisations learn. Personal contact can play a key role: for instance, where board members attend user involvement meetings and engage in direct debate, there may be more user influence than where user recommendations are placed on formal agendas. This is less transparent and relies on political astuteness. Put another way, the absence of evidence of the impact of user involvement should not be mistaken for absence of effect. The impact can be too subtle and untraceable to be picked up by research, however sophisticated its instruments.

2.1.2 User involvement in cancer services: recent developments and research to date

The 1990s witnessed a revival in interest within the NHS in the idea of public and user involvement, starting with a focus on information for patients (Department of Health 1991) and subsequently developing into a broader concern with involvement in policy and planning (NHS Executive 1996; Department of Health 1999). This culminated in a requirement of the Health and Social Care Act (2001) for primary care trusts and strategic health authorities to involve and consult with patients, carers and the public (Section 11) on the planning and delivery of services (Department of Health 2003).

This drive had a parallel focus within documents on cancer services. The 1995 Calman-Hine report (Expert Advisory Group on Cancer 1995) stressed the need for services to be not only patient-centred but also to take account of their views and preferences. This view was also reflected in the National Cancer Plan (Department of Health 2000), which noted the need to empower patients to improve services. Indeed, the user and partnership groups under study here can be seen to stem from this Plan. Developments on the ground are expected to accelerate with the publication in March 2004 of the National Institute of Clinical Excellence (NICE) service guidance on Improving Supportive and Palliative Care for Adults with Cancer with a topic devoted to User Involvement.

Despite a plethora of books, papers and research reports on user involvement in health service planning in general – and certain other fields, such as mental health, in particular – there is surprisingly little research on user involvement in the field of cancer. One paper usefully documents the potential systems employed, notes some changes introduced as a result and recommends the systematic establishment of partnership groups across cancer networks (Bradburn 2001). Some other papers describe experience with particular mechanisms (Hunt et al 2002) or explore key issues arising in the process of implementation (Gott et al 2002).

User involvement is notable by its absence in an evaluation of the first phase of the Cancer Services Collaborative (CSC) (Robert et al 2003). It is surprising to find that this makes no mention of user involvement as such. The CSC was
heavily underpinned by a patient perspective and did call on users’ views by various traditional research methods. In addition, a CPP representative sat on the CSC Steering Group, and a joint CSC/CPP conference was held in December 2002. Other published sources indicate that some growth in user involvement as the CSC, and there is now a particular work stream dedicated to patient information (Cancer Services Collaborative 2002).

Nonetheless, there have been two sizeable studies in this field. One examined the views of both patients with cancer, recruited from local user and self-help groups, and service providers with responsibility for user involvement about arrangements for such involvement in cancer care services in one NHS region (Gott et al 2000). The researchers found considerable consensus between them on the importance of user involvement, but at the same time much confusion about what was meant by the term. Both felt it was important to achieve a degree of partnership and for any systems not to be one-off or purely token exercises. Nonetheless, a number of difficulties were identified in implementing user involvement at a strategic level, including problems of recruitment to achieve representativeness (both of ethnic minority groups and people with less common forms of cancer), limited resources and a legacy of scepticism among professionals. At the operational level, there were problems of information, communication and training; some user groups were not keen to take part because they were focused on other issues, such as mutual support.

The second, a three year study funded by the Department of Health, addressed the key factors facilitating or limiting user involvement in cancer services, undertaken in another region (Titter et al 2003a). This also involved interviews with users and professionals, but in addition entailed a mapping exercise of mechanisms for user involvement in the area and case studies about the process of user involvement in three trusts.

The team also developed a practical toolkit to help others to introduce systems for user involvement, published separately (Titter et al 2004), and a number of academic articles on selected aspects of their research (Titter et al 2003b).

Like the earlier study, this research also found widespread agreement on the importance of user involvement, but considerable disagreement on the appropriate scope or the people who should be involved. The views of professionals were felt to be key to the success of user involvement mechanisms and a need for more training in this area was stressed. Few users (less than one quarter) had any experience of any involvement and these were primarily in drug trials, fund-raising and questionnaire surveys, i.e. not direct involvement of primary interest here. Many in any case did not wish to become involved and those who did were unclear as to how to do so. The differing perspectives of users and professionals about user involvement, including considerable professional doubts about the appropriateness of such
involvement, are highlighted in a paper from the research team (Daykin et al 2002). In terms of actual practice in this area, user involvement was often integrated with complaints procedures or clinical governance strategies, creating a distrust among staff to be involved. Indeed, there was limited evidence of formal user involvement policies in cancer services and little designated funding for such activities. The arrangements that did exist were often one-off exercises, not integrated into service planning or practice.

A general dearth of research is also the case in the more specific field of palliative care. Although there are a growing number of papers on user involvement in palliative care, most of these are discussion papers about the pertinence of the topic in this context (Tower 1999; National Council for Hospice and Specialist Care Services 2000; Oliviere 2001; Cotterell 2002) or descriptions of methods employed (Kraus et al 2003). The one major study on the topic, based on interviews with patients, excluded cancer patients from its remit (Small & Rhodes 2000).

Moreover, very little research appears to have addressed the role of cancer support groups. A somewhat dated study (Bradburn et al 1992) found such groups to be a valuable resource for cancer patients, offering mutual support together with a range of services not provided elsewhere. Hospital staff were not well informed about such groups, however, and were reluctant to refer patients to them. A more recent evaluation of an advocacy training programme for patients with breast cancer, undertaken in Australia, found that this resulted in a significant increase in participants’ involvement in boards and committees, clinical trials and breast cancer advocacy groups (Davis & Redman 2001). On the other hand, there was no change in their involvement in other key activities, such as lobbying for change, serving on government advisory committees or involvement in key breast cancer organisations.

Of course, research on user views as such can also be influential on local policy and practice, either by being widely accepted as indicative of what should be done (National Cancer Alliance 1996) or because it was commissioned expressly for this purpose (Birchall et al 2002). This report, however, is not about such indirect means of involving users.

It is more than likely to prove difficult to reconcile the rhetoric of user consultation with the practicalities of its implementation. The very high expectations placed on often small and fragile bodies to bring an element of democracy or accountability into the health service almost set them up to fail. User involvement is often assumed to be an intrinsic good, without attention to the complexities necessarily involved (Florin & Dixon 2004).
2.2 The Cancer Partnership Project

The Cancer Partnership Project (CPP) was a three-year joint Macmillan Cancer Relief, Department of Health initiative to support the development of user involvement in cancer networks in England. The CPP was established in order to implement a strategy for user involvement in cancer services endorsed by the National Cancer Task Force in April 1999, to develop a coordinated, more integrated approach to user involvement in cancer services.

The CPP recognised the need for support, training and adequate resourcing if user involvement in NHS cancer services is to be effective. The project provided three years funding of £15,000 per annum per cancer network (£10,000 from Department of Health (DoH) and £5,000 from Macmillan Cancer Relief). The DoH funding was provided for each of the financial years 2001/02, 2002/03, and 2003/04. The Macmillan funding was provided for each of the calendar years 2002, 2003, and 2004. CPP funding therefore will cease completely at the end of 2004.

The CPP Project Outline (Department of Health / Macmillan Cancer Relief 2002) stated that the aim of the CPP was to support the development of cancer service user involvement in cancer services by:
1. Working together with the 34 cancer networks in England to establish cancer partnership and user groups.
2. Supporting the recruitment and training of user involvement facilitators in cancer networks.
4. Supporting user representatives to inform the development of cancer services and research at both network and national levels.
5. Linking effectively with other DH initiatives and organisations (including the PPI strategy, Primary Care Trusts, and Cancer Services Collaboratives).

2.3 The ‘history’ of the Cancer Partnership Project

A more detailed account of the history and development of the Cancer Partnership Project now follows. This section of the report was kindly developed by Jane Bradburn.

2.3.1 Background to the Project

The CancerVOICES project was developed by Jane Bradburn and Cancerlink in 1998 to establish a national network of trained and supported cancer service users who wanted to work in partnership with health professionals. Success in engaging cancer service users who wanted to have their voices heard did however serve to highlight the lack of systematic ways in which they could engage with NHS cancer services.
In 1999 there was little evidence of any structures to support routine and systematic user involvement in the cancer networks. A report to the National Cancer Taskforce (Bradburn, 2001) proposed that a structure of Cancer Partnership Groups be set up in the 34 networks and made suggestions about how this might be implemented. Attention was drawn to the fact that the development of partnership groups was an emerging model across many cancer networks following the Calman-Hine Report, with groups appearing in East Sussex, Rotherham, Nottingham, Sheffield, Bristol, Buckinghamshire, Oxford, Hull, Worcester and Northampton. The model appeared to have the advantage of both engaging users and providing the users with group support from both peers and/or professionals. Users working together gained confidence from one another in identifying issues of concern and being able to put these forward in a way which individual patients often find difficult. Groups appeared to offer users a way of being involved collaboratively with health professionals to develop local cancer services.

2.3.2 ‘User Involvement in Cancer Services’– a blueprint for cancer networks

The April 2001 paper proposed that each cancer network should have a Cancer Partnership Group. This group would be set up as an integral part of the network structure to include equal numbers of users and professionals.

The Chair of the Group should be a user and at least two users should be members of the Executive Board and Steering Group for the network. Its task would be to facilitate and advise on user involvement for the whole network and to raise local issues. The Group would provide a pool of cancer service user representatives from different backgrounds and with experience of different cancers, able to work with a variety of working groups (including research) within the network. It was further proposed that this structure should cross health and social service boundaries and include representatives from all relevant agencies.

2.3.3 Integration

‘Integration into the cancer network structure in order that users have influence and do not become marginalised or tokenistic.’

This aspect was seen as the key to success. There was recognition that network structures varied but that the partnership group should be positioned in order to be able to influence the network and facilitate and advise on user involvement throughout the whole network. Networks were advised to map out existing mechanisms for user involvement and ensure that any existing user forums and groups were represented on the Network Cancer Partnership Group.
Many user groups were established before cancer networks developed. Linking these into the structure of the networks was to be a priority. For example in the Four Counties Cancer Network (now Thames Valley Cancer Network) there were three user groups, one in Oxfordshire, one in Buckinghamshire and one in Northamptonshire. These groups worked together to link user involvement across the whole network.

Groups had developed in a range of different settings: health authorities, NHS Trust or community based resource centres. Building flexibility into the development of groups was seen as key in order to ensure local ownership and user-led development. It was recognised that each network would have different local networks and configuration of services and that it was important that any national policy on user involvement build upon existing networks and groups rather than ignoring or replacing them with a top down approach.

2.3.4 Inclusion

‘Users need to be able to engage in different ways and at different levels according to their abilities and interests.’

The structure that was set up was encouraged to take account of the need for inclusion. It was recommended that group composition should include users (patients and carers), voluntary sector members, and health care professionals (both clinical and managerial). Gathering a broad spectrum of views could be facilitated through patient surveys, focus groups and other methods. It was suggested that these might provide a mechanism for ensuring the inclusion of minority ethnic groups and other marginalised groups and other members of the community who are not able or do not wish to sit on a forum or committee.

2.3.5 Resources

‘User groups need to be adequately resourced and supported.’

Adequate resourcing and support was also seen as key. User groups required funds for travel expenses, conference attendance, books and information, publicity, venues, refreshments and training. Some groups paid the user Chair of the group for the time they gave to the role and for facilities to support the groups work. This practice was recommended.

Facilitators (or development workers) were seen as a vital resource for the development of groups. Those user groups that were supported by a development worker or co-ordinator appeared to have benefited. In 1991 there were development worker posts in 6 areas in England to our knowledge (Sheffield, Nottingham, Hull, Bradford and Bristol). Most were part-time Health Authority funded posts, but funding was often precarious. The role the facilitator
took was that of assisting the group to develop and make connections within the NHS. They did not lead the group but did play a crucial role in smoothing the process of users and health professionals working together and in linking the user group with community, self help and ‘hard to reach’ groups.

2.3.6 Links to other NHS patient and partnership initiatives

'It is not helpful to users to have many different organisations and agencies asking for their participation. Boundaries that exist between research and services in the NHS may be obstructive to users who might want to participate in both or either.'

It was suggested that within the context of cancer networks, the partnership group should also link to the Supportive and Palliative Care Networks, as well as the Cancer Research Networks.

Links to emerging Patient Forums (now referred to as Patient and Public Involvement Forums) were also seen as vital. It was suggested that these could be made through members of the Partnership Group providing representatives on those forums and on other initiatives.

2.3.7 Recommendations of the April 1999 paper

The Paper made the following recommendations

- Cancer service users should be involved in the development, policy and planning of cancer services and research.
- Cancer service user involvement should be built into the structure of cancer services notably in the cancer networks.
- Cancer networks should develop a user involvement strategy, identifying a senior user involvement champion.
- Systematic mapping and evaluation of user involvement in cancer services should be undertaken with users to find appropriate models.
- Adequate resources should be made available to support effective user involvement in cancer services.
- Methods to build capacity to support user involvement in a sustained way, as well as appropriate monitoring and evaluation involving users need to be adopted.
- A programme for User Involvement Beacons in Cancer Services should be developed and the concept of User Involvement Collaborative investigated.

2.3.8 Establishment of the Cancer Partnership Project

The National Cancer Task Force endorsed the proposal that user involvement be built into the structure of cancer services through the development of Partnership Groups and User Groups within cancer networks. Subsequent to
this the Department of Health and Macmillan Cancer Relief set up the Cancer Partnership Project.

Partnership groups have been developed at network level to facilitate and advise on user involvement throughout cancer networks. Increasingly groups developed at local level based around NHS Trusts where local people could play an active part in their cancer services.

The groups have been developed by networks with the support of the Macmillan Community Development Co-ordinators. Development days to establish user involvement in cancer networks have been used as a mechanism for engaging local users and enabling them to determine the way in which they wish to be involved. When a group is established, they have been offered CancerVOICES training in order to equip the group to work effectively with health professionals.

The first phase of the project aims to work with partnership and user groups to appoint facilitators to support them to develop user involvement in cancer networks and to provide training for those facilitators. A facilitator support programme was developed and regular meeting held both nationally and regionally. The Project has produced a CancerVOICES Resource Pack for users incorporating much of the collective learning from the partnership groups.

A national BME network developed by Macmillan together with other cancer charities has linked with the Project to address the involvement of BME communities. This has resulted in the development of local network BME forums in some cancer networks and has raised awareness of the issue of inclusion within partnership groups.

The project has worked closely with other NHS initiatives particularly the Cancer Service Collaborative (CSC) and the work of the Patient Experience Project and the Patient and Public Involvement Forums.

CancerVOICES, now supported by Macmillan Cancer Relief, has continued to provide grass roots development for the Cancer Partnership Project through its national networking and links to cancer self help and support groups.
3 Methods

This section of the report describes the processes followed in order to collect information from study participants. This work consisted of two different activities, with a total of four separate ‘sets’ of participants providing data.

The first activity was a ‘mapping exercise’ to collect factual information on Partnership Group activity from each of the 34 cancer networks in England. This information was collected via a telephone interview with one representative (normally the Chairperson) from one Partnership Group from each network. We refer to this group of ‘Key Informants’ as ‘Set 1’.

Second, we made visits to six selected cancer networks in order to talk in person with a range of service users and NHS staff about various aspects of their involvement in the group, and to ascertain their views of the group and its influence on local NHS services. We refer to these six networks as our in-depth ‘case sites’. We interviewed three different categories of people: service user members of Partnership Groups (these we refer to as ‘Set 2’); NHS staff members of Partnership Groups (Set 3); and local NHS managers and senior clinicians not involved in Partnership Groups (Set 4).

Section 3.1 describes details of recruitment, data collection and analysis for the mapping exercise, and Section 3.2 describes these details for Sets 2, 3 and 4. Section 3.3 describes the user involvement within this evaluation project. Research Governance and NHS Ethics Committee approval are noted in Section 3.4. Finally, Section 3.5 is a brief reflection on the methods employed in the evaluation.

3.1 Mapping exercise

3.1.1 Step One: Recruitment of Key Informants

The evaluation plan for the scoping exercise was to collect information from each network-level Partnership Group, nominally one group for each of the 34 cancer networks in England. Due to Data Protection Act restrictions on the sharing of personal identifiable information, the evaluation commissioners – Macmillan Cancer Relief (Macmillan) – were not in a position to provide the research team with a contact list for Partnership Groups taken from their database. The process agreed, therefore, was that Macmillan would act as an intermediary for initial contact between the research team and the groups.

The following process was pursued. First, the research team prepared a sealed ‘Contact Pack’ for each of the 34 networks and mailed the batch of ‘Contact
Packs’ to Macmillan. Macmillan then forwarded a Contact Pack to a user involvement contact person in each cancer network. It was left to Macmillan to select the most appropriate contact person in each network, but typically this would be the network User Involvement Facilitator, or equivalent. In those networks where no network-level contact existed, Macmillan was asked to select the contact for a known locality user involvement group within the network.

Each Contact Pack contained a letter of introduction to the project and a project ‘Lay Summary’ document, both for the contact person. The pack contained a third enclosure, a sealed envelope marked “CHAIRPERSON”. The letter requested that the contact pass this sealed envelope on to the Chairperson of the network-level Partnership Group at their earliest possible convenience. In the absence of a network-level Partnership Group, the contact was requested to forward the enclosure to the Chairperson of any other Cancer Partnership Group active in the network area.

The enclosure marked CHAIRPERSON was the Set 1 ‘Invitation Pack’. This pack contained: a letter of introduction to the project, a Participant Information Sheet that provided a full description of the evaluation, a project ‘Lay Summary’ document that provided a summary of key points of the evaluation, and an optional letter for the Key Informant’s GP.

The letter invited the Chairperson to participate in the study and to respond directly to the research team by a fixed date to state whether or not he/she would consider taking part in a telephone interview. If the Chairperson (or the equivalent Key Informant) was not in a position to participate, or declined, the letter of introduction requested that the SET 1 Invitation Pack be passed on to another member of the group who was willing to act as Key Informant.

Three reminders were sent via Macmillan to non-responding networks, with additional explanations of the nature and purpose of the evaluation.

Upon receiving a response, a member of the research team (PC) made telephone contact with the respondent to discuss the study and the prospective interview, and to establish whether or not the Chairperson was willing to be interviewed. If the respondent was willing to be interviewed, we arranged an interview date and time. We then sent two copies of the project Consent Form to the respondent for signature and return prior to interview. Upon receipt of the signed Consent Forms, the forms were countersigned by the member of the research team who had discussed the study with the respondent; one copy was filed in the research office and the other returned to the participant for his/her records. We also sent the Key Informant a list of the questions to be asked in the interview (‘Set 1 Topic List’), to enable the interviewee to prepare for the interview.
3.1.2 Description of the Set 1 Key Informants

<table>
<thead>
<tr>
<th>Type</th>
<th>All groups N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sole Chairperson – Service User</td>
<td>16 (55%)</td>
</tr>
<tr>
<td>Sole Chairperson – Facilitator</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Co-Chairperson – Service User</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Rotating Chairperson – Service User</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Acting Chairperson</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Group member – Service User</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>All types</td>
<td>29 (100%)</td>
</tr>
</tbody>
</table>

The default interviewee for each group was the Chairperson of the group. Twenty-nine of the 34 networks identified a Key Informant who consented to be interviewed. We were unable to secure a telephone interview with one other group within the data collection period, however a group representative kindly sent a written response and additional documentary material by post.

In 17 of the 29 cases, the interviewee was the ‘Sole Chairperson’ of the group; in two of these the Chairperson was a carer; in one the group Facilitator; and in the remaining 14, a patient. In four other groups, the chair’s role was shared between two ‘Co-Chairpersons’ and we interviewed one of these for each group; in one case the interviewee was a carer, and in the three others a patient. In two other groups, the chairing role was shared among the members, with each taking the chair on a rota basis. We therefore interviewed two ‘rotating’ Chairpersons.

In two cases an ‘acting chairperson’ was the interviewee: in one case, the Chairperson recently had died and two Vice-Chairpersons were sharing the role, one of whom was interviewed; in the other case, the group was then in the process of recruiting both a Chairperson and Vice-Chairperson, and the cancer network Lead Nurse was Acting Chairperson of the Partnership Group.

In four cases the interviewee was an ‘ordinary’ group member: in one case the Chairperson (and Facilitator) was a member of the Reference Group for this project and therefore inappropriate as an informant; in one case the Chairperson’s post was vacant; in another the Chairperson was unwell; and in the fourth case the interview was delegated by the acting Chairperson (a health professional) to a service user group member.
So, of the 29 interviewees: 27 were Service Users (either patients or carers); one was a health professional; and one a group facilitator.

