Cancer Care
Research Centre
Linking reality with science

Evidence of Impact of the Cancer Care Research Centre's Developing Cancer Services: Patient and Carer Experiences Programme

Final Report

August 2007

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Table of Contents

EXECUTIVE SUMMARY

This document reports on the evaluation of the three year Developing Cancer Services: Patient and Carer Experiences Programme funded by the Scottish Executive Health Department. The research explored how patient experiences can be identified and utilised alongside patient engagement, 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 evaluation of the Developing Cancer Services: Patient and Carer Experiences Programme (referred to as 'the Programme') used a mixed-method approach, combining an impact file, interviews with key stakeholders (n=6) and a survey of contacts (n=104).

The results of the evaluation demonstrate that the Programme has fostered more positive views of involvement both for people affected by cancer and people involved in cancer care. Impact was demonstrated both in principles of involvement (in particular, feeling positive about involvement) as well as behaviours (such as using information and data from the Centre, discussing involvement with others and encouraging involvement activities).

The evidence from this evaluation identifies that significant work is required to support NHS implementation of the involvement agenda. For example, there was some discord between people affected by cancer and clinicians working in cancer care regarding the NHS's provision of training and involvement of more than one person in committees and groups.

Despite difficulties in implementing involvement within the NHS, the data provides clear signals that the Programme has been successful in driving forward the Patient Focus and Public Involvement agenda, connecting with patients, carers and clinicians.

The evaluation identified that people affected by cancer and people involved in cancer care feel that the Programme has changed the way people think about and act on ideas about involvement. Although stakeholders were unsure about the extent of the impact of the Programme in contributing to a culture change in involvement activities in Scottish cancer services, evidence from the survey suggests that this has been achieved.

Analysis and synthesis of the evaluation data indicates a number of areas for further work by the Cancer Care Research Centre, people involved in cancer care in Scotland and the Patient Focus and Public Involvement agenda.

Recommendations

The data indicated a dearth of involvement-friendly systems within the Scottish NHS, and that far from being fully embedded within health service systems, there was significant room for improvement. The majority of involvement activities reported by respondents indicates the use of techniques based on solitary patient representatives on committees and focus groups. Additionally, benchmarks such as adopting clear systems on travel expenses, involving more than one patient/carer at each meeting and providing training, which are considered fundamental requirements for involving patients and family members, have yet to be systematically instituted.

A number of core recommendations are indicated by this evaluation.

Recommendation 1: Clinicians, policy makers and other key stakeholders should be encouraged to move toward directly engaging with patients in steering change in cancer care services. This should involve increased engagement in service redesign, moving away from patient representatives on committees. Clear offers of training should be made for people affected by cancer, and core principles such as ensuring that out of pocket expenses are met should be adhered to.

Recommendation 2: CCRC or a similar organisation should take a lead role in disseminating key areas for best practice for involving patients. Further dissemination should be in the form of leaflets, newsletter articles, best practice articles on the appropriate websites or by signposting existing resources.

Recommendation 3: CCRC or a similar organisation should provide training for patients, family members and clinicians on engagement. This would provide support for clinicians and patients/family members to implement the positive effect of the Programme on their thinking about involvement, to changing how they go about involvement.

Recommendation 4: CCRC or a similar organisation, in collaboration with Managed Clinical Networks, should provide mechanisms for connecting people affected by cancer with clinicians to explore the use of patient experiences to improve cancer services. This could involve a mix of methods, including supplying patient experience data to clinicians, brokering relationships between people affected by cancer and clinicians, and providing support in developing collaborative working relationships.

Respondents indicated the desire for more involvement opportunities, which gives the Centre and similar organisations an opportunity to engage with a larger number of people affected by cancer or working in cancer care and drive forward the involvement agenda. Additionally, the evidence indicates that many of the Programme's contacts are people affected by cancer. To increase the reach and impact of the Programme further networks need to be established. This would also encourage the adoption of engagement ideas in new arenas.

Recommendation 5: The CCRC, or a similar organisation, should focus on joined-up working with other organisations (such as the cancer networks) to ensure collaborative working and prevent duplication of efforts. Taking a lead role with the cancer networks, and becoming a centralised resource of best practice in involvement would encourage further shared-learning across Scotland and opportunities for cross-fertilisation of techniques of involvement.

Recommendation 6: Clinical staff would benefit from specific targeted attention for linking with the Programme's methods and substantive findings, for example GPs and oncology consultants.

The impact evidence suggests that while the Programme has been successful in accessing 'hard to reach populations', contacts and collaborators are primarily associated with two of the four most prevalent cancers in the UK. This suggests scope to increase representation from the four most prevalent cancers and for rarer, but increasingly prevalent, cancers.

Recommendation 7: CCRC, and other similar organizations, should focus on developing contacts and networks with people with a wider range of cancer types including those which are most prevalent in the UK population, for example those anticipated to increase in prevalence.

The Centre demonstrates a strong track record for publishing, which was evidenced through the Impact File and interviews with key stakeholder. Programme staff have achieved considerable recognition in their presentations and publications in national and international forums.

Recommendation 8: Increasing the number of articles published in methodological, mainstream medical and social science journals would strengthen the reputation of the Programme in domains beyond cancer nursing.

The Programme has had positive media coverage; however a limited amount of this has been in the widest circulated newspapers or large features articles.

Recommendation 9: Further targeted media work should be conducted regarding the outcome of the Project, with particular emphasis on the high readership newspapers, focusing on the outcome of the Programme.

SUMMARY (PLAIN ENGLISH)

A three year piece of work was funded by the Scottish Executive Health Department called Developing Cancer Services: Patient and Carer Experiences. An evaluation was conducted to see how well the Cancer Care Research Centre had conducted this work, and how much impact it had on involving people with cancer in Scottish cancer services.

The evaluation used a range of ways to measure the impact of the work, including an 'impact file' (which included a list of academic publications, newspaper/ magazine/ radio articles about the work and letters to Centre staff), interviews with six key contacts and a questionnaire which was completed by 104 people.

Analysis of all the information showed that the Programme had been in touch with people affected by cancer and people working in cancer care across Scotland. The Centre had received a lot of positive feedback on the Programme of work and had results published in a range of academic journals, focusing mainly on nursing publications. Key contacts had very high expectations of the Programme, and said that the work had largely met these hopes.

The three year Programme of work was felt to have had a positive influence on how people working in the NHS think about involving people affected by cancer. The Programme also led to people doing more involvement work within the NHS.

There was felt to be room for improvement, for example: more emphasis should be placed on involving people with rarer cancer and cancers which are being diagnosed more often. There should also be more emphasis on involving people living in the Highlands and Borders. Newspapers should be encouraged to report on the Programme so that the public learns about people's experiences and involving patients in cancer care.

The evaluation points to some key recommendations, including a need for organisations, such as the Cancer Care Research Centre, to take on a role in helping people working in the NHS and people affected by cancer learn about the best ideas and ways of involving people.

Section 1: INTRODUCTION

1.1 Background

The Cancer Care Research Centre (CCRC) was established in October 2003 following considerable investment by the University of Stirling for academic posts in cancer care. This innovative development created a focus for patient and carer centred cancer care research, which is unparalleled elsewhere in Scotland or the UK. The aim of the CCRC is to facilitate the development of a platform for research activity that addresses Scottish Executive health priorities, including patient involvement and variations in service delivery, with particular focus on the complex needs of people with cancer and their carers. Additionally the CCRC aims to function as a national resource to ensure that Scotland leads patient focused cancer care research in the UK.

One core component of the Centre's work between 2004 and 2007 was the Developing Cancer Services: Patient and Carer Experiences Programme (referred to as 'the Programme'), funded by a grant from the Scottish Executive Health Department. This was research exploring 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).

- ***Phase 3*** - Enabling Change. The final piece of the work drew together the learning from phases 1 and 2, applying knowledge about understandings and experiences of cancer and applied patient involvement. Three lung cancer teams were involved in working collaboratively with the Centre and people affected by cancer to improve cancer services. An evaluation was conducted to assess the impact of this work (Knighting et al., 2007).

In 2006/7, the implementation of the Programme, was subjected to an evaluation to determine the extent to which it was having its desired impact on Scottish cancer care.

The evaluation was designed to gather data to scrutinise the influence and reach of the Programme. Demonstrating the impact of the Programme is crucial in the impact on clinical outcomes for people affected by cancer, future collaborations with clinical partners and understanding the Programme's reputation.

The evaluation employed a mixed-method design where evidence was collated from a number of different sources to identify a wide range of impacts. These methods are described in more detail in section 1.2.

1.2 Evaluation questions

The core evaluation questions were:

- In what ways has the Programme impacted on academic, practice, policy and public perceptions of cancer care?
- What formal and informal feedback has the CCRC had on its activities related to the Programme?

- What audiences has the Programme disseminated to?
- What contact have different organisations and individuals had with the CCRC?
- To what extent has the CCRC met the hopes and expectations of key policy stakeholders through the Programme?

This report sets out the methods, findings and recommendations stemming from the impact analysis, stakeholder interviews and survey of contacts, and presents short chapters focusing on the data corpus. A final section draws together recommendations from the analysis of the evaluation for the Centre, suggesting areas for growth and change.

1.3 Summary of methods

The evaluation of impact was conducted using four distinct methods that were combined to explore the overall influence of the Programme:

- An 'impact file' (the collation and analysis of data sources that demonstrate the impact of the work)
- Interviews with key stakeholders
- A survey of CCRC contacts
- The impact of the Enabling Change work (an intervention conducted in three lung cancer services)

The first three of these evaluation methods are presented in this report, while the impact of the Enabling Change work is available as a separate report (Knighting et al., 2007).

This study was conceptualised as a formative evaluation, an approach which enables a focus on improving and enhancing programmes (Themessl-Huber, Lasenbatt and Taylor, in press). This is in contrast to summative evaluation, which would judge overall effectiveness. The choice of evaluation styles was informed by three features: the purpose of evaluation, the stakeholders and the nature of the programme under evaluation (Pawson and Tilley, 1997).

The formative nature of the work ensures that the evaluation is focused on learning, allowing a process of reflecting upon and (thereby in the long-run) improvement of the programme

(Hansen, 2005). The formative evaluation describes and evidences the processes of how patient and carer experiences are used in context.

