SCN Partnership Group

part of the NHS Sussex Cancer Network

NHS

sussex cancer network

SUSSEX CANCER NETWORK

PATIENT AND PUBLIC INVOLVEMENT STRATEGY 2010 – 13

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Executive Summary

The SCN PPI Strategy 2010-2013 reviews progress on the SCN 2004-2008 PPI Strategy. It describes the vision and direction for PPI for the next 3 years to support the SCN to achieve its Cancer Reform Strategy objectives, vision and values.

The SCN will demonstrate the core principles of meaningful PPI to ensure a positive impact such as: engaging early and planning involvement, preparing and supporting users, embedding the right user involvement initiatives at all key stages of development, removing barriers, canvassing the needs of patients and carers, ensuring involvement is properly resourced and identifying the impact involvement has had.

A summary is provided on the key achievements of the SCN 2004-08 PPI Strategy.

The key objectives of the Cancer Reform Strategy are used as a framework for strengthening current PPI initiatives and developing new PPI initiatives across the SCN. Patient and public involvement initiatives in SCN span the whole continuum of involvement; from giving information through to partnership forums for debate. The SCN Patient Information Strategy is outlined, to support all SCN provider organisations to engage in the use of the national cancer information pathways and prescriptions. The second phase of the SCN Cancer Experience surveys (radiotherapy, chemotherapy and surgery) will begin in December 2009, with quarterly feedback to the Multidisciplinary teams, chemotherapy and radiotherapy departments and tumour groups. Each MDT will incorporate the discussions and agreement on any changes needed into their annual report. The SCN Partnership Group will support the development, over the next 2 years, of a rolling self-reporting system for patients/carers to continuously feed back their experiences of services. The SCN and Partnership Group will strive to get information from other sources, for example from analysis of complaints made to PCTs and contact with Patient Advice and Liaison services.

In light of World Class Commissioning, there is an increasing desire to involve patients/carers and the public at all levels, but this does start to impact on a limited/valuable resource. In order to ensure that recruitment and refreshing of membership is maintained professionals working in cancer services will promote and provide patients and carers with information about the SCN Partnership Group or other ways of being involved in improving services. In addition the SCN Partnership Group will utilise their involvement in local patient-information initiatives, including their bi-monthly Newsletter, and cancer conferences/awareness events/ visits to local support groups to invite involvement and further develop their relationship with other avenues of engagement within the local health economy for example, PCT based health user banks and Local Involvement Networks.

The SCN will strengthen the participation of patients and carers in the tumour groups and generic groups, the Sussex Cancer Research Network, peer review and service improvement; all of which will strengthen their involvement in commissioning.

In summary, the SCN Partnership Group will ensure that by 2010:

- The best practice principles of involvement have been implemented
- The impact of involvement is clear
- The SCN Partnership Group have been integral to the implementation of the Cancer Reform Strategy across the SCN
- Patients and carers have full access to the information, including research trials, that they need to enable them to work in partnership
- The culture of partnership between managers, commissioners, clinical staff, patients, carers and the public is seen as the norm in the planning, buying and monitoring of cancer services
- Patient and public involvement is co-ordinated and communicated across all key groups

1 Introduction

The purpose of this second SCN Patient and Public Involvement (PPI) strategy is to:

- review progress against the first strategy (2004-2008)
- describe the vision and set a direction for the period 2010 to 2013

The intended consequences of the new SCN PPI Strategy

- to demonstrate the alignment of the objectives and work plan of the SCN Partnership Group with the overarching SCN objectives to demonstrate the partnership delivery of the Cancer Reform Strategy recommendations
- to develop and demonstrate measurable outcomes which show the impact of PPI initiatives across the SCN

1.1 What is the Sussex Cancer Network?

The Sussex Cancer Network (SCN) is a managed clinical network – a governed partnership between acute trusts, PCTs and the voluntary sector, overseen by the Network Executive Board. The SCN was first established in 1996 and its patient partnership group first met in 1999.

1.2 What is the aim of the SCN?

To ensure that high quality, patient focused cancer care services are provided on an equal basis to everyone across the region.

1.3 What is the vision of the SCN?

- Endeavour to reduce the incidence of cancer
- Deliver World Class Cancer Services that maximise the quality and length of life of those diagnosed with cancer

1.4 What are the values of the Sussex Cancer Network?

- **Endeavour to reduce the incidence of cancer**
- **Deliver world class cancer services that maximise the quality and length of life of those diagnosed with cancer**

2 Background

2.1 Practice principles in patient and public involvement

There are many PPI Manuals, Guidelines and toolkits which contain lists of principles for patient and carer involvement. The following list is taken from the Care Quality Commission Statement of Involvement (2009) Real Involvement (DH 2009) and other relevant sources.

In the SCN we will work to ensure that these principles are adhered to in our work with patients, carers and the public:

- Engage early and plan ahead
- Embed involvement in work process so that service users and the public are informed and involved at all key stages
- Include all the right people at the right time
- Act on what we learn to ensure that PPI has a positive impact
- Remove barriers to involvement through inclusive working methods
- Ask people what they need, not just about how satisfied they are with a service
- Enable patients and carers to gather views and experiences from their own communities so that they can become experts in user involvement
- Patients and carers work with professionals to shape the methods used to engage/involve them
- Involvement is two way – it includes feedback – what happened as a result of the involvement
- There are repeated opportunities to become more involved and patients and carers are helped to take on more in-depth involvement should they wish
- There are demonstrable outcomes set for and achieved for patient and carer involvement; everyone can point to how user involvement made a difference

- Patient and public involvement initiatives are resourced properly – through facilitation, expenses, support and training etc
- There are clear role specifications for service users who sit on committees or who have specific roles.

2.2 Demonstrating the impact of patient and public involvement

National reports on the effectiveness of patient and public involvement and PPI practice guidance often make the point that, whilst it is easy to demonstrate that the volume and range of involvement activity in the NHS has increased, it is far less easy to demonstrate the impact of that involvement on improvements in the experiences of patients and carers.,

Within SCN patients and carers are involved in many ways from being full members of the SCN Executive Board to completing surveys and taking part in focus groups at local level. It is important that patients and carers who give their time voluntarily to get involved and professionals who undertake involvement work know the impact of their endeavours.

The SCN will continue to explore and refine ways to evaluate the impact of patient, carer and public involvement during the strategic period. The following principles will be used as a starting point.

- Involvement is concerned with organisational level interventions in the planning, delivery and evaluation of services. It is not concerned with individual patient's involvement in decisions about their own care and treatment,
- Patient and carer experience of cancer services should be the primary criterion for measuring the impact of involvement
- Equal attention will be given to the qualitative and quantitative impacts of involvement
- The outcomes of involvement will not be confused with the impact of involvement. (The outcomes of involvement can be very positive but unless they have impact they are of limited value)
- At the commencement of any involvement project, success criteria for involvement will be identified in order that impact against those criteria can be evaluated at the end of the project
- At the end of any involvement initiative, pause to take stock and reflect on what needs to happen to ensure the involvement has a desired impact
- The Partnership Group and SCN will keep a record of the impact of involvement and report on this in the SCN Partnership Group Annual Report
- The SCN will disseminate the annual report to PCTs and other organisations so that the impact of involvement can be broadened.

2.3 Demonstrating the impact of the SCN Partnership Group

As the primary source of patient and carer input into the SCN, the Partnership Group needs to ensure that it is 'fit for purpose' During the Strategic period it will:

- make periodic assessments of the overall impact its work has had on the 'planning, delivery and evaluation' of cancer care services within SCN. Is the Partnership Group 'making a (positive) difference'? Is it focussing on the priority issues? Is it working to strengthen the capability of its membership (in terms of diversity in social cultural and ethnic background, in terms of the breadth of members and their experience?) Is it offering the kind of induction, mentoring and training to members which will improve the User Partnerships capacity to bring about change?
- ask, in the light of answers to the above question: 'Where does the Partnership Group want to be, and how will it get there?'
- Establish aims and intended outcomes concerning the improvement of performance of the user partnership group in its work (e.g. building member confidence and effectiveness through induction programmes and skills and mentoring)
- Developing a plan to achieve these improvement aims and outcomes – looking, for example, to group development and capacity building and skills development training
- Assess and review progress made

(Ideas in the above section have been taken from a paper entitled 'Service User Involvement in Cancer Care - An 'Issues paper' prepared for the National User Steering Group for National Cancer Peer Review ' by Hugh Butcher, June 2009

2.4 The first Public and Patient Involvement Strategy for Sussex Cancer Network (2004-2008)

This strategy covered the four years to 2008 during a period of significant organisational change within the NHS, through the introduction of the Cancer Reform Strategy, through a period when a new legal requirement for the NHS to involve and consult patients and the public came into force and through changes in the Network's Partnership Group.

In 2004 the Network acknowledged that it had been successful in developing a Partnership Group (established in 1998) as well as undertaking a range of ad hoc patient involvement initiatives. The challenge then was to set out clearly how patient and public involvement could be integrated more fully across the SCN so that it became part of 'how we work around here'.

In 2009 involving patients and carers is certainly 'how we work around here' for many Network professionals. Patients and carers are members of all significant Network groups and Committees and work in partnership with professionals on many issues of policy and practice. There are many examples of genuine involvement.

Challenges still exist, and these include;

- embedding involvement in primary care cancer services,
- ensuring that involvement has a positive impact and is not just an activity in itself,
- making it easier for a wider range of people to get involved,

- developing ways that patients and carers can get involved in commissioning cancer services and
- making sure we link effectively with the involvement structures of other organisations to avoid duplication

2.4.1 How did we do against our vision for Patient and Public Involvement in SCN by 2008?

In 2004 we made a number of statements about what we wanted to achieve by 2008. Below are those statements with a brief summary of progress. Generally there has been an increasing range of involvement and much more acceptance of involvement as a way of working at all levels. However the challenge remains to make sure that where changes are identified through patient and public involvement, they become a reality.

There will be a wide spectrum of initiatives and approaches to patient and public involvement across the network and the cancer patient pathway including involvement of the 'public' e.g. in service reconfiguration and redesign issues.

During the strategic period, Fit for the Future and the Lord Darzi Review of the NHS meant that members of the public had an opportunity to be involved in large scale events concerning the configuration of services. The broad principles from these initiatives are a very useful platform from which further local patient and public involvement can be developed.

Within the Network, patients and the public have been involved in systematic patient experience surveys, the design of new services and implementation of NICE Improving Outcomes Guidance. Extensive work involving patients and carers on SCN patient information pathways was undertaken during a two year Macmillan funded project.

Patient and public involvement will be an ongoing dialogue, part of every day business and will not be a series of stand alone initiatives.

Since 2004, patient and carers have become members of the Network Executive Board, the Clinical Advisory Group and the tumour and generic groups within the Network. Whilst there are still gaps in membership to be filled, this inclusive approach to involvement has meant that an ongoing dialogue is developing and systems are in place for it to be maintained, both within the individual groups and across groups. The 'traffic light' diagram at appendix 1 shows where the Network has patient and public representation on its groups. An evaluation of the impact of involvement on these groups needs to be undertaken, however early indications are that impact has been positive.

Initiatives will utilise and be integrated with existing structures for patient and public involvement not just those within cancer.

Organisational changes within the NHS, particularly the reconfiguration of Primary Care Trusts has meant that progress on integrating with existing structures for patient

and public involvement has been slow. However, collaboration in 2009 with PCTs on involvement in commissioning cancer services has provided opportunities to link with PCT based involvement mechanisms such as 'health user banks' panels and reference groups.
The development of Local Involvement Networks, which replaced Patient and Public Involvement Forums, will also provide an opportunity for the Network to integrate with other wider involvement structures.

