

Peninsula Cancer Network

User Involvement Principles and Strategic Framework

Engaging patients and the public to improve and develop cancer services in the Peninsula

'The experience of cancer care is by definition subjective and efforts to improve the quality of care must start from patients' and carers' own experiences'

National Cancer Peer Review Programme

Service User Involvement in Cancer Care – Policy, Principles and Practice

'It is self evident, but worth repeating, that the NHS can meet people's needs better if we listen to what people tell us, instead of relying on existing knowledge and assumptions. We can develop better, more responsive services if we involve and truly listen not only to those who are already using services, but those who are not'

NHS Institute for Innovation and Improvement

Patient and Public Engagement Toolkit for World Class Commissioning

REVIEWING THE APPROACH TO PUBLIC AND PATIENT INVOLVEMENT

The Peninsula Cancer Network (PCN) exists to secure equal access to high quality care for all cancer patients, strive for better clinical outcomes and improve the experience of patients, their carers and families throughout screening, diagnosis, treatment, aftercare and survival. The Network has an increasing role in the prevention of cancer and reducing health inequalities. To achieve these goals it collaborates with patients and their carers, all healthcare providers and commissioners, throughout Devon, Cornwall and the Isles of Scilly. The Network is committed to ensure that effective patient, carer and public involvement is integral to our work, putting patient, carer and public experience and involvement at the heart of cancer service design and delivery across the Peninsula.

A starting point for discussion

The Network recognises that designing its public and patient engagement strategy is not just an internal process. As a result the Network is working on a developmental approach to building the most effective strategy in an open and transparent way **with** those people who have the best knowledge of the impact of cancer care services.

The users of services, together with their carers, families and the people who work with them in health, social and voluntary care have valuable and unique insights into their experience of and aspects of care. The Network wants to harness the deep knowledge and understanding of the people who use services, and the staff who deliver them, to improve cancer services.

Users of services, carers and staff also understand what works well in terms of engagement and this framework sets out actions for developing effective methods and approaches to engagement and partnership working. **As a starting point the Network drafted a framework building on the ideas and priorities of those with an interest in developing cancer services across the Peninsula**

The first draft framework set out some principles for achieving effective engagement across a wide and diverse geography using a variety of approaches. There was recognition that patients, carers and staff had already identified areas for improvement in the Network's involvement

processes and told us how things could develop and build towards an effective and sustainable structure and process for involvement; a summary of what we heard in earlier engagement, and influenced the development of the first draft framework is included in this document.

The next step was to build on the priorities and ideas by engaging further with a group of patients, carers and stakeholders in an engagement event on 15th December 2010. By working with the people who had an interest in or perspective on cancer services the Network would find out what methods of engagement would work well and incorporate their views on the principles, ideas and approaches set out in the draft framework. People with a particular interest may be carers, those who have experienced cancer, and those who understand the impact of cancer on patients, carers and families (either from support groups or working as a professional in health, social or voluntary services).

The Network also recognises that some groups of people have particular difficulties, not only in accessing services, but also in making their voices heard. We also want to ensure that we understand the specific needs for cancer services of people from diverse backgrounds, different geographical areas, or from different age groups, for example children and young people, older people or people with learning disabilities. The framework also sets out principles and approaches for reaching the diverse communities of interest and place across the Peninsula.

The Network is committed to ensuring that the right approach is developed. It is important that perspectives from all these different groups influence the way forward.

WHERE ARE WE NOW?

Some drivers for change

A number of developments resulted in the review of the Network's approach to improving cancer services for patients across the Peninsula. Central to the review is an evaluation of the way patients, carers and a wide range of stakeholders are involved at all stages of development, design, and delivery of cancer services, especially when potential service reconfiguration may result.

Firstly, in July 2010, the Department of Health issued four key tests for any service reconfiguration that must be applied '*to ensure patients get the best care possible, delivered to the highest standards in the most effective, efficient and personalised way*'. Importantly, one of the tests is focused on the demonstration of 'strengthened public and patient engagement' in any proposals for substantial service change.

Secondly, the report of the Independent Reconfiguration Panel on upper gastro-intestinal cancer surgery centralisation pointed to the need to revise processes. There was particular emphasis on wide engagement from the start, and certainly before any solutions are proposed.

The engagement event

The engagement event held on 15th December 2010 as part of the continuing dialogue with patients, carers and stakeholders, reinforced many of the priorities and messages heard in earlier engagement. A full report of the process and feedback from the event accompanies this framework document and a summary of the key themes and next steps is included in the ***What we have heard – key themes from patients, carers and stakeholders*** section of this framework. This feedback not only confirmed many of the priorities signalled in the first draft framework, but identified new issues and has had a significant impact on the direction of travel and way forward to improve patient and public involvement in cancer services.

Moving forward

The feedback report from the engagement event, together with a summary document, is being circulated to all who took part in the engagement event. This revised and updated framework, based on stakeholder priorities and recommendations, is also being circulated for comment.

