



# Developing Cancer Services: Patient and Carer Experiences

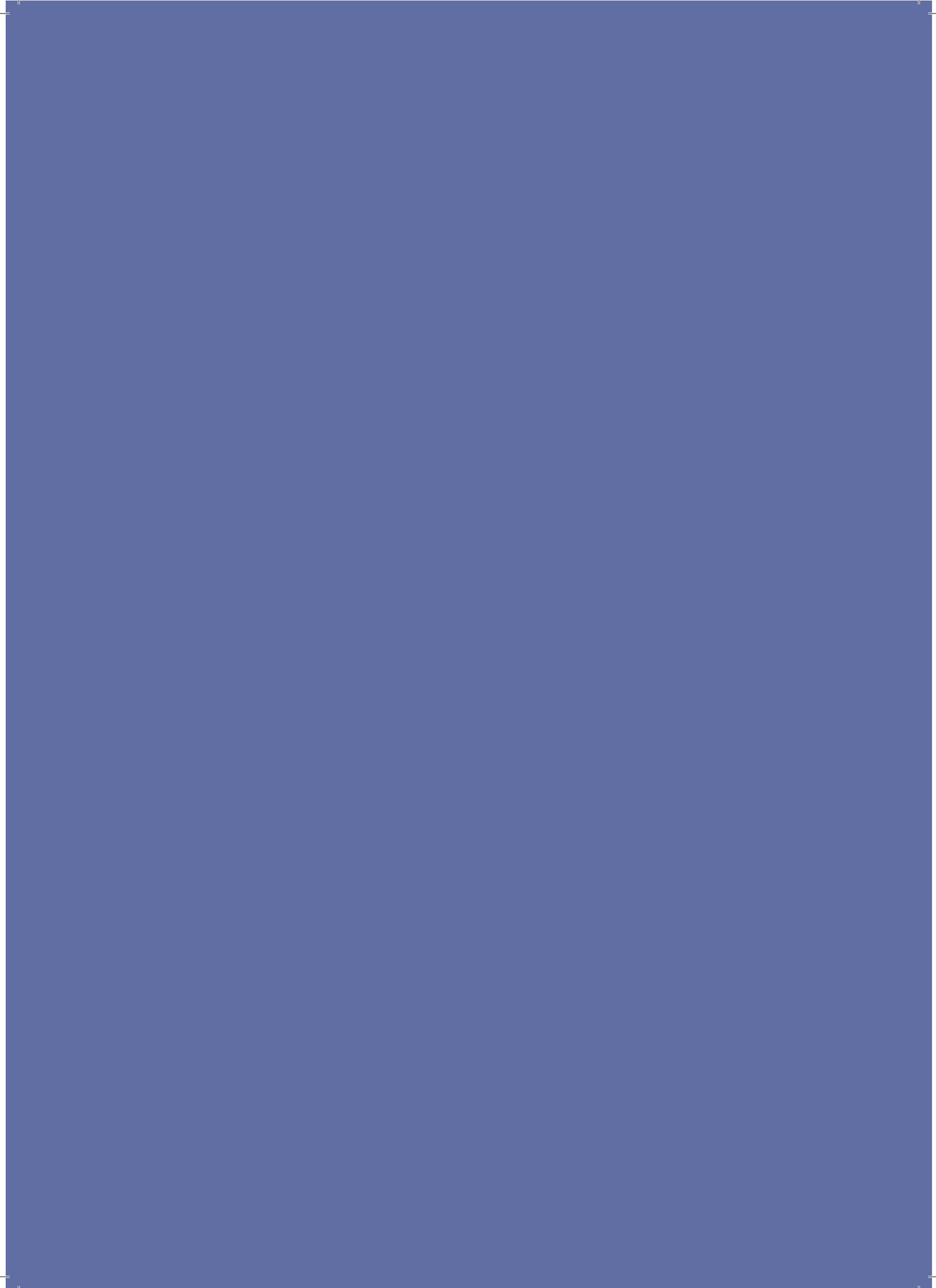
Final Report

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# Section 1: INTRODUCTION

## 1.1 Report Aim

This is the Final Report of the Developing Cancer Services: Patient and Carer Experiences programme funded by the Scottish Executive Health Department undertaken by the Cancer Care Research Centre (CCRC). The report draws on a series of eight projects conducted as part of the programme between 2004 and 2007. There are separate final reports for each of these projects, which provide details of the methods, findings, conclusions and recommendations for each aspect of the work. These reports are available on the CCRC website [www.cancercare.stir.ac.uk](http://www.cancercare.stir.ac.uk)

The purpose of this Final Report is to present conclusions of this programme of work, the first of its kind in Scotland, and present a model for engaging with people affected by cancer. The model aims to support the development of cancer services that are responsive to the needs, both clinical and personal, of people affected by cancer in Scotland.

This report is intentionally succinct and does not reiterate either the substantial evidence gathered or the body of literature drawn upon throughout this programme of work as these are articulated clearly in each of the individual reports. Rather, this Final Report provides a summation of the findings elicited from the whole programme of work in the form of a model to improve the experiences of people affected by cancer.

## 1.2 Background

Scotland experiences higher incidence and mortality rates of cancer compared with other western European countries (SEHD 2001; ONS 2007; Berrino et al 2007; Verdecchia et al 2007)<sup>a</sup> and cancer continues to be the leading cause of death for people under 75 years

<sup>a</sup> All references to the reports generated by the three year programme of work are cited within the text in Vancouver referencing style. All external supporting work has been referenced using Harvard style.

(SEHD 2004). Current figures suggest an annual incidence of cancer in Scotland of 26,000 individuals and this figure is estimated to rise to around 33,000 by 2020 with approximately 17,000 deaths per annum (SEHD 2005a). Scotland's ageing population will clearly contribute to the rising incidence of cancer. By 2031 people aged over 65 are projected to constitute 26.6% of the population with the growth of the over 80s proportionately even more rapid constituting 8.2% of the population (National Planning Team 2005). This ageing profile will not only mean higher incidence of cancer but also result in patients with cancer who have other co-morbid conditions (Extermann 2000).

Since 2001, Scottish public policy and guidance (SEHD 2001; 2003a; 2005a,b; 2006; 2007) including that relating to cancer care (SEHD 2003b; 2004) aimed to ensure that future healthcare services:

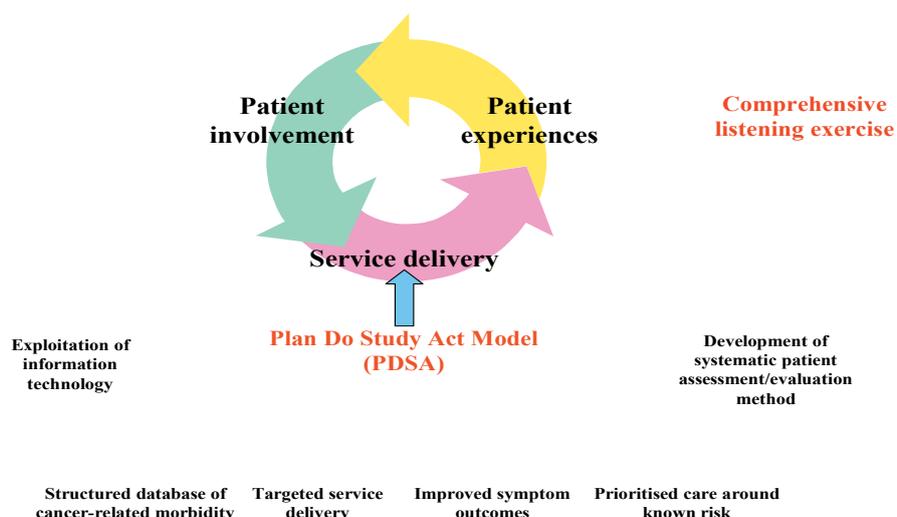
- » involve patients, carers and members of the public
- » provide seamless care through partnerships and joint working
- » improve the provision of community-based care
- » develop a culture of caring throughout the health service
- » acknowledge and support the role of family members and carers

The Developing Cancer Services: Patient and Carer Experiences programme of work was carried out during the development and progression of this policy. This programme of work, therefore, is able to provide critique of the key tenets of this policy and cancer care from the perspective and experiences of people affected by cancer. This critique can be found within the individual project reports. Within this Final Report the findings of the programme's individual projects are interpreted in order to present a model for improving people's experiences of cancer. Recommendations to support the implementation of the model are also presented.