3.1.3 **Step Two: Data collection**

3.1.3.1 **Sources of information supplementary to Set 1 interviews**

In addition to the information provided through interviews with Key Informants, we extracted information from published and unpublished sources. First, we accessed information previously provided to Macmillan by groups for a ‘self-evaluation’ exercise. This ‘self-evaluation’ collected data using a self-report proforma and was conducted in April/May 2003.1

Second, we collected and extracted information from documents such as groups’ Annual Reports, newsletters and Terms of Reference; some of these were on file at Macmillan, others accessible via cancer networks’ sites on the World Wide Web. Of the 30 networks with Partnership groups, 19 had a network World Wide Web site; of these 19 sites, 12 included some information on Partnership Group activity.

<table>
<thead>
<tr>
<th>Table 3.1.3.1</th>
<th>Mapping exercise data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data source</td>
<td>All groups N (%)</td>
</tr>
<tr>
<td>Macmillan ‘self-evaluation’ completed proforma</td>
<td>19 (63%)</td>
</tr>
<tr>
<td>World Wide Web site</td>
<td>12 (40%)</td>
</tr>
<tr>
<td>Set 1 Telephone interview</td>
<td>29 (97%)</td>
</tr>
<tr>
<td>Group documentation</td>
<td>13 (43%)</td>
</tr>
</tbody>
</table>

3.1.3.2 **Set 1 interviews**

The telephone interview schedule is reproduced in section 6.3 of this report. We anticipated that the telephone interview would take up to one hour but this time actually varied considerably. A few interviews were completed in less than one hour but for many an hour and a quarter or an hour and a half was required to complete the whole interview schedule. On two occasions the interview was completed in two parts because of the length of the interview. Despite the length of the interview, informally participants reflected favourably on the interview, with some stating that the interview had ‘helped them think through’ some issues that they felt could help their group develop.

The telephone interviews were tape-recorded and permission for this was explicitly sought prior to the interview commencing. Participants were informed

---

1 Further information on this self-evaluation exercise is available at (correct in March 2004): http://www.users.globalnet.co.uk/~maythorp/Usegroups/index.htm
that the interview data would be kept in strict confidence within the research team, and that the tapes would be stored securely in the Research Department at Worthing & Southlands Hospitals NHS Trust.

3.1.4 Step Three: Data analysis and interpretation

The process of data analysis and interpretation were iterative and, via the project’s Reference Group, was as inclusive of service users’ perspectives and insights as possible.

Responses to Set 1 telephone interview questions were entered into a Microsoft Excel spreadsheet, which acted as a platform for analysis. As data were largely qualitative, analysis was undertaken by two researchers working through the spreadsheet one question at a time to reach an agreed understanding that elucidated each response. An interim analysis of these data was presented to the project Reference Group via a teleconference and further interesting and helpful interpretations were highlighted and included in the analysis. Similarly, a draft report of final findings was presented to and discussed by the Reference Group.

3.2 In-depth case studies

3.2.1 Step One: Identification of Case Sites

The research team selected the six case sites on the basis of a number of factors. We wanted to access groups in a variety of areas across England with the intention of gaining accounts from an array of differing locations that reflected the diverse nature of the country. We were not attempting to gain a representative sample of groups (as in reality no two groups are alike) but rather as wide a variety of groups as possible. With this in mind, we selected groups on the basis of: urban versus rural location; areas with greater versus smaller black and minority ethnic community presence; north versus south, and east versus west; new versus older groups; more versus less active groups; and local versus network groups. The Reference Group were involved at an early stage in identifying these required factors from which to select groups but, to avoid bias, the decision remained with the research team.

3.2.2 Step Two: Recruitment of interviewees

The majority of participants were recruited in December 2003 with data collection commencing in case sites in January 2004.

Our intention was to interview, at each case site group:

- two or three service users: these interviewees formed Set 2;
- two or three NHS professionals: these interviewees formed Set 3;
two or three cancer managers or commissioners who were not members of the group but who worked within the group’s geographical area of activity: these interviewees formed Set 4.

3.2.2.1 Recruitment of Set 2 and Set 3 interviewees

All initial contacts for the Set 2 and 3 interviews were made through each group’s ‘Macmillan contact’ (see 3.1.1 for an explanation of this term). We prepared a batch of Invitation Packs for each group and, as with the Set 1 interviews, these were forwarded by Macmillan to the group’s contact. For each group, we sent ten packs labelled for service users and ten packs labelled for professionals. One or two groups requested more packs, which were duly sent.

A covering letter to the facilitator asked the facilitator to distribute the invitation packs unopened to group members. Each invitation pack contained: a letter of introduction to the project; a project Lay Summary document; an optional letter for the participant’s GP (for service users); and the Participant Information Sheet. The letter of introduction invited the group member to participate in the study and to let us know if they were willing to participate, at their earliest convenience. Participants therefore were self-selecting.

Upon receiving a response from an individual, a member of the research team made telephone contact with the respondent to discuss the study and the prospective interview, and to establish whether or not the respondent was willing to be interviewed ‘face-to-face’, or if not by telephone. If the respondent was willing to be interviewed, we arranged an interview location, date and time. We then sent two copies of the project Consent Form to the respondent for signature and return prior to interview. Upon receipt of the signed Consent Forms, the forms were countersigned by the member of the research team who had discussed the study with the respondent; one copy was filed in the research office and the other returned to the participant for his/her records. We also sent the Key Informant a list of the questions to be asked in the interview (Set 2 or 3 Topic List, as appropriate), to enable the interviewee to prepare for the interview.

3.2.2.2 Recruitment of Set 4 interviewees

Set 4 recruitment was achieved via cancer network lead nurses and/or managers; these contact details were taken from publicly accessible documents on the Department of Health website. We initially telephoned each contact, and then sent each a batch of Set 4 Invitation Packs. The contact kindly distributed the packs. In the telephone discussion, and reiterated in a covering letter with the packs, we suggested that suitable interviewees might include: acute trust cancer managers, PCT cancer managers, lead cancer clinicians, cancer commissioning managers and any other NHS professional with a decision-making role in cancer services.
Each invitation pack contained a letter of introduction to the project, a project Lay Summary document, and the Participant Information Sheet. The recruitment process from thereon in was the same as for Sets 2 and 3.

### 3.2.3 Description of the Sets 2, 3 and 4 participants

#### Table 3.2.3a

<table>
<thead>
<tr>
<th>Set</th>
<th>Number recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set 2: Service User members of Partnership Groups</td>
<td>12</td>
</tr>
<tr>
<td>Set 3: NHS members of Partnership Groups</td>
<td>11</td>
</tr>
<tr>
<td>Set 4: NHS staff not members of Partnership Groups</td>
<td>6</td>
</tr>
<tr>
<td><strong>All sets</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>

#### Table 3.2.3b

<table>
<thead>
<tr>
<th>Set</th>
<th>Male</th>
<th>Female</th>
<th>Average age (years) [range]</th>
<th>% White British</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set 2</td>
<td>3</td>
<td>9</td>
<td>57 [41 to 73]</td>
<td>100%</td>
</tr>
<tr>
<td>Set 3</td>
<td>3</td>
<td>8</td>
<td>44 [26 to 57]</td>
<td>72.8%</td>
</tr>
<tr>
<td>Set 4</td>
<td>2</td>
<td>4</td>
<td>42 [37 to 53]</td>
<td>83.4%</td>
</tr>
<tr>
<td><strong>All sets</strong></td>
<td><strong>8</strong></td>
<td><strong>21</strong></td>
<td><strong>49 [26 to 73]</strong></td>
<td><strong>86%</strong></td>
</tr>
</tbody>
</table>

### 3.2.4 Step Three: Data collection

No interviews were conducted via telephone, and so all data were collected via one-to-one, face-to-face semi-structured interviews with participants (See section 6.3 for interview schedules). These interviews were tape-recorded and subsequently transcribed.

We conducted each interview in a location chosen by the interviewee; typically, for service user interviewees, in their own home; and for NHS staff, in their workplace. In one case site most participants chose to meet the researcher at a location they also used for their group meetings. This was an unsolicited offer by the participants to prevent the researcher navigating around multiple locations.
around a city centre. The same considerations and processes regarding confidentiality and informed consent were followed as for Set 1 participants.

We spent two days in each case site area in order to meet participants and conduct the interviews.

### 3.2.5 Step Four: Data analysis and interpretation

The interview logs provided anonymised responses from each interview. A thematic analysis of these responses was conducted collectively by two members of the research team and three other qualitative researchers who had not been involved in this project. This ‘collective’ analysis proved to be an effective and relatively rapid approach to data analysis, and also allowed researchers very ‘close’ to the data to discuss the data with others more distant from it. Essentially, the analysis group enabled a level of ‘investigator triangulation’ of the data to take place.

A draft report of final findings was presented to and discussed by the project Reference Group, who provided further interesting and helpful interpretations.

### 3.3 User involvement in this evaluation

From the outset, all parties to this study were committed to the active participation of service users in guiding and informing the work. A reference group was established at the commencement of this evaluation and consisted of representatives from the commissioners and external academics as well as service users (See section 6.1 for a full member list).

We had hoped to work closely with service users in two networks to conduct a ‘participatory evaluation’, but it soon became apparent that the resources and time allocated for the study would not make possible this activity. This activity therefore was not pursued.

### 3.4 Research ethics and governance

As data were to be collected from NHS patients and staff across England, favourable opinion from a Multi-Centre Research Ethics Committee was required prior to commencement of the research. Subsequently, as required by Department of Health policy, we informed all relevant Local Research Ethics Committees that this work was being undertaken in their localities.

Worthing and Southlands Hospitals NHS Trust acted as the Research Sponsor for the study, and ensured that the requirements laid down in the Research Governance Framework were met.
‘Principal Investigator’ Research Governance approval was gained from the Research Approval and Monitoring Committee of the Sussex NHS Research Consortium. We contacted as many NHS organisations in each network as we could within the short timescale of the project to seek clarification of their own Research Governance requirements. Some organisations provided approval through recognition of the prior approval noted above; others required that we submit a full application to their own committee or equivalent. In one case, a member of the research team was required to submit an application for an NHS honorary contract (despite being an NHS employee elsewhere).

All participants were provided with an information sheet and written consent was obtained from each individual prior to participation. Informants were not asked to comment on the practices of named professionals or service users, and any disclosures of practices relating to identifiable individuals were not included, to ensure anonymity, in the analysis or this report.

All documentary evidence, tapes and anonymised interview logs are stored in a locked archive cabinet in the Research Department, Worthing Hospital. Electronic data is stored on a secure server at Worthing Hospital. Personal identifiable data will be stored for five years; anonymised data will be archived for ten years.

Whilst not wanting to assume that the service user participants were all ‘vulnerable’, we did want to ensure the interview specifically and the participant’s general involvement in the research was as sensitive and humane as possible. Due to the questions being primarily – but not exclusively – designed to elicit non-personal information, we did not anticipate causing distress for participants, but we knew that the possibility remained. Consequently we ensured that we briefed participants at first contact about the nature of the research and the interview questions. Many participants commented on the benefit of receiving the interview questions in advance and this, in some way, helped them to prepare for the interview and to see what was expected of them. Participants also were informed of their right to withdraw at any stage. At the time of the interview, it was highlighted with participants that they could pause or stop the interview at any stage. No participant did this nor did any participant need to break from the interview due to tiredness, pain or any other problem. At completion of the interview participants were asked for their thoughts on the interview and to identify any problems with it. Participants invariably reported no adverse effects and mostly were glad to have been involved. Many participants spoke of hoping to assist with understanding the nature of Partnership Groups and user involvement, and expressed the hope that this research and its findings would offer some meaningful and helpful outcome for them and their groups.

Similarly, the MREC which provided approval was of the opinion that the study was very unlikely to raise any issues that might affect a service user participant’s
health or health care, and so advised that each individual participant should make the decision as to whether or not to inform their General Practitioner of their participation in the study. A template letter for GPs was provided in a sealed envelope to each service user participant for them to use if they chose to do so.

3.5 **Some reflections on methodological aspects**

As a consequence of the recruitment strategy we were required to pursue (due to legal advice on data protection issues) and the time constraints of the study, we were totally reliant upon people outside the research team for the identification of potential participants for all Sets and for the forwarding of recruitment information to these participants. In some cases, this involved a ‘chain’ with at least three or four links.

Following repeated reminders we obtained a high response rate for Set 1 participants, and the minimum acceptable numbers of participants were obtained for Sets 2 and 3. However, the number of Set 4 participants was disappointingly low; despite repeated requests, few willing interviewees came forward. We remain unsure of the reasons for this, but we speculate that we received a poor response because this work was perceived as low priority by one or more ‘links’ in the chain. In one of the six case sites network, our contact manager was explicitly very reluctant to accept and distribute packs for Set 4, giving the distinct impression that this was an unimportant chore. Clearly, the ‘recruitment chain’ itself formed a substantial barrier, particularly given the short time allowed for recruitment and data collection.

In all, 58 people were interviewed for this study, which in our mind is an acceptable number for these findings to be regarded as reliable and valid. Given that the Sets 2/3/4 participants were essentially self-selecting, it might be argued that these samples are biased. We have no way of knowing if these samples are indeed biased – i.e. not representative of the larger populations from which they were drawn – nor, if they are, of the nature and extent of the bias incurred. All we can say is that the participants were by no means uniform in their responses, and that we do feel a good range of opinion is represented in this report.

Ideally, a future evaluation would allow direct recruitment of participants, with some element of random selection, for example from a membership list. This evaluation has been a snap shot in time and further work would benefit from adopting prospective data collection methods. This evaluation was not commissioned to include facilitators or the network senior management team as informants. Including greater emphasis on the work, role and dynamics of these key positions in any future research would be constructive.
Findings

The findings from the evaluation are rehearsed in this section of the report. Whilst there were two principal data collection activities (the telephone interview with a representative of each partnership group and face-to-face interviews with service users and health professionals in the six case sites), the findings will be presented according to the themes that arose in either or both activity. Information from both activities is used throughout.

Sections 4.1, 4.2, and 4.3 provide a description of the various types of groups operating within networks, along with information on their particular features, for example the nature of ‘leadership’ and membership. Issues such as power, commitment and relationships with other organisations are elaborated on in sections 4.4 and 4.5. Sections 4.6 and 4.7 describe how the groups are working to influence the NHS, with an analysis of their activities and their achievements. Finally, sections 4.8 and 4.9 discuss financial aspects, and strategies for support and development of Partnership Groups.

4.1 Working arrangements of Partnership Groups

4.1.1 Models of Partnership Group activity

We identified five different Partnership Group models among the 30 networks. These are described in the figures and accompanying text below. In these descriptions, a ‘network-level’ group means a group operating across the cancer network; a ‘locality-level’ group means a group operating only within a specific locality, typically developed by an NHS Trust, hospice, or Primary Care Trust, some being a ‘Partnership Group’ with both service users and NHS staff members, and others a ‘Service User Group’ (SUG) with no NHS members. ‘CN Board-level Group’ means a Cancer Network Board, or equivalent.

Model A

‘Stand-alone’ locality PG or SUG. No formal representation on CN Board-level Group, but typically active within other (e.g. tumour site-specific) CN groups.
Model B
One or more Locality-level PGs or SUGs, each with formal representation on CN Board-level Group.

Model C
One or more Locality-level PGs or SUGs, represented on CN Board-level Group through an intermediary, “Chairs’ Group”.

Model D
‘Cluster’ of inter-related Locality-level PGs. In some cases the ‘cluster’ has developed from a single ‘main’ or longer-standing group. Formal representation on CN Board-level Group from the ‘cluster’.

Model E
Single, network-level PG with formal representation on CN Board or equivalent, with informal links to a variety of Locality-level groups.
4.1.2 Types of groups in this study

All 30 groups defined themselves as ‘partnership’ groups, as opposed to ‘service user only’ groups. The common usage of ‘Partnership Group’ was to indicate a group that acted as a prime mechanism for partnership (NHS and Service User) working. The term did not necessarily indicate that the membership comprised both Service User and NHS members. In the Model C groups in particular, the NHS ‘membership’ often was limited to the individual with a lead for service user involvement in that locality, for example a trust Lead Cancer Nurse.

Table 4.1.2 shows the frequency of each PG model in the 30 networks. Five of the Model E groups were ‘in development’, i.e. not fully functioning in line with the model but working towards that model.

By far the most common model was Model E, in which a single group worked as a centralised Partnership Group for the whole network. This model appears to link directly to that proposed in recommendations to the National cancer Taskforce (Bradburn, 2001). In some cases this model was perceived as too centralised; in one network, as a consequence, an alternative model has emerged (Model D), wherein the original sole group has effectively divided into a number of closely-linked locality groups, with a shared facilitator.

Of the 30 groups we studied, only those five among Models A and B were not operating under the auspices of the cancer network: typically, these groups were based within an NHS trust cancer unit, operated independently of the cancer network, and often pre-dated the network.

The sample included two Model C ‘Chairs’ Groups’. These are network groups that act as a formal, representative intermediary between locality groups and the CN Board Level, or equivalent, Group. Only one or two representatives from each locality group sit on the Chairs’ Group, and the Chairs’ Group includes only one or no health professionals; therefore their ‘membership’ is small.

Throughout the remainder of this report, the term ‘Locality PGs’ will be used to refer to the five groups within Models A and B, and the term ‘Network PGs’ will be used to refer to refer to the 25 groups within Models C, D and E.
### Table 4.1.2

<table>
<thead>
<tr>
<th>Model</th>
<th>Summary characteristic</th>
<th>Networks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model A</td>
<td>Stand-alone, non-network locality group with no representation on CN Board Level, or equivalent, Groups</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Model B</td>
<td>Locality groups each with separate representation on CN Board Level, or equivalent, Groups</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Model C</td>
<td>Non-network locality groups represented on CN Board Level, or equivalent, Groups through an intermediary, network “Chairs’ Group”</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Model D</td>
<td>Linked, network locality groups with co-ordinated representation on CN Board Level, or equivalent, Groups</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Model E</td>
<td>Single network-level PG with representation on CN Board Level, or equivalent, Groups</td>
<td>22 (73%)</td>
</tr>
<tr>
<td>All models</td>
<td></td>
<td>30 (100%)</td>
</tr>
</tbody>
</table>

### 4.1.3 Establishment of the group

#### 4.1.3.1 ‘Age’ of the groups

The 30 groups had been active for a (median) average of 21 months as of December 2003. ‘Locality’ Partnership Groups in Models A/B had been established longer than ‘Network’ Partnership Groups in Models C/D/E (median 32 months versus 18 months).

The ‘age’ of groups ranged from less than six months (in the case of three Model C/D/E Network groups) to almost eight years (a Model A/B Locality group). The large majority (83%) of groups had been active for three years or less. Of Model C/D/E groups, almost 90% had been active three years or less, and almost 40% for one year or less. The three Model C/D/E network groups that had been active for three years or more had developed incrementally from pre-existing locality groups based within former health authorities.

### Table 4.1.3.1

<table>
<thead>
<tr>
<th>‘Age’ of groups (in categories)</th>
<th>All groups N (%)</th>
<th>Locality PGs N (%)</th>
<th>Network PGs N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active for one year or less</td>
<td>9 (30%)</td>
<td>0</td>
<td>9 (36%)</td>
</tr>
<tr>
<td>Active for between one and three years</td>
<td>16 (53%)</td>
<td>3 (60%)</td>
<td>13 (52%)</td>
</tr>
<tr>
<td>Active for three years or more</td>
<td>5 (17%)</td>
<td>2 (40%)</td>
<td>3 (12%)</td>
</tr>
</tbody>
</table>
4.1.3.2 Impetus for establishment

When asked to describe the origins of the group, without exception the interviewees indicated that the group’s establishment had been led by an NHS organisation (trust, health authority or cancer network) as a strategic development of service user involvement. A number of interviewees perceived that the NHS organisation had acted in response to a national directive or initiative, such as the Calman-Hine Report or NHS Cancer Plan.

For the recently-established Model C/D/E Network Partnership Groups, the Cancer Network Lead Nurse often was cited as the ‘driving force’ behind the establishment of the group, with the process typically involving an advertising campaign to attract service users to a ‘development day’ at which a forward plan could be discussed inclusively and agreed by consensus. Several respondents noted the support and input of Macmillan for these development days. These events seem largely to have been well attended and successful: one network reported that 200 people took part in the day:

“The Lead Nurse asked for people to be involved. There were only a few people to start with. In [month] 2003 we had a ‘User Involvement Day’, asking people what they wanted. An oncologist spoke, and the lead manager, then we went into little groups brainstorming. It was a successful day.” (Participant 14)

In other cases the process ran less smoothly:

“Flyers and posters were used to advertise and the Cancer Services Manager asked all hospital Clinical Nurse Specialist to recruit potential members of a group. It was a struggle to gain interest. It’s significant that initial members thought it would be a support group and consequently left.” (Participant 2)

The three older Network Partnership Groups (Sussex; Avon, Somerset and Wiltshire; Humber & Yorkshire Coast) had been established prior to the emergence of cancer networks, then operating under the auspices of a trust or health authority. Each had successfully made the transition from non-network to network group.