This approach facilitates the gathering of a variety of data about strengths and weaknesses, with the expectation that both will be found and that each can be used to inform an ongoing cycle of reflection and innovation. Formative evaluations typically aim to report to the work itself – thereby being accountable to the NHS clinicians and people affected by cancer who have engaged with the Centre through the Programme. The emphasis is on the on-going element of formative evaluation, rather than being outcome driven:

> 'Formative evaluations strengthen or improve the object being evaluated - they help form it by examining the delivery of the program or technology, the quality of its implementation, and the assessment of the organizational context, personnel, procedures, inputs, and so on.'
>
> *(Trochim, 2006).*

The evaluation draws on Pawson and Tilley's (1997) model of realistic evaluation, which identifies programme evaluation as a result of a complex interaction between the intervention and the context.

The overall method was based on a framework developed for the Centre by independent consultants from University of St Andrew's Research Unit for Research Utilisation (RURU, 2005). The St Andrew's consultant offered reflections on appropriate methods of collating data, informed by a sequence of interactions with Centre staff and stakeholders. The aim was to provide objective support in identifying the most appropriate methods to provide optimum information on the impact of the Programme.

The evaluation was primarily conducted by members of the CCRC team. The stakeholder interviews were conducted by a consultant external to the Centre who conducted the empirical work and analysis, to ensure anonymity of respondents.

Section 2: METHODS

2.1 Overview

The methods, analysis and limitations for each element of the evaluation are presented separately in this section.

2.2 The Impact File

The impact file was compiled by CCRC staff who were requested to contribute materials that demonstrate views of the Centre's work, with particular reference to the Programme. The file included outputs and impact evidence. The evidence is necessarily ad hoc, wide-ranging and non-systematic; as such the documents represent more subjective assessments of impact than the other methods. The data in this evaluation drew from the following sources:

- Newspaper articles citing CCRC work
- Correspondence received by Centre staff
- Other documents noting the Centre's work
- Publications by Centre staff
- Conference presentations by Centre staff
- Awards and qualifications of Centre staff

Impact evidence was gathered on a monthly basis from all Programme team members between October 2006 and the end of April 2007. Programme staff were also asked to contribute items retrospectively to generate as much data possible reflecting on the programme's impact, however, evidence of this kind is limited.

Following Scott's (1990) work on questioning documentary evidence, all sources were assessed on three levels, regarding their

- authenticity (how genuine the sources were)
- credibility (accuracy)
- representativeness (how typical the cases were)

In each instance care was taken to retrieve original documentation to ensure authenticity and credibility. Regarding representativeness, all instances of evidence within each category was collected as a method of ensuring that the data corpus was as wide as possible, with multiple sources being checked for public records of impact evidence.

Data sources were varied. The media file comprised articles published throughout the life of the Programme. The documents are considered 'non-reactive' sources which have arisen through print and broadcast mediums rather than through empirical research design (Bryman, 2004, p381).

Elements of the data are routinely collated through CCRC mechanisms, for example publications, media presence and conference attendance data. For completeness, and to ensure authenticity and representativeness, data was also cross-checked with other databases. For example, in addition to media articles placed in the impact file, a further search of LexisNexis (a web-based collection of databases containing the content of 176 UK newspapers) was conducted to ensure all print-press media sources were included.

Email feedback on the Centre's work was interpreted in a similar manner to other forms of correspondence (for example letters), though their limitation as a quicker medium of communication which is often based around personal and private issues rather than public records is acknowledged (McCulloch, 2004). Their likelihood of capturing rapid-response communications is similarly acknowledged, though there is no evidence to suggest that this offers lower quality data, or data which should be interpreted substantially differently.

Web sources provide less problematic evidence since the only impact data comes from a formal public record (for example, the BBC news website) providing authentic and credible sources of data rather than personal uploads such as Blogs.

2.2.1 Analysis

Analysis of the impact file documents was informed by the principles of content analysis (Weber, 1985). Media article analysis drew on principles of media analysis (Deacon, Pickering, Golding and Murdock, 1999; Bell and Garnet, 1998). The media analysis also draws on descriptive statistics to indicate the patterns of feedback on the Programme, as well as thematic analysis of the content of articles. Overall, the analysis focuses on both content (including constructions of cancer care and the CCRC) and audience (location of data and reach of the message).

Data is presented in anonymised formats, to adhere to copyright issues (with print press and broadcast media) and ethical concerns with regard to personal communications.

The majority of evidence refers to the Centre as a whole; where distinctions can be made between Programme work and other Centre activities this is indicated in the analysis. A further subdivision is offered with regard to publications where articles are indicated to be published by staff that do and do not directly contribute clearly to cancer care priorities, for example those pertaining directly to cancer care, cancer symptoms, experiences of cancer, involvement, or research methods and methodologies utilised by the Centre.

No hierarchy of validity of evidence is assumed in the data presented below.

2.2.2 Methodological limitations

The methods of collating impact file data were subject to several limitations. The formal period of data collection ran from October 2006 to April 2007, focusing on the final months of the Programme. This resulted in data outside of this period potentially not being contributed. This may have resulted in a skewed sample of data, with some staff contributing more information from the later part of the Programme. This allows for less interpretative analysis about the changing profile of the Centre and patient experiences work over the three year Programme.

Additionally, data deletion may potentially have led to more positive sources being identified for analysis. Not all members of staff contributed feedback and it is not known the proportion of data that was lost to deletion.

Representativeness may be compromised by staff not wishing to contribute items deemed to be negative feedback, although anonymity and confidentiality was assured. It is clear that with very few exceptions positive communications were the focus of communications deposited in the Impact File.

Data from the impact file is presented in sections 3-6.

2.3 Stakeholder views of the Cancer Care Research Centre

Interviews were conducted with key stakeholders of the CCRC, by a consultant independent of the CCRC, but familiar with aspects of the Programme.

The interview sample was a subset of people who had previously been interviewed by a different independent researcher at the beginning of 2005. The 2005 study formed the baseline for part of the evaluation, and involved interviews with eleven people who, by virtue of their role in cancer care, cancer policy or research were considered key stakeholders in the Programme. The 2005 sample included four members of the Centre's Steering Group, two members of the Research Advisory Group (RAG), one clinician, two policy makers and two people from the voluntary sector. The 2005 study asked respondents to identify their hopes for the Programme, focusing on impact, patient involvement, the use of patient experiences to drive change, and research outputs.

The 2007 study interviewed six of these key stakeholders again, focusing on whether their hopes for the Programme had been met. The respondent sub-sample included one member of the RAG, two members of the Centre's Steering Group, a clinician, a representative of a voluntary organisation and a funding agency representative. Two of the interviewees had personal experience of cancer.

Face to face interviews were conducted in March and April 2007. The interviews were audio-recorded, and written notes were taken simultaneously. The interview schedule was devised by the Centre, to identify stakeholder views of the extent to which the Programme had met their expectations, as expressed in the 2005 interviews. The interviews and analysis were conducted by an independent researcher, to ensure confidentiality and anonymity for the participants.

2.3.1 Analysis

Thematic and content analysis was conducted on the interviews by the independent consultant. Interview notes were supplemented by excerpts from the audio-recorded conversation. The analysis is presented within broad themes without identifying details of the speakers.

2.3.2 Methodological limitations

This round of stakeholder interviews elicited only six (rather than the original eleven) interviews, thereby restricting the range of views and opinions expressed about the Programme of work. However, there was not considerable diversity in the views expressed, and different categories of stakeholder opinions were canvassed to ensure the widest possible coverage of views.

Only three of the interviewees reported that they were familiar with all stages of the Programme; it was hypothesised that this would be similar across the larger sample interviewed in 2005. The three most familiar with the Programme were steering group members and the funding agency representative. Of the other three, two had been involved closely with the Programme at particular stages, but reported that their involvement had come to an end some time ago. One respondent expressed that since RAG meetings had become less frequent they felt 'a little out of touch' with the Centre's work.

Some interviewees had involvement in the work of the Centre beyond the Programme and at times their views were influenced by this other knowledge.

The change in research consultant collecting and analysing the data may also have adversely impacted on the data collected. A change in interviewing style and lack of relational-history with interviewees may have resulted in eliciting different responses.

Finally, as with the other methods of impact evaluation, this component of the study was conducted before the final phase of the work had ended. This thereby limited the ability of respondents to reflect fully on the entire Programme of work.

Data from the stakeholder interviews is presented in section 7.

2.4 Survey of Contacts, Collaborators, People affected by cancer and Stakeholders

A survey was designed to address the research questions regarding the impact of the Programme with contacts, collaborators, people affected by cancer and stakeholders in Scotland.

288 people were sent the survey either electronically (linked to a dedicated website, n=246) or via post (n=42). The survey was open to respondents from the beginning of February 2007 to the end of March 2007. A reminder was sent 10 days before the survey closed to all potential respondents. Respondents were assured anonymity in their responses.

The survey was piloted prior to administration, with someone affected by cancer and two clinicians working in cancer care. The piloting led to some minor amendments to the wording of questions and response categories.

The sample comprised people in touch with the CCRC as part of the Programme, drawn from contacts, collaborators, stakeholders and patients and carers. Each of these groups is further defined as follows:

a. Contacts: individuals who have been in touch with the CCRC about the Programme, who provided the Programme with information, or who received information about the Programme.
b. Collaborators: Individuals who with active involvement in facilitating the Programme work, and where there is an understanding about working together on a joint/common goal.
c. People affected by cancer: Individuals who attend meetings or have one-to-one contact with CCRC in their capacity as a patient or family member of someone affected by cancer.

d. Stakeholders: These are people who are involved strategically in the Programme. This included members of the steering group and Research Advisory Group.

CCRC databases were searched for individuals who fall under these definitions. The databases refer to work on all three phases of the work including: Phase 1: Public Involvement Project, Morbidity Database, Scoping Exercise; Phase 2: Patient Experiences work; Phase 3: Enabling Change work.

The survey sample was constructed with reference to the Data Protection Act, 1998, to ensure that its administration did not contravene the Act's provisions through the use of personal data (contact details) from these databases.

The following criteria were used for sampling:

a. Exclusion of contacts was centred on people who were involved in specific research-related or one-off engagement with the Centre, and who consequently had no expectation of ongoing contact, and had not given permission for their contact details to be used for this purpose. (See Schedule 1, part 1 of the Data Protection principles: Data Protection Act, 1998). Such use could be considered to breach the first and second Data Protection principles.
b. The person must reside/work in Scotland, with the exception of 'collaborators' who may reside within any country of the UK. (Further evaluation work will be conducted to take in UK and international contacts when the Centre is more mature).

Individuals excluded from this survey were:

a. Patients or carers who were only in touch with the Centre as research participants.
b. Contacts/collaborators who were only in touch with the Centre as research participants.
c. Former members of Centre staff on the Programme.