The work began with an initial model for patient-directed cancer services as indicated in Figure 1, which was the basis of the initial proposal to the Scottish Executive Health Department in 2003. Delivering a patient-directed service requires systems to be in place

which allow patients to be involved, and their experiences of cancer and cancer care viewed as central to clinical practice, service development, policy, and research.

*Figure 1: Patient-directed cancer services model (Kearney et al. 2003)*



The initial model presented a vision for a health service that starts from the patient experience, engages the public, and involves patients in their own care. The model was aligned to cancer services policy; for example, putting patients at the centre of quality improvement and frameworks so that services are designed round the needs of patients and better outcomes secured (SEHD 2004). This agenda of involving and placing the experience of patients with cancer at the centre of service organisation and delivery was emphasised in the Calman-Hine Report (Calman and Hine 1995). This patient focus has gained momentum during the last few years through projects such as the Cancer Partnership Project, a three year project funded by Macmillan Cancer Support and the Department of Health, aimed at promoting user involvement activity in all cancer networks in England (Sitzia et al. 2004). This three year project Developing Cancer Services: Patient and Carer

**Table 1: Individual projects completed within the programme<sup>b</sup>**

PROJECT	AIM	OUTPUT
<b>Study 1:</b> Involvement of people affected by cancer in research, policy and planning, and practice: a review of literature	To find out what is already published and known about involving people affected by cancer	Hubbard et al. (2005) Phase 1 report: Literature Review, CCRC, University of Stirling <sup>1</sup> <a href="http://www.cancercare.stir.ac.uk/documents/Phase1LitReview.pdf">http://www.cancercare.stir.ac.uk/documents/Phase1LitReview.pdf</a>
<b>Study 2:</b> Public Involvement	To find out what people in Scotland think about cancer and cancer care	Kearney et al. (2005) Public involvement, CCRC, University of Stirling <sup>2</sup> <a href="http://www.cancercare.stir.ac.uk/documents/Phase1PublicInv.pdf">http://www.cancercare.stir.ac.uk/documents/Phase1PublicInv.pdf</a>
<b>Study 3:</b> Scoping exercise	To identify how patient experiences are captured through involvement activities and research to influence research, policy, planning and practice	Ryan et al. (2005) A review of how patient experience is captured through patient involvement activities, CCRC, University of Stirling <sup>3</sup> <a href="http://www.cancercare.stir.ac.uk/documents/Phase1Scoping.pdf">http://www.cancercare.stir.ac.uk/documents/Phase1Scoping.pdf</a>
<b>Study 4:</b> Patient and carer advisory groups	To establish advisory groups of people affected by cancer across Scotland and identify core themes in their experiences which would inform the research programme	Worth et al. (2005). Patient Advisory Groups, CCRC, University of Stirling <sup>4</sup> <a href="http://www.cancercare.stir.ac.uk/documents/Phase1PAG.pdf">http://www.cancercare.stir.ac.uk/documents/Phase1PAG.pdf</a>
<b>Study 5:</b> People's experience of cancer within the first year following diagnosis	To find out about patients' experiences of cancer and cancer care within the first year following diagnosis	Hubbard et al. (2007) Phase 2 report: People's experience of cancer within the first year following diagnosis, CCRC, University of Stirling <sup>5</sup>
<b>Study 6:</b> Secondary analysis of cancer treatment related morbidity datasets	To assess the symptom burden of patients receiving cancer chemotherapy throughout a course of treatment	Kearney et al. Retrospective Review of cancer treatment related morbidity . <a href="http://www.cancercare.stir.ac.uk/projects/morbidity.htm">http://www.cancercare.stir.ac.uk/projects/morbidity.htm</a>
<b>Study 7:</b> Working in partnership with clinicians to use some of the key findings of Phases 1 & 2 to develop cancer care services	To implement the learning from the programme to date by working collaboratively with cancer teams and people affected by cancer to drive forward service change.	Knighting et al. 2007 <sup>7</sup> Enabling Change <a href="http://www.cancercare.stir.ac.uk/projects/sse_intro.htm">http://www.cancercare.stir.ac.uk/projects/sse_intro.htm</a>
<b>Study 8:</b> Evaluation of the Programme	To evaluate the programme of work from the viewpoint of people affected by cancer, people working in cancer care and key stakeholders.	Forbat et al. 2007 <sup>8</sup> Evidence of impact of Cancer Care Research Centre's Developing Cancer Services: Patient And Carer Experiences project <a href="http://www.cancercare.stir.ac.uk/projects/pce_intro.htm">http://www.cancercare.stir.ac.uk/projects/pce_intro.htm</a>

<sup>b</sup>All references to the reports generated by the three year programme of work are cited within the text in Vancouver referencing style. All external supporting work has been referenced using Harvard style.

Experiences has led to a revision of the model presented in Figure 1 in light of the evidence generated throughout the programme.

The commissioning of this three year programme of work, the first of its kind in Scotland, by the Scottish Executive Health Department enabled an in-depth exploration of cancer care from the experience of people affected by cancer. The programme of work was composed of three phases that involved around 2000 people and eight separate projects, as indicated in Table 1:

**Phase 1:** This phase aimed to map public perceptions of cancer and cancer care, current conceptualisation and understandings of the agenda of patient and public involvement, and identify who was involving people affected by cancer in policy and planning and research.