Two of the Locality Partnership Groups stated specifically that the group was established as part of the accreditation process for the NHS trust cancer centre as a consequence of the Calman-Hine report.
4.1.3.3 **Groups’ names**

No guidance on names was given to groups by the CPP steering group. There was no uniformity in the groups' names; indeed there were nearly as many names as groups. A few interviewees indicated that the group’s name typically had been decided early in the group’s history by consensus, others that the name was chosen by the Chair or a network manager. It is interesting to note that the CPP steering group introduced the term ‘partnership group’ and therefore groups that preceded the project are the ones likely to be referred to by different names.

Names adopted by Network PGs (typically with the prefix ‘Cancer’ or ‘Cancer Network’):
- Partnership
- Partnership Forum
- Partnership Group
- Partnership Panel
- Partnership Panel - User Involvement Group
- Patient and Carer Group
- Patient and Public Partnership Group
- Patient/Carer Partnership
- Patient Involvement Group
- Patient/User Forum
- Patient User Partnership
- Patients Forum
- User Involvement Group
- User Involvement Partnership
- User Group
- User Partnership Group
- User/Partnership Involvement Group

Names adopted by Locality PGs (typically with the prefix ‘Cancer’ or ‘Cancer Services’):
- Advisory Group
- Patient & Carers Oncology Council
- Patient Advisory Cancer Team (PACT)
- User Group
- User Liaison Group

4.1.4 **The charter of the group**

4.1.4.1 **Terms of Reference**

We attempted to ascertain from the Set 1 interviewees whether or not each group worked to a formal, written Terms of Reference (ToR). Of the 29 interviewees, 28 stated that the group did have formal ToR; the other
interviewee, who was the Chairperson of the group, was unsure whether the
group had ‘Terms of Reference’ or not. We requested a copy of the ToR from
each interviewee and also looked at available network websites to see if ToR
were accessible via the site. At time of writing, the researchers have on file ToR
for 16 groups collected in these ways. We understand that the CPP steering
group provided specimen ToR documents as templates to each group at the
outset of the CPP initiative.

4.1.4.2 Objectives

We asked the Set 1 interviewees if the group worked ‘strategically’ to defined
objectives and, if so, the process by which those objectives had been decided
upon.

Of the 30 groups, 21 (70%) worked to a written, defined set of objectives. The
level of formality of these objectives varied: in at least three cases, the group
had in place a work programme set in a one-year or three-year plan, with a
timescale and review date for each action point. In most cases, however, the
objectives were a more fluid list of priorities with less exact targets, reviewed
perhaps annually or on a rolling basis. In a minority of groups, the objectives
were developed by a ‘sub-group’ (e.g. Chairperson, Vice-Chairperson and
Facilitator) and then put to the group as a whole for agreement. For most of the
21 groups however, the objectives had been agreed through inclusive group
discussions and ‘brainstorming’, often through a dedicated ‘development day’ or
similar event:

“The group brainstormed and chose realistic things to tackle.”
(Principal 22)

Nine of the 30 groups (30%) did not work to a defined set of objectives. In these
cases, including one group which had at one stage drawn up a list of objectives
but later “abandoned them”, the respondents indicated that the group was
satisfied working to a broad agenda and adopting specific issues on an ad-hoc
basis:

“Yes, we have objectives but they are fluid. They’re agreed through
discussion at the group. For example, a health professional brings
an issue and the group then decides if it is appropriate for the group
to pursue.” (Principal 30)

The importance of a group having ‘strategic objectives’ is of course open to
debate. One argument for ‘objectives’ might be that the group’s energies are
focused on pursuing agreed priorities rather than expended in a more random
way. Another might be that ‘objectives’ help the group function as a discrete
entity, rather than as a platform from which an individual can pursue a ‘personal’
issue:
“They were agreed by consensus. We had an ‘open forum’ to look at objectives. We have to be careful that it’s not a personal crusade and that you do have strategies.” (Participant 4)

4.1.5 Frequency, location and timing of meetings

4.1.5.1 Frequency of meetings

One of the 30 groups, a recently established group, had not yet decided upon frequency of meetings. Of the other 29: five (17%) met quarterly, six (21%) met two-monthly, six (21%) met six-weekly, and 12 (41%) met monthly.

A number of interviewees from Model C/D/E groups noted that the meeting schedule reflected the intention to link and fit with the schedule for the Network Board meeting; the Partnership groups that met quarterly, for example, did so because the Network Board met quarterly. One or two groups mentioned that the frequency of meetings had been greater in the ‘start-up’ phase of the group and had since reduced, for example, because sub-groups or working groups had been established which met in between ‘main group’ meetings. This initial frequency of meetings was advised by the CPP steering group and was based on experience of what appeared to work well. Conversely, one or two other groups noted that the frequency of meetings had increased as the group became established, to cope with an ever-longer agenda and increasing workload.

4.1.5.2 Location of meetings

Meetings venues were chosen by groups on the basis of accessibility and comfort, balanced with cost. A large proportion of groups (77%) regularly used NHS premises as the primary venue for meetings, typically either a meeting room in a hospital (not infrequently in a clinical oncology setting) or in an NHS office building. The remaining groups used mainly non-NHS premises: one group regularly used the offices of a health insurance company (provided free of charge), and others in assorted venues including an hotel, council/community premises, public houses, hospices, and a complementary therapies centre.

4.1.5.3 Timing of meetings

The question of when – on which day, at what time – the Partnership Group meetings should be held was one that appeared to exercise many groups, generally without satisfactory resolution. Many groups noted that they had ‘experimented’ with timings: weekday daytime, weekday evening, a weekend morning or afternoon. Broadly speaking, the interviewees’ perception was that weekday daytime meetings are convenient for (and therefore attract attendance from) NHS staff, but that such meetings are inconvenient for, indeed exclude,
those groups of service users who have working time commitments: people in employment, people in full-time education, people with caring commitments, for example. Weekend meetings were perceived as being more widely accessible by service users, but unattractive to NHS staff.

As an interesting example, in an attempt to get the best of both worlds one group alternated its meeting times between Saturday morning and a weekday evening. Attendance at Saturday morning meetings typically was 12 or 13 people, of whom three or four (approximately 25-30%) were NHS staff; at the weekday meetings, however, the number of service users in attendance fell to five or six while the number of NHS staff rose up to 15, so that now service users formed the 25-30% minority of attendees.

4.1.6 Minutes, and communication between meetings

All of the 30 groups made and distributed a formal written record of Partnership Group meetings, with one exception. The exception was a Model C (Chairs’) Group. This group worked strictly as an intermediary channel of communication between a number of locality groups and the CN Board. At each meeting the group (1) considered a synopsis of the minutes of the previous CN Board meeting, then (2) received activity reports from each of the ‘feeder’ locality groups, then (3) agreed the items and issues to be raised at the next CN Board meeting.

Other than via minutes, groups used a wide and varied range of modes of communication in between meetings. E-mail was widely used for wide circulation of documents and messages: many groups stated that nearly all, if not all, members used e-mail. To keep members informed of developments, Facilitators and Chairpersons also used conference calls, ‘global letters’, and newsletters, in a few cases.

Group members almost universally considered themselves well informed about committee business between meetings. The ‘providers’ typically were the Facilitator, Chairperson and Vice-Chairperson. Many Service Users mentioned that they received meeting papers regularly and in good time, and noted that this is important for informed inclusion in discussions.

Of perhaps more interest was the reported high level of communication between ‘ordinary’ members between meetings. It seemed typical for members to have regular contact between meetings, sometimes to pursue group business but perhaps more often simply to be in touch on a more friendly, supportive basis. This – often unintentional – functioning as a ‘support group’ is further described in section 4.5.3 of this report.
A small minority of Service Users indicated that they felt a lack of personal contact between meetings. One stated that he would like to be “given more duties” involving contact with the public: “Nothing happens between group meetings.” Another respondent had the perception that she received only the minutes, whereas other members of the group were active in between meetings – for example attending events and conferences – and that other members had much more contact with the Facilitator than did she. The respondent did not feel aggrieved – she stated that she herself ‘held back’ – and was reluctant to ‘trouble’ the Facilitator between meetings as the Facilitator also had nursing duties.

4.1.7 Group World Wide Web site

At time of writing in March 2004, 12 (40%) of the 30 Partnership Groups had a ‘live’ World Wide Web site, either a site specific to the group or pages within a cancer network’s site. Judged subjectively by the research team, two or three sites provided an excellent resource, containing archives of information such as newsletters, strategic plans, Terms of Reference, minutes of meetings, network structure charts showing the role of the Partnership Group, contact details for the Facilitator and Chairperson, a diary of events, Annual Reports, and an agenda for the next meeting, with details of time, location and access. The WWW addresses for all 12 sites are provided in section 6.2 of this report.²

4.1.8 Networks with no Partnership Group activity

As described in section 2.2, the first objective of the Cancer Partnership Project was to establish cancer partnership and user groups in the 34 cancer networks in England.

At the time of the evaluation, partnership or user groups had been established in 30 of the 34 cancer networks in England. With regards to the remaining four networks, in three cases the research team was unable to establish any contact with any member of staff with any knowledge of user involvement in the network, and therefore the level of user involvement and of any partnership or user group development remains unclear. The network that did communicate with the research team explained that they adopted a considered approach to user involvement, and indeed this network has developed and published a substantial Strategy for Cancer Patient and Public Involvement (North East London Cancer Network 2003). The strategy places the establishment of a Partnership Group within a wider plan of service user involvement, and includes a detailed Action Plan to implement the strategy. As a first step in the action plan, the network appointed a User Involvement Facilitator in November 2003; it is reasonable to expect a Partnership Group to be set up in the course of 2004.

² In addition to these sites, a CancerVOICES website was launched in 2004. This site contains information about Partnership Groups and is one of the main ways in which Macmillan Cancer Relief are supporting Partnership Groups, through facilitating shared learning and putting people in touch with their local group.
Macmillan provided the following information to the research on the other three networks: One of these networks has pioneered an alternative approach to user involvement with a ‘Patients as Teachers’ initiative rather than a Partnership Group initiative. A second network had been a pilot site for early work on developing the partnership model but had not been successful in creating an active network level partnership group themselves. However, there had been locality partnership developments, in hospital trusts for example, and the establishment of a cancer support and information centre. Changes in network staff have also made the development of partnership groups in this, and other networks, difficult; Macmillan considered this a particular problem in the London cancer networks. The third network did have at least one active Locality Partnership Group, that was in existence prior to CPP. It was Macmillan’s understanding that the CN Lead Nurse had attempted to set up groups in other parts of the network but that this has been challenging and to date unsuccessful.

4.2 Leading the group: the Chairperson and the Facilitator

4.2.1 The Chairperson

At the time of data collection, 20 of 29 groups had a sole Chairperson; four other Network groups had either one or two Acting Chairpersons in place whilst in the process of recruiting for a ‘permanent’ Service User Chairperson; three others had a permanent Co-Chairperson arrangement whereby two members shared this role; and the remaining three groups had a permanent Rotating Chairperson arrangement whereby several group members shared the role.

Of the four groups with temporary Chairperson arrangements, two were being chaired by a member of cancer network staff, and the other two by Service Users. Excluding these four groups with temporary arrangements, but including the three groups with Rotating Chairpersons, 24 of the 26 groups (92% of groups) were chaired by a Service User. The other two groups, both Network PGs, were chaired by the group’s Facilitator.

<table>
<thead>
<tr>
<th>Type</th>
<th>All groups N (%)</th>
<th>Locality PGs N (%)</th>
<th>Network PGs N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user</td>
<td>24 (92%)</td>
<td>5 (100%)</td>
<td>19 (90%)</td>
</tr>
<tr>
<td>Paid facilitator</td>
<td>2 (8%)</td>
<td>0</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

From the face-to-face interviews with group members, there emerged a consensus that, in principle, the Chairperson of a group devoted to Service User
involvement should her/himself be a Service User (and as noted above this is the case in 92% of groups). Some respondents considered this an actual advantage in that the Chairperson would better understand the patients' perspective on cancer issues:

“Our chair is a patient. It helps if it is a patient or carer. It helps if they are over their own experience but can see that the energy and angst of other peoples’ experience can be channelled into making a difference somehow.” (Participant 43)

However, other attributes were regarded as being of equal or greater importance to direct experience as a service user. An ‘ideal’ Chairperson would be confident, have energy and ideas, be assertive, respected and also respectful of others, and have knowledge of national cancer policy context and would have strong ‘chairing’ skills: be well-prepared for meetings; remain calm; ensure everyone gets a say and that others listen; be able to reach a consensus; and importantly to ensure members feel included, important, and worthwhile, for example by welcoming people individually.

“It’s got to be someone who the group trusts ... someone who can be a spokesperson, someone who is committed to the aims of the group and you need someone who has the time and resources to do it. If they have previous experience of chairing, that helps”. (Participant 49)

Only one respondent mentioned a potential disadvantage of the Chairperson being a Service User: that in the respondent’s experience the Chairperson had not been assertive enough with Health Professionals when they dominated meetings and other Health Professionals had to “step in.”

The ‘satisfaction’ of members with their Chairpersons varied widely: roughly, about one-third were very satisfied; another third were more or less content, but felt the Chairperson lacked some chairing skills, being too dominant or not encouraging others to talk; for example:

“At my first meeting the chairman opened his mouth at 10.15 a.m. and didn’t close it again until 11.20 a.m.” (Participant 32)

The final third were quite dissatisfied with their group's Chairperson, indicating that ‘leadership’ was not being provided.

4.2.2 The Facilitator

The appointment of facilitators was actively encouraged by the CPP Steering Group at the outset of the project, but it was left to each group to make an
individual decision as to whether or not to have a facilitator. Twenty-five of the 30 groups had a ‘Facilitator’ and five groups had no Facilitator; in these latter groups the (Service User) Chairperson also did the work of a Facilitator. Two of these latter five were Locality PGs; these both indicated that lack of resources were the main reason for the lack of a Facilitator, although both had received some Cancer Partnership Project funding. The other three were Network PGs; one had decided not to have a paid facilitator, and the other two groups wanted a Facilitator but had not yet recruited one for various reasons (e.g. the absence of a CN Lead Nurse to act as line manager).

Of the 25 facilitators, 21 had service user involvement as their ‘core’ role. In the four other cases, the facilitator role was secondary to another NHS role – one was the cancer network Lead Nurse, two were cancer information managers, the fourth a trust-based oncology specialist nurse.

Of the 21 ‘core role’ facilitators, 18 were salaried NHS staff and three were freelancers, independent contractors working under contract for the relevant cancer network. The NHS posts were typically part-time posts, for two or three days per week.

<table>
<thead>
<tr>
<th>Table 4.2.2 Type of Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type</strong></td>
</tr>
<tr>
<td>‘Core role’ facilitator</td>
</tr>
<tr>
<td>‘Secondary role’ facilitator</td>
</tr>
<tr>
<td>No facilitator</td>
</tr>
</tbody>
</table>

The overwhelming majority of all respondents were very positive about their group’s Facilitator, and saw the role as absolutely critical to the success of the group. It is of importance that the Facilitator was valued not for ‘doing’ activities but for ‘enabling’ others to do, for negotiating, guiding and supporting. Many respondents used the words ‘brilliant’ and ‘fantastic’ in describing their group’s facilitator.

The attributes of an ideal Facilitator would include: “An excellent communicator, great interpersonal skills, enormous energy, an understanding of cancer services, and an appreciation of the issues faced by people with cancer” (Participant 52). A Facilitator must not be afraid to ‘tackle’ health professionals, should be good at enlisting help, be approachable, self-motivated and organised, and must ‘fly the flag’ for service user involvement. In short, they “must be all things to all people at all times” (Participant 39).
Communication was highlighted as a key role. The Facilitator acted as a ‘communication lynchpin’, not only in the sense of disseminating information but also as an ‘enabler’ of communication between service users and health professionals. One respondent talked about the Facilitator being a ‘bridge’ between the two sides, and the importance of ‘impartiality’ and of having ‘credibility’ with all constituencies were mentioned frequently. As an example, one service user described the Facilitator as:

“Very good, very discreet, very committed. Doesn’t collude in criticism. Non-confrontational without being soft. Good at enlisting help. Very strong character.” (Participant 40)

A second key role was ‘enabling’ work: enlisting help, managing projects, arranging meetings, ensuring that actions get taken forward, advising and guiding. One health professional stated:

“[The Facilitator] is fantastic. [The Facilitator] sits back, non-biased, and allows patients to make own decisions, leading them slightly by getting all the issues on the table. [The Facilitator] helps them find their direction.” (Participant 48)

Broadly, the ‘core role’ Facilitator model seemed to work better than the ‘secondary role’ model. As well as the practical limitations of the secondary model – less time, less flexibility, less accessibility – a key drawback was the difficulty in defining, and working to, boundaries. One ‘secondary role’ Facilitator, a senior nurse, said:

“I have to think about what I am doing, whether I am trying to respond from a trust perspective in terms of cancer services or whether I am trying to facilitate. I’m not sure if they fit. The Facilitator needs to be someone from outside the group.” (Participant 51)

The relationship between Facilitator and Chairperson appeared to be very important. Generally, this relationship appeared to be harmonious and working well, which had a strong positive impact on the group. Conversely, when this relationship was not working well, the group function far less happily and successfully. Although unusual, a key cause was the lack of ‘ground rules’ or clarity over boundaries, roles and responsibilities. This seemed to arise upon the appointment of a new Chairperson to a situation where the facilitator had been the sole lead for a group, and the ‘handing over’ of the leadership role to the Chairperson had not been discussed or agreed.
4.3 Membership of the group

4.3.1 Numbers, age and gender of group members

On average, approximately 20 people attended group meetings (for both Network PGs and Locality PGs); but it was often noted that attendance fluctuated: for example, attendance at one group ranged from ‘ten or twelve’ up to ‘thirty or forty’. Some interviewees noted that the group mailing list ‘membership’ was, however, substantially greater than the regular attendance, with mailing list membership up to 100 members in some cases.

In most groups, most attendees were women. Women were in the minority in only two of the 30 groups, and in a typical group two-thirds of attendees were women and one-third men. In 13 of the 30 groups (43% of groups), 75% or more of the attendees were women.

In most groups, the large majority of members were ‘middle-aged’. On average, around 75% of attendees were between 40 and 65 years of age, with the remainder divided equally between older people (aged 65 and over) and younger people (aged under 40). The inclusion of younger service users was raised repeatedly as a concern. In almost half of the 30 groups, less than one in ten attendees was aged under 40, and five of the 30 groups had no members at all under the age of 40. Furthermore, in many cases these younger members were NHS staff, not service users.

On average, two-thirds of members were service users and one-third NHS members. Of the service user members, in the average group 75% were NHS patients, and 25% carers. A handful of groups had one or two other members who were ‘interested members of the public’.

4.3.2 Representation of Black and Minority Ethnic (BME) communities

The overwhelming majority of people involved in Partnership Groups were of White British ethnic origin. Of the 29 groups for which these data were available, 28 had a membership that was at least 90% White British; 14 groups (48% of groups with data) had no representation whatsoever from members of local black and minority ethnic communities. Furthermore, in the groups where one or two people from these communities were attending members, in many cases these members were NHS staff rather than service users. For example, one group noted that the only black and minority ethnic members were doctors.

We compared the proportion of BME members within each group to the proportion of BME members in the group’s local population using the 2001
Census Ethnic Group estimates (Chart 4.3.2). Using these estimates, seven of the 29 groups (24%) had the statistically expected representation of BME groups, whereas the other 22 did not. In the most extreme case, a network group that had no BME members sat within a population of whom around 47% were from BME groups.

4.3.3 Cancer types experienced by, and health status of, service users

The service user membership of all groups encompassed experience of a wide variety of types of cancer, including many rarer cancers. Service users who had experienced the most common cancers in England were all well represented – breast, colon, prostate, gynaecological. A notable exception was lung cancer, which was hardly represented at all across the 30 groups.

