



## **NICaN Patient Information Forum**

Tuesday 16 September 2008

10am – 12noon

Lecture Hall, South Tyrone Hospital, Dungannon

### **Record of Attendees**

- Margaret Grayson, Belfast Trust
- Sally Campalani, Belfast Trust
- Janis McCulla, NICaN
- Lorna Nevin, NICaN
- Christina Doyle, Belfast HSC Trust
- Breige O’Kane, NILSG
- Paula Kealey, Macmillan
- Danny Sinclair, NICaN
- Margaret McManus, Belfast HSC Trust - Macmillan Support & Information Centre
- Myra Perrot, NILSG
- Oliver Molloy, Cancer Choices
- Pat Beaddie, UCF

### Apologies:

George Allen, IA

Peggy McCann, NI Hospice

Richard Dixon, EHSSC

Susan Gibson

Jill Willis, SE HSCT

Cherith Semple, SE HSCT

Elizabeth England, WHSCT

1. Danny welcomed everyone to the meeting and everyone introduced themselves. Pat Beaddie is a cancer information nurse at UCF and is replacing Sheena Stothers on the group as Sheena has been appointed to a new post. Myra Perrot attended as a patient representative of NI Lymphoedema Support Group.
2. The notes from previous meeting were agreed.
3. **Patient Information updates**

#### **(i) Advanced cancer information pathway**

The advanced cancer information pathway group’s agreed purpose is to develop a pathway of information resources for people affected by advanced cancer for whom care is considered non-curative.

The pathway will be endorsed by S&PC Network for use in all of the tumour specific information pathways and across organisational boundaries. It will be for adult patients but will include relevant children’s issues e.g. bereavement. Carers’ needs will be assessed during the work and will be included as appropriate.

## Work done so far

A wide range of information topics have been identified by members, incorporating national and regional work. The group has agreed 'inclusion criteria' for any potential resources.

Detail on the group's membership and all of the above is available at

[www.cancerni.net/infopathways/advancedcancer](http://www.cancerni.net/infopathways/advancedcancer).

Group members are now identifying and appraising existing patient information materials:

1. Does the resource meet the inclusion criteria?
2. Which of the identified topics does it cover?

Then using this to:

1. Agree which resources go on the pathway.
2. Undertake gap analysis and decide how to proceed.

This group raised that social work need to have input to the work and supported that there is a need for the information pathway to include carers' needs. It was raised again that in delivering information, there needs to be an assessment of whether the patient wants the information or not. There is however some information that the patient must be provided, in terms of governance.

### **(ii) Breast cancer information pathway**

The Breast cancer information pathway is now complete and available at [www.cancerni.net/infopathways/breast](http://www.cancerni.net/infopathways/breast). It was signed off by the regional network group on 3 September. This was on the basis that as generic information is developed in the future, this information can be added to the breast cancer information pathway and the regional group advised of this and asked to approve the amended pathway.

### **(iii) Lung cancer information pathway**

The lung cancer information pathway is still under development. It is a complex list, covering many of the generic issues that apply to patients regardless of their cancer type. Danny acknowledged misjudging the timescale for this work.

The lung information pathway will be consulted on among regional network group members and others in the service during October. It is anticipated that it will then be consulted on through this forum, the Patient & Public Involvement Forum and via the website during November. Nb: this is Lung Cancer Awareness month. See [www.cancerni.net/infopathways/lung](http://www.cancerni.net/infopathways/lung).

An application for funding is being made to Macmillan. This is for the delivery of the lung information pathway through the means of a 'pack', that is, a folder with core items already in it, with information for the patient about what they can expect to be offered and what they can request as they move along their cancer journey. This is being developed in such a way that it would be possible to apply it to other cancer types in due course. Belfast HSC Trust are piloting the use of the information pack, including training of staff in its use.

Danny acknowledged the contributions of Mrs Anne Colville to the group's work. Anne was the lung cancer patient representative who had been working with the group. She passed away in July.

#### **(iv) Radiotherapy patient information evenings**

Margaret Grayson explained that there is research to support the value of patient orientation to their treatment environment before treatment is given. The Radiotherapy department at the Cancer Centre are piloting information evenings for patients and their carers - please see poster attached with these minutes. This information should be shared with any patients/clients who are part of the target audience for the events (see poster), but not targeted at the wider public.

#### **(v) Finance & Benefits standard in the Cancer Services Framework**

The Cancer Services Framework is going through a period of 'negotiation' with the Department of Health before being consulted on. Sally Campalani reported that the Finance & Benefits standard has been integrated into the Patient Information standard in that signposting to Finance & Benefits assistance services will be a part of each information pathway developed. Please note that the webpage where the latest version of the Cancer Services Framework is available is [www.cancer.ni.net/csf](http://www.cancer.ni.net/csf).

#### **(vi) Macmillan Cancer Support update**

Paula explained that Macmillan are undertaking a scoping exercise to look at the Finance and Benefits services available in NI.

They are also undertaking a scoping exercise for models of information delivery across NI, starting in SHSCT area. This work will commence late 2008 or early 2009.

Partnership working between the network and Macmillan could be further developed through NICaN Patient & Public Involvement Forum being willing to link with Macmillan in lobbying for services improvements.

### **4. Terms of Reference**

It is proving difficult to match the current membership of the group to what is needed in terms of an authoritative body who can represent - and decision make on behalf of - the wide range of patient information stakeholders.

