Cancer Care
Research Centre
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Enabling Change: Patient Experience as
a Driver for Service Improvement

Final Report

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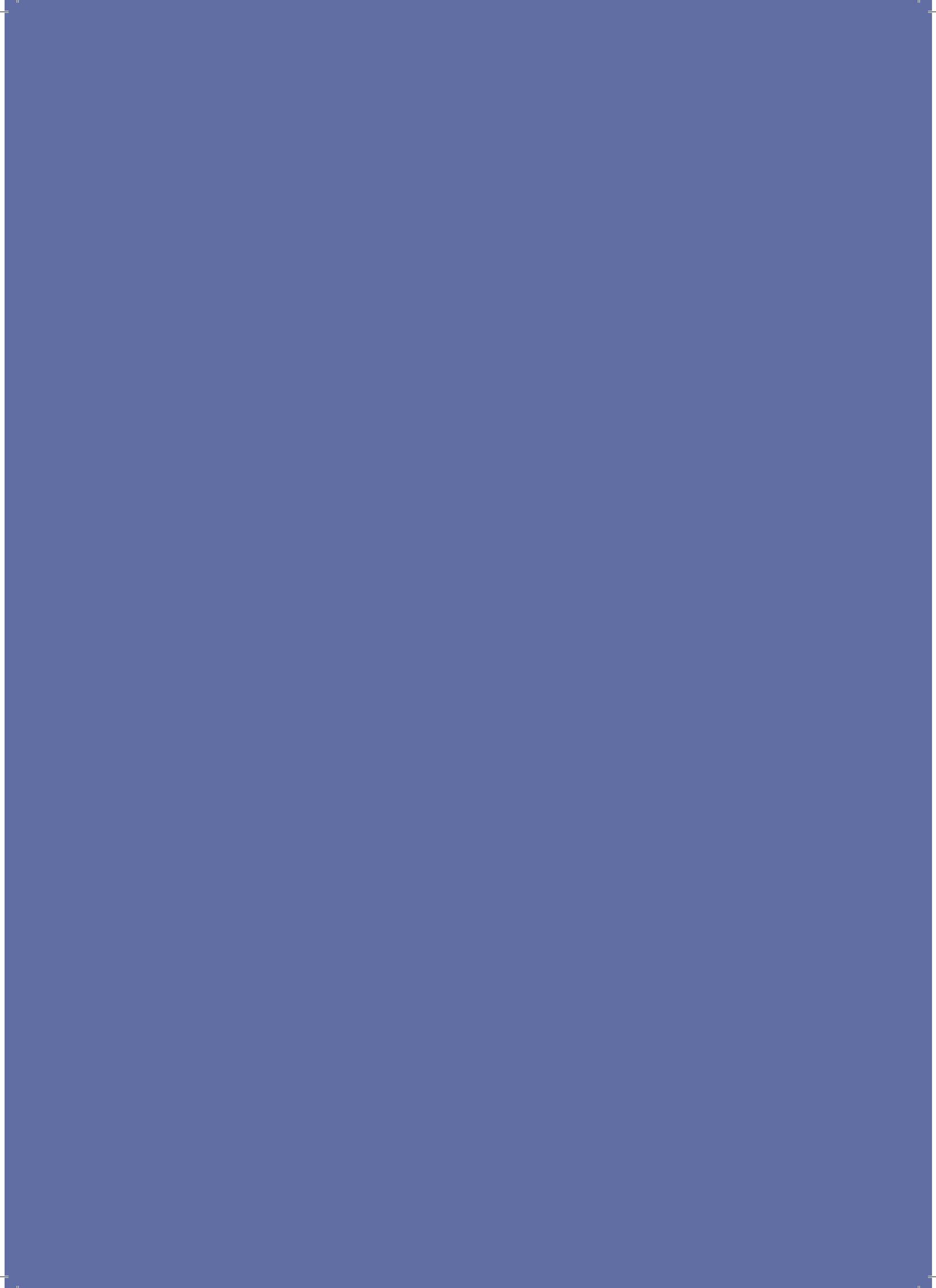
DEPARTMENT OF
NURSING AND MIDWIFERY

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EXECUTIVE SUMMARY

This project focused on collaborative work between practitioners working in lung cancer services, people affected by cancer and the Cancer Care Research Centre (CCRC). The work aimed to facilitate and evaluate the use of patient experience data as a driver for change, in two strands:

- » Test a model of using patient experience to implement service improvement (referred to as 'the Enabling Change work')
- » Evaluation of the process and outcomes of the service improvement work using the Enabling Change model (referred to as 'the Evaluation')

The main aims were to:
- » Improve patient involvement in service design and delivery
- » Identify and test a practical, effective and sustainable model which uses patient experiences and patient involvement to drive improvements in cancer care services
- » Evaluate the impact of involving patients and drawing on their experiences to effect service change, in knowledge and practice of involvement.

Lung cancer services at five Health Boards were recruited to the project. Three sites conducted the Enabling Change work to test the model (referred to as 'intervention sites'). The other two sites were not actively involved and acted as control sites (referred to as 'non-intervention sites').

The project teams at the three interventions sites consisted of patients, family members and multi-disciplinary cancer care professionals from the lung cancer service. Participants at the non-intervention sites were matched accordingly.

The intervention sites used the Plan, Study, Do, Act (PDSA) approach to service improvement taken from the Model for Improvement (Langley, Nolan and Nolan, 1992).

Seven PDSA plans, across the three intervention sites, were developed, tested and successfully implemented during the Enabling Change project. The projects teams are now working to spread the use of these materials across their organisation and cancer networks.

Clinical staff, people affected by cancer and Chief Executives do not have clear ideas of what constitutes involvement. Ideas about patients having a say in treatment options and community-wide forums where the public are informed of health service change were both posited as examples of involvement. The role of people affected by cancer in informing health service improvements was rarely mentioned prior to the intervention.

Numerous barriers to involving people affected by cancer in service change were identified.

This work highlighted a number of core learnings in the implementation of collaborative working between people working in cancer care and people affected by cancer to inform service improvement.

Recommendation 1: NHS Quality Improvement Scotland (NHS QIS) and NES should consider developing guidelines to enhance conceptual clarity in formulating 'involvement', and ensure that 'consultation' 'complaints' and 'communication' are presented as separate to 'involvement'.

Recommendation 2: The change work conducted by the intervention sites should be used as evidence for year-on-year growth in the quantity and specialism of involvement activities.

Recommendation 3: The Scottish Health Council's role as an objective surveyor of involvement should be extended. Future involvement work should promote access to external collaborators who can perform joint roles of facilitating and monitoring the involvement work.

Recommendation 4: Uniform use of change plans and methods across Scotland will ensure that implementation can be compared and audited nationally.

Recommendation 5: Involvement of people affected by cancer in change work should include outcome measures, including quality/impact as well as frequency and type of involvement, in order that accountability to service users and policy makers may be demonstrated.

Recommendation 6: Internal communication should be improved to ensure that Chief Executives are aware of collaborative initiatives, particularly if they have previously signed-up to the work and offered their support.

Recommendation 7: Improved communication processes via Managed Clinical Networks around the practice and practicalities of patient involvement in service redesign should be developed. The process and impact of change initiatives should routinely be shared in these forums.

Recommendation 8: The Scottish Health Council, Health Boards and local clinical teams should all ensure that outcomes and impact of involvement initiatives are adequately publicised.

Recommendation 9: Staff engaging in patient involvement should have access to education, focusing on communication and chairing skills.

Recommendation 10: Training sessions for people affected by cancer on involvement should be widely available.

Recommendation 11: Clear national guidelines should be developed to enable involvement work and ensure that boundaries and expectations for all participants are established. The guidelines should include:

  » The involvement of people affected by cancer to influence the priorities for
     change and informing service planning by drawing on experiences.
  » The involvement of informal carers, as partners in care, should be invited to
     contribute to service planning.

» Change methods should be rolled-out across tumour types and across health specialities.

» Clear boundaries, role and responsibilities for patients, family members and professionals should be defined as far as possible at the outset of any project. A contract should be drawn up regarding expectations for each party with clear reference to power sharing.

» Patients, family members and the public should be involved early in decision making about service change, mirroring the methods used in the Enabling Change work.

» People affected by cancer should routinely be invited to take part in involvement work, and this could be suggested early in the patient's journey.

Recommendation 12: Involvement should take place in a setting close to where patients and family members live. Whenever possible, meetings should not be located in facilities where they have received treatment.

Recommendation 13: Consideration should be given to supportive measures to ensure that people affected by cancer are facilitated to be involved to their potential. This should be negotiated with participants throughout the involvement work, as their needs may change throughout.

Section 1:   INTRODUCTION AND AIMS

1.1 Introduction

Developing a patient and public focus in healthcare is not a new concept to the NHS in Scotland. Throughout the UK, health care providers have sought to promote the agenda of service improvement and one key strategy to achieving this has been through involving users. Emphasis has been placed on service improvement within the NHS to drive up standards of care and delivery. In 2000, Our National Health: a plan for action, a plan for change defined a patient-focused NHS as 'a service that exists for the patient and which is designed to meet the needs and wishes of the individual receiving care and treatment' (Scottish Executive, 2000, p50). This was followed in 2001, with the publication of Patient Focus and Public Involvement (Scottish Executive, 2001), which sought to build on existing work and provide a framework for change with greater priority given to involving patients and carers in the design, delivery and evaluation of services.

The involvement of patients in service improvement was furthered in 2003 by Partnership for Care (Scottish Executive, 2003) which promotes the idea of partnership working between patients, staff and government and to 'listen to patients and respond to patients in order to develop the patient-centred services we have talked about for so long' (p5, Ministerial foreword). Partnership for Care noted that listening to patients positions them as equal and full partners in their healthcare; it invokes the three parallel ideas of participation, empowerment and partnership as routes to improving services. The report indicates a move toward a more thoughtful process of public engagement and involvement and required NHS Scotland to adopt an approach which allowed it to 'recognise and respond sensitively to the individual needs, background and circumstances of people's lives' (ibid, p20).

The white paper, Delivering for Health (Scottish Executive, 2005a) outlines plans for service improvement and development across health and social services in Scotland. A small focus of this document is on service redesign, particularly with reference to the use of local services and the introduction of service systems to reduce waiting times. It indicates that patient satisfaction surveys have been important methods of gauging patient experiences of services, and notes that around 90% of 1,937 people surveyed in 2004 reported high levels of satisfaction. However, such methods provide only crude measures of people's lived experiences of health services, and while patients and carers may be satisfied overall, they often have suggestions or complaints which can be fed into service design (Haas, 1999). The high levels of satisfaction reported in the survey, therefore need to be interpreted with care. Also in Scotland, the Centre for Change and Innovation offers support (in the form of toolkits and service improvement guides) to NHS staff to drive forward changes which improve patient care. They work with service redesign committees located in Health Boards across Scotland. One emphasis of their work is to encourage people to keep changes small and achievable, using change facilitators who draw on toolboxes of ideas and approaches.

In England, the NHS Modernisation Agency has promoted the use of patient and carer experiences to drive service improvement (Modernisation Agency, 2002). The opening phase of their work focused on satisfaction reports of service use. The second phase, however, took an important leap towards a broader remit of service evaluation by engaging in questions of involvement and working with patient experiences. For example, the Cancer Services Collaborative (2005) promotes a holistic view of services, promoting service re-design to take account of the patient's whole journey. Offering examples from a wide range of oncology services, it offers a three point plan for ensuring the use of patient consultation is of high impact: (i) consider the whole patient journey, (ii) demonstrate what needs to change to make the largest impact on that journey, (iii) ensure that changes are clinically valid, and are tested with patients and evidenced to produce appropriate improvements. The overall aim is to improve patients' experiences of care. However, patient involvement in service design and delivery is not explicitly described, and it concludes by noting that 'seeing the whole patient's journey through the eyes of the patients and their carers' as one of several remaining significant challenges. Fundamental elements of pursuing the involvement agenda then appear to be under-developed.

This approach is aligned to the more iterative and dynamic work in service improvement such as the Plan Do Study Act (PDSA) methodology from the Model for Improvement (Langley,

Nolan & Nolan, 1992). PDSA is a simple yet powerful tool for creating rapid, significant improvements in care by testing out new structures or approaches. It is promoted primarily as a model for building sustainable improvement through quick iterative cycles, which are predicated on well articulated aims, clearly identified goals, defined actions and measurable outcomes.   The model has been used successfully by hundreds of health care organisations in many countries to improve many different health care processes and outcomes. Many examples and guides can be found at the Institute for Healthcare Improvement website http://www.ihi.org.

The Model for Improvement has two parts:
1. Three fundamental questions, which can be addressed in any order:
   » What are we trying to accomplish? (Project aims)
   » How will we know that a change is an improvement? (Global measures)
   » What changes can we make that will result in improvement? (Change Principles)
1. The Plan-Do-Study-Act (PDSA) cycle to test and implement changes in real work settings.   The PDSA cycle guides the test of a change to determine if the change is an improvement. Later if the change is an improvement, the PDSA cycles can be expanded and gradually incorporate increasingly larger samples until the team is confident that the changes should be adopted more widely throughout the organisation with further implementation and spread.

Involving the right people in a process improvement team is critical to a successful improvement effort. Effective teams should include members representing different kinds of expertise and authority within the organisation to ensure that there is sufficient authority to make the changes, expertise of the subject or process, and clear day-to-day leadership to drive the project forward.

Other models have developed which are based along similar lines such as Rapid Cycle Improvement (Besserman, Brennan and Brown, 1998) and the RAID approach (Rogers, 2006). There are many similarities amongst these models and all have been used widely in the health service.

Underpinning these models and approaches to service improvement are the extensive ideas presented in Greenhaugh's (2004) systematic review of how best practice can be disseminated in a sustainable manner in health service delivery and organisation. This report suggests a number of key mechanisms which facilitate and bolster the adoption and sustained use of service change. A seven point framework indicates the key issues to consider when planning service improvement developments. Greenhaugh indicates the need to consider the inner and outside working contexts of the organisations (being aware of inside and external networks of people, organisations and policy drivers). Emphasis is given to understanding how change is sustained through use of psychological mechanisms (readiness for change and preparation as well as observable and transferable ideas), social forces (such as social influence) and organisational readiness (staff commitment, a necessary tension for change, and the capacity to evaluate the intervention).

The health service is now compelled by policy to engage with the public and service users to improve the design and delivery of its services (Scottish Executive, 2003). Barriers to user involvement have, however, been identified, though there is little consensus about what features create barriers to true involvement and the way practitioners construct blocks to full engagement (Daykin et al., 2002, Daykin et al., 2004). Recent research conducted as part of the Patient Experience project has identified that there has been limited progress in establishing collaborative patient involvement for service improvement with most examples being small one-off projects which have consulted patients on matters such as improving information leaflets (Hubbard, et al., 2005; Ryan et al., 2005).

This report presents findings from Phase 3 of the Developing Cancer Services: Patient and Carer Experiences Programme (referred to as 'the Programme'), funded by a grant from the Scottish Executive. The research explores how patient experiences can be identified and utilised alongside patient involvement, to ensure that services are designed to improve patient experiences. The Programme aimed to establish a comprehensive body of information on the experiences and needs of people affected by cancer in Scotland.

The three-phase programme involved the following components:
» *Phase 1* - Scoping Exercise. This included public Involvement rapid appraisals in 10 locations across Scotland (Kearney et al., 2005), a systematic literature review (Hubbard et al., 2005), a scoping exercise of patient involvement (Ryan et al., 2005), and an assessment of cancer and a cancer treatment-related

morbidity database. Patient and carer advisory groups were also set-up and ran throughout the course of the Programme (Worth et al., 2005).

» *Phase 2* - Patient Experiences and Patient Involvement. This involved prospective interviews and monthly symptom questionnaires with 66 people affected by cancer, exploring their experiences in the first year following diagnosis. The work focused on people affected by bowel, breast, prostate, lung and gynaecological cancers (Hubbard et al., 2007). In addition a retrospective case note review of 1000 people receiving chemotherapy for breast, lung or colorectal cancer was undertaken to assess cancer treatment related morbidity.

The Enabling Change project was the final phase of this Programme, drawing together the learning from phases 1 and 2, applying knowledge about understandings and experiences of cancer and applied patient involvement. The Enabling Change project aimed to develop the evidence base of patient involvement for service improvement, by testing a model of collaborative working with practitioners working in cancer services and people affected by cancer to use patient experiences to enable service change.

1.2 Aims

The Enabling Change phase of the Programme focused on a piece of collaborative work between people working in lung cancer services, people affected by cancer and the Cancer Care Research Centre (CCRC). The work aimed to facilitate and evaluate the use of patient experience data as a driver for change, in two strands:

» Test the Enabling Change model of using patient experience to implement service improvement (referred to as 'the Enabling Change intervention work')
» Evaluate the process and outcomes of the service improvement work (referred to as 'the Evaluation')

The two strands aimed to:

   » Improve patient involvement in service design and delivery
   » Identify and test a practical, effective and sustainable model which uses
     patient experiences to drive improvements in cancer care services
   » Identify and review a practical, effective and sustainable model for involving
     patients and carers in activities that drive service delivery and improvement
   » Evaluate the impact of involving patients and drawing on their experiences to
     effect service change, in people's knowledge and practice of involvement.

The two strands of work addressed a number of interrelated questions, each of which is
linked with instrumental changes as well as attitudes, knowledge and understanding:

   1. What methods of involvement using patient experiences are in use by
      practitioners involved in lung cancer care and people affected by lung cancer
      across five Health Boards in Scotland at the beginning and end of the work?
   2. How different is the process and content of patient involvement across five
      Health Boards?
   3. What impact has the Enabling Change work had on the understandings of
      involvement for Health Board staff, people affected by cancer and Health
      Board Chief Executives?
   4. How do the project teams, testing the Enabling Change model, apply the
      accounts of patient and carer experiences to specific projects of service
      improvement?
   5. What outcomes are evidenced in the specific projects of service improvement
      work that were developed while testing the Enabling Change model?
   6. Is the Enabling Change model of using patient and carer experiences to
      inform service improvements practical, effective and sustainable?
   7. Is the Enabling Change model of drawing on patient and carer experiences
      transferable to areas outside of cancer care?

1.3 Ethical Issues

The Enabling Change work is service development, and for the purposes of the Central
Office for Research Ethics Committees (COREC) is not defined as research. Consequently it

did not require formal NHS ethical review. However, research staff adhered to professional ethical guidelines and conduct, for example, the British Psychological Association.

Throughout this report the participant identities are anonymised to preserve confidentiality.

1.4 External Collaboration

The Enabling Change project team collaborated with external consultants and advisors in planning this work. Dr Jocelyn Cornwell, an independent healthcare consultant, has been involved in the planning of the project methods and timeline. Caroline Powell, Deputy Chief Executive of the Picker Institute provided guidance and advice from their experience of the Patients Affecting Change programme. Carrie Marr, Associate Director of Change and Innovation at NHS Tayside has worked with the CCRC Project Lead to ensure that training in the methods and support were offered to all participants throughout the project, and to ensure that evidence is gathered to demonstrate any change made to services. Carrie Marr also provided the tailored training to the intervention teams.