When asked, most Chairpersons confirmed that the group included some members with active cancer (though many interviewees noted that this information was not know to them, as such personal details were not made public in the group). Some interviewees made the point that even seriously ill people wanted to play, and continued to play, an active part in the group. For example:

“We’ve had several members who have died in the last year, but they have been along to our meetings right up to the end. We have people who have had major surgery in the last couple of months and

---

3. These estimates map on to the areas covered by Strategic Health Authorities, rather than cancer networks.
yet are still going, and if they are not well enough to attend on a day will send in a written report.” (Participant 5)

4.3.4 A ‘typical’ group
As a summary of the findings above, the characteristics of a ‘typical’ group are:
- Approximately two years old
- Meets monthly / six-weekly / bi-monthly
- Has direct representation on cancer network Board, or equivalent
- Has a service user Chairperson and a part-time paid Facilitator
- Approximately 20 members regular attend meetings, with a larger ‘mailing list’ membership
- Two-thirds of members are women
- Three-quarters of members are aged between 40 and 65 years
- Two-thirds of members are service users, and one-third are NHS members
- There is little representation of Black and Minority Ethnic communities
- Service users bring experience of a broad range of cancers, including rarer cancers, except lung cancer, which is poorly ‘represented’.

4.3.5 Recruitment, and issues of inclusion
Two challenges to inclusion were repeatedly identified.

4.3.5.1 Recruitment
The first concern was that, simply, not enough people wanted to be actively involved in groups: generally, relatively (very) low numbers of patients seem to want to be involved in NHS partnership activities. Recruitment – of anyone – was a common challenge. Groups, however, were proactive and had experimented with numerous recruitment strategies: direct recruitment from support groups, adverts in local newspapers, radio broadcasts, posters in clinics, open days, stalls at community events, canvassing at football matches, distributing leaflets and newsletters widely. Respondents were despondent about recruitment; no strategy seemed consistently to yield a result:

“I’ve been disappointed at the lack of interest from other patients. When I go to [the cancer centre], the outpatients foyer there is absolutely heaving with people, there’s loads of people. And when I think of all those people there, and how relatively few turn up at a [group] meeting, it’s a great shame.” (Participant 54)

“We did a leaflet drive, but we got no response. You see them in the surgery in mint condition.” (Participant 35)
“Leaflets are hopeless, you get no response. We arranged open meetings, three in three localities. No one turned up. Well, one person came to one, thinking it was a support group, and went away again; and no-one turned up to the other two.” (Participant 19)

Respondents had considered why recruitment wasn’t working, suggesting:

- “If you’ve had cancer, you’ve probably had enough of it.” (Participant 54)
- Some people who have experienced cancer, once they have finished their treatment and are in remission want to ‘put cancer behind them’; these people don’t want to talk about cancer, they don’t want to hear about cancer, they don’t want to think about cancer any more;
- There is no immediately obvious benefit for the individual; this is essentially an altruistic activity, and not everybody is altruistic by nature;
- Many people simply are not interested in this kind of activity;
- Some people do not understand the purpose of the group; they think it’s a support group, or simply a ‘talking-shop’, rather than a real force for change.

Poor recruitment was an acknowledged concern both for the present and the future. For the present, while groups were able to continue functioning with the ‘core’ membership, the lack of new members means that the ‘pressure’ is always on the same people, which is not sustainable. In the long-term, there was the concern that as the ‘founding’ members grew tired, or ill, or lost interest, as inevitably happens, there would be no new ‘second wave’ to replace them. This latter issue is further discussed in the context of future development in section 4.9.2.2.

4.3.5.2 Inclusion and representation

The second issue of concern among members was ‘representation’. As noted in the sections above, the ‘typical’ Partnership Group membership might be described as predominantly female, middle-aged, and White British, with experience of the commoner types of cancer. Across the board, respondents were aware of issues of representation and of the fact that the ‘mix’ of service users in their group typically did not reflect the diversity of NHS cancer service users:

“The only element of recruitment that gives me cause for concern is that we tend to be white, middle class people with a bit of time on our hands; and so while we are quite articulate and assertive … we are not very representative and that’s a bit of a concern really.” (Participant 44)

This ‘external NHS’ interviewee echoed others in associating representativeness with ‘credibility’:
“The other aspect is how to ensure that service user representation is representing the vast majority and not a vocal minority. This is a significant risk amongst service user involvement as the people who come forward tend to have very strong views of how a service should be delivered and this may not necessarily be the view of the majority of service users. Therefore, developing a network of users who can then offer a more balanced view would be a way forward.”  
(Participant 1)

In particular, many interviewees commented upon the difficulty in attracting members from Black and Ethnic Minority communities, in attracting younger people, men, and people with experience of services for lung cancer. Most groups had disabled people among their members, often people who were experiencing a physical impairment as a direct result of cancer. No respondent identified any ‘issue’ regarding access for disabled people; all confirmed, for example, that their meeting venues were fully wheelchair-accessible.

Universally, the Chairpersons we interviewed expressed an awareness of the lack of representation of BME communities within the groups. The groups’ responses to this imbalance varied. Most groups indicated that this position was not ideal, but lacked either strategies to promote inclusion or the time to execute such strategies. Three or four groups were actively pursuing such a strategy, for example by trying to engage community leaders as a point of access, or through BME cancer outreach workers, or enlisting the help of the local Council for Voluntary Services, or by speaking at community group meetings.

However, some groups noted that the pursuance of the strategy was difficult and time-consuming, and had reaped little ‘reward’ in terms of new recruits. Furthermore, one or two other groups stated that they had pursued such proactive strategies in the past but had now abandoned them, due to lack of success, as this quote illustrates:

“It has exercised a lot of out time and energy and discussion. We’ve expended a lot of energy trying to make sure we have a diversity of members. For example, we are still not being successful in engaging the local Asian community, despite massive efforts on our part. It’s a significant issue for us. We go out to speak to groups, and I telephone and write to community representatives. I have visited and spoken with [the local] Race Equality Unit, and I have worked through our cancer support groups locally to try and recruit. In fact, we’ve now come to the decision that we have to draw our energies in and concentrate on the work that we can do.”  (Participant 30)

A few interviewees were of the opinion that BME communities found the whole concept of a universal group unattractive. One reason offered was that cancer is
a stigma among some communities, that patients tend to ‘hide away’ and not talk about it, and so public participation in a cancer-related group would be the last thing they would want to do. A second reason offered was that people generally prefer meeting with members of their own communities:

“Going back to my experience of working with Asian groups in [town] and in [town] in other capacities, I’m not sure whether the things are absolutely transferable but certainly in Asian communities in [towns], my experience was that people want to look after themselves. There are very, very strong support networks within the communities. There’s often a shame attached to being ill, particularly if that illness involves some sort of obvious mutilation, if there’s some sort of visible impairment.” (Participant 18)

Two Chairpersons stated that the group used previously to have BME members but that “they had stopped coming.”

We did not ask direct questions about group members’ attitudes to BME members. However, one interviewee made a (clearly disturbing) spontaneous comment regarding such attitudes:

“The other thing is, there’s a major problem with racism. There are some people on that group who, if anybody who was not white came to it, I think they would be made to feel extremely uncomfortable. It’s horrible, it really is quite unpleasant, it’s really very, very offensive. I just don’t know how you deal with that ... That is definitely there and I think a major problem would be if any one from an ethnic minority group came, they would be like a token person and I think that makes you feel uncomfortable anyway and as I say the undercurrent from some people ... I think it would be really horrible. So my feeling is, at present, unless you get a critical number of people who are not white turning up, I think anybody who came would have quite a difficult time. I can fully understand why people won’t come to it, actually, but how you get round that ... I was really quite shocked at some of things I’ve heard said in that group, really quite upset by it, very, very unpleasant”. (Participant 18)

4.3.5.3 Endnote

Two further points should be noted regarding recruitment and inclusion. First, Service Users seemed to engage with the issue far more than NHS members, and Service Users seemed much more involved in the process of actual recruitment than did NHS members. Second, almost exclusively, when discussing these issues respondents talked only about service user members, not health professionals: there were few references to issues of recruitment of, or diversity of, or representation of, NHS members.
4.4 The dynamics of partnership

4.4.1 The mix of service users and NHS members

From information provided by the groups’ Chairpersons, the ratio of service users to NHS staff members in 29 groups for which data were available ranged from 20:1 in favour in service users, to 6:4 in favour of NHS members. Service users were in the majority in 23 of the 29 groups (79%), and NHS members in the majority in three groups (10%), with the remaining three groups having equal numbers of service users and NHS staff.

In the average group, two-thirds of attendees were service users or carers and one-third NHS staff (including health care professionals, network staff, and facilitators); so, on average, of the 20 attendees 13 or 14 were service users and six or seven NHS staff.

![Chart 4.4.1 Proportion of Service Users and of NHS staff within each group](image)

4.4.2 NHS members of the group

(Note that the remainder of section 4.4 excludes reference to the role of the group Facilitator, which is discussed above in section 4.2.2).

Data were available for 29 groups. A wide variety of NHS professionals attended meetings of the 29 groups. Among network groups, the most common and consistent attendees were cancer network staff (Table 4.4.2). The network Lead Nurse was active in 83% of groups, network Lead Clinicians in 12% of groups, and other network staff – principally the network Manager, and Service
Improvement Facilitators (SIFs) – active in 67%. Almost all groups included one or more of these three post holders. Network Lead Clinicians typically received meeting papers, but in only three of the 24 network groups had the Lead Clinician attended meetings more than once or twice. A range of NHS trust staff also attended meetings, the most common among these being cancer nurse specialists based in cancer units and centres.

It is interesting to note that the pattern of NHS membership of locality groups was quite different to that of network groups. Locality groups had less inclusion of cancer network postholders, but more inclusion of local NHS staff. 60% of locality groups, for example, had a regular member who was a cancer doctor, as opposed to 21% of network groups. Cancer services managers and other NHS staff were also more prevalent in locality groups than in network groups.

The 29 groups included an array of NHS members, including: oncologists, radiographers, clinical psychologists, specialist nurses, General Practitioners, district nurses, counsellors, hospice directors, PCT Chief Executives, PCT cancer leads, PCT planning managers, PALS managers, appliance officers, Audit Managers, endoscopy nurses, research nurses, and research assistants. Some non-NHS staff also attended a few groups, including a university lecturer, staff from cancer charities and a social services homecare manager.

<table>
<thead>
<tr>
<th>Type</th>
<th>All groups N (%)</th>
<th>Locality PGs N (%)</th>
<th>Network PGs N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CN Lead Clinician</td>
<td>4 (14%)</td>
<td>1 (20%)</td>
<td>3 (12%)</td>
</tr>
<tr>
<td>CN Lead Nurse</td>
<td>22 (76%)</td>
<td>2 (40%)</td>
<td>20 (83%)</td>
</tr>
<tr>
<td>CN Manager / SIF / other</td>
<td>18 (62%)</td>
<td>2 (40%)</td>
<td>16 (67%)</td>
</tr>
<tr>
<td>Doctor (other than CN Lead Clinician)</td>
<td>8 (28%)</td>
<td>3 (60%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>Cancer Nurse (other than CN Lead Nurse)</td>
<td>19 (66%)</td>
<td>3 (60%)</td>
<td>16 (67%)</td>
</tr>
<tr>
<td>Trust Cancer Manager</td>
<td>14 (48%)</td>
<td>4 (80%)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Other NHS staff</td>
<td>15 (52%)</td>
<td>4 (80%)</td>
<td>11 (46%)</td>
</tr>
<tr>
<td>Other non-NHS staff</td>
<td>8 (28%)</td>
<td>1 (20%)</td>
<td>7 (29%)</td>
</tr>
</tbody>
</table>
4.4.3 **Roles of NHS members**

In general, groups appeared each to have a small ‘core’ of ‘active’ NHS members, with a larger number of ‘inactive’ NHS members who rarely or never attended meetings; i.e. the pattern of membership that was also evident among service user members.

4.4.3.1 **Support and advice**

Interviewees felt strongly that the NHS staff members had two key roles. The first was to ‘support’ the group. The ‘core’ of NHS members mentioned above varied in each group. Not unusually, this core included a steadfast clinical ‘champion’, such as a senior nurse or consultant oncologist. This ‘champion’ supported the group by attending meetings, engaging with the aims and activities of the group, and by ‘championing’ the group and ‘influencing’ on behalf of the group among colleagues in the cancer service. An important aspect of this supportive engagement was the provision of guidance and advice. With few exceptions, service users perceived the NHS members to be important and helpful:

“They are working in the NHS and they know what can be managed, they have the power to move the group forward. They know other people who know other people that can help or pull strings. Users have a voice but no real elbow. We tend to look to the professionals to get us moving.” (Participant 14)
“They assist the group in the best way to leverage their objective. They point us in the right direction. They know the system so they advise the non-professionals on the best way to get there.” (Participant 11)

Some interviewees, it should be noted, pointed to an element of necessity in this collaboration:

“If you don’t work with them then you can whistle in the wind. I’ve had personal experience of this, so I know.” (Participant 16)

In addition, network Lead Nurses often were singled out by the interviewees as being particularly influential and helpful; for example:

“She is really good at explaining the system in a very clear way and she is very knowledgeable, so she is very good at answering any questions that we’ve got and clarifying things for us. She is also very good at helping us to prioritise [activities and meetings] … it’s difficult for us to judge which are going to be the most beneficial for us to attend, so we do look very much to [the Lead Nurse] to point us in the right direction.” (Participant 23)

This trait might be a simple reflection of their typically having the lead responsibility for Patient and Public Involvement within the networks; but it was clear that in some cases the Lead Nurse was a critical support to the group, indeed instrumental to the group’s establishment and smooth running; however, in a minority of networks it was felt that the Lead Nurse (and therefore) the network was not supportive enough.

4.4.3.2 Information

The second key role for NHS members was to act as a provider and recipient of information. On the one hand, NHS members passed on to the group up-to-date information on national, regional and local developments in cancer services, as indicated by this consultant oncologist:

“I see my role really as being a source of information for them, rather than perhaps being an active partner. I feel it’s their group. I’m just really there to answer questions or help in any way.” (Participant 41)

Groups also invited external speakers to provide information on specific subjects.

On the other hand, information also flowed in the other direction, and the ‘communication’ role of NHS staff included listening to service users questions
and concerns; indeed, not only listening but also responding to concerns. One Chairperson said:

“I think [the NHS staff] are there as a source of experience within the NHS. When the users and carers are bringing issues up, they’re there as a resource to say, ‘Yes, we are aware of this problem and x, y, z, is already being done about it’; or, ‘Nothing is being done and yes, you’re right, we need to do something about it’. Their experience of what is going on in the NHS is very valuable to the group.” (Participant 20)

In this role, the NHS staff contribute therefore to a ‘first line’ of debate about an issue and the inclusion of all parties facilitates a more ‘rounded’ debate.

4.4.4 The ‘dynamics’ of Partnership Groups

4.4.4.1 The balance of power

“We have got to be quite assertive as a group. We have got to be reasonable human beings and realise that what we are suggesting is within reason and workable but to also say that it is necessary. I think we have got to break down some prejudices from some medical professionals that patients have a voice and it needs to be heard; I’m not talking about a moaning voice but a positive strategy to improve services for everyone.” (Participant 6)

Generally speaking, interviewees reported that a harmonious, respectful working relationship existed between service users and NHS staff in the groups, with both sides perceiving an ‘equal partnership’:

“We all have an equal influence. It’s a proper partnership.” (Participant 8)

Indeed one Chairperson said:

“They guide us and help us to make decisions but they don’t necessarily influence us in a big way – which is how we would want it to be. We don’t do as they tell us – it’s the other way round!” (Participant 23)

One or two groups reported ‘teething troubles’ in the early days of the group, with some health professionals expecting to ‘dominate’ the group, but these members soon left. On the same theme, it is important to note that some service users were pleasantly surprised when it was clear the relationship was good:
“I have been very impressed by the professionals on the group, in that they are very receptive to the patients and carers, and very helpful. I wouldn’t have been surprised if the health professionals had taken the view, ‘Well what do these people (the service users) know about cancer and the NHS and the technicalities and so on. [However], without exception nobody has taken that ‘Well we know better than you’ standpoint, there’s not even an underlying feeling of that. They’ve all been very helpful to talk, to suggest things, to take on our involvement as patients, welcome us into the groups and so on.” (Participant 54)

“The professionals are brilliant, actually. I was very worried when I first started … We could do with more representation from clinicians.” (Participant 49)

The harmoniousness of the relationship naturally varied across the groups, and a number of members – both service users and health professionals – noted the importance of maintaining a numerical majority of service users in the group. The point also was frequently made that efforts must be made to avoid or explain ‘jargon’. In only one group was there any indication at all of any ongoing friction:

“The network manager tries to influence the group in ways the service users don’t like sometimes, it’s pressure.” (Participant 3)

Interviewees from a minority of groups suggested that the relationship was still immature and required development; and, as would be expected, most groups reported some ‘issues’ that had arisen, discussed in following sections.

4.4.4.2 Disclosure

One aspect of service user involvement in this context – cancer care – that appeared to prompt some perplexity among some NHS members was the ‘disclosure’ by service users of personal experiences and feelings. On a first level, disclosure on occasion raised an ‘ethical’ concern, as articulated by this health professional:

“I’m just a bit astounded that they are quite so willing to share their personal being with other people, when we have to be so careful these days with data protection and patient confidentiality. It’s drummed into us … and then the patients are spouting it all out!” (Participant 39)

On a second level, problems arose when negative NHS experiences were expressed in a particular way by service users; that is, when an experience,
usually conveyed as a ‘grievance’, was recounted in what was perceived as an ‘inappropriate’ manner:

“Occasionally patients with bad experiences get vocal – it’s like a ‘tirade’ – which is very inappropriate. Other members are polite and don’t react but in private say that they get frustrated with this – it detracts from ‘business’ of the meeting.” (Participant 56)

“It is very difficult dealing with that, because obviously you don’t want to minimise the problems that somebody is having but, you know, the group is about looking at things on a wider basis. I think some of the professionals sometimes can get quite defensive and sometimes the way they speak to some of the users isn’t right … but actually other users [also] get quite frustrated and they will challenge somebody’s views if they feel they’re representing [their experiences] as what happened to everybody or they will say, ‘We can see that that was a problem for you but this isn’t the place to raise that.’ ” (Participant 52)

Whilst both these quotes are from NHS members, the service user members who spoke about this, whilst empathising with an individual’s desire to ‘have their story heard’, equally considered it inappropriate and unhelpful in this context. Such ‘behaviour’ conflicted with group ‘ground rules’ (introduced via CancerVoices training), it caused bad feeling between the ‘two sides’ and was a distraction from the purpose of the meeting. It was seen as the role of the Chairperson to manage these situations, respectfully but firmly.

4.4.4.3 The ‘imbalance’ of commitment

The third theme that emerged under this heading concerned a perceived ‘imbalance’ of commitment from the two sides – NHS members and service users – in some groups. This theme drew comments on several topics, including timing of meetings, attendance at meetings, commitment to the ‘cause’ of user involvement, and willingness to do work for the group. The ‘commitment’ theme further is discussed in section 4.5.2.

4.4.5 Relationship with the cancer network and the wider NHS

4.4.5.1 External NHS awareness of the group

All six ‘external’ (i.e. non-group) NHS respondents were aware of the existence of the group and indeed demonstrated good knowledge of the group. All respondents were familiar with the group’s purpose and working arrangements, and had a good appreciation of the numbers and types of members involved. Four of the six respondents had made use of the group as part of their job.
4.4.5.2 External NHS views of service user involvement

All six of the ‘external NHS’ respondents viewed user involvement as a valuable and necessary activity. This respondent, the Head of Planning and Performance for a PCT, made a useful observation:

“There are distinct benefits to having service user involvement in the development of services. The challenge is to define exactly what is expected of this involvement and the role that they can play. It is very difficult when routine activity has to be commissioned to involve service users in a meaningful way, but when new services are being developed or services being redesigned service users give an important perspective upon how the service should be considered. Having service users involved in service development and redesign adds an extra facet to the deliberations. Service users views are vital to making sure care remains patient-focussed and holistic.” (Participant 1)

All six interviewees were of the opinion that their Partnership Group should be funded and maintained in the long-term, and five considered that the group could and should be more influential.