All service providers and commissioners will be clear on the context in which they involve patients and the public and reasons for involvement

Ongoing dialogues between patient and carer representatives and provider staff at Executive Board, Clinical Advisory Group and tumour group level helps to ensure that the reasons for involvement and the involvement's impact on services are regularly considered. This is an area of work which the Network's Partnership Group will continue to focus on as it is important that patients and the public who give their time voluntarily are clear about what they are able to influence and that their expectations on the involvement process are met.

Patients, public and staff will have the opportunity to learn and train together on patient and public involvement

During the period covered by the strategy there have been several opportunities for patients, carers and staff to learn and train together. A workshop was held on arrangements for involving patients and carers in tumour and generic groups and specific training was delivered by patients and carers to Network staff on user involvement. Members of the Partnership Group have regularly given talks to cancer nurses at the University and are involved in curriculum development. The introduction of speakers at the regular Partnership Group meetings affords an opportunity for patients, carers and professionals to exchange ideas in an informal setting.

In 2009 projects on user involvement in commissioning have developed in the SCN as part of a National Cancer Action Team programme. These will enable reflective learning is part of the project process.

Patient and public involvement is owned by the network and it is part of everyone's job, reflected in personal objectives and performance managed.

As a starting point for the involvement of patients and carers on the SCN Tumour Groups and Generic Groups a specification was drawn up, which outlined the responsibility of the representative and the Chair. This is now part of the role of the Chair and has been incorporated into the constitution documents of those groups, reflecting their role in partnership working with patients/carers and the Group's responsibility in recruiting new members. The SHA Cancer Nursing Strategy launched in March 2009, stipulates the responsibility of cancer nurses in involving patients in service improvement. These objectives will be performance managed through the SCN Annual report.

Patients and the public will be involved:

- Not just when a major change is proposed, but in the ongoing planning of services
- Not just when considering a proposal but in developing that proposal
- In decisions that may affect the operation of services
- In delivery and evaluating services

Through the Network's Partnership Group, patients and the public have been involved at the very earliest stages of service development, in decision making and in evaluating service delivery. Examples during the strategic period include;

- Improving Outcomes guidance for Head and Neck, Sarcoma, Central Nervous System and Skin
- Upper GI Services – decisions about service location
- Supportive and Palliative Care Guidance
- Gynaecology patient-initiated follow up

Services are developed which are responsive to patient's wishes and needs

Phase 1 of the SCN patient experience surveys, initiated by the SCN Partnership Group is now complete. As a result the Multidisciplinary teams have initiated actions to address the shortfalls identified against the supportive care standards such as:

- Patients are given the contact details of a 'key worker'
- Patients are offered a 'permanent record' of any significant consultations
- Patients are offered generic information, such as finances, support groups and complementary therapies

Services value patient and public involvement and see partnership working as an integral part of care

Anecdotal feedback from professionals to patients and carers who have been involved in initiatives has often been positive. Although difficult to measure, the network group members have reported greater clarity on discussions and agreements as a result of patient and carer membership. All patient information is now developed in collaboration between health care professionals and patients.

Patient and public information is of a high quality and is accessible at all stages of the patient journey

A two year project funded by Macmillan Cancer Support during the strategic period focused on ensuring high quality patient information at appropriate points on the patient pathway. Patients, carers and members of the Network's Partnership Group were involved throughout the project and the Partnership Group continues to monitor the resultant Patient Information Strategy.

Patients have greater involvement in decisions about their treatment

The SCN Tumour Groups have been working with the patient/carer members to ensure patients are aware of and offered the choice of treatment options such as access to laparoscopic surgery. Minimum standards have been set in relation to CNS services for patients, where preference of treatment are recorded and advocated, if necessary.

Patients are given greater choice on where to access services and appointments

The SCN Tumour Groups have been working with the patient/carer members to ensure patients are aware of and offered the choice of treatment providers such as:

- Pancreatic services
- Breast reconstruction services

The SCN Palliative Care Group, including 2 patient/carer representatives have completed the cancer services directory for 12 out of the 14 organisations. The directory is shared with all patients so they are aware of the services available.

3 Why a second patient and public involvement strategy for the SCN?

In short because our partnership with patients and the public continues to evolve and there's more to be done!

When the first strategy was developed in 2004, the network set out its reasons for developing a specific strategy for patient and public involvement. Those reasons still hold true and are reproduced below with some updating of relevant legislation.

- To value the views of those who are affected by cancer as part of our partnership approach to delivering the overall SCN Strategy
- So that the views of patients and the public can be integral to the way cancer services are planned, developed, redesigned and evaluated within the SCN
- To inform the ongoing improvement and quality of services in the SCN
- To develop multiple perspectives on issues so that 'best fit' solutions can be achieved
- To reflect the requirements of Section 242(1B) of the NHS Act 2006 which places a duty on the NHS to ensure that users are involved in
    - The planning of services
    - The development and consideration of proposals for changes in the way those services are provided and
    - Decisions to be made affecting the operation of those services

- To reflect the requirements of Section 244 of the NHS Act 2006 to consult with the Overview and Scrutiny Committee
- To serve as a constant reminder to all NHS staff involved in decision making that the patient should always be 'sovereign' in the NHS.
- To make clear that patient involvement is not just about inviting patients to attend meetings
- As part of the SCN implementation plan for Improving Supportive and Palliative care for adults with cancer (DH 2004)

In addition, since our first involvement strategy, the Cancer Reform Strategy has been published, and this sets a useful framework for involving patients and the public in its six key areas for action.

4 Framework for patient and public involvement in SCN: The Cancer Reform Strategy 6 key themes

The Cancer reform Strategy provides a useful framework for structuring patient and public involvement around its six key areas for action. The SCN and Partnership Group have agreed to structure involvement activity in this way during the strategy period, adopting the aspirations for patients and carers at appendix 2. The SCN and the Partnership Group will work to improve the patient and carer experience across the six key themes and in line with these aspirations.

Below is a table which identifies the six Cancer Reform Strategy themes and the key functions or mechanisms through which patient and public involvement will be progressed.

The six key themes of the Cancer Reform Strategy and our contribution to the SCN Objectives					
Prevention	Diagnosing Cancer Earlier	Ensuring Better Treatment	Living with and beyond Cancer	Reducing Cancer Inequalities	Delivering Care in the most appropriate setting
Patient and carer involvement in the SCN tumour Groups and generic groups					
Patient and carer involvement in the Sussex Cancer Research Network					
Patient and carer involvement in Peer Review					
Patient and public involvement in commissioning cancer services					
Patient and public involvement in service improvement techniques					
Strengthening the co-ordination of patient and public involvement in SCN and beyond link up?					
Demonstrating the impact of patient and public involvement					

4.1 Objectives of the Sussex Cancer Network and how the SCN Partnership Group is supporting or will support the delivery of those objectives

SCN Objectives	**Examples from the SCN Partnership Group work plan**
Preventing cancer – reduce the risk of developing cancer through improved awareness of risk factors	➢ Involvement in PCT Local Awareness and Early Detection projects
Diagnosing cancer earlier – increase the earlier detection of cancer through improving symptom awareness, ensuring access to	➢ Involvement in the planning and delivery of primary care GP education. Position statement developed and circulated giving guidance on

screening programmes and ensuring prompt and appropriate referral	the involvement of patients in primary care education ➢ Involvement in the East Sussex PCTs and BHC PCT Early Awareness initiatives ➢ Lay version of the signs and symptoms of cancer incorporated into the 2009 Information, Awareness and Support booklet
Ensuring better treatment – Ensure timely access to high quality, clinically effective and cost effective treatments and care for all cancers, at every stage of the cancer journey, through delivery of waiting time standards, expansion in capacity and the effectiveness of radiotherapy services through to end of life care. Ensure that Sussex-wide issues for patients at the end of life (from any diagnosis) which prevent full implementation of the End of Life Care Strategy and quality markers, are addressed through collective initiatives	➢ Membership of the SCN tumour groups and generic groups ➢ Involvement in the West Sussex PCT radiotherapy programme Board and Patient Reference panel ➢ Involvement in the East Sussex PCTs chemotherapy and radiotherapy Patient and public Reference panel and Programme Boards ➢ Membership of the SCN Palliative Care Group
Living with and beyond cancer – inform and empower cancer patients and their families to take as active a role in their care as they wish, by ensuring the availability of clinical nurse specialists and allied health care professionals and appropriate, high quality, tailored information and support	➢ Contribution to the SEC Cancer Nursing Strategy and monitoring delivery through the SCN Executive Board ➢ Monitoring the implementation of the Supportive and Palliative Care IOG recommendations on psychological support
Reducing cancer inequalities – provide patients with the best possible experience and outcomes by delivering equitable, high quality, clinically safe and cost effective cancer services	➢ Agreement that the SCN work plan for 2010-2011 will include working with the SWSH cancer network on 'hard to reach' groups to ensure PPI is inclusive such as: rare cancers, the elderly, the young, patients with learning difficulties, black and ethnic minorities.
Delivering care in the most appropriate setting - ensure integrated cancer care, delivered in the most clinically appropriate and convenient setting for the patient, according to Improving Outcomes Guidance, with length of hospital stay reduced where appropriate and emergency admissions minimised	➢ PPI involvement in SCN in-patient service improvement projects ➢ SCN Partnership visits to the chemotherapy and haematology departments ➢ Involvement in peer review
Using information to improve quality and choice - ensure the availability of robust, accessible information on the performance of cancer services to support patient choice and quality	➢ Working closely with the SCN Macmillan Information project to enable access to the national patient information pathways and prescriptions ➢ Tumour group members to be involved in the review of local evidence to support the national information pathways.
Build for the future - ensure the availability of	➢ Macmillan cancer voices training to be

a skilled and flexible cancer workforce, that can embrace treatment innovation, with the necessary training and equipment, to support the delivery of world class cancer services and research programmes	repeated in 2010 for patients/carers and professionals
We will achieve these objectives through:	
Working collectively and collaboratively with all stakeholder organisations within and outside the SCN boundaries	➢ Membership of the tumour groups and generic groups, SEC Drugs and Therapeutics Group, service improvement initiatives.
Engaging clinical staff, patients, carers, local authorities, the voluntary sector and the general public in all aspects of cancer services planning, design, provision and quality assurance	➢ Partnership Group bi-monthly newsletter to widen the engagement of patients across the SCN
Promoting and strengthening commissioning processes, supported by an expert cancer management team (whose functions are the provision of specialist advice on service improvement, investment and prioritisation; facilitation of changes needed to implement national and local policies; quality assurance of the pathways provided; and, enabling and informing the members of the partnership on national and local data and future developments)	➢ Involvement in the national PPI in commissioning pilots ➢ Peer Review ➢ Network Development Programme
Making the best use of available resource by funding cost effective cancer services that make a difference to patients	➢ Involvement in the national PPI in commissioning pilots

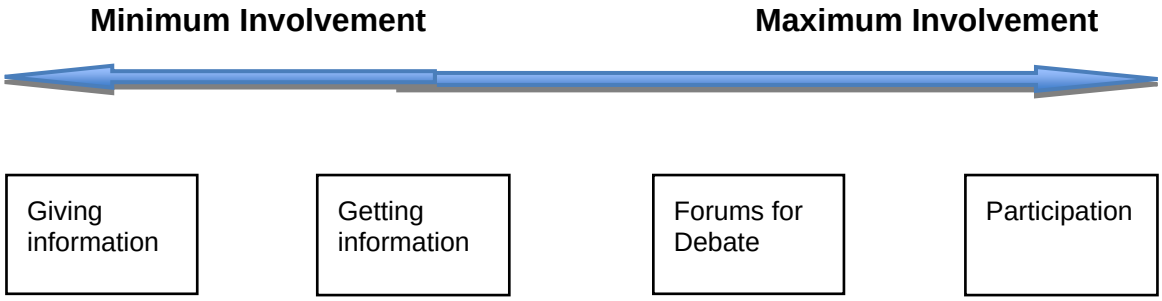
In addition the SCN and Partnership Group have identified a number of key operating functions through which its PPI work will be progressed during the strategic period.