2.4.1 Analysis

Analysis was primarily conducted using descriptive statistics, indicating the basic features of the data by percentage responses to forced-choice categories. Where appropriate, inferential statistics in the form of chi squared tests were conducted on responses.

Content analysis of open-responses was informed by investigating the relationship between responses and respondent categories, for example people involved in cancer care or people affected by cancer. Where possible, responses from patients/family members and NHS practitioners are distinguished from each other in the analysis.

Some incomplete questionnaires were returned; partial responses have been included in the analysis where possible. Descriptive statistics in each table show the total number of respondents to individual questions, at times these add up to more than 100% as respondents could choose more than one answer, or had presented themselves as both person affected by cancer and someone involved in cancer care.

2.4.2 Methodological limitations

The survey achieved a 36% response rate. Although this response rate is regarded as respectable, it does indicate that many opinions about the Centre are not represented in the data.

This component of the evaluation elicited views prior to the end of the Programme, thereby not identifying all potential impacts of the work.

Data from the survey is presented in section 8.

2.5 Ethics

This piece of work was an evaluation of the Programme, and for the purposes of National Research Ethics Service clearance was not defined as research. Consequently it did not require formal ethical review. However, research staff adhered to professional ethical guidelines and conduct, referring to those laid out by the British Sociological Association, British Psychological Association and Nursing and Midwifery Council.

Section 3: EVIDENCE OF IMPACT: MEDIA COVERAGE

3.1 Summary of media coverage

42 items of media coverage were submitted to the impact file. The data indicate that a range of print, broadcast and new media were utilised in the study period. Of the 42 items, 29 (69%) were directly related to the Programme.

34 of the 42 articles were in newspapers, with cancer/nursing magazine accounting for a further five articles, and website coverage two articles. One radio interview was also noted.

The majority of print-press coverage was positive. Articles focused on the Centre's ongoing work in Scotland throughout 2004-7, in particular components of the Public Involvement work and the Advisory Groups.

Only one submission was framed in negative terms, though the article was not related to the work of the Centre but reported on health care policy, citing the Centre's Director as part of a working group on health reform which was criticised in the Scottish national press (The Herald, 2004).

3.1.1 Scope of media coverage

Reach of Publication	Total number of CCRC articles	Programme articles
Scotland-Wide	3	2
Scotland local	32	23
UK	2	1
International	5	3

Press coverage reached across Scotland, including the North East (n=16), Stirling (n=six), the Western Isles (n=four), Tayside (n=four) and Ayrshire (n=one). One article which appeared in the Scottish national press (The Herald) discussed health policy and the movement of care from hospitals to local services; the Centre's Director was noted as a member of the working group's advisory committee.

3.1.2 Readership of newspapers

Articles appeared in newspapers across Scotland:

Newspaper	No. of CCRC articles	Readership
Press & Journal	9	84,612
Stirling Observer	5	27,305
Stornoway Gazette	3	12,954
Dundee Evening Telegraph	2	25,545
Stirling News	2	36,254
Herald	1	83,077
Daily Record	1	503,077

The above table indicates uptake of stories in a high-readership newspaper (as defined in Scottish Executive, 2001), the Press & Journal. Scotland's highest readership paper (The Daily Record) only published one article about the Centre and, of the 34 newspaper articles in the data corpus, was the shortest publication (two paragraphs, with a total of 33 words). The highest circulation paper, Metro, published no articles on the Programme.

3.1.3 All media articles by year of publication

Analysis by year indicates a steady stream of press coverage:

Year of publication	Total no. of articles	Programme articles
2003	2	2
2004	14	12
2005	13	9
2006	10	6
2007	3	0

The data clearly indicates that the Programme has had the highest media profile of all the work ongoing at the Centre.

Lower numbers of published articles are apparent in 2003 (the Centre opened in October, thereby limiting the potential number of months of press-coverage) and 2007 (since the cut-off date for publication to be included in this evaluation was 30 April).

The peak of articles relating to the Programme was in 2004: its first full year of operation, with much coverage was elicited with the launch of the Programme. Articles during 2004 also included local calls for participation of the paper's readership in the Public Involvement work.

3.1.4 Breakdown of media content

Topic coved	No.of articles
Patient and Carer Advisory Groups	10
Programme funding	7
Public Involvement (Phase 1 of the Programme)	6
Other Programme articles	6
ASyMS© (mobile phone, symptom management study)	4
Highland Hospice study	4
Other	11

29 items of media coverage (69%) were directly related to the Programme. Of these, seven referred directly to the £1.5million award from the Scottish Executive Health Department. The majority of articles related to the Advisory Group work.

3.1.5 Use of ‘cancer’ or ‘cancer research’ in newspaper headlines

Headlines	No.of articles
Use of ‘cancer’ or ‘cancer research’	26
Use of ‘hospice’ in headline	5
Use of ‘cancer’ in secondary headline	1
Other headlines	3
No headline	1

Headlines are widely thought to have a significant impact on readers’ views of content (Bell and Garnet 1998). Newspaper articles were found to predominantly cite ‘cancer’ or ‘cancer research’ as a way of framing the work. The only clear alternate to this was the use of ‘hospice’ though this was used in a minority of instances. Further detailed textual analysis of the articles provides further insight into how the Centre is being positioned and constructed in the media and is presented in next section.

3.2 Analysis of content of articles

3.2.1 Textual analysis of newspaper articles [1]

» In the majority of articles, the construction of cancer is in line with the Centre’s expressed mission and strategy, indicating the necessity and appropriateness of centralising patient and carer views of cancer care.

» Quotations from CCRC staff are common in these articles, which describe in more detail the ethos of the research centre as based around understanding patients’ experiences of cancer care and cancer treatment.

» Quotations from people affected by cancer are rarer, with only three instances.

---

[1] Data is unavailable for the radio broadcast, and as such is not included in this analysis.

In each case speech was reported from people affected by cancer who liaise with the Centre's Advisory Groups.

- Notions of 'gathering views' and 'piloting' research were used in all but four newspaper articles.
- Although the ideology of cancer is generally consistent with that advocated by the Centre and the Programme, one article headline drew on the idea of cancer as 'trauma', and another constructed the idea of 'airing views'. These articles position cancer as a troubled and potentially sensitive topic.
- One article headline uses the term 'cancer research appeal' drawing on charity discourses. The first paragraph of the article however indicates this is an appeal for 'help' from people affected by cancer, rather than financial contributions.
- All newspaper items were based around press releases from the Centre, rather than articles on cancer care where journalists have contacted Centre staff to elicit expert opinion.
- Articles refer to Centre staff primarily as 'cancer experts' and 'researchers'; a minority refer to 'academics' and none refer to Centre staff as health care practitioners in their own right.
- The idea of collaborative working is identified in many articles, with explicit note made of other organisations who are liaising with the Centre, for example cancer charities and palliative care providers.
- The CCRC is specifically mentioned in 35 of the articles, with six instances referring only to the University of Stirling.
- Centre staff were often named in articles. This was primarily the Director (n=19), followed by the former Depute Director (n=four) and senior research fellows (n=five). Research assistants and other staff were named in six instances. Nine articles did not name any Centre member.

3.2.2 Page placement

This section refers only to the newspaper articles where full data is available (28 of 34 articles). Articles placed on the facing side of papers (1,3,5 and so on) are considered by newspaper layout designers to be more important and therefore deemed to have higher impact than those on the inside sheets (i.e. pages 2,4,6…).

- 12 articles were placed on the facing side of the paper, five of which appeared on page 3 and one appearing on page one.
- The article appearing on page one was celebrating the £1.5m grant from the Scottish Executive headlined: 'Major cash boost for cancer centre', and occupies an area of approximately a third of the front page. This was published in a local Scottish paper, with a readership of approximately 27,000.
- Data on 28 articles had preserved the location of the item on the page indicating that many were in prime (top and centre) positions on the page:
- 6 at the top of the page
- 4 in the centre of the page
- 8 in side columns
- 10 in the lower half of the page.

3.2.3 Images and photographs

14 articles have photographs or images accompanying them. Of these, nine were in newspapers, with the remaining in magazines and on a website.

The nine newspaper images were used in eight articles. The images were of:

- The Director, the Health Minister and the University Principal (a similar photograph is used in two newspapers)
- Centre staff (two articles with two named staff members, one with a secondee)
- Collaborators (Health Board Chief Executive; Conference delegates)
- The ASyMS© Handset
- Centre Steering Group member in receipt of an OBE.

Photographs in the newspapers are all indicated as purposefully produced images which were taken by journalists, rather than provided from library archives.

The magazines and other publications use photographs that predominantly (three of four times) show the CCRC Director. The remaining photograph is a library image of studious-looking nurses. This accompanies an article describing the need for qualitative data on patient experiences. Two items offer pictures which are not directly related to the Centre's work – with the website article (bbc.co.uk) using a library picture of a woman being screened for breast cancer. It depicts a clinical image, of the patient placed against a mammogram machine, with a female nurse in uniform instructing how to position herself. This contributes to the Centre's image as clinical and health-related, drawing on common discourses of cancer by using mammogram photographs to depict cancer care. A further image is used in the Herald article. This is a standard logo for the newspaper indicating that the article is part of 'The Herald Heath Debate' positioning the Centre as central to emerging debates in Scottish health care.

Section 4: EVIDENCE OF IMPACT: PUBLICATIONS AND CONFERENCE PAPERS

The following sections set out the publications and conference presentations made by CCRC staff between October 2003 and the end of April 2007.

Since many staff joined the Centre between those times and had published in previous posts, their contributions are included in the summary total. The breakdown of publications helps indicate the profile of Centre staff generally, as well as work directly relevant to cancer care practice and policy focusing on: cancer care, cancer symptoms, experiences of cancer and involvement. Papers referring to research methods and methodologies utilised by the Centre and Programme are also included in the breakdown of 'directly relevant' publications.

Publications from former team members are also included, since those documents represent work which draws on and contributes to the Programme's profile and impact.

4.1 Peer review publications

90 peer reviewed journal articles were published by Centre staff during the study's data capturing timeframe. 64 fit the definition of being directly related to the concerns of health care policy. 18 peer review papers are authored by staff who have subsequently ceased employment with the Centre.

The 64 articles directly relevant to health care practice and policy can be broken into several categories. The remaining papers are typically ones written by Centre staff before joining CCRC and are focused on areas not directly relevant to the Programme of work or cancer care practice and policy, for example on the substantive topic of dementia.