Section 2:   METHODS

2.1 Enabling Change Model

The PDSA model, described in the introduction, was adapted for the purposes of this project. The Enabling Change model below in Figure 1 builds in two new aspects which were informed by the Patient Experience project. These two elements are: that any change work undertaken must be driven by patient experiences; and people affected by cancer must be involved throughout the project.

The Enabling Change model is based on the principle that any service improvement work that aims to improve patient experience must begin with understanding the patient experience and involve people affected by cancer in the decisions about what changes to make and how to make them.

The model begins on the left side by introducing the concept of patient experiences driving forward service change. In this project patient experiences are drawn from the Phase 2 interview study (Hubbard et al, 2007) and from the experience of patient and family members within the project teams at each clinical site.

Moving across the model, from left to right, the main steps of the process are illustrated from conducting the pre-work to establishing the clinical partnerships where the work would take place and identifying project teams. This moved into the learning sessions/site meetings where the patient experience data was fed into the teams to inform their priority setting for the change work. The next step was planning future meetings to monitoring the project while testing PDSA cycles. The model also includes pre- and post-focus groups to be held with the project teams to evaluate the process and the Enabling Change model.

Figure 1.   Enabling Change model
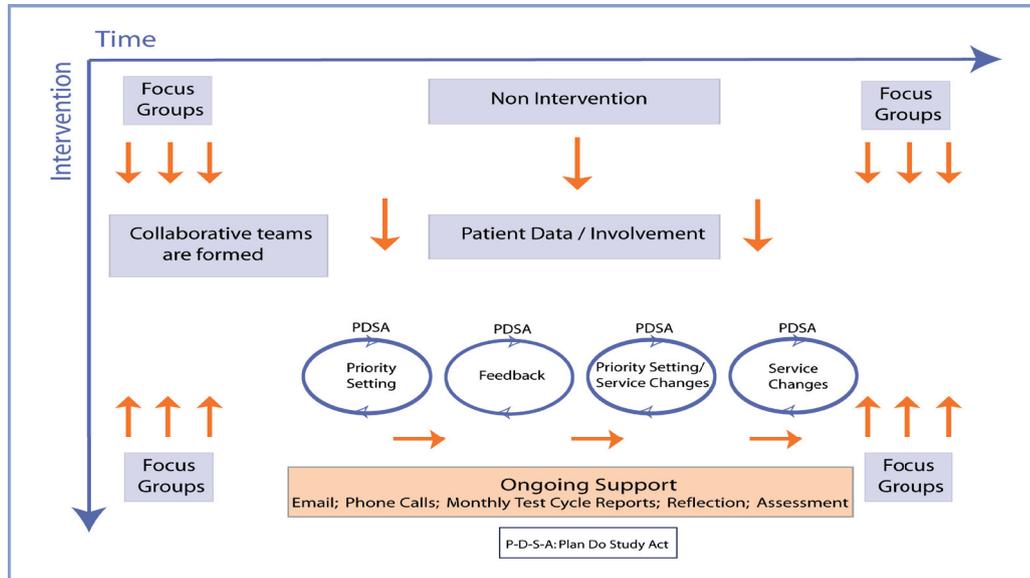
2.2 Participants and Recruitment

2.2.1 Health Board recruitment

Purposive intensity sampling (Patton, 1990) was used to recruit Health Boards to the Enabling Change project. This approach selects participants who have an active and expressed interest in the aims of a project. The CCRC had pre-established collaborations with four Health Boards who facilitated recruitment of patients for an earlier phase of the Programme (Hubbard et al., 2007). These four Health Boards and one Board who was not involved previously, but had expressed an interest in collaborating with CCRC, were invited to take part in the Enabling Change project.   After consultation with senior staff, each Health Board was allocated to the intervention or non-intervention group after a process of reflecting on:

    a. Perception of readiness to engage in intervention work (based on researchers'
        review of the Health Board).

    b. Rural/urban representation (with associated proximity with specialist
        oncology centres).

    c. The three intervention sites were located across the three Scottish cancer
        networks areas.

Three Health Boards agreed to collaborate with the CCRC to test the Enabling Change model. These areas are referred to as 'intervention sites'. Two Health Boards who were not actively involved in the change work and where no intervention was conducted acted as control sites, and are referred to as 'non-intervention sites'.

2.2.2 Recruitment of teams at the three intervention sites

Initial discussions about the project took place between the Director of the CCRC and Chief Executives, Medical Directors and Lead Cancer Clinicians in each site during 2006. After full approval for the project was granted in each site, additional consultation with local Lead Cancer Clinicians and other key staff was undertaken at the intervention sites to agree the project plan. It was at these meetings where the type of cancer for intervention was decided. Sites were offered a choice of lung cancer or colorectal cancer as these had the largest amount of data gathered by CCRC. All three intervention sites selected the lung cancer service for the project.

Once the potential teams had been identified by senior staff, members of the team were contacted individually by the CCRC. They were sent information about the project including the expectations and responsibilities for those who became involved in the project, and invited to attend the first site meeting.

The timeline for the Enabling Change project is outlined in the flowchart in Appendix 1.

2.2.3 Participants in the project teams at the intervention sites

The project teams at the three intervention sites consisted of patients, family members and cancer care professionals. The staff initially invited to join the project team at each of the intervention sites were a cross-section of the lung team. The range of staff invited to be part of the project team differed across the three clinical sites is illustrated in table 1.

Table 1. Staff in the intervention site project teams

- » Clinical Nurse Specialists
- » Staff Nurses
- » Research Nurses
- » Consultant Cancer Nurse
- » Consultant Respiratory Physicians
- » Consultant Clinical Oncologists
- » Physiotherapists
- » Consultant Medical Oncologist
- » Cardio-Thoracic surgeon
- » Specialist Radiographer
- » Consultant in Palliative Medicine
- » Social Worker

- » Dietitian
- » Lead Clinician for Cancer
- » Associate Director of Modernisation & Development
- » Cancer Network Service Improvement Manager
- » Community Palliative Care Consultant and Registrar
- » Site Group Co-ordinator
- » Clinical Group Manager
- » Clinical Team Manager

2.2.4 Recruiting patients at the clinical sites

Inclusion criteria were developed for patients who would be invited to be part of the project team at intervention sites and the focus groups at non-intervention sites. The criteria stated that people affected by cancer should have experience of the lung service. They would have completed active treatment so they would not be working in a project team with professionals still actively involved in their care.

The number of patients and family members involved varied across the three project teams at the intervention sites but typically consisted of two to five patient members, with approximately half of the patients also involving a family member, typically a spouse or partner. At one clinical site, patients and family members who formed part of the project team were recruited from a patient forum – and reported back to that forum. Thus, while only a small number of patients attended working meetings with clinicians in each area,

they were linked in with a wider patient forum who provided views, suggestions and support.

Typically, people affected by cancer were approached to participate in the Enabling Change work by a Clinical Nurse Specialist, although at one site the member of staff had patient involvement as a specific aspect of their job. Letters of invitation and information about the project were passed to the identified staff member by the CCRC team for distribution.

2.3 Expectations and responsibilities of project teams and CCRC

Clarity over roles and responsibilities was essential given the mix of people involved in the project teams, and the need to help people decide whether they wanted to be involved in the project. There were different requirements for each of the different levels of participation at each site.

Chief Executive:
- » Make the overall decision to support and participate in the project
- » Liaise with the Lead cancer clinician to select the tumour group for their site
- » Liaise with the Lead cancer clinician to identify a group of senior staff who will meet with the CCRC team
- » Participate in an individual interview about patient engagement, prior to and following the Enabling Change work

Senior staff:
- » Meet with the CCRC team to discuss the aims of the project and membership of the Enabling Change team, including the recruitment of people affected by cancer
- » Ensure that the staff members of the project team have time to attend the sessions and implement the change plans within their clinical setting
- » Ensure that patients are treated fairly and are fully supported in line with accepted recommendations for patient involvement (Department of Health, 2006)

Project team (including staff and patients):
- » Attend the training session and 'Sharing Experiences' workshop at the CCRC
- » Attend the project team meetings at their site

» Identify a lead for each group from the staff component
» Complete independent work outside of the session
» Implement change within their clinical setting using Enabling Change methods
» Provide monthly updates to the CCRC lead
» All team members will complete on-going evaluation sheets and final review of the process
» Project team to write up their final Enabling Change models
» Participate in separate staff and patient focus groups about patient engagement prior to work beginning at the site and afterwards.

Expectations and responsibilities of the CCRC team:
» Provide clear aims and objectives for all stages of the project
» Provide the materials for all stages of the project
» Provide patient data for the service priorities identified by each site from data gathered as part of the Patient Experience project
» Provide on-going support by phone, email and site visits
» Provide Enabling Change training to all members of the project teams
» Provide quarterly updates to the Chief Executive
» Provide monthly updates to the patient members of the project teams groups during the implementation phase
» Facilitate shared learning across sites and encourage a peer support network for project team leads
» Host a 'Sharing Experiences' workshop to share learning and disseminate good practice
» Provide a copy of the full report to each site

Section 3:   PROCEDURE

This section describes the procedures used for data collection at the intervention and non-intervention sites across the five Health Boards.

3.1 Intervention Sites Procedure

3.1.1 Use of patient data in the development of PDSA change plans

Patient experiences data were presented to each Enabling Change team at the first meeting. The data included the key findings from the CCRC's work, including the Advisory Groups (Worth et al, 2005); the interim report for patients with a diagnosis of lung cancer from a study exploring people's experiences of cancer within the first year following diagnosis (Hubbard et al, 2007), and feedback received on interim reports from the Advisory Groups (http://www.cancercare.stir.ac.uk/projects/ptr_index.htm). Further data about people's experiences of lung cancer gathered during the Phase 2 interviews were reported to the teams at subsequent meetings.

The patient experience data alongside the experiences of the project team members informed the teams' decision-making about their local priorities for service improvement. Project teams created PDSA change plans to be tested during the three month period of the project from January to April 2007.

3.1.2 Intervention site Procedure

A range of methods were used to support and monitor the process of Enabling Change at the intervention sites. The main methods were:
  » A minimum of three site visits by the researchers provided the teams with the

opportunity to discuss their expectations of the project, report on progress and discuss any issues and problems they encountered.

» Monthly phone/e-contact between the researcher and the site teams, provided an opportunity for further updates on progress, identify any support needs and provide motivation to the teams.

» Summary interim progress reports of the Enabling Change work were circulated to the teams and Chief Executives. These interim reports documented the status of the project and Enabling Change plans at each site, and gave an indication of future implementation and any resources required.

» To facilitate shared learning between the three intervention sites several different activities were undertaken: (i) all site teams attended an 'Enabling Change' training workshop led by Carrie Marr, Associate Director of Modernisation and Development in NHS Tayside in January 2007. The workshop provided an introduction to change management and Enabling Change techniques, and supported teams to develop their initial Enabling Change plans. It also provided the teams with the opportunity to discuss their plans for their service improvement; (ii) Sharing feedback from the patient members of the project teams on Enabling Change plan priorities between the site teams; (iii) The plans and templates developed on the training day were shared across all teams by email; (iv) The 'Sharing Experiences' workshop in April 2007 provided another opportunity for the teams to come together and share learning about their experience of the project and outcome of their change plans; (v) Conference calls were planned between the CCRC and the Enabling Change leads at each site to discuss their team's progress and learn from other sites throughout the project.

Feedback questionnaires were completed by the teams after each site meeting in order to provide additional information for the evaluation of the project.

3.2 Evaluation Procedure

The evaluation of the Enabling Change model was carried out in the intervention and non-intervention sites. As described below, two methods of data collection were used for the purposes of the evaluation. The aim of the evaluation was to document each site's practices

and beliefs of patient involvement at two time points: (i) before the Enabling Change work began, and (ii) when the Enabling Change work terminated.

People working in cancer care, people affected by cancer and Chief Executives were asked to reflect on their current understanding of involvement, and their thoughts regarding key issues which had been raised in the course of the Enabling Change work, for example training needs.

Drawing data from the three sites with project teams and two sites where no intervention took place, before and after the intervention, means that conclusions can be drawn about the impact of the Enabling Change work on participants' approaches, methods and views of involvement.

3.2.1 Evaluation focus groups

Focus groups were carried out at the five sites involved in the project (three intervention and two non-intervention sites). People from the intervention and non-intervention sites were invited to join focus groups. Due to pressure of work for staff and ill health and bereavement for people affected by cancer, some new members joined and others were unavailable.

Focus group interview schedules were formulated to allow for identification of understandings of patient and carer involvement, current methods for involving people, models and processes employed and perceived barriers to patient and carer involvement (see Appendices 2-3). Focus groups were facilitated by experienced CCRC researchers.

3.2.2 Evaluation interviews

The Chief Executives of the five Health Boards were interviewed by a member of the CCRC's patient advisory forum. This person received training from CCRC researchers prior to conducting the interviews.

Interview schedules explored Chief Executive roles and responsibilities around patient and carer involvement and engagement, perceptions of barriers and the political affordances

and constraints within their Health Board for involvement and engagement work (see Appendices 4-5).

3.2.3 Non-intervention site participants

Pre- and post-intervention focus groups were conducted at the two non-intervention sites using the same questions. This was to identify the current involvement work in each Health Board area and to monitor any change during the time of the project. The focus groups consisted of multi-disciplinary health professionals working in lung cancer and people who had received treatment for lung cancer (but were not currently under active treatment) and their relatives. Both staff and people affected by cancer alike were identified by a Clinical Nurse Specialist in lung cancer at each site. Staff in the non-intervention group were matched for role against the intervention staff where possible.

The data on which analysis for the evaluation is based is detailed in table 2 below.

Table 2. Evaluation data gathered pre-intervention and post-intervention

Data source	Time 1 (Pre-intervention)	Time 2 (Post-intervention)
Practitioners working in cancer care	5 Focus groups (all sites)	5 Focus groups (all sites)
Patients/family members	4 Focus groups (3 intervention and 1 non-intervention site)	4 Focus groups/interviews (2 intervention and 2 non-intervention sites)
Chief Executive	4 Chief Executives (2 intervention and 2 non-intervention sites)	5 Chief Executives (3 intervention and 2 non-intervention sites)

3.3 Data Analysis

The data generated by the intervention and non-intervention sites was primarily qualitative. The intervention sites also generated some basic quantitative data from the test cycles of their Enabling Change plans.

Combining the qualitative and descriptive quantitative analysis enabled tracking of the progress of both the process of change and the content/outcomes. The six month period of evaluation and data collection ensured the ability to track changes within the sites and comment on the development of the use of patient experiences/involvement in cancer care services.

A collaborative approach to the analysis and final report was taken; the CCRC provided the project teams, Chief Executives and other key senior staff involved with site recruitment at the clinical sites with a copy of the draft report enabling them to provide feedback and any further contextual information for inclusion in the report. The person affected by cancer who conducted the Chief Executive interviews also reviewed the draft report of the evaluation.

3.3.1 Intervention site analysis

The main analysis conducted on the Enabling Change work at the intervention sites was a process analysis which focused on reflection of the experience of the project teams. The analysis has drawn on field notes of the CCRC team, site team meeting notes and communications received from the team members throughout the project. The analysis is presented in Section 4 of the report.

3.3.2 Evaluation analysis for all sites

All interviews and focus groups were recorded and transcribed verbatim. Participants' names and all identifiers were removed/altered to preserve anonymity.

Thematic and interpretative analysis was conducted on the pre- and post-intervention focus groups and individual interviews to identify the views and experiences of staff and people affected by lung cancer. Analysis focused on comparing responses from the intervention

areas and the non-intervention areas, to map out differences and similarities. This facilitated the identification of involvement methods being used and the impact of the intervention on involvement activities and beliefs.

Data was analysed using content analysis to identify broad categories describing key themes or issues, within which related components were grouped as subcategories. These codes were developed by one researcher and discussed, developed and refined within the research team.

Section 4:   KEY FINDINGS

4.1 Introduction

This section outlines the key findings of the Enabling Change project and the Evaluation. The section begins by presenting reflections on the process of the three intervention site teams followed by findings of the formative evaluation of all five clinical sites.

4.2 Enabling Change in Three Intervention Sites

This section reflects on the content and process of conducting the Enabling Change work at the three intervention sites based on field notes of the CCRC team, and informal feedback including correspondence with the project teams. The section includes a brief overview of the Enabling Change plans developed and tested at each site; what was learnt about the organisation and climate for creating change based on patient experience at the intervention sites; and the facilitators that the teams experienced while testing their plans and working towards their desired change.

4.2.1 Overview of Enabling Change plans

The three Project teams developed seven PDSA change plans based on the patient experience data presented to them alongside their personal experience. The full details of the plans, patient and professional feedback during the cycles, and their future implementation plans are in appendices.

> » Site A ran one Enabling Change plan to pilot a patient-held record which
>   provides personal information about a patient's diagnosis and treatment
>   which is updated with information as they progress through their journey

(Appendix 6). The record contains detailed information which, in addition to providing information for the patient and their family, would be useful to other health and social professionals such as Accident and Emergency staff if the patient was admitted. The plan's implementation was led by a Clinical Nurse Specialist.

» Site B ran four Enabling Change plans: the first plan was to improve communication between the hospital clinic and GP by faxing details of any diagnosis for new patients led by a Respiratory Consultant and Clinical Nurse Specialists (Appendix 7); the second plan was to develop an advice leaflet for patients after lung resection led by a Cardio-thoracic surgeon (Appendix 8); the third plan was to develop a physiotherapy advice leaflet for post-operative thoracic patients lead by a Physiotherapist (Appendix 9); the fourth plan was to develop an information leaflet for patients receiving radical radiotherapy led by a Clinical Nurse Specialist (Appendix 10).

» Site C ran two plans to pilot a patient-held record of information about different stages of the patient's journey from pre-diagnosis onwards. The plan would be updated at each stage and have space for patients and family members to prepare questions for their next clinic visit. The team began with the pre-diagnosis stage and then developed a record for the diagnosis stage. Both plans were led by a Clinical Nurse Specialist (Appendices 11-12).

4.2.2 Recruitment to the project

4.2.2.1 'Top down' recruitment of staff

As outlined in the methods section, staff participants were identified by senior staff at each site. Letters and information about the project were sent out to all nominated staff with details of the initial meeting, in an attempt to involve all appropriate personnel. The turnout at the first meeting was good at all sites, with a minimum of two thirds of the invited staff attending. Staff at two of the sites, however, commented that they would have like to have been more involved earlier on in the project instead of such a 'top down' approach. This is an area which could be explored for future projects, although element of this 'top down' approach may always be required when approval for a project is required from senior staff such as Chief Executives and Medical Directors.

4.2.2.2 Recruitment of people affected by cancer

As outlined in the methods section, inclusion criteria were set at the beginning of the project. However, it became clear during the project that given the level of illness and the high mortality rate in lung cancer, that these criteria were impacting on patient recruitment and retention. During the project, teams found it difficult to replace members who withdrew (due to illness or death) by recruiting any additional patients and family members who had been through the local cancer services. One team approached their local cancer network patient forum and successfully recruited an additional three members to their team who had not had a diagnosis of lung cancer. These three people continued their involvement for the rest of the project. During the project it became clear that although it was valuable to involve patients and family members who had been through a specific service, it was also valuable to involve patients and family members from other established groups who had the time and well-being to make a contribution.