**Phase 2:** This phase aimed to explore people's lived experiences of cancer and cancer care.

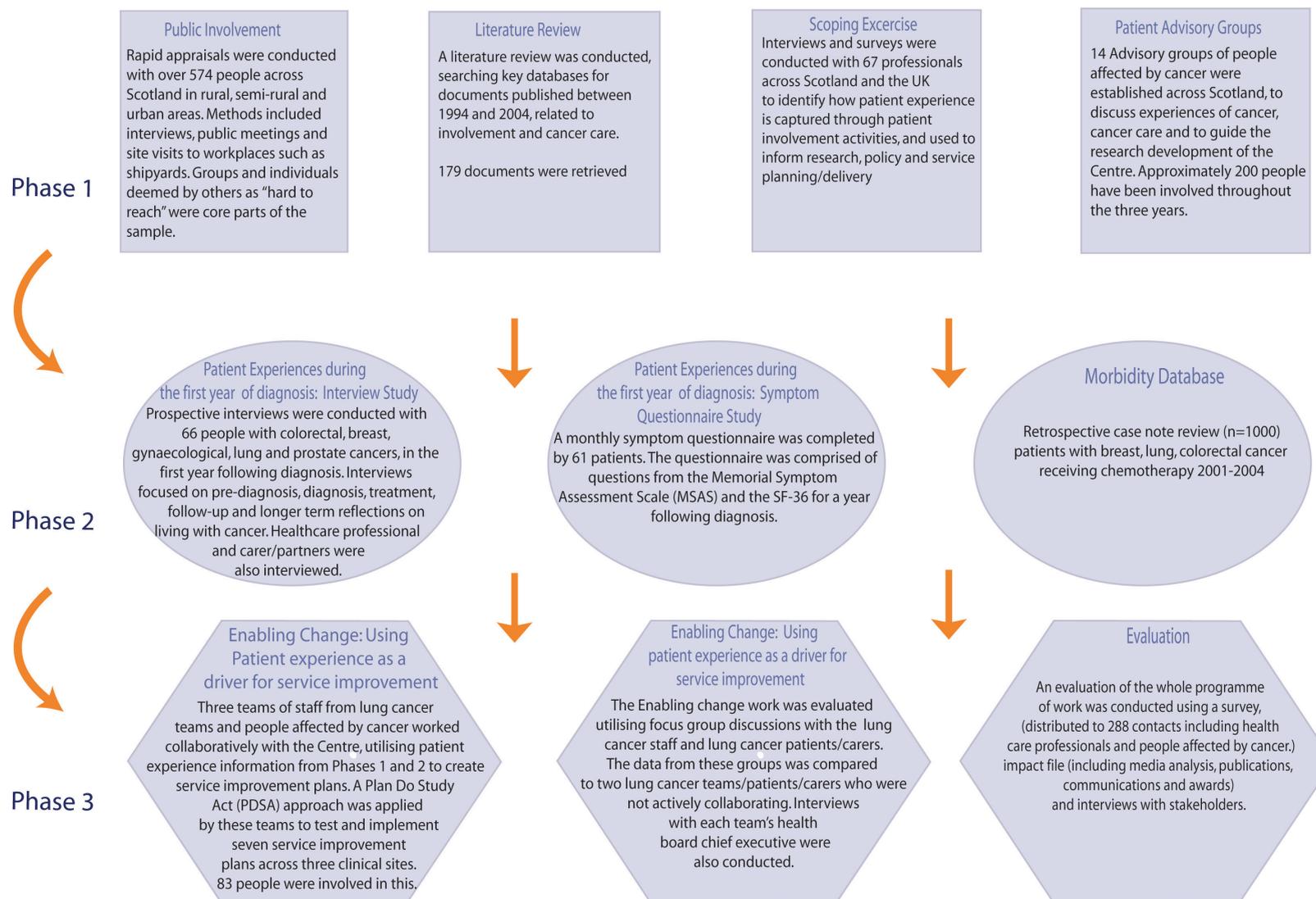
**Phase 3:** This phase aimed to use the findings from Phases 1 and 2 to drive forward service improvement and to evaluate the programme of work.

A range of methodological approaches were utilised for the different projects. An overview of these methods is presented in Figure 2. Detailed descriptions of the methods can be found within each of the project reports.

It was anticipated that undertaking this work would result in a number of outputs. These outputs were outlined in the approved Business Plan supported by SEHD and how these have been achieved are detailed in Appendix 1.

The final outcome of the programme of work is the development of a revised model for cancer care which is presented in this report.

**Figure 2: Summary of methods used in each of the projects**



## **Section 2 : EVIDENCE TO SUPPORT A NEW MODEL OF CANCER CARE**

### **2.1 Evidence to Support a Model to Improve the Experiences of People Affected by Cancer**

The Developing Cancer Services: Patient and Carer Experiences programme of work has generated some significant findings that, if implemented, could assist in improving the experiences of people affected by cancer in Scotland. This synthesis of the findings and conclusions has resulted in the development of a new model for cancer care that places the experiences of people affected by cancer as the key driver.

Over the past three years the Developing Cancer Services: Patient and Carer Experiences programme of work has remained cognisant of the policy context and clinical developments in cancer care. However, in undertaking this unique piece of work and following analysis of the data generated from all the components of the programme, it is clear that a different model of care is required across Scotland if the experiences of people affected by cancer are to improve. In this section of the report the evidence from this programme of work is presented which supports the model. It provides the rationale for a shift in the delivery and development of cancer care that has the experiences of people affected by cancer as the driver for change. This discussion is followed by the presentation of a new model for cancer services that focuses on the person and their cancer as being equally important within a caring paradigm.

There were inevitably gaps in the programme of work, for instance death, dying and bereavement did not receive sufficient attention, and some of the emergent issues that are discussed within the eight individual project reports require further research. It is also important to appreciate that wider public policy issues such as healthcare funding, and

policy generated from other Scottish Executive departments that may be relevant, for example, education and training and economy, were not closely examined.

Nevertheless, the outputs from the work provide the most substantial evidence available on the experiences of people affected by cancer and are sufficiently robust to allow the development of the model.

At the outset of this programme of work the aim was to develop a model that would facilitate improvements in the experiences of people affected by cancer. As indicated in Figure 2, the work involved a series of interlinked projects that informed the development of a model that is useful for cancer care and could also be applied to other areas of health care.

Synthesis of the data from all aspects of the three year programme informed the development of a model to improve the experiences of people affected by cancer. This section of the Final Report draws on evidence gathered throughout the programme, including the body of literature reviewed within each of the eight components of the work that supported the development of the model. The purpose of this section of the Report is to summarise the evidence from the programme of work which led to the construction of the model. The new model has been discussed and developed with an advisory group of people affected by cancer who debated its definitions, key components, use and scope.

While other models for cancer care have been developed, none offer the cohesive approach to truly integrating the interrelationships between the essential components as indicated in the model proposed in this report. Person-centred models (for example, McCormack and McCance 2006; and McIlfatrick et al. 2004), tend to physically represent the patient at the centre of services, but remain disconnected from the notion of experience or experiential knowledge.

The model proposed in this report offers a way of challenging the disconnection apparent in these models and draws on two complimentary theoretical frameworks: (i) the social model of health and (ii) a whole systems approach. The social model of health moves away from a purely medical understanding of understanding disease. It considers how determinants wider than the presence or absence of disease have an impact on health. Some of these wider determinants are socio-economic, cultural and environmental conditions, community networks, and lifestyle. The interaction of these features with cancer care can

be demonstrated through the impact of environment on individual lifestyle factors, such as smoking habits, diet and physical activity.

The term, whole system approach, focuses on the ways in which the entire context of a person's life is taken into account (the context includes those defined within the social health model, but is also informed by the influence of different professions and organisations). It is premised on the principle that the sum (the total life/care system) is greater than its parts. It follows, therefore, that what happens in one part of the system has a knock-on effect elsewhere.

The term, whole systems approach, is used differently within health care (where it is focused on health service systems) and outside of health care (where its meaning is used more broadly, and includes health service systems as part of a wider context that also includes social and personal milieu, including, for example, health beliefs). In this report, the broader definition is drawn on, to ensure that the model connects with recent drives towards partnership and joint working, but also advances the understanding to take in context beyond health service structures.

The complexity of cancer services necessitates a multilayered and interlinked approach if the experiences of people affected by cancer are to improve. From this programme of work it is clear that despite a range of discrete interventions to improve services, some people affected by cancer continue to experience less than ideal care<sup>5</sup> and comparably low survival rates (ONS 2007; Berrino et al 2007; Verdecchia et al 2007). The model, therefore, takes on this challenge of integrating all the core components of cancer care. Before introducing the model, definitions and evidence of each component are offered to ensure the precise meaning of each concept is clearly understood.