5 How do we involve people and how will we sustain and strengthen PPI in the SCN?

For patient and public involvement to be real in the SCN, clarity is required about the level of involvement which is being offered or being sought by patients and the public.

In the first strategy the SCN used a continuum of involvement to map the work it had done, to identify gaps and to ensure a spread of involvement throughout the Network, balanced across programmes. The continuum, which is reproduced below (in a

slightly revised format is found within “Real Involvement” (DH 2008)). The purpose of the continuum within this strategy is to ensure that there is clarity and honesty about the level at which patients and carers are being invited to get involved.



Patient and public involvement initiatives in SCN span the whole continuum of involvement. Since the first strategy there has been a shift in emphasis along the continuum from getting information from patients and carers towards debate with those who use services and ultimately shared decision making. This shift in emphasis is perhaps best referenced by the presentation given by Partnership Group members at the SCN conference in September 2008. This demonstrated how patients and carers have become involved in debates at all levels of the SCN’s work.

5.1 Giving Information

Alongside this general shift has been a greater emphasis on giving information to patients and carers which is demonstrated by the significant patient information projects undertaken locally. Patients and carers need to be well informed to enable them to become engaged in the development of services. Therefore, in addition to, ensuring that patients and carers are kept informed about key areas of development needed across the SCN, the SCN Macmillan Information project manager will develop an implementation plan to ensure all patients are offered information from the national information pathways, supplemented with information about local services. Strategically, this will include ensuring a robust process is set up to ensure any Information and Support Centres which are developed, local information hubs and primary care have access to relevant, high quality information (see appendix 3).

5.2 Getting Information

The purpose of the SCN getting information is in order to understand more about the patient and carer experience of cancer services locally so that they can be monitored and improvements made.

Currently, one of the main ways that the SCN and the Partnership Group get information is through the patient experience surveys which are part of the work of every tumour group, and through targeted focus groups. The SCN Partnership Group will support the development, over the next 2 years, of a rolling self-reporting system for patients/carers to continuously feed back their experiences of services.

During the strategic period, the SCN and Partnership Group will strive to get information from other sources, for example from analysis of complaints made to PCTs and contact with Patient Advice and Liaison services. It is anticipated that Local Involvement Networks will also be a source of information about patient experience once they are fully established locally.

5.3 Forums for debate and participation

In order to ensure that debates and participation with patients/carers is effective, it is crucial to ensure that there are sufficient numbers of patients/carers who are able to engage in the process. In light of World Class Commissioning, there is an increasing desire to involve patients/carers and the public at all levels, but this does start to impact on a limited/valuable resource. In order to ensure that recruitment and refreshing of membership is maintained the following should be implemented:

- Professionals verbally giving patients and carers information about the Partnership Group or other ways of being involved in improving services
- Utilising publicity on cancer-related topics to invite involvement
- Utilising all avenues of engagement within the local health economy for example, PCT based health user banks and Local Involvement Networks
- Distribute Partnership Group newsletter as widely as possible both in hard copy format and email
- SCN Partnership Group to attend cancer conferences / awareness events with a display stand and leaflet information advertising the Group and other methods of involvement
- SCN Partnership Group members to attend cancer patient support group meetings with a *PowerPoint* presentation explaining what the Group does and explains how people can become involved in improving services

5.3.1 Involvement in the SCN Tumour Groups and Generic Groups

The SCN Partnership Group has outlined to all SCN Tumour and Generic Groups through their constitution documents, their recommendations on how those groups will enable patient involvement in their work plans.

Prior to joining the tumour group, the patient/carer will be contacted by the SCN Macmillan Nurse Director to discuss the role and function of the group. The Chair will be informed and an introductory welcome will set arranged between the representative and the Chair of the group utilising the agreed person specification agreed by the SCN Partnership Group in August 2008. At the representative's first meeting, the SCN Macmillan Nurse Director or one of the Clinical Nurse Specialists will be designated to support the patient/carer. If more than 2 representatives would like to join the tumour group, this will be discussed and agreed by the Chair.

1. **When there are two patient/carer representatives on a tumour group we expect the tumour group to;**
   - Allow sufficient time for patient/carer members of the tumour group to understand the content of the work plan
   - Through it's chair, facilitate the patient/carer members of the tumour group to ask questions and formulate suggestions about how other patients/carers are to be involved in the work plan
   - Appreciate that the role of patient/carer members is to represent the range of views of the Partnership Group and to encourage wider patient and public involvement in the Tumour Group's work
   - Work through the patient/carer representatives in seeking the views of the Partnership Group and allowing the representatives to raise issues of concern from the Partnership Group as appropriate.
   - Ensure the tumour group nominated lead for User Involvement supports those patient/carer members at the meeting and is accessible between meetings to explain any complex issues which require verbal explanation.

2. **When there is only one patient/carer representative on a tumour group we expect the tumour group to:**
   - Adhere to the above expectations
   - Notify the Macmillan Nurse Director when a patient/carer vacancy arises so that a suitable representative can be found from within the Partnership Group membership.
   - Actively work through the CNSs to recruit a second patient carer representative when one cannot be found from within the Partnership Group. The Partnership Group will offer support to any new members and will facilitate briefing and training where required.

It is the view of the Partnership Group that it is ultimately the responsibility of tumour groups to recruit appropriate patient/carer representatives. Wherever possible the Partnership Group will try to find representatives. The Partnership Group is always willing to assist with briefing and induction of new representatives and actively encourages then to join the Partnership Group.

3. **When there are no representatives on a tumour group we expect the tumour group to:**
   - Actively work through the CNSs to recruit a patient/carer representative when one cannot be found from within the Partnership Group.
   - Welcome a patient/carer member who has not had that type of cancer or treatment to support the group to explore and implement involvement of local patients/carers into their work plan.
   - The group to explore innovative ways of involving patients/carers who are unable to attend the tumour group meetings but would like to be involved and contribute.
   - Discuss with the Partnership Group how the range of patient/carer views can best be represented. This might be through a user group of support groups or through national groups where appropriate.

- Ensure that mechanisms are in place to canvass the views of patients and carers through innovative means
- The nominated tumour group user lead will ensure that alternative methods of ensuring patients and carers are involved with the development of services are implemented and report to the group on how this will be achieved and the results of that involvement.

The above is to be read in conjunction with the Role Specification for Representatives on tumour groups which provides additional information.

5.3.2 Involvement in the Sussex Cancer Research Network

Engagement with research happens in two principal ways: firstly via the Partnership group representatives on Network Tumour Groups, and secondly via consumer members on the Network's Research Management Group.

Tumour Group representatives are involved in the discussion of site - specific trials in the Network, looking at issues such as equity of access, recruitment & communication with patients and their carers. There are a number of cross-cutting groups (chemotherapy, palliative care) in the SCN who will review and consider access to trials.

PPI members of the Network's Research Management Group contribute on similar issues Network wide, with additionally an overview of the Networks' Research Strategy.

The ‘vision’ for strengthening patient/carer involvement in research trials is about ensuring that:

- Patients are offered information about the trials available locally, across the SCN or in tertiary centres in a timely manner
- Patients are supported with verbal information about trials
- The patient/carer members of the SCN Tumour/generic group are provided with information about trials to enable them to contribute to discussions about access, availability, equity and recruitment into trials

5.3.3 Involvement in Peer Review

Peer Review is shorthand for the National Cancer Peer Review (NCPR) programme, through which the performance of cancer teams across the country is reviewed against standards (‘quality measures’) set out in the NHS Manual for Cancer Services (2008). In Peer Review, the people doing the reviewing are the teams’ peers - clinical staff and patients/carers.

2009 marks the start of the third round of Peer Review (previous rounds being conducted in 2001 and 2004-07). In summary, Peer Review assesses every team that delivers a cancer service as follows:

Process	Description	Frequency	By whom
Self Assessment	Desktop review of evidence	Annual	Members of own MDT or Tumour Group
Internal Validation	Review of documents; interview	Annual	Members of a different MDT, patient/carer, Trust Cancer Executive Lead, PCT Commissioner
External Verification and peer review visit	Review of documents; interview	At least every 5 years	Clinical staff, managers and patients/carers from another Network organised through the South zone peer review team

The SCN sees Peer Review as a very direct way of involving patients and public in examining, evaluating and developing cancer services. Accordingly, within the SCN, patients and carers will be involved in all stages of Peer Review:

- as members of Internal Validation panels (e.g. SCN breast tumour group members reviewing SCN skin tumour group evidence)
- as members of External Verification and Peer Review Visit panels for other Networks
- as members of the Tumour Groups responsible for providing evidence for Peer Review and for implementing changes
- as developers and deliverers of Peer Review training

The SCN will seek feedback from patients, carers and NHS staff involved in Peer Review and use this to ensure continual improvement of the process. The SCN Partership Group will review the expenses offered to participants to ensure involvement is not hampered by the time commitment needed.

5.3.4 Involvement in commissioning cancer services

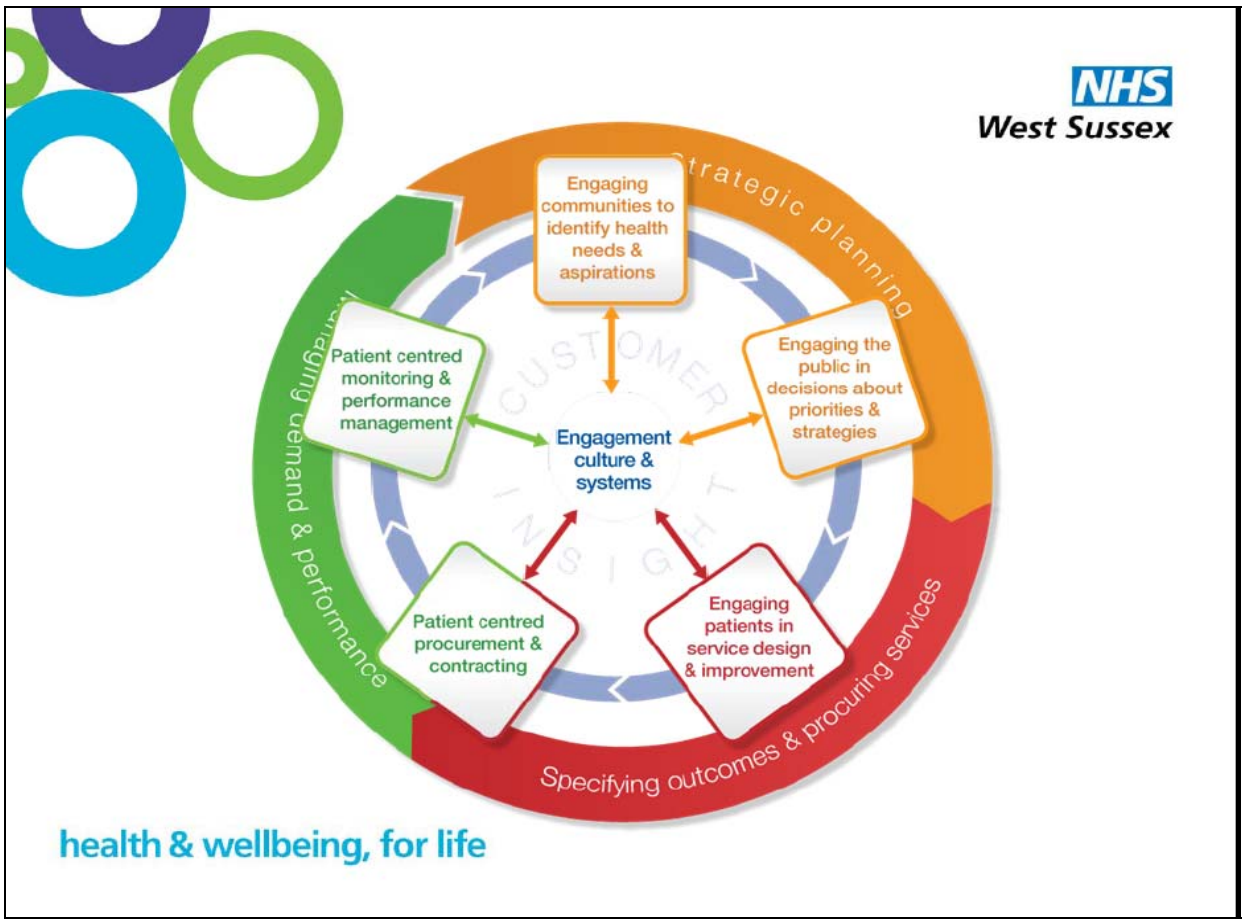
The term ‘commissioning’ means planning, buying and checking services, based on the needs of people, best value for money and quality and can be used to describe many levels of decision-making, from top-level strategic decisions made by commissioning boards, through to the smallest decisions about a particular service.