4.2.3 Climate for change based on patient experience

4.2.3.1 Involving people affected by cancer in collaborative work

One of the most positive outcomes of the process was the significant change in staff views on patient involvement, with staff reporting more positive views about incorporating patient involvement into the process of service improvement as they progressed through the project. Some team members found that patients and staff recognised many of the same gaps in the current service and had similar ideas about the local priorities for service improvement. Some staff were surprised to find that the changes patients felt would improve their experience were often small, achievable changes rather than large service overhauls which required large financial resources.

Some patients greatly underestimated their input, which contrasted with how other members of the team perceived their role. One example of this came from a patient who had been involved with the project from the beginning, helped the team decide priorities, commented on every part of the development and testing of the plans, taken part in most of the meetings and evaluation focus groups, who said they felt that they 'hadn't done much'. It was surprising to professionals that their patient representative did not recognise their value to the project team despite the team stating this regularly at meetings.

4.2.3.2 Engagement with patient experience data as a driver for change

During the first meeting at the intervention sites, key findings and recommendations for policy and practice focused on the experiences of patients with a diagnosis of lung cancer were presented (Hubbard et al,. 2007). The attitudes of the teams to research, their motivation for creating change and the nature of their organisational culture were strong issues in determining their engagement with the findings and recommendations. All site teams felt that they were making progress on the main recommendations of the CCRC patient experiences research project, for example improving communication and information. It was challenging for some staff to accept that these may still be areas requiring future improvement in their service. The volume of data and the potential areas for service improvement appeared to be overwhelming for some teams. Despite initial reluctance the majority of staff members did accept the possibility that further work was needed in some areas to improve patient experience. The patients and family members in the project teams were valuable in highlighting this issue to the staff in a constructive way, particularly in teams where the staff felt the data was too critical. They also brought their own experience of each service to the meetings which fed additional patient experience data to the teams.

At one site there was a strong feeling amongst some of the staff that they were already doing what was recommended in the CCRC patient experiences research project report and were already involving patients in their service development. Their account of involving patients in service development, however, did not match the aims and objectives of the Enabling Change project. For example, this team cited instances of involvement as participants being included in clinical studies. This form of working with patients was not considered 'involvement' by this project. Involvement in the context of the Enabling Change work meant patients being more than research subjects.

Many of the team at this site were resistant to attempts to engage them in discussing areas for potential improvement. The turning point in the first meeting came through one of the patient representatives refuting the team's claim that they were already responding to some of the key recommendations of the CCRC patient experiences research project. The patient told the team that although they received excellent care there were areas that could be improved by implementing some small changes. The resistance at this site is felt by the CCRC team to have had a particularly strong impact on staff engagement. The number of

staff who remained involved with the project after the first meeting reduced throughout the project until there were only two key members of staff attending site meetings and carrying out the Enabling Change plan, from an initial 14 staff who were invited to be part of the project.

4.2.4 Decision-making process

Each team identified areas for service improvement. The initial list of local priorities at each site was quite long and represented a range of topics including:

- » Post-surgical information and support
- » Development of rehabilitation programmes
- » Advice and support around sleeping problems
- » Advice and support on breathlessness
- » GP referral, communications and limited experience of cancer
- » Experience of gaps or delays along the treatment journey
- » Delivery of diagnosis to patients
- » Development of a multi-disciplinary support clinic including dieticians, physiotherapist and so on
- » Information needs of patients just after diagnosis
- » Involving patients who were post-treatment to provide support and stories of their experience to patients recently given a diagnosis of cancer.

The decision-making process of the teams typically consisted of different team members expressing their views on the findings and recommendations of the CCRC Patient Experiences research project, and their reflections on their own experience of receiving or providing the local cancer services. In all three groups patient members of the teams had a strong influence on the local priorities chosen. When making their final choice of local priorities project teams were reminded to consider the following: (i) the teams had three months to test their Enabling Change plans; (ii) the change plans tested in the project had to be clearly based on patient experience; (iii) as the changes were to be tested by practitioners in the lung cancer services team of the hospital, the team could include other relevant staff but there must be a clear link to the work of the lung cancer group; and (iv) each plan had to be an improvement, and have appropriate aims and measures for feedback to demonstrate change.

At one site the priority chosen mapped onto a current issue under discussion in the service. At another site several priorities were chosen due to the range of issues the team were interested in working on. The training workshop in January 2007 demonstrated how the patient members of the teams could have an impact on the planning of other sites. One patient who was unable to attend the training day had emailed detailed notes about their opinion on the development of the patient-held record which was being developed at their site. With the permission of the patient, these notes were shared between the two sites developing patient-held records. It was interesting to note that another site team were very positive about the patient's comments and incorporated more of the suggestions into their record than the team the patient was part of.

4.2.5 Project leads

Once each site's local priorities had been identified it was important to identify a lead for each plan. The lead would drive the work forward and be a key contact for the CCRC researchers. The leads at all sites were very motivated and drove their plans forward. In teams where engagement with the project was high, the leads had support and feedback from the teams and other colleagues while developing their plans and testing them. In one team, however, the lead had support from only one other colleague, which was experienced as isolating.

When talking to senior staff at each site it was hoped that one person would become a local 'champion' who would support and motivate the project team throughout the project. This aspect of the project did not work as well as intended. At one site the senior member of staff remained engaged with the project throughout, attending the site meetings and providing support for practical issues such as organising meetings. At the second site the senior member of staff did not engage with the project team in this way and one of the leads in this site of another Enabling Change plan took over this role of encouraging and supporting the other project team members and organising the meetings in addition to leading their own plan and clinical duties. At the third site the champion withdrew early in the project, but the lead had support from another colleague in the team. Given the vital role of a local champion to support the team, ensuring that the work is embedded in current practice and that any learning can be disseminated throughout the organisation, this role should be given more attention and value in future work.

4.2.6 Implementation, activities and progress

Implementation of the Enabling Change plans was scheduled to begin soon after the training day to continue the momentum. However, there were delays for two of the sites. At one site this was due to the team feeling it was necessary for approval to be granted from senior staff on the specific Enabling Change plan that was chosen. It is not typical for further approval to be sought from senior staff when trialling an Enabling Change plan on a small scale, so this had not been built in the timeline of the project. Seeking further approval resulted in considerable delay at this site; however, once approval was granted the team moved quickly and successfully tested their plan within the time frame and are looking at wider implementation across their Health Board.

The other site which had a delay was due to staff changes in the organisation which resulted in a key person leaving the project team and one member of staff being left to run the plan. After a short delay, however, they successfully developed and completed their Enabling Change plans.

4.2.6.1 Staff and patient motivation

The motivation and efforts of the teams should be considered one of the most important facilitators to the project. Staff motivation to carry out plans and to work as a team with the patient and family members has been excellent across the three sites. Staff encouraged patient input in the team and were guided by their comments throughout. The patients and family members who took part in the team were highly motivated to contribute the project and support it through to a successful end. Patient members commented that they valued being part of a project that will bring about change and improvement to other patients who come through the lung service. One patient wrote:

'The only observations that I have is to thank everyone who has taken part and for their devotion in trying to eliminate this illness or at least to help any sufferers.'

4.2.6.2 Buy-in from the wider cancer services team

Two of the project teams reported their main challenge was the lack of buy-in from other practitioners working in cancer services. For example, one Clinical Nurse Specialist testing

a patient-held record reported that there was no medical support in completing the record. If medical staff had participated by completing sections of the patient-held record, this may have led to the record being used more fully. It would also have reinforced for patients that it was a valuable record of their journey which would be updated by all the practitioners they met throughout their treatment.

The project teams have reported that the lack of buy-in from the wider teams did not result in them being unable to test their materials. They are hopeful about the future wider implementation with other members of the team now they have data to support the use of the new materials. However, they felt that earlier engagement of the wider team may have enhanced the original rounds of testing and reduced the burden on the designated leads.

4.2.6.3 Staff time

All the project teams reported the challenge of completing the required paperwork (the Enabling Change plan, test cycle sheets) in addition to piloting the plan measures and continuing with their normal clinical workloads. Limited staff time led to the CCRC team abandoning the use of evaluation sheets in order to reduce the paperwork demand on the team. The challenge of completing the test cycle sheets during the project led to some Enabling Change plans having a lack of evidence to support the changes made, despite them being reported as successful by the plan leads. It may be that staff overestimated the amount of detail required on the forms, making them appear more onerous than they should have been. Additionally, finding the time to complete service improvement work within their already busy roles appeared, form some, too much of a challenge at the time of the project.

The plans chosen may also have had an impact on the lack of paperwork completed as there were no specified 'targets' so collecting numerical data was not required. In many cases the feedback from test cycles was very positive with only small changes suggested, so it was possible for teams to incorporate feedback to leaflets and forms easily and this may have reduced the importance for the teams of recording the changes made.

4.2.6.4 Support from the CCRC

The teams spoke of the support received from the CCRC as a facilitator to progress during the project. The patient members who joined during the project reported their frustrations

at the lack of progress with other patient involvement activities they had engaged with previously, and their hope that having an external organisation involved would ensure faster progress and achievement of the project goals. This was a strong motivator for the patient members of one team, who reported that having the CCRC involved had indeed made a difference to the productivity and progress of the project.

Support was provided to the teams throughout the project, primarily by a CCRC researcher through site team meetings, emails and phone calls. There was some variation in the amount and type of communication between the plan leads and the CCRC. This was due to different progress rates in rolling out the Enabling Change cycles, the level of feedback about progress on the plans and the level of support requested by the leads.

Site meetings were felt to be useful for reflection and to gather support from the wider team and the CCRC. The regular emails or calls from the CCRC researcher were felt to be useful reminders of what should be happening throughout the project and helped to keep the plan leads on target whilst providing support and encouragement in an understanding manner.

4.2.6.5 Peer support and shared learning between sites

It had been the intention of the CCRC researchers to facilitate on-going support and shared learning between the three intervention sites during the implementation phase of the project by arranging conference calls between the Enabling Change plan leads. This was not possible in the early stages of the implementation due to the impact of the delayed start in two sites. Once all sites were up and running the teams did not feel it was necessary. Shared learning therefore focused on the two events when the teams came together at the training day and 'Sharing Experiences' workshop, and by sharing any new plans or leaflets by email with all project teams. It would, however, have been useful to explore with teams at the beginning of the project other methods of providing peer support for colleagues working in different areas to ensure that learning is disseminated across organisations and cancer networks by various methods.

4.2.6.6 Resources

The project teams did not receive any additional time or resources for the plans they implemented. All of the plans have some required resource (noted in appendices 6-12),

ranging from one pence for the printing of a leaflet through to the cost of a fax machine to help speed up communication between the clinic and GPs. The future implementation of any of the plans on a wider scale will require resource even if it is limited to printing costs of new leaflets. This will need to be considered by staff when they are looking at implementing their plan across their organisation or cancer network.

4.2.7 Challenges

There were several challenges for the project teams during the intervention work. Some of the challenges were evident for all of the teams, some were specific to teams and individuals.

The following outlines the core challenges:

» Resources and support
The need for practical resources to support future work. In some areas this includes issues such as having a room near to the clinic with access to IT facilities, easy access to a fax in clinic, access to a photocopier so a copy of a letter template can be made to go into the patient notes.

The teams would like to see support for further change work from their organisations and with the support of an external organisation such as the CCRC.

» Staff time
The time required to implement change and complete test paperwork in addition to existing clinical duties was very challenging for staff. Staff felt that protected time for team leader would be valuable, with the possibility of a secondment, particularly if working on a large project. If protected time was not possible, staff felt that some secretarial support for future projects would support them in completing the necessary paperwork.

» Evaluation
The teams felt that evaluation of any service change was important, and that where large scale improvement work was being run it would be best to have an external organisation involved to provide support and maximise objectivity.

» Team working

The teams felt it was vital that there are clear roles and responsibilities for all team members, with clear leadership. This relates to the principle of strong leads and a champion at a senior level who will provide support and motivation to the team, whilst ensuring that all the work is disseminated to promote best practice and improving patient experience throughout the organisation.

4.2.8 Benefits of patient involvement and working collaboratively

The teams have also reflected on the patient involvement in the project, identifying several key benefits of working collaboratively with patients and family members:

1. This project has broken down barriers for staff and patients who found it encouraging and refreshing to have 'good patient involvement' which aided the process of the project throughout.
2. The project demonstrated to teams that collaborative working aids effective decision-making about service improvement.
3. Patients and staff recognised the same gaps in service provision and had similar ideas for the local priorities.
4. Involving patients and family members from the beginning of any project, leads to it being more meaningful and powerful, rather than a tick box process.
5. Strong motivation for the teams came from conversations and contact with people affected by cancer throughout the project.
6. Patients have been empowered through involvement in the project and have had active input rather than being consulted following the project.
7. Patient members of the teams have described the project as a 'positive experience' while staff have demonstrated a change in their views: 'It took away the protracted image of patient involvement' (CNS).
8. Patient involvement ensured that the patient perspective of the service was understood by the teams and the teams recognised that such collaborative working can lead to services becoming more patient-centred.

4.2.9 Patient involvement challenges

The teams also identified potential challenges to maintaining patient involvement and ensuring that patients and family members were well supported throughout any future project:

1. The current project had initial inclusion criteria which were abandoned in order to ensure that patient involvement could be maintained during the project. Involvement of patients from a wider group is needed to ensure continuous involvement in the project if patients become ill and need to withdraw, i.e. local cancer support groups or cancer network forums - not just including patients who have been through the lung service, although it would be good to include some of these patients or family members where possible.

2. There may be some barriers to involvement including the potential impact of a previous clinician-patient relationship on the power dynamics with any project team.

3. There is a need to ensure that meetings are planned well in advance, so that clinicians can attend. This also means it will be possible to take into account the different demands on staff who may be working across different systems and the impact on patient/family member lives who may be busy and working.

4. Staff need to be aware of their language and use of acronyms in meetings which can be confusing to patients.

5. It is important to recognise that some staff may hold a negative view of patient involvement or feel that it is not a valuable way to decide and act on service improvements.

4.3 Summary of the Enabling Change work

In order for the project to be a success it was expected that the operating climate of the organisations would need to be supportive to the time and resources needed by the project teams to carry out their Enabling Change plans and achieve the desired change. Previous experience with the PDSA methodology and of working collaboratively with patients for service change was also seen as potentially giving an advantage to one of the teams. However, it was found that the there was no difference in the achievement of the

teams based on previous experience with the methodology, and that no additional time or resources were given to the leads to facilitate their aims and outcomes. The most significant facilitator to the progress of the project was the willingness of team members to engage with the project and their motivation to improve patient experience of their services.

The project improved the process of involvement of patients and family members in service improvement in each of the three intervention sites, as well as improving services based on patient experiences. The implemented changes have made an improvement to the patients who were involved in the testing period. The teams have reported very positively on the feedback from patients and other professionals who have provided feedback on developed plans and who have taken part in the testing period. These improvements have been shown to be sustainable as by their nature they can be rolled out with all new patients within current practice of the staff.

The teams are now looking to further implement their plans by sharing the materials and findings of the test cycles with their colleagues and at the lung cancer meetings for the cancer networks. The materials have also been shared between the teams due to the interest between teams at using each other's materials. These will be tested within their own areas. The materials will also be shared with non-intervention sites so they can test them within their own setting. Overall, the project has had a positive impact on the teams involved and, they claim, on the care provided in the lung cancer services. It is recognised by all staff as being an achievement and has raised the profile of improvement projects. Spread of the materials has occurred at a local level and there has also been national level interest through the cancer networks.

4.4 Formative Evaluation

This section reports the findings of the evaluation. The results are separated into intervention and non-intervention sites, and further subdivided into participant groups: people affected by cancer, staff and Chief Executives. These distinctions are maintained as each group reports different perspectives. This section also discusses the changes in perceptions over the six month intervention period within each group of participants, particularly with regard to understandings of involvement and barriers to involvement.

4.4.1 Intervention Sites: people affected by cancer

4.4.1.1 Overview

Prior to the intervention people affected by cancer had limited awareness about the range of meanings and methods of involvement. After the intervention their views had developed and become more crystallised. More complex views were expressed indicating a much wider understanding of involvement, with increased focus on achievements, rather than barriers, associated with involving people affected by lung cancer.

4.4.1.2 People affected by cancer's views on the meaning of patient involvement; Pre-intervention

People affected by cancer initially identified patient involvement as a form of decision making in relation to their own care as opposed to involvement in service improvement. Involvement also was constructed as attending group sessions for help and support for cancer-related physical, mental or emotional issues. Invariably, making a difference to other people's experiences of cancer was the impetus behind attending meetings or groups:

> *'…if it's going to help somebody else, you know, that's the reason why I came, that's the only reason why I came…'*

4.4.1.3 People affected by cancer's views on barriers to involvement; Pre-intervention

Prior to the intervention people affected by cancer referred to the belief that input from patients was unwanted or unwelcome: patients were told what to do and the 'surgeon's decision is final, not mine'. This appears to stem from the belief that involvement is restricted to care practice, rather than consideration of involvement in service improvement.

People affected by cancer expressed a large number of concerns in relation to participation in the Enabling Change project. These encompassed personal and social issues: those who became involved felt that they were looked upon as being in better health, being more articulate, better educated and having time and resources to participate. The rapid progression of lung cancer and its associated debilitating symptoms were seen as posing difficulties in recruiting patients. Participants felt that the people who were willing and able to get involved were few in number, and tended to be atypical and thus possibly unable

to represent the concerns of the majority. This group reported that apathy and fear played a role; talking about experiences of lung cancer might be too uncomfortable for many people.

Physical and organisational issues were also proposed as potential barriers. Travelling distance to groups/meetings and associated difficulties of transport were outlined as a significant concern. Costs were also pertinent. For those living at distance and without resources, the problems were perceived to be almost insurmountable. Participants did not refer to offers of reimbursement for travel, suggesting that interviewees had not understood this was possible.

4.4.1.4 People affected by cancer's reasons for and expectations of involvement in Enabling Change work; Pre-intervention

Despite being unsure of what to expect, people affected by cancer reported that they chose to become involved in the change work because they had been asked by their healthcare contact if they would take part. They were also propelled by curiosity as to what involvement entailed, and felt that they wished to 'give something back' to the health care system. Participants were mindful of the future benefits to others:

> *'…if it can help things change for the better for everybody, particular[y] patients and their family members for the future then that's the reason why we got involved…'*

However, they had very little to say about expectations of working in a group with staff, the benefits that might accrue from such collaboration and what they might expect to achieve.

4.4.1.5 People affected by cancer's perspectives; Post-intervention

Following the intervention, perceptions of patient involvement had expanded. The notion of patient forums was raised as an arena where issues of relevance could be discussed, with staff and patients coming together to instigate service change.

Participation in the Enabling Change work was felt to have been a positive experience. Participants reported that the barriers they had initially identified (such as the belief that

professionals did not welcome their input) had been addressed. They had also developed a greater understanding of how working in partnership with practitioners can be challenging, and reported barriers such as those imposed by the hierarchical structures of the health service, particularly where involvement meant that patients could be working in the same group as their consultants: 'it puts a barrier up, an unconscious barrier…. their name, rank and serial number'. Informality in group membership was seen as a key to better working alliances.

Working together as equals was perceived as important, with patients' illness experience complementing professionals' medical knowledge and clinical experience. Adopting effective communication styles on both sides was also seen as key.

