



## Guidance document

The Northern Ireland Cancer Network (NICaN) brings individuals and organisations involved in health care together in order to plan, develop and monitor cancer services. Health care professionals involved in cancer care from areas of Northern Ireland meet regularly together as part of the Cancer Network to progress current and future aspects of care.

This paper outlines how individuals throughout Northern Ireland can become actively involved in the planning and shaping of cancer services. *One* of the ways to make a difference is by becoming an active member of a regional cancer group.

The Cancer Network is keen to ensure that the perspective of patients and family members is central to all aspects of cancer. Becoming a Patient and Public Involvement Representative will afford you the opportunity to be a part of the Cancer Network and have a voice in shaping current and future services and make a difference to the lives of many individuals.

Please find overleaf details of existing groups within the Cancer Network as well as an outline of what the role of Patient and Public Representative would involve.

Please do not hesitate to contact NICaN should you have any queries regarding Patient and Public Involvement. Contact details are; Telephone 028 9056 5860 or email any queries to [nican.office@hscni.net](mailto:nican.office@hscni.net). The Cancer Network website also contains details which you may find useful - [www.cancerni.net](http://www.cancerni.net)

The following are frequently asked questions regarding the Cancer Tumour groups. However, should you have other questions please contact the Cancer Network office.

#### **WHAT IS A CANCER NETWORK SITE SPECIFIC GROUP?**

This is a group of individuals meeting to address a particular type of cancer e.g. lung or breast etc. Each group is made up of health care professionals and individuals affected by cancer who meet to discuss and plan both current and future developments which will affect the care of patients.

The work undertaken through these groups is critical in shaping cancer services within Northern Ireland. Hence, the active participation by those individuals who have used such services is of utmost importance

#### **WHAT CURRENT SITE SPECIFIC GROUPS EXIST WITHIN THE CANCER NETWORK?**

Breast  
Colorectal (bowel, rectum)  
Gynaecology  
Lung  
Skin  
Upper G.I (gullet and stomach)  
Urology  
Head and Neck

#### **WHAT KIND OF WORK DO THE SITE SPECIFIC GROUPS CARRY OUT?**

The Site Specific groups work on a variety of topics. Current examples include the development of care pathways, patient information, GP referral guidance and the development of standards.

#### **WHAT WILL BEING A PATIENT AND PUBLIC REPRESENTATIVE INVOLVE?**

Becoming a member of a Cancer Network group will mean:

- Representing the views of patients and the public at Tumour groups within the Cancer Network
- Being actively involved in discussions with health care professionals
- Sharing information with Forum Leads in order to guide the overall work of Patient and Public Involvement within the Cancer Network
- Providing information *to* the health care professionals in the groups but also being a means of ensuring that information *from* the Site Specific group is filtered out to patients and the public, thereby creating a flow of relevant information
- Being part of a mechanism which will allow the representative to draw upon the experiences of other individuals affected by cancer
- Directly working on current projects relevant to the specific cancer services

#### **WHO WOULD I BE WORKING ALONGSIDE IF I BECAME INVOLVED WITH A NETWORK GROUP?**

- other Patient and Public representatives
- health care professionals with each group is comprised of

- a chairperson
- health care professionals working in the specific area of cancer services including nursing and medical staff, staff allied to health professions e.g. physiotherapists, occupational therapists, dieticians, pharmacists as well as staff who work in the primary care and hospital setting and representatives from supportive and palliative care
- representatives from the Department of Health, Health and Social Care Board and the Public Health Agency.

#### **HOW WILL PATIENT AND PUBLIC INVOLVEMENT REPRESENTATIVES BE SUPPORTED WITHIN THE GROUPS?**

- Through creating an open , friendly atmosphere where the input of all members is acknowledged to be of equal value
- Through providing *ongoing* training and education specifically for patient and public representatives
- Having the opportunity to discuss the agenda in advance of meetings with a named individual from the group, thereby giving individuals the opportunity to ask questions, have issues relating to patient and public involvement brought to the agenda etc
- Through regular meetings with Forum Leads (Mr Alex McGuiggan and Ms Nicola Porter) and NICaN staff to allow representatives to discuss their roles and how their input can be enhanced

#### **WHO CAN BECOME A PATIENT AND PUBLIC REPRESENTATIVE?**

- Individuals who have had cancer , who have come to terms with their diagnosis and feel able to participate OR
- Family carers of those individuals who have been diagnosed with the specific cancer relating to the Site Specific groups listed above OR
- Individuals already involved in support groups who can feedback information to and from the group or, if not , a willingness to liaise with others in support groups through Northern Ireland