## 2.2 Experience

**Experience refers to knowledge and understanding of cancer and cancer care, which is derived through actually living with cancer. This definition acknowledges the totality of experience and includes survival, morbidity (physical and psychological), social and family issues.**

This programme of work highlighted a lack of understanding of the conceptual and practical use of the experiences of people affected by cancer in Scotland<sup>2, 5, 7</sup>. From the

work, a conceptual framework for understanding patient experience has been developed and empirical evidence about patient experience gathered<sup>5</sup>. This evidence will be of value for those tasked with implementing a dynamic model of healthcare in light of evidence about people's experiences of cancer and cancer care.

People's experiences of cancer and cancer care have to be gathered, understood and used in all parts of the model. Without this amalgamation, cancer services will not be developed according to patients' values, needs and preferences. The data generated from the work provides a substantial corpus of information hitherto not available. Combining the findings from the Phase 1 work on the views of the Scottish public in relation to cancer and cancer care<sup>2</sup>, the ongoing work with Patient and Carer Advisory Groups<sup>4</sup>, as well as the in-depth understanding afforded by the prospective collation of patient experiences in the first year following diagnosis<sup>5</sup>, has increased our understanding of the experiences of people affected by cancer. Furthermore the Enabling Change component of this programme has shown how the experiences of people affected by cancer can inform service improvement<sup>7</sup>.

The programme demonstrated that it is important to include the experiences of individuals at risk of developing cancer as well as those who develop the disease, from pre-diagnosis through to living with, or dying from, cancer. This means considering the perceptions and experiences of the public towards cancer as well as systematic assessment of morbidity (physical, emotional), social issues as well as disease monitoring and mortality. People's experiences of the impact of cancer on other areas of their lives, such as family and work, should also be considered core components of care delivery.

The term 'people' is consciously used in preference to 'patient' to ensure the inclusion of the general public (whose views of cancer aetiology impact on the uptake of health promotion messages) and family members (whose roles are often core in the experience of the condition). Based on this understanding of experience and the learning from the work on engagement and service improvement, the model is focused on the total experience of people affected by cancer and is the key driver for the model as well as being the object of improvement.

The programme highlighted that much of the care provided to people with cancer was good or excellent, yet problems and difficulties were also encountered<sup>4, 5</sup>. This is often because the patient's disease is viewed in isolation, and wider issues important to patients

are less well addressed, including symptom management, emotional and psychological issues, as well as social and familial circumstances<sup>5</sup>. Evidence suggests that individual healthcare professionals are aware of the social, psychological and employment impacts of cancer but do not always have the skills or opportunities to support patients in these areas. A lack of a culture of caring predominates, which can make patients feel disrespected and isolated.

Evidence about patients' experiences from the programme of work raises a number of issues about current policy and guidance (SEHD 2001; SEHD 2004; NICE 2004; SEHD 2005a,b; NHS QIS 2007). First; there remains much work to be done in implementing policy and guidance across Scotland so that all people affected by cancer consistently experience the benefit that this should provide. Second; although policy and guidance rhetoric appears to be formally correct, it is failing because it is not grounded in, or driven by, patient experience. Third; people affected by cancer require a whole systems approach to embedding experiences, because different policy and guidance agendas will impact on each other, and reviewing one area in isolation will not bring about sustained improvements. Evidence from this programme suggests that people with cancer value policy directives to reduce waiting times and improve access to treatment. However, this should not be to the detriment of other policy goals such as developing a culture of caring throughout the health service that reflects the whole patient experience, not just how the disease is managed.

Understanding the experiences of individuals diagnosed with cancer is fundamental to improving care. However, the impact of cancer is more widespread than the individual diagnosed with the illness. Throughout this programme the impact of cancer was evident in family members of those diagnosed with cancer<sup>5</sup> and cancer continues to significantly concern the wider public<sup>2</sup>. Evidence from the programme demonstrates that people's experiences of cancer and their relationship to it differs by a number of features, including deprivation and rurality<sup>2</sup>. Furthermore, knowledge of, and attitudes to, cancer are formed at an early age. Core beliefs about the aetiology of cancer and the potential for curative treatment are mediated by these axes of social contexts. The evidence suggests that basic health promotion messages are often not connecting with the understandings and experiences of people in these communities<sup>2</sup>.

Given the understanding of experiences of people affected by cancer generated throughout this programme of work leads to the conclusion that a model to improve the overall experience of people affected by cancer is urgently required.

There is no policy related specifically to patient experience and no clear conceptual framework that helps practitioners implement a model of care that is derived from patient experiences. In Scotland, the call to build a health service based on patient experience is currently embedded in policy relating to the agenda of involvement. There is some evidence of collating patient experiences (Centre for Change and Innovation 2004), however, this was a one-off initiative and related to people's experiences of services rather than experiences per se. In England, patient views of services are predominantly captured via satisfaction questionnaires, which have limitations in their ability to elicit patient-defined experiences of cancer and cancer care (Haas 1999). In contrast, this programme of work has produced a detailed understanding of people's experience of cancer which will facilitate more meaningful engagement.

## 2.3 Engagement

**The term engagement refers to working in partnership with people affected by cancer, having them inform (i) their own care and treatment, (ii) service redesign/improvement, (iii) policy and (iv) research.**

Evidence from this programme reinforced the notion that engagement of individuals affected by cancer remains largely tokenistic and is situated within a poorly articulated involvement framework.

The programme generated vast data on the status of involvement in Scottish cancer care. Evidence is presented in the literature review<sup>1</sup>, Public Involvement<sup>2</sup>, the Scoping Exercise<sup>3</sup>, Patient Advisory Groups<sup>4</sup>, Enabling Change<sup>7</sup> and Patient Experiences Evaluation<sup>8</sup> Reports. The term engagement is used, rather than involvement, within this Final Report as a component of the proposed model. Evidence from this work demonstrates that engagement is a more active process than involvement; it is rooted in a partnership approach and is more meaningful for people affected by cancer. Engagement moves beyond the concept of involvement which is often predetermined and facilitates a collaborative partnership which demands understanding rather than purely an information seeking process. However,

throughout this programme of work, people within cancer care referred to *involvement*, so where relevant, this word will be utilised within this report. Within the model, however, and when discussing CCRC activity, the term engagement is adopted.

Involvement of people affected by cancer in Scotland exists predominately in one-off and board level activities<sup>3</sup>. These options are not satisfactory for many who become involved, who would prefer other methods where involvement is less tokenistic and a relationship is developed and continues over the course of a project<sup>5, 7</sup>. Evidence from the programme demonstrates that there is little emphasis on initiatives led by people affected by cancer<sup>3</sup>. Yet, this programme of work demonstrated that it is possible to meaningfully engage with people affected by cancer in driving the research agenda and to collaborate with health care professionals to drive forward service change.

It is clear from this programme of work that people affected by cancer have to be engaged in all aspects of cancer care. If they are not engaged, they will not be able to influence what is happening. The programme demonstrated that people with cancer are willing to: (i) be active collaborators in their own care; (ii) act as participants in research projects so that their experiences are gathered; (iii) engage with researchers to plan, design and carry out research; and (iv) be involved in service improvement. In each of these domains, varying levels of participation are identified, from consultation (whereby well worked-up ideas are discussed with patients/public), through to collaboration (use of active, on-going partnerships between health care professionals/researchers/policy makers and people affected by cancer), and to user-led (whereby people affected by cancer are in control of driving forward and leading initiatives). It is also important to note that meaningful engagement has to be negotiated at an individual level, is context- dependent and can vary over time.