Perceptions of the lack of representativeness of patients who might participate in lung cancer involvement was not articulated at the post-intervention discussions, though this may be due to many of the patients becoming too unwell to continue their involvement, underlining the idea that perhaps the group's members did indeed include those who were less well.

It was suggested that involvement could potentially be introduced to patients at the diagnosis and treatment stages as well as later. In general, the proposition of being sent ideas of issues to work on with CCRC was received positively.

4.4.2 Intervention Sites: staff

4.4.2.1 Overview

Staff reported a range of ways of involving patients at the pre-intervention focus group, though these were largely around the use of patient satisfaction questionnaires. They identified the need to focus on small projects, and identified a large range of barriers to involvement. Following the intervention, staff were very positive about the project, showed evidence of having learnt a great deal about patient involvement methods and processes, and were excited about the possibilities that it had opened up.

4.4.2.2 Staff views on the meaning of patient involvement; Pre-intervention

Staff talked of patient involvement as a series of small-scale interactions carried out as part of their day to day duties, for example providing individual patients with choices and discussing treatment and care with them. Staff indicated that sophisticated interactions focusing on service development had not been common in the recent past.

Thus, staff perceived that involvement and engagement work was already being conducted in the lung teams and elsewhere in the Health Board. Ongoing involvement work ranged from indirect patient and/or family member involvement via staff in clinical areas, group meetings to which patients were invited and forums such as patient support groups, through to patient questionnaires, needs assessments and structured interviews, short term studies and information development to audit. The most common method of involvement was the use of patient satisfaction questionnaires, used as a means of appraising patients' feelings with regards to their symptoms and treatments and their views on the services involved in their journey through the healthcare system.

Staff perceived overall that short or small studies were preferable to longer or more complex interventions because of other commitments and concerns about the support required for longer projects.

Staff reported involving patients in developing research grant proposals and evaluating patient views in relation to service improvements. Reasons given for the considerable importance of obtaining service users' views was related to patients' perceptions of health and associated services as being different to staff's.

Although staff believed that patient involvement entailed shared responsibilities, the implication existed that patient involvement was a contract of action with and for the benefit of patients:

> '…at the end of the day you can set goals… jointly but unless you actively have their active participation it's not really going to make any change to them… for patient engagement at the end of the day I think you'd have to cross that barrier of whether patients are going to actually look at their role in an active way'.

While shared responsibilities were discussed, family members were not mentioned as part of this, or as useful source of experiences of the healthcare system.

4.4.2.3 Staff views on barriers to and facilitators of involvement; Pre-intervention

Staff reported many barriers to involving patients and this was the primary focus of discussion prior to the intervention. Their greatest concerns were the time, support and resources to sustain patient involvement. Staff observed that patient involvement projects create a reliance on someone to drive the work forward, and this was problematic given the constraints imposed by their other clinical responsibilities.

> *'From a patient involvement, scared… slightly because of the, I think the presumption on our part that it was going to be very time consuming for us also… the commitment that we have to give these patient family members because it's support and other patients in particular to make them feel involved in service development.'*

Staff also highlighted that as the numbers of patients with cancer increased, with an ageing population, the level of patient involvement achievable was in danger of slipping. They stated that they felt unable to maintain even the current degree of expertise and help they provided to patients within existing resources.

Staff perceived that physical and emotional barriers related to the patient's diagnosis/ prognosis, existing co-morbidities and type of cancer, could lead to non-typical representation in involvement. Staff also saw apathy, as well as the emotional cost to the patient, as a strong limiting factor in patient involvement. The archetypal patient with lung cancer was seen as unwilling to participate in group work because the patient is:

> *'…not articulate, is not willing to put themselves forward and is not good at accessing services… very few of my patients, one or two, but they would be giving completely the wrong point of view of what the average person's experience is because they are in that 16% of social class 1 rather than the 59% of social class 5, who don't know how to sit up and brave a lot of professionals using big words…'*

The above extract implies that professionals are aware that they tend to use jargon, though this was not explicitly presented as a barrier by staff groups. Likewise, changes in patient-

professional roles, power, and paternalism in the healthcare system also contributed to the barriers. Although staff recognised the value and policy impetus of patient and public involvement they felt a need to ensure that professional roles are not compromised by participation, and that patients and family members do not feel intimidated.

Barriers and constraints were also perceived to be imposed by the systems and structures in which engagement could take place, for example transport, accessibility, space and privacy, as well as distances and costs.

Facilitators of involvement were much less frequently mentioned by staff, although three areas were mentioned: (i) empowering patients to express themselves, (ii) the advantage of clear roles and remits for patients, family members and others taking part in patient involvement work and (iii) having an independent person leading involvement, who is removed from the clinical area as this is seen to encourage patient openness. As well as encouraging patient involvement as part of normal team thinking and infusing this collaboration as part of the health service ethos, there is also a strong need for evidence that participation results in changes to the system.

4.4.2.4 Staff views on training and support needs; Pre-intervention

On the whole, although welcoming patient involvement, staff were guarded in accepting long term participation for themselves, due to concerns around sustaining the commitment. Staff reported a need for education on the minutiae of patient involvement, including an awareness of patient needs, issues and level of knowledge. They felt that it was important that the person leading involvement work was skilled in, for example, chairing meetings and that this would be important in the potential success of the involvement initiative.

Staff suggested a need for training for patients and family members, though they offered little detail about what this would entail.

4.4.2.5 Staff reasons for and expectations of involvement in Enabling Change work

Staff motivations for participating ranged from being strongly encouraged by senior colleagues to take part in the collaborative work, to hoping to receive advice on how to

accomplish patient involvement. Previous experiences with CCRC were felt to have been interesting and positive.

The Enabling Change work was felt to provide a range of opportunities, including raising the profile of lung cancer, improving staff understandings and practice of patient involvement, making a difference to patient outcomes and influencing policy:

'…it's to help us but it's also, I mean presumably your project is being funded by the Scottish Executive and you'll come back to them with some ideas or you know… we want to also influence [them]…'

Staff expectations about continuing involvement activities included improved patient care, provision of a better service, and opportunities to bring research into the workplace.

4.4.2.6 Staff views of involvement; Post-intervention

Staff reported that there had been neither policy shifts nor other changes related to the context of patient involvement in their Health Board areas within the timeline of the project. This suggests that substantive changes between the pre and post-intervention discussions could be associated with involvement in the Enabling Change work.

Staff understandings of what constitutes involvement had been substantially added to; while they continued to construct involvement as the use of patient questionnaires and interviews, they also reflected smaller-scale and more active modes of involvement where patients were directly engaged in service redesign.

Staff indicated that in retrospect, they would have liked to have been more proactive in involving patients in a much more structured system within the Health board area, with the local Patient and Public Involvement Officer employed to orchestrate patient engagement and to 'bring the patients on board'. Staff felt that they should have been much more aware of other sources for patient input, such as the patient forum. Allied to this, staff had learned that patient involvement was not as daunting as first believed and patient feedback could and should be used positively to create service change, through a methodology such as PDSA.

Staff reported a growing realisation that previous engagement had tended to be paternalistic or superficial, paying 'lip service to patient and public involvement'. They also identified patient involvement as 'something that has to be part of our service and how we develop our service'. The Enabling Change project was perceived to have helpfully blurred the role boundaries between patients and staff; engagement was perceived to be a joint process between patients and staff, with shared responsibilities within the group; staff expressed surprise at how willing patients were to participate. Dissatisfaction was expressed at the perceptible hierarchies and power imbalances between health professionals and patients/families. However, it was noted that there appeared to be a restructuring of some of the roles of nurses and some allied health professionals, and challenge to the idea of patients adopting a passive role.

Many of the barriers mentioned prior to the intervention had not been directly addressed, for example quiet environments where involvement could take place. However, throughout the course of the change work, and at the post intervention focus group, these were not reported as continuing concerns, indicating that perhaps the staff teams had found solutions without consciously processing this element of change. Accounts of the barriers of time, resources and support, were somewhat softened in the post-intervention interviews.
Staff recognised that their ideas about patients' views of services were not accurate. This was found to be a useful realisation that patients' suggestions about change were not as challenging as staff had anticipated.

Staff reflected on the need for more structure and support for involvement and the need to 'get the buy-in' of the whole clinical team and the 'legitimate authority within the organisation' to proceed to ensure that patient involvement progressed.

It was perceived that future, larger projects would benefit from input at an organisational level, such as the use of change and modernisation teams, and by taking advantage of any professional facilitation available locally. Staff experiences in the change work led them to believe that small discrete pieces of work were more achievable and cited this as one reason for the success of the project. Having successfully implemented the changes at local level however, staff then envisioned rolling out the results of the project and disseminating at events such as clinical leads' meetings, interest groups, stakeholder events and via cancer networks or by using an existing web-based 'chain of good practice and innovation'.

It was noted that relevant data and tools must be available to others if they wanted to roll out specific changes. Staff were, however, aware that there was a lack of uniformity amongst Health Board areas and that making the results of projects such as methods and tools accessible to all could prove problematic.

It was seen as essential that clear role outlines were in place for staff, patients and family members at the outset, defining both the roles and the commitment expected. One of the perceived difficulties was that people were anxious to know in advance what they were expected to commit to in terms of time involved for organisation and meetings.

Staff reiterated the concern expressed at the beginning of the work that the impact of lung cancer symptoms and poor prognosis constitute barriers to patient involvement. However, this view shifted slightly during the course of the work, taking on a new conceptualisation of younger patients:

> *'I think the younger patient groups are starting to be more vocal now… a lot of the older generation – they accept it - that's the expert, they know exactly what they're doing, I think that barrier is still very much evident'.*

The process of involving patients with lung cancer and family members had been felt to be challenging, but 'the fact that we were encouraged to go down that way meant that we got something valuable and different and, and really positive out of it'. Staff acknowledged that as a result the Enabling Change project, they now had direct experience of gaining patients' experiences and thoughts about services. An additional perspective was that 'it's very important to empower not just the patient but the carer'. Input from family members was considered very valuable, including working with those who had been bereaved.

Staff reported that the patient experience data (generated from Phase 2 of the project (Hubbard et al., 2007)) provided them with insight into issues to be addressed. They were particularly interested in the main themes of patients' and family members' experiences, particularly those related to follow-up care, as well as data related to patients with specific tumour types. Staff felt it imperative that other healthcare professionals should be made aware of the messages coming from the data.

Experience of working with CCRC had shown staff that involvement did not have to be a long-term process with large commitments of time and effort. Collaboration with the CCRC was viewed in a positive light, providing staff with the opportunity and motivation to engage more meaningfully with patients and gave the group more confidence that being involved with a project would eventually result in changes in the system, albeit over time. They enjoyed the highly structured and supportive manner of collaborative working and felt that they responded well to frequent prompts about the next action required to drive forward service change.

4.4.3 Intervention Sites: Chief Executives
4.4.3.1 Overview

Chief Executives constructed themselves as being personally engaged in patient involvement, though they were informed by a limited number of methods and means of involvement. Following the intervention, Chief Executives were receptive to the feedback that had come from CCRC and were pleased with the progress of teams in their area. In particular they spoke about rolling out the model of change and the service improvements further in their Health Board areas and local cancer networks, identifying the transferability of the work.

4.4.3.2 Chief Executive understandings of involvement; Pre-intervention

Descriptions and understandings of involvement were comparable across each of the Chief Executives, although each had a slightly different emphasis. Each Chief Executive felt that their Health Board was doing well in applying the Patient Focus and Public Involvement (PFPI) agenda and had confidence in their methods and results. Involvement was felt to be *'very much in keeping with our philosophy'.*

Chief Executives reported learning from previous initiatives and feeling as though there was common understanding about how to take things forward within service design and delivery. Chief Executives were, however, reflexive about their Health Board's need to continue to learn and develop. There was no evidence of Chief Executives' understanding how other Health Boards were implementing involvement.

Each Chief Executive reported that they had an active role in involvement work – citing examples of participating in and chairing public meetings where service delivery was under discussion. Chief Executives' personal experiences of participating in PFPI activities ranged from systematically conducting large public meetings to ad hoc conversations with people. The idea of not avoiding the difficult public meetings where closure of services was under discussion was made clear, indicating a need to see Chief Executives as engaged in 'hard' consultations. Their experiences extended across a range of specialities, including mental health and learning disabilities. One Chief Executive reported thoughts about a movement toward smaller, more focused and structured consultations with patients rather than large public meetings. Complaints were also indicated as a core way in which patients are involved in health care

> *'We've done a lot of work in [this Health Board] on complaints and trying to make sure that we learn from complaints and where appropriate we can roll out any learning across the organisation'.*

The Chief Executive role was focused at three levels: (i) strategic overview, (ii) directing senior staffing resources to support the work, and (iii) financial responsibility to ensure that staff teams had sufficient resources. Chief Executives recognised a need to feed back learning about involvement to other Health Boards. Communication between Health Boards regarding best practice did not appear to be well developed, and aside from Managed Clinical Networks, no other ideas were cited as ways of sharing practice.

Chief Executives did not have detailed information on the implementation of the PFPI agenda. This was not presented as a troubled position, however, since this should be seen in the context of their reach within the Health Board. Chief Executives mentioned specific staff within their Health Board by name who had been appointed to take on a role around PFPI or change work; these individuals then keep the Chief Executive up to date, a role which was constructed as highly valued by Chief Executives. These people had been appointed in a variety of ways and into a range of roles (e.g. from PR, corporate communications and hired as part of a team).

Though Chief Executives were asked specifically about both involvement and experiences, only one mentioned patient experiences as distinct from involvement as a necessary component to understanding how to develop services.

Prior to the intervention, Chief Executives were very receptive to joint working with the CCRC, though there were few specific ideas on what this would entail. Involvement was also constructed as something that made good business sense. They had high hopes for involvement:

> *'Building in systematic engagement and involvement to some aspects of our decision making processes …' and 'for something tangible to come out of the collaboration'.*

4.4.3.3 Chief Executive views of barriers to involvement; Pre-intervention

Barriers to involvement were not well developed within Chief Executive accounts; only a small number of barriers were identified and discussed. One barrier, however, that was discussed across each of the Health Boards was the challenge that their location brought to them. Although each is diverse in terms of their populations and settings (some urban, some rural and covering each of the three cancer networks) Chief Executives felt that their location was a challenge, referring to local political issues affecting their area and population geographies. Each Chief Executive reported various aspects to their local context as a complexity that others do not face. While each Board area struggles with issues, this indicates perhaps that no area should be considered further forward or behind as a consequence.

Chief Executives were concerned about only accessing the 'expert patient' in involvement activities and the need to 'find' patients who can address broader agendas. One Chief Executive offered a useful reframing of this, suggesting there is a need to 'try to stop, eh, you know, burdening individuals'. This approach is open to multiple interpretations, for example a positive reframing of the idea of being weighed-down through over involvement as being a way of opening out involvement to other patients. By contrast, this construct of 'burden' can be used to distance responsibility for engaging with people who have availed themselves.

A further barrier identified was the use of episodic rather than continued involvement, though no reflections were offered on how this sits with their own experiences of one-off public consultation events.

Chief Executives also, at times, displayed knowledge of how specific cancer types such as lung cancer impact on the kind of involvement that can be expected within services,

indicating an awareness of the potential barriers that might be faced during the Enabling Change work:

> *'I suppose part of the difficulty is continuity of input in patients from the lung cancer pathway is because of the illness itself and I guess that can be restrictive to individual patients you know, because of the progress of the illness and the speed of the illness'.*

4.4.3.4 Chief Executive views of involvement; Post-intervention

Formal, scheduled, feedback on the Enabling Change was a provided by the CCRC toward the end of the intervention period. This was received by Chief Executives prior to their follow-up interview and provided much of the information on which they based their reflections on the success and limitations of the work. The report detailed the change plans being implemented by their local lung cancer team and the barriers and facilitators that had been identified. Chief Executives otherwise had heard very little from the lung cancer teams collaborating with the CCRC, though there had been some informal feedback about one of the change plans and some feedback from within the organisation but not directly from clinicians. There was also a hint of confusion about projects that were part of the collaborative work with CCRC and what had been driven from elsewhere.

The feedback that had been received by Chief Executives led to positive reflections on the change work:

> *'I think this whole business of how the services are re-designed and repositioned around the patient is really powerful and if that's informed by, as you and I were speaking about before we started, if that's informed by really powerful and good information on the patient's experience, such that that is capable of being translated into changes in practice'.*

Chief Executive views of involvement methods had not shifted substantially throughout the course of the intervention, which may be attributed to the lack of direct contact with the staff and patients involved. Only one Chief Executive reported a change to the context of working, progress of the cancer network, which might have contributed to altering views of involvement methods and outcomes. However, on further exploration of this, the network's reported progress was not related (by methods, process or outcomes) to the change work. This indicates tensions in understandings of the connections between different pieces of

work, and perhaps explains broad sweeping comments about the positive uptake of PFPI when there is limited insight into what is happening.

This is further exemplified by a comment suggesting an uncritical stance on the Health Board's approach to PFPI:

> *'I don't think we have any philosophic or conceptual, cultural barriers'.*

Thus, while this is an admirable goal, Chief Executive perspectives are at times at odds with the views of staff and patients and perhaps divorced from the daily realities of implementing the policy agenda, for example the views reported above, where the influence of powerful hierarchies is seen to operate.

4.4.3.5 Chief Executive views on the support for patient involvement and Enabling Change work

Ideas around supportive measures for staff undertaking change and involvement work had not developed substantially during the course of the intervention, although training on change techniques was offered as a focus for directing resources and ideas had been prompted by the feedback from CCRC. However, Chief Executives did not reflect on any training needs relating to methods or measures of involvement.

Despite the lack of discussion of methods and skills in involvement, views about how staff were supported during the work varied; ideas included the notion that support was expressed through allowing the work to happen. This led to discussion of the idea that there is a need to see involvement processes hardwired into workloads, rather than being seen as add-ons. At other points, Chief Executive views indicated recognition that involvement and change work added to clinicians' workloads, and that the additional time and paperwork created may be experienced as a burden. However, in the context of a successful project, this was not constructed as a barrier.

One Chief Executive reported several ideas about the kind of support that people would need in continuing involvement work, displaying a range of ideas from psychological support in seeing positive change in clinical relationships, through to addressing workload issues.

> *'They're talking about positive things like the impact on patient relationships, supporting relationship building and assisting with the patient's journey so I think as*

long as staff see that there is a positive output from the additional work they tend to be happy to engage with it'.

Support needs were also constructed at the practical level of stationery and IT resources to ensure that implementation of PDSA plans could be continued.

'Well, what I would want to do is to try and capture the additional workloads which, well, we've identified through this project in terms of administrator support and so on and what does that translate to in terms of time, equipment and so on. There are one or two things I think highlighted in the report, things like plastic folders, photocopying you know stationery costs, I sure that we could look at that very positively'.

4.4.3.6 Chief Executive Views on the Impact of the Enabling Change Work

Chief Executives felt that the work was 'positive and encouraging' and had made 'a real difference to the relationship between the clinicians and the patient' and that CCRC had a direct impact on change:

'If you look at the whole way they give people information, how they set up the stuff on the websites, how they communicated with people, the kind of, the, the leaflets, the documentation, all of that was I think quite heavily influenced by it'.