One of the clear outcomes from the engagement event discussions was the recommendation to set up a ***Working Group*** to provide a practical mechanism for moving things forward and firming up a final version of the framework for involvement. Interest in membership of the group was invited at the event and a first meeting to consider terms of reference, wider membership, and the future of a Network Partnership Group in patient and public involvement, was planned for the early months of 2011.

WHY INVOLVE PATIENTS, CARERS AND THE PUBLIC?

The Policy Context

Service user involvement is not a new concept. In recent years there has been a great deal of emphasis in the policy documentation on involving patients and the public within the NHS in general and around cancer services in particular. A key principle of the NHS Cancer Plan is patient and public involvement. The Plan stipulates that cancer networks will be expected to take into consideration the views of patients and carers when planning services.

The impetus for service user involvement has been stressed in a number of policy documents and in 2007 the Cancer Reform Strategy affirmed that *'patients, local voluntary service providers, alternative providers and other stakeholders should be involved in influencing the way in which services develop'*. In the following year, the Next Stage Review of the NHS stated that effective user involvement should play a central role in improving the quality of patient care and delivery of a patient centred NHS.

In 2008, Section 242 (1b) came into force, giving further legal backing to user involvement. It placed a responsibility on NHS organisations to make arrangements to involve and consult service users in:

- The planning and provision of health services;
- The development and consideration of proposals for changes in the way services are provided, and;
- Decisions affecting the operation of services

In 2009 patient and public involvement became enshrined in the NHS Constitution. The Constitution refers to patients' rights and makes various 'pledges' and 'commitments' necessary to give power to those rights:

You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.

A key principle of the approach to the National Cancer Peer Review process is that patients and carers are a vital and integral part of the review process

and it is expected that patients and carers will be 'active participants in the internal validation of self assessments'.

As cancer networks seek to improve outcomes and quality in cancer services they need to review the way that services are designed.

The Benefits of Involvement

Involving patients, carers and the public when planning, improving and delivering services makes sense. If we want to know what works, what doesn't, and how to make services more accessible and effective, then we need to hear from the people who the services are aimed at and those who are currently using them.

Involvement also brings genuine benefits to users, providers and planners of services because it:

- Helps produce effective, well coordinated pathways of care responsive to patient needs and preferences in a timely manner
- Patients feel more involved and partners in their care with more influence over the services they use
- Creates a learning environment when users' feedback has an impact on service quality, design and development
- Helps staff see their roles from the users' point of view and the impact that their role has on individuals
- Promotes a democratic process
- Provides an effective mechanism to monitor the quality of services
- Produces better quality, better designed and more appropriate services
- Helps users appreciate the issues faced by all NHS staff and an understanding of health services
- Helps to improve organisational learning
- Helps to develop and disseminate good practice

WHAT IS PATIENT, CARER AND PUBLIC INVOLVEMENT?

Patient and public involvement or engagement is the active participation of patients, carers, community representatives and groups, and the public in how services are planned, delivered and evaluated. There are a many ways in which patients, carers and the public can get involved in influencing the planning, delivery and evaluation of health services. The Peninsula Cancer Network is committed to providing as many opportunities, methods and forums for people who have experienced cancer and who have an understanding of the impact of cancer on patients, carers and families. Good patient involvement ensures that everyone can take part in the way that suits them best. This may be:

- **Receiving information and finding out about issues through leaflets, support and self help groups, websites and the internet**
- **Opportunities for immediate feedback as part of treatment**
- **Responding to discussions and surveys as an individual**
- **Involvement as part of a group or committee**
- **Taking an active part in developing pathways or strategies**

The range of involvement has often been portrayed as a ladder with each rung representing a stage from minimum to maximum involvement. The most widely known model is Arnstein's (1969) 'ladder of participation'. For present purposes it is useful to distinguish five levels, or 'rungs' of user involvement:

Level 1

Information

At this level, patients, carers and the public feed information into the planning, delivery and evaluation of services (abbreviated to PDE) process. The information may be requested by health professionals, for example an

invitation to complete a questionnaire on travel and access to an outpatient clinic. Alternatively, information could be collected and put forward by patients and carers themselves, for example providing information that they feel that health professionals should take into account before any changes are made to a service, such as visiting times

Level 2

Consultation

This level involved inviting those consulted to express a view or a preference, which might be open ended or involve choice from a range of pre-determined options. For example, health professionals may consult patients, carers and the public about their preferences concerning the design features of a new facility.

Level 3

Partnership

This level involves service users engaging jointly with health professionals and, through collaborative work, progressing an element of PDE, for example joint work on the development of a patient pathway

Level 4

Delegated Authority

This level involves the responsibility for particular tasks, processes or decisions in PDE being delegated to a group of service users, for example as part of a Network's programme of user surveys and enquiries. In another example, the Network Partnership Group may be given the responsibility for planning, running and writing up a number of focus groups on the support needs of post primary treatment 'survivors'

Level 5

Service User Control

This level involves service users taking full decisional responsibility for initiating and seeing through a piece of work, from planning, resourcing, implementing, monitoring and evaluating it, for example service users plan and run a day workshop on 'Making our Partnership Work'

In practical terms many user involvement initiatives entail working at a number of different levels at the same time, from receiving or giving information to undertaking engagement activity such as surveys, and contributing to the development of policy or strategy.