Evidence from the programme demonstrates that health care professionals perceive a number of barriers to involvement with people affected by cancer<sup>7, 8</sup>. Concerns focus on patient representativeness, health care professionals' beliefs that they already know patient priorities, inadequate funding and inadequate time. However, the evidence from this programme shows that those health care professionals who do actively involve people affected by cancer focus more on the potential for positive change, and identify a range of other challenges, such as the potential for role conflict when working collaboratively<sup>7</sup>.

Once underway with engagement initiatives, they rapidly identify the positives and are less concerned with what they perceive would be barriers to such relationships.

Concerns regarding achieving representativeness of people affected by cancer should be considered a diversion as it focuses attention on barriers to involvement (which are not upheld with health care professionals) and can be understood as a way of managing the anxiety regarding the changing role of patient from being passive to having agency and being empowered. What should be encouraged is a nuanced approach whereby patients' experiences are used and understood as partial. Where possible, people should be linked with others whose opinions and experiences are drawn together.

Given adequate emphasis and appropriate methods of accessing different communities, it is possible to involve a wider constituency of people affected by cancer, including those who, traditionally, are not involved. The programme demonstrated that it is possible to canvass the views of wide ranges of people, including those considered "*hard to reach*". The core to the approach advocated by this research is that people should not be considered "*hard to reach*" as this places the locus of responsibility on patient/public attributes. People at the end of life, younger people, men affected by cancer, those from rural communities, deprived communities and minoritised ethnic groups are all considered "*hard to reach*", but were successfully engaged within this programme as a result of assertive outreach by the research team<sup>2, 4</sup>. Key learning from the programme indicates that to access those considered "*hard to reach*", strategies should be developed that are based on meeting those groups within their own domains and communities<sup>2</sup>.

One of the greatest barriers to truly integrating meaningful engagement into health service, policy and research is ideological. Shifting the attitudes of policy makers, managers, and health care professionals so that they fully understand the value in patients' experiences informing services and research is paramount. Combining this with a rigorous approach to training is essential for the agenda to progress. There is a pressing need to challenge the belief that health care professionals know patient views by virtue of their role in delivering cancer care. It is clear that key factors need addressing to enable meaningful engagement to progress, including adequate training/support for health care professionals and people affected by cancer, human and financial resources, and clear boundaries and role responsibilities for all partners<sup>7</sup>.

To ensure meaningful engagement people need to be sufficiently empowered. This means, at a minimum, adequate support, power sharing, training and commitment from staff. While recognising NHSScotland has a highly skilled workforce, the skills utilised in involvement are necessarily different from clinical skills. Experiential learning has a significant impact on how people working in cancer care think of involvement<sup>7</sup>. Indeed, for the agenda of engagement to progress within the health service there is a need for health care professionals to experiment with small scale projects to enable them to interrogate and evaluate their assumptions about the barriers and potential for success. This programme of work demonstrated that meaningful engagement could lead to improved services.

## 2.4 Service Improvement

**Service improvement refers to sustained changes in the delivery of cancer services actioned through partnership between people affected by cancer and professionals to improve outcomes**

Whilst progress has been made in the area of service development through the cancer networks, there remain significant challenges within cancer care that need to be addressed to ensure sustained improvements to patient outcomes.

Service improvement initiatives are often driven from patient complaints. This approach is problematic, and needs to be distinguished from truly engaging with patients to improve services. Whilst complaints offer the patient an opportunity to drive their agenda, this approach feeds into the idea of narrow improvements rather than thinking more laterally about service improvement. Moving away from complaints and public meetings as a communication exercise means adopting the position in the National Framework for Service Change (SEHD 2005a), of seeing patients as partners in service planning. This level of partnership was rarely evident during this programme of work. There is a need, therefore, to increase the ability of health boards to seek out views to give the public "*a greater say in the way their NHS is run*" and "*redesigning services around the needs of patients*" (SEHD, 2005a, p. vi; p2), thus indicating a need to involve patients and the public before key decisions have been made, particularly in identifying specific targets for involvement.

Engaging with people affected by cancer to draw on their experiences when setting priorities and developing local services is a key element of a partnership approach to service

improvement. There has been limited progress in establishing this partnership method in Scotland, and most examples of patient involvement in service improvement have focused on small one-off projects<sup>1,3</sup>. However, this programme demonstrated that people affected by cancer and the wider public are willing and able to get involved in improving services, as long as there are clear aims and objectives so they feel that their contribution is valued and geared towards improving current services<sup>2,3,4,7</sup>.

Within this programme, most staff and people affected by cancer associated involvement primarily with ideas of patient involvement in their own care, or sitting on committees. This reflects a restricted uptake of the levels of involvement indicated in the PFPI strategy (SEHD 2001) and is likely to limit service improvement. Furthermore, involving people affected by cancer in improving quality of care and in service design was not consistently demonstrated by clinical staff<sup>7</sup>. A further distinction in how people respond to involvement was demonstrated through the tendency to equate involvement activity solely with patients; the role of family members was relatively rarely mentioned prior to this programme's intervention<sup>7</sup>.

Incorporating patient involvement for service improvement into staff's everyday job remains challenging. It is typically not contained within their routine clinical duties in the way that patient involvement in care practice is. Other key barriers include lack of private space, time, and resources for involving people affected by cancer<sup>7</sup>. However, although the number of reported barriers to engagement was vast prior to collaborative work with the CCRC as part of this programme of work, barriers received far less emphasis afterwards<sup>7</sup>.

This programme demonstrated that it is possible to create meaningful service improvement based on patient experience data while involving people affected by cancer as partners<sup>7,8</sup>. The programme has contributed to the limited evidence base regarding the impact of patient engagement and has clearly identified that people affected by cancer want to know that their involvement has the desired influence on services, research and care practice<sup>1,2,3,8</sup>. The application of partnership work between people affected by cancer and people working in cancer care to drive service improvement in this programme led to a wealth of learning for policy, practice and research<sup>7</sup>. Being involved in collaborative projects around service improvement did have a significant positive impact on staff views about engagement and how it can be incorporated into their work, for example increasing the knowledge and experience of patient engagement methods and processes of teams<sup>7</sup>. The

above indicates that when actively involved in engagement work, there is more emphasis on learning and partnership working than on the tensions<sup>7</sup>.

People affected by cancer are driven to get involved with service improvement initiatives to make a difference or help others who come after them. Therefore it is imperative that engaging people affected by cancer to use their experience in order to improve services is given the same attention and resource as service efficacy, reliability and governance. Such weighting was not apparent from this programme of work. Yet, taking an approach which starts and finishes with the experiences of those using a service is crucial if we are to meet the vision of an NHS which equally values the person and treatment of disease.

Given the lack of evidence documenting the impact of involving people affected by cancer in service improvement, it is also essential to evaluate the process of involving people to ensure that their involvement is valued and plays an integral part in the changes being implemented.

## 2.5 Research

**Research refers to investigating people's total experience of cancer, which includes survival, morbidity (physical and psychological) associated with cancer and its treatment, and social and family issues.**

Research is a fundamental component of cancer care, and spans from the laboratory to translational research, including basic scientific research, quantitative and qualitative investigations of treatment, supportive care and palliative care, and service evaluation. All of these components are required to provide the evidence necessary to improve both the process and outcome of care. This programme of work focused on research relating to the experiences of people affected by cancer and the wider clinical and scientific research agendas were not reviewed.

This programme highlighted the lack of engagement of patients affected by cancer in research. However, through this programme, people affected by cancer were willing and able to engage in all levels of research activity taking on a number of diverse roles, including: sharing their experiences of cancer care to inform the research agenda; advising on specific research projects; working collaboratively with researchers to develop funding bids; acting as critical colleagues in reviewing reports; contributing to identifying and implementing service change priorities with NHS cancer teams; acting as co-researchers in interviewing respondents and devising interview schedules; and presenting posters and oral presentations at conferences.