Primary Care Trusts are the main commissioners of services in the NHS and have a legal duty to involve patients and the public under section 242(B) of the NHS Act 2006 as well as a duty to report on consultation about commissioning decisions under section 24(A) of the same act. In addition one of the competencies within the national policy document, World Class Commissioning, determines that PCTs should ‘proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health. It therefore makes sense for the PCTs and the SCN to work collaboratively on involvement in commissioning.

In 2009 the four PCTs in Sussex and the SCN have commenced work on User Involvement in Commissioning, 2 of which are part of a National Cancer Action Team Pilot:

- West Sussex PCT – Review of radiotherapy services
- Brighton and Hove City PCT-Chemotherapy closer to home
- East Sussex Downs & Weald PCT and Hastings & Rother PCT – Late presentation of cancer (now withdrawn from pilot programme)

The pilot projects will inform the National Cancer Action Team and the SCN Partnership Group about future standards for patient involvement in commissioning cancer services.



The three projects listed above have acted as a catalyst for closer working between the SCN and the PPI departments of each PCT. We shall aim to build on this throughout the strategic period.

5.3.5 Patient and public Involvement in service improvement

The vision for patient and public involvement in Service Improvement builds on the elements set out in the SCN PPI strategy 2004-08, updated in line with Section 242(1B) of the NHS Act 2006:

- Patients and the public will be involved in:
  - The planning of the provision of services
  - The development and consideration of proposals for changes in the way those services are provided
  - Decisions to be made affecting the operation of those services

- Services are developed which are responsive to patients' wishes and needs

- Services value patient and public involvement and see partnership working as an integral part of care

In short, patients and the public will be involved in: identifying, prioritising, scoping, designing, implementing and reviewing service improvements. The SCN's aim is to achieve this within the strategic period by:

- Working closely with statutory and voluntary sector clinical and managerial teams, PALS and PPI departments to help them establish effective methods of patient and public involvement, adhering to the principles outlined in Section 2;

- Developing resources to enable clinical teams to undertake their own patient and public involvement;

- Reviewing on-going patient and public involvement with clinical teams, patients and public to identify and effect improvements.

As the first step in this process, a one-year project in 2008-09 focussed on providing PPI support to across the SCN. The output from this project including a report on lessons the learned from the PPI work undertaken in the year can be found in appendix 4

6 How do we strengthen the co-ordination of PPI in the SCN?

How does patient and public involvement in SCN link up?
In some ways this is an impossible question to answer because every day within the SCN there are numerous examples of patient and public involvement carried out by staff at every level. What is important is that work is not duplicated and that the SCN makes best possible use of the available structures both within and outside the SCN to communicate the outcomes of involvement work.

In 2007 the SCN Partnership Group undertook work to map links with existing groups and structures and to identify the key ways in which patient and public involvement work could be communicated and linked together. The following is a summary of that work and identifies information flows.

	SCN Partnership Group contributing to these Groups	**SCN Partnership Group disseminating information from these groups**
SCN Clinical and management Groups		
➢ Executive Board ➢ Clinical Advisory	➢ Discussion of key issues at SCN Partnership Group	➢ Summary in Partnership Group bi-monthly

Group ➢ Tumour and generic groups ➢ LCN/AHP Group	fed into the groups by members. ➢ SCN Partnership Group will contribute via the SCN Macmillan Nurse Director or will attend adhoc meetings to support key user involvement issues ➢ Partnership Group members presenting items on issues agreed by the Partnership Group ➢ SN Partnership Group sharing position statements ➢ SCN Patient experience surveys ➢ Support Groups and lay members of the local Cancer Action Groups, sent the details of tumour group members to feed key issues in to.	newsletter sent to PALS, PPI Leads, SCN Lead Managers and Commissioners, all local support groups and user groups, SCN Team. ➢ Members report back from Groups attended at each Partnership Group meeting but at least once a year ➢ Twice yearly meeting of all patient/carer members of tumour groups to share key experiences and themes. ➢ Members given a list of key contacts to disseminate information
➢ Commissioning and Lead Managers	➢ SCN Partnership Group user involvement in commissioning projects ➢ SCN annual report and work plan disseminated	➢ SCN Macmillan Nurse Director's bi-monthly report for the SCN Partnership Group Newsletter
Local Cancer Groups		
➢ Support Groups ➢ Cancer Action Groups ➢ SCC Information and Support Centre Group	➢ Partnership Group Newsletter ➢ Involving local groups about local issues and activity (such as local chemotherapy group visits) ➢ Letter sent to all local support groups offering for Partnership members to visit to hear their views. Several Groups visited in 2008/09.	➢ Request for articles/updates from lay members of local groups for the SCN Partnership Group Newsletter ➢ SCN Partnership Group receives the minutes from the ESHT Cancer User Group for the Newsletter ➢ Contact details of SCN PG Chair, Vice Chairs and names of tumour group patient/carer members for any

		issues they want fed back to the SCN.
Local User Groups		
➢ PCT Health User Banks ➢ PCT and Trust PPI Leads and Pals ➢ Local Involvement Networks (LInKs)	➢ SCN Partnership Group Newsletter ➢ SCN Partnership Group responding to requests for support and involvement	➢ SCN Partnership Group Newsletter ➢ SCN Partnership Group involving PPI Leads on wider issues and seek wider involvement ➢ PPI Leads have the contact details of the SCN Macmillan Nurse Director
National Cancer Involvement Groups		
➢ Network Development Programme Patient Forum	➢ SCN Partnership Group Chair, SWSH/SCN members and SCN Independent Facilitate attend and contribute	➢ Meeting summarised in the SCN PG Newsletter. Items for further discussion added to the agenda of the Partnership Group and discussed bi-monthly

7. The vision and direction for PPI in the SCN for 2010 to 2013

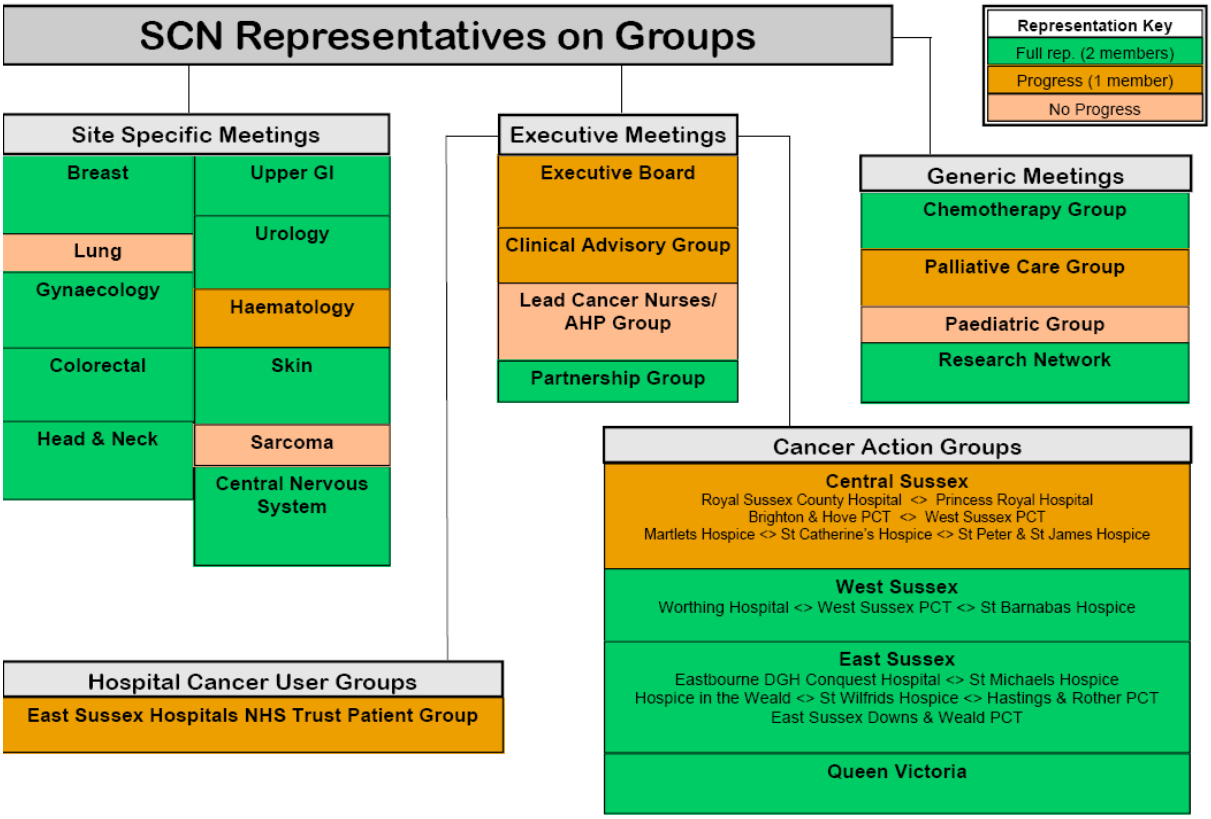
The SCN Partnership Group will ensure Patient and Public Involvement continues to develop through ensuring that by 2013:

- The best practice principles of involvement have been implemented
- The impact of involvement is clear
- The SCN Partnership Group's have been integral to the implementation of the Cancer Reform Strategy across the SCN
- Patients and carers have full access to the information, including research trials they need to enable them to work in partnership
- The culture of managers, commissioners, clinical staff, patients, carers and the public is seen as the norm in the planning, buying and monitoring of cancer services
- Patient and public involvement is co-ordinated and communicated across all key groups

Report end

Appendix 1

SCN Partnership Group representatives on SCN Groups



The SCN would like to thank the Dorset Cancer Network Partnership Group, who developed this chart, which has been adapted.