4.4.5.3 The question of NHS commitment

The extent and nature of the commitment to user involvement from the local and wider NHS was often challenged. ‘Commitment’ appeared as a multi-faceted, shifting concept, an ethereal notion whose manifestations were open to wide and conflicting interpretations and judgements. A level of circumspection seemed fairly widespread; few groups or members felt wholly secure. Some respondents thought national policy the root cause:

“It’s all very well the Department of Health saying that patients should be involved in this, that and the other if they’re not going to fund it themselves. That was the view of the group. We find it very strange that patient involvement is the flavour of the month but the government don’t really want to pay for it.” (Participant 19)

At the level of the cancer network, while most Chairpersons considered the network support to be genuine, there were a few cases of doubt as to real motives. One Chairperson of a local group used this argument:

“Users come to a group because it’s a local issue, it’s a personal experience, to change experiences at a local level. The network is a tick box exercise and users don’t buy into that.” (Participant 26)

Another, the Chairperson of a Locality PG, stated:
“Health professionals find it difficult. They see user representation as a tick box exercise. As they are part of the network they find it very difficult to deal with local issues. Since the introduction of the network, our relationship with professionals has deteriorated. Instead of working in partnership – it’s not as conciliatory as it used to be, because they are being judged as a network. Users have local issues but professionals have a network brief.” (Participant 26)

As another example, one NHS manager stated:

“I have concerns about the thoughts higher up the network about the partnership group, and whether they are paying lip service to it really. It’s just the impression I get.” (Participant 52)

Finally, the priority given to user involvement at a local level was sometimes questioned, typically when actions were not taken forward. The first comment below is from an NHS group member, the second from a service user:

“[Sometimes] a manager has come to the group to talk something through and says, ‘Yes, that’s a good idea, we’ll look at that,’ but the first time they hit a problem they down tools. Whereas if it was the Chief Executive that had said, ‘I think we should be doing this,’ there is no way they would have given up at the first hurdle. The group thinks, ‘This person doesn’t want it to happen.’ Some managers are told to go and they can talk a decent talk in the meeting but then you find the actions aren’t being delivered. You know their heart isn’t in it or they’re not fearful of the group. If the group was as scary for them as the Chief Executive, things would happen.” (Participant 43)

“My concern is that what we discuss and think are good ideas, we don’t seem to have anywhere to take them. The lead cancer nurse is coming to our meetings and does hear what we say but she doesn’t seem to put it into practice at the hospital.” (Participant 36)

4.5 Motivation and commitment of group members

4.5.1 Members’ prior experiences of NHS cancer services

The service user members whom we interviewed had experienced a diversity of cancers, and some were in active treatment. Some had been diagnosed over thirty years ago. A large proportion of the 11 NHS group members whom we interviewed had personal caring or family experience of cancer. Of the 12 service users interviewed, only two (17%) had had a bad NHS experience. The 12 service users included a number of people who were also NHS professionals.
4.5.2 Motivation and commitment

4.5.2.1 Motivation and commitment of service user members

Service users were recruited to the group through a variety of processes: response to a newspaper article, through a friend on the group, via a poster in the hospital oncology department, personal recruitment by a Macmillan nurse, from a breast cancer support group.

When asked why they joined – and remained active in – their group, four main ‘motivating factors’ emerged:

- **Wanting to ‘give something back’ to the NHS, from a mix of altruism and gratitude:**

  “No system is perfect [but] the whole reason I got involved in [the group] is because I think I had excellent treatment from the National Health Service, overall it’s been very good. I think you can’t beat the National Health Service … When the chips are down it can do virtually anything that needs to be done, which is far better than any private hospital. I think the National Health Service is brilliant. I just felt I wanted to put something back into it, I wanted to help in some way.” (Participant 54)

  “I just wanted to put something back because I’ve had so much out of the NHS and cancer services and, as with everything, there’s always room for improvement. I thought if I come along to join the group I can put my input and share my experiences … mostly its been very positive, my experience”. (Participant 34)

- **Wanting to help improve services and influence change:**

  “I’d like to think that patients are going to get a better deal out of this. I don’t think they get a hugely bad deal at the moment but I’m sure there are areas where there could be improvements. That is my driving force.” (Participant 50)

  “I am the sort of person who gets involved, that’s just my modus operandi. I had reasonable treatment myself. Grass roots involvement — it’s here that the actual differences are made.” (Participant 49)

- **Empowering patients, ensuring patients had a ‘voice’:**

  “I think the patient should have a voice. There are lots of needs, and unless the professionals know about the needs, how can they meet them?” (Participant 35)
As a representative of a support group or other constituency, often with exchange of information as a priority.

A bad NHS experience did not appear as a motivating factor; to reiterate, almost all service user members we spoke to had perceived their treatment as being good. It is of some concern, then, that many of the NHS members we spoke to seemed to think that many members were driven by their own, personal bad experiences.

The groups generally worked to the principle that members can choose to be as active – or inactive – as they like. However, it was clear that there was underlying tension around this principle: a group might work concurrently on numerous and diverse ‘fronts’, the group’s capacity to influence change limited only by the work capacity of its members and paid staff. In other words, the more people who volunteer for work, the more the group can achieve. It is fair to say that, common to all groups, there was the perception that a ‘core’ of volunteers did all the work, for example:

“I do all sorts of other things: other committees, steering groups, sub-sections, strategic working groups, interviews … It is lovely to have user involvement but it’s too much for one person. We need more people, we need to spread the load.” (Participant 49)

Most service users carried out activities for the group in between meetings. Most common were sub-group or ‘working party’ meetings to take forward specific projects, and working on documents such as patient information leaflets. Reading was an implicit activity that nevertheless required time; some respondents mentioned three or four hours per week of reading, either of documents of direct interest to the Partnership Group or of documents passed to the group ‘for consultation’, such as a new local policy proposal. Respondents also made mention of the fact that many members were active on other groups: locality groups, support groups, non-cancer Patients’ Forums, and so on.

4.5.2.2 Motivation and commitment of NHS members

The majority of NHS members were involved in the group as part of their job. One or two were invited to join the group having been identified as ‘influential actors’ in cancer services, and one or two others had attended meetings for their own motives – to get patients’ opinions on something, to publicise a service, and so on – and had ended up staying on the group. The NHS members all stated that they supported the ‘cause’ of user involvement, with sincerity. A cancer services manager made this comment:

“I’m interested. I work more than my allotted hours each week, I’d like to think the excess I work is for this group. Emotionally, it is
where my heart is, a few hours a week out of my own time. I’ve seen
cancer patients, I’ve been a carer for a couple, I’m quite well
motivated. You gradually build up a level of experience in dealing
with user reps that makes you realise that they can be pushed aside
a bit too easily, they don’t know when to kick back. You have to train
them to kick back. I’m poacher turned gamekeeper.” (Participant 43)

Another NHS member mentioned that he wasn’t supported by his line manager,
who didn’t think he should be attending the group. Other NHS members referred
to the group as enjoyable, down-to-earth, ‘a breath of fresh air’, as well as being
worthwhile:

“I actually enjoy being with the group, it’s very useful, it’s quite
positive. I actually believe in user involvement; I mean, yes, it’s quite
slow and I’d like things to happen quicker but I think things take
time.” (Participant 57)

Service users also perceived a ‘core’ of NHS members to be committed to user
involvement:

The [NHS] people who are interested in it are serious about it: they’re not just
following the party line, they mean it.” (Participant 54)

But they perceived other NHS members to have less commitment. One
Chairperson said:

“The core are very committed and come to most meetings, others
not often. Some people turn up because they’ve been allocated that
role.” (Participant 18)

Other respondents expressed similar sentiments. So, whilst some NHS
members typically were regarded as committed, others were perceived as going
through the motions and simply required to attend as part of their paid role. One
Chairperson stated that some NHS members sit through meetings “irritated and
bored” (Participant 18), other respondents that it was annoying when NHS
members arrived late and left early in meetings.

Having presumably sensed this sentiment, one or two NHS members made
comments in their own defence:

“I think sometimes the patients don’t actually appreciate we all have
a job of work to do and they think because we are on site we ought
to turn up two minutes [before the start] …” (Participant 39)
In contrast to the service user members, with a few exceptions, NHS members (excluding the group’s Facilitator) took on minimal (or indeed no) group-related commitments between meetings, and these commitments generally concerned the provision of information, finding out some performance data, for example, from a trust.

4.5.3 ‘Impact’ of this activity upon the members involved

In the ‘case site’ interviews, we asked interviewees if their involvement in the group had had any discernible ‘impact’ upon them personally. We advised that broad definition of ‘impact’ should be used, covering aspects such as personal financial cost, health status, and emotional well being.

Importantly, only one NHS member interviewed considered the group had any noteworthy personal impact upon her/himself. In contrast, service users identified both positive and negative impacts.

Foremost, service users placed substantial emphasis on the personal benefits of involvement: it gave a sense of purpose, of being active and doing something useful, of developing and learning, of feeling in control and empowered. All these engendered self-respect, and made people feel good about themselves:

“Once you are told you have cancer you don’t think you have any ability to give anything back, and even those people who are terminal have this great opportunity to actually feel empowered. From something which is the worst thing that can happen to you … can actually really re-change your life, can make you – I don’t know – it can make you significant, it can make you fulfilled. I don’t think you could put that in a bottle, but you could sell it!” (Participant 38)

More than one person referred to involvement as ‘therapeutic’:

“This is doing me a lot of good belonging to this group because they are grooming me and getting me to do things. It’s enhancing in a sense to belong to it because you do that feel you’re not just passively sitting back and letting things happen to you. It’s very enhancing, it’s lovely. To actually be listened to seriously by people you respect is very good for you, I think.” (Participant 40)

Another recurring theme was that Partnership Groups raise emotional challenges, some of which are to be expected in any committee work (e.g. frustration, disappointment), but others that perhaps are not usually encountered in NHS committees. Members get ill and pass away, and several members spoke about how upsetting this was, how the morale of the group was affected.
Bereavement aside, the whole nature of the group sometimes drew an emotional response, as this carer told us:

“You never quite know with this business and sometimes something quite innocent can touch a raw nerve and the very fact that you’re doing something like this, you are exposing yourself to more opportunities for a raw nerve to be exposed. It’s almost inevitable if you are attending a group of this kind and you are sharing a large amount of common experiences, I think you will find there are moments when it does catch you a bit.” (Participant 50)

One challenge identified by an NHS member was the ‘pressure’ of being seen as person of influence:

“The most challenging thing is when there’s an issue that I can’t get sorted for them and then have to explain that to them. That’s probably emotionally challenging because I don’t feel I’m living up to their expectations when they raise an issue that they expect to be sorted, trying to explain to them that it’s not actually quite that simple, and that does pose emotional challenges because I think it should be that simple. I often feel frustrated and at times I feel like I’ve let them down.” (Participant 51)

Finally, some service users noted that their involvement at times caused ‘money worries’. One or two respondents were unhappy about the delays and practical difficulties in claiming expenses:

“It takes a month to get expenses through. [Last month] I had to borrow money and I’m still owed money. I have to find the money up front and I have had to go into overdraft. I was owed £250 to £300 collectively over a two-month period, so I get penalised for that. What’s actually happening is that economically I am subsidising … this user involvement and it’s something I’m not happy with.” (Participant 37)

However, most service users stated that they never claimed expenses, seemingly as a matter of principle. This service user, from a fully CPP-funded network group, was indicative of this widespread reluctance to claim expenses:

“I never claim expenses. It costs me about £18 a meeting. We’ve been told we can have reimbursement but we don’t [claim], because there’s not enough in the kitty and we don’t know for how long we shall be given money.” (Participant 33)
4.6 Views on the ‘influence’ of the group

4.6.1 What is – or should be – the main aim of the group?

As noted above, we were provided with copies of Terms of Reference from 16 of the 30 groups. Below is a selection of statements of principal aim taken at random from these 16:

• 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. (Yorkshire)
• To work in partnership with health professionals to contribute to decision making in service provision, planning, policy and research within the cancer network and to provide and independent voice for patients/users and carers. (West Anglia)
• To improve the quality of cancer services and ensure that the patient and carer are central to all decision-making processes. (Thames Valley)
• To bring together patients, carers and health professionals involved in cancer care across the network and to provide effective links between these parties and to provide patients and carers with a voice to influence services and promote high quality cancer care. (Teesside, South Durham & North Yorkshire)
• To represent to the network Strategy Board the views of cancer patients, their families and carers and the general public covering all aspects of cancer care.

While no two statements are the same, some core elements can be identified:

• The aim to provide a ‘voice’ for service users
• The aim to work in partnership with other parties
• The aim to ensure service users are involved in decision-making
• The aim to ‘influence’ policy and services
• The aim to improve care for patients.

The interviewees in the case sites, both group members and external NHS staff, all demonstrated a good awareness of the aims and purposes of their Partnership Group.

4.6.2 The influence of the group

When asked about the ‘influence’ of the group, many respondents prefaced their comments by acknowledging that service user involvement is a huge and complex challenge, which, if taken to a literal conclusion, would require massive shifts in NHS culture, funding, and systems. The size of the endeavour is important: even the most meaningful of achievement seems but a small step forwards. Finally, another preface was that ‘influence’ is impossible to measure in any but the crudest sense.
Bearing these points in mind, overall, respondents felt very positively that the groups were ‘making a difference’ to local NHS cancer services. All groups felt that progress had been made in involving service users, and some felt that the groups were actually influencing practice. The examples provided by respondents are described in section 4.7 below.

A small minority were of the opinion that the groups were making no ‘real’ difference at all. However, respondents who responded negatively or were undecided related almost exclusively to groups that were in a fledgling stage or had other operational difficulties: it wasn’t that a vibrant, well-organised group was making no difference, it was that the group wasn’t yet working ‘properly’. The point was stressed repeatedly that things take time – groups take time to form, work takes time to do, change takes time to happen – and that user-influenced change is a long-term project:

“I think it’s starting to. I can’t say for definite if it’s really making a difference – come back in twelve months time!” (Participant 52)

More than one service user referred to the sense of being a ‘pioneer’, and others made other comments on a similar theme:

“It’s a very exciting time within the NHS, isn’t it? It’s just the time to be influencing.” (Participant 35)

The respondents often mentioned the enormity of the task of changing NHS culture:

“The NHS is like a huge oil tanker, it takes a long time to turn around. The culture needs to change, people have got to learn to do things differently.” (Participant 16)

Given the size and complexity of the undertaking, it was noted as critical that groups have a ‘realistic’ understanding of the ‘workings’ of the local NHS, and adopt effective strategies to work with it. This NHS member gives an example of what other interviewees referred to as the ‘chipping away’ or ‘drip, drip, drip’ approach to influence and change:

“I know the size of the mountain they have got to push. They may feel frustrated [but] soon learn that it is not enough to say their views once, they need to echo things and wait for the right opportunities and sometimes they are told there is no chance of changing what they want and. There’s a little air of deceit sometimes; we invite people in because we want to hear them and then we don’t do anything with what they tell us.” (Participant 43)
Partnership Groups need to “learn to work the system”, to know which buttons to push, to know who has influence and who does not:

“You have to get to people who can make a difference … ideally it’s the Chief Executive of the acute trust”. (Participant 44)

“The feedback loop is important. You need to be looped back into key influential figures, like the commissioning managers. The groups need to have local strong links that can actually influence. To me, without that part of the loop they end up being – possibly being – nothing more than a support group to each other.” (Participant 55)

In addition to slowly ‘chipping away’, and ‘learning to work the system’, a third strategy for influence was to focus on ‘small hits’: achievements that might not be huge systems change but have a real, positive impact upon patients’ lives.

“It’s about making differences with individuals, I don’t think differences with systems, I don’t think we make any differences with those. But if you can have some impact with a group of individuals who look at things differently as a result, that’s all to the good.” (Participant 44)

“Yes, influence in little ways, only little ways. You can’t do anything [more] because our health authority is part of the big, national NHS, so it’s got to do what it’s told.” (Participant 33)

4.6.3 Helps and hindrances to ‘influence’

We asked all interviewees to identify factors that either helped or hindered the group in achieving its aims. Those issues identified as having an ‘impact’ upon individual members are discussed in section 4.5.3. The issue of recruitment and representation, also raised under this category, is discussed in section 4.3.5.

4.6.3.1 Helps and supports

- Positive group dynamics
  Service users in particular placed emphasis upon the importance of being a friendly group with a strong, positive identity, with members that are keen and motivated and active, respectful of all sides, caring about each other and giving each other support. A ‘supportive culture’ in the group was of firm importance to service users. The majority of service users definitely felt they were supported, by the Chairperson and Facilitator, but also strongly by other members:
“Support? Definitely. The facilitator is always at the end of the phone, and I often pop up to see her when at the hospital. The group members are there if you need them, if you’ve got a personal problem and you want to share with someone in the group. No, there are no times when I’ve felt unsupported.” (Participant 34)

The support of influential NHS staff in local trusts and the cancer network also was seen as critical, and some respondents pointed to national networks, such as the Rarer Cancers Forum, as providing that all-important ‘community’ for some members.

‘Support’ seemed less significant to NHS members. When asked about support in the group, a good number of NHS members responded that it was a strange question, that they saw their role as providing support, not receiving it. One NHS member said:

“I don’t think I’d say I feel supported – I don’t feel unsupported, I don’t feel I go to be supported though. I think I go to support them and to participate. I don’t expect to get support out of it.” (Participant 39)

However, interpreting the question more broadly, NHS members generally said that they felt they were respected and listened to in the group, and that the group was friendly and welcoming and helpful; a cancer network Lead Clinician, for example, said:

“They have been tremendously helpful to me. If I had an issue, I have felt I can approach them with that problem we’re discussing and they will respond and make useful suggestions and even get involved and do something about it. So I do feel supported … I find [the group] quite refreshing because there’s a lot of common sense there.” (Participant 41)

- **Working strategically**
  Respondents emphasised the point that groups worked best when following a clear direction, a focus, knowing where the group fits in the scheme of things.

- **Support from NHS senior managers and clinicians**
  NHS support was identified as crucial to the success of the group, particularly support in the form of NHS professionals who are active, vocal champions for user involvement.
4.6.3.2 Hindrances and barriers

Four main hindrances and barriers to effective involvement were identified:

- **Leadership problems**
  Leadership problems included the absence of a Chairperson or Facilitator, or a poor relationship between these two key posts, or poor succession planning. (See section 4.2 for more detail.)

- **Instability**
  Respondents told us that a lack of continuity among members and personnel can be very disruptive. While some changes are unavoidable, service users regarded as unacceptable the practice of NHS members appearing infrequently or sending random deputies:
  
  “It undervalues what we’re doing if the professionals can’t come or send a representative” (Participant 36)

- **Geographical area**
  Some Network PGs working as sole groups within large geographical areas had encountered certain problems: travel distances, isolated communities, and a large number of localities each with distinct issues.

- **Concern over funding**
  As noted in section 4.8 below, many groups felt some considerable anxiety regarding their future due to insecurity of group funding arrangements. Not least, the need to address this insecurity took up the groups’ time in discussions and planning, time that members felt would be better spent on actual activities.

4.7 Activities and achievements

The average group, in its short lifespan, had carried out an impressive range of activities. Well-established, active groups could point to many achievements and points of influence, activities and projects. Sixteen groups provided a list of achievements; the list reproduced verbatim below from a newsletter (from the West Anglia PG) is an example selected at random:

- Launch event October 2001
- Developed standards for Breaking Bad News, and implemented them across the network
- Reviewed patient literature to ensure information is accurate, easy to understand, user friendly and accessible
- Made representation to PCTs, CancerVOICES National Conference, and the (DoH Cancer Action Team) National Development Programme
- Improved parking facilities for chemotherapy patients at Peterborough
• Been instrumental in shorter waiting times at Peterborough
• Involved patients in proposals for the new oncology department at West Suffolk hospital
• Been invited to comment on new publications relevant to cancer
• Contributed to prioritising the Strategic Service Delivery Plan for the network
• Taping consultations pilot at Papworth Hospital
• Involvement in Focus Groups and Project Teams within the Patients as Teachers initiative.

As noted previously, group members did not overstate the ‘impact’ of their activities upon patient care, but these activities typically were closely aimed at improving the patients’ experience and, almost beyond doubt, would not have happened had the group not been in existence. What follows is essentially a categorised summary of the most common themes in activities and achievements; it was not out remit to judge the ‘quality’ of these activities in any sense, simply to document and bring them to light.

4.7.1 Establishment of the group itself

A first point to note is that, bearing in mind that over 80% of groups had been active for less than three years at December 2003, some groups could point only to ‘set up’ work – recruiting for and establishing the group, drawing up Terms of Reference, agreeing a strategy, and so on. Some respondents were rather apologetic for this ‘slow progress’, while others saw that this is a very necessary, if somewhat dull and frustrating, stage of group development. Respondents from both new and older groups noted that simply maintaining the group – organising meetings, meeting paperwork, communications, and so on – in itself provided a substantial workload.

Other respondents pointed to the simple existence of the group as in itself an achievement and cause for celebration. Their judgment was that, typically for the first time, a formal and accessible channel of regular, businesslike communication was open between service users and senior local NHS staff. Moreover, service users were becoming involved, albeit it gradually, in NHS decision-making processes; service users were “at the table” and certainly this was not something to be sniffed at. Moreover, the group provided a catalyst for user involvement, a focus, a forum, a body to drive user involvement forward.

