

**Agenda Item: 6**

**From: Tonia Dawson (Nurse Director)**

**Justine Thompson, (Patient & User Group Facilitator)**

## **BOARD REPORT – Patient and Public Involvement Strategy**

### **1 Purpose**

To set out the vision for Patient and Public Involvement in cancer services in Anglia, especially with regard to the implementation of the service strategy 'Moving Forward on Cancer Services In Anglia'. This report has been drafted by the Patient Partnership Group and it is being brought to the Board for discussion and agreement.

### **2 Background**

Support and active involvement from patients, carers and those whose lives are affected by cancer is vital if the Network is to implement the Network Strategy for transforming cancer care successfully. The Patient Partnership Group is a cornerstone of this involvement, and the active voice of the patient. Here the Group sets out its strategy for working with the Network.

### **3 Key Points**

- The document describes why the cancer initiatives currently being undertaken by the Network are important to patients.
- It includes pertinent case studies, which can be used with patient groups to explain the benefits of these initiatives.
- The document has been written by patients for patients, and avoids much of the NHS management language used elsewhere. The case studies also illustrate how patients see the issues, and how we can communicate better with patients and carers.

### **4 Future Action**

- The document requires some further revision and art work. The intention then is to publish it and make it available for local discussion.

### **5 Recommendations**

The Board is asked to support the development of the PPI strategy and approve the document.



Anglia Cancer Network

# Patient Partnership Group Strategy 2011 to 2013

Ref: AngCN-40  
Cancer Standards Measure:

NOTE: On authorisation and publishing DRAFT watermark will be replaced by  
Anglia Cancer Network Map