Appendix 2
Cancer Reform Strategy – Aspirations for Patients and Carers

Our Aspirations for Patients and Carers within the Cancer Reform Strategy Six Key Areas for Action					
Prevention	**Diagnosing cancer earlier**	**Ensuring better treatment**	**Living with and beyond cancer**	**Reducing cancer inequalities**	**Delivering care in the most appropriate setting**
The public across the SCN will be provided with accessible information (internet, leaflets, social marketing) on the risk factors of cancer	The public across the SCN will recognise the signs and symptoms of cancer through the provision of information	Patients will be given information in advance of their hospital appointment about what to expect	Patients are offered verbal and written information about managing any side effects of treatment, and generic supportive information such as finance advice, support groups finance	All patients who want radiotherapy are not restricted from doing so because of travel	All patients have access to high quality, safe treatment as local as possible
The public across the SCN will be provided with support to make informed choices about the risk factors for cancer	The public across the SCN will be aware of the success of cancer treatment to reduce the fear of seeking help	Patients will be offered verbal and written information about investigations and treatment options, including research trials	Patients will be able to access local and Sussex Cancer Centre bases for agreed national and local information pathway materials	All members of the public, including those from black and ethnic communities, travellers, the elderly, those with learning difficulties are supported to gain equal access to cancer services	No patient is admitted to hospital unnecessarily and an appropriate length of hospital stay
The public are supported to make an informed choice about access to screening	The public across the SCN will be aware of GP support available if any of the symptoms of cancer occur	Patients will be offered a 'key worker' and be clear about their role	Patients receive a care plan at the end of treatment which gives guidance on patient-initiated follow up and access to support if needed	All patients are offered verbal and written information which meets their cultural/educational needs	
	The public will be listened to and welcomed by primary care when they present with the signs and symptoms of cancer	All patients are offered a copy of the GP letter/patient Held Record/taped consultation	Patients are provided with verbal and written information about how to become involved in the development of cancer services	The Partnership Group will be actively working towards achieving a membership that reflects the makeup of the diverse communities,	

			and the SCN Partnership Group	and will continue to encourage and develop initiatives for the under-represented. They will ensure that equal rights and diversity are a high priority and an integral part of the way the Partnership Group operates. They will continue to be committed to playing an active role in combating discrimination and exclusion.	
	All patients with the signs and symptoms of cancer will be referred urgently for assessment by a cancer MDT	Patients are assessed 'holistically' (i.e. physical, psychological, social, sexual and spiritual)			
	All patients will be aware if they are being referred urgently for a possible cancer diagnosis	Patients will be offered the opportunity to have a Clinical Nurse Specialist with them at the time of diagnosis			
		Patients will be advised to bring someone with them when they are told their diagnosis			
		Patients will be supported by their 'key worker' after their diagnosis			
		Patients will be well informed to enable them to make an informed decision about their treatment plan			

		Patients are treated with dignity at all times			
		Patients are aware who to contact in and out of hours for support and advice and access a knowledgeable health care professional who can address any issues			
		All patients, who are willing and able, are treated within 31 days of diagnosis and for each subsequent treatment			
		All patients are supported to access the national patient information pathways and prescriptions			
		All patients are treated by health care professional who are members of a designated cancer Multidisciplinary team and who have completed the national Advanced Communication skills training course			

Appendix 3
SCN Patient Information Strategy
PATIENT INFORMATION STRATEGY
2009 - 2012

Sussex Cancer Network NHS

INTRODUCTION

With the main driver of patient information being to improve the patient experience, the development of a network patient information strategy is key to ensure the Cancer Reform Strategy (2007) vision; that all patients and carers will have access to high quality, tailored information that is timely and stage-appropriate at the point of need regardless of tumour type. This document sets out the strategy developed by the Sussex Cancer Network (SCN) to ensure cancer patients across the network area are offered national information, supplemented by information about local services via the national information pathways.

AIM OF THE STRATEGY

The aim of the strategy is to ensure that patients within the SCN are offered their own tailored 'information prescription', composed of information from the national pathways and supplementary information about local services within the SCN. By working with the National Cancer Action Team (NCAT) and taking part in the pilot stage of the national information pathways and prescriptions project, the SCN will benefit from early adoption of the national information pathways, so every cancer patient will receive:

- Standardised national information, supported by local information
- Information that is tailored, as much as possible, to the individual at their point of need
- High quality written information as a platform for improved face-to-face information

This document will detail the SCN strategy for the roll-out of national information pathways and prescriptions, and will be reviewed and updated after the publication of the national strategy for patient information in December 2009.

POLICY CONTEXT & BACKGROUND

The importance of patient information is explicit in a number of key documents, especially:

- The NHS Executive Cancer Information Strategy (1998)
- The NHS Cancer Plan (2000)
- The NICE Supportive and Palliative Care Guidance (2004)

The need for understandable information that is tailored to an individual's situation, and timely in its delivery, is becoming more important than ever before, especially if patients and their carers are to become knowledgeable partners and active participants in their healthcare and treatment plan.

"Providing information alongside the support to understand and act on that information, can empower patients to retain or regain control over their lives."
Cancer Reform Strategy (2007)

Building on existing policy initiatives and guidance, the Cancer Reform Strategy (CRS) 2007 set out an ambitious vision for improving the delivery of information to people affected by cancer. It highlights the need for all patients and their carers to have access to written information at a national level via nationally agreed pathways at key stages of their 'cancer journey'. As noted in the CRS 2007, Patient information is central to:

- Enabling choice
- Raising standards
- Improving experience
- Driving up outcomes
- Reducing costs

GUIDING PRINCIPLES

The SCN and its trusts have a duty to ensure that all patients are recognised as individuals with personal needs, family circumstances and life history, all of which must be considered in the assessment of information needs of the patient and their family. In developing the framework for delivering patient information, the following observations must be considered:

- High quality information provision is a prerequisite for patients to be able to participate in decision-making about their care
- Patients and their families and carers are provided with access to information throughout the care pathway
- Recognition that the information needs of patients are changing
- Integrated action is taken at both national and local levels regarding information provision
- Written information is a key enabler, not a substitute for, high quality communication with patients

The SCN must therefore:

- Shape information services around the needs and preferences of individual patients, their families and carers
- Provide open access to both national and local information about cancer, services, treatments and lifestyle
- Respond to the various needs of diverse populations
- Work across the network to ensure a seamless service for patients

IMPLEMENTATION

The national cancer patient information pathways roll-out into secondary care will be phased throughout 2009/2010, as content for each of the tumour types becomes available and is published for use. After the national pathways have been rolled-out successfully into secondary care, focus will shift to the primary care community, as indicated in the stages below:

1 Roll-out national pathways via pilot system to Clinical Nurse Specialist (CNS) teams and Multi-Disciplinary Teams (MDTs)
2 NHS Choices Information Prescription Generator (IPG) Tool go-live, including:
    - Additional Tumour Pathways Published
    - Roll-out of additional pathways to CNS teams and MDTs
    - Changeover from pilot system to IPG for existing pathways users
    - Addition of local service information to IPG Tool
    - Roll-out to SCN Hospices
3 'Operationalise' national information pathways and prescriptions:
    - MDT level
    - Trust level
    - Network level
    - Peer review
4 Agree strategy plan on roll-out to primary care
5 Hub and spoke mechanism
    - Central 'information hub' to provide leadership and support to local information support facilities
    - Local Information reviewed and updated on an annual basis
    - Changes to patient information cascaded to local information areas from central 'information hub'

STAGE 1 – PATHWAYS ROLL-OUT VIA THE PILOT SYSTEM

Work has already commenced in 2009 to engage the SCN hospital Trusts, with the initial stages of the project focusing on uptake by the CNS teams as primary information givers and patient key workers within the specific tumour groups. With a restricted number of tumour pathways available for pilot, breast, gynae and prostrate pathways are being introduced as a first phase. Following adoption by these CNS teams, use of the national pathways will be further extended to interested parties from their respective tumour groups, ensuring the engagement of key individuals from the various MDTs. Use of the national pathways via the pilot system will be further extended to CNS teams and MDTs from the bowel, chemotherapy, lung, palliative care and radiotherapy groups from 2010.

As levels of access to equipment and the availability of local information support facilities vary within the different trusts, the Macmillan Patient Information Project Manager will work with participating teams to ensure the most effective methods of information prescription delivery within the constraints of each individual working environment. The provision of training and support to participating teams is also crucial to ensure staff are

competent in using the new system and committed to actively providing information prescriptions to patients and carers via the national information pathways.

Throughout this stage, the Macmillan Patient Information Project Manager will also work with participating nurse groups to facilitate the identification of additional local trust information with which to supplement the national pathways content. The local SCN pathways for those tumour groups currently unavailable on the pilot system will also be reviewed.

STAGE 2 - PATHWAYS ROLL-OUT VIA THE NHS CHOICES IPG TOOL

The NHS Choices IPG Tool is currently projected to go-live in April 2010. The go-live date of the IPG tool will mark stage 2 of the project strategy, and will enable the following:

- **Additional Tumour Pathways Published**

The NHS Choices IPG Tool live-launch will host existing pathways information in addition to currently unpublished national information pathways, including bladder, head & neck, kidney, lymphoma, oesophagus, pancreas, skin and stomach.

- **Roll-out of additional pathways to CNS teams and MDTs**

As with stage 1, stage 2 roll-out will focus primarily on the SCN hospital Trusts, with the initial emphasis being the uptake of the IPG Tool by the CNS groups of the newly published pathways. Following adoption by the CNS teams, use of the national pathways will be further extended to interested parties from their respective tumour groups, ensuring the engagement of key individuals from the various MDT's.

- **Changeover from pilot system to IPG for existing users**

Over a phased period, CNS groups and MDTs involved in the stage 1 pilot will be trained on the new functionality of the NHS Choices system, after which they will transfer over from using the pilot system to the new IPG Tool.

- **Addition of local service information to IPG Tool**

Throughout this stage, the Macmillan Patient Information Project Manager will work with participating nurse groups to facilitate the identification of additional local trust information with which to supplement the national pathways content. After agreement on local information has been reached, the selected information for all available pathways will be uploaded to the NHS Choices IPG Tool for inclusion in the tailored information prescriptions.

- **Roll-out to SCN Hospices**

After implementation of the NHS Choices IPG Tool within the hospital trusts, roll-out of the national pathways and prescriptions will be extended to SCN hospice staff.

STAGE 3 – OPERATIONALISE NATIONAL PATHWAYS & PRESCRIPTIONS

- **MDT level**

After a period of continued pathways use in an operational environment, the Macmillan Patient Information Project Manager will work closely with clinical teams from each trust to help identify and document the most appropriate modes of using the national information pathways within each clinical setting, taking the specific environment and availability of local information support facilities into account. Operating procedures featuring 'Day in the Life of' scenarios will be agreed and signed off for each area, and responsibility for training and support duties will be transferred to a named member of the MDT within each tumour group.

- **Trust level**

The Macmillan Patient Information Project Manager will work with Cancer Management teams from each trust to ensure commitment to the continued use of the national information pathways within their teams. High level operating models will be agreed and signed off for each trust, and ownership of training and support duties will be transferred to a named individual within the cancer management team. Methods of assessing patient need, prescribing information from the pathways and dispensing information will also be included in trust level information plans, also utilising available information support facilities for the provision of national information pathways and prescriptions, where possible. Following a phased hand-over period during which robust operational policies will be implemented, overall responsibility for national pathways use will be signed-over to a named individual from each trust.

- **Network level**

The Macmillan Patient Information Project Manager will work with the Network Information Lead to ensure use of the national pathways and prescriptions is adhered to by all trusts and hospices via annual work plans, and the network commitment to the national pathways is evident in future information plans and strategy. Links to the NHS Choices IPG Tool will also be provided on the Network website.

- **Peer review**

To further ensure continued use of the national information pathways at MDT, Trust and Network levels, use of the NHS Choices IPG tool will be will be supported by peer review measures, with the summary sheets generated by the system providing auditable evidence regarding information provision.

The above measures will establish the work of the national pathways and prescriptions project and ensure the pathways continue to be used after the project ends.

STAGE 4 – AGREE STRATEGY FOR ROLL-OUT TO PRIMARY CARE

After the national pathways and prescriptions project has been implemented and ownership embedded into trust-level operational policy within secondary care, the strategy to introduce the use of the national pathways and prescriptions into the primary care setting will be agreed.

Although as mentioned in the 'Aim of the Strategy' section (page 1) the National Cancer Patient Information Strategy is currently unpublished, taking account of the primary care infrastructure within the SCN area, it is likely that the roll-out of the national pathways and prescriptions into GP surgeries would be co-ordinated at a network level, working with Macmillan GP facilitators. It would also require that a named individual from each Primary Care Trust be responsible for patient information pathways implementation.