Transferability was felt to be central to the work, and there was excitement at connecting up the learning from the Enabling Change work across the Health Board to ensure learning and sharing across different tumour types. Chief Executives were keen to roll out the intervention to other clinicians, across the cancer network as well as within the board's other clinics and hospitals, indicating the value-added nature of the work:

'It was a big improvement on what we had before and that already the team were thinking about how they might be able to roll it out into to other cancer sites'.

The change work had initiated a certain degree of pride and celebration within Health Boards, and recognition of the potential for staff to engage in exciting work which changes practice:

'Transformational change comes from the bottom, it comes from the people who do the job on a day to day basis, but for them to unleash that power they have to be given the time, the space to do it and what they also have to be given is top level endorsement for their work, so I think its not for me to direct these people, but its for me to say I want you to do this and when you've done it, for me to celebrate and acknowledge what it is you've done'.

This illustrates how keen Chief Executives were to express their happiness at what had been achieved by staff, but frequently views focused only on the staff, neglecting the very important role of patients and family members in driving forward service change.

Though keen to celebrate the skills and development in staff teams, some concern was expressed about staff with leadership roles in change being recruited or 'poached' by other Health Boards. Staff with well developed skills might therefore be lost to other organisations. The focus of concerns on leadership in change however, highlights the underlying belief that this is not 'everyone's business' but the domain of few.

Transferability across health services (within Scotland and England) was seen to be important. Transferability was seen as embedded somewhat in the model for improvement (PDSA plans) with clear applicability across tumour types and clinical settings. Chief Executives also felt that there were particular strengths in the change methodology:

'With PDSA you actually start with one patient and one clinician or two clinicians looking at the evidence base around their interventions, so it doesn't really matter the number'.

Opportunities for learning from other sites involved in the change work was also embraced, but not felt to have happened already:

'I probably don't know enough about whether we've had added value from the shared learning and the relationships with others that have been involved'.

Importantly there was felt to be a shift in ideology and commitment to the goals of involving patients in change initiatives:

'One of the bits of feedback that I've had in connection with the project is that there may be some clinical colleagues who maybe were a bit sceptical to begin with have actually come on board in terms of the added value'.

This shift in ideology was bolstered by a reframing of the type of patient feedback being gathered, moving from quantitative measures of waiting times to experiences of care pathways: 'we recognise there's a fair amount of ground still to be covered'.

Although Chief Executives identified the positive impact of the project, they expressed no clear understanding of the role of CCRC staff, structures and supports throughout the change work. Unlike the lung cancer staff who reflected on the impact of structured support, Chief Executives were unaware of the impact of that on the achievability of the change work. As a consequence it seems likely that Chief Executives will need support to identify the needs of staff teams to make further change possible.

This was reinforced by reports of training needs, which were not constructed as a high priority. When discussing necessary skills for involvement, ideas focused on communication rather than modes of involvement or methods of supporting patients through involvement. The idea was raised, however, that training should be part of staff induction programmes, which widens it from what had gone before which was to provide 'specific training for folks for our staff involved in PFPI but that's kind of fallen away'. Consequently, there is recognition of the need to embed involvement further into all staff remits, though specific plans are not in place.

Overall, the change work was considered to have operated on three levels, (i) rolling out of specific tools (ii) contributing to development in staff perspectives and use of involvement models (iii) contributing to the PFPI strategy.

4.4.3.7 Chief Executive ideas regarding future work with the CCRC

The possibility of further joint working was enthusiastically met as a way of drawing on CCRC patient experience data. All three Chief Executives expressed a wish to see further data and explore the potential for continued collaborative working, using patient experiences to make changes in services.

The idea of transferability from lung cancer to other cancers was also voiced as a potential focus for further collaboration, alongside using the CCRC to add to in-house expertise and systems:

'It comes in two or three different ways you know to tap into the expertise that the cancer centre has and how can they facilitate some of the work that we would like to do and I think that there's also the networks that you would have there, how can we tap into these and I suppose it's providing expert facilitation'.

4.4.4 Non-intervention sites: people affected by cancer

4.4.4.1 Overview

Patients and family members understood involvement as participation in committees and working groups, with motivation stemming from a desire to make a difference. Patients were felt to be agentic in their relationship with the health care system, but need encouragement from staff to take on this role. Concerns about tokenism and not being wanted on committees were also expressed. Perceptions at the six month follow-up had not shifted significantly, and patients/family members expressed similar barriers.

4.4.4.2 People affected by cancer's views on the meaning of patient involvement; Pre-intervention

The term 'patient involvement' was relatively unfamiliar to patients and family members in the non-intervention groups, but was formulated as patients sitting on relevant cancer groups or committees and attending meetings, often by invitation from staff, and by publicising cancer or cancer treatments by giving interviews or taking part in media events. The idea of encouraging or reassuring other patients, of making a difference to their journey was also considered part of involvement.

There was an additional perception that involvement and engagement meant being a patient advocate. They felt that it was the patient's responsibility to take charge of their own journey, to find out who to contact in the health service and to keep pushing to ensure that their own concerns were attended to appropriately and in a timely fashion.

4.4.4.3 People affected by cancer's views on barriers to involvement; Pre-intervention

Patients and family members saw barriers around giving up their own time to take part. Another perceived restriction was volunteering only because there was no-one else to take part. Patients did recognise that although difficult, and probably not suitable for many people, participation could be a worthwhile endeavour:

> *'… it's not everybody... that's suitable for it but that doesn't mean to say other people don't have really good points, their points are better than ones I could think up but they didn't know how to get it down on paper or whatever. So it's not all that easy a job. I suppose both of us feel it's worth giving up some of our time'.*

Apathy was perceived as a further barrier in patient involvement, and patients felt that 'committees are notoriously bad at people never wanting to go on them'. Unless strongly encouraged by staff, individuals are unlikely to take part voluntarily.

Similar to the views of the intervention patient group, practical issues such as travelling were raised. Patients were concerned that involvement might take place in venues which were unsuitable because of difficulties with parking, or being far from their homes meaning a long drive was necessary. Patients felt that the costs to those less well off could not be borne and was therefore a significant barrier. Other commitments such as paid employment were felt to preclude participation for some, particularly given the need to move on with life, post-treatment, and re-engage with work.

Concerns about power relations between patients and professionals in clinical settings (as opposed to the patient involvement setting) were also clearly in evidence, and raise concerns about how such dynamics are transferred into active patient involvement:

> *'…as a patient you feel quite far down in the pecking order. I mean the two of us were nearly deferential…'*

Active involvement in service design and delivery therefore poses potential anxiety for patients who then move back to a position 'lower down the pecking order' than that assumed in collaborative involvement tasks. Experiences reported by some patients and family members pre-intervention suggested that professional attitudes created a significant

barrier. The focus group data points towards feelings of tokenism, where patient input is felt to be unwelcome and unwanted.

4.4.4.4 People affected by cancer's reasons for and expectations of involvement in the Enabling Change work

The role of people affected by cancer in this part of the Enabling Change work was limited by being in the non-intervention sites. However, patients and family members conveyed the idea that being involved was based on the wish to give something back to the healthcare system, as it was acknowledged that the involvement of patients with lung cancer was limited by the effects of the disease.

4.4.4.5 People Affected by Cancer's Views; Post-intervention

In general, views had not altered during the time of the study: patients and family members equated patient involvement with attending groups and sharing their experiences in order to make a difference to the experiences of other patients. The view that articulate and willing patients should be involved to advocate for the other patients with lung cancer who are too unwell or unwilling to participate was upheld:

> *'I did it because it's not fair on all these people who just wouldn't speak for themselves. I thought, dear God, if I can do nothing else I can speak'.*

Similar views around barriers were evident to the pre-intervention ideas. However, an additional view was added, regarding the idea that some patients might not contribute to involvement, informed by a belief that they were responsible for their own cancer by lifestyle choices such as smoking:

> *'If you've got something to live for you get on with it and if you're stuck in a multi-story and haven't had a good life and you've smoked you probably think, 'well this is my just deserts and I'll just bow out quietly'...'*

The perception of power imbalance and medical hierarchies had not changed at the follow-up discussion, and in fact appeared to have become stronger in relation to patient involvement, with the view that 'there's a pecking order that needs to be abolished, to be

able to speak up, to speak freely'. It was also apparent that unless power relations could be addressed health service issues would not or could not be resolved.

Training for patients and family members taking part in patient involvement was seen as worthwhile, but change was not perceived to be possible unless research findings specific to the lung cancer group were pushed forward in a policy setting.

It was suggested that the large amount of research data generated by the Patient Experience project should be lung-cancer specific and presented in booklet form rather than electronic in order that there was something 'in the hand' for patients to refer to.

4.4.5 Non-intervention sites: staff

4.4.5.1 Overview

Prior to the intervention staff associated involvement with communication about decision making around treatments. Much of the discussion was taken up with descriptions of perceived barriers. Following the intervention, further ideas about methods of promoting involvement were discussed but there was no evidence of changes to their practice having taken place.

4.4.5.2 Staff views on the meaning of patient involvement; Pre-intervention

Staff in non-intervention sites felt that patient involvement related primarily to informally registering patient concerns, ideas and issues in everyday consultations. The terms also equated to patients being involved in decisions regarding their own treatment.

Staff identified the potential for patients to have roles in planning and goal-setting in service delivery and design, although this type of involvement was felt to be developmentally immature within the Health Boards. Staff noted the range of forums in which they knew patients were involved, but had limited experience themselves of this level of patient involvement. Staff felt that patients could sit on groups but there was a need to protect them as vulnerable group members; few ideas were raised, however, about the nature of this protection.

Staff expressed awareness of their own lack of knowledge of people affected by cancer, their needs, issues and levels of understanding; integral to this was a staff need for education on how to involve patients, how to discern what was appropriate/not appropriate and how to bring out minority viewpoints. Other staff felt that patients might feel intimidated by a group of health care specialists when putting forward views, could lack confidence in getting their voice across and feel restricted in what they could articulate in a 'boardroom-type kind of set up', where patient involvement was 'a tick box thing' apparent to patients and family members as well as staff. Such paternalism could also give rise to the observation that patients were reluctant to give negative feedback, a situation perceived as detrimental to service improvement. Staff also sensed that patients did not believe that they could change the system.

4.4.5.3 Staff views on barriers to and facilitators of involvement; Pre-intervention

As with the intervention staff focus group, the non-intervention discussion focused largely around barriers, rather than facilitators, to involvement. Staff pointed to barriers in a range of domains including within the lung group, the cancer services, and in the Health Board area as a whole. The two most frequently cited barriers were time and resources.

Staff identified personal and social issues that could impinge on involvement, with participation biased towards articulate, fit and willing patients, leaving others unrepresented. Physical and emotional barriers relating to health status and type of cancer could also lead to unbalanced patient representation. Staff felt that there was potentially a high emotional cost to the patient for their involvement.

Where involvement had been achieved in the past, barriers were perceived in terms of sustaining the intensity of the work. This was identified as having resource implications in terms of staff time and input:

> '…involvement workers in the [areas] were funded by [charity] for a three year period and the aim was at the end of the period that patient involvement would be embedded into the culture, but we've now got this huge gap because they've all gone now but patient involvement's not embedded…'

A common concern was the potential tensions between being in a clinical role with a patient and then working collaboratively with them in service delivery projects, mirroring the concerns of the intervention group prior to the change work. Concerns focused on perceived difficulties in patients upholding necessary task and role clarity. This was further troubled by a perception that patient expectations were very high, and could be unreasonable, leading to unhelpful communications if involving patients in service design discussions.

'You could argue cynically, you're going to get a load of requests for inappropriate treatments… and normally people are very reasonable, if you can, you know, discuss things openly and freely and all the rest of it, but if that's not coming across then you, then you have problems – no, no, no [when] patients are in charge, "I want this" – it doesn't work … then you say "You're not getting it", [the patient says] "I'll write to my MP", do you know where I'm coming from? Again it's just, we've got, you know, and it's, it's almost this, there's a wee bit of black, there's a wee bit of white and an awful lot of gray…"

An additional perceived barrier to patient involvement was the potential for meetings to be disrupted by individual patients pursuing their own agendas, instead of engaging on behalf of patient views more generally.

Staff felt that communication within and between various healthcare disciplines, hospitals and health centre settings was inadequate. This issue encompassed perceived deficiencies in team-working involving various disciplines such as social work as well as the multidisciplinary team. Shift-working, large sites and numbers of patients, and working between sites where conditions may be different appeared to cause a number of tensions for staff where patient involvement was concerned. Staff also described patient and family member reluctance to add to the workload of health specialists by raising concerns.

It is apparent that perceived barriers to patient involvement comprise a large part of the reluctance to become involved in this form of collaboration for health service improvement, particularly from staff viewpoints. However, the reasons for this may be the result of local or regional constraints. Engagement and involvement could be dissimilar in different centres, with diverse approaches used, depending on the care focus and the types or types of treatment or care provided to people affected by cancer.

In general, facilitators for patient involvement tended to relate to addressing the barriers considered above, entailing, for example, resources, suitable forums and education. Staff also perceived a need for clear role directions for patients and family members participating in patient involvement. In order to provide such transparent remits, staff felt that strong control of involvement groups was required; a system in place, such as some sort of contract development, was considered beneficial to patient involvement. Staff members were also clear that there were issues around the most appropriate method of involving and engaging patients in groups and that means of so doing were underdeveloped.

Management, facilitation skills and a strong group chair were perceived as necessary to the empowerment of patients and the regulation of group dynamics, although the phrases 'briefing patient…beforehand' and 'plainer sort of language' when dealing with patients in groups suggested a perception that group direction was the province of staff, rather than patient group members, a perception that did not change over time. It was also noted that basic communication skills were necessary to chair a patient involvement group.

Staff were limited in their responses when asked to anticipate what differences to involvement and engagement work would exist if all the barriers to it were removed. From the perspective of service change and patient feedback, issues other than resources were involved:

> *'… it's getting the balance... patients don't probably, although they want to be asked they don't want to be constantly asked "Do you want to change anything?"'*

4.4.5.4 Staff perspectives six months on; Post-intervention

Perceptions of patient involvement and engagement had altered a little over the six month period of the project. Participants put forward ideas on methods of involving patients and gaining patient experiences; these included shadowing a patient or providing a daily diary to enable patients to convey their experiences. Staff also indicated that a continually updated database of patients who would be interested in getting involved would be useful; it was also pointed out that relatives would be a good source of input. However, little change appeared to have occurred in relation to patient involvement in respect of in-house methods of working or the methods/requirements for involving patients in deciding on local priorities on which to work.

The ideology of involvement in service redesign was explicitly mentioned, but felt to be immature at the follow-up focus groups. However, patient representation was put forward as something that would be sought in any new working group that was set up. This was constructed with a caveat that there were a limited number of patients that could be called upon, and that barriers to participation, such as time and fitness, were still rife.

Staff largely continued to use the term 'involvement' to encompass the informal day-to-day communication with patients over relevant issues of care and the exchange of such information with other staff, and patient input into their own care.

Thus, in some respects views about involvement had adopted a more negative vein over the period of the study, for example, that focus group participation by patients was probably not beneficial:

> *'I'm not sure [a] focus group is the best place to have the patients… it wasn't the right forum I think for them to get any benefit from it…'*

However, patient representation on working groups was considered useful despite the perceived lack of suitable persons in the lung cancer group.

Time to involve patients persisted as a barrier leading to the belief that this unhelpfully promoted health service working style: *'services are reactive rather than proactive'.*

Barriers were still felt to be great, but staff recognised that engagement and involvement could be dissimilar in different areas and dependant upon the local situation. The tensions of being in a collaborative and clinical relationship with patients and family members was still reported to constitute a key barrier and staff reiterated their view that patient involvement and engagement would not progress without policy responses to positively transform research into service change.

Staff felt that inviting patients to undertake training might deter them from being involved, although patients were perceived to need technical advice and role clarification, in order that they could see the wider cancer perspective, contribute positively and understand what was expected of them. It was also pointed out that specific facilitation and interpersonal skills were required in patient involvement forums.

4.4.5.5 Staff views of the enabling Change Work

Information did not appear to have been exchanged with the three lung cancer teams working closely with the CCRC regarding the use of patient experiences to create change. However, staff did express interest in learning more about the data generated by the patient experience project with a view to informing their work, though they were unsure of what kind of data would be most useful for their needs or what could be extracted of relevance. Staff nevertheless perceived that such data would provide a good way of promoting issues dealing with specific cancers through regional advisory group and local cancer network meetings.

Staff indicated interest in receiving a summary report via regional cancer advisory groups on the Enabling Change work, as well as more general information presented in leaflets. They expressed interest in linking with the three intervention teams at study days, to learn more about the process of patient involvement, as well as the specific service changes made by the teams, with recommendations for their own practice. Participants also thought it was important to disseminate the findings from the Patient Experience part of the project, particularly given the role of patients in the work.

4.4.6 Non intervention sites: Chief Executives

4.4.6.1 Overview

Chief Executives felt that their Health Boards, despite challenges of physical and population geographies, and ongoing organisational change, were doing well in relation to the involvement agenda. At the six-month follow up interview little change was noted within these Health Board areas related to conceptualising involvement, or methods or outcomes of patient involvement. Chief Executives expressed interest in learning from the change work and the applications for their Health Board of data around patient experiences and patient involvement.

4.4.6.2 Chief Executive views of the meaning of involvement; Pre-intervention

Chief Executives expressed their belief that staff are committed to the ideology of asking people affected by cancer about their experiences. Chief Executives recognised the face validity of the need to understand patients' views of their treatment.

Chief Executives named key staff within the Health Board who led involvement at strategic and operational levels, on whom they relied for their information and updates on the progression of the PFPI agenda. The role of the Chief Executive was presented as developing strategic connections with Community Health Partnerships and Community Health and Care Partnerships, and ensuring adequate financial support for staffing senior level posts to drive involvement to 'give them a fighting chance of being able to do justice to the responsibilities'. Involvement was seen as well developed in terms of the numbers of people the Health Board were in touch with, citing several thousand people whose opinions could be canvassed through current systems. One Chief Executive noted that although they have increased their involvement work, they do not have specific targets for the number of activities which involve patients.

Chief Executives indicated similar methods of involvement to those identified by the intervention sites, focusing on their roles in patient participation in cancer forums, public consultations and Managed Clinical Networks. Chief Executives again had participated in public consultation forums regarding a wide range of issues. They indicated that the public were rarely asked to attend the hospital to have their views heard as there was a tendency for NHS staff to go out to meet people in their own communities.

There were considerable tensions in the way in which involvement was spoken about within the interviews; at times being described as Health Board-led consultation and at other times more public-led agendas. Overall, Chief Executives used the term 'involvement' loosely, and gave an impression that much involvement work was 'public involvement' rather than with 'patients'. Chief Executives clearly articulated use of the term 'involvement' as a way of managing public expectations around health service delivery and a way of communicating health service agenda to local citizens:

> *'Sometimes it is about getting messages across, you know "We are not shutting X Hospital or X Hospital, here's what we're doing" – it's different.'*

Such use of the term 'involvement' points to a limited uptake of the ideology behind the PFPI policy framework and the idea that getting the public on board with health service decision making is a sufficient method of working with citizens.