Focus of articles relevant to the CCRC Strategic Plan	Number of articles
Improving clinical practice	21
End of life care	9
Patient Experiences documentation	8
Methodology	8
Symptoms and symptom management	8
Older people	7
Patient involvement	3

Location of CCRC relevant publications	Number of articles
UK journals	17
International journals	46
Unknown	1

36 articles were published in journals with recognised impact factors (that is, a measure of the citations to science and social science journals giving an indicative score to the importance of the publication in the field). Impact factors were identified in June 2007, through ISI Web of Knowledge and via journal homepages.

Journal	Impact factor	No. of articles
British Medical Journal	7.038	3
Annals of Oncology	4.335	4
European Journal of Cancer	3.706	3
Journal of Clinical Epidemiology	2.440	1
Palliative Medicine	1.939	2
British Journal of General Practice	1.938	3
Health Education Research	1.623	1
Supportive Care in Cancer	1.590	2
Patient Education and Counselling	1.429	2
Journal of Advanced Nursing	1.342	1
Journal of Medical Ethics	1.312	1
European Journal of cancer Care	1.038	6
Health and Social Care in the Community	1.010	1
Cancer Nursing	0.965	1
Qualitative Health Research	0.938	2
International Journal of Nursing Studies	0.692	2
Scottish Medical Journal	0.531	1

Publications relevant to health care policy and practice appeared in journals related to nursing, medicine, cancer and research methods:

Discipline of journals	Number of articles
Oncology-specific	26
Nursing (not oncology)	10
Medical journal	10
Methodology	2
Other	16

Overall, 19 staff are included in the above statistics as authors of peer review publications (including eleven current and eight former members of staff). At present the Centre has 19 research staff, indicating that nearly half of those in current employment (58%) were not involved in authoring peer reviewed publications relevant to cancer care practice and policy.

4.2 Books and book chapters

CCRC staff have written the following books and book chapters between 2003-7:

Type of publication	Number	Topic
Single-authored books	1	Care relationships
Edited books	2	Cancer nursing Care relationships
Book chapters	5	Experiences of care Informal carers Older people & frailty Language & learning difficulty Research methods.

These eight contributions were written by three members of the CCRC team. None refer directly to the Programme, though many of their topics are connected with cancer care practice and policy around documenting and improving illness experiences.

4.3 Conference papers

Current members of CCRC staff have contributed to the following conferences between 2003-7 (data is unavailable for former CCRC employees):

- 49 conference papers were presented by CCRC staff
- 29 of these were international conferences; 20 were UK conferences
- 37 conference papers were relevant to the CCRC's strategic mission (22 international conferences;15 UK conferences)
- Of the 37 relevant to CCRC's strategic mission, 31 were cancer and palliative

care conferences. The remaining conference presentations were related to gerontology, the health service, social policy and evaluation methods.

Section 5: EVIDENCE OF IMPACT: AWARDS AND QUALIFICATIONS

Between October 2003 and May 2007 the following awards and qualifications were bestowed upon Centre staff and associates:

- » Oncology Nursing Society's 2007 Excellence in Care of the Older Adult with Cancer Award: awarded to CCRC Director. Noted for 'championing' older people and cancer.
- » Anna Reynvaan Memorial Award (2006) from the Amsterdam Medical Centre: awarded to CCRC Director
- » Charles Cully Medal Award by the Irish Cancer Society (2006): awarded to CCRC Director
- » PhD: one awarded to a CCRC research fellow, one thesis submitted by a CCRC research assistant
- » OBE: awarded to a member of the Centre's steering group

Section 6: EVIDENCE OF IMPACT: COMMUNICATIONS WITH THE CENTRE

6.1 Overview of communication impact

38 contributions to the impact file were made detailing communications with Centre staff. The majority of communications with the CCRC contained feedback from people affected by cancer who attend the advisory groups (n=15). Communications also came from funders (n=five), collaborators (n=four) and other contacts (n=14).
Eight pieces of correspondence were in the form of a letter or note to Centre staff, all other communications were via email.

Recorded feedback increased significantly during 2006, and the proportionate number of communications in 2007 (to close of data collection at the end of April) indicates a similarly high number of communications. The low number of communications in 2004 and 2005 is indicative of the retrospective nature of data collection.

Correspondence on the Centre's work by year

Correspondence on the Centre's work by year	Number
2004	2
2005	1
2006	24
2007	11

The majority of correspondence was related to the Programme:

Subject of correspondence	Number
The Programme	18
General	4
2006 Conference	9
Feedback from funders	4
Feedback from collaborators	3

The table below indicates the subjective content of correspondence. Most communications featured positive feedback, including praise for the Centre's progress in centralising patients' experiences in cancer care and reported satisfaction regarding the relationship between the Centre and the correspondent. Direct negative feedback was received in one communication relating to inappropriate timing of meetings where patients were invited to attend.

Mixed feedback and suggestions referred to requests for prioritising specific areas of cancer care.

Subjective content of correspondence	Number
Positive	33
Negative	1
Suggestions	2
Mixed	1
Offer of help	1

6.2 Communications from people affected by cancer

15 communications submitted to the Impact File were written by patients and family members. Each of the following was sent to the Centre without prior prompt for feedback. Evidence is therefore not taken from research interactions, such as patient interviews as part of the Programme unless participants had specifically sent correspondence detailing this.

Feedback indicates the very positive way in which people affected by cancer experience the relationship they have with the Centre and how they value the work being conducted. Only one communication detailed a patient's concerns about the Centre.

Feedback from patient members of the advisory groups:

- *'It's easy to see how committed everyone is at the Centre.'*
- A member of an advisory group explains that her life is too complicated to continue the meetings, and says 'I have felt privileged to be included and I wish you and everyone involved all the very best…I will miss being part of

the group but I will be very pleased to be kept up to date with how you are progressing.'

- At times, invited guests attend patient and carer advisory groups. Feedback from these guests was very positive 'May I say thank you for inviting me to your meeting last night. I very much enjoyed our discussions and, as always when I meet with patients and carers, I came away stimulated but at the same time grounded by your insight and experiences, without which we (I) would find it much more difficult to understand the issues and the environment in which we operate and continuously seek to improve.'
- One email was received from a patient explaining her withdrawal from being an advisor to the Centre. She expressed her disappointment that the group she was involved in had only been discussing their experiences while other groups had been much more actively involved in CCRC's research. She was pleased to be invited to help interview job candidates at the Centre, but felt that she hadn't been given sufficient time to prepare for this. She explained that this was reminiscent of feeling disempowered during treatment, and wished that the Centre's communication was better: 'I had hoped that given all the times the group has talked about this, it would not happen with CCRC Staff.'

Feedback on being a participant in the Programme

- *'The year of participation has given me a fascinating insight into research work. The Interim Report is very interesting (esp. when you recognise yourself in the words!)'*

Other comments on the Centre's work

- A patient asked for a copy of an interim report from the Programme which he can tell others about: 'I hope that using it will also increase the visibility of CCRC.'
- Patient feedback on a report stated 'I have just got round to reading the 'Phase 1 report: Patient Advisory Groups' and think it is an excellent paper. Well done to all those involved.'
- A practitioner gave feedback in an email following a presentation on the advisory group work with patients using their service: 'Thank you very much for making the time to come and feed back to the team at <name of service>

the summary of the focus group sessions and the wider aspects of your on going projects at the CCRC. It was a very worthwhile session, and offered plenty of reassurances as well as provoking thoughts on other areas of the service that could be explored. We really did appreciate it very much, and look forward to continuing our working relationships in the months ahead.'

- Feedback from the University's Principal was also received: 'I had also heard directly from <external visitor> how impressed he and our visitors were with you and your team. So thank you again. I know how busy you are and am grateful to you for showcasing the University so successfully.'

Overall, these direct communications elicited a range of positive feedback on the Programme, from a number of different stakeholders including people affected by cancer, practitioners, service providers and University of Stirling directors. The comments focusing on critical feedback offer reflections about taking the work of the Centre forward and further centralising people affected by cancer.

6.3 Evidence of impact: Other communications

Three further pieces of correspondence were received, including correspondence from visitor to the Centre and offers of help from a local student.

One item was submitted to the file, indicating a debate held at the Scottish Parliament. The following is drawn from the transcript of a parliamentary session at Holyrood in March 2007:

> ***I welcome the programme described by the Minister and the work that NHS Lothian has been doing in that area for some time. Will the Minister ensure that there is a focus on the full range of patients' qualitative experience of care, rather than simply patient satisfaction surveys? Will he ensure that the initiative draws on the work of those who are already experts in the field, such as the team at the cancer care research centre at the University of Stirling? Crucially, will he ensure that the information about patient experience is acted upon to improve patient care further?***
>
> *Malcolm Chisholm*

> ***I am happy to give Malcolm Chisholm assurances on all those areas. I pay tribute to the work of the cancer care research centre at the University of Stirling, which has, to a substantial degree, scoped out and informed the patient experience programme that we are introducing. The purpose of the programme is to build on the centre's work, to extend it beyond cancer to the whole range of patient experiences, to go beyond—as Mr Chisholm suggests—patient satisfaction surveys or complaints processes to gather as wide a range of qualitative information as we can about patient experience, and to ensure that that information is used to drive up the quality of patients' experience in future.***
>
> *Lewis Macdonald*

This excerpt from the Holyrood debate positions CCRC staff as experts in cancer care and indicates an uptake of the Centre's expressed ideology in the Parliament, in moving away from satisfaction questionnaires and toward a more nuanced and qualitative approach to understanding patient experience. The representation of this way of conceptualising patient experience is crucial in ensuring that policy-makers are conscious of the benefits of well informed methods. Importantly this passage also reflects positive reinforcement of the Programme's work as a central plank to further initiatives which are being rolled out to improve patient experience in Scotland.

Section 7: EVALUATION OF THE DEVELOPING CANCER SERVICES: PATIENT AND CARER EXPERIENCES PROGRAMME: THE VIEWS OF STAKEHOLDERS

Interviews with stakeholders were conducted by Dr Charlotte MacDonald, Independent Consultant, on behalf of the Cancer Care Research Centre.

7.1 Introduction

This section presents a summary of the views expressed about the Programme's achievements in relation to: patient involvement in research and in the NHS; dissemination of research findings; practical applications of the learning around involvement; influence on policy; the application of learning beyond cancer care. Responses are also summarised on whether expectations of the Programme have been met.