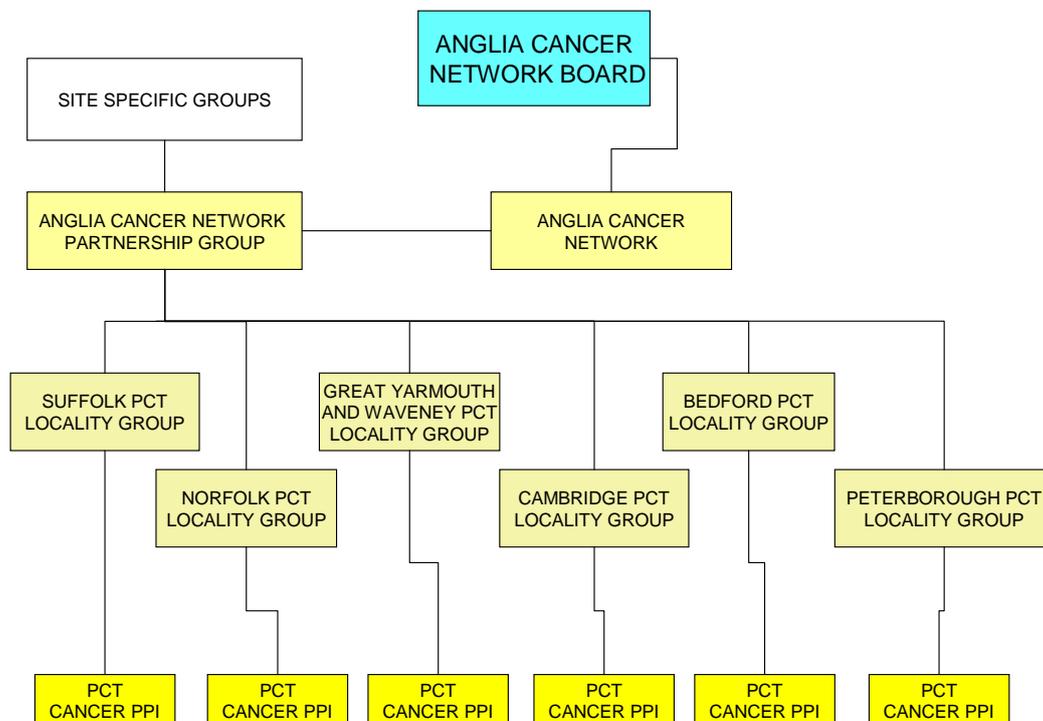
## 1 Introduction

The vision of the Anglia Cancer Network (AngCN) is to have the best cancer survival rates in England, and for patients living with and beyond cancer to experience real improvements to their care and support. It is a vision that patients, carers and the public across the region whole-heartedly support. In 2011/12, more than ever before, there is a need for the patient voice to be heard, as the nation's health service undergoes profound restructuring. The AngCN's Patient and Public Involvement Group is the cornerstone of that voice in the Anglia region, ensuring real dialogue between the users of our cancer services and those who provide them. Through this partnership the AngCN will ensure that service improvements are of real benefit, restructuring is soundly based on what the patient needs and wants, and services provided by everyone from our hospital specialists to community nurses and GPs are among the best in Britain.

This strategy sets out the PPI Group's vision for the coming years, as it seeks to support the region's health services through the changes ahead to a better future for cancer patients, survivors and their families and carers.

## 2 What is the PPI?

The Anglia Cancer Network's Patient and Public Involvement Group is a committee of the AngCN Board. It is made up of patient representatives from locality user groups across the region, Network Site Specific Groups, and cancer professionals and facilitators. There is a chair and a vice chair - both patient representatives - who have seats on the Network Board. The group is a powerful and influential body. It is the Network's main source of advice on patient-related issues as it goes about its business of planning, managing and quality controlling the region's cancer services.



### 3 Group constitution and membership

The group will be constituted as required by the terms of the Partnership Group Peer Review measures 2011, namely:

- At least one rep from each of the localities
- A named Chair
- A health professional member of the Network Board
- A User Group Facilitator
- At least one nurse member from an NSSG
- At least one Lead Clinician from an NSSG
- An NHS employed member nominated by the Board as the Network Lead for users' issues and information.
- Nominated Secretarial/admin support
- Additional members can be agreed by the group in addition to the above

### 4 Role of the group

The group is the primary means by which the AngCN Board and officers consults with patients, carers and the public about cancer services. It is a credible patient voice, which consults widely with patients, carers and the public through formal and informal channels.

Its overarching purpose is to ensure that within East Anglia all service providers take account of the views, opinions and experience of the cancer patients and carers who use and receive their services. The group will bring user issues and problems to the fore, and thus act as a safety net ensuring that areas of patient concern are quickly uncovered.

The group will also be the primary means of consultation and involvement in changes to the practice and provision of the region's cancer services.

In its work, the PPI Group will also support and be mindful of the AngCN's five strategic goals:

1. Reduce cancer inequalities across the AngCN
2. Improve patient experience of cancer services
3. Provide safe and effective care and treatment
4. Help patients live with and after cancer
5. Develop the AngCN to support all partners in improving cancer services

### 5 Key priorities

In this critical period for the nation's health care in general - and cancer care in particular - the PPI Group has identified **eight key patient priorities** in the evolving picture of cancer service provision. Addressing these priorities will form its strategic goals for 2011 and beyond. These goals also support the Network's overall strategic goals (above).

#### 5.1 Survivorship

- To monitor the 'Living with cancer' support available in each region
- To support the role-out of the AngCN pilot Survivorship Initiative from Ipswich to other hospital trusts/GP commissioning groups across the region and the Macmillan Self management programmes

WHY: There are currently around two million people living with cancer in the UK - and this number is set to rise to four million by 2030. An estimated 90,000 of these are living in the Anglia region. The Survivorship Initiative aims to help improve the lives of those living with and beyond cancer, by helping them and their families to manage their condition and feel more confident about the future; it also signposts them to further help where appropriate.

Survivorship is also about changing the ways in which cancer patients are followed up in the future. There may be less regular contact with clinicians but increased supported self management. The PPI Group needs to be involved with these changes to ensure a positive benefit to patients and their families.

The needs of patients with metastatic disease - those living with chronic or progressive cancer - must also be considered and addressed through the Survivorship agenda and this should be monitored by the PPI Group. The White Paper 'Improving outcomes - a strategy for cancer' (2011) said that although there had been 'significant improvements in support for people living with and beyond cancer, more needs to be done.' This should include things such as increasing the number of cancer patients who are able to return to work or education.

