

**NICaN Patient Information Forum
Tuesday 27th May 2008
Board Room, Bush House, Antrim Area Hospital**

Record of Attendees

- George Allen, Ileostomy & Internal Pouch Support Group
- Margaret Grayson, Belfast Trust
- Cherith Semple, SE Trust
- Sally Campalani, Belfast Trust
- Janis McCulla, NICaN
- Lorna Nevin, NICaN
- Peggy McCann, NI Hospice Care
- Gerry Cunningham, Marie Curie
- Liddean McStravog, Cancer Lifeline
- Paula Kealey, Macmillan
- Danny Sinclair, NICaN
- Jill Willis, SE Trust
- Margaret McManus, Belfast HSC Trust - Macmillan Support & Information Centre
- Liz Osborne, CLIC Sargent
- Sheena Stothers, UCF
- Christina Doyle, Belfast HSC Trust
- Roy McMullan, Oesophageal Patients' Association NI
- Bryan Irwin, Cancer Lifeline

Apologies:

Liz Henderson, NICaN
Jenny Kelly, Men Against Cancer/BCH Urology
Lesley Munro, Macmillan Cancer Support
Deirdre Conlon, UCF
Heather Monteverde, Macmillan
Gillian Creevy, NI Cancer Fund for Children
Wilma Boyd-Carson, SE HSC Trust
Richard Dixon, EHSSC

1. Welcome and introductions

Ms Sinclair welcomed all to the meeting and particularly to new members, Peggy McCann, Gerry Cunningham and Christina Doyle.

2. Notes from previous meeting

The notes of 31 January 2008 were agreed as an accurate reflection of the discussions at the meeting. It was noted that Ms Sinclair had issued 'Patient Information News' in April 2008 to keep members up-to-date because the March meeting had been cancelled.

3. Network Patient Information update

i. Regional

Patient Information pathways for Breast and Lung

Ms Sinclair indicated that forum members will shortly be offered an opportunity to consult on these pathways.

Patient Information pathway for Advanced Disease

Ms Sinclair is presenting at the regional Supportive & Palliative Care Network meeting on 30 May to seek interested members to develop an advanced disease information pathway. This will be used to supplement each tumour site's pathway. Each tumour site's working group will have an opportunity to identify any additional tumour-specific advanced disease patient information needs. Action: Ms McCulla offered to approach Ms Joy Montgomery who may be interested in membership within this group, to represent the carer's perspective. Ms Kealey offered to be a PI Forum member within the group.

Cancer Services Framework

The Cancer Services Framework was submitted to DHSSPSNI on 18 May, including standards for Cancer Patient Information, User involvement and Communication. It is expected that the framework will be issued for public consultation in November 2008, formally launched in February 2009 for implementation from April 2009.

National pathways

National information pathways featuring national resources will be piloted by several English cancer networks in the summer. These are for Breast cancer, Gynae cancers, Prostate cancer and Bowel cancer. Lung cancer was meant to be part of this first set but has had to be postponed.

The national information pathways are being supported with the development of a web-based system which can be viewed at www.nationalcancerpathways.org.uk. Please note that the resources featured on this website are for the pilot sites to use only, and are protected by copyright against other use.

A future phase of this work will be to make the web system 'more local' including having it host local information resources as well as the national ones that are already on it.

Signposting Handbook

It was suggested that the Signposting working group be asked to consider including NHS services in the handbook next time. It was acknowledged that different language and titles are used between services providing similar services. This could be confusing for patients and the public, especially in a single resource covering many such services. It was suggested that the Chief Nursing Officer, Mr Martin Bradley, might be lobbied about having language and titles made common.

Action: Ms Sinclair to email all PI Forum members with a PDF of the Signposting Handbook cover to be used as a poster to raise awareness of it.

It was suggested that it is important to raise awareness and make copies available through Primary Care. Action: Ms Sinclair and Ms McCulla to bring this suggestion to the working group at their next meeting.

ii. Carers' Week

Margaret McManus explained the scheduled activities at the Macmillan Support & Information Centre for Carers' Week (9-15 June). Action: Ms McManus to email further information to Ms Sinclair for forwarding to members.

4. Terms of Reference

Discussion took place around the draft Terms of Reference circulated by Ms Sinclair before the meeting. Action: Ms Sinclair to update the draft document to reflect discussions and to re-circulate to forum members.

5. Website www.cancerni.net including testing

Update since the meeting:

1. Switchover to the new website scheduled: 1 September 2008. From this date, www.cancerni.net will be 'live', www.capricorn-ni.org and www.nican.n-i.nhs.uk will be pointed forwards.
2. Provisional launch date: 21 October 2008 – for press etc.

PI Forum members are still welcome to make suggestions about use of the site for the forum's functions and to make suggestions of features that work well within other patient information sites.

Action: All members are asked to comment on an offline version of the website. Feedback is welcomed very much although there is no obligation to take part. A simple form is being emailed out to gather essential feedback.

6. Regional audit

GAIN has agreed funding for the regional audit of cancer patient information provision. Patient Information Forum members already involved in this work are Margaret McManus, Alison Porter (Southern HSCT) and Danny Sinclair.

The audit proposal form has already been circulated (in Patient Information news April 2008), indicating two elements to this work; an audit of **provision** of written information to patients and an audit of the quality of individual **written resources** in NI.

Ms Kealey raised the importance of representation from charities on this group and offered to be a member of it.

7. Patient Information Strategy – forming a subgroup

Members were asked to consider involvement in a sub-group to commence this work. The following forum members agreed to be involved:

Margaret McManus
Liz Osborne (or other children's representative)
Paula Kealey (or Heather Monteverde)
Margaret Grayson

It has been noted that the strategy needs to include training in assessing information needs and targeting hard to reach groups.

8. AOB

PPI representation in the PI forum

The question was raised about PPI representation in the forum. Ms McCulla explained that, in attending from various local support groups/organisations, several members of the forum were also representing patients, carers and the regional PPI Forum.

Geographical coverage in the PI forum

To encourage representation at forum meetings from across the region, it was agreed to alternate the venue between Northern/Antrim area and Southern/Dungannon/Cookstown areas. Action: Ms Sinclair to book next two meetings with this in mind.

1. Future meetings were scheduled as follows:

Tuesday 16 September 2008. 10am – 12noon.
Lecture Hall, South Tyrone Hospital.

Tuesday 18 November 2008. 10am – 12 noon.
Conference Suite, Holywell Hospital.