WHAT HAVE WE HEARD – KEY THEMES FROM PATIENTS, CARERS AND STAKEHOLDERS

When users and carers take the time to become involved and identify the issues that have the highest importance for them, it is vital that those planning and delivering services feed back how they have responded and taken action on the outcome of involvement. People quickly become disillusioned if they are regularly engaged but no action is taken or information given on how their feedback has impacted on decisions and services.

Patients and carers also provide valuable information on the way they want to be involved and what methods and approaches are the most effective. Organisations need to take these views into account when they want to improve involvement of patients and the public in the NHS. The Network

recognises that patients, carers, people in the voluntary sector and healthcare workers have a wealth of experience and knowledge about effective involvement.

Feedback from a Patient Involvement Event September 2009

In September 2009 the Network held a Patient Involvement Event. Participants on the day put forward their views to the Network on the way patient and carer involvement should look, current structures for involvement and the way professionals and users can work together to improve services.

Some key themes emerged which are a useful starting point for the dialogue with patients, carers, staff and people in contact with patients using cancer services to develop the Network's strategy, vision and objectives:

- ***Recognise the value of patient and carer views***
- ***Involve patients and carers in ways that suit them, recognising the different levels of engagement needed***
- ***There are existing structures and points of contact that could be used even more effectively for patient and carer involvement, for example the Clinical Nurse Specialists and User Groups***
- ***The Network should work with patients/carers to build on the mechanisms that have potential and are working to develop a structure and mechanisms for involvement***

- *User groups should continue for both patients and carers. They should be more focused and empowered to make a difference. This means that those involved should be professionally supported and encouraged to take part*
- *Remove the barriers to improve communication between patient/carers and the professionals/decision makers*
- *Develop a network of contacts and relationships. User groups should communicate with each other to share successes, concerns and activities*

Recommendations from the Independent Reconfiguration Panel

Over the past year issues regarding the way that the Network needs to develop involvement structures and methods have been highlighted. In June 2010, the Independent Reconfiguration Panel reported its advice to the Secretary of State on the reconfiguration of upper gastro-intestinal cancer services in the South West. The Panel heard evidence from user representatives and a number of themes emerged resulting in recommendations for future action. The key issues from the IRP report that will influence the development of involvement structures and methods are:

- *Recognition that patients and user representatives were not adequately involved in the development of proposals and that public engagement and involvement mechanisms were not fully used*
- *The Network needs to build on the effective public engagement that took place later in the process to ensure that patient and user involvement is embedded at every level of service development and change, not just during the practical implementation stage*

- *There should also be a review of how the experiences of patients will be captured and used to design and deliver better cancer services within six months*
- *The process of re-establishing an effective and fully functioning Partnership Group needs to be completed*
- *Engagement and involvement will not be effective without appropriate resources, support and organisational leadership*
- *New partnership arrangements will need strong support and facilitation to ensure their influence and effectiveness continues*

Feedback and key themes from *Shaping PPI in Cancer Services*, an Engagement Event 15th December 2010

The event utilised a range of engagement methods, including, drawing, symbols, and discussion to identify three areas for development of a patient and public involvement strategy:

- Current or early priorities
- What future patient and public involvement should look like
- Effective involvement for a wide range of patients, carers, groups and stakeholders

Key Themes

Current and early priorities – key themes

- ***Support by means of information, training, funding, transport, appropriate use of language and good communication was needed***

for users, carers and families to get involved and contribute to groups and other methods for involvement

- *Don't always expect users to come to you - use of more **innovative methods of communication** to overcome the problems of travel to venues across the Peninsula for engagement activities should be explored, with remote conferencing cited as helpful*
- *Clarity regarding what effective user involvement should look like and **reality** about what was achievable was needed*
- *Developing **relationships** between professionals, patients, public and stakeholders to ensure all perspectives were heard and influenced cancer services development*

What should patient and public involvement look like?

Key themes – what patient and public involvement should look like

- *Common understanding and **reality** of what is achievable with user involvement*
- ***Direct involvement**, understanding and commitment from clinicians*
- ***Focus on specific conditions**, site specific groups and review approach*

- ***Influencing services from patient perspective***
- ***Capturing perspectives from users and stakeholders not currently influencing***

Key themes – effective involvement for a wide range of patients, carers, groups and stakeholders

- ***Reach out to a wider population of patients and families reflecting different needs and perspectives, especially children and parents, hard to reach groups and those with specific needs***
- ***Collect and use information to influence, look at how data is collected and existing contact with service users by health professionals***
- ***Identify and develop partnerships, commitment and agreed ways of working***
- ***Identify good practice in engagement, methods and communication, using innovative methods such as patient diaries and interactive technology***
- ***Review, utilise and support existing successful engagement and approaches***
- ***Design engagement to meet all needs, reach out and develop existing networks***

Next steps and way forward

It was suggested that a **Working Group** should be set up and participants at the engagement event who had an interest in membership were invited to put their names forward, with wider membership and nominations for an independent chair invited.