It is also expected that the roll-out of NHS Choices into primary care will be accompanied by a national publicity campaign, in alignment with the long term conditions agenda, which would also highlight the use of the 'self-prescribing' facility of the NHS Choices IPG Tool by patients and carers directly. Publicity is expected to focus on internet use at home, or access provided by community based information areas, such as community library settings. A further stage of analysis regarding the inclusion of local information would need to be undertaken during this stage to take account of the increasing user audience.

STAGE 5 – HUB AND SPOKE MECHANISM

Leadership and support regarding information dissemination within the network will follow a 'hub and spoke' mechanism.

- **Central 'information hub' to provide leadership and support to local information support facilities**

Information and support areas are being developed, which will operate through an interconnected network-wide 'hub and spoke' mechanism, with the hub providing leadership and direction regarding patient information best practice to the local information area 'spokes'. Whilst each information area will support their local communities, patients from across the network will also have access to the additional services provided by the 'information hub'.

- **Local Information reviewed and updated on an annual basis**

On an annual basis, the central 'information hub' will work with local information support areas and SCN Tumour Groups to coordinate the review and update of local information. Changes will then be fed back across the network by the 'information hub' to ensure consistency of information provision. Updates to the national information pathways will be managed centrally by the NHS Choices team.

- **Changes to patient information cascaded to local information areas from central 'information hub'**

Any additional changes to patient information or information policy will also be co-ordinated at a network-wide level by the 'information hub', and cascaded to local patient information units, as above.

The above measures will ensure the pathways continue to be maintained and developed after the project ends.

CONCLUSION

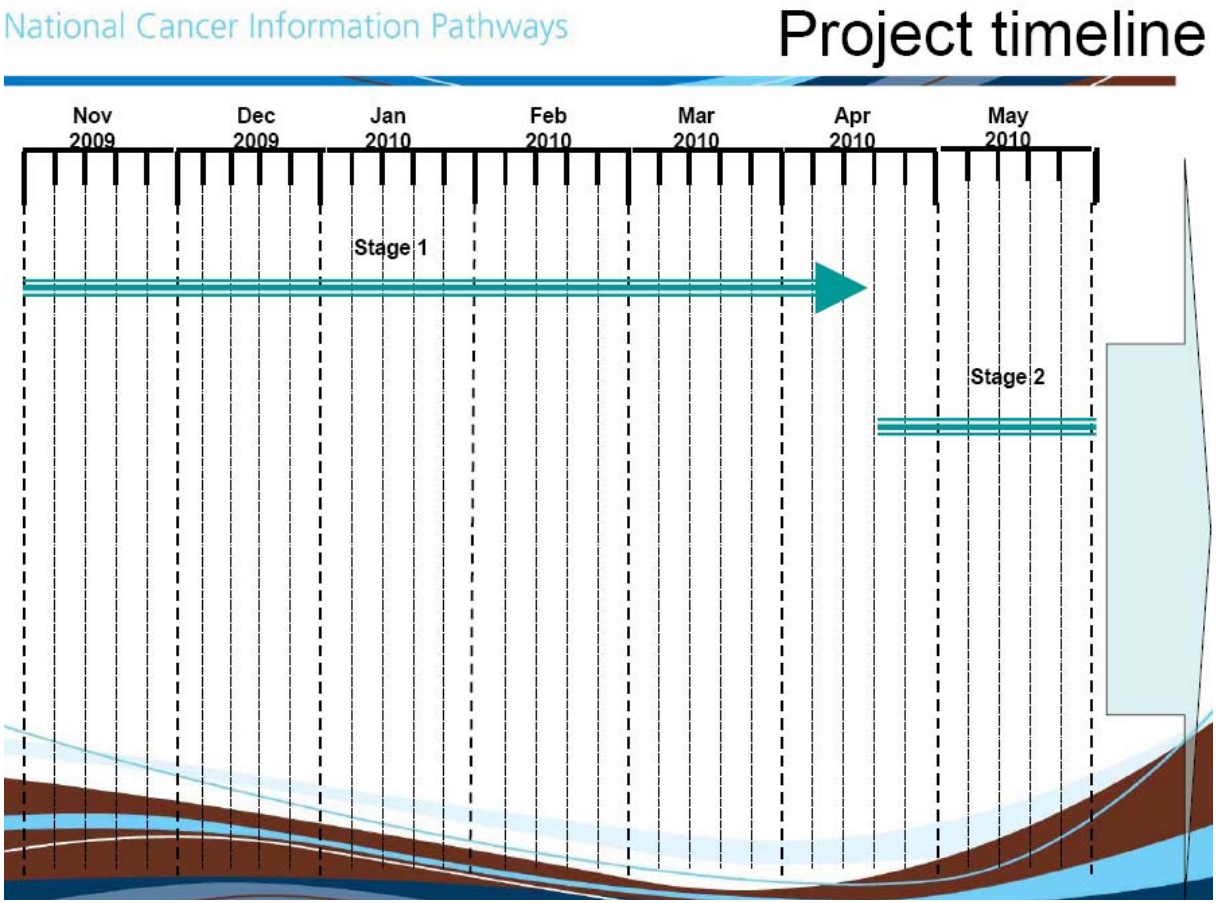
In signing up to the national cancer information pathways, cancer networks can ensure cancer patients and carers are offered quality, consistent, core information wherever they are in the country, irrespective of location, postcode or network. National information will be supplemented by locally-agreed materials to ensure the correct balance of national and relevant local materials are provided. These Pathways will enhance the quality of care given to patients with cancer or suspected cancer by ensuring that all patients are offered a full and comprehensive catalogue of information which has been developed both from locally mapped network tumour specific pathways, national collaborative workshops, and wider stakeholder consultation.

[This project] *"has the potential to make a huge difference to the lives of cancer patients. It is an extremely exciting time with work on the first long-term conditions information prescriptions healthcare professional facing tool being developed, largely modelled on work that has been undertaken in cancer."*
Paula Lloyd, Associate Director Patient Experience, National Cancer Action Team

The SCN is committed to realising the CRS vision via the successful implementation of the national pathways and prescriptions project, ensuring patients are provided with the best possible patient experience, across the network.

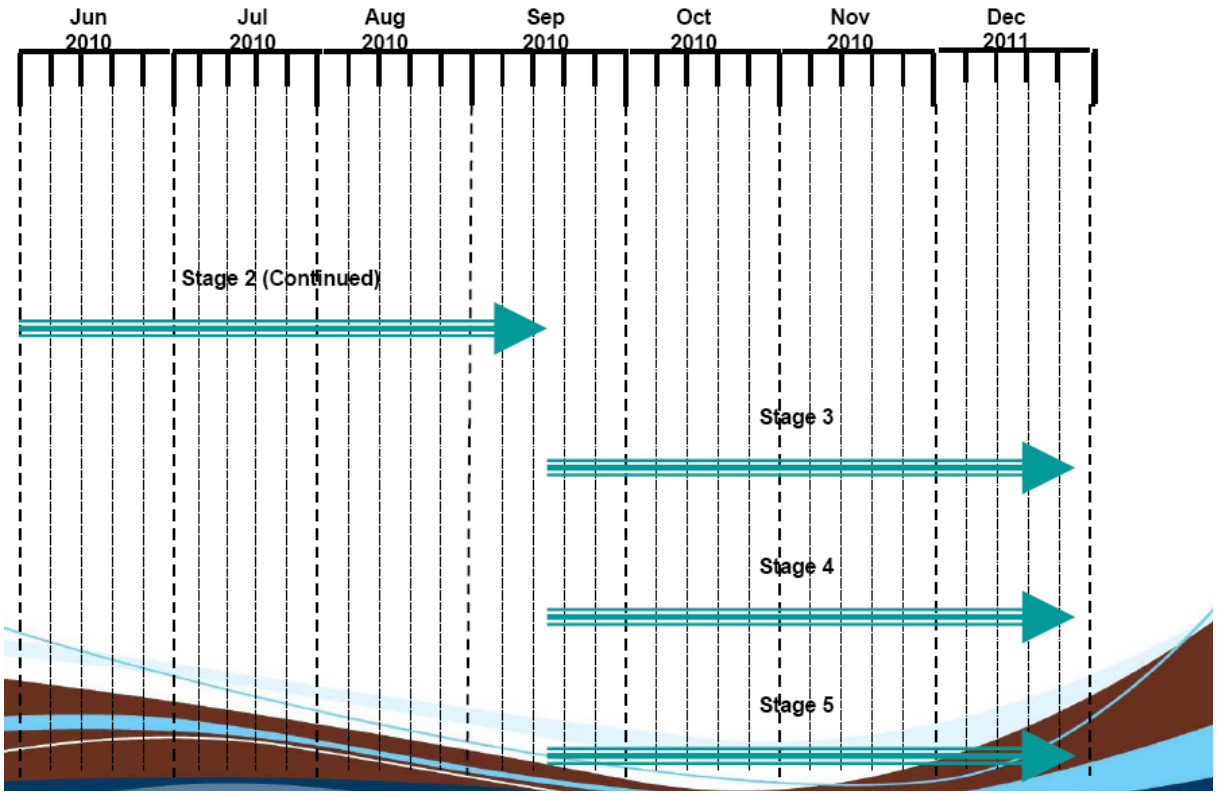
Key/Abbreviations:

CNS: Clinical Nurse Specialist
IPG: Information Prescriptions Generator
MDT: Multi-Disciplinary Team
NCAT: National Cancer Action Team
SCN: Sussex Cancer Network


National Cancer Information Pathways
Project timeline
Nov 2009
Dec 2009
Jan 2010
Feb 2010
Mar 2010
Apr 2010
May 2010
Stage 1
Stage 2

National Cancer Information Pathways

Project timeline (Cont)



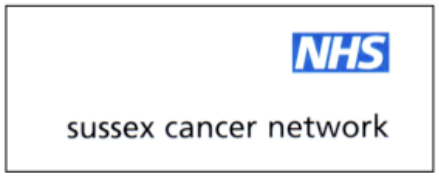
National Cancer Information Pathways

Project Stages

- Stage 1 – Piloting Breast, Prostate, Gynae, Bowel, Lung and All Cancers information (Clinical, Non Clinical and Palliative Care and EOL) pathways, including:
  - Recruitment of CNS teams
  - Continued roll-out to staff within Multi-Disciplinary Teams (MDTs)
- Stage 2 – Go-live of NHS Choices IPG Tool, including bladder, head & neck, kidney, lymphoma, oesophagus, pancreas, skin and stomach pathways
  - As with Stage 1 this stage will be split into 2 phases
- Stage 3 – Operationalise National Pathways and Prescriptions
  - MDT level
  - Trust level
  - Network level
  - Peer Review
- Stage 4 – Agree strategy for roll-out to primary care
- Stage 5 – Implementation of 'Hub and Spoke' mechanism regarding information review and update

Appendix 4
PPI in service improvement

Final report



Sussex Cancer Network

Patient & Public Involvement in Cancer Care Service Improvement

1-year Post September 2008 – August 2009

Introduction

The Sussex Cancer Network (SCN) Partnership Group's 2008-09 work plan was supported by two, one-year posts (15 hours per week each) running from September 2008 to August 2009: one post delivering a sustainable and diverse recruitment strategy and the other delivering a more structured and sustainable approach to patient, public and carer involvement (PPI) in service improvement.

The latter post was funded by SCN Service Improvement fund. Its objectives were as follows:

- To assist Primary Care Trusts (PCTs) and hospital Trusts with patient and public involvement (PPI) in their service improvement projects in the year September 2008 to August 2009;
- To identify key elements of PPI in cancer care that differentiate it from more general PPI;
- To prepare a guide on PPI in cancer care for use by staff in the SCN, using the findings of the year's work.

This report summarises the outcomes of the project.

Note on the use of 'PPI' in this document

The term 'patient and public involvement', abbreviated to **PPI**, is widely used inside and outside the NHS. Although the importance of the role of carers is increasingly acknowledged – for example, in the National Council for Palliative Care's *Guide to involving patients, carers and the public in palliative care and end of life care services* (2009) – the abbreviation PCPI is not yet an established term. Consequently, the abbreviation PPI will be used to refer to 'patient, carer and public involvement'.