4.7.2 Acting as a ‘reference group’ for consultation

A prime activity of most groups was to act as a ‘reference group’ for consultation, providing an accessible resource, clearly valued by NHS staff and others, to access service users’ views. At one end of the scale this might involve a health professional asking for feedback on the wording and distribution a local patient
survey questionnaire; at the other, it might involve service users working alongside NHS staff on a service redesign or development project.

One group, for example, had been substantially involved in the planning of a new cancer centre. An NHS member of the group said of the service users:

“They’ve taken a very active role in designing the building, turning up to all the meetings and saying ‘This will work, this won’t work, you should do it this way, you should do it that way’. They’re on all levels of that process, from the very high-level project group to the working parties, and they have made a big difference to the way that building is being designed. I think it’s an excellent group. It’s been a great privilege to work with them.” (Participant 41)

Another group provided a good example relating to cancer research:

“At the behest of the network Research Group, we’ve been looking at how to recruit more patients into trials. We discussed why there were problems recruiting people, from the patients’ point of view, and advised that perhaps information be given out earlier on in the process, rather than just being asked – full stop – when you are about to go into the trial. They’ve taken that on board, and somebody has produced a piece of paper now which can be given to all patients on diagnosis ... which explains that they might be asked at a later stage to join a trial, and explains what trials are, and how your treatment isn’t any worse if you don’t join them, etcetera, to get people in the frame of mind, if you like, so it isn’t such a stark choice when the time comes.” (Participant 19)

4.7.3 Networking, and representation on other groups

Almost without exception, Partnership Groups provided the nucleus for an incredibly wide network of user involvement in other groups and committees. With one or two exceptions, groups were represented upon the cancer network Board or equivalent group, along with a wide array of other network and non-network, cancer-related and non-cancer-related, local, regional and national groups. This list from a Network PG was not untypical:

- Cancer Network Management Group, Service Improvement Partnership, Patient Information Group, Palliative Care Steering Group, Research Network Steering Group
- Three Tumour Site-Specific Groups
- The Cancer Action groups in three acute trusts, plus a number of trust-based project groups
- All PCT Cancer Clinical Lead groups
• Macmillan Listening Study Steering Group, national research group in palliative care.

4.7.4 Patient information and communication

Many groups reported that their activities included projects concerned with patient information and communication. Partnership Groups had developed booklets, leaflets, and template letters for a wide array of purposes, some had established sub-groups dedicated to Patient Information, and at least one group had compiled an information directory to enable patients to access existing resources more easily.

Another topic, which arose from several groups, was that of ‘breaking bad news’. At least one groups had a ‘Breaking Bad News’ working party, another had been involved in training for NHS staff, and others had worked on drawing up, ensuring the implementation of, Breaking Bad News policies and standards. This quote from a group Chairperson shows the steps taken in such a process:

“We have successfully drawn up, and now implemented them, Breaking Bad News standards. It came up in an initial brainstorming session the group had, and it was a manageable chunk of work that we could do. I felt, as Chair, it was very important to have an initiative that we could start and see a finish to, to really encourage people to carry on and do something a bit bigger.

We looked at how we would want to have bad news given to us. We had a whole list of things on a flip chart and then from that we drafted up our guidelines. They were taken to the network Policy Board for endorsement, endorsed and introduced as a standard across the network. A sub-group – with the support of the audit department – have developed audit of the standards … Patients now will be given bad news in a respectful and dignified manner. They shouldn’t be told in open ward, it should be done in a sensitive manner, and they have the choice of having carer or relative with them.” (Participant 22)

A further, widespread information-related activity was ‘awareness raising’, sometimes with a clinical focus – e.g. a campaign to raise men’s awareness of the symptoms of testicular cancer – or with a user involvement focus, the aim being to raise awareness of the Partnership Group or other user groups.

4.7.5 Proactive influencing

Last – but by no means least – groups saw ‘proactive influencing’ as a vital element of their role. The tactics used to influence the shaping of cancer services were many and varied: getting people onto decision-making groups,
Groups sought to influence not only the NHS but also other bodies whose systems or working practices affected the lives of local cancer patients. Access to services was one common focus for this influencing, with groups actively working to bring about positive changes to car parking arrangements, public transport provision, or — in the case of the Humber & Yorkshire Coast network — toll charges on the Humber Bridge.

4.8 Financial aspects

4.8.1 Cancer Partnership Project funding and other funding

As noted in section 2.2, the Cancer Partnership Project (CPP) provided three years funding of £15,000 per annum per cancer network, with the large proportion of this funding being delivered in the two-year period from March 2002 and March 2004.

Most groups received little funding outside the CPP allocations, and this was in the form of support funding for one-off events, for example. However, two of the 25 Network PGs and one Locality PG stated that the cancer network had ‘matched’ the CPP funding (i.e. providing an additional £15,000 per annum); another Network PG had received £10,000 per annum, and another Locality PG received £12,000 per annum from four local PCTs. So, of the 30 networks, five provided substantial, recurrent additional funding for service user involvement. Another group received a one-off sum of £10,000 from network Specialist Palliative Care monies to develop user involvement. However, a number of Chairpersons noted that the network contributed ‘in kind’, providing facilities, administrative support, the time of the Lead Nurse, and so on.

It must be noted that Network PG Chairpersons generally lacked detailed knowledge of the funding status for the group. Of the 24 Network PG interviewees, 11 (46%) acknowledged that they were wholly unsure or had no knowledge of funding amounts or details; of the remaining 13, only two interviewees knew precisely how much each funding stream had provided. These responses serve as examples:

“I think we received £10,000 last year … I’m not sure how much was from Macmillan or Department of Health.” (Participant 4)

“I know that the group has funding but I don’t know where it is from.” (Participant 14)
“Yes, we had some [funding], but I don’t know the figures.”
(Participant 9)

It is perhaps of particular concern that many respondents were unaware exactly when the CPP income would cease or, if underspends were being carried forward locally, when the monies would ‘run out’.

The five Chairpersons of Locality PGs had a more detailed knowledge of funding. Two of the five groups had a clear, recurrent ‘share’ of the CPP funding; two others had received funding, but irregularly (e.g. “£10,000 two years ago”); the fifth group had not received any CPP funding, the Chairperson stating:

“The network manager said [the funding] is for setting up new groups, not for ones already in existence.” (Participant 12)

4.8.2 Financial management

With the exception of one local group, whose funding was managed by the local NHS trust, Partnership Groups’ funding was managed by the cancer network host organisation. Budget signatories commonly were the group’s facilitator and a senior network manager, but only rarely the PG Chairperson.

There was wide variation in the level of involvement of the group in financial decision-making. A small minority of groups appeared to have involvement in financial management, for example through regular financial reports or through a service user ‘treasurer’ role. The majority of groups, however, appeared to have little knowledge of or influence over financial decision-making. Whilst typically the Network Board received financial reports (as would be expected, as the funding is within a network budget), it seems that many Partnership Groups did not. Most groups seemed content to leave financial management entirely to the facilitator, perhaps seeing it as an administrative function:

“Finances is not something that we’ve concerned ourselves with as a group … we’ve tended to leave that to the health professionals.”
(Participant 23)

However, for other groups this lack of control was unsatisfactory. For example, one Network PG Chairperson told us:

“The network [manager] manages the money. This needs to be addressed. We have never had a financial report. We feel the expenses should be managed locally and would like to have responsibility for this.” (Participant 4)
4.8.3 Spending

We asked group Chairpersons to identify key items of expenditure from CPP funding, and to say if the DoH and Macmillan allocations were used in different ways. The first point to note is that respondents made no distinction between the streams and were not interested in this level of income detail. On a practical level, as far as we could ascertain, CPP funding typically goes into a single network cost centre (budget) for user involvement (for, it can be assumed, both pay and non-pay transactions): expenditure items can therefore be only notionally marked against a particular income stream.

Chairs identified the main items of expenditure as:
- Facilitator pay and non-pay costs
- Administrative support
- Meeting costs: room hire, refreshments
- Members’ out-of-pocket expenses, such as travel expenses (although many members do not claim these)
- Conference fees and training costs
- Costs associated with events, such as group ‘development days’ and one-day conferences
- Printing costs for leaflets, patient information, posters and newsletters
- Other costs associated with activities
- Small contributions to other groups: ‘local user forums’, locality groups
- Capital items, such as ‘a laptop’,
- Overheads charged by network as host organisation.

4.8.4 Future funding

Of the 30 groups, seven (23%) confirmed that they had funding in place post-CPP; four had a ‘long-term’ commitment from either the cancer network or local PCTs, and another three a ‘short-term’ commitment of support for a year or 18 months post-CPP. Of the remaining 23 groups, 21 were sure that no funding was in place and the other two replied ‘don’t know’.

Sixteen of the Chairpersons (53%) stated that their group was concerned about ongoing funding, and many of these groups were in the process of trying to secure future funding from the network, and indeed one group was applying for a grant from the National Lottery Community Fund. Some respondents were optimistic about the outcome, others less so, for example:

“...I have recently written to and attended a meeting of the network ‘Priorities Board’, and I am hopeful that the network will fund the facilitator next year. But the network said that if they fund this then something else will have to go. It is so dire in our network … I hear at national conferences that other networks are getting a lot of
money and I’m thinking, ‘Where are we going wrong here?’” (Participant 4)

The other fourteen Chairpersons (47%) stated that their groups were unconcerned however, including six groups who had no future funding. One prevalent attitude was that the matter was being sorted out ‘behind the scenes’ and that funding would be secured at some point, suggesting a faith that the group was part of some ‘bigger system’ that would not allow this limb to be severed. Another belief was the group actually didn’t need any funding, or not much anyway, based upon the argument that members’ expenses would be the only loss if funding ceased:

“No, we’re not too bothered for expenses. Members help with printing and other jobs.” (Participant 25)

The quote above was from a group with no facilitator, and so is perhaps understandable, but 12 of the 14 ‘unconcerned’ groups had a paid facilitator; this is an example from a Network Partnership Group:

“[Funding] has never been discussed. It’s not seen as an issue. I don’t raise it as a concern. Our costs are minimal, in fact the transport expenses obtained by members are given to [a local cancer charity].” (Participant 2)

This attitude is puzzling, as it appears to disassociate the group from the arguably ‘hidden’ costs of maintaining and developing the group – such as Facilitator salary – focusing instead on the most visible, direct cost.

4.9 Strategies for development

4.9.1 Training

4.9.1.1 CancerVOICES training

By far the best-attended training for group members was training provided under the Macmillan CancerVOICES initiative. Only one group had not undertaken the CancerVOICES training; this network group had been in existence for less than 18 months, and training was being planned. This training was very well attended: in a large number of cases, all active members of groups, or almost all, had completed the training, and in many – but not all – cases the NHS staff members attended the training alongside the service user members.

The large majority of groups found the training helpful to the group’s ability to be effective. Three benefits were repeatedly stated. First, the training increased participants’ understanding about the NHS and cancer services, and helped them think about how to influence the service; second, the training help the
group to ‘bond’, to become more cohesive; third, the training helped build confidence within the group and for individual members, particularly confidence to work as equals with health professionals, and more prepared to “speak up and speak out” (Participant 8). This response was typical:

“Very good, very good indeed. It gives you confidence, particularly when you go onto groups that are full of professionals, as representatives, and that’s when it really, really gives you the edge I think … making a case, collecting evidence and putting it forward - and not taking ‘no’ for an answer!” (Participant 19)

A number of respondents mentioned that the training would be particularly helpful to newly formed groups; one Chairperson said, as an example:

“It is useful when a group first gets together. It gives an opportunity for people to meet each other and get to know each other and, for people not into user involvement before, it gives confidence and [helps people] not be scared. It helps meetings to go better, it gets the conversation between health professionals and users going a lot better.” (Participant 20)

Other comments were that the training was well organised and user-friendly, that the ‘glossary of acronyms’ was helpful, that the facilitators were excellent, that it gave the group space and time ‘to think’, and that participants felt ‘empowered’ by it.

Two or three Chairpersons identified a need for more advanced training now that their groups had progressed beyond the fledgling stage, training on areas such as public speaking, making a business case, budget management, and other subjects specific to the work of Partnership Groups:

However, the Chairpersons from two groups responded that the group had a negative view of CancerVOICES training, and indeed a strongly negative – as opposed to an indifferent – view:

“The feedback from the members was that the one-day course was ‘disastrous’ and the two-day course had ‘lots of jargon’. They were disappointed in the training and two people said they would never go to CancerVOICES things again. Getting to London was expensive and tiring, and the training was tiring for people not used to being attentive for such long periods. Expecting members to gain an understanding of NHS and cancer services in one or two days is asking a lot.” (Participant 2)
Having said that, the Chairperson went on to say that the group was now planning to have the CancerVOICES training repeated locally, with all members attending: "I'm trying to persuade members to do it again."

4.9.1.2 Other training

Only eight of the 30 groups (27%) had undertaken training other than CancerVOICES training, covering: meeting skills and media training, budget skills, presentation skills, Patient and Public Involvement training, telephone counselling, and 'NHS overview' training.

Some NHS staff members of groups stated that they had “no need” for training, as they had long experience of talking to and listening to patients.

4.9.2 Other strategies for development

In addition to training, the Chairpersons identified a few other key aspects of development that required consideration and action: these are discussed in the three sections below.

4.9.2.1 Facilitator

Five of the 30 groups had no facilitator. Among them there was some – though not universal – sentiment that a facilitator would be important to future development. At least three were in negotiation with their cancer network regarding the funding and establishment of a facilitator post.

4.9.2.2 Recruitment and succession strategies

As discussed above, poor recruitment was a widespread concern and perceived as a threat to development. Some respondents expressed a real worry that as the initial flush of enthusiasm waned, and as ‘founding’ members grew older or – not infrequently – became ill again, so membership would dwindle as no replacements were coming forward. One Chairperson estimated that membership turnover was 50% per year.

Groups generally were developing strategies to prevent this situation. Several groups talked about ‘targeted recruitment’, approaching people via, for example, Tumour Site-Specific Groups, community groups, hospital groups, and support groups. Groups were setting up databases of a wider ‘mailing list membership’, with individuals’ contact details, to ‘nurture’ potential members over time through the sharing of information (e.g. newsletters) and invitations to events. One group had established a working party on recruitment and training; another was setting up a ‘buddy’ system to attract and retain new members. Several groups had ideas for recruitment events, such as coffee mornings, and others for renewed and more sophisticated advertising campaigns.
A number of Chairpersons also noted the importance of ‘succession planning’ for their role, the need to identify potential leaders and to provide support and training towards this. This was borne out by the experiences of other groups in which the departure of the Chairperson had left a vacuum, and often quite a lengthy vacuum, that hindered the activities and development of the group.

4.9.2.3 Being active

For the group to be healthy and progressing, it was important to have a range of ‘real’ and substantial projects and activities under way. Members’ interest had to be maintained, and importantly members had to know they were doing something worthwhile, not tokenistic:

“We have got to be seen as individuals who can add value. I’ve made it clear we are competing for these peoples’ time, and unless we can add value we’ll not be there. We have to make sure that we make the best use of the time they are prepared to give, to use their time productively to enhance the service from a users’ perspective. If we don’t we will have failed. This group will fundamentally change its membership if we’re just there to tick the boxes. People won’t attend, they’ve got better things to do.” (Participant 29)
5 Conclusions and Recommendations

This final section of the report draws together and reflects upon key aspects of the project and its findings. Section 5.1 aims to give an overview of findings and draw some general conclusions. Section 5.2 considers the extent to which the original objectives of the CPP, as stated in the CPP Project Outline, were met. Key findings are identified and discussed in Section 5.3. Our recommendations for action are listed in Section 5.4.

5.1 Summary evaluation

The formation of partnership groups across cancer networks in England has been a substantial undertaking. This has attracted high levels of commitment and enthusiasm by those who have taken this project forward. Few Partnership Groups were in existence prior to the Cancer Partnership Project and the majority of groups that are now active have been formed and developed under the auspices of the CPP. This achievement in itself, and the time and effort involved, should not be underestimated. The establishment and early developmental work of groups took energy and determination, attributes not in short supply among the original ‘pioneers’. Indeed it largely appears to be these same people, who were so instrumental in the early stages of group development three or so years ago, who now continue as inspirational and energetic forces within the groups.

Partnership Groups are at various stages of development and they appear to move through an evolutionary process, at first establishing an initial presence within cancer networks, moving on to a reactive phase, before reaching a proactive phase of working. The activities and influence of the group appear to gain strength through this evolution. In the early stages of development, groups typically acted in a consultative capacity for the network. As groups developed and agendas and objectives were clarified, this function was expanded upon and enhanced. Groups became represented via their members on a large number of working groups and committees in order to move their objectives forward. This ‘networking’ technique was seen as essential to facilitate their progress and ability to influence at a high level.

A typical group was about two years old, had direct representation on the network board or its equivalent (Model E), had a service user as chairperson, a part-time paid facilitator, and had about twenty active members, two thirds of whom were women and three quarters of whom were middle-aged. Two thirds of the typical group were comprised of service users and there was little representation of Black and Minority Ethnic communities within the group. The
manner in which these groups were first established and now operate has been influenced both by the national agenda of the CPP Steering Group and a variety of local considerations.

This evaluation has illustrated the significant achievements of Partnership Groups, and demonstrated that members have been involved in a broad spectrum of activities ranging from consultation, networking, patient information and communication and proactive influencing. The groups have been pivotal in taking service user involvement forward within cancer networks and have had wider influence through a multitude of formal and informal groups and networks. A high level of commitment to both the concept and work programme of the group is present. Effective and skilled leadership is widely seen as an essential element in a group’s success, both internally (regarding the smooth running of a group) and externally (regarding their productive relationship with key personnel in the cancer networks). Working in ‘partnership’ with professionals has broadly worked well, with some specific areas of tension found between service users and professionals in the groups.

Through the course of the project it became clear that there are a number of factors that have the potential to impact on the effectiveness of Partnership Groups. These include recruitment and retention of members, the skills of, and relationships between, both the facilitator and the chairperson, commitment of local NHS professionals and organisations to user involvement, and achieving influence both at and beyond the Cancer Network Board. The partnership agenda is at a relatively early stage of development and if its impact is to be first sustained and with time extended further investment will be necessary in the areas of facilitator support and education and training (both for service users and NHS professionals).

5.2 Attainment of stated objectives

5.2.1 Working together with the 34 cancer networks in England to establish cancer partnership and user groups

The first aim identified for the CPP Steering Group was the establishment of cancer partnership or user groups in all 34 cancer networks across England. We found that this largely has been achieved. The groups from the 30 networks included in this evaluation identified themselves as partnership groups. Four networks were not included in this evaluation, as no partnership group had been established, but we were informed that there has been a degree of user involvement in each and that local user groups were in existence.

It is clear that the Steering Group and CPP paid staff played a key role in facilitating the sharing of good practice as a key approach to development within the groups, whilst supporting flexibility to enable groups to develop in their own way.
5.2.2 Supporting the recruitment and training of user involvement facilitators in cancer networks

25 out of the 30 groups had a facilitator in post. Of the five groups that did not have a facilitator, four either wanted one in the future or stated lack of funding as the reason for non-appointment. Of the 21 facilitators whose ‘core role’ was that of service user involvement, 18 were salaried NHS staff. In discussions around funding and expenditure, groups highlighted that one of the main uses of CPP funding was for the facilitator’s salary and non-pay costs. CPP funding was clearly vital in supporting these posts.

Facilitators were evaluated highly by the group members we spoke to and had often participated in the CancerVoices training with other group members.

The CPP set up a Support Programme for facilitators, and four national meetings have been held. In addition, facilitators are members of regional forums which meet approximately four times per year and include Macmillan Regional Development Co-ordinators and CancerVOICES regional contacts. Facilitators also meet regularly as part of the Network Development Programme Partnership Forum which has been set up with the DH Cancer Action Team to facilitate the support of Partnership Groups. Finally, a Resource Pack on user involvement in cancer services aimed at service users has been made available to facilitators for distribution.

5.2.3 Monitoring the development of user involvement in cancer networks

The CPP continuously monitored the development of groups throughout the life of the project, maintaining a database that was regularly updated. Contact information was published in order to facilitate shared learning and raise awareness of the existence of groups. A ‘self-evaluation’ monitoring exercise among groups, co-ordinated by Macmillan and linked to funding, was carried out in April/May 2003. 63% of groups participated, completing a proforma that generated preliminary evaluative data for the CPP funding bodies. In addition, development days offered by Macmillan to each network establishing a partnership group were evaluated through questionnaire. The number of attendees participating in development days, training days and other network activities were recorded. Finally, this end-of-project report constitutes a substantial component of the CPP Steering Group’s monitoring activity.