The **Working Group** could provide a practical mechanism for moving things forward and firming up a final version of the framework and define the blueprint for patient and public engagement in cancer services across the Peninsula. The Group should also consider the key question of the usefulness

of a Partnership Group as the core mechanism for patient and public involvement.

Suggested terms of reference for the Working Group:

- To determine whether there is a function for a new Network Partnership Group and to determine its usefulness as a vehicle for patient and public involvement
- To identify the functions and role of a new Network Partnership Group, if the Working Group determined that the Partnership Group has a role to play in patient and public involvement in cancer services
- To examine the methods and approaches to engagement in respect of a specific issue or development of a cancer service such a gynaecological cancer. Learning from a successful approaches in a small scale pilot could be utilised in the development and refinement of the patient and public involvement framework

Priorities for future action

- Recognition of the importance of user contribution by the Network supported by a statement from the Chair of Network
- Revisit functions of local user groups as all function differently; learn from good practice and ensure that all have the same standards and support
- Identify how can we harness intelligence from localities, services and current users to ensure that user feedback is relevant, up to date and can genuinely influence current and future practice in cancer services

A continuing dialogue

The future of patient and public involvement in cancer services across the Peninsula will not be determined solely by the recommendations of a Working Group or by the Peninsula Cancer Network. The Network is committed to continuing the development of structures, methods and approaches to involvement through dialogue and learning from pilots and feedback. The framework is a living document, subject to change and

improvement, and will be adapted and refined to reflect local and national developments in policy, methods and feedback from those with direct experience of cancer services.

PATIENT AND PUBLIC INVOLVEMENT – VISION, AIM AND OBJECTIVES

The first draft framework set out a vision for patient and public involvement in cancer services that incorporated the priorities and suggestions for building effective involvement heard from patients, carers and a wide range of stakeholders, including the IRP. The vision set out here has been developed as a consequence of the feedback from the engagement event in December 2010 and subsequent views from stakeholders following circulation of the draft of this framework.

Our Vision

The Peninsula Cancer Network will create a partnership with patients, carers and other key stakeholders to ensure that there are opportunities to make their voices heard in ways that suit them best.

The Network will ensure that patients, carers and other key stakeholders will be involved at all levels of decision making and contact points with services.

Their views will have a genuine influence on the development and improvement of cancer services and they will receive feedback on the impact their contribution has made.

The Network will develop broad and effective structures and build networks and contacts for service user involvement so that the involvement of patients, carers, the public and other key partners becomes integral to the work of the Peninsula Cancer Network.

Aim

To continue an open and transparent development process for building effective patient and public involvement structures and methods, based on the principles and suggested actions in this framework. The process is to be driven by means of discussion and engagement with patients, carers, and

those who understand the impact of cancer on patients, carers and families, either from support groups or working as a professional in health, social or voluntary services.

The priorities and focus for development of effective patient and public involvement should be:

- The development of a Working Group to take forward the recommendations and issues from patients, carers and others contributing views on developing involvement structures and methods, including the future of a Cancer Network Partnership Group
- The examination of the potential terms of reference and support for a Chair, Vice Chair and members for a Network Partnership Group, if its role is seen to be core to the development of effective patient and public involvement
- Reviewing the structures of involvement by building on and developing the initiatives, structures and groups already in place and building further strong networks, contacts and mechanisms for engagement
- Developing methods for involvement building on successful engagement previously undertaken and discussions about effective involvement with patients, carers, support groups and professionals
- Supporting the local cancer groups, through training and resources to be the 'expert voice' and identify what further support is needed for individuals and groups to contribute effectively
- Clarifying the responsibilities of the local cancer groups

- Ensure wider coverage of diverse and rural geography and to identify effective, innovative and appropriate methods for engagement and capturing perspectives from users and stakeholders not currently influencing the debate
- Building on and developing partnerships, networks and links with existing communities of interest and place, that is, those already engaging with users of cancer services and carers across Devon, Cornwall and the Isles of Scilly
- Focusing on knowledge and understanding of patient and carer needs relating to specific types of cancer by reviewing how they contribute to the improvement of cancer services through existing structures and groups
- Ensuring that continuous improvement and development of involvement processes, structures and methods is reviewed and shaped by patients, carers and the public

Objectives

1. To ensure that there is an understanding of and a commitment to patient, carers and public involvement throughout the Network
2. To add value to the continuous improvement goal of cancer services across the Network
3. To establish a coordinated and consistent approach to patient, carer and public involvement across the Network

4. To review the success, development and outcomes of involvement, with patients, carers, the public, staff and groups with an interest in the development and impact of cancer services, and feed back learning into practice
5. To ensure that patient, carer and public involvement activities, feedback and priorities impact on pathway development and service delivery
6. To establish positive and strong partnership working with health, social care, local authority and voluntary sector professionals
7. Monitor and evaluate policy initiatives both locally and nationally to ensure opportunities for involvement are identified and implemented
8. Ensure that patient, carer and public involvement is integral to the commissioning process and influence commissioning priorities and activities of PCN, Primary Care Trusts (latterly GP Consortia), Local Authorities (Health and Wellbeing Boards)