Collaboration in research is essential if the outcomes for people affected by cancer are to improve and must involve all researchers involved in cancer related research. However, ensuring research in cancer care takes place is not sufficient, and applying research in clinical practice is paramount if we are to improve cancer care. It was clear from this programme of work that this was not standard practice. Whilst much good care was evident across Scotland, some patients with cancer continue to report suboptimal cancer care, suggesting that available research evidence is not implemented in clinical practice<sup>2, 4, 5</sup>. This, coupled with the recent survival data (ONS 2007; Berrino et al 2007; Verdecchia et al 2007), would suggest that a shift in culture in relation to translating research findings into improved outcomes is urgently required. This collaboration is particularly important in relation to health promotion given the evidence generated within this programme of work<sup>2</sup> and could have a very significant impact on survival figures for cancer in Scotland in the longer term.

This programme of work raises questions concerning the focus of research and suggests the need for a national strategy for research that encompasses the totality of experience of people affected by cancer, including survival, morbidity (physical and psychological), social and family issues. Bringing together all those involved in cancer research, including people affected by cancer, to determine priorities, may be the first step in really addressing Scotland's poor performance in this area.

To fully embed the relationship between research, engagement, experience and service improvement, it is crucial that research draws on partnership working. This programme of work successfully developed partnership relationships to research the status of cancer care in Scotland with the voluntary sector<sup>2, 4</sup>, statutory sector cancer clinicians<sup>5, 7, 8</sup>, people affected by cancer<sup>4, 5</sup>, and the public<sup>2</sup>.

## 2.6 Partnership Working

Partnership working refers to the relationship and interactions between individuals, professions, health and social care services and other agencies.

Partnership and joint working has been a key component of health policy in Scotland for nearly a decade and this programme of work demonstrates that more needs to be done to deliver it<sup>2,3,4,5,7</sup>.

Whilst there remains a lack of consensus about definitions and meanings, the term is used in this report to refer to collaboration and linkage between different sectors, organisations and agencies, as well as between different people such as patients, carers and healthcare professionals.

Joint Future (Scottish Executive 2007) is the leading national policy on joint working between local authorities and the NHS. Community Health and Care Partnerships (CHPs) have been established locally in order to implement this policy directive. Alongside these partnerships, three Regional Cancer Networks operate (WOSCAN, SCAN and NOSCAN), and within these are Managed Clinical Networks (MCNs) that centre on specific cancer types, for example, breast cancer. However, how CHPs and MCNs formally collaborate is not clear from policy documentation, although individual professionals may be involved in both. There is a danger, therefore, that cancer strategies are uncoupled from those that are designed to improve health and well-being in general.

Partnership working within the context of the proposed model, therefore, is not a reiteration of MCNs, as it was clear from this programme that there are currently limitations to the effectiveness of such networks with evidence of poor partnership working<sup>5</sup>, lack of shared learning across Scotland<sup>3,7</sup>, and poor collaboration with the wider community agenda of health improvement<sup>2</sup>.

People with cancer and those caring for them identified, in particular, the need to bridge the gap between tertiary (cancer centre), secondary (hospital) and primary care<sup>5</sup>. This gap is particularly problematic given the prominent role primary care is anticipated to play in a healthcare future where people are being increasingly cared for in their local communities. Moreover, given that people experience cancer beyond the clinical environment and in

social and wider contexts, welfare advice, transport and employment agencies may also be considered as partners in supporting people with cancer. The programme of work highlighted a rationale for widening partnerships beyond health and social care because the impact of cancer permeates all aspects of people's lives including employment and financial circumstances<sup>5</sup>. Whilst it is not a given that extending partnership working to other agencies will improve outcomes for people living with cancer, it should encourage a focus of care that moves beyond the disease.

Partnership working, however, is not simply about relationships between different health, or even health and social care agencies. Evidence suggests that partnership must be embedded in local communities and be responsible for a community approach to health and well-being that is fully aware of the needs and concerns of the community<sup>2</sup>. There is a long tradition of community approaches to improving health in deprived communities, but this programme of work suggests that without systematically involving and engaging people to understand their beliefs and perceptions of cancer, these approaches are less likely to succeed<sup>2</sup>. Engagement of local communities in cancer care strategies means that greater awareness of cancer, and adoption of bespoke local strategies to reduce the risks of cancer at an individual level, may be seen.

Alongside organisational partnerships is the partnership between the patient and partner/carer (the dyad) and healthcare professionals (the triad). The role of partners/carers in supporting people with cancer is increasingly recognised in health and social policy and healthcare practitioners are expected to work in partnership with them. Evidence from this work indicates that practitioners fall short of implementing these policies because of a lack of understanding of how, why and when individuals with cancer include family/carers, and how family relationships change throughout the course of the illness<sup>5</sup>. Moreover, without understanding family dynamics, working with and supporting carers will be limited and suboptimal for those affected by cancer, thereby restricting the achievement of core patient-focused outcomes.

It is clear that if we are to achieve better outcomes for people affected by cancer, then there is a need to consider, as a matter of urgency, the partnerships that are required to enable such improvements.

## 2.7 Patient and Public Outcomes

**Outcomes refer to the key measurable determinants of improvements in the experiences of people affected by cancer. These include survival, reduced morbidity (physical and psychological) and wider experiences relevant to the individual.**

It is apparent from this programme of work that the current processes which drive cancer care often fail to acknowledge the total experiences of people affected by cancer<sup>3, 4, 5, 6, 7</sup> or the public who may be at risk of cancer<sup>2</sup> and in the main, do not engage in a meaningful way to ensure services reflect the needs of individuals<sup>2, 4, 5</sup>. It would appear, therefore, that if outcomes relating to cancer (incidence, survival, living with and dying from cancer) are to be improved then a different approach to cancer care is required. This programme of work would suggest that such an approach has to focus on the multiple concerns of individuals at risk, as well as maintaining the focus on disease outcomes. Whilst this combined approach may appear obvious, it is currently not the situation that exists in Scotland<sup>2, 4, 5, 6, 7</sup>.

Above all, the most important outcome for people affected by cancer is survival from the disease. However, evidence suggests that people affected by cancer have significant morbidity associated with their cancer and related treatment which they feel should be addressed with the same importance<sup>5</sup>. People affected by cancer want a service that tackles the disease (evidenced through improvement in morbidity and mortality) and one that treats them as a person (evidenced through improvements of their total experience).

Scotland's overall performance in relation to cancer lags behind other UK and European countries (Berrino et al 2007; Verdecchia et al 2007; ONS 2007). The outcomes referred to in such reports, however, tell only a fraction of the story for most people affected by cancer. This programme of work has demonstrated that what these data fail to capture are the totality of the outcomes for people affected by cancer<sup>2, 4, 5, 6</sup> and it is imperative that future cancer care in Scotland recognises and establishes processes of care that addresses the multiple outcomes that are important to those affected by cancer as well as their interrelationships.

It is without doubt that people want to have earlier diagnosis, quick access to the best possible treatment and optimal supportive care. Yet, this study identifies that there are fundamental flaws in the system that mean that such options are not consistently available

across Scotland<sup>2, 4, 5, 6</sup>. It is clear that the key outcomes for cancer are often determined by those involved in the delivery of cancer services, and it is these outcomes that appear to have driven the policy developments that shape the practice of cancer care. Such knowledge and experiences are vitally important, however, unless people affected by cancer are engaged with to understand the outcomes that are important to them, then there is a risk that overall outcomes for people with cancer will not improve.