5.2.4 Supporting user representatives to inform the development of cancer services and research at both network and national levels

Partnership groups were engaged in a wide range of activities including consultation, networking, patient information and communication, and proactive influencing. Through the CPP initiative most groups had members who attended
meetings at network board level and also participated in regional or national initiatives. A minority of group members had involvement with various research projects and where this involvement existed it generally took the form of consultation rather than collaboration. One exception to this was the involvement of service users in the National Cancer Research Institute Consumer Liaison Group. This area of service user influence is due to be developed by a joint Macmillan Cancer Relief / National Cancer Research Network project commencing in June 2004.

5.2.5 Linking effectively with other DH initiatives and organisations (including the DH Patient and Public Involvement (PPI) strategy, Primary Care Trusts, and Cancer Services Collaboratives)

Many groups were active within a range of Department of Health initiatives such as Modernisation Agency Service Improvement Partnerships and the Cancer Action Team. Involvement was observed within the context of primary and acute care trusts at various levels and through patient forums. Often, but not always, this activity developed from an initial request for representation and a meaningful link appeared to exist between the group and these external organisations.

It was unclear from the accounts given by group members whether or not there was overlap or integration between Partnership Groups and local developing PPI strategies. Some service user group members were members of PPI patient forum groups, though these have only recently been formed, and others were in the process of developing links with such groups. Groups did, however, conceptualise themselves as 'proactive influencers' working within a broader PPI agenda, and it seems reasonable to assume that over time active engagement with PPI initiatives will be pursued.

5.3 Key themes

5.3.1 Leadership

Service users and professional members alike agreed that 'leadership' was pivotal to a group's success in many different ways. The chairperson and facilitator were identified as the key providers of leadership for groups. We also observed a degree of consistency amongst all group members as regard their opinion on the duties and responsibilities of the chairperson and facilitator, and respondents suggested a long and varied list of skills and attributes required in an ideal candidate. The majority of interviewees were very satisfied with the chairperson and facilitator in their own group.

There was general, but not universal, acknowledgement that the chairperson should be a service user if possible. We understand that the appointment of service users to the chair role was considered 'best practice' by, and so encouraged by, the CPP Steering Group. It was argued that the concept and
practice of partnership groups are focused on championing service user involvement in cancer networks and that this involvement is best led by service users themselves. There was agreement that service users in this role brought a passion to the role borne from direct experience which usually led them to be strong advocates for both the group and service user issues. Experience as a service user or carer engendered trust and confidence that the chairperson would work with the group to fulfil its aims, as they themselves were motivated by the same concerns as other service user members of the group.

However, in two of the 30 groups the chairperson was not a service user but rather the paid facilitator. This arrangement was chosen by the group, and – we make the point strongly – in neither case was there the slightest perception that this placed the group at a disadvantage in any way, or that the facilitator/chair’s commitment was any less than a service user chair’s might have been, or generally that this practice was in any way ‘second best’. We spoke to several members in one of these groups, and without exception they considered the facilitator to be an excellent chair, and had absolutely no reservations regarding the arrangement.

The key factors highlighted in an ideal chair were a wholehearted commitment to the cause of Patient and Public Involvement, sound ‘chairing’ skills, and the ability to assert their group’s perspective to health professionals and managers. Ideally, the chair would also be a service user. A central focus for service users was the need to influence, change and improve cancer services, and therefore effective chairpersons were essential in presenting these concerns at the necessary levels in the health care system. Some chairs appeared to have a natural flair for this leadership role but in other cases group members made it clear that some help and support for the chair was required to help the chair more effectively fulfil his/her duties. Some form of training for chairs clearly is called for.

Facilitators also were evaluated positively, more positively even than chairs. Only one of the 30 groups had made the decision not to employ a paid facilitator. Among groups with facilitators, there was agreement that this role was most effective if it was the postholder’s ‘core’ role, and not a ‘secondary’ role tacked onto a more substantial primary post. A second key message is that facilitators need time to fulfil their wide array of responsibilities. Group members linked the facilitator’s work to the development and survival of the group itself. They were seen as enablers and key in ‘tackling’ health professionals and managers with regard to the group’s concerns and priorities. Facilitators were seen as supporters or advocates for service users, and had a good understanding and empathy for service users’ concerns. Facilitators could be relied upon to act genuinely and sincerely for the group, and often acted as a ‘bridge’ or mediator between the group and external NHS groups or professionals.
Groups expected their chairs and facilitators to engage effectively with cancer networks at a high level, that is with senior clinicians and senior managers, including Chief Executive Officers. It was perceived that those in leadership positions both with cancer networks and within NHS and Primary Care trusts need to be engaged with and supportive of their group, to share the group’s vision of the group and to act on this vision. Senior health care professionals need to be accessible and committed to the needs and priorities of the groups, and to demonstrate this by working collaboratively with the group’s chair and facilitator. Groups were aware of the numerous competing demands upon NHS organisations, and of competing priorities and values, but they emphasised the point that they do not want to operate on the margins of cancer networks and services, but rather as part of the mainstream.

Key to the leadership roles of chairperson and facilitator was the ability to share a vision of the group’s work and role, and to communicate that vision both within and beyond the group. The roles were about taking people forward and motivating them, and for this to occur the chairperson and the facilitator were required to work together constructively. For the most part this did occur but when this joint working was less than effective the group and its achievements appeared to suffer. The two roles needed time, understanding and energy to make them work well.

Thought and action needs to be focused upon succession planning for chairs and facilitators. These roles are essential and leadership training, a recruitment cycle and planned hand over of roles will be important to the smooth running of groups.

5.3.2 Membership

5.3.2.1 Participants provided a great deal of information on the subject of group membership, an aspect that raised some concerns and a wide range of thoughtful responses. Those involved in the user involvement agenda for some time felt that they had a personal stake both in maintaining and in developing their group and its activities. There was strong and widespread support for the models of partnership groups and partnership working that formed the core ethos of the CPP.

Group membership numbers often were high, with some groups reporting a membership of one hundred people. Average attendance at group meetings was typically around twenty people, though attendance could vary considerably depending on meeting day and time, with groups finding that weekend meetings were more agreeable to service users whilst weekday meetings brought greater attendance from professionals. Some groups reported a compromise in meeting early evening on a working day. Meeting location was also important and
required compromise, as a few service users found it disagreeable to meet in a hospital where they had themselves received treatment.

Groups were likely to have a majority of members who were women, and 75% of members were between 40 and 65 years of age. Most members had experienced one of the common cancer types, although members with rarer cancers and advanced disease were also represented. Service users constituted two thirds of members in the typical group. Health care professional members were drawn from a range of different jobs and roles in NHS cancer services. The most frequent professional group represented was of network lead nurses, followed by other cancer nurse representatives.

5.3.2.2 Recruitment

Group members reported that recruitment to groups was a significant concern. Whilst both service user and professional group members took this issue very seriously, service users appeared more engaged with the issue. It was service users predominantly who considered and acted upon initiatives and strategies designed to enlist new members. Concern and activity about recruitment was invariably focused on recruiting service users rather than health care professionals. Perhaps this was because professionals played a less ‘active’ role in groups, or perhaps there was a perceived ready supply of professionals available within networks and the wider health economy. Groups reported an initial flood of interest when the group was first established and invariably initial recruitment was not considered problematic. However, it was widely reported that as the ‘initial flood’ dried up, groups had encountered significant problems in sustaining and replenishing membership. Some further consideration of variation in recruitment might be informative.

Groups tended to have a ‘core’ membership of regular attendees who worked actively projects, represented the group, and generally provided the drive and energy that was taking the group forward. Attendance was less consistent – and commitment generally less visible – from a wider group membership. In many groups the majority of ‘core’ members had been involved since the inception of the group and real worries were expressed regarding the future viability of the groups should these original members be no longer able to be active, perhaps through tiredness, loss of interest, or ill-health. Recruitment strategies, whilst entered into with enthusiasm and imagination, invariably reaped small reward. This was a source of frustration and concern.

Group members identified a delicate relationship between workload and recruitment and retention: whilst new members needed to be attracted by the possibility of having ‘real’ projects to ‘get their teeth into’, it was important to ensure that the ‘workload’ did not become excessive. Service user members we interviewed typically described a large volume of ‘business’ conducted for the group: projects, campaigns, group meetings, sub-group meetings, meetings of
associated groups and committees. This level of work brought pressures, pressures that were usually manageable and accepted, but at times felt oppressive and detrimental.

Stakeholders on partnership groups need to recognise the importance of the sustainability issue. Exploration of key factors in recruitment and retention is required urgently, and options to improve recruitment and retention need to be identified and tested. The issue of ‘burn out’ amongst service users needs to be carefully addressed, as does the question of how to attract new members. It would be worth exploring lessons from other areas of ‘community representation’, an exploration, as examples, of the incentives and barriers for school governors, magistrates or local councillors.

5.3.2.3 Inclusion and representation

Respondents talked about a range of issues on the subjects of inclusion and representation. They spoke of the difficulty of attracting members from certain groups such as younger people, men, the rural poor, those from socially deprived areas, and people whose disease was at an advanced stage. However the issue that drew most comment was the inclusion, or the difficulty of inclusion, of people from local black and minority ethnic (BME) communities.

The members of the 30 groups in this study were predominantly of White British ethnic origin. Nearly 50% of groups had no black and minority ethnic members at all. One network group located within a population 47% of which was people from black and minority ethnic groups had not a single representative from these communities. Using the government’s 2001 Census Ethnic Group estimates, we calculated that less than one in four groups had the statistically expected proportion of BME members.

Group members we spoke to were aware and often concerned about the lack of BME members, expressing an unease that their group members were not representative of all the communities the group was there to represent. Many groups had tried to access BME communities, and some groups were actively engaged with BME community leaders and had developed strategies to work with these communities, hoping that over time an engagement would develop. On the whole though, these efforts were perceived as having had little effect; and as with the issue of recruitment generally, members appeared frustrated and tired by the group’s ‘failure’ in this area, and had run out of ideas and energy to continue pressing the issue.

On a positive note, we are aware that Macmillan has acknowledged the inclusion of BME people as a particular challenge and that, with support from the CPP, a BME Network has been established to address these issues.4 We are also

---

4 Macmillan BME Network is co-ordinated by Damyanti Patel, contact Macmillan UK office main switchboard Tel: 020 7840 7840.
It is interesting to consider the reason for this explicit focus on inclusion of BME community representatives amongst the people we interviewed. Interviewees knew we were interested in issues of diversity and in the topic list they were sent prior to interview it stated this as an area to be discussed in interview. It also however stated many other aspects for discussion that elicited little response. It may be that members are acutely aware of this as an issue nationally and are taking steps locally to address it. This emphasis may though reflect a degree of ‘social desirability response bias’, meaning that research participants provide responses that they consider to be socially desirable or acceptable rather that saying what they really think.

5.3.3 The dynamics of partnership

Partnership groups were formed predominantly of service users but with significant numbers of health care professionals and service managers. The overall impression of service users was that partnership working was essential to achieving the group’s aims and objectives and that overall this partnership was working well. NHS professional members were seen as ‘friendly experts’, an important resource and supporters of user involvement, and in positions to further the group’s aims within the NHS. Generally, service users and professionals invariably spoke positively about the group and working with each other, and both ‘parties’ felt comfortable within the group.

It was apparent from the data however that some tensions and imbalances occurred. NHS members were considered less committed than service users to the group and to the group’s work. This was apparent, for example, when service users spoke of professionals being late for group meetings or simply not attending, or in professionals ‘looking bored’ at meetings, or in professionals not engaging with projects the group was taking forward. Whilst an imbalance of commitment was perceived, most service users were not greatly troubled by this; in short, service users expected professionals to be actively engaged in meetings, but did not expect professionals – other than those with a remit to work for the group – to carry out activities outside meetings. When professionals did carry out work outside meetings, this was noted and greatly valued by service users.

---

5 Researchers from the University of Nottingham School of Nursing have joined together with Self Help Nottingham to investigate Black and Minority Ethnic communities’ involvement in cancer self-help groups. The project aims to give a higher profile to self-help/mutual aid in these communities and to encourage the development of supportive policies for involvement. For further information contact Mark Avis, Reader, Tel: 0115-924-9924 ext 41427 or Seeta Patel, Research Associate, Tel: 0115-924-9924 ext 42464.
We also identified some tensions around issues of self-disclosure. Service user members who shared intimate information about their experience of cancer and cancer services at meetings were likely to be viewed as expressing inappropriate information. Professionals felt profoundly uncomfortable when such disclosure occurred, being of the opinion that such disclosure was inappropriate. Service users thought it equally unfortunate, both as an unwanted distraction from the meeting agenda and as ‘unprofessional behaviour’, but were understanding of the need for people to draw on their personal experiences from time to time and thought that such occurrences should be gently and firmly managed by the chair rather than disapprovingly frowned upon.

Finally, we identified a tension around emotional congruence in groups. Service user members reported experiencing a range of emotions that they saw as part and parcel of their motivation to be involved. They said they were ‘passionate’ about the group and their ability to get involved and to ‘have a say’ in the NHS. Their participation was therapeutic, ‘doing them good’, and yet at times by sharing common experiences a ‘raw nerve’ was exposed. Service users also talked of their feelings of pain, sadness and loss when other service user members became ill or died. This emotional labour was a strong feature of involvement for service user which, it is important to note, brings with it issues of responsibility for emotional well being and of support.

By contrast there was little acknowledgement of emotional impact by professionals. Professionals seemed rarely to engage on an emotional level with the group and its work, and some seemed to experience problems with raising contentious issues or being honest with service users in the group. It is possible that the well-defined social roles of patient and professional, defined decades ago by Parsons (1951), are harder to change than members would like or expected. The dissonance between professional and service user perspectives and experiences is discussed by Wilson (1995), who describes the distinct ‘two worlds’ that the groups occupy and highlights the lack of awareness that can inhibit good working relationships.

These underlying, ill defined, and ill expressed tensions need to be acknowledged as both present and potentially problematic. Interpersonal dynamics should be addressed and resolved if groups are to move forward with maturity and confidence. The particular contributions of service users and professionals alike need to be accepted if equal and effective interaction is to continue.
5.3.4 Motivation and commitment

Service users' were motivated to join partnership groups by a number of factors.

Some wanted to 'give something back' to an NHS system that had treated them well. It is interesting to note that service users’ experiences of NHS care were in most cases positive, and typically they were very supportive and defensive of the NHS. However, NHS professionals believed that service users on the whole were motivated by negative previous personal experiences. It is possible that our sample of service users was unrepresentative, i.e. that we gained access only to those with positive accounts, but this is unlikely due to the self-selecting recruitment method adopted. It seems more likely that NHS professionals simply were mistaken in their belief. This is a concern for groups, not least because it indicates a worrying lack of understanding within the group of members’ personal backgrounds and motivations. We would recommend that group leaders make efforts to promote a level of understanding between NHS and service user members, for example through the use of induction packs or group ‘awaydays’.

A second motivation for service users was that they wanted to play a role in the development and improvement of services. The issue of ‘locality’ was important here: people wanted to get involved in local services, services that they and their families and friends themselves used. A key challenge for network-level partnership groups, particularly those in geographically large networks or networks including a large number of localities, for example a large number of cancer units, is to be able to satisfy this aspiration of members to work at a ‘local’ level. One network had already developed a model of linked, locality partnership groups (Model D) to replace a single, network-wide group (Model E), and we spoke to other Model E groups who were considering a similar restructure.

A third motivation for service users was a desire to contribute to the patient and public involvement agenda more generally, and a fourth was to represent a particular group that they belonged to. Many, if not all, of these four reasons offered by service users for their involvement would appear to run counter to claims made elsewhere in the context of cancer care, in which service users’ motivation regarding user involvement was seen in terms of obligation, as responsible citizenship, and of moral coercion (Small & Rhodes 2000). The perspectives found in this evaluation challenge these somewhat negative views.

As might be expected there were marked differences between service users and professionals in terms of their motivation for joining and being a member of a partnership group, and in their level of commitment to the group. Professionals often became members simply as part of their job or professional responsibility. Some NHS staff were invited to join, as their job was perceived as helpful or
complementary to the work of the group, and conversely some others joined as they hoped the group would be useful to them at some point in the future. Other NHS staff, it must be noted, expressed a personal commitment to the principle of user involvement and were involved because they regarded user involvement as an important aspect of NHS cancer service development.

All groups offered a flexible approach to the individual member’s level of involvement and group work. Members were able to do as much or as little for the group as they wanted. This was a universal ethos that groups accepted but it did cause some tensions in groups. A core of service user members appeared to undertake the bulk of the group’s work. For many groups this volume of work was huge. Members were very aware that it fell on just a few shoulders, and for some this situation was frustrating and disappointing.

Service users generally viewed professional members as less committed in terms of attendance at meetings and in helping with the work of the group. However, as with service users in the group, there was considered to be another ‘core’ group, this time of professionals, who would be willing to take on extra work. Some professionals saw this as reciprocation: “if the group help me I’ll help the group.” Professionals readily acknowledged the fact that they didn’t carry out much of the group’s work, but few expressed any unease with this situation. Some felt that too much ‘involvement’ by NHS staff would erode the autonomy of such user-led groups, and that NHS staff should stick to the roles of supporters, ‘champions’, and providers of information.

Finally, there were widespread doubts, both amongst group members and among non-group NHS staff, as to the commitment of senior NHS managers to partnership working. Many respondents were of the opinion that, despite supportive rhetoric, senior NHS staff were ambivalent towards service user involvement. This lack of commitment or interest was considered the main stumbling block to effective engagement with senior managers and commissioners. Verification of this claim was beyond the scope of this evaluation, but suffice to say that genuine commitment and support from cancer networks and the broader healthcare community are essential if Partnership Groups are to fulfil their prescribed role.

No respondent mentioned whether or not these tensions concerning commitment were discussed openly at group meetings.

5.3.5 Activities and achievements

The list of achievements from a typical group (section 4.7) shows the impressive breadth and depth of the partnership groups’ activities. Groups have been involved in and instigated numerous pieces of work and activities at local level, and often at regional and national levels. These achievements are the more
impressive when we consider that these groups have been in existence for a relatively short length of time. The achievements we documented were focused upon improving the patient experience in a direct way at many different levels and these improvements were unlikely to have occurred were it not for the presence of these partnership groups.

The activities of a group progress in scale and complexity as a group develops. First, a substantial amount of time and effort were required for ‘setting-up’ activities. Although the establishment of a group is rarely regarded as an ‘achievement’ in itself, in the context of user involvement in cancer services this were perceived by respondents as a significant feat, a milestone and success in its own right. Many groups saw their mere existence, and the fact that service users were now ‘at the table’ with cancer services managers, as tremendous achievements in their own right. Service users often found that they were the first service user to be actively involved at the level of service policy and provision in the cancer network, and some spoke of feeling like ‘pioneers’. Moreover, time spent on establishment of the group, on discussing Terms of Reference and working practices, was regarded as crucial to the future working and achievements of the group.

Following quickly upon the heels of establishment and ‘bedding-in’, as a second stage groups found that they were in demand as a ‘reference group’ for NHS consultations. One group chair, for example, noted that in the early days the group was overwhelmed by demands for them to read and comment on documents, to give the ‘patient’s perspective’ on plan or a job description or a proposal of some kind. Another group had taken the decision to limit such requests to one per meeting, as they were taking up too much time. Clearly this function, of the group as a ready-made, easily-accessible source of non-professional opinion, has considerable value to the NHS.

As a third function, groups provide a pool of representatives to sit upon other groups and committees, and to work alongside professionals on initiatives. We found that service user members were active in a vast array of sub-groups, clinical groups, multi-disciplinary teams, and committees within their cancer network, the local primary and acute trusts, and regional and national organisations. The ‘networking’ undertaken routinely by the typical group was substantial in volume, and in clinical and geographical spread, the group having links with literally dozens of other groups. Understandably given the time and resources available, few groups reported that they made any systematic effort to feed the bulk of the knowledge gained into their own system; rather, members kept a ‘watching brief’ to alert the group to important developments.

As a fourth function, groups appeared keen soon after establishment groups to ‘get their teeth into’ some work around local problems. There was often a clear vision from the chair and facilitator to start with these small, manageable projects
that would ‘make a difference’ to local patients. Some of these were long-
standing concerns, for example an assignment to gain improved sign posting for
chemotherapy outpatients within a hospital. Some projects arose in response to
suggestions or requests from local professionals, but often service user
members identified priorities, sometimes by talking informally with other patients,
in outpatient departments for example.