Section 2

WORKING TOGETHER TO DEVELOP PATIENT AND PUBLIC INVOLVEMENT

A PROPOSED ACTION PLAN

TAKING FORWARD THE VISION, AIM AND OBJECTIVES

This framework has been strongly influenced by the feedback from patients, carers and stakeholders, in particular by the priorities and suggested direction of travel identified at the engagement event held in December 2010. A number of actions had been outlined in the first draft framework used as a basis for discussion at the engagement event. However, there were some clear messages about the key issues that need to be discussed further and the potential priorities for a Working Group to develop the ideas and suggested actions further.

This section of the framework provides an action plan reviewed in the light of the latest feedback from patients, carers and stakeholders.

REVIEW THE SCOPE OF INVOLVEMENT

The engagement event feedback told us clearly that we need to ensure wider coverage of diverse and rural geography and to identify effective, innovative and appropriate methods for engagement and capturing perspectives from users and stakeholders not currently influencing the debate.

In order to take forward the vision, aim, objectives and the ideas proposed here, the Network, Working Group and the wider group of those with an interest in the development of patient and public involvement in cancer services should review how the Network involves people now, together with its structures for involvement and methods.

One discussion session at the engagement event focused on:

- ***Who is involved now?***
- ***Who else needs to be involved?***

- ***Actions needed to widen and improve involvement***

The following is a synthesis of feedback from those discussions and a review of the draft action plan proposed in the first draft framework.

Who is involved now?

- Patients, carers and members of the public, work alongside healthcare professionals to ensure that quality cancer services are provided and developed. The most common ways for individuals with experience of cancer to get involved is in ***local cancer user groups, Network Site Specific and Cross Cutting Groups***. Their direct experience of cancer services, different types of cancer and its impact, and the needs of people who have experienced cancer and their families, provides vital and relevant information, knowledge activities to influence improvement and change to future cancer services
- There is recognition that ***these groups need to develop and be supported*** to provide effective forums for involvement
- ***Patients and carers are also involved in self help and support groups*** which focus on providing support to the individual through their cancer journey. Individuals involved contribute views and information on their experience of services to those providing support and others within the groups
- Statutory patient and public engagement bodies such as ***LINKs*** have been involved through current structures and have a network of contacts and members who reflect a range of experiences, different conditions, needs and populations across the area. Under proposed NHS reforms, new bodies, Healthwatch, are to be developed to replace LINKs
- ***Local partners in health and social care, such as PCTs, provider trusts, local authorities and other care organisations, including charities***, collect information about patient and carer experience as part

of their engagement activities and are partners in developing appropriate care and services

- Monitoring bodies such as ***Health Overview and Scrutiny Committees and local authorities*** have valuable information about issues relating to cancer care and hear evidence directly from members of the public, LINKs and health organisations
- ***Professionals in health, social and voluntary led care, working with people experiencing cancer***, carers and families, hear about the experiences of individuals and work with them to improve their experience directly, but can also use that information to influence the improvement of services overall
- ***The Network has also commissioned specific engagement*** projects that included ***surveys, focus groups and in-depth interviews*** with individuals who reflected a wide range of experience and different population areas.

Who else needs to be involved?

The Network recognises that the perspectives of people using cancer services, together with those who understand that experience, for example, carers, families and professionals, has direct relevance for developing services to meet needs and improve quality. We also want to hear from people who may not currently be involved in cancer user groups or one of the other valuable forums for involvement.

Feedback from the engagement event tells us that we need to bring together a wide range of perspectives that reflect the broad base of people currently using and experiencing services so that the diversity and needs of the population across the Peninsula area are captured and influence policy, practice and services. In order to do this the Network wants to build on current involvement structures and contacts and the engagement work undertaken to date. The Network recognises that it is important to hear from

people currently involved about the most effective methods of tapping into this unheard information.

Some of the groups that need to be involved were identified at the engagement event:

Organisations and contact points

- Social services
- Follow up appointments at outpatients
- Occupational Health
- Employers
- Primary care, including AHPs, dentists

Wider group of charities and community groups – reaching out

- Who are the charities (local) not just cancer ones?
- Generic community groups – don't expect people to come to us; we need to go to them

Wider population of patients and families reflecting different needs and perspectives

- Wider population of patients, including all tumour groups
- Children and parents
- Teenagers
- People with learning disabilities
- Willing former patients
- Hard to reach groups – BME, carers, people with learning disabilities, people with mental health issues, people with physical disabilities, young people, travellers, asylum seekers, transsexual and homosexual individuals and communities

People using a range of services

- Hospice patients and carers

PRIORITY ACTIONS TO DEVELOP INVOLVEMENT IN CANCER SERVICES

Influence the debate and clarity about cancer care and services

There needs to be a mature debate with clarity on what the NHS should fund, eg money spent on transport cannot be spent on care. To move forward it's important to take the politics out of discussion and information sharing

Collect and use information to influence

Data collection and capturing the experience of current service users through information collected by health professionals such as CNSs is important to inform the development of services. Act on feedback and reporting on actions taken as a result of feedback with absolute clarity on what can and cannot be influenced

Partnerships, commitment and agreed ways of working

Identify who are our partners, ensure that we are meeting with clinical teams and have joint agreements, sign up and commitment from organisation and professionals. There needs to be continuous joined up working and a balance of patient and professionals at meetings.