This item is therefore being carried forward to a future meeting and in the meantime, Danny is meeting with Liz Henderson and Sally to discuss appropriate ways to seek implementation of regional patient information work in Trusts.

### **5. Signposting handbook - next edition and this forum's role**

Margaret McManus gave an update on the Signposting group's work on the handbook. The group has been considering what to change in the book when the 2<sup>nd</sup> edition is being designed. These changes will include:

1. A short description of what each area of help means
2. 2 pages per service – so that the areas of help they offer can be listed beside their main details
3. Font size increased
4. Short description of roles e.g. social worker, and how to access their services. This won't be their contact details but will be for example 'Seek a referral from your GP'.

This forum raised that it would be good to add to the booklet where an up-to-date list of Welfare Rights/CAB services can be found. Given that this is a developing area, it may be best to maintain the list online and use the book to signpost people to that list.

Group members are asked to gather in feedback about the handbook from people who have been given it. This can be done through using the questionnaire (see attached). People being given the handbook can also be pointed to page 65 where they can send in a request for a questionnaire.

It was noted that the onus is on each service to ensure that the information they submit **accurately reflects** what they offer to people affected by cancer.

The Signposting group recognises that their membership range could be improved.

Paula raised that a call was received at Macmillan from someone who said that NICaN office had told them there weren't any handbooks available there.

Please note: HSC Trust staff should seek copies from:

- Belfast – Sally Campalani,
- Western – Elizabeth England,
- South Eastern – Wilma Boyd Carson,
- Northern – Eileen Deery,
- Southern – Alison Porter/Hazel Neill.

Other organisations can seek additional copies while they are available from NICaN – telephone 90 56 58 60.

Please notify Danny or Janis about any services that are not listed in the handbook, so that they can be included in the 2<sup>nd</sup> edition.

Danny reminded members that posters are available for printing and a ready reckoner can be printed from [www.cancerni.net/handbook](http://www.cancerni.net/handbook). A laminated version of the ready reckoner is also available for information providers to use (not suitable for patients/carers). Please email Danny if you want one.

## 6. Website [www.cancerni.net](http://www.cancerni.net)

Danny gave an update that the website is now available for use and encouraged group members to use the 'Comments' function to send through feedback or alerts about information that needs changed on the website.

She also explained that each organisation in the Signposting handbook had been contacted asking for people who would hold roles such as PR, training etc. The people who were named by each organisation have been invited to a 'web workshop' on 30 September where they can learn how to add content.

## 7. AOB

### General patient information discussions

Some general comments were made about information provision: Side effect information needs to be included as part of treatment decision making, rather than just after the treatment has been given.

The environment in which bad news is given to patients is not always within a 'cancer clinic' setting. This has implications on how information pathways are implemented by Trusts and this also applies to with the network's work on Advanced Communication skills training.

It was raised that secondary care needs to be involved and/or kept informed about patient information work. This can be achieved through Trust representatives on this group having a communication structure with their secondary care colleagues and an openness to secondary care involvement in any of the work being done.

### **PI Strategy**

Danny explained that the development of an information strategy for NI will be informed by the publication of the Cancer Services Framework, the regional audit and the Macmillan scoping exercise.

The group agreed with Danny's suggestion that this work can be 'parked' for now. This will also allow for group members who have volunteered to be involved to be freed up from other existing patient information work that they are currently involved in.

### **PPI leaflet**

Janis gave out copies of a draft leaflet for patients and the public. This leaflet is to encourage their involvement in the work of NICaN. She asked this group's members to feedback any comments to her by the end of the month.

### **The Long Term Conditions Alliance for NI**

The Long Term Conditions Alliance for NI event "Long term conditions – working together" (8 October) was highlighted as of possible interest to members of this group.

### **Regional audit of patient information**

The project group's first meeting is scheduled for 22 September 2008. Information about this project can be seen at [www.cancer-ni.net/audit/patientinformation](http://www.cancer-ni.net/audit/patientinformation).

### **NICaN updates:**

New Director – Cara McCay has been appointed

New Primary Care Director – Dr Eddie O'Neill has been appointed

### **Next meeting:**

**18 November 2008, 10am-12noon**

**Conference Suite, Holywell Hospital, Antrim.**

## **RADIOTHERAPY DEPARTMENT**

# **PATIENT INFORMATION EVENINGS**

### **Who can attend?**

Information evenings are open to all patients (including family members) who have yet to start their radiotherapy treatment as well as those who have already started.

### **Where?**

Radiotherapy Reception  
Cancer Centre  
Belfast City Hospital

### **When?**

At 7.00pm (finishing at 8.00pm) on the following dates:

Tuesday 21<sup>st</sup> October 2008

Tuesday 18<sup>th</sup> November 2008

Tuesday 16<sup>th</sup> December 2008

### **What to expect?**

- Meet with Therapy Radiographers
- Introductory talk
- Tour of the Radiotherapy Department
- Informal chat over a cup of tea or coffee  
(provided by Friends of the Cancer Centre)

The aim of the evening is to provide you with a better understanding of your radiotherapy treatment journey.

If you are planning to attend this evening you will be required to provide your own transport.

If you would like to come along please telephone (028) 9069 9383 anytime. This number may be directed to a voicemail service, so please leave a message including your name and telephone number and we will return your call as soon as possible.