Key Point Guide to Patient & Public Involvement in Cancer Care

This section presents a Key Point Guide to patient and public involvement in cancer care, building on the lessons learned from the main projects outlined in Section 0 and other learning and experiences from the year's work. Some of the points are common to almost all projects and activities, whilst others relate more directly to PPI in general and others are quite specific to PPI in cancer care.

The eight key points are listed below in summarised form so that they may be used as a quick reference guide. Further details are provided on the following pages.

1. **Ask yourself: Why *shouldn't* we involve patients, carers and the public?**

   If PPI has crossed your mind, then it is probably worth exploring further. In cases where PPI might not be considered as a matter of course, asking the question above may well bring about a new way of doing things.

2. **Make use of available expertise**

   This is essential! It will underpin everything else you do. Every Trust has in-house PPI expertise, while the SCN also has access to specialist cancer PPI expertise through its Independent Facilitator, Macmillan Nurse Director and members of the SCN Partnership Group. Use this resource!

3. **Ensure that you are clear about your objectives**

   The following three questions are extremely helpful at all stages and should be asked regularly, as a check that you are still heading in the right direction:

   1. What do we want to know?
   2. Why do we want to know it?
   3. What are we going to do with the information once you have it?

4. **Establish how you will measure the success of your PPI**

   The most important criterion is the impact on the way that people experience services. Ask yourself, regularly and repeatedly:

   "*What will successful PPI in this project look like?*"

5. **Gain high-level commitment to PPI** from those responsible for the outcome of the project *in each organisation*, as PPI in cancer care is likely to cross organisational boundaries.

6. **Communicate the value of PPI**

   Bring your colleagues along with you – understand that they might be unfamiliar with PPI or have reservations, explain the benefits of PPI and make sure that they are comfortable throughout.

7. **Plan ahead**

   In essence, it is never too early to involve people, even when you are just starting to think about making some changes. Never underestimate how long it takes to organise PPI well. See also (8) below – *be aware of the needs of those you involve*.

8. **Be aware of the needs of those you involve**

   Whatever the level of involvement - from providing information via a leaflet or website to understanding emotional or psychological effects or working together to redesign a service - you have a duty of care to ensure that you do not adversely affect the wellbeing of those that you involve, whether they are health professionals or members of the public. This may be just a little extra thought about how to phrase a question on a survey, allowing extra flexibility in a project schedule, additional facilities at a venue, the provision of psychological and emotional support, ensuring regular feedback etc. Remember that the public perception of cancer and its sometimes-terminal nature brings additional needs. It is essential to maintain this awareness throughout any PPI activity. Don't be afraid to ask.

1. Why shouldn't we involve patients, carers and the public?

In order to help PPI become an integral part of your organisation's culture – 'the way we work around here' – it is helpful to ask, at the formulation stage of any new project or activity:

'Why shouldn't we involve patients, carers and the public?'

PPI will not always be appropriate but, if it has crossed your mind, then it is probably worth exploring further. In cases where PPI might not be considered as a matter of course, asking the question above may well bring about a new way of doing things.

2. Expert input

It is impossible to overstate how important it is to seek expert advice, and all too easy to underestimate how much it will help.

Every Trust has in-house PPI expertise. The SCN also has access to specialist cancer PPI expertise through its Independent Facilitator, Macmillan Nurse Director and members of the SCN Partnership Group. ***Use it!***

Get in touch with an expert right at the start – at the stage when PPI is just a glimmer of an inkling of an idea. This expert input will help you with question 1 above and support and guide you through all the stages of your PPI activity. You will avoid many pitfalls and the PPI will be a much more successful and satisfying experience for everyone involved.

3. Clear objectives

As with any project, clear, agreed objectives are essential. They will help you determine whom to involve and how to involve them. The following three questions are extremely helpful at all stages and should be asked regularly, as a check that you are still heading in the right direction:

1. What do we want to know?
2. Why do we want to know it?
3. What are we going to do with the information once you have it?

These three questions will lead to many others and will help you understand the nature of the involvement required. For example:

- Is it clear what we want to know?
- Are we sure?
- Will involving patients, carers and the public *really* make a difference? How restricted is the scope of the project? It is essential to recognise

and state existing constraints (e.g. budget) that limit what you can do, right from the start.

- Do we need patients, carers and the public to help us formulate our questions/project e.g. on a steering group?
- Whom should we invite to be involved? Experienced 'expert' patients/carers, people currently undergoing treatment, members of the public with a general interest? All of the above? Etc …
- How are we going to involve people (i.e. which method(s) are we going to use)?
- How big / small / frequent etc will the involvement be?

4. Measuring the impact of PPI

The impact of PPI can take many forms, from clear, short-term measurable improvements in services to less tangible, but no less real, long-term changes in culture. This complexity means that the evaluation of the PPI in any project must be built-in from the start, and itself must be assessed as the project progresses. It is good practice to ask yourself, regularly and repeatedly:

"*What will successful PPI in this project look like?*"

This will enable reflection and further learning throughout and at the end of the project.

The NHS is here to provide the best care it can to patients, carers and the public – so **the most important criterion** is the impact on the way that people experience services. In September 2009, the Secretary of State for Health, Andy Burnham, announced plans to link hospital budgets to patient satisfaction with the aim of improving patient experience. The policy could be introduced as early as 2010 when hospital tariffs (how hospitals are paid) are reviewed. Announcing the plans to The Sunday Times, Mr Burnham said: "Sometimes hospitals are missing the point. How you are spoken to, how you are dealt with, whether you are treated in a friendly way - these things can be as important as medical care."

It is important to note that almost all PPI will provide learning on PPI itself – how it works and how to improve it in your organisation. Ways to capture this learning should be incorporated into the project.

5. High-level commitment

The nature of cancer care means that PPI is often likely to cross organisational boundaries, both within and outside the SCN. As a result, the commitment to PPI of those responsible for the outcome of the project *in each organisation* is essential if involvement is to be effective.

6. Communicating the value of PPI

If you are considering PPI then you have probably already had at least one positive experience of an involvement activity. It is also likely that, by the time you come to propose PPI to your future project team, you have been thinking about it for some time and are fairly well convinced of how it might work and what the benefits are likely to be.

Remember that your colleagues will not necessarily be (a) as knowledgeable about PPI as you are nor (b) as convinced about its value - in general or specifically with regard to the subject you are working on. It is quite possible that some may have had a negative experience that might adversely affect their view of what you are suggesting. Consequently it is important to 'bring them along with you' – understand their starting positions, explain the benefits of undertaking PPI and make sure that they are comfortable throughout.

7. Planning

The first item in the SCN's PPI Principles (see Section 2) is '*engage early and plan ahead*'.

In essence, it is never too early to involve people, even when you are just starting to think about making some changes. However, it is vital to be clear - to yourself and to those that you are seeking to involve - about what you are expecting. The three questions in (2) above will help with this.

There are many factors involved in the need to engage early and plan ahead, including the following:

- Only a small proportion of the total population are willing to get involved at all;
- An even smaller proportion are willing to be involved regularly;
- There is an increasing number of organisations, both within and outside the NHS, asking for user involvement;
- People who get involved tend to be 'do-ers' i.e. they are likely to be involved in many other things, apart from their jobs, and thus will probably have various demands on their time;
- People's interests change over time.

So, for example, if you are planning an event or meeting, include patients, carers of other members of the public as you would any attending member of staff, by checking that they will be available – they are as much a part of the 'team' as NHS staff. Asking people well in advance to 'save the date', even if later on you cancel, is preferable to waiting and then finding that they are

unavailable – in fact, they may well thank you for giving them 'extra' time if you do cancel!

Appendix B contains NHS Brighton & Hove PPI Department's 15 practical 'Top Tips' for involving patients, carers and public.

8. Awareness of the needs of those you involve

Whatever the level of involvement - from providing information via a leaflet or website to understanding emotional or psychological effects or working together to redesign a service – you have a duty of care to ensure that you do not adversely affect the wellbeing of those that you involve, whether they are health professionals or members of the public.

The wide range of types of PPI will mean that your relationship with the PCP involved in each activity will vary. In long-term, partnership involvement, such as with a Partnership Group, you may get to know each other very well, whereas in a simple getting-information questionnaire exercise you may never meet the people involved. Nonetheless, a relationship is formed, even if it is simply in the wording of a questionnaire, and is crucial to the effectiveness of the involvement.

A strong, long-term relationship, such as that established with members of the SCN Partnership Group, can help in various ways: a larger pool of experienced volunteers, a greater two-way understanding helping identification of the right people to involve and, of potentially great value – the rescuing of a situation if things start to go off-course!

The contribution of new people is also essential to ensure that the experiences of current patients and carers are represented. The help of experienced volunteers - to 'hold the hands' of those new to involvement, who may be unfamiliar either with PPI in general or just in cancer care - is often invaluable. In certain circumstances, it may be preferable to 'hand-select' the people to be involved, to ensure that everyone is comfortable and not intimidated by an environment, even though this may on the surface seem contrary to the general principle of neutrality and lack of bias.

It is important to continue to build the relationship throughout the activity - ensure that those involved are kept informed of what is happening, before and during activities or events. Simple things such as meeting, greeting and accompanying people can make a world of difference. Ensure that people know when they will receive feedback – ask how they would like to receive it - and ask them how they found their involvement. It is important to recognise when things do not go as well as planned, and to ask for help in improving them.

All of the above apply to PPI in general as well as to PPI in cancer care. Although within the medical community cancer is increasingly treated as a long-term illness, for many of those diagnosed with cancer, because of their age and hence the generational culture in which they grew up, cancer is still the 'Big C', a certain killer; this view is also widespread among younger members of the population. In addition, treatments for cancer, such as chemotherapy and radiotherapy, often have unpleasant side-effects. For these reasons, and many others, people may come to involvement in cancer care with particular emotional, psychological and physical needs.

Some considerations that apply to PPI in cancer care also apply to PPI in palliative and end-of-life care. **Box 3** presents some of these points, taken from 'A guide to involving patients, carers and the public in palliative care and end of live care services' (National Council for Palliative Care / NHS National Centre for Involvement, 2009).

Box 3: Special considerations for PPI in palliative and end of life care

- Discomfort discussing end of life / dying matters.
- Patients' poor health – physical (mobility and speech) and concentration difficulties.
- Crosses organisational boundaries – health and social care, care homes, housing, independent and voluntary sectors, relevant to almost all branches of medicine.
- Death and dying are often 'medicalised'.
- People do not generally have direct experience of being with, talking about or observing death or dying.
- Discussion of death and dying does not generally take place openly.
- Support/mentoring for patients, carers and staff is often required
- Patient/carer attendance (at meetings) may be difficult or unpredictable; extra time may be needed for 1:1 involvement or rescheduling of meetings.
- Questionnaires may not be appropriate owing to potential sensitivities of subject area. If used, need to ensure care with wording.
- Prompt feedback required owing to the time-limited nature of palliative/end-of-life involvement.
- People with life-limiting conditions may not be able to contribute on a long-term basis.

Main Projects

Brief descriptions and principal lessons learned from each of the main projects are given below. Where appropriate, the learning is categorised in *italics*.

Cancer Reform Strategy: The Role of General Practice

A half-day Protected Learning Set training event for GPs and other Primary Care professionals in Brighton & Hove City PCT (BHCPCT) and the former Mid-Sussex CAG area was held on 13th May 2009. Approximately 90 professionals and five members of the public attended. The event's agenda is included in Appendix C.

