



## Patient and Public Involvement in the planning and development of cancer services

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 me should you have any queries regarding Patient and Public Involvement. I can be contacted on 028 9056 5860 or email any queries to [admin@nican.n-i.nhs.uk](mailto:admin@nican.n-i.nhs.uk) The Cancer Network website also contains details which you may find useful - [www.nican.n-i.nhs.uk](http://www.nican.n-i.nhs.uk)

Best wishes,  
Janis

Janis McCulla  
Regional Co-Ordinator for Patient and Public Involvement

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)

Haematology (blood malignancies, such as leukaemia or lymphoma)

Gynaecology

Lung

Skin

Upper G.I (gullet and stomach)

#### 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 bring 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?

- one other Patient and Public representative
- 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

#### 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 , Mrs Bernie Montgomery and Mrs Madeline Mulgrew) and Janis McCulla, Regional Co-Ordinator for Patient and Public Involvement, 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

#### 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 we have 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 Tumour Groups.

Should you have any queries please contact Janis McCulla , Regional Co-Ordinator for Patient and Public Involvement, at the Cancer Network office.

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