7.2 Patient involvement in the Programme

Interviewees had different levels of knowledge relating to different aspects of the Programme. Those respondents familiar with the direct patient involvement work were enthusiastic for the most part about what the method has achieved in providing practical examples of involvement and influencing perceptions and opinions. They expressed a range of views:

» by involving patients at every level in the Programme, the Centre has shown the willingness of patients to be involved and what could be achieved both in research and development
» the Centre had been successful in reaching people who are often considered 'hard to reach'

- the Programme demonstrated the potential for real engagement, as distinct from tokenistic involvement which was felt to have been witnessed in Cancer Networks
- the Programme has been influential in contributing to a cultural change in relation to patient involvement.

Many of the views expressed related to patient involvement per se, that is, the methods used and the success in engaging with groups and individuals. Only one interviewee commented specifically on the impact of involvement on research, stating an impression that the patient advisory groups were involved in deciding future priorities for research rather than in the design and analysis of the research itself:

> ***'I think that elements of the Centre's work are beginning to be heard in terms of involvement of service users in deciding priorities for research and to some extent in the process of research'.***

One interviewee was 'apprehensive' about the future of the patient advisory groups and that they would come to an end with the Programme. Whilst recognising that patient involvement was an evolving process, this interviewee was concerned that the people involved should continue to have their voices heard.

7.3 Patient involvement in the NHS

Interviewees were able to identify little specific evidence of the Programme's influence over patient involvement in the NHS. However there were quite diverse views about why this should be. Some felt that it was too early to judge. Another view was that, although hard evidence was difficult to identify, the Programme has contributed to a culture change (in line with Delivering for Health, Scottish Executive 2005), and that some elements within the NHS have changed their attitude to patient involvement as a result. A third view was that the Centre was not in a position, as a group of University based researchers, to influence the way the NHS conducted patient involvement.

Those who felt it was too early to judge the influence on the NHS commented on what they saw as NHS resistance to change. These interviewees were not very optimistic about how open the Cancer Networks are to adapting their approach to patient involvement, and saw the final phase of the Programme, underway at the time of the interviews, as critical in deciding whether the Programme is able to influence them. One commented that it would not be the fault of the Programme if the desired changes in patient involvement did not come about:

> ***'Cancer Networks are not that clear about the nature of patient involvement they were setting up. I think the Centre's work would have made people sit up because it's a much more joined up approach…but I don't have any evidence of this happening.'***

In spite of this sense of there being little hard evidence there were some observations attributed to the Programme's influence within the context of a more general culture change. One interviewee had been 'quite astonished' to hear very recently the changed views of a clinician, who had been heard expressing strong reservations about the value of the Programme at a meeting held around the time it was set up:

> ***'He has actually changed his view because he said it's not the big stuff it's the small stuff that needs to change – all the things that came out of last year's (CCRC) conference about communications: information, information being given in an accessible way. He actually said on Friday that they have to listen to what people want. I don't know that he would admit that Stirling was one of the drivers behind what he said but I think it has definitely helped. Because his network has people in it who've been involved with Stirling. I was quite astonished. User involvement in their network was quite controlled to fit into the Network structure. Now they're changing the way they tap into people's experiences – asking people how they feel about things in an open way. He seems to now want to do that on an ongoing basis and pick issues up as they arise. That's very different from his behaviour at that first meeting.'***

Another observation, made by two interviewees, is that individual service users have been 'empowered' to be more actively involved as a result of participating in the Centre's Programme:

> ***'If you empower patients through involvement then they become advocates both for Centres like this but also for demanding change.'***

One of the interviewees making this point had come across 'involved' patients in the NHS who had been part of the Centre's Programme and concluded that they had been encouraged by that participation.

This contrasts with the view noted above that it was unrealistic to expect the Programme to directly influence patient involvement in the NHS because patient involvement was already 'a fact of life' with the Programme running separately from NHS patient involvement structures.

7.4 Dissemination of Programme outputs

Two separate issues were raised in relation to dissemination: success in presenting and publishing findings in a range of media and success in reaching the right audiences.

Most people felt the Centre had been successful in presenting its findings in one medium or another. These included: dissemination at conferences where it was felt that results have been presented in readable and accessible ways; papers given by Centre staff at national and international conferences; and articles published in peer reviewed journals.

One person stressed how well staff had tackled the Phase 1 literature review:

> ***'They've done a very good job of taking a very complex piece of work and putting it into peer reviewed publications.'***

Interviewees were less convinced about the Programme's success in reaching the breadth of appropriate audiences, for example service managers and clinicians. One view was that since service managers do not read peer reviewed publications the impact of this form of dissemination contributed little to service change. A second view was that by not getting articles published in 'mainstream' medical journals the findings were not reaching those parts of the medical establishment for whom they were relevant.

Similarly, but more sympathetically, the view was expressed that the Programme researchers could only do so much in terms of making the findings available to the right audiences. It was then up to others to learn from them and make changes. One person thought the Centre's conference in 2006 was a significant dissemination event:

> ***'They have highlighted issues which were not being acknowledged. The conference brought this out very clearly … Their findings were well presented and robust… The VIPs at the conference took it seriously but I don't know what exact effect it had.'***

7.5 Practical applications of the Programme's learning

Interviewees seemed to have difficulty pointing to practical outcomes of the learning from the research. It was understood that the final part of the Programme, Enabling Change, was designed to take on this particular aim – the 'acid test' according to one interviewee. However, this was ongoing at the time of interviews and respondents were unsure of how the work was progressing or its impact at that time.

A 'potential link' was identified by an interviewee, between the activities of their voluntary organisation and issues brought up in the Programme, implying that this could help them develop their support on issues such as welfare benefits.

Another interviewee had observed that the development of patient advisory groups in selected localities had encouraged help seeking behaviour by patients in those areas. This was evidenced by more calls to the organisation's helpline. The interviewee reported that this was helpful to the voluntary organisation in its aim of reaching people who have a need for its service. From the Programme's point of view, it is not clear whether this is a positive outcome of the patient involvement activity or one which suggests that participants in the involvement work were not getting adequate answers to their questions.

One person was critical of the Phase 3 (Enabling Change) approach to applying learning from the Programme, though they admitted not being fully up to date with the plans. This person felt that draft plans had not been clear about how the qualitative findings from Phase 2 (Patient Experience) could be incorporated into ongoing service developments. Phase 3, in this person's view, should not have been attempted as it was not an area of expertise for the Centre: they felt that it would have been better to have collaborated with NHS or academic experts in the field of change management.

A second interviewee had been critical of the way some of the findings from Phase 2 had been presented. The criticism arose because it seemed that a patient's views on clinical care matters were being presented on the Centre's website as recommendations for clinical practice; the interviewee considered this to be inappropriate. It is unclear whether the reference is to a researcher produced report or to patient comments on a report, both of which appeared on the Centre's website.

7.6 Influence on policy

According to three of the interviewees, the Scottish Executive Health Department took the view that reports of the Programme's work did not tell them anything they did not already know. The value of the work lay in its confirmation of what was already known.

One person felt that policy makers have potentially a much greater stake in the Centre than clinicians, and several people commented on the growth in influence of the Centre:

> ***'[It is] stronger now than it was – sense of critical mass of people being drawn in.'***

> ***'I think the Centre is now well placed to influence things so that patient involvement is fundamental to everything that happens in NHS Scotland.'***

However, one person commented that attitudes to the Centre, in both the research and policy worlds, are divided between those who are supportive of the overall approach and those who question the rigour of the research methods and therefore the usefulness of the approach.

Interviewees could not point to any examples of where a Health Board's policy had been influenced directly, and one person felt disappointed that there had not been greater input to the local Health Board. On the other hand, an interviewee who had been involved with the patient advisory groups could see some potential for indirect influence:

> ***'The Centre has been very good at making sure that whatever area they were working in the Health Board was aware of what they were doing…keeping key opinion leaders informed.'***

7.7 Value of the Programme for people with other health conditions

There was broad agreement that the learning could be generalised across conditions since many of the issues which had emerged as being of concern to people affected by cancer are also relevant to other groups of patients:

> ***'Most of the issues raised in patient involvement work are not cancer specific because they are about practical aspects of care and not about clinical treatment.'***

One person explained how the focus of the Centre's work on the individual rather than the disease made it relevant to everyone, not just to people affected by cancer.

There were no specific examples given of where learning derived from the Centre had been applied in other health fields. However a point made about the role of the Centre in staff development is relevant in this context:

> ***'In the process of developing the patient involvement work it has become an exciting and innovative Centre for staff development which leads to sustainability in relation to the wider health care context.'***

The same person also considered that learning from the Programme had fed into research proposals in other clinical areas, citing palliative care as an example.

One person felt strongly that the integration of patient involvement in cancer care research with the patient involvement agenda in the NHS should have been a priority for the Programme. They regretted that it had not been a formal part of the remit. This person also felt that it was harder to generalise the learning about patient involvement because of the way the Programme had been defined.

There was particular praise for the Programme's development of patient advisory groups from most of the interviewees who saw this as having a general application:

> ***'I think they've pretty much cracked the mechanics of engaging with people. It's quite a difficult thing to do – to engage with people without alienating them and I think they've done that really well.'***

However it was pointed out that patient involvement has existed in other health care fields, notably mental health, for some time, implying that what the Centre is doing may not be altogether new.

7.8 Expectations of the Programme

There was broad agreement that the Programme had met expectations although two people qualified this by pointing out that the planned sample size for Phase 2 had proved impossible to achieve. For the wider impact of the Programme most people felt it was too early to judge, commenting that research evidence takes a long time to influence practice.

Two interviewees felt that the Programme had met, or exceeded their expectations in relation to developing a model for patient involvement which captured the patient experience:

> ***'I didn't know of anywhere else that was trying to capture the patient experience in the same way … looking back at what I expected it has more than delivered what I expected.'***
>
> ***'Expectations have been met – they have done what they set out to do. The rest of the world is not in step… [they] have highlighted issues which were not being acknowledged.'***

One person felt that the Programme was too ambitious, had thought this from the outset and had had their view confirmed. Specifically, this person felt that the Programme should have worked with experienced clinicians to disseminate the learning from Phase 1 about what has worked well in patient involvement, rather than try to get involved directly in service development:

> ***'There are people trying to develop user involvement all over the country and researchers can play an important role in bringing the findings of the literature review to the attention of those people – knowledge transfer to support development.'***

7.9 Summary

Four of the six interviewees were enthusiastic about the Centre's approach to patient involvement and what had been achieved within the Programme. They were realistic about how much impact the Programme has had on the NHS to date, but could point to some clear examples of ways in which they thought the Programme has already influenced attitudes.