One Chief Executive discussed the balance of where ideas stemmed from, and the extent to which the public guide service changes, saying that some events are based around public ideas, and the Health Board designs:

> *'A programme around that, or if people haven't given us ideas we have ideas, then the people who, the people who come along to those events em, represent a much, much broader cross-section of opinion than the people who turn up at public meetings'.*

A flexible system which recognises the need to canvass the views of a wide range of public views was therefore integrated into Chief Executive perspectives.

Chief Executives did suggest that more value may come from more micro-level engagement and systematic methods of involving patients; however, they did not articulate how they would operationalise this in terms of implementation and support. They indicated a need to build relations with a range of patient groups, and how their involvement work had developed in recent years.

4.4.6.3 Chief Executive views on training and support needs; Pre-intervention

There was little discussion of the training and support needs for Chief Executives or other staff in involvement work, though communication skills were mentioned as a core proficiency for lead staff.

4.4.6.4 Chief Executive views on barriers to involvement; Pre-intervention

Barriers were felt to exist largely around the same areas identified by the intervention Chief Executives, such as difficulty in recruiting representative patients and one-off consultations rather than more developed relationships. Continuous involvement was presented as the ideal scenario.

Chief Executives also cited their political and geographical location as one of their challenges, which they felt put them at a disadvantage, compared to other sites. Additionally, public mistrust was cited as a barrier to full involvement and engagement, where there is suspicion at the activities of Health Boards. Chief Executives (in intervention and non-intervention sites) identified the media as adopting an unhelpful role in the NHS's reputation and public profile.

4.4.6.5 Chief Executive perspectives; Post-intervention

Following the intervention, there was little perceptible change in the methods, processes or barriers to involvement. However, some views were expressed which had not been recorded previously. One such example was a clear call for a sharper rationale from the Scottish Executive about how and when to involve patients and the public:

> *'Over the years it's been, you know, changes that are likely to create some kind of discussion or consultation in the community need to go through this process and you know, arguably it could reach a point where relatively minor changes get that kind of full consultative treatment'.*

A further idea not expressed elsewhere in the data bolsters this scepticism about driving forward the involvement agenda uncritically, for example, concerns about the extent of the work necessary and the Scottish Executive's role in overseeing and driving patient involvement:

> *'There are a number of support needs one of them the kind of support that we need from Scottish Executive level about what is a reasonable level of engagement to undertake…I really don't think at times the Scottish Executive has a full understanding of just what people have been through both at an emotional level and in a work level but also in terms of, you know, the sheer magnitude of the information that's had to be generated and the work that's had to be done to meet what they would consider to be the appropriate public involvement requirements'.*

This is premised on an understanding of involvement as an add-on, and something which is a problematised component to Health Board activity. It derives from a perception of

involvement as driven top-down by requirements from policy rather than an ideologically informed desire to engage with patients:

> *'Public involvement is a mantra, we will support the importance of public involvement but it's how the public involvement is done and the point at which it becomes so onerous that it becomes [an issue with] diminishing returns that I think we need to think carefully about'.*

Such views are important in documenting the expectations and tensions that Health Boards identify in implementing policies. It is of interest that this stands in marked contrast to the views of staff teams in intervention sites, where involvement was no longer constructed as onerous.

Cutting across this were positive views of developments within the regions, for example the priority given to developing links between the local patient forum and the Regional Cancer Advisory Group. This had been a particularly positive episode as the patients did not fall into the stereotyped role of demanding immediate service change but:

> *'A much more reflective piece about areas that had seen to work satisfactorily and some thoughts about how that network might develop over the course of the next year'.*

There was also an idea that staff were onboard with involvement, but the remaining barrier of time prevented more developed approaches:

> *'The challenge I think at times can be finding the capacity, I don't think there's a challenge in having to persuade staff that in the area of cancer care is vitally important to keep the views of cancer sufferers and other carers and other support organisations closely involved in this'.*

Chief Executives expressed the need to fully embed involvement in organisational structures and individuals' responsibilities as a key method of ensuring the agenda is taken forward by staff and integrated into roles, rather than deemed an add-on. The Managed Clinical Networks (MCNs) were cited as a key location for practitioners driving forward involvement and for it to be formally recognised and embedded in employment contracts:

'…trying to build it in where it makes sense as a core element within the work of either individual networks or the work of individual professional groups and so for example it has become an elemental part of the work or the managed clinical networks that there are patient interests and perspectives involved and represented there'.

One Chief Executive reported data on the number of patients/public who had expressed interest in involvement, suggesting a vast improvement in their networks compared to several years ago:

'If we need to go out and take soundings to get views about some of our big strategies then we've now got a much better developed and sustainable network and mechanism than I think we had em two, two and a half years ago'.

This Chief Executive reported that one impact of having large networks to draw from means that the Health Board feels justified in trying out a range of approaches to identify what works best. Examples of this range of methods however were not expressed at interview. There were also reported concerns about local facilities and underlining the commitment to involvement in shaping new services, but without detailed explanation of how patients would be involved:

'One of the projects we've got in place is to try improve that infrastructure and you know we would want to pursue that kind of development project with patient involvement as we do with all things…. we are incredibly, heavily involved with patients on a whole raft of fronts'.

4.4.6.6 Chief Executive views on training and support needs; Post-intervention

Communication skills were seen to be at the heart of staff's training/support needs related to involvement. This notion may have stemmed from Chief Executives' own experiences of garnering patient and public views at large public meetings, rather than a more nuanced approach that would come from detailed work on a specific project. Chief Executives, for example, identified learning how to ask open questions as a core part of training.

There was recognition of the high workloads of clinicians; taking staff out of their usual clinical roles, and finding money to support this, was thought to be a successful option which has worked well in the past and enabled them 'to capture patient involvement across the entire suite of clinical MCNs'. Supporting staff was, however, constructed as focused on re-directing clinical hours into leadership tasks that would take in involvement and change work. Chief Executives did not, however, divulge local plans for operationalising this in their Health Board area. The role of patients and eliciting and using patient experiences was felt to be the next step in this developmental work, which would be bolstered by the embedded nature of involvement in the clinical lead's job.

The issue of providing support to patients was also raised, for example financial support in reimbursing out of pocket expenses and carer sit-in services, which had not been expressed by Chief Executives in the intervention group. This was presented as something which was the minimum patients could expect and the most the Health Board was able to offer. Ex-gratia payments were recognised as being a particular goal, but which at the present time are unattainable.

4.4.6.7 Chief Executive views on future joint working

Chief Executives were *'very receptive'* to ideas and suggestions from other groups about how to involve patients more effectively. Practical results were reported as the most important learning from collaboration with the CCRC.
Chief Executives had, to this point, not been well informed about the Enabling Change work that was ongoing in the other sites, although they received an overview of the ongoing work at the three intervention sites. This indicates a lack of communication across Health Board areas and sharing of work and ideas. Responsibility for communication was placed with the CCRC by one Chief Executive:

> *'I need to consider the fact that I I've got little or no knowledge about that but the other aspect to it of course is perhaps to the extent to which you and your people have publicised the work that you've been doing'.*

They warmly welcomed the opportunity to learn about patients' experiences from CCRC and work on specific project ideas that they had identified from their Health Board areas.

Section 5:   KEY LEARNING, DISCUSSION, LIMITATIONS AND CONCLUSIONS

5.1 Introduction

This section reflects the main lessons learnt about the challenges of the Enabling Change work. It lays out a discussion of the key issues raised by the project, the limitations of the methodology and the recommendations for the health service to further improve patient involvement.

5.2 Key learning

Key learning is drawn from data gathered at the 'Sharing Experiences' workshop at the end of the project and the evaluation focus groups and interviews.

Overall, Enabling Change had been a positive experience which teams reported that they would be willing to extend to work on other priorities. Getting started quickly on a small scale and achieve some 'quick wins' were important components to making progress and team motivation.

Staff indicated that if the project was repeated, significantly more advance notice would be appropriate, in order to have clarification of the project at the beginning and to ensure that the project focus was maintained and that patients were seminal in setting the agenda. One participant remarked '…there wasn't a lot of time to know about what was happening before we actually got involved'. At least four weeks was suggested.

Organisational, administrative and other structural support 'at the coal face' was also seen as necessary at the beginning in order that responsibility for project involvement could be recognised, assigned and maintained, and the process of identifying local contacts

and local support could be accomplished within an agreed timeframe. There is a need to consider case-loads of clinical staff to ensure they are able to contribute to change plans whilst maintaining high clinical standards.

Staff identified that more 'buy-in' from relevant departments within their own areas, as well as community staff, would have aided patient recruitment and the rolling-out of change plans, as staff involved in the project had felt that they were left on their own. Such buy-in was felt to be particularly important further down the line when rolling out any changes accomplished through projects was likely to become a reality, with mechanisms in place for feeding outcomes back to patients. Despite this, staff reported that it was possible to trial service improvements with even one member of staff. It is, however, important to consider how further spread of the improvement will be implemented if there has only been limited engagement.

Communication with some sites was very challenging as there was little or no response to emails and telephone calls. Improving this in future projects will be important. However, site meetings functioned as valuable feedback sessions, particularly for the patients and family members involved. This offered a formal opportunity to review progress of the changes at each site.

Team meetings also provided a good forum for ideas for this and future projects. At the first site meeting two of the teams generated a long list of potential local priorities. Due to the timeline of the project some of these could not be tackled, but teams were interested in the opportunities to run projects on these 'meatier' issues.

Several key learning points were identified by the project teams for patient involvement in future service improvement work.

Staff indicated that they would have liked to have been more proactive in involving patients in a much more structured system within the Health Board area, with the local Patient and Public Involvement Officer employed to orchestrate patient engagement and to 'bring the patients on board' as numbers were felt to be too low. Participants recognised that they tended to focus on people who were more proactive and vocal, which was a poor reflection of the majority of the patients with lung cancer group, and proposed that

more representative group, with a good facilitator to encourage and empower patients in a group setting, would be advantageous.

Staff also felt that they should have been much more aware of other sources for patient input, such as Patient Forums. The inclusion of patients from wider groups such as Patient Forums should be done from the beginning of any new project, as well as patients who have been through the service where improvement work is being conducted. Allied to this, staff had learned that patient involvement was not as daunting as first believed.

Patients can find it difficult when they find themselves sitting across the table from clinicians who were responsible for their care. Thus, patient members should know which clinicians are going to be at meetings in advance; the patient and staff member should have the opportunity to meet prior to the first meeting to establish a different relationship as equal members of the team. Use of first names without titles in the meeting and introductions can also useful in this situation. This is part of the establishment of ground rules for the group which should include clear descriptions of everybody's roles and responsibilities.

People affected by cancer felt that it may be useful to have a 'buddy' to discuss their ideas with, prior to meetings.

Prior to the first meeting there should be a needs assessment to identify any training or support issues for example team working skills which will increase confidence, and reduce worries or fears of patients and family members. Staff should also take responsibility for ensuring that suitable mechanisms are in place to support patient involvement such as reimbursement of travel claims.

Involvement needs to take on board a range of methods of working in partnership with people affected by cancer. This should include looking at alternative ways of involving people who are not able to attend face to face meetings. There is strength in including people from established patient forums as well as patients known directly to the service which is under improvement

5.3 Discussion

The purpose of this section of the report is to address the key questions of the Enabling Change intervention and evaluation:

What methods of involvement are in use by practitioners involved in lung cancer care and people affected by lung cancer across five Health Boards in Scotland at the beginning and end of the Enabling Change project?

There are numerous perceived methods of involvement currently in use by practitioners involved in lung cancer care across the five Health Boards in Scotland that range from limited informal patient contact to the structured form of needs assessments and the complaints procedure. However, these tend to see patients as passive recipients of services rather than active partners in service planning.

How different is the process and content of patient involvement for the five clinical teams?

The five clinical teams contained elements of similarity prior to the intervention. Prior to the intervention, limited involvement work was reported in all but one Health Board (an intervention site which reported several methods not used elsewhere, for example involving people affected by cancer in funding bids). Similar levels and types of activities were reported by people affected by cancer and Chief Executives across all five sites.

However, following six months of collaborative and supported involvement in the Enabling Change work, the intervention teams demonstrated more sophisticated understandings of involvement.

The number of reported barriers to involvement was vast prior to the intervention, but received far less emphasis afterward for the Enabling Change teams. This indicates that when actively engaged in involvement work, there is more emphasis on learning and collaborative working than on the tensions.

The intervention groups of staff and people affected by cancer reported significant learning as an outcome of the work. In particular, identifying and addressing clinician/patient power relationships was a key area for growth for staff, patients and family members.

What impact has the change work had on staff, people affected by cancer and Chief Executive understandings of involvement?

The change work has impacted on clinicians, people affected by cancer and Chief Executive understandings of involvement to the extent that: several misconceptions have been removed regarding the definitions and scope of patient involvement. Perceptions of activities that constituted involvement have extended to include more active means of involving patients directly in service redesign. There was an improved awareness amongst staff of a range ways of accessing patient input, more knowledge of and confidence in the process and method of patient involvement; realisation of a staff/patient divide and means to improve it and a shift in ideology and commitment to the goals of involving patients in change initiatives.

How do the project teams at the intervention sites testing the Enabling Change model apply the accounts of patient and carer experiences to specific pieces of service improvement?

All project teams fulfilled the Enabling Change model requirements of using patient experience and patient involvement to drive service improvements in order to improve patient experience. The teams drew on the patient experience data presented by the CCRC team and their own personal experience when deciding on their local priorities. At each site the materials being developed were further modified based on patient and professional feedback until no further changes were suggested.

What outcomes are evidenced in the specific pieces of service improvement work that were informed by the experiences of patients and carers and developed while testing the Enabling Change model?

The project teams have run seven PDSA plans which resulted in seven outcomes: (i) two different versions of a patient-held record; (ii) a template for informing GPs of new patient diagnosis which is faxed to the surgery while the patient is still in the clinic to speed up communication between tertiary and primary care; (iii) a new information leaflet for patients receiving short-term radiotherapy; (iv) a new information leaflet for patients who have undergone thoracic surgery; and (v) a new physiotherapy information leaflet for patients who have undergone thoracic surgery.

These outcomes have been well received by patients and the professionals who have provided feedback during the PDSA test cycles. At each site the outcomes developed have been discussed at the lung cancer meetings of the cancer networks and been welcomed by other colleagues. There are plans to continue the implementation of these outcomes on a wider scale at each site. One example of planned further development and implementation is the holding of a stakeholder event at one site to discuss the patient-held record with a wider audience and discuss the future development for a Health Board-wide record.

The outcomes will also be shared between all five clinical sites that have taken part in the project to ensure that all sites will benefit from the learning and testing that has taken place during the project.

Is the Enabling Change model of transferring patient and carer experiences into action practical, effective and sustainable?

The success of testing the Enabling Change model at each of the intervention sites in this project suggested that it is a model which is practical and effective at creating service improvement based on patient experience. It is noted, however, that there were areas of key learning identified at each site which would facilitate future implementation of the model. Each category of respondent in the evaluation of the Enabling Change work indicated their views on how practical, effective and sustainable the work was. They identified five core components:

1. Small, discrete pieces of involvement and change work were found to be appropriate and manageable.
2. Clear definitions of patient involvement were perceived as necessary to ensure success implementation, alongside a contract outlining shared responsibilities.
3. A comprehensive strategy for 'hardwiring' patient involvement into the health service ethos was seen as obligatory, with involvement integrated into staff roles as formal recognition within employment contracts, rather than appended to already busy clinical roles. Additional top-down organisational structure and support, with greater buy-in at high level, which could include the use of existing change and modernisation teams would all facilitate greater impact of patient involvement in driving forward service change.

4. There is a need for external support and evaluation of service improvement work. External support (provided by academic partners or the Scottish Health Council) to the project team provides additional motivation which makes a difference to the productivity and progress of the service improvement work. This also provides guaranteed support for the project teams who at times experienced creating change in isolation from the wider team.

5. Evaluation ensures that the impact of involving people affected by cancer is captured. This can then add to the evidence base of involvement work and provides space for reflection that changes to the service are for the better.

Only with this approach is change and involvement seen as truly sustainable. Ensuring that the models used are practical, effective and sustainable requires that structured and supportive collaborative working, with formal, scheduled, feedback is circulated. Sustainability needs to be addressed through resources and specific, supported staff positions.

Is the Enabling Change model of drawing on patient and carer experiences transferable to areas outside of cancer care?

Transferability beyond cancer care was understood to be embedded in the utility of the Enabling Change model methodology (PDSA) which has been used in a wide range of organisation and areas of health care. Interventions can be rolled out across the cancer networks and into the full range of clinics and hospitals.

The tenets and learning on methods of patient involvement work has clear relevancy across cancer types and other diseases.

5.4 Limitations

Several limitations were identified in the Enabling Change and Evaluation strands of the work.

In the Evaluation it was difficult to recruit participants to focus groups in the non-intervention sites, particularly people affected by cancer. One site reported that they did not have a formal mechanism for noting patients' interests in involvement activities which

made recruitment difficult. Additionally, recruitment appeared to have been impaired by being a non-intervention site, where there was less motivation to participate purely in discussions which would not lead to direct change in non-intervention sites.

The work did not focus on people who find themselves socially excluded because of their ethnicity. Future work of this kind could encourage the involvement and engagement of people affected by cancer and people working in cancer care who represent the ethnic diversity of Scotland and the NHS. However, given the paucity of research with people affected by lung cancer, and the epidemiology of lung cancer patients as people from socially deprived backgrounds, we do consider this group to be marginalised on some axes of social difference.

One Chief Executive from an intervention site was unavailable for interview until the end of the project, which meant their views prior to the intervention were gathered alongside their reflections at the end of the work. This time-lag will have impacted on recall, and impaired the data corpus for monitoring the impact of the intervention.

Due to the delays in setting up the project at some of the intervention sites the time available to the teams for testing their PDSA plans was limited to three months, or less, rather than the six months which had been envisaged at the beginning of the project. The limited time period for testing change had an impact on the PDSA plans that some project teams chose to work on as they felt they needed to be realistic of what could be achieved in the three months. All project teams had identified larger projects which would take more time to test and implement which they would like the opportunity to develop in the future.

Another impact of the delays at some intervention sites was that the opportunities for teams to learn from each other and support each other through the test cycles was limited.

It had been anticipated that the PDSA change plans at each of the intervention sites would be based primarily on the patient experience data presented to the team. It became clear during the first meeting at the intervention sites that although the patient experience data did influence the identification of local priorities for service improvement, the experiences of the people affected by cancer in the project teams played a strong role too. The use of the engaged patients' experiences was to be expected and encouraged. The data presented set the context of the plans which were developed but the detail was driven more by the experience of the project teams.

In order to assess the sustainability of service improvements it would be beneficial to conduct a follow up evaluation 6 months after the intervention. The evaluation would identify how the ideas and practices have bedded down, such as the positive views of involvement, and to review the spread of the changes across the organisations or cancer networks. Further evaluation would document the longer term impact of the Enabling Change plans on people affected by cancer and service systems.

Implementing and testing the PDSA change model presented opportunity costs. Other models of change were reviewed, but it was felt expedient to apply the PDSA method, since it was already known within the NHS.

5.5 Conclusions and Recommendations

The Enabling Change work and the Evaluation focused on involvement as a core component of current health care policy.

The following recommendations stem from the data from the formative and process evaluations. The recommendations connect with key health care policy, notably Patient Focus and Public Involvement (Scottish Executive, 2001), Delivering for Health (Scottish Executive, 2005a), A National Framework for Service Change (Scottish Executive, 2005b), and the Draft Core Standards Cancer Services (NHS QIS 2007).