- **The patient's view**

Mick Whiley, prostate cancer patient, Ipswich: "My wife and I both took part in the 'Moving On' programme at our local hospital and it was really, really helpful. A cancer diagnosis comes as such a bombshell. After the rollercoaster of all the surgery and treatment I was physically recovered but mentally we were both lost and confused. We had four sessions on the programme and, although it wasn't always easy to talk about things, we felt completely supported. I also think it was very important that we could do it together as my cancer diagnosis was affecting both of us. Moving On has given us hope and we're now ready to face the future again."

Transforming in-patient care

- To monitor and support the transforming in-patient care vision
- To consider the patient experience resulting from these changes

WHY: In-patient care matters to patients - most are admitted to hospital at some point in their cancer journey.

England has a higher bed use for cancer than other countries; yet if patients are well enough it is better for them to be out of hospital and away from infections and enforced immobility. Patients who return home more quickly are likely to recover more quickly too.

National Cancer Director Prof Sir Mike Richards has estimated that the in-patient care initiative could save the NHS a million bed days - money that could potentially be used to improve other aspects of the cancer service.

Enhanced recovery, a part of the in-patient care programme, can

significantly improve recovery time for patients and allow them to go home earlier. This is achieved through use of up-to-date techniques for surgery and anaesthesia, and considering and planning for patient discharge prior to admission. The PPI Group and Network Site Specific Group patient representatives must be involved in the monitoring and roll-out of these changes and supportive where these are in the best interests of patients.

The AngCN is a pilot area for the Breast 23 hour model. The PPI Group and NSSG patient reps will be involved and consulted at every stage of this roll-out and supportive of any change in practice that is in the best interests of patients. In particular they should monitor the quality of the patient experience in this area.

- **The patient's view**

Breast cancer patient, Cambridge: "I was due to have a day-case lumpectomy and went into hospital at 7:30am. Nobody was able to tell me exactly when my operation would be and I wasn't operated on until about 4:00pm. The waiting and anticipation were difficult. Also I was starving. I was offered very little to eat or drink in all that time. In the event I had to stay in overnight because I was operated on so late, and there were complications. In the morning I had to ask for something to eat again. I now realise this may have been because they didn't expect me to be there!"

## 5.2 The role of the Cancer Nurse Specialist

- To encourage the appointment of Clinical Nurse Specialists and champion the introduction of community cancer nurses

WHY: The Cancer Patient Experience Survey 2010 revealed that patients valued the support offered by Clinical Nurse Specialists (CNSs) very highly, with those who had access to them reporting a better patient experience. Clinical Nurse Specialists can also improve efficiency, reduce emergency patient admissions and lead to financial savings. However, not all cancer patients in the region have access to such a specialist.

With the advent of GP commissioning there will also be a place for community cancer nurses to help support and care for patients in the community. We will work with the network looking at new ways of providing care so that patients receive the support they need in the community. We will review similar posts that exist within the community and help the network design new models of care.

Currently across the Anglia region there is a shortage of CNSs, particularly across less common tumour sites, such as brain and sarcoma. The PPI Group will consider the impact of this shortage on these patients and carers and ensure this need is understood by service providers and Commissioners.

- **The patient's view**

Josie Phillips, brain tumour patient, Norwich: "When my tumour was diagnosed I was living in Cardiff where there was a specialist neuro-oncology nurse. I found the help she gave me and my family absolutely invaluable, and I still rely on her as a source of support today as there is no one in our local area. Being diagnosed with a brain tumour is a massive shock and you have to learn how to deal with it. Friends and family can't necessarily help, as they may not have the understanding or experience and are going through some of the same pain with you. Specialist nurses can take the time to help you work out how to carry on and cope with life. They provide emotional support but also practical advice and help with access to services and funding as well as providing a link with consultants/surgeons who it may be difficult to talk to directly."