The other two interviewees, whilst agreeing that the objectives in relation to patient involvement in the research had been achieved, also had significant criticisms of the Programme design which underpinned their views about the impact of the Programme specifically on developments in the NHS. One of these two people made it clear that they were not fully up to date with the Programme's work.

Section 8: SURVEY OF CONTACTS, COLLABORATORS, PEOPLE AFFECTED BY CANCER, STAKEHOLDERS

8.1 Respondent demographics

8.1.1 Survey respondents

104 responses were received, representing a response rate of 36%.

Respondents were asked to state their status as patient, relative, policy maker or practitioner to give an understanding of the balance of people the CCRC is in touch with.

Who are you (in relation to cancer care services)? (You may select more than one answer)

	Response Percent	Response Total
I am a patient/former patient	34.7%	36
I am a relative/friend of someone with cancer	22.1%	23
I am a health care professional	38.4%	40
I am a policy-maker	3.8%	4
I am a researcher	4.8%	5
I have another professional role in cancer care	10.6%	11
Other (please specify)	7.7%	8

This indicated: 57%[3] of respondents were patients or family members, and 38% were health care professionals. Of those who indicated they held another role, respondents indicated:

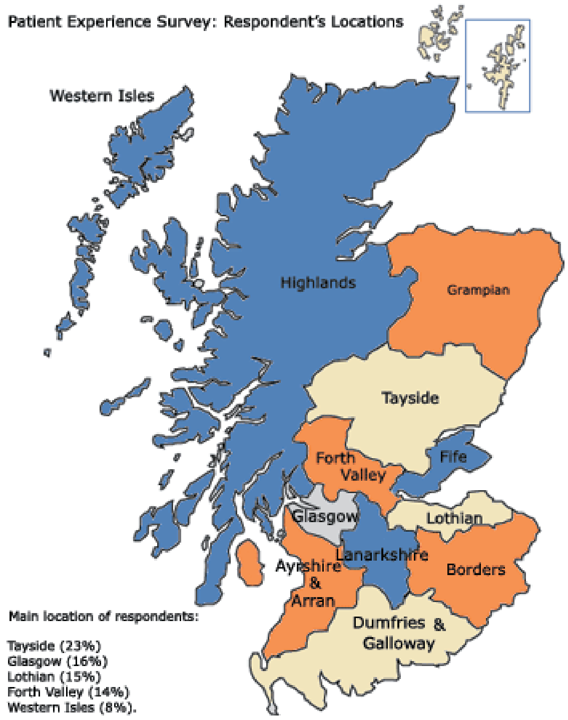
Public Involvement worker (n=2), befriending service (n=2), lecturer, volunteer, support group co-ordinator, cancer charity administrator.

8.1.2 Geographical location of respondents

Respondents stated their location to give an understanding of the geographical reach of the Programme. The data indicates respondents in the following areas:

- Tayside (23%)
- Glasgow (16%)
- Lothian (15%)
- Forth Valley (14%)
- Western Isles (8%)

Responses, in lower numbers, were also received from all other health board areas, with the exception of NHS Orkney and Shetland.



8.1.3 Cancer types affecting patients and family members

The survey was completed by people affected by a range of cancer types, indicating a diverse population reached by the Programme. People affected by cancer had experience of the following cancers:

For patients and family members: What kind of cancer are you/your family member affected by?

	Response Percent	Response Total
Breast cancer	30.7%	16
Prostate cancer	19.2%	10
Head and neck cancer	15.3%	8
Bowel Cancer	11.5%	6
Lung cancer	7.6%	4
Haematological cancer	5.7%	3
Gynaecological cancer	5.7%	3
Skin cancer	5.7%	3
Other (please specify) - Brain; Adrenal	3.8%	2
Total respondents	53	

---

[3] In-text percentages are rounded up.

The four most common cancers affecting people in the UK account for around 69% of respondents. People affected by breast cancer form the majority group of patients and family members responding to the questionnaire (31%).

8.1.4 Work context of practitioners

For professionals: What cancer service are you involved in?

	Response Percent	Response Total
Cancer nurse	33%	21
Manager	9.5%	6
Medical Oncology	6.3%	4
Radiation Oncology	4.7%	3
Researcher	4.8%	3
Cancer care policy	4.8%	3
Educator	3.2%	3
Other (please specify)	33.3%	21
Total respondents	63	

For practitioners, respondents were primarily cancer nurses (33%), followed by managers (10%) and medical oncologists (6%). Other disciplines completing the survey were: involvement workers, a surgeon, a GP, psychologists, and health promotion workers.

8.2 Contact with the CCRC

8.2.1 Timing of learning of the CCRC

When did you first hear about the CCRC?

	Response Percent	Response Total
In the last year	22%	22
1-2 years ago	53%	53
3 years ago	23%	23
Don’t remember	2%	2
Total respondents	100	

Data regarding when people learnt of the CCRC indicates substantial incremental growth over the last few years with a considerable number of people learning of the Centre in the last year. 35 of the 59 patients and family members responding to the survey had heard about the Centre between one and two years ago. Attrition rates of people involved in the Centre cannot be surmised from this data.

Health care professionals became aware of the Centre significantly longer ago than people affected by cancer responding to this question ($p<0.05$).

8.2.2 First involvement with the CCRC

When did you first get involved with the CCRC?

	Response Percent	Response Total
In the last year	31%	31
1-2 years ago	49%	49
3 years ago	14%	14
Don't remember	6%	6
Total respondents	100	

Comparing the data in this table to that in 8.2.1 indicates that there is often a time-lag between hearing of the Centre and actively getting involved or in touch. This is more prevalent for practitioners than for patients and family members.

8.2.3 Method of learning of the CCRC

How did you hear about the CCRC?

	Response Percent	Response Total
Direct contact from a member of CCRC staff	33%	33
At a conference	18%	18
Told about it by practitioner (nurse, doctor etc) / policy maker	17%	17
An advertisement / article in a newspaper	10%	10
Told about it by a patient/family member	6%	6
Don't remember	5%	5
Searching the web	1%	1
In a cancer journal	0%	0
Other (please specify)	10%	10
Total respondent	100	

All 10 of the people who had heard of the Centre via newspapers were patients. Eight of 18 people who had learnt of the Centre through a conference were patients. Primarily, clinicians became aware of the CCRC via individual contact with Centre staff (17 of the 33 responses). There was also a clear tendency for people to have learnt of the Centre through a health care professional (17%), a trend which is statistically significantly higher for health care practitioners ($p<0.05$).

8.2.4 What kind of relationship do you have with the Centre?

Many people had more than one relationship with the Centre (percentages therefore add up to more than 100). Responses to the question give an understanding of the range and balance of ways of involving people affected by cancer and practitioners within the Programme.

Throughout all your contacts with the CCRC which of the following have you been involved in? (You may select more than one answer)

	Response Percent	Response Total
Talking about experiences of cancer care in a patient and carer research advisory group	40%	40
Attended the CCRC conference in 2006	31%	31
As a clinical collaborator (helping recruit patients to research studies or working with CCRC to make changes in cancer services)	24%	24
Talking about experiences of cancer care individually with CCRC staff	19%	19
Receiving the CCRC newsletter	19%	19
On the CCRC steering group or Patient Experience Steering Group (not one of the general advisory groups)	14%	14
Other, please specify	11%	11
As a co-researcher (e.g. co-writing proposals, running focus groups with CCRC staff, interviewing people)	6%	6
As a seconded researcher	1%	4
Total respondents	100	

The majority of contacts are conducted through patient and carer advisory groups, as clinical collaborators and via the Centre's conference. The number of seconded researchers and co-researchers represented the lowest of the fixed-choice categories – indicating the potential for more active collaborative approaches to involving people involved in cancer care and affected by cancer in the Centre's work.

56 respondents only had one form of contact with the Centre. People attending advisory groups accounted for the largest proportion of people who only had one form of contact with the Centre (18 respondents), while 13 clinical collaborators' only contact was around recruiting patients and family members to research studies.

8.2.5 CCRC methods of keeping in touch with contacts

How does the CCRC currently keep in touch with you? (You may select more than one answer)

	Response Percent	Response Total
Through meetings	32.3%	31
Through individual staff members	32.3%	31
Via the newsletter	28.1%	27
Through updates on the website	19.8%	19
Other	47.9%	46
Total respondents	100	

Responses to this question indicate the ways in which the CCRC communicates with contacts and collaborators. Most respondents had multiple forms of contact with the Centre, with Patient and Carer Research Advisory Groups being one of the main methods cited in the 'other' category, alongside contact from individual staff members, updates on the website and via the newsletter.

Respondents were asked to indicate the frequency of contact with the Centre. Overall, people found it hard to say how often they heard from the CCRC, as it varied a great deal. However, 34% were able to indicate that they hear from the CCRC at least every couple of months.

8.2.6 Preferred method of contact with the CCRC

How would you like the CCRC to keep you up-to-date with their work? (You may select more than one answer)

	Response Percent	Response Total
Via the newsletter	81%	77
In open meetings/open days	45.2%	43
Through updates on the website	44.2%	42
Through conferences	33.6%	32
Other (please specify) (email: 4)	9.4%	9
Total respondents	95	

The data around preferred communication styles indicates that the newsletter, website and Open Days[4] are considered most important. The newsletter was the clear preference of patients and family members respondents. Practitioners demonstrated a preference for website updates and the newsletter.

---

[4] The Centre's first Open Day was held after this survey closed, on May 1st 2007.

8.3 Impact of CCRC on involvement

8.3.1 The impact of CCRC on ideas about involvement

The survey aimed to map out ideological changes in the way people perceive and respond to involvement work. Responses indicate a shift in people's priorities in involvement work. The following table sets out the views of people affected by cancer and indicates an overwhelming shift towards a more positive approach to involvement. Respondents could select more than one answer, resulting in percentages totalling more than 100.

For Patients/family members: has being in touch with the CCRC changed your ideas about getting involved in research or having a say in cancer care?

	Response Percent	Response Total
Yes, I feel more positive about involvement	81%	28
Yes, I have discussed involvement with other people	45.2%	18
Yes, I have encouraged other people to use involvement	44.2%	16
Yes, I think more often about involvement	33.6%	14
No, No-one else around here likes to think too much about involvement	9.4%	2
No, I find the ideas confusing	2.3%	1
Yes, I have discouraged other people to use involvement	0%	0
No, CCRC haven't told me anything I didn't already know	0%	0
Other (please specify)	4.7%	2
Total respondents	43	

76 of 80 responses to this question indicated clearly that being in touch with the CCRC had a positive impact on patient and family member thoughts about involvement. Importantly, no patient and family members' relationship with the Centre was reported to have led them to discourage others from involvement activities.