Recognise the proposed statutory changes to the NHS and strengthen partnership working with Local Authorities

Recognise the strengthened role of local government in promoting local wellbeing and the new statutory arrangements establishing *Health and Wellbeing Boards*, and build partnerships for service changes and establishing local priorities

Develop and utilise good practice in engagement, methods and communication

Identify good practice and celebrate local engagement. Many suggestions have been made for methods and approaches, including:

- Develop DVD
- Patient/carer designed questionnaire
- End of treatment opportunity to feed back – develop leaflet
- Undertake direct engagement with individuals through focus groups, workshops, in depth interviews
- Reflect the cancer journey through patient diaries and other reflective methods
- Give details of user involvement groups

- More detailed information on patient pathway for patients – opportunity to feed back
- Emails
- Facebook
- Twitter
- Interactive website for patients – check feedback
- Publicity and motivation – explain why people should participate

Review, utilise and support successful engagement and approaches

There is a need to review successful engagement and approaches with wider application to the Network involvement strategy in the future:

- Utilise the range of methods and approaches in the engagement process relating to IOG's review work on Head and Neck/Gynaecological cancers
- The Network should develop and support the existing range of activities and forums for debate, including the Network Partnership Group

Design engagement to meet all needs – reaching out and networks

- Appreciate and design engagement to meet all people's needs/health/social
- Approach community forums
- Design engagement that allows a range of ways to get involved
- Develop networks and contact with existing patients, carer and voluntary sector groups with an interest in cancer care
- Develop networks and contact with community groups across the Peninsula area
- Benchmark with other Cancer Networks to achieve learning and therefore best practice engagement for all

Public health and education activity

- Broaden the debate and approach to the public health and good health education agenda
- Recognise the central role of local government and local communities at the heart of improving health and wellbeing for their populations outlined in the new Strategy for Public Health in England *Healthy Lives, Healthy*

People; develop stronger partnerships and joint working to address the approach to public health, improving health and cancer prevention

NEXT STEPS AND WAY FORWARD

The first draft framework identified a potential timetable and list of actions for developing the strategy and mechanisms for effective patient and public involvement in cancer services across the Peninsula. Following the engagement event, the approach has been reviewed:

Take forward recommendations from the engagement event and shape the Framework for Involvement

January 2011

- A report of the engagement event process and feedback to be produced and circulated to all involved and interested stakeholders.
- The first draft framework to be shaped and developed as a direct consequence of the views, understanding and knowledge of those involved at the engagement event in December 2010.
- The revised framework to be circulated to all involved in the engagement event and interested stakeholders, with comments invited
- The framework and report from the engagement event to be reviewed following feedback from stakeholders

Establish a Working Group

December 2010 – March 2011

- Identify interested participants in a Working Group to work in partnership with the Network to take forward the recommendations emerging from the engagement event, develop and finalise the framework, structures for involvement and establish whether a Network Partnership Group should have a function in patient and public involvement and act as a focal point for engagement
- Identify draft terms of reference for a Working Group to review and develop effective Network Partnership working and other issues emerging from the engagement event
- Agree an outline role description for members of the Working Group with participants
- The terms of reference and the outline role description for membership of the Group will be circulated to contacts and groups with an interest in the development of cancer services and reflecting the different populations across the Peninsula
- A role description for an independent Working Group Chair will be agreed with participants, circulated widely and applications invited
- Ensure participation and commitment from leading personnel in the Network at the first meeting of the Working Group

Consult on draft Working Group Terms of Reference

December 2010 – March 2011

The following draft terms of reference for the Working Group were developed as a result of the discussion and priorities identified at the engagement event in December 2010:

- Work in partnership with the Network to take forward the recommendations emerging from the engagement event including the development of the final version of the framework for involvement
- To determine whether there is a function for a new Network Partnership Group and to determine its usefulness as a vehicle for patient and public involvement
- To identify the functions and role of a new Network Partnership Group, if the Working Group determined that the Partnership Group has a role to play in patient and public involvement in cancer services
- To examine the methods and approaches to engagement in respect of a specific issue or development of a cancer service such a gynaecological cancer. Learning from a successful approaches in a small scale pilot could be utilised in the development and refinement of the patient and public involvement framework
- Review the existing structures for involvement and incorporate recommendations and agreed actions from the engagement event
- Review and refine the framework and strategy for involvement