### 5.3 Palliative/End of Life Care

- To look at the pathway for palliative and End of Life care and ensure it meets the needs of patients, carers and their families
- To ensure that those people who want to die in their own homes are supported to do so

WHY: The care of patients is changing with initiatives like survivorship and self-care but alongside this there may also be a benefit for patients to access palliative care services at an earlier stage, to ensure they are supported throughout their cancer journey.

Palliative care can come into play throughout a patient's life, whereas End of Life care is a different pathway and comes into play in the last weeks and days of a patient's life.

There is a need for patients and families to be more aware of what palliative care can provide for them and less afraid of the 'palliative' label - the PPI Group could help to refocus the message of palliative care. With less fear more patients with their professionals might access services such as 'just in case bags' within the community. They can also be supported to make decisions about where they want to die.

The PPI group will also look at the provision of appropriate community nursing to allow patients who wish to do so to die in the place of their choice. All too often cancer patients are being rushed into hospital, to die just hours later, when this final undignified trauma could have been prevented with planning and appropriate service provision. We need to understand whether we have sufficient numbers of trained palliative/community care staff, to look after patients at home seven days a week and what work is being done to improve this situation?

- **The patient's view**

Breast cancer patient, Peterborough: "I've recently returned home from a stint in our local hospice for pain control, and the care I had was fantastic. I am aware that I will probably not live for much longer. If it was up to me I would like to die at home but I have to think of my children and the impact it might have on them. After talking it through with the excellent staff at the hospice I have requested to die there, and I feel reassured they will care for me and my family very well when the time comes."

#### 5.4 The Patient Experience

- To monitor the cancer journey for patients - from diagnostic testing to remission/end of life - and to push for that experience to be as positive and co-ordinated as possible.
- To develop a comprehensive and relevant model of patient experience.
- To call for increased psychological support to help improve the Patient Experience

WHY: It is crucial to the achievement of the Network's Aims and Objectives that all patients have the best cancer journey that can be achieved, as this is fundamental to their well-being and that of their families. To this end the PPI group is working with the professionals of the AngCN to develop a comprehensive and relevant model of patient experience.

The PPI group also considers it an essential part of the experience of patients, carers and close family that they have access to a high level of psychological and/or socio-spiritual support. This is an area where the Network faces a severe deficit. Currently there are some 1.9 whole time equivalent (WTE) staff qualified to levels 4. NICE guidelines indicate that across the Network there should be 6.5WTE posts. This is an issue that needs to be addressed and monitored and the PPI group will be strongly encouraging the development of increased psychological, social and spiritual support.

- **The patient's view**

Jacqui Williams Durkin, chronic lymphocytic leukaemia patient, Huntingdon: "Psychological support is nonexistent for most people in this area - unless you are the sort of person who can jump up and down and really demand it. It was six years before I managed to get any counselling, which I could only access through the local hospice. By that time I was really angry and in a very bad way about things. I can't help feeling that if I'd had psychological support right from the start I would never have got into such a state and the whole experience would have been much less traumatic for me."

## 5.5 Patient Information

- To monitor and support the introduction of Patient Information initiatives such as 'Information Prescriptions' and 'Information Pathways'
- To help ensure patients are directed to quality information that is appropriate to their needs at each point of their cancer journey
- To monitor the delivery of information by health service professionals

WHY: "No decision about me without me" is the new Coalition Government's mantra for the health service. Informing patients in a manner tailored to them as individuals will greatly improve the patient experience and their ability to give informed consent before treatment. Recognition should be made of the fact that information can be given in a variety of forms, and that a leaflet offered at the end of an appointment is rarely sufficient. It is also important that professionals should understand the impact of the information they are giving, and should have the necessary communication skills to deliver this in a sensitive and empathetic manner. Information should also be available to carers and family members as it can help them support the patient, as well as addressing some of their own concerns. To this end the PPI group will be supporting the introduction of the 'Information Prescription' model of information, which is tailored to the needs of the individual patients. The group will also work with the AngCN Patient Information Manager to help evaluate new models of information across the region.

### • The patient's view

June Kay, lung cancer patient, Norfolk: "I was diagnosed six years ago and at that time things were very different and not so many people had internet access. I found the information I was given good enough at the time. I had a leaflet that was adequate but, apart from that, if I wanted to know anything I just asked. But that was me and I know how to stick up for myself. I think there are probably others who might not find it so easy to ask questions and they need help and encouragement to do so, as well as being given the relevant information as and when they need it."