5.5.1 Conceptualising Involvement

A striking feature evidenced in the evaluation of Enabling Change was a need for conceptual distinctions to be drawn between public involvement and other communications with patients and the public. The focus groups and interviews indicate a need for greater clarity about what constitutes involvement and how this is different from public meetings that are used as information giving exercises. The potential for harm to the involvement agenda in the long run may be the public's refusal to take part in involvement initiatives, believing the decisions are predetermined prior to the public meetings. People affected by cancer already identify that their role often feels like part of a tick-box exercise.

Focusing on patient complaints is problematic, and needs distinguishing from involvement. While complaints place control with the patient, reliance on this feeds into narrow fields of

improvements, rather than more lateral thinking about service development. Moving away from complaints and public meetings as communication exercise means adopting the position in Delivering for Health and the National Framework for Service Change (Scottish Executive 2005a,b), of seeing patients as partners in service planning. There is a need to increase the ability of Health Boards to seek out views, addressing the call in Delivering for Health to give the public 'a greater say in the way their NHS is run' and 'redesigning services around the needs of patients' (Scottish Executive, 2005a, p. vi; p2). This indicates a need to involve patients and the public before key decisions have been made, particularly in identifying specific targets for involvement.

Staff and people affected by cancer associated involvement primarily with ideas of patient involvement in their own care, or sitting on committees. These roles reflect a restricted uptake of the levels of involvement indicated in the PFPI strategy (Scottish Executive, 2001). Improving quality of care and involvement in service design were largely absent from pre-intervention and non-intervention discussions. A further distinction in how people respond to involvement was demonstrated by staff and Chief Executives who tended to equate involvement activity solely with the public and patients; the role of family members was relatively rarely mentioned prior to interventions, but was appreciated post-intervention by staff teams.

Recommendation 1: NHS Quality Improvement Scotland (NHS QIS) and NES should consider developing guidelines to enhance conceptual clarity in formulating 'involvement', and ensure that 'consultation' 'complaints' and 'communication' are presented as separate to 'involvement'.

5.5.2 The Context of Involvement

Chief Executives referred to the challenging and disadvantageous nature of their political and geographical locations, suggesting that the healthcare system is perceived as regionally heterogeneous. National rolling out of the methods and (flexibly adopted) change plans across Scotland will enable national audits of feedback from people affected by cancer and bolster claims to transferability of the change model. This will complement the call for audit data to support quality improvement (NHS QIS, 2007).

External support for involvement was deemed critical. Evidence from staff groups at the intervention sites indicated that they felt encouraged, supported and motivated by their

relationship with the CCRC. Surveillance goal achievements should be integrated and extended in systems such as the Scottish Health council and health board targets, ensuring accountability to people using the health service. Setting and achieving targets will contribute to the agenda of underpinning involvement within NHS Scotland. By bolstering NHS staff expertise there is the potential to further embed involvement. PFPI leads could hold a key role in providing support to people involved in cancer care and people affected by cancer.

Little learning from the Enabling Change teams had filtered through to the Chief Executives and non-intervention site staff/people affected by cancer. Knowledge transfer and sharing good practice at these levels was therefore not adequately developed. Addressing this is core to facilitating good practice and innovation.

Recommendation 2: The change work conducted by the intervention sites should be used as evidence for year-on-year growth in the quantity and specialism of involvement activities.

Recommendation 3: The Scottish Health Council's role as an objective surveyor of involvement should be extended. Future involvement work should promote access to external collaborators who can perform joint roles of facilitating and monitoring the involvement work.

Recommendation 4: Uniform use of change plans and methods across Scotland will ensure that implementation can be compared and audited nationally.

Recommendation 5: Involvement of people affected by cancer in change work should include outcome measures, including quality/impact as well as frequency and type of involvement, in order that accountability to service users and policy makers may be demonstrated.

Recommendation 6: Internal communication should be improved to ensure that Chief Executives are aware of collaborative initiatives, particularly if they have previously signed-up to the work and offered their support.

5.5.3 Implementing Involvement

Difficulties in viewing involvement as an achievable, not as an onerous, activity points to the power of learning through engagement in change and involvement work. This indicates a need for communication about the nature and impact of the work for all Scottish Health Boards. Additionally, taking on board a reconceptualisation of involvement (as indicated in recommendation 1) will facilitate greater interest and uptake of involvement.

Chief Executives indicate the transferability of the change models and the individual change plans. It is recommended therefore that there is a focus for NHS staff on capacity building and skill development to ensure optimum uptake.

Training of staff is a critical area for development, and was raised by all stakeholders in the intervention sites. It is important that staff are supported in a range of ways to involve patients and carers, to meet policy requirements in influencing decision making around service change (Scottish Executive, 2005b).

Staff felt that the independence of the person leading patient and public involvement was a strong facilitator of patient involvement. Chief Executives and staff spoke of the need to integrate involvement into regular duties and roles, although this was often framed within the context of Managed Clinical Networks. This thereby excludes a vast range of practitioners and reinforces the view that involvement is the domain of few, not all, staff. Positive reinforcement of the benefits of collaborating with patients will encourage a less problem-focused understanding of involvement. Clinical staff need support to identify the benefits of undertaking involvement work, and be reassured that involving people affected by cancer in service design and delivery is not a burden.

Given the plethora of views on patient/public involvement in the health service, a new methodological approach should be put in place that ensures views from patients are communicated upwards to service providers and hierarchical power structures are challenged.

Structuring involvement requires specific attention. Staff and people affected by cancer reported the need for well-directed projects involving small steps which could be successively implemented. Clarity around role expectations, including financial and

time commitments was also deemed crucial, as uncertainty is potentially detrimental to recruitment for involvement. The location of involvement was also important to patients and family members, with a preference not to meet in hospitals which can hold unpleasant memories for them.

Staff expressed concerns regarding the physical and emotional impact of involvement on people affected by cancer. However, the extent of such impacts was not specified, nor were they expressly articulated by patients or family members.

The following recommendations should be adopted in partnership with the Scottish Health Council.

Recommendation 7: Improved communication processes via Managed Clinical Networks around the practice and practicalities of patient involvement in service redesign should be developed. The process and outcomes of change initiatives should routinely be shared in these forums.

Recommendation 8: The Scottish Health Council, Health Boards and local clinical teams should all ensure that outcomes and impact of involvement initiatives are adequately publicised.

Recommendation 9: Staff engaging in patient involvement should have access to education, focusing on communication and chairing skills.

Recommendation 10: Training sessions for people affected by cancer on involvement should be widely available.

Recommendation 11: Clear national guidelines should be developed to enable involvement work, to ensure that boundaries and expectations for all participants are established. The guidelines should include:

- » The involvement of people affected by cancer to influence the priorities for change and informing service planning by drawing on experiences.
- » The involvement of informal carers, as partners in care, to contribute to service planning.

» Change methods should be rolled-out across tumour types and across health specialities.

» Clear boundaries, role and responsibilities for patients, family members and professionals should be defined as far as possible at the outset of any project. A contract should be drawn up regarding expectations for each party with clear reference to power sharing.

» Patients, family members and the public should be involved early in decision making about service change, mirroring the methods used in the Enabling Change work.

» People affected by cancer should routinely be invited to take part in involvement work, and this could be suggested early in the patient's journey.

Recommendation 12: Involvement should take place in a setting close to where patients and family members live. Whenever possible, meetings should not be located in facilities where they have received treatment.

Recommendation 13: Consideration should be given to supportive measures to ensure that people affected by cancer are facilitated to be involved to their potential. This should be negotiated with participants throughout the involvement work, as their needs may change throughout.

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Appendix 1: Flowchart of the enabling change process at intervention sites and evaluation time points at non-intervention sites

Invitation and discussion with Chief Executives (Spring/Summer 06)

Meetings with senior staff (Aug 06)

Conduct separate pre-intervention focus groups with staff and with patients (Nov/Dec 06)

Conduct pre-intervention interview with Chief Executive (Nov/Dec 06)

1st site visit with Enabling Change project teams (Nov/Dec 06)

PDSA Training workshop (Jan 07)

Further data summaries on local priorities agreed for PDSA plans group to be sent out to project teams from CCRC

Further site visits with Enabling Change project teams (Dec/Feb/Mar 06)

Implementation phase at site by project teams (Jan-March 07)

'Sharing Experiences' workshop (April 07)

Conduct separate post-intervention focus groups with staff and with patients (April/May 07)

Conduct post-intervention interview with Chief Executive (April/May 07)

Final report submitted to Scottish Executive (August 07)

Support from CCRC team

Appendix 2:   Focus group schedule, pre-intervention

Slight changes in wording of the following questions were used for staff and people affected by cancer from intervention and non-intervention sites.

1. We are interested in patient and carer involvement and engagement. What do these terms mean to you?
   - » If unable to provide definitions or description of the concepts, ask if they know of any examples of involvement work.

2. What involvement and engagement work is going on currently here in the lung group?
   - » Gather details on level, methods used, any evaluation of impact/change, talking about involvement, culture/support for involvement work.
   - » If none in lung group ask about wider involvement work in the cancer services or Health Board.
   - » If no work known, are there any plans for future work e.g. in the next 6 months?

3. What do you think are the current barriers and facilitators to involvement/engagement work in the lung group/cancer services/Health Board area?
   - » How are you attempting to overcome them?

4. If you woke up tomorrow and all the barriers were gone,
   - » What would involvement/engagement work look like?
   - » What would you be doing differently?

5. Why have you chosen to be involved in this project with the CCRC?

6. What expectations do you have about this project, and what might be achieved?

Appendix 3: Focus group schedule, post-intervention

Slight changes in wording of the following questions were used for staff and people affected by cancer from intervention and non-intervention sites.

Overview

1.We are interested in patient and carer involvement and engagement.
What do these terms mean to you now?

2.In the last 6 months, do you think there have been any changes to the barriers to involvement/engagement work?

The Enabling Change work

3. To what extent were you able to use of the data from Phase 2 of the project when deciding on priorities? (e.g. communication, information, decision making, or during the presentation at the January event or the training day handouts) If not used – why not and what would have helped them use it more?

4. Do you feel that the final priorities chosen were based on patient and carer experiences? How? What other factors influenced your choices?

5. Has working with the CCRC resulted in you developing any changes to how you work with patients?

6.Do you now have ideas on how to gain patient experiences yourself?

7.What are your ideas now on how to involve patients?

8.How do you feel about the plans you have tested and changes you have made as part of the Enabling Change project with the CCRC?

9.Has the work you have been doing impacted on other staff outside of the project team? Has it changed their working practices in terms of involvement or engagement?

10. How might you go about rolling out this style of Patient Involvement across the network?

11. How might you roll out the specific work plans across the network?

12. At the workshop in Stirling in April, one of the intervention teams talked about training – but didn't say what this should be. What are your thoughts on the kind of training needed, and for whom, to do more involvement and engagement work?

13. What needs to be in place for a whole team buy-in to the process of involving patients in deciding on topics to work on? Did this happen in your team?

14. Would you be interested in using the full research data which is now available from this project? If so, what would the CCRC need to do to facilitate this?
  » How would it need to be presented?
  » How would we know what topic/data to pull out?
  » Could we send you ideas on what to work on from the key themes in the data?

Final reflections
15. Returning to your thoughts back in the autumn of 2006, what are your thoughts now on your expectations of the work project, and what might be achieved?

16. What are the key learning points for you as a result of this work?

Appendix 4: Interview schedule chief executives, pre-intervention

A: Background to involvement and engagement work with patients and the public

1.   What is your role as Chief Executive in relation to PFPI?
2.   What are the current barriers and difficulties in involvement/engagement work for your Health Board?
3.   Do you have any challenges within your Health Board that others do not?
4.   What does your Health Board need to be doing in the future around patient engagement and involvement?
5.   If you woke up tomorrow and all the barriers were gone,
a.   What would involvement/engagement work look like?
b.   What would you/your Health Board be doing differently?

B: Patient involvement in cancer care

6.   Do you have a patient involvement strategy for your Health Board?
7.   Where has your Health Board been most successful at involving patients, and carers in cancer care?
8.   How is your Health Board engaging with patients and carers around cancer care?
9.   What work has your Health Board done on gaining patient feedback from the whole community, thinking particularly around diversity – ethnicity, deprivation and so on?
10.   Targets drive a lot of service change. Do you have specific targets for cancer involvement/engagement work?
11.   You have mentioned some ways this Health Board is involving patients, what is your view on how sustainable these activities and methods are?
12.   What staff (at what level) are working on engagement/involvement at present?
13.   What training is offered to clinical staff and other support staff (e.g. receptionists) in patient engagement/involvement work?
14.   What structures are in place to support PFPI leads and cancer staff to support them in engagement/involvement work?
15.   Is your Health Board able to use a range of different methods of working with

people, e.g. seeing the patient in their community (e.g. a local hotel) rather than within hospitals?

C: Your relationship with the Cancer Care Research Centre

16. The Cancer Care Research Centre is engaged in a programme of work that maps out public, patient and carer experiences of cancer care, and then works with practitioners to use this data to inform service changes. What would your Health Board need from us to use the data we have (for example: receiving a diagnosis of lung cancer) to feed into practice?
17. Phase 3 of the Centre's work involves researchers from the Cancer Care Research Centre working with your Health Board staff and patients to effect change in lung cancer care? What are your hopes for this piece of work (only for Intervention Sites)
18. Are there any areas you would be interested in working with the CCRC on in the future?

Appendix 5: Interview schedule chief executives, post-intervention

Slight changes in wording of the following questions were used for Chief Executives from intervention and non-intervention sites.

A: The 'Enabling Change' work

1.   You should have received an update in the last week on what has been happening in the work with your lung cancer teams and the CCRC. What are your thoughts, as Chief Executive, to the Phase 3 work?
2.   Tell me about the feedback that have you had, about Phase 3.
3.   Were you surprised at anything that you heard about the Phase 3 work?
4.   Do you think the model of intervention was successful?
5.   Do you think the work with the Lung Cancer teams has helped develop models of involvement that can be transferred from cancer to other service areas?
6.   As far as you are aware, has this piece of work had an impact on involvement beyond the lung cancer clinicians? (e.g. other clinical areas)
7.   We are interested in the barriers to continuing this kind of work. What are your thoughts on where your Health Board stands on specific barriers now?
8.   Since we spoke last, do you think the context of involvement and engagement has changed in this Health Board?
9.   We are interested in the support needs of teams. Do you think the team had enough support from its organisation?
10.   What are your thoughts about Health Board support for:
    » Training
    » Wider support issues
11.   If the lung teams wanted to roll-out their work, how would your Health Board facilitate this?
12.   What is your view on how sustainable the activities and methods are that have been used in Phase 3?

B: Your relationship with the Cancer Care Research Centre

13.   In our conversation 6 months ago, we spoke about your hopes for working with
        CCRC in Phase 3. How well have your expectations and hopes been met?

14.   Are there any areas you would be interested in working with the CCRC on in the
        future?

Appendix 6: Site a plan 1: patient-held record

Site A ran one PDSA plan led by the Clinical Nurse Specialist.

Aim: To pilot a patient-held record that provides personal information about a patient's diagnosis and treatment plan, which will be updated as they progress through their journey.

Detail: The project team chose this as their priority as the Patient Experience project patient data and patient members of the project team expressing a clear need for patients to have more written, personal information throughout their journey. This also supported local plans to review and revise the current patient-held record to provide the best level of information for patients and to increase communication and information for emergency care professionals.

Number of test cycles: 2
Number of patients in test cycles: 7 patients with a new diagnosis of lung cancer
Number of professionals who have given feedback: 14 from health and social care professions

Feedback from patients
Five patients who came back to the clinic were asked for feedback on the patient-held record, two of these completed feedback forms. The other two patients became surgical patients so were not seen again by the Clinical Nurse Specialist during the test period of the project.

Patient feedback form questions for Site A
Patients were asked for feedback on the patient-held record, using a feedback form with the following questions:

1. When were you given the patient-held record?
2. Is the information on the patient-held record useful?
3. Would any other information have been useful for you?
4. If yes, what information?
5. Have you seen your GP since the last clinic appointment?

6. Did you show the patient-held record to your GP?
7. If Yes, were you happy with your GP's level of understanding of the information?
8. Would any other information have been useful for your GP?
9. If Yes, what information?
10. Would you like to have letters/written information at future appointments?
11. Do you think the patient-held record was given to you at the right time?
12. If No, when would you like to have been given it?
13. Do you think the patient-held record would be a helpful resource for other patients and health/social care staff?
14. Do you have any other comments about the patient-held record?

Summary of feedback from patients

Most patients had been given the patient-held record at their first appointment at the clinic, although one was given to a patient while on a ward visit. Although a couple of patients questioned whether the level of information was necessary, others commented that it was very useful when they were being seen between two hospitals in the area as they cannot access test results done at each others sites and having the information on the patient-held record meant that patients were not having unnecessary repeat tests performed. Patients did not list any other information that would have been useful.

One patient had seen their GP and shown them the patient-held record but they reported that the GP did not acknowledge the recent diagnosis. Two patients said that they would like to have written information at their future appointments updating their patient-held record. Patients were happy with the timing of being given the patient-held record. Patients thought that the patient-held record would be a helpful resource.

All patients gave very positive feedback about the use of the patient-held record. The main comment for improvement was to consider the use of language as one patient felt that it was too much to have written *'not curative'* on their patient-held record even if they had been told this by the Consultant or Nurse. One patient reported

 'I found it very useful and beneficial and [my] daughter-in-law who is a District Nurse was very impressed.'

Feedback from health and social care professionals

The project team had sought feedback from GPs and District Nurses in the first instance. The team found it difficult to gain feedback from GPs and broadened the feedback group to include other allied health and social professionals who may come into contact with this patient group. The project team sent them a copy of the patient-held record and a feedback form to complete with their comments. Responses were received from 14 professionals: 4 Physiotherapists, 2 Social Workers, 2 Occupational Therapists, 3 District Nurses, 2 Speech and Language Therapist, and 1 Dietician.

Professional feedback form questions for Site A

Professionals were asked for feedback on the patient-held record using a feedback form with the following questions:

Have you seen the patient-held record?
Yes=10, No=2

Were you shown it by…Patient=2, Project team member=9, Other=3

Did you think the information was useful?
Yes= 2, No=0

Is there any other information that would have been useful for you?
 Yes=6, No=4

If Yes, what information? (see additional comments boxes below)

Would you be happy to update any relevant sections on the patient-held record?
Yes=11, No=0

Do you think the patient-held record will help improve communication between professionals about the care/treatment a patient is receiving?
Yes=11,No=0

Do you think the patient-held record would be a helpful resource for other patients groups and health/social care staff?
Yes=10, No=0

Do you have any other comments about the patient-held record?
Yes=4, No=5

Summary of feedback from professionals

The professional feedback about the pilot patient-held record was very positive and would improve communication, with many reporting that they would be happy to update the record through their contact with patients. On the whole it was thought to be 'A simplistic and easy to follow record. All the initially required information is there'. District Nurses who saw patients at home have also commented that the more detailed information available on the record has helped them when talking to patients in their own homes.

Professionals made several suggestions for improvements to the current design and text of the form which are presented below.