The respondent who had indicated that they found the ideas confusing had also shown an interest elsewhere in the survey in training patients and family members about how to get involved in cancer research and cancer service changes. This indicates a willingness to grapple with the complexities of involvement and seek out training opportunities.

The following table sets out the responses from health care practitioners about the impact of CCRC on their ideas of involvement. As above, the indications are of a very positive influence. Respondents could select more than one answer, resulting in percentages totalling more than 100.

For Practitioners: has being in touch with the CCRC changed *your ideas* about involving patients or carer/family members in research, cancer care or cancer care policy? (You may select more than one answer)

	Response Percent	Response Total
Yes, I feel more positive about involvement	38.6%	17
Yes, I have discussed involvement with other people	36.4%	16
Yes, I think more often about involvement	31.8%	14
Yes, I have encouraged other people to use involvement	20.5%	9
No, CCRC haven't told me anything I didn't already know	2.3%	1
No, No-one else around here likes to think too much about involvement	2.3%	1
No, I find the ideas confusing	0%	0
Yes, I have discouraged other people to use involvement	0%	0
Other (please specify)	15.9%	7
Total respondents	44	

The respondent who selected 'No, CCRC haven't told me anything I didn't already know' indicated elsewhere in the survey that their only contact with CCRC was through receiving the newsletter. This indicates a need to attend to the content of the newsletter and ensure that Programme findings and best practice in involvement are included in newsletter articles.

The respondent who selected 'No, no-one else around here likes to think too much about involvement' indicated elsewhere that they only have annual contact from CCRC staff. This indicates a need to be attentive to involvement networks either via CCRC or in clinical workplaces.

A range of, largely positive, views were inserted in the free-text box. The following are direct quotes from the surveys:

- 'The advice I have got from centre staff [is] helpful. The evidence provided by the research into involvement has also been useful.'
- 'I have a rehab background and [have been] an active proponent of self care and involvement for 20 years, the materials from CCRC (have) confirmed my views and encouraged me to continue doing what I have always done.'
- 'I've enjoyed hearing what CCRC has discovered from involvement but I've been involved with involvement for a while now - CCRC hasn't made a difference to my involvement.'
-

Overall, responses are very encouraging and demonstrate a positive impact of CCRC on involvement work amongst practitioners and people affected by cancer.

Though just under the 95% confidence level for statistical significance, there is a trend for people affected by cancer to report feeling more positive about involvement than practitioners. The other responses do not show statistically significant differences, indicating broadly similar reactions to the impact of the Centre on involvement.

8.3.2 Impact of CCRC on involvement activities

All respondents who had answered the previous question about the impact of CCRC on their ideas also indicated how the Centre had influence their actions. The following table combines both practitioner and patient/family member responses, mapping out an ideological change in the way contacts perceive and respond to involvement work.

Has being in touch with the CCRC changed how or whether you get involved in making a difference in research or cancer care?

	Response Percent	Response Total
Yes, I am doing more	28.8%	26
Yes, I have changed what I focus on	25.3%	22
Yes, I have used findings from CCRC	20.7%	18
No, I haven't changed anything I do	17.2%	15
No, There just isn't time	4.6%	4
No, I can't think of how to involve people/ how to get involved	2.3%	2
Other comments	12.6%	11
Total respondents	87	

Overall CCRC has had a positive impact on the quantity and focus of involvement work as well as the way in which people think about involvement of patients in cancer care. 28% of respondents said they were doing more, while 25% reported that they had changed what they focused on, and 20% had used the findings from CCRC. Patients reported more frequently than other categories of respondent that CCRC had changed what they focused on.

15 people (17%) reported that CCRC had not impacted on their involvement activities; so while respondents identified that they were thinking more positively about involvement (as identified in section 8.3.1) this had not in every instance translated directly into acting on

these ideas. Free responses in the 'other comments' area did not provide further explanation for the reasons for this, though it is likely that time is needed for new ideas to become embedded or trialled in changed practice.

8.4 Mapping involvement

8.4.1 Involvement over the past year

Over the past year, which of the following have you been directly involved in? (You may select more than one answer)

	Response Percent	Response Total
Focus groups to discuss NHS cancer care services	58.6%	51
Cancer forums (like WOSCAN, SCAN and NOSCAN)	44.8%	39
Patient satisfaction surveys on NHS services	26.4%	23
Health service committee, looking at changes in cancer care services	21.8%	19
Individual interviews about NHS cancer care services, with NHS staff	18.4%	16
Other surveys on NHS services	17.2%	15
Large NHS consultation meetings with members of the public	14.9%	13
Other (please specify)	18.3%	16
Total respondents	44	

The main mode of involvement was focus groups which were used to discuss cancer care (the majority of these responses were indicated by people affected by cancer), as well as large cancer forums such as the cancer networks. Patient satisfaction surveys were indicated by 26% of respondents, accounting for nearly half of the respondents to this question. Less involvement was evident on an individual or small-scale basis.

8.4.2 NHS methods and processes of involvement

Respondents were asked to indicate their awareness of the methods and processes of NHS involvement, to indicate where further work on best practice could be directed by the Centre.

Figures in bold in this table indicate the most frequently reported responses for each question.

The data indicate varied practices within NHS systems regarding the methods and processes of involvement. For example, travel expenses were paid in only 54% of cases, and 44% of respondents indicated that there was a reliance on one person to represent patients and family members' views.

Further analysis of this data using inferential statistics reveals a level of discord between practitioners and patients/family members. There is a statistically significant difference between views of whether training was offered; that is, patients and carers were significantly more likely to indicate that training was not offered ($p<0.05$) [5].

There is also a statistically significant difference between practitioners and people affected by cancer regarding whether more than one patient was invited to contribute, with practitioners indicating that this was the case and patients/family members indicating it was not ($p<0.05$).

---

[5] Respondents choosing 'it varies' were counted as a 'yes' response, since the training or other support had been offered at least once.

8.5 Future directions

8.5.1 What should the CCRC do more of?

Identifying respondents' ideas on what should the CCRC do more of enabled a mapping of areas of expansion for the Centre.

53 people offered their ideas, which ranged from commentary on current working styles to ideas for new connections:

- 19 ideas on the Centre's strategy were suggested, including: more media liaison; enabling more people to learn of the work of the Centre; and more joined-up working – particularly focusing on communication and liaison with voluntary organisations, the Scottish cancer networks and GPs.
- 14 ideas for future work were put forward, including: cancer as a long-term condition; the incidence of cancer on Scottish Islands; patients' fears about seeing GPs with symptoms; patient surveys in clinics; complimentary therapies; healthy eating.
- Eight ideas regarding the practical implications of the work were suggested, including: co-ordination between hospital departments; interdisciplinary research; and finding ways of ensuring 'research results are absorbed in the professional community, perhaps by move involvement with bodies such as Quality Improvement Scotland'.

8.5.2 What should the CCRC do differently that would be of interest to you?

Respondents were also asked to identify potential changes to the CCRC's approaches which could be implemented to make the work more interesting to them. 39 people offered their thoughts:

- 16 comments reflected on the potential to increase the Centre's involvement profile, including: placing involvement ideas in newsletters; involving a more diverse range of the public; getting advisory groups to become actively involved in research rather than focusing on sharing experiences; and giving examples where Advisory Group input has made a difference.

- Seven comments focused on improving communication/networks with patients and practitioners – involving disseminating research findings and encouraging secondment opportunities.
- Four comments noted ideas for future work, for example: research on bowel cancer; and applying the research findings to practice.

A large number of positive comments were also entered in response to this question, including: 'Continue 'employing' patients/carers in their research and putting their views and ideas to good use'; 'Continue encouraging and supporting patients/carers and showing that their views are important'.

8.5.3 What should the CCRC do differently that would be helpful?

A further question elicited ideas that would be helpful to respondents and which may potentially impact on how the Centre's data and approach are used in practice settings in the future.

40 respondents offered comments, the majority of which reiterated their response to the previous question:

Six people requested further dissemination, for example distributing leaflets with key findings; sharing work with those in the NHS; and indicating what impact the policy has had on the Executive. The issue at the heart of these ideas was expressed by one respondent: 'To know that the time and information given has not just ended up with a better understanding of how people feel but to have that valued and validated by further action'.

- Three comments were made about increasing the potential for secondment opportunities and further collaborative working.
- Two respondents gave positive feedback on the Centre's work.
- Other comments focused on specific feedback on involvement, for example 'run training courses on involvement'; and 'give advice whether patients can claim travel expenses to attend meetings'.

8.5.4 Methods for encouraging and supporting more involvement work

Respondents were encouraged to log as many ideas as they wished regarding methods that CCRC could adopt to encourage and support increased involvement work (figures therefore add up to more than 100%).

How could the CCRC encourage/support cancer care practitioners to involve patients and family members more?

	Response Percent	Response Total
Training practitioners on ways of involving people	66.2%	51
Training patients and family members about how to get involved in cancer research and cancer service changes	58.4%	45
Writing summaries of best practice in involvement which can be used by practitioners	58.4%	45
Giving presentations to clinical staff	44.1%	31
Other (please specify)	5.2%	4
Total respondents	77	

Responses to this question indicate a need to focus on training practitioners and patients/family members in involvement and writing best-practice summaries on involvement. Patients and family members were the majority group requesting training for themselves (n=17), although practitioners were also aware of a need for patients and family members to receive training (n=15). Likewise, health care professionals also indicated their own need for training (n=19).

Responses recorded under 'other' indicated a need to be 'out and about', to communicate with all stakeholders, and to produce a best practice manual.

8.6 The future of the Cancer Care Research Centre

8.6.1 Future involvement opportunities in the Centre

This table summarises all received responses regarding how people would like to continue their involvement with the Centre.

Which of these ways would you like to be involved with the Centre in the future, if we offer the right level of support, and your own circumstances allow: (You may select more than one answer)

	Response Percent	Response Total
Receive the CCRC newsletter	71.1%	51
Attend the CCRC conference	43.4%	45
Work with clinical teams to make changes happen and helping them engage with patients and carers	40.8%	45
Be a member of a patient and carer advisory group, talking generally about experiences of cancer care	21.1%	31
Be a co-researcher (e.g. running focus groups with CCRC staff, interviewing people, co-writing proposals, co-writing results papers)	19.7%	4
Comment on the work of the CCRC as an individual (not group) member	11.8%	
Be seconded from my job to be a research with the CCRC	10.5%	
Present your own ideas at the CCRC conference	9.2%	
Other, please specify	5.3%	
Total respondents	76	

50% of practitioners responding to this question indicated newsletters and conferences as their preference, with 46% wanting to work with patients and carers in their clinical teams. Patients and family members showed a preference for the newsletter, advisory group membership and working with clinical teams.