Finally, as groups matured, working practices became routine and members
gained experience and confidence, so they became more proactive and took up
more challenging issues. Some of these issues were complex and difficult to
unravel within the complexity of NHS clinical and management systems, and
groups required diplomacy, perseverance, patience and imagination to succeed.
Such projects required substantial time and effort. One example was a project to
produce and disseminate a patient information booklet for all new patients in
cancer services covered by a network. Seemingly a straightforward task, the
production of the booklet required substantial work, but in addition months of
negotiation were required to convince the network to meet the print costs and to
sustain this support for further reprints.

Many group members spoke of the complexity of the NHS, cancer services and
the culture of health care. Understanding and knowing how to work within the
mainstream of the ‘system’ was an important goal in itself, and learning who to
contact and how to influence them were recognised as essential lessons. This
aspect of involvement is one of the areas of shared learning included in the CPP
Resource Pack for service users. Influencing change seemed effective when
relationships were developed with key people, and groups put effort into
nurturing these relationships in a strategy to further their influence. In summary,
groups appeared to have learnt the basics of change management, introduced
through CancerVoices training; and some identified a more sophisticated
understanding of change processes in the NHS as essential for the group’s
motivation and survival.

5.3.6 Evolution

Although this was not a prospective study that tracked groups’ development over
time, even with our retrospective data on a cross-section of groups at different
stages of development it was clear that groups were evolving organically over
time. It is important that we understand this evolution. As groups evolve and
stakeholders become more adept and experienced, the group’s working
practices and subsequent achievements also evolve. This evolution is
dependant on many factors, not least the skills, interests and motivations of
group members, their working environment, and the degree to which the
patient’s influence and perspective are accepted and utilised by the NHS.
In terms of activity, the stages that we can expect to see in the first two or three years of a group’s life were mapped out in section 5.3.5 above. This evolutionary process needs to be acknowledged in order to understand the needs of service user group members at different stages in this process and to appreciate the level and type of achievement possible at each phase. It may be that different training needs exist at different stages of development, as suggested by some members of more established groups.

The report entitled *Sharing the learning on patient and public involvement from CHI’s work*, recently published by the Commission of Health Improvement (CHI 2004), provides a summary of the progress of patient and public involvement in 300 NHS organisations. CHI found that NHS organisations routinely gather feedback from service users, but that very few are doing anything that allows service users directly to influence policy and practice. In our view, Cancer Partnership Groups have provided a mechanism through which patient and public involvement has taken one sizeable step beyond this level of ‘consumer feedback’, and this current report describes in detail the structures and activities that constitute this step.

Nevertheless, our data suggest that the more established partnership groups, those established say for three years or more, with a strong core memberships and a portfolio of projects, are beginning to talk about and think about the next step, the third stage of PPI. These respondents felt that, while their groups were achieving much, they remained – to use a phrase from the CHI report – at the ‘periphery of corporate decision making.’ This third stage is one in which PPI activities are integrated with other efforts to improve services and in which PPI is regarded as a core activity for the NHS organisation: that is, PPI becomes part of everyday practice across an organisation.

For longer-term success, groups need to be secure in the knowledge that they are valued by local NHS clinicians and managers, that partnership groups are seen as important and relevant, and that over time both sides are working towards service users being at the core – rather than the periphery – of corporate decision making. For the present, a commitment to ongoing NHS funding is required in order for groups to continue working on this long-term strategy.

It would be valuable to conduct more work, possibly through employing a prospective approach, to further understand the stages of evolution of partnership groups, and in particular to identify strategies for the next stage of development.
5.4 Recommendations

5.4.1 Recommendations for the Department of Health and NHS organisations

1. Service commissioners, working through cancer networks, should identify and secure the resources required to ensure the sustainability of Partnership Groups. This needs to be a flexible, long-term commitment. This commitment will be evident both in the provision of funding for Partnership Groups and in the active promotion of partnership working and user involvement more broadly. As a priority and as a minimum, service commissioners should make a commitment to meet the costs of a paid User Involvement Facilitator and of regular Partnership Group meetings.

2. Service commissioners working through cancer networks should make a policy commitment to place equal value upon the priorities for service change identified by service users via Partnership Groups as upon those identified by NHS staff. This commitment will be evident in explicit changes to the internal mechanisms employed to set, resource and deliver priorities.

3. NHS organisations and professionals should note the clear value of user involvement activities documented in this report. NHS organisations should engage in education and raise awareness within their organisations of the importance of service user involvement, the high significance of patients’ priorities, and the central role of user involvement in the shift towards patient-centred care.

5.4.2 Recommendations for Macmillan Cancer Relief

1. There is a clear need for a better understanding of issues around diversity and inclusion in the context of Partnership Groups, particularly related to black and minority ethnic groups, men, children and young people, and very sick people. We recommend that Macmillan commission work to collect perspectives on inclusion/exclusion and to further explore barriers to user involvement for these and other less included groups.

2. There is a clear need for dedicated training for group Chairpersons to support their role, with an emphasis upon chairing skills. We recommend that Macmillan make arrangements for provision of this training on an ongoing basis.

3. It is clear that the long-term success of user involvement depends upon genuine collaboration between users and NHS cancer professionals. The
attitudes of NHS staff are therefore critical to the viability of user involvement. We recommend that Macmillan commission research to gain a better understanding of NHS cancer professionals' attitudes to user involvement.

4. Macmillan should work with the Department of Health, cancer networks and NHS professionals to encourage training in service user involvement.

5. Macmillan should develop a strategy for the long-term support of groups, embracing evolution and development, and cognisant of the wider PPI agenda.
### 6.1 Reference Group membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gwen Harlow</td>
<td>Service user and Chair of the Rarer Cancers Forum</td>
</tr>
<tr>
<td>Steve Hawley</td>
<td>Service user, member of CancerVOICES Steering Group</td>
</tr>
<tr>
<td>Margaret Johnson</td>
<td>Service user, CancerVOICES regional contact for Eastern region</td>
</tr>
<tr>
<td>Pete Madeley</td>
<td>Service user, CancerVOICES regional contact for Northern &amp; Yorkshire</td>
</tr>
<tr>
<td>Karen Wilman</td>
<td>Service user</td>
</tr>
<tr>
<td>Mike Burns</td>
<td>Group Facilitator, Arden Cancer Network</td>
</tr>
<tr>
<td>Andrew Gallini</td>
<td>Group Facilitator &amp; Lead Cancer Nurse, Central South Coast Cancer Network</td>
</tr>
<tr>
<td>Sarah Haworth</td>
<td>Group Facilitator, Greater Manchester &amp; Cheshire Cancer Network</td>
</tr>
<tr>
<td>Carol Munn-Giddings</td>
<td>Reader in Participative Inquiry, School of Community Health &amp; Social Studies, Anglia Polytechnic University</td>
</tr>
<tr>
<td>Zena Robertson</td>
<td>Lead Cancer Nurse, Humber &amp; Yorkshire Coast Cancer Network</td>
</tr>
<tr>
<td>Annie Young</td>
<td>Lead Cancer Nurse, 3 Counties Cancer Network</td>
</tr>
<tr>
<td>Cheryl Cavanagh</td>
<td>Team Manager, Cancer Treatment and Quality, Department of Health</td>
</tr>
<tr>
<td>Justine Windsor</td>
<td>Cancer Policy Manager, Department of Health</td>
</tr>
<tr>
<td>Judith McNeill</td>
<td>Head of Community Links, Macmillan Cancer Relief</td>
</tr>
<tr>
<td>Jane Bradburn</td>
<td>User Involvement Adviser, Macmillan Cancer Relief</td>
</tr>
<tr>
<td>Siobhan Peattie</td>
<td>User Involvement Co-ordinator, Macmillan Cancer Relief</td>
</tr>
<tr>
<td>John Sitzia</td>
<td>Head of Research and Development, Patient and Public Involvement Research Unit, Worthing and Southlands Hospitals NHS Trust</td>
</tr>
<tr>
<td>Phil Cotterell</td>
<td>Research Fellow, Patient and Public Involvement Research Unit, Worthing and Southlands Hospitals NHS Trust</td>
</tr>
<tr>
<td>Alison Richardson</td>
<td>Chair of Cancer and Palliative Nursing Care, Florence Nightingale School of Nursing and Midwifery, King’s College London</td>
</tr>
</tbody>
</table>
### A list of the 30 groups in the study

<table>
<thead>
<tr>
<th>Network</th>
<th>Group name</th>
<th>Website address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arden</td>
<td>Arden CN User Group</td>
<td>none</td>
</tr>
<tr>
<td>Avon, Somerset &amp; Wiltshire</td>
<td>ASW Cancer Services User Involvement Group</td>
<td><a href="http://www.aswcs.nhs.uk/">http://www.aswcs.nhs.uk/</a></td>
</tr>
<tr>
<td>Black Country</td>
<td>Dudley Patient Advisory Cancer Team (PACT)</td>
<td>none</td>
</tr>
<tr>
<td>Central South Coast</td>
<td>CSC CN User/Partnership Involvement Group</td>
<td>none</td>
</tr>
<tr>
<td>Derby/Burton</td>
<td>Derby-Burton Cancer Partnership Forum</td>
<td>none</td>
</tr>
<tr>
<td>Greater Manchester &amp; Cheshire</td>
<td>Patient User Partnership</td>
<td><a href="http://www.gmccn.nhs.uk">www.gmccn.nhs.uk</a></td>
</tr>
<tr>
<td>Humber &amp; Yorkshire Coast</td>
<td>Patient Involvement Group</td>
<td><a href="http://www.pig.org.uk">www.pig.org.uk</a></td>
</tr>
<tr>
<td>Kent &amp; Medway</td>
<td>Kent &amp; Medway Patient/Carer Partnership Forum</td>
<td>none</td>
</tr>
<tr>
<td>Lancashire &amp; South Cumbria</td>
<td>Cancer Partnership Group</td>
<td><a href="http://www.cancercumbria.org.uk">http://www.cancercumbria.org.uk</a></td>
</tr>
<tr>
<td>Leicestershire, Northamptonshire &amp; Rutland</td>
<td>Patient &amp; Carers Oncology Council</td>
<td>none</td>
</tr>
<tr>
<td>Merseyside &amp; Cheshire</td>
<td>Patient and Carer CN group</td>
<td><a href="http://www.mccn.nhs.uk/intro/home.asp">http://www.mccn.nhs.uk/intro/home.asp</a></td>
</tr>
<tr>
<td>Mid Anglia</td>
<td>Ipswich NHS Trust Cancer Services Users Group</td>
<td><a href="http://www.midangliacancerwork.nhs.uk/asp/macn_splash.asp">http://www.midangliacancerwork.nhs.uk/asp/macn_splash.asp</a></td>
</tr>
<tr>
<td>Mid Trent</td>
<td>Mid Trent CN Patient and Public Partnership Group</td>
<td><a href="http://www.midtrentcancer.nhs.uk/midtrentcancer/">http://www.midtrentcancer.nhs.uk/midtrentcancer/</a></td>
</tr>
<tr>
<td>Norfolk &amp; Waveney</td>
<td>Patient Partnership Group</td>
<td><a href="http://www.canternw.com/">http://www.canternw.com/</a></td>
</tr>
<tr>
<td>North London</td>
<td>North London CN Partnership Group</td>
<td><a href="http://www.nlcn.org.uk/">http://www.nlcn.org.uk/</a></td>
</tr>
<tr>
<td>North Trent</td>
<td>Sheffield Cancer Services Advisory Group</td>
<td><a href="http://www.sth.nhs.uk/NTCNet_nhs/">http://www.sth.nhs.uk/NTCNet_nhs/</a></td>
</tr>
<tr>
<td>Northern</td>
<td>Northern CN Partnership Panel</td>
<td><a href="http://www.cancernorth.nhs.uk/">http://www.cancernorth.nhs.uk/</a></td>
</tr>
<tr>
<td>Pan Birmingham</td>
<td>Pan Birmingham CN Partnership Group</td>
<td>none</td>
</tr>
<tr>
<td>Peninsula</td>
<td>Peninsula CN User Group</td>
<td><a href="http://www.pcn.nhs.uk/">http://www.pcn.nhs.uk/</a></td>
</tr>
<tr>
<td>South East London</td>
<td>User Liaison Group of Guys, Kings &amp; St.Thomas’ Oncology Department</td>
<td>none</td>
</tr>
<tr>
<td>South Essex</td>
<td>South Essex User Involvement Partnership</td>
<td>none</td>
</tr>
<tr>
<td>South West London</td>
<td>SWL CN Partnership</td>
<td><a href="http://www.south-west-london-cancer-network-partnership.org.uk">www.south-west-london-cancer-network-partnership.org.uk</a></td>
</tr>
<tr>
<td>Region</td>
<td>User/Partnership Group</td>
<td>Website</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Surrey, West Sussex &amp; Hampshire</td>
<td>SWSH User Partnership Group</td>
<td></td>
</tr>
<tr>
<td>Teesside, South Durham &amp; North Yorkshire</td>
<td>Cancer Care Alliance of Teesside, South Durham &amp; North Yorkshire Patient and Carer Group</td>
<td></td>
</tr>
<tr>
<td>Three Counties</td>
<td>The 3 Counties CN Partnership Group</td>
<td><a href="http://www.the3ccancernet.org.uk/index.asp?siteID=1&amp;pageID=1">http://www.the3ccancernet.org.uk/index.asp?siteID=1&amp;pageID=1</a></td>
</tr>
</tbody>
</table>
6.3 References and further reading


of a Department of Health research study. University of Manchester / University of Leeds, unpublished paper.


6.4 The interview questionnaires

6.4.1 The Set 1 questions (Chairpersons)

1. Confirm name of cancer network
2. Confirm name of group
3. Confirm group type: (1) Network / Local (hospital trust/PCT or locality group/community resource centre) / Disease-specific / other; (2) Service User / Partnership / other
4. Why was group type selected and what impact has this had upon achievements?
5. Confirm Chairperson’s name
6. Is the Chairperson a Service User / Professional or both?
7. Does the group have (access to) a facilitator? (or lead nurse if acting as facilitator?)
8. Confirm facilitator(s) name
9. Confirm if facilitator is a service user or an NHS professional?
10. Which institution employs the facilitator?
11. Confirm date of group’s formation
12. Confirm frequency of meetings
13. Confirm location of meetings
14. Does the group keep minutes of the meetings?
15. Average attendance
16. Composition and diversity
   a. Number and % of: service users (types: patients, carers, professionals, others)
   b. BME members
   c. Age range
   d. Gender mix
   e. Types of disease experienced by members
   f. Health status of group members (active or non-active disease?)
   g. Do any members have significant physical impairments or learning difficulties?
17. Professionals in the group: number / attendance / roles / ‘influence’ on the group
18. What challenges are there to the inclusion of a diversity of members?
19. What strategies are used to try to overcome these?
20. Does the group have a set of ‘objectives’ (a list of the most important things that the group works on?)
21. Was this list drawn up and agreed by the whole group?
22. Does the group revisit / update this list? How does this process happen?
23. What are the processes by which group members are kept informed?
24. Does the group have / work to a Terms of Reference? (Ask to be sent a hard copy)
25. Ask for details of CPP Funding received, broken down by streams
26. Has local NHS provided any additional funding?
27. Is any other funding received?
28. How is funding used? Broken down by streams, if possible
29. What is the funding management system?
30. Does the group have any funding in place post-CPP?
31. Is the group concerned about on-going funding?
32. Has the group undertaken CancerVOICES training? Ask for details of who exactly attended: service users and NHS members
33. Was the CancerVOICES training important in the ability of the group to make an impact or be effective?
34. Have Service Users been offered any other training in any topic?
35. What sources of support are most important to group?
36. Has there been any explicit or distinctive support from the local NHS?
37. Which of the group’s activities have the most influence or impact upon local/regional/national NHS delivery?
38. What activities/strategies were needed to set the group up?
39. What activities/strategies are used to develop the group?
40. Does the group have any particular activities/strategies to encourage diversity in the group?
41. Ask for details of activities of service users on other local NHS bodies, e.g.:
   a. Network Board / Executive / Policy boards
   b. Network disease site-specific groups
   c. Local PCT/Trust cancer-related groups
   d. Local PCT/Trust Patients Forums and other non-cancer-related groups
   e. Regional / national groups and bodies.
42. Generally, were members approached/invited to participate in these groups – or did members make the approach and the other organisation (e.g. PCT) respond?
43. Any other activities and achievements not mentioned?
44. What are main barriers and challenges to achieving aims of the group?
45. What strategies are being used to overcome these?
46. Anything else not covered
6.4.2 **The Set 2 questions (Service users in groups)**

1. Can you tell me your age, gender and ethnic origin please?
2. What has been your experience as a user of NHS cancer services?
3. Have you had any experience as a professional in the NHS?
4. Have you had any experience in other voluntary organisations / user groups? Can you describe these please?
5. When did you start attending this group?
6. Why did you join the group? What motivated you to join?
7. How often do you attend meetings?
8. What is your commitment outside of meetings? i.e. Do you need to complete work for the group outside of meetings? If so, how much/frequently?
9. Why do you remain involved?
10. Do you feel informed/updated about the work of the group?
11. What in your mind should be the principal aim of the group?
12. Does the group work well in achieving its aims?
13. What factors help it work well and what hinders it?
14. Thinking about the mix of service users and professionals in the group, has this brought up any challenges or issues? Please describe.
15. Does recruitment to the group pose any challenges? Please describe.
16. How well does the role of facilitator work?
17. What factors make a ‘good’ or effective facilitator?
18. How well does the role of chairperson work?
19. What factors make a ‘good’ or effective chairperson?
20. What type of training have you had for the work of the group?
21. What training have you found useful and what training have you found not so useful? Can you explain why?
22. Do you feel supported in the group? In what ways have you (not) been supported?
23. What have you personally found as issues and challenges to being involved in the group? Explore: practical and economic (e.g. effects on benefits, transport issues); physical; emotional (feelings of well-being, empowerment, etc.); Any other area?
24. In your opinion, has the group’s work influenced local NHS cancer care in terms of policy or service developments or service organisation?
25. Is there anything else you would like to add?
6.4.3 The Set 3 questions (NHS members in groups)

1. Can you tell me your age, gender and ethnic origin please?
2. What is your current job and what is your background as a professional in NHS cancer services?
3. Have you had any experience as a service user in the NHS?
4. Have you had any experience in other voluntary organisations / user groups? Can you describe these please?
5. When did you start attending this group?
6. Why did you join the group? What motivated you to join?
7. How often do you attend meetings?
8. What is your commitment outside of meetings? i.e. Do you need to complete work for the group outside of meetings? If so, how much/frequently?
9. Why do you remain involved?
10. Do you feel informed/updated about the work of the group?
11. What in your mind should be the principal aim of the group?
12. Does the group work well in achieving its aims?
13. What factors help it work well and what hinders it?
14. Thinking about the mix of service users and professionals in the group, has this brought up any challenges or issues? Please describe.
15. Does recruitment to the group pose any challenges? Please describe.
16. How well does the role of facilitator work?
17. What factors make a ‘good’ or effective facilitator?
18. How well does the role of chairperson work?
19. What factors make a ‘good’ or effective chairperson?
20. What type of training have you had for the work of the group?
21. What training have you found useful and what training have you found not so useful? Can you explain why?
22. Do you feel supported in the group? In what ways have you (not) been supported?
23. What have you personally found as issues and challenges to being involved in the group? Explore: practical and economic (e.g. effects on benefits, transport issues); physical; emotional (feelings of well-being, empowerment, etc.); Any other area?
24. In your opinion, has the group’s work influenced local NHS cancer care in terms of policy or service developments or service organisation?
25. Is there anything else you would like to add?
6.4.4 The Set 4 questions (NHS staff not in groups)

1. Can you tell me your age, gender and ethnic origin please?
2. What is your current job and what is your background as a professional in NHS cancer services?
3. What do you know about and what is your opinion of service user involvement in the delivery and organisation of cancer services?
4. Have you had any training on service user involvement?
5. Are you aware of (name group)?
6. What do you know about the group? Explore: What is the group’s function or aim? Who are members of the group? Who should be involved? Do other initiatives link into the group e.g. PALS, site-specific group? If so, to what effect?
7. Have you used the group in any way for any reason? Explore: What was the group used for? What was the result? If not might you use it in the future?
8. Other than (name group), what methods for accessing service users views/needs/priorities exist or need developing locally?
9. Do you think (name group) fulfils its function or aim?
10. Do communication channels exist between the group and local service managers/commissioners? Can you describe these? Are these communication channels adequate and/or effective?
11. Has the group made a difference to local NHS cancer care and/or services in any way? Ask for description / examples.
12. Do you think service users locally should be MORE influential in cancer service delivery and planning? If YES, how? If NO, why not?
13. Should (name group) or other such partnership/user groups be maintained in the future? If YES, how may this be achieved? If NO, why not?
14. Is there anything else you would like to add?