Improvements for current design

Some of the suggestions/comments relate to sections that the professionals would complete:

> ***'Social work is not an AHP, suggest heading of Multi-Professional Referrals'***
> ***'It is very medically designed, suggest Your address, Your Dr and nurse details'***
> ***'Addition of Your [patient] goals (to be discussed with the team)'***
> ***'Call it a notes page rather progress notes'***
> ***'In A3 booklet form would be neater and travel better'***
> ***'I think anyone completing it must sign, print name, profession and date'***

Professionals also made several suggestions for additional improvements that could be further developed which are presented below. Most of these suggestions relate to concerns on how patients would find using the form. Some of these issues were not raised by the

patients in the pilot and will need to be explored further with other patients to see if they share the concerns prior to any further changes to the patient-held record.

Issues to be considered by patients

Other comments raise issues to be explored further with patients:

> *'The diagnosis section needs to be clearer for patients'*
> *'Would the patient understand the abbreviations used under diagnosis?'*
> *'The form perhaps had too much detail for the patient – particularly staging at bottom of page'*
> *'Concerned that although patients will have been told aim of treatment it may be too much to see it in 'black and white''*
> *'Query if diagnosis information is 'patient friendly''*

Professionals also made several suggestions for further development of the form by including additional information which are presented in below.

Examples of comments for further development of the form

Some professionals provided comments on how the forms could be further developed and suggestions of other information which may be useful to include:

> *'Depending if record is ongoing, maybe having additional forms which can be added i.e. end of life wishes, i.e. home, hospice'*
> *'Space for other relevant diagnoses'*
> *'Space for other team members' details'*
> *'Named AHP contact and is treatment continuing and have they been seen and discharged'*
> *'More about the person e.g. any allergies/sensitivities'*
> *'Home circumstances e.g. alone, with family etc'*
> *'Senses: sight, hearing, speech'*
> *'Medications'*
> *"Section for care services'*
> *'Consider including a section for PMH (i.e. that affects ADL, mobility also)'*

Future implementation plans

Initially the team plan to disseminate information about the pilot to other professionals working in the services for people with lung cancer to conduct a test of wider implementation, most likely involving the ward staff.

The current duplication of information on the different records used across Site A is an issue to be reviewed in any future implementation of the patient-held record. Given the positive feedback from patients and professionals the Chief Executive of the Health Board has supported the organisation in hosting a stakeholder event with people affected by cancer and all relevant professionals in September 2007 to review the different forms currently being used and the findings of this Phase 3 project to finalise the development a patient-held record that will meet the needs of those who will use it. The finalised patient-record will then be tested and lead to full implementation in the Health Board.

Resources

Depending on the outcome of the stakeholder event in September 2007 there may be resource issues for the full implementation of the patient-held record, however, this will need to be considered in light of the current cost of producing the various forms used. A review of any resource implications for the final development and implementation will be considered as part of the stakeholder event.

Appendix 7:   Site B Plan 1: Improving communication between hospital clinic and GPs

This plan was led by the Consultant Respiratory Physician with support from Clinical Nurse Specialists.

Aim: To pilot faxing a letter to GPs of probable new lung cancer patients, to improve the speed of communication so that GPs are informed. The aim is to assess any impact this may have on patient care. The letter will be faxed at the patient's first clinic appointment.

Detail: The project team chose this as their priority as the Patient Experience project patient data had clearly identified that patients feel there is a lack of support and linking in with GPs once they have a diagnosis of cancer and are being supported by hospital services. This experience was recognised by the Respiratory Consultant who had a clear desire to pilot a method of speeding up communication with GPs.

Number of test cycles: 2 cycles without change to letter template
Number of patients in test cycles: 6 patients, feedback from 5
Number of professionals who have given feedback: 6 GPs, feedback from 4

Feedback from patients

Five patients who came back to the clinic were asked for feedback to identify whether they had seen their GP since the last clinic appointment, to explore whether the fax had improved their experience of seeing the GP and to identify whether the patient had done anything with the copy of the letter given to them in their first clinic appointment.

Patient feedback form questions for Plan 1 at Site B

Patients were asked for feedback on the faxed letter using a feedback from with the follow questions:

   » Did you give the letter to your GP surgery?
   » If Yes, who did you give the letter to?

- » Have you seen the GP since last clinic appointment?
- » If Yes, were you happy with the GP's level of understanding?
- » Would any other information have been useful in the letter?
- » If Yes, what information?
- » Would you like to have letters/written information at future appointments?

Summary of feedback from patients

All the patients had given the letter to the receptionist at their GP practice. Only 3 patients had seen their GP since their last clinic appointment but all were happy with their GP's level of understanding. There were no suggestions made about any other information that would have been useful but all patients said they would like to have letters or written information at their future appointments.

Feedback from General Practitioners

The Clinical Nurse Specialists contacted GPs to ask for feedback on the faxed letter to see how it had been received and if there were any other comments or suggestions they had to improve the letter template. The nurses were able to contact four of the GPs for feedback.

Professional feedback form questions for Plan 1 at Site B

The GPs were asked for feedback on the faxed letter using a feedback form with the following questions:

- » Did the GP receive the letter?
- » How did the GP receive the letter?
- » Was the letter useful?
- » Would any other information have been useful?
- » If Yes, what information?
- » Would the GP like to receive any further faxes?
- » If Yes when?

Summary of GP feedback

All four of the GPs had received the letter either through the fax or by both the fax and the patients. Three reported that the letter was useful and that they would like to receive further faxes when there was any further information such as treatment decisions. There were no suggestions made for any other information that would have been useful. The only comment for any change was from one GP who queried the use of an abbreviation on the form for an unfamiliar test and requested that no abbreviations or acronyms were used, 'What is EBUS – explain and don't use abbreviations.'

Summary of feedback for Plan 1 at Site B

The project team felt that the pilot letter had been well received by GPs and received positive feedback from patients. Additional comments provided by the team include patients reporting that they felt their GPs understood more about their condition and that in some cases the GP had made contact with the patient after receiving the fax. There have been no changes to the letter template although the Consultant now avoids using any abbreviations or acronyms which may not be recognised in Primary Care.

Future implementation plans

The project team have spoken about this pilot at their Cancer Network meeting for lung cancer professionals and are currently talking with colleagues to roll out use of the letter template across the Health Board. An additional cycle will be used to test the use of the letter to confirm a non-diagnosis with GPs as well as confirming a diagnosis.

Resources

The project team have been using a fax machine in the clinic of another speciality as they do not have access to one in the outreach lung clinic which takes place in another unit. This has implications for the staff time as the nurses need to go to the other clinic while the patient is still in clinic to use the fax machine and then return the letter to the patient before they leave the clinic. Additional resources such as a fax machine or a photocopier or a printer would reduce the time needed as a copy could be made of the letter in the clinic and then all new patient faxes could be faxed to the GPs at the end of clinic, reducing

the staff trips to the other clinic and providing an extra copy of the letter to go into the patient's notes. A basic fax machine with copying facilities costs approximately £50. If the faxed letter is to be implemented across other lung clinics who see new patients, additional resources may be required, depending on the equipment set up of the clinic.

Appendix 8:   Site b plan 2: advice leaflet for patients after lung resection

This plan was led by a Cardio-thoracic Surgeon.

Aim: To develop and assess an advice leaflet for patients after lung resection. The leaflet will be given to patients with a feedback questionnaire immediately before discharge and then asked again for feedback at their clinic follow up appointment in six weeks.

Detail: The project team chose this as their priority as several of the patient members of the project team felt that the information for patients after surgery could be improved. This priority linked strongly with the Patient Experience project data where patients have clearly stated the need for clear, concise information throughout their journey. Due to this being identified as a priority the project team lead contacted a Cardio-thoracic surgeon who was developing an information leaflet and the project team became involved in its development and testing.

Number of test cycles: 2 cycles completed without change to leaflet

Number of patients in test cycles: 7 patients

Number of professionals who have given feedback: Project team and other colleagues on the cardio-thoracic team

Feedback from patients

Patients were given the advice leaflet and a short feedback questionnaire prior to being discharged from the hospital. Across the two cycles seven patients provided feedback.

Patient feedback form questions for Plan 2 at Site B

Patients were for feedback on the advice leaflet using a feedback form with the following questions:

1) Was the advice booklet given at the appropriate time?   Yes/No
2) Did you find the content easy to understand?   Yes/No
3) If no, how could we make it easier to understand?

4) Was the information given, relevant to you?   Yes/No

5) Any other comments?

The seven patients were very positive about the leaflet in all of the immediate questionnaires with patients reporting that the leaflets were 'very useful' and that the length of the leaflet was 'just right'. Two patients reported that they would have liked to see the leaflet before attending for staging. Some minor changes were suggested in the physiotherapy section but as this will be a separate leaflet these have been passed onto the physiotherapist. There have been no changes to the post-surgical advice leaflet.

Feedback from professionals

The feedback from professionals was very positive and lead to only minor changes to the leaflet during the test cycle.

Future implementation plans

No updates have been received since the middle of the project but the wider project team believe the leaflet has been presented and spoken about at the Cancer Network lung meeting, and been placed on their website for use by any other colleagues in the network.

Resources

The only identified resource for this plan is the printing cost of the leaflet which is expected to be no more than 1 pence per leaflet as it can be printed internally.

Appendix 9:   Site b plan 3: physiotherapy advice leaflet for post-operative patients

This plan was led by the Physiotherapist.

Aim: To develop and assess a physiotherapy advice leaflet for post-operative thoracic patients

Detail: Like the previous advice leaflet plan, the project team chose this as one of their priorities as several of the patient members of the project team felt that the information for patients after surgery could be improved. This priority linked strongly with the Patient Experience project data where patients have clearly stated the need for clear, concise information throughout their journey. Due to this being identified as a priority the project team lead contacted a Physiotherapist who was developing an information leaflet and the project team became involved in its development and testing. The pilot was led by the Physiotherapist.

Number of test cycles: 3 cycles with some changes

Number of patients in test cycles: 12

Number of professionals who have given feedback: Lung team and project team

Feedback

Patient feedback form questions for Plan 3 at Site B

Patients were asked for feedback on the advice leaflet using a feedback form with the following questions:

1) Was the advice booklet given at the appropriate time?   Yes/No

2) Did you find the content easy to understand?   Yes/No

3) If no, how could we make it easier to understand?

4) Was the information given, relevant to you?   Yes/No

5) Any other comments? [no information was submitted on the details of the feedback received for these forms]

Feedback from professionals

The project team and wider physiotherapy and cardio-thoracic teams have commented on the leaflet. The feedback received was very positive resulting in only minor changes for the information during the test cycles.

Summary of feedback

1st cycle: The advice leaflet was initially tested with 2 patients and the lung team. The feedback was very positive, saying the booklet was 'excellent' with appropriate advice. Some changes were made to the booklet such as making a larger print version available and adding a diagram of lungs to assist explanation.

2nd cycle: Ten copies of the revised second booklet were then made and given out with a feedback questionnaire. Some additional minor changes were suggested.

3rd cycle: The team produced a third version of the booklet and no further changes were suggested.

The project team report that overall the booklet has been very well received by patients with positive and constructive feedback. .

Future implementation plans

No updates have been received since the middle of the project but the wider project team believe the leaflet has been presented and spoken about at the Cancer Network lung meeting, and been placed on their website for use by any other colleagues in the network.

Resources

The only identified resource for this plan is the printing cost of the leaflet which is expected to be no more than 1 pence per leaflet as it can be printed internally.

Appendix 10: Site b plan 4: information leaflet for patients receiving post radical radiotherapy

This plan was led by the Clinical Nurse Specialist.

Aim: To develop and asses an information leaflet for patients receiving post radical radiotherapy to aid with the recovery of side effects from treatment.

Detail: The project team chose this as their priority as it was felt that this is an under-represented patient group and it was supported by the Patient Experience project data where patients have clearly stated the need for clear, concise information about support and symptoms, particularly when they have been discharged from hospital post-treatment.

Number of test cycles: 4 cycles completed

Number of patients in test cycles: 7 patients

Number of professionals who have given feedback: Project team, lung cancer team colleagues, Oncology Physiotherapist, Occupational Therapist

Feedback from patients

Feedback was receiving from four patients who were receiving post radical radiotherapy on the feedback forms.

Patient feedback form questions for Plan 4 at Site B

Patients were asked for feedback on the information leaflet using a feedback form with the following questions:

1) Do you think the booklet is helpful?
2) Did you find it easy to understand?
3) Is there any information that you would want added?
4) When would be the best time to receive the leaflet?
5) Please feel free to add any comments that you think may be helpful to us.

All four patients thought the booklet was helpful and easy to understand. All patients provided comment on when they would like to receive the leaflets. Their comments reflected different preferences to be given the leaflet at the beginning of treatment or at the end of treatment:

> *'I would like to have received this leaflet at the start of my radiotherapy treatment, which would have given me a greater insight, as what to expect regards after effects'.*

> *'Anytime'.*

> *'At the start of the treatment course'.*

> *'Near end of treatment'.*

Two patients circled that they would like other information added but provided no comment on what that would be. The written responses to question 5 did not make specific suggestions, rather they made general comments about the leaflets and the standard of care they received from the staff:

> *'I can't think of any other comments that might be helpful except keep up the star treatment that your patients receive, we couldn't ask for better. Thank you everyone.'*

> *'As a cancer sufferer it is a comfort to know that what you are experiencing is normal with the treatment and you are not alone.'*

> *'I feel that the staff at the Cancer Centre are the best of the best. I would like to advise others who are about to have treatment not to worry of be afraid to ask the staff for help or advice, as they will go more than out of their way to help. Thank you'.*

Another patient provided written feedback for the different sections of the leaflet.

Additional patient feedback for Plan 4 at Site B

'Fatigue – given the number of patients observed with mobility problems at the cancer centre, could other suggestions apart from walking be included?

Shortness of breath – 'Your nurse'? Clarification i.e. nurse specialist, district nurse, GP nurse or any one of!

Cough – as above

Skin changes – maybe worthwhile mentioning in the text that this is quite normal and will disappear in time (preferably, if possible, as in 2-3 weeks quoted under 'swallowing' [section]

Money & finances – 'nurse' as ii) and iii) above

Holidays & insurance – 'Nurse' thing again. Grammatically the word 'too' should perhaps be spelt 'to' i.e. A preposition as opposed to an adverb (Call me pernickety if you wish)

Clinic appointment – would it not be better if, after the final radiotherapy treatment, the patient was given an appointment card which would ensure the continuance of the previously seamless care/treatment programme.

General comment – it may be prudent to issue the leaflet on the second last session of treatment enabling the patient to digest the information and give them the opportunity to ask questions of the radiotherapy team at the final session.'

Feedback from professionals

The project team and wider lung services staff reviewed the leaflet and provided feedback on the content. Some minor changes were suggested to clarify or add to the information available.

Summary of feedback

The project team ran four test cycles of the leaflet. The patients were very positive about their care when originally asked about the leaflet so the team found it very useful to use the feedback form in future test cycles to structure their responses. There was some variation of when patients wanted to receive the leaflet, and the team have reported that they would want to go through it with patients to ensure that they understood the information and could ask any additional questions. It seems likely that the leaflet will be given out prior to the end of treatment. Changes made to the leaflet through the cycles have been minor amendments to spelling and grammar, and the addition of some more specific information around when to fly, and forms of exercise in addition to walking.

Future implementation plans

The leaflet has been presented and spoken about at the Cancer Network lung meeting, and been placed on their website for use by any other colleagues in the network. It will now be used with all new patients receiving radical radiotherapy who go through the Cancer Centre, which is expected to be approximately 50 patients a year.

Resources

The main resource identified for this plan is the cost of photocopying the leaflet. The leaflet is copied internally at a cost of approximately 1p per leaflet and the team predict that they will see 50 new patients in a year so the estimated cost of producing and distributing this leaflet to all new patients is 50 pence.

Appendix 11: Site C plan 1: patient-held record for pre-diagnosis stage of the patient journey

This plan was led by Clinical Nurse Specialist.

Aim: To develop and pilot a patient-held record that will be held by the patient and updated.

Detail: The project team chose this as their priority as the Patient Experience project patient data and patient members of the project team expressing a clear need for patients to have more written, personal information throughout the stages of their journey.

Number of test cycles: 3 cycles with minor changes

Number of patients in test cycles: 15 patients

Number of professionals who have given feedback: Project team

Feedback from patients

During the three cycles 15 patients gave feedback on the pre-diagnosis patient-held record.

Patient feedback form questions for Site B

Patients were asked for feedback on the patient-held record in all cycles using a feedback form with the following questions:

1. What did you think was good about the leaflet?
2. Did you think there was any bad about the leaflet?
Is there anything that you would change?

Summary of patient feedback

1st cycle: Four patients gave feedback in the first cycle. The feedback from patients was generally very good and the changes made at the end of the first cycle were very minor.

2nd cycle: Four new patients took part in the second cycle, suggesting one minor change

of the title of one section of the form be changed from 'Summary of discussion' to 'Patient's understanding of discussion'.

3rd cycle: Seven new patients took part in the third cycle. No changes were suggested and the overall comments were very positive. Patients found the record useful, felt more in control, found it useful to look at after consultation, felt it was good to have a clear contact person identified, it was useful to show to other health professionals, and clear easy to find information. No negative comments were made at this stage.

Feedback received during project team meetings has included that the record was changed to an A5 size to make it fit more easily into a handbag. Patients have used the template in a proactive manner, continuing to bring their plastic folder to clinic which holds their record and other information they are given.

The feedback from the Clinical Nurse Specialist leading the plan has also highlighted that although the use of the template has changed the way she works and requires some additional time for each patient, it has led to a positive impact on the nurse-patient relationship as it supports relationship building with the patient and the continuity of care experienced by patients. Due to the success of this record the Clinical Nurse Specialist has developed a further template to use at the diagnosis stage of the patient journey.

Appendix 12: Site C plan 2: patient-held record for diagnosis stage of the patient journey

The pilot of the diagnosis record is led by the Clinical Nurse Specialist.

Aim: To continue the development of records for each stage of the patient journey, the team have developed and piloted a patient-held record for the diagnosis stage.

Number of test cycles: 2 cycles
Number of patients in test cycles: 10 patients
Number of professionals who have given feedback:

Feedback from patients

1st cycle: Four patients provided feedback in the first cycle. One minor change was made to the form to increase the size of the free text box for the patient to write any notes or questions.

2nd cycle: Six new patients provided feedback in the cycle. There were no changes suggested. Overall comments were very positive and similar to those received for the pre-diagnosis form.

Future implementation plans

The clinical nurse specialist has spoken about the pilot with colleagues at the lung group meeting and the other nurses are going to trial the pre-diagnosis and diagnosis forms with all new patients in their nurse-led clinics. Approaches are being made to other colleagues who see the patients, such as consultants, to seek if they will also update the forms during appointments where a CNS is not present.

The project team are also in discussion with the local patient forum to work together to develop the support information that would accompany the patient-held record to standardise the type and level of information that is provided to all patients.

Resources

There are approximately 320 patients diagnosed with lung cancer each year in this area and it is expected that 200 of these patients will receive the patient record. The resources required for this plan include a simple plastic folder and the printing of the templates at the pre-diagnosis and diagnosis stage of the patient journey. These costs are thought to be approximately £14.25.

Reader Information

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