Respondents who had identified secondment as something they wished for also indicated that this was likely to be difficult (though the reasons why this might be problematic were not made explicit).

8.7 Further reflections on the Centre

A free-response section prompted further thoughts on the Centre. 24 people offered their reflections, half of which were from patients though the content of the comments do not differ between respondent groups.

8.7.1 Further thoughts or comments on the Centre

- 16 comments included direct praise for the Centre: '*The work achieved to date has been very valuable & will be valuable in the future proofing of services.'*
- Three further respondents offered reflections on the work. One respondent said: *'I think its efforts are to be greatly valued, but the NHS is like a great ship whose captain never visits the crew rarely interacts in a user-friendly way with passengers/consumers.'*
- Three comments indicated a lack of general awareness of the Centre, including someone affected by cancer who said: '*I am still surprised that clinicians and other health professionals working in the cancer field do not know about CCRC.'*

Section 9: RECOMMENDATIONS

Analysis and synthesis of the evaluation data indicates a number of recommended areas for further work by the Cancer Care Research Centre and people involved in cancer care in Scotland.

The evaluation identified that people affected by cancer and people involved in cancer care felt that involvement with the Centre's Programme had changed the way people thought about and acted on ideas about involvement. Although stakeholders were unsure about the extent of the impact of the Programme in contributing to a culture change in involvement activities in Scottish cancer services, other evidence suggests that this has been achieved.

Data indicated a dearth of involvement-friendly systems within the Scottish NHS, and that far from being fully embedded within health service systems, there was significant room for improvement. The majority of involvement activities reported by respondents indicated the use of techniques based on patient representatives on committees and the use of focus groups. Additionally, benchmarks such as adopting clear systems on travel expenses, involving more than one patient/carer at each meeting and providing training, which are considered fundamental requirements for involving patients and family members, have yet to be systematically instituted.

Recommendation 1: Clinicians, policy makers and other key stakeholders should be encouraged to move toward directly engaging with patients in steering change in cancer care services. This should involve increased engagement in service redesign, moving away from patient representatives on committees. Clear offers of training should be made for people affected by cancer, and core principles such as ensuring that out of pocket expenses are met should be adhered to.

Recommendation 2: CCRC or a similar organisation should take a lead role in disseminating key areas for best practice for involving patients. Further dissemination should be in the form of leaflets, newsletter articles, best practice articles on the appropriate websites or by signposting existing resources.

Recommendation 3: CCRC or a similar organisation should provide training for patients, family members and clinicians on engagement. This would provide support for clinicians and patients/family members to implement the positive effect of the Programme on their thinking about involvement, to changing how they go about involvement.

Recommendation 4: CCRC or a similar organisation, in collaboration with Managed Clinical Networks, should provide mechanisms for connecting people affected by cancer with clinicians to explore the use of patient experiences to improve cancer services. This could involve a mix of methods, including supplying patient experience data to clinicians, brokering relationships between people affected by cancer and clinicians, and providing support in developing collaborative working relationships.

Respondents indicated the desire for more involvement opportunities, which gives the Centre and similar organisations an opportunity to engage with a larger number of people affected by cancer or working in cancer care and drive forward the involvement agenda. Additionally, the evidence indicates that many of the Programme's contacts are people affected by cancer. To increase the reach and impact of the Programme further networks need to be established. This would also encourage the adoption of engagement ideas in new arenas.

Recommendation 5: CCRC, or a similar organisation, should focus on joined-up working with other organisations (such as the cancer networks) to ensure collaborative working and prevent duplication of efforts. Taking a lead role with the cancer networks, and becoming a centralised resource of best practice in involvement would encourage further shared-learning across Scotland and opportunities for cross-fertilisation of techniques of involvement.

Recommendation 6: Clinical staff would benefit from specific targeted attention for linking with the Programme's methods and substantive findings, for example GPs and oncology consultants. Developing clinical secondment opportunities for clinical staff would also be of benefit.

The impact evidence suggests that while the Programme has been successful in accessing ‘hard to reach populations’, contacts and collaborators are primarily associated with two of the four most prevalent cancers in the UK. This suggests scope to increase representation from the four most prevalent cancers and for rarer, but increasingly prevalent, cancers.

Recommendation 7: CCRC, and other similar organizations, should focus on developing contacts and networks with people with a wider range of cancer types including those which are most prevalent in the UK population, for example those anticipated to increase in prevalence.

The Centre demonstrates a strong track record for publishing, which was evidenced through the Impact File and interviews with key stakeholder. Programme staff have achieved considerable recognition in their presentations and publications in national and international forums. The Programme would benefit from specific attention to the developing publication profile.

Recommendation 8: Increasing the number of articles published in methodological, mainstream medical and social science journals would strengthen the reputation of the Programme in domains beyond cancer nursing.

The Programme has had positive media coverage; however a limited amount of this has been in the widest circulated newspapers or large features articles.

Recommendation 9: Further targeted media work should be conducted regarding the outcome of the Project, with particular emphasis on the high readership newspapers, focusing on the outcome of the Programme.

Section 10: CONCLUSIONS

The results of this mixed-method evaluation demonstrate that the Developing Cancer Services: Patient and Carer Experiences Programme has impacted on practice, policy and perceptions of involvement in cancer care.

Being in touch with the Programme was clearly associated with positive views of involvement for people affected by cancer and people involved in cancer care. Impact was demonstrated both in ideology of involvement (in particular, feeling positive about involvement) as well as impacting on behaviours (such as using information and data from the Programme, discussing involvement with others and encouraging involvement activities). These are clear signals that the Programme has been successful in driving forward the Patient Focus and Public Involvement agenda, connecting with patients, carers and clinicians.

Impact on academic audiences is inferred through dissemination of substantive and methodological advancements at national and international conferences and peer reviewed publications. This has included a range of journals, focusing primarily on cancer nursing and involvement. Further focus on policy and practitioner audiences would augment the dissemination strategy and facilitate knowledge transfer.

The CCRC has received a range of formal and informal feedback on its activities related to the Programme, including reference in the Scottish Parliament, and from a range of people affected by cancer and people working in cancer care. The survey clearly demonstrated positive feedback on the progress of the Centre's contribution to the involvement and experiences agenda in cancer care.

Key policy stakeholders of the Programme held high expectations for the work. The CCRC has met many of their hopes and successfully engaged with a range of people affected by cancer, including those considered ‘hard to reach’ and to forge ongoing collaborative relationships with advisory groups.

Despite the recognised progress of the Programme in informing involvement work in Scottish Cancer care, there remains significant room for improvement. There is scope for further collaborative working between the Centre and people involved in cancer care to operationalise the Patient Focus and Public Involvement policy. Attention should be paid to the call for training, support and collaboration indicated in this evaluation from NHS staff and people affected by cancer.

The Programme’s impact will continue to reverberate throughout Scottish cancer care, and beyond, as further dissemination through networks of contacts, collaborators and people affected by cancer are established. Further, publications and reports from the latter phases of the Programme’s work will also facilitate the uptake of the models and methods developed to ensure that patient experiences are identified and utilised alongside patient involvement to improve the experience of cancer care services.

Section 11: REFERENCES

Bell, A,. and Garnet, P (eds.) (1998) Approaches to Media Discourse. Blackwell: Oxford.

Bryman, A (2004) Social Research Methods. Oxford University Press: Oxford.

Data Protection Act (1998) London: HMSO

Deacon, D,. Pickering, M,. Golding, P. and Murdock, G. (1999) Researching communications. A practical guide to methods in media and cultural analysis. Arnold: London.

Hansen, FH (2005) Choosing Evaluation Models. Evaluation. 11(4): 447-462.

Hemessl-Huber, M,. Lasenbatt, A,. and Taylor, J (in press) Health inequalities: A practical and evidence-based evaluation framework. Journal of the Royal Society for the Promotion of Health.

Hubbard, G et al., (2005). Involvement of people affected by cancer in research, policy and planning and practice, CCRC, University of Stirling

Hubbard, G et al, (2007) People's experiences of cancer within the first year following diagnosis. CCRC, University of Stirling

Kearney, N, et al., (2005). Public involvement, CCRC, University of Stirling.

Knighting, K et al., (2007). Enabling change: Using patient experience as a driver for service improvement. CCRC, University of Stirling.

McCulloch, G (2004) Documentary Research in Education, History and the Social Sciences. Routledge: London.

Pawson, R and Tilley N (1997) Realistic Evaluation. London: Sage.

Research Unit for Research Utilisation (2005) Final Report, Impact Evaluation Phase 1 Project. University of St Andrews.

Ryan et al., (2005). A review of how patient experience is capture through patient involvement activities, CCRC, University of Stirling.

Scott, J. (1990) A Matter of Record. Polity Press: London.

Scottish Executive (2001) Social Statistics. http://www.scotland.gov.uk/stats/sss/docs/sss10-05.asp viewed June 2007

Scottish Executive (2004). Cancer in Scotland: Sustaining Change. Cancer incidence Projections for Scotland, 2001-2020. Edinburgh: Scottish Executive.

Scottish Executive (2005) Delivering for Health. Edinburgh: Scottish Executive

Trochim, WMK. (2006) Introduction to Evaluation Research. Social Research Methods. http://www.socialresearchmethods.net/kb/intreval.htm accessed October 13th 2006

Weber, RP. (1985) Basic Content Analysis. Sage: London.

Worth, A et al., (2005). Patient Advisory Groups, CCRC, University of Stirling

Reader Information

Document Purpose	Evaluation of a three year programme of work, Developing Cancer Services: Patient and Carer Experiences
Authors	Dr Liz Forbat, Dr Katherine Knighting, Dr Charlotte MacDonald, Mike Wilson, Dr Gill Hubbard, Professor Nora Kearney
Publisher	Cancer Care Research Centre, University of Stirling
Publication Date	August, 2007
Target Audience	Health and social care professionals; researchers; policy makers
Further Copies From	cancercare@stir.ac.uk
Copyright	This publication is copyright CCRC and may be reproduced free of charge in any format or medium. Any material used must be fully acknowledged, and the title of the publication, authors and date of publication specified
Internet Address	www.cancercare.stir.ac.uk
Price	Free