This programme of work demonstrates that people affected by cancer are willing and able to share their experiences of cancer and cancer care, which inform understandings of what outcomes they want from a service. Specifically, people in Scotland want clearer information about their risk of developing cancer and easier access to services should they become concerned they may have cancer. They want optimal treatment of the disease and they want support to manage the physical, psychological and social impacts of living with or dying from cancer.

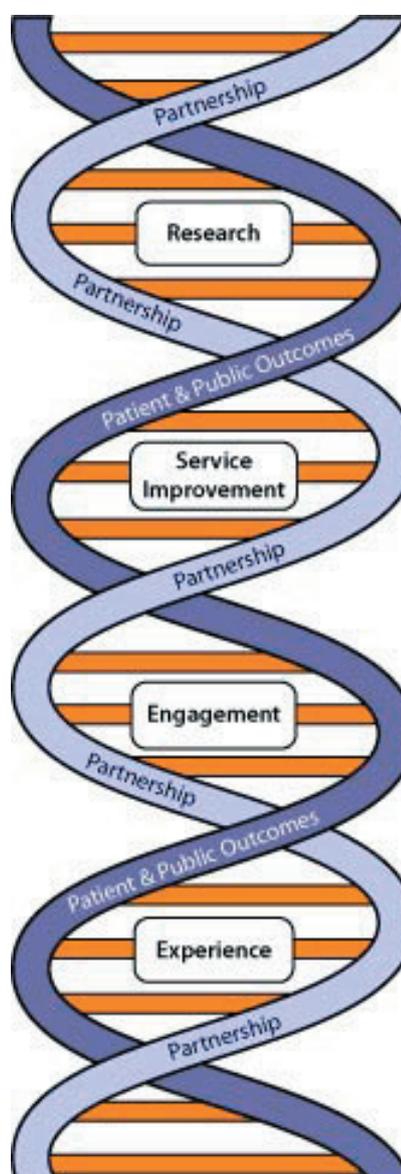
## **Section 3 : MODEL TO IMPROVE THE EXPERIENCES OF PEOPLE WITH CANCER (MIE-CANCER)**

### **3.1 MIE-Cancer**

Given the evidence presented above, and the stated intention at the outset of this programme of work, the following section presents a new model for taking forward cancer care in Scotland. The main elements of the model are not new and some of the elements are already well developed. However, what is novel about the proposed model is the integration of the components which situates experience as the core element. The model has been developed so that it can be applied at local service, regional and national levels, and in clinical practice, policy and planning and research.

As demonstrated in Figure 3 below, the model is intentionally structured within a double helix which is both figuratively and scientifically meaningful within cancer care. The key process strand of partnership working and outcome strand of patient/public outcomes are interdependent, and the fundamental cross-linking bases which form the basis of the model are: people's experiences; meaningful engagement with people affected by cancer; service improvement; and research.

**Figure 3: Proposed Model to Improve the Experiences of people affected by cancer (MIE-Cancer)**



The proposed model is one whose components interact, evolve and impact on each other. The components are informed by, and create a context in which, the person experiences illness and wellbeing. It is constructed with a number of components, including:

**Outcome Strand:** Improving outcomes for people affected by cancer is the key aim.

Patient and public outcomes are the key drivers for the model and should be the starting point for all policy and service development. Outcomes must consider both the person and their cancer.

**Process Strand:** Partnership and partnership working between all parts of the model is the key process. Without this, the model will not function effectively.

The process strand ensures knowledge transfer at, and between, all levels within the model.

**Cross-Linking Bases:** The four cross-linking bases are the fundamental basis of the model that have to be integrated at all levels of the model and absence of one or more of these will render the model ineffective.

Experience is the core driver for the model and is also the subject of improvement for the model. Engagement is required at all levels of the model and for this to be effective it must be negotiated with individuals. Service Improvement is the interface between experiences, engagement and research. Research is required to improve both the process and outcome of care.

## 3.2 Implementing the Model

The scope of the Model to Improve the Experiences of people affected by cancer (MIE-cancer) is extensive and can be used at a local, regional and national level. This application can range from small scale service improvement projects within local clinical areas to large scale national cancer service improvement programmes and in public health initiatives, and all phases of cancer care.

Key to its success is the determination, from the outset, of the desired outcome/s for people affected by cancer, which must be derived from actual experience and meaningful engagement. Underpinning any activity with relevant evidence (where this exists or generating it where it doesn't) and ensuring a service improvement model that incorporates the above will result in optimal outcomes which reflect patient experience (including tumour burden, psychological and symptom experience, and social context). Furthermore, the process of identifying and/or establishing the necessary partnership working required will ensure the necessary processes are in place to support the functionality of the model.

It is acknowledged that the application of the model within the realms of translational/ biomedical research has not been tested, however, from this programme of work it is clear that people affected by cancer would like to be informed and involved in this type of research and they feel that their experiences are particularly important in relation to the direction and content of such programmes of research.

## Section 4: CONCLUSION

### 4.1 Conclusion and Recommendations

People's experiences of cancer and cancer care must be the foundation upon which future cancer policy and planning, practice and research is built. The experiences of people with cancer that were elicited during this three year programme of work suggest that NHSScotland should:

- » Develop services that treat the disease and the person. The current dualism should be avoided, and instead, it should be recognised that the two are inextricably interlinked.
- » Deliver services so that there is a synergy between professional expertise and patient and public experiences.
- » Strengthen joint working between tertiary, secondary and primary care and expand partnerships to include social care, employment and welfare agencies.

At the outset of this work it was proposed that *"a national strategy which ensures a sound research base to underpin developing policy and practice in cancer care, with patients' and carers' unique experiences as a core driver"* (CCRC Business Plan to SEHD 2004) was required. The wealth of data generated from this programme of work has provided much of this evidence and produced a new model for the development of cancer services that, if implemented, will improve the experiences of people affected by cancer in Scotland.

Throughout the three years of this programme, many examples of good care and highly motivated clinical staff whose main aim is to provide the best possible care to people with

cancer were evident. Yet, for a range of reasons, many people affected by cancer expressed the view that this was not always their experience.

It is without question that many aspects of the model proposed within this Final Report are currently in place across the NHS in Scotland. However, evidence from this programme has demonstrated that outcomes for people with cancer could be improved, suggesting that a different approach is required. It is clear from this programme of work that acting at one level of the model (for example, service development) does not lead to optimal cancer care. What appears to be missing is an understanding of the interdependency of all the components articulated in the model. Therefore adopting this interlinked model for cancer care that centres on the person and their cancer, whilst contextualising this within the person's experience and the wider influences of cancer services has greater potential to effect change and ensure that improvements are sustained.

In constructing the model a number of issues wider than the disease model of cancer were considered, for example, how determinants wider than the presence or absence of disease impact on people's health. This is becoming more and more important, as many people are living longer with cancer and for some people cancer is now a long term condition. In addition, it was recognised that the majority of people with cancer are older and are likely to have more than one illness and suffer from a number of co-morbidities. The model has been developed to be responsive to these experiences, and services provided for people should reflect this complex picture. People with cancer should be viewed as such and not as an individual who "hosts" the disease.

The model was developed so that it could be utilised in other areas of health and social care to improve the health and wellbeing of the people of Scotland. Whilst its transferability beyond cancer has not been tested, the core aspects of the model relate to individuals and processes, not services, to enable its usage in other contexts.