## 5.6 The changing face of patient involvement

- To consider the role and influence of the PPI group during the evolution of GP Commissioning
- To educate and inform user reps about changes to healthcare commissioning and how they can become involved
- To monitor the introduction and influence of the new patient body Healthwatch - with particular interest in its relevance to cancer patients and services

WHY: Patient involvement is crucial to the future success of cancer care -

and to its safety. The PPI group needs to be at the forefront of any changes in influence – i.e. with GP Commissioners and with the beginnings of Healthwatch - to ensure the patient voice is heard in this crucial period of flux. Patient involvement is especially essential as healthcare reforms take place, so that teething problems can be swiftly voiced and responded to.

There is also a need to inform and educate patient representatives to help them understand the new systems of commissioning and provision. In turn, this will help them to make the patient voice heard at appropriate points and with the relevant people.

- **The patient's view**

Tony Rollo, Chair of the AngCN PPI group: "Patient involvement is now more crucial than at any other period in the evolution of the NHS. With wide scale changes ahead, it is essential that cancer patients in particular are heard loud and clear at each stage of in their implementation. If anything isn't working, it will be the patients who suffer first, so measures must be in place to ensure the patient voice is heard loud and clear through the challenging processes ahead."

#### 5.7 Cancer 'volunteers' and the National Cancer Partnership

- To join in development consultations for the proposed Department of Health 'Cancer Partnership'
- To help collate and develop a region-wide network of support groups, with the aim of sharing information and best practice
- To help collate and develop a region-wide network of volunteers, who are properly trained and assessed, to assist in cancer support and information roles

WHY: The Government White Paper 'Improving Outcomes - A Strategy for Cancer' (Jan 2011) announced a new Cancer Partnership of voluntary organisations, support groups, charities and businesses, all coming together under its Big Society umbrella. The aim of the Partnership is to stimulate new community action to raise awareness of cancer and to support those suffering from cancer and their families.

Supporting organisations will be asked to sign up to a number of initiatives including, for businesses, making the workplace a more 'cancer-friendly' environment, with employees and customers being signposted to cancer information and support, and employees being supported to return to work following a cancer diagnosis.

Cancer support groups will also have their part to play in this new partnership, and the PPG will take steps to collate, meet and work with these groups to help further the aims of supporting cancer sufferers, raising awareness of the disease, encouraging volunteers and establishing best practice.

Furthermore, the PPI group will also work to help establish a network of volunteers, who can be trained and motivated to work across hospitals, hospices and support groups for the good of fellow cancer patients and carers.

- **The patient's view**

Alan Bateman, cancer patient, Ipswich: "There are lots of free, willing and talented volunteers who really want to do more in the support space but need organising better and perhaps 'registering' in some way. The support on offer town-by-town is varied and difficult to quantify as a patient. It tends to be communicated by grapevine or local user groups, with the result that many newly diagnosed people struggle to find what they need, or understand the standard offered in their area. It would help tremendously if we could try to organise these people and groups so that they can reach the people who need them and make a difference."

## 6 Monitoring the Effectiveness of the Strategy

A work programme will be written to take forward the work of the strategy and to monitor and review ongoing progress and effectiveness.

a) Process for Monitoring compliance and Effectiveness - Review of compliance as determined by audit. Any non compliance to be presented by QA Manager to the AngCN Business Meeting on an annual basis – the minutes of this meeting are retained for a minimum of five years.

b) Standards/Key Performance Indicators – This process forms part of a quality system working to, but not accredited to, International Standard BS EN ISO 9001:2008. The effectiveness of the process will be monitored in accordance with the methods given in the quality manual, AngCN-QM

### Equality and Diversity Statement

This document complies with the Suffolk PCT Equality and Diversity statement – an EqIA assessment is available on request to Anglia Cancer Network QA Manager, Gibson Centre, Exning Road, Newmarket, CB8 7JG.

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## Document management

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