Establish final Working Group Terms of Reference

January – March 2011

Following consultation on the draft framework document the following draft terms of reference have been suggested. The first meeting of the Working Group will consider the draft terms of reference suggested by participants at the engagement event together with the following:

- To identify and evaluate effective and appropriate methods for engaging patients and the public in the development of (specific) cancer services within the Network's provider organisations. *This task could include piloted studies based upon models of good practice from other public services*
- To determine whether or not a formal Partnership Group, operating at Peninsula Network level, could make a meaningful contribution to the process of engaging patients and the public in the development of cancer services and to advise the Network Board accordingly
- To make recommendations, should the Board wish to establish a new Partnership Group, regarding its role, composition, terms of reference and working practices

Agree priorities for future action

February – March 2011

A number of priorities for future action by the Network and a Working Group were agreed at the conclusion of the engagement event:

- Recognition of the importance of user contribution by the Network supported by a statement from the Chair of Network
- Revisit functions of local user groups as all function differently; learn from good practice and ensure that all have the same standards and support
- Identify how can we harness intelligence from localities, services and current users to ensure that user feedback is relevant, up to date and can genuinely influence current and future practice in cancer services

Review structures, approaches and methods for patient and public involvement

March 2011 – March 2012

The Network, local partners, patients and the public and external reviewers will only know if patient and public involvement has improved and is effective by reviewing outcomes and satisfaction. There are a number of measures that will provide evidence on whether the Peninsula Cancer Network has developed effective and sustainable patient and carer involvement which leads to improvements in cancer care across the network:

- ***Review within local revised structures for engagement***
- ***Review by local partners and key stakeholders***
- ***External review by the Independent Reconfiguration Panel***

Review and monitoring should be a continuous process, with feedback shaping the approach, structure and methods for involvement. However, a more formal process of review could take place one year from the start of the Working Group's activities.

Review within local revised structures for engagement, by local partners and key stakeholders

There will need to be regular reviews by the Network, the Working Group and key partners in future structures for involvement, including local NHS, voluntary sector and statutory organisations such as local authorities and LINKs. Review will need to take into account the wider impact of user

involvement by means of engagement with patients and carers currently using services.

It should be noted that the new statutory arrangements for patient and public engagement and for health and wellbeing (the establishment of Healthwatch and Health and Wellbeing Boards) and the abolition of PCTs will potentially be in place within the next few years and arrangements will need to be reviewed.

There should be a review within one year of the establishment of the Working Group which should examine:

- **How far has the User Involvement Strategy increased the quality of patient and public involvement interventions?**
- **What tangible outcomes and improvements to cancer care have resulted directly from user involvement priorities and issues?**
- **What wider application does the approach taken for patient, carer and public involvement in the development, improvement and configuration of gynaecological and head and neck cancer services in the South West Peninsula have for the PCN strategy for user involvement in all cancer care services?**
- **How should the User Involvement Strategy be developed and changed to reflect any gaps or needs for different approaches?**
- **If a Partnership Group has been established, how well is it fulfilling its Terms of Reference and what is the impact of its work on cancer services and user involvement?**

External Review

In addition, the Independent Reconfiguration Panel made recommendations that will need to be reviewed externally in terms of fulfilment in **early 2011:**

- **How the experiences of patients are captured and used to design and deliver better cancer services**
- **Demonstration of the re-establishment of a effective and fully functioning Partnership Group or other arrangements for patient and public involvement**
- **Evidence of appropriate resources, support and organisational leadership for engagement and involvement**
- **Evidence of strong support and facilitation to ensure the influence and effectiveness of new partnership arrangements continues**

Your views

This framework for involvement acts as both guidance and a consultative document; it provides information, principles, recommendations and proposed actions based on the views of patients, carers and key stakeholders. However, as stated early in the framework, it is a living document, to be shaped and directed by those people who have an interest in the development of effective patient and public involvement to improve cancer services across the Peninsula.

Please let us know what you think about the principles, proposed actions and way forward suggested here by sending comments to:

Cath Broderick, email office@weconsult.co.uk and

Nikki Thomas, email nikki.thomas@nhs.net

Your views, ideas and involvement are vital and welcome.

Appendix One

What should patient and public involvement look like?

Participants in the engagement event in December 2010 considered what their vision of patient and public involvement would be; they were asked to describe a structure, relationships and issues that needed to be addressed and found it useful to describe how a future model of involvement would look by means of a diagram. Models such as these may be helpful but comments from stakeholders following the circulation of the report from the engagement event have stated that they may have limited application at this stage.

Model structures and lines of influence

User groups

Support groups

Charities

Influence services

Stronger link to professionals and user groups

How to harness feedback from users/ carers/ clinical participation

Info flows

Services(primary/acute)

Working Group

Engagement activities

Working relationships

Network

PCTs

GPs

Appendix Two

The Working Group is to consider whether there is a function for a new Network Partnership Group. If the Group considers that there is a role for a Partnership Group, it will need to identify Terms of Reference. The following is based on the National Cancer Peer Review Programme *Manual for Cancer Services 2009 Network Partnership Group Measures* and the former Network Partnership Group remit:

Terms of Reference for a Network Partnership Group

Terms of Reference (TOR) for a Network Partnership Group, would include the definition of the Group's role, priorities, tasks and ways of working.