Over the past decade Scotland has made significant improvements in services for people with cancer. However, it was evident from this programme of work that, in relation to improving the experiences of people affected by cancer, more remains to be done. Furthermore, recent data indicates that in terms of survival, Scotland's performance remains poor (Berrino et al 2007; Verdecchia et al 2007). Continuing to tackle experiences

and survival as individual constructs is unlikely to result in sustained and optimal outcomes for people affected by cancer.

This programme of work, commissioned by the Scottish Executive Health Department, has demonstrated the potential for a different model for cancer care. Applying this model would afford an opportunity to adopt a new mode of working in which all partners involved in cancer care and cancer research collaborate, placing the experiences of people affected by cancer at its core thereby ensuring improved outcomes for people affected by cancer.

To achieve this NHS Scotland should consider the following recommendations:

**RECOMMENDATION 1:** National clinical standards should be developed that explicitly addresses the totality of the patient experience and ensures systematic assessment of all aspects of cancer and cancer treatment-related morbidity, and family and social circumstances.

**RECOMMENDATION 2:** A national framework should be developed to establish meaningful public and patient engagement in (i) care treatment, (ii) service design/development, (iii) policy, and (iv) research; and its application should be evaluated.

**RECOMMENDATION 3:** A clear framework for cohesive partnership working in cancer care should be developed, implemented and evaluated across Scotland (this framework is not a reiteration of the cancer networks but recognition of the multiple networks involved in patient care and a clear articulation of these).

**RECOMMENDATION 4:** Review health promotion initiatives in relation to cancer with particular emphasis on rural and deprived areas of Scotland and develop, implement and evaluate, in collaboration with these communities, appropriate interventions with the aim of reducing the incidence of cancer.

**RECOMMENDATION 5:** A national strategy for research should be developed that encompasses the totality of the patient experience. The development and implementation of this strategy should involve researchers involved in all aspects of cancer and cancer care as well as people affected by cancer.

**RECOMMENDATION 6:** Implement the proposed model across one cancer network and evaluate its impact on patient outcomes prior to Scotland-wide application.

## Section 5: REFERENCES

All references to the reports generated by the three year programme of work are cited within the text in Vancouver referencing style. All external supporting work has been referenced using Harvard style.

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## APPENDIX 1 Outputs of the Patient Experience project 2004-2007 as indicated in the Business Plan to SEHD

Year 1	Agreed outputs and project dates	Outputs at June 2007
Systematic literature review	Written report (month 12)	Hubbard, G., Kidd, L., Donaghy, E., MacDonald, C., Simpson, M., Haig, A., & Walker, S. (2005). Phase 1 Report: Literature Review. Involvement of people affected by cancer in research, policy and planning and practice. CCRC Report.
Report on current activity (Scoping Exercise)	Written report (month 8) Web-based, dynamic version (month 8) <sup>C</sup>	Ryan, K., Worth, A., & Kearney, N. (2005). Phase 1 Report: Scoping Exercise. A review of how patient experience is captured through patient involvement activities and research to influence research, policy, planning and practice. CCRC Report.
Initial report from patient groups (Advisory groups)	Written report (month 6)	Worth, A., Rowa-Dewar, N., Hubbard, G., & Kearney, N. (2005). Phase 1 Report: Patient Advisory Groups. Involving people affected by cancer in advisory groups to inform research into cancer care in Scotland. CCRC report.
Papers on best practice in patient involvement	1st paper submitted end of year 1 then ongoing	<p>Publications:</p> <ol style="list-style-type: none"> <li>Hubbard, G, Kidd, L, Donaghy, E, (in press), Involving people in research: a review of literature, European Journal of Cancer Care.</li> <li>Hubbard, G, Kidd, L, Donaghy, E, (in press), People's preferences for involvement in treatment decision-making for cancer: a review of literature, Clinical Medicine: Oncology</li> <li>Hubbard, G, Kidd, L, Donaghy, E, McDonald, C, Kearney, N, (2007) A review about involving people affected by cancer in research, policy and planning and practice, Patient Education and Counseling, 65, 21-33.</li> <li>Rowa-Dewar, N., Ager, W., Kearney, N., Ryan, K., Hargan, I., Hubbard, G &amp; Thomson, M. (in press). Public views on cancer: reflections on using rapid appraisal in a nationwide, multi site public involvement study in Scotland.</li> </ol> <p>Other publications in preparation:</p> <ol style="list-style-type: none"> <li>Kearney, N., Rowa-Dewar, N., Ager, W., Ryan, K., Hargan, I., and Hubbard, G. The Widening Gap: Perceptions of cancer in affluent and deprived communities in Scotland. A population based study.</li> <li>Knighting, K., Rowa-Dewar, N., Kearney, N. &amp; Gibson, F. The use of the 'draw and write' technique to explore what primary school children think about health, cancer and cancer care.</li> </ol>
Website live	6 months	<a href="http://www.cancercare.stir.ac.uk">www.cancercare.stir.ac.uk</a>

<sup>C</sup> The web-based dynamic version of the scoping exercise was not developed due to the lack of information submitted by participants. It was agreed that the Scottish Executive would facilitate the sending out of a follow up questionnaire to all the PFPI Directors across Scotland this has not yet been actioned

Year 2		
Report from discussion meetings (Public Involvement)	Report (month 15)	Kearney, N., Rowa-Dewar, N., Ager, W., Ryan, K., Hargan, I., Gibson, F., Worth, A., Hubbard, G. & Walker, S. (2005). Phase 1 Report: Public Involvement. CCRC Report.
Report from focus groups	Report (month 20)	Knighting, K., Forbat, L., Cayless, S., & Kearney, N. (2007). Enabling Change: Patient Experience as a Driver for Service Improvement.
Identification of training and support needs	Report (month 22)	Knighting, K., Forbat, L., Cayless, S., & Kearney, N. (2007). Enabling Change: Patient Experience as a Driver for Service Improvement.
National database of patient experiences	Establish web database month 16 then ongoing development	Interim report and feedback from patients is available at <a href="http://www.cancercares.stir.ac.uk">www.cancercares.stir.ac.uk</a>
Year 3		
Report from Phase 2 interviews	Report (month 26-28)	Hubbard, G., Knighting, K., Rowa-Dewar, N., Forbat, L., Illingworth, N., Wilson, M. & Kearney, N. (2007). People's Experience of Cancer within the First Year Following Diagnosis. CCRC Report.
Report from combined focus groups	Report (month 28)	Knighting, K., Forbat, L., Cayless, S., & Kearney, N. (2007). Enabling Change: Patient Experience as a Driver for Service Improvement.
Construction, testing and utilisation of a sustainable model of patient focused service development	No date	Knighting, K., Forbat, L., Cayless, S., & Kearney, N. (2007). Enabling Change: Using Patient e Experience as a Driver for Service Improvement.
Morbidity database		Kearney et al. 2007 Retrospective Review of cancer treatment related morbidity.
Final report for the Scottish Executive and dissemination of best practice via the Networks	Report (month 38)	Kearney, et al. (2007). Developing Cancer Services: Patient And Carer Experiences. Final Report.

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Document Purpose	Final Report for three year programme of work, Developing Cancer Services: Patient and Carer Experiences
Authors	Professor Nora Kearney, Dr Gill Hubbard, Dr Liz Forbat Dr Katherine Knighting
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	<a href="mailto:cancercare@stir.ac.uk">cancercare@stir.ac.uk</a>
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Internet Address	<a href="http://www.cancercare.stir.ac.uk">www.cancercare.stir.ac.uk</a>
Price	Free

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