#### **HOW ARE PATIENT AND PUBLIC REPRESENTATIVES IDENTIFIED?**

- Clinical Members of the Network Site Specific Group propose interested patient/carer representatives
- Network Site Specific Group identify established patient support groups where a nomination can be secured
- Expressions of interest are sought from HSC Trust Service User and Carer Groups
- The Cancer Charities Alliance propose interested patient/carer representatives (These mechanisms were agreed at the PPI forum meeting December 2013)

#### **ARE THERE PARTICULAR KNOWLEDGE/SKILLS THAT REPRESENTATIVES WOULD NEED TO HAVE?**

- Having a very clear understanding of how cancer affects individuals diagnosed with the disease as well as their family circle
- Understanding that being a member of a Network group will involve representing others and not bringing merely one voice to the table
- Being able to listen to the opinions of others at group meetings

- Being able to communicate the opinions of others to the group
- A willingness to travel to the meetings

#### **HOW MANY MEETINGS WOULD I HAVE TO ATTEND?**

- Usually there are 4 meetings per year for each group. These are held in various localities although the majority tend to be around the Antrim area to facilitate use of the motorway. They are all held in the afternoon and last approximately 3 hours
- Regular support meetings are held which aim to provide support to all PPI Representatives
- Access to a car or driver would be necessary in order to attend meetings

#### **WILL I RECEIVE REMUNERATION FOR TRAVELLING/ATTENDING MEETINGS?**

- Yes- it is the aim of the Cancer Network that no Patient and Public representative will be out of pocket as a result of attending Site Specific group meetings.

#### **COMPLETING THE ATTACHED FORM**

It is vital that there is an open and transparent way of ensuring that all individuals who feel that they would like to participate as a patient and public representative within the Cancer Network have the opportunity of doing so.

The attached form will allow any interested individuals to register an expression of interest and forward their personal details. Those who do express an interest will be invited to meet the Forum Leads to find out more about involvement in the Network Site Specific Groups.

Should you have any queries please contact the NICaN office.

Northern Ireland Cancer Network  
 1<sup>st</sup> Floor, IT Department  
 Back Entrance Knockbracken Clinic  
 Knockbracken Health Park  
 Saintfield Road  
 Belfast  
 BT8 8DH

028 9056 5860

[nican.office@hscni.net](mailto:nican.office@hscni.net)

#### **References**

Valuing People, Valuing their Participation, consultation document; A Strategy for Personal and Public Involvement for the Public Health Agency and Health and Social Care Board, 2011

The National Institute for Health and Care Excellence, Patient and Public Involvement Policy, 2013

**Northern Ireland Cancer Network**  
**Patient and Public Involvement in Network Groups**  
**EXPRESSION OF INTEREST**

<p>Please read the attached cover letter before completing this form as an explanation of the Network groups and contact details for any queries is included within it.  Please complete and return this form by post or email to the NICaN office.  Meetings with the Forum Leads &amp; Regional Co-Ordinator will then be arranged.  PLEASE TICK THE SITE SPECIFIC GROUP YOU WOULD LIKE TO EXPRESS AN INTEREST IN:  Breast <input type="checkbox"/> Colorectal <input type="checkbox"/> Gynaecology <input type="checkbox"/> Urology <input type="checkbox"/> Lung <input type="checkbox"/>  Skin <input type="checkbox"/> Upper Gastro Intestinal <input type="checkbox"/> Head &amp; Neck <input type="checkbox"/></p>	
<b>Title &amp; Name (Mr, Mrs, Ms, Dr. etc)</b>	
<b>Home Address and Tel No.</b>	
<b>E-mail address</b>	
<b>Date of birth</b>	
<b>Working Career/ Occupation (if relevant)</b>	
<b>Membership of organisations, posts held and dates</b>	
<p><b>Relevant skills and experience. For example, have you been part of any support group or supported anyone on a one-one basis?</b></p> <p><b>relevant skills and experience continued...</b></p>	<p>Please say here what you believe you are able to bring to the role of Patient and Public Involvement Representative in a Cancer Network group. Highlight the relevant skills and experiences you have gained through your own journey and/or drawing upon the experiences of your immediate family and friends. Employment, voluntary or community activities as well as any professional involvement in a health care profession will also be important here.</p>

<b>Other interests and activities</b>	
<b>Referee</b> (please provide the name and address of an individual who would be relevant to this application)	How do you know this person (e.g. employer, on same committee, work colleague, personal):
<b>Signed:</b>	
<b>Date:</b>	