The former Network Partnership Group had a remit which included a range of tasks and fulfilled two interrelated functions within the Network:

- i. Contributing to continuous improvement of the patient and carer experience of cancer services. This function entails service users working in partnership with health professionals to provide advice and guidance to the Network Board on those experiences of cancer care known to be of importance to patients and carers, including:
 - Patient-centred care
 - Supportive care
 - Transitional and self managed
- ii. Ensuring that authentic and effective service user involvement underpins work to improve the patient and carer experience of services across the Network

Example of Terms of Reference

Membership

- Membership of the Partnership Group should reflect patient and carer perspectives across the Network area and fulfil the following:
 - One representative drawn from each of the localities of the network, with 'localities' to be agreed, for example geographical areas of population and/or acute trust catchment areas;
 - A named chair drawn from the representative agreed by the Partnership Group membership;
 - A health professional member of the Network Board;
 - A network partnership group facilitator;
 - At least one nurse core member from an MDT in the network;
 - At least one lead clinician core member from an MDT in the network;
 - An NHS employed member nominated by the Network Board as the network lead for users' issues and information for patients and carers;
 - Named secretarial/administrative support

- A role description for members will be agreed with the Network and members

- The Chair of the Network Partnership Group should have an Annual Review with the Nurse Director and/or a member of the Network Board to discuss the work of the Partnership Group

Strategy

- The Partnership Group should produce a three year strategy for the Board

- The Partnership Group should agree an annual work programme with the Board

- The Partnership Group should produce an annual report for the Board

Responsibilities and Work Programme

- Hear information on development of cancer services and contribute a patient and carer perspective:
 - Agree the network guidelines for the development and delivery of patient centred care
 - Agree the network guidelines for development and delivery of supportive care
 - Agree the network guidelines for transitional and managed care
- Agree the network guidelines for user involvement, including where and how patient and carer feedback is to be obtained by the Partnership Group, MDTs, NSSGs and Cross Cutting Groups (CCGs) and wider service user and public engagement
- Hear feedback on results of local engagement with users and staff and make suggestions for the improvement and relevance of cancer services based on priorities emerging
- Take an overview of how PCN is undertaking and developing involvement. Review the success and effectiveness of methods used and structure for involvement and contribute views on ways to improve user engagement:
 - The partnership Group should identify what patient experience of care and service user involvement is in place
 - Develop a three year service specification for what patient experience of care and service user involvement should be in place across the network

- Identify gaps between what is in place and what should be in place through service needs assessments
- Review the existing strategy and develop an approach regarding what needs to be done in order to achieve what should be in place
- Specifically contribute to the approach to patient, carer and public involvement in the development, improvement and configuration of gynaecological and head and neck cancer services in the South West Peninsula
- Identify wider application of successful and appropriate PPE methods, approaches and partnership working to PCN patient and public involvement strategy
- Influence the development and improvement of cancer services across the Peninsula by reviewing the priorities identified through user engagement activities of PCN and providers

Development of the Partnership Group

- Make periodic assessments of the overall positive impact its work has had on the planning, delivery and evaluation of cancer care services in the area
- Make periodic assessments of the overall positive impact its work has had on the way in which patient experience and service user involvement is undertaken in the network area
- Review membership training and support needs, capability, breadth of experience and diversity to meet the Partnership Group's capacity to bring about change

Some Examples of Ways that the Network Partnership Group could work

In Section 1 of this framework we provided some information on the different levels of involvement at which individuals and groups can work. If the Working Group agrees that there is a role and function for a Network Partnership Group it may wish to consider how the revised Partnership Group could work in future. Examples could be:

Information on the patient/carer experience

The Partnership Group wants to find out about and understand what shapes patients' and carers' experience of cancer services. They decide to receive information and review the findings of recently conducted Network user experience surveys.

However they may work at a different level and generate their own information through conducting focus groups, deliberative events, mystery shopping initiatives, involving patients in clinical decision pathways or interviewing patients and carers. They would then feed this back to the Network and service providers to influence service quality and development.

Co-design of projects and programmes

This could involve Partnership Groups drawing up a plan designed to bring about necessary improvements to the patient/carer experience. Usually this means specifying some aims and outcomes designed to improve matters and working with the Network to devise a strategy and action plan outlining what needs to be done in concrete terms to make changes.

Another example would be the co-design of the Network's approach to patient and public involvement and the structure for involvement.

Being responsible for developing a programme of work or strategy

This involves deciding on a priority for a work topic, developing a strategy and programme of work to take forward. The outcome of the work would

inform the strategic direction taken by the Network or the way in which the Partnership Group works in the future.

An example would be reviewing the Group's terms of reference, the impact its work has had on the planning, delivery and evaluation of cancer care services in the area, and developing a strategy for future programmes of work and priorities.