What went well

- Brighton & Hove PCT commissioners were very much in favour of PPI and strongly encouraged a 'user-involvement' element in the event. *High-level commitment*

- Five members of the public (two SCN Partnership Group members and three BHCPCT Health User Bank members) attended. *Relationship with PCP*

- Although not all PCP members felt that they were able to contribute as they would have wished on the day, they were invited to, and did so, afterwards by email. *Relationship with PCP*

- Other PCTs being able to benefit from lessons learnt in their planning of similar events. *Identification and inclusion of key stakeholders*

What could be improved

- Initial discussion around PPI assumed that PPI would be organised by SCN and did not include the PCT's PPI department. *Role and responsibility definition; identification and inclusion of key stakeholders*

- Although the principle of PPI was supported from the start, the objectives of the PPI were not clearly defined and it was not an integral part of the planning of the day – in hindsight, it was more a case of "this is what we'll do and we'll invite a few members of the public along". *Clear objectives*

- This uncertainty led to delays in identifying right people for event and contacting PCPs and hence a small number of attendees. *Planning; identification and inclusion of key stakeholders*

- There was initial resistance from the GP representative to PCP involvement in the workshops. *Communicating the value of PPI*

- Adequate arrangements for meeting and greeting PCPs were not made, and name badges were not issued, so some were left uncertain of what to do and where to go until identified by SCN PPI lead. *Understanding of PCP needs*

- Not enough time was given to the workshops – 30 mins each with no room-transfer time between. The workshops overran so people only attended one rather than both. This was a source of dissatisfaction for the PCPs because they had been invited to the event specifically to contribute to the workshops. *Clear objectives; planning*

- Size of workshops and identification of PCPs. Some of the PCPs felt that they wanted to contribute in the workshops but were unable to for various reasons, including: the size of the each group (~ 40 people) meant that there was not enough time to hear all those who wanted to speak; the chairs of the workshops did not know who were the PCPs and thus could not proactively invite them to contribute. *Clear objectives; planning*

Lung surgery patients' and carers' focus groups

Focus groups were held on 5th May 2009 for patients, who had been transferred to Guy's and St Thomas' Hospital in London for lung surgery or tests, and their carers/partners. Obtaining patient and carer feedback on this section of the patient pathway was part of the Lung CNS's workplan for 2008/09. Six patients and three carers attended the focus groups. On the advice of the SCN PG's Independent Facilitator, separate focus groups were held, one for patients and one for carers/partners. The final report of the focus group is included in Appendix C.

<u>What went well</u>

- Sufficient numbers of patients and carers were able to attend at quite short notice (1 month). *Planning; relationship with PCP*

- Venue: several rooms, same level, catering on hand. *Planning (location)*

- The separate focus groups, one for patients and one for carers, facilitated the identification of matters of concern, raising some different issues and different perspectives on the same issues. *Clear objectives; expert input*

- Presence of CNSs to provide emotional support and information to patients. *Understanding of PCP needs*

- The development of an action plan based on the findings of the focus groups has been embraced by the Lung CNS's Group and Lung Tumour Group. *High-level commitment; understanding of value of PPI*

<u>What could be improved</u>

- Owing to staff absence, patients were contacted at different times to invite them to the event: some a month in advance, others with less than a week's notice. Invitation letters were only sent out once sufficient numbers had been confirmed (less than a week before the event), which meant that some patients who had verbally agreed earlier were left in doubt as to whether the event was going ahead, whilst others did not receive the letters confirming details of time, location and objectives.

St Barnabas House Hospice First Assessments: patient and carer feedback

The Specialist Palliative Care Team (SPCT) at St Barnabas House Hospice in Worthing asked the SCN to help it obtain patient feedback on its 'first assessments'. Semi-structured, audio-recorded interviews were selected as the most suitable approach. Interviews were held with 7 patients, of whom 4 were accompanied by their partners.

<u>What went well</u>

- Selection of patients to be contacted for interview was undertaken by the members of the SPCT undertaking the first assessments. None of the patients contacted by the SCN initially declined to be interviewed. Two subsequently withdrew owing to poor health and one decided, on reflection, not to take part. One patient decided, on the day, not to have the interview recorded. *Planning; relationship with PCP*

- The format of the interview (semi-structured) allowed for exploration of the key issues and additional information to be provided. The question set covered the main topics well. *Clear objectives; planning; relationship with PCP*

<u>What could be improved</u>

- No method of ensuring neutrality in selection was incorporated in the study, i.e. a way of ensuring that patients were not selected only if they were considered likely to give positive comments. *Clear objectives; planning*

- Although the interviews were focused on the first assessment, patients and carers did talk more widely about their experiences of cancer. Consideration should be given to psychological support for the interviewees and interviewer. *Clear objectives; planning*

NCAT user involvement – East Sussex, West Sussex and Brighton & Hove

All four PCTs in the SCN agreed to take part in the User Involvement in Commissioning pilot project run by the National Cancer Action Team (NCAT). Initial meetings were held in the summer of 2009. The projects are as follows:

- *East Sussex PCTs* (Hastings & Rother PCT and East Sussex, Downs & Weald PCT): awareness and early diagnosis of cancer
- *West Sussex PCT*: radiotherapy provision
- *Brighton & Hove PCT*: chemotherapy provision

At the time of writing , the East Sussex PCTs have just withdrawn their project from the national pilot programme (see below) but patient, carers and public involvement is still central to the project; West Sussex is about to hold its first stakeholder involvement event; and Brighton & Hove is planning 'listening posts' at the Sussex Cancer Centre and the Haematology and Inpatients departments at the Royal Sussex County Hospital. The projects are in their early stages so the lessons to be learned are necessarily limited.

<u>What went well</u>

- Co-operation between the SCN and PCT PPI departments in all three projects resulted in effective patient and carer contributions to scoping, defining and initial planning of the projects. In West Sussex the focus of thought was changed by patient involvement from the purchase and siting of new equipment to the wider question of improved access to radiotherapy services, with patients and the public being involved in agreeing the standards of service the PCT should be purchasing in the future. In East Sussex, patient concern about the scope of the project resulted in the redefinition of its aims and its withdrawal from the NCAT pilot programme. *Clear objectives; planning; identification and inclusion of key stakeholders*
- The involvement of key stakeholders is allowing all three projects to move ahead purposefully (including redefined East Sussex PCTs project). *High-level commitment; identification and inclusion of key stakeholders*

<u>What could be improved</u>

- The initial scope of the East Sussex PCTs project led to some confusion as to whether the project was about how best to involve PCP in commissioning or how to address awareness and early diagnosis of cancer. As described above, involvement of the right people allowed redefinition of the project. *Clear objectives; identification and inclusion of key stakeholders*

Peer Review

A revised-format Peer Review was introduced in 2009, with a requirement for PCP membership of internal validation panels for selected hospital MDTs and network tumour groups. In 2009, these were: Breast, Gynae and Lung.

What went well

- A Peer Review training session run by the National Peer Review team was attended by 8 members of the SCN and SWSH Partnership Groups. *Planning; identification and inclusion of key stakeholders*

- PCP members were present on all required internal validation panels; informal feedback from NHS staff was that their contribution was very valuable, while PCP feedback was that the process was worthwhile and enjoyable. *Planning; identification and inclusion of key stakeholders*

What could be improved

- 2009 being the first year of the new-format Peer Review, many things were unclear, including responsibility for recruiting and training PCP members of internal validation panels. Although PCP representation on all panels was fulfilled, at times this was last-minute and less evenly shared than might have been desired. On the other hand, learning was enhanced and relationships built for those who participated several panels, especially for the same acute Trust. *Planning*

- The Peer Review training given in April 2009 understandably had a national perspective and contained a significant amount of information on the whole Peer Review process. Now that the Trusts and Tumour Groups have developed their own evidence templates, training in future years can be more localised and focused on review of internal validation documentation. *Clear objectives; planning*

Appendix A: Examples of Involvement Methods (from NHS Brighton & Hove training material)

Giving Information	Getting Information	Forums for Debate	Participation	Partnership
Newsletters Notice boards Exhibitions at events Leaflets and other written documents Local press Face-to-face	Patient diaries Self-completed questionnaires One-to-one interviews (structured or semi-structured) Patient discovery interviews Story-telling / experience sharing Focus / working groups PALS Patient experience trackers (e.g. Dr Foster / Picker)	Focus groups Meetings Community groups Public meetings Seminars / workshops Targeting interested people e.g. community and voluntary sector	Health panels Shadowing Community health development – this reflects the enabling activities required before meaningful involvement can happen – particularly from hard-to-reach groups Large group processes e.g. conferences, seminars Participatory appraisal	User / carer groups Expert patients Community and voluntary sector groups Local partnership groups (e.g. SCN Partnership Group) LINks

Appendix B: Top Tips for involving patients and the public in your work (from NHS Brighton & Hove training material)

1. **Practicalities**. What are the barriers to people attending? Access to venue, travel, caring responsibilities, carers accompanying participants etc.

2. **Payments**. Cover expenses. Think about payments – cash or tokens? Petty cash is a good idea for reimbursing small amounts on the day.

3. **Venue and reception**. Venues speak volumes! Community centres, local authority rooms etc can often be had a reasonable fees. What is best for those attending? Make sure that people know where to go and are met on arrival.

4. **Timing**. Whom do you want to engage? Evenings or weekends might be better if people are working. Avoid early mornings! If over lunchtime, offer food.

5. **Refreshments**. Make sure that refreshments are available – tea, coffee, water at minimum. Biscuits are often very much appreciated!

6. **Special requirements**. Check beforehand if there are any special requirements e.g. wheelchair access, chairs with arms, hearing loop etc.

7. **Start as you mean to go on**. Open and respectful communication, full introductions, name badges and open exercises to break the ice. Try to involve your patients/public groups as early as you can – this will save time in the long run. Presenting ideas and plans for feedback is consultation and quite different from ideas and plans generated by partnerships. The latter is not necessarily better, depending on the context, but requires different management.

8. **Understand PCP motivation and interests early on**. Spend some time finding out why PCP are there, what they want and what they have to give. This may need to be an explicit exercise, as they may not be used to being asked this type of question! Consider what 'gains' there may be for them in terms of increased skills and understanding. Are there any training opportunities in your organisation that the PCP could benefit from?

9. **Establish how the group can work effectively**. Ground rules are essential. Make sure that they are clear and understood by all and be prepared to act on them if needed. Where necessary create some guidance or description of the role that you would like the PCP to undertake e.g. role specification / terms of reference. This will help

manage expectations and provide a clear focus for the activity. Consider training issues to support their involvement. Arrange access to library facilities if required.

10. **Support**. Think about 'buddying' service used with staff. Pre-meet, de-brief.

11. **Fresh eyes**. Try to look at what you do with fresh eyes. Ask someone to comment on the facilitation, look at the handouts/slides etc. – do they make sense? Is here an implicit level of understanding required? If necessary, re-do them. Remember to provide glossaries and explanations of key concepts if required.

12. **Get the balance right**. Mixed groups often work best when active and engaged. Mix the style of what you do to involve the groups with you and with each other.

13. **Don't be afraid of conflict**. Think about how you would manage difficult situations. Have a chat with a colleague or someone with training/teaching experience. Conflict can often bring about the most interesting of developments within groups; use the ground rules – that is what they are there for! Manage the relationships from the start. If needed, consider a 'neutral' chairperson for groups/meetings.

14. **Promote networks and peer support**. Provide contact lists for each workshop/meeting and allow plenty of time for networking and discussion (for data protection remember to get permission from the group to do this before publicly sharing this information). Remember to keep the patients/public groups in the communication loop regarding the development of the work, even is there is nothing much to say! Agree a pragmatic communications schedule and stick to it.

15. **Supporting materials**. Be prepared to provide supporting materials – don't assume anything! Materials should be clearly presented with up-to-date, useful information. Copies of slides used are always welcomed. Try to use at least font size 12 (minimum requirement for the visually impaired) and be careful with colours. Black text on pale colours works best for readability. Don't be afraid of using visual images and pictures to illustrate points.

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