

**NICaN Patient Information Forum
Tuesday 25th September 2007
Bush House, Antrim Area Hospital**

Record of Attendees

George Allen, Ileostomy & Internal Pouch Support Group	Paula Kealey, Macmillan
Deirdre Conlon, UCF	Janis McCulla, NICaN
Margaret Grayson, BCH	Heather Monteverde, Macmillan
Liz Henderson, NICaN/BCH	Lesley Munro, Macmillan
Bryan Irwin, Cancer Lifeline	Danny Sinclair, NICaN
	Jill Willis, South Eastern Trust

Apologies:

Gillian Creevy, NI Cancer Fund for Children
Eileen Deery, Northern HSC Trust
Isobel Dunlop, Relatives Association
Jenny Kelly, Men Against Cancer/BCH Urology
Margaret McManus, Macmillan Support & Information Centre
Roy McMullan, Oesophageal Patients' Association
Oliver Molloy, Cancer Choices
Breige O'Kane, NI Lymphoedema Support Group
Liz Osborne, CLIC Sargent

Welcome and Introductions

Danny Sinclair welcomed everyone and thanked them for attending, extending particular thanks to those who had travelled far and/or also attended the NICaN PPI Regional Forum the previous evening.

Patient Information and NICaN

She explained that Margaret McManus had sent a letter to the NICaN Network Manager requesting that a Patient Information forum be set up for the region. While Ms McManus had been unable to attend this meeting, she had asked that Margaret Grayson represent her interests.

Liz Henderson introduced the Northern Ireland Cancer Network (NICaN) as a mechanism introduced to facilitate communication and decision making between everyone involved in providing care and services to people affected by cancer in Northern Ireland. This is to ensure equity in terms of the quality of treatment, care and support that is provided, with a view to improving the patient's experience and outcomes. She also provided an explanation of the 'clusters' of professionals in place, e.g. site specific tumour groups.

Ms Sinclair outlined her role as to lead on ensuring patient access to high quality, consistent and up-to-date information across the network.

She outlined her current work areas as:

- Developing regional Patient Information protocols for Breast and Lung.
- Drafting a Patient Information standard for the 'Cancer' Service Framework.
- Working with the NICaN PPI Signposting group in developing a Handbook to direct people affected by cancer to existing voluntary sector services.
- Working on the integration of the CAPriCORN and NICaN websites.
- Member of a group set up by the Equality Commission for an information campaign on the changing definition of disability in terms of cancer (also MS, HIV, mental health).
- Supporting the establishment of this forum.

Ms Sinclair went on to say that her future work would include rolling out the development of regional protocols for other tumour sites and the development of a Patient Information Strategy for the network.

NICaN Patient Information Forum

Ms Sinclair invited those present to outline their thoughts on the functions that the forum could perform. She invited opinion on who should be involved and how the forum could link with other groups. Practical arrangements for future forum meetings and communication between meetings were discussed.

After much discussion, it was agreed that the forum would present an opportunity to steer how the network progresses regionally in terms of patient information. Through its advisory role, the forum may be able to guide the prioritisation of work areas for Ms Sinclair. Importantly, the forum would enable the sharing of local practice as well as best practice elsewhere.

It was noted that the concept of a forum had been well received among key patient information representatives. With a potentially large number of members, the agreed model would include open membership to with a smaller steering group.

The views of relevant existing groups, e.g. Primary Care, Palliative & Supportive Care and Patient & Public Involvement, would need sought through linking with those groups. This could be in many cases through the relevant NICaN groups.

Forum meetings will be arranged by Ms Sinclair and, to suit their regional nature, an Antrim venue would be preferred.

It was suggested that a facility to share information could be set up. This would involve representatives providing Ms Sinclair with updates, for

uploading to the web. A 'web update notification' could be generated and emailed to all members.

Developing a Service Framework for Cancer Prevention, Treatment and Care

Ms Sinclair briefly introduced the Service Framework for Cancer Prevention, Treatment and Care. She pointed members to the NICaN website for comprehensive information about the framework.

Ms Sinclair outlined that Patient Information has been prioritised as a standard for the framework by both the Patient & Public Involvement Regional Forum and the Supportive & Palliative Care Group.

She outlined her intention to circulate a draft standard for Patient Information to all representatives invited to become part of the forum. Comments would be sought to help inform the development of this standard. Ms Sinclair explained that the timescale would be short but that all comments would be valued. The standard will be submitted to the Project Team for the workshop that has been arranged for 12 October.

Meeting Close

Ms Sinclair closed the meeting by thanking all those who attended for their contributions. The date for the following meeting was noted.

29 November 2007; 10am-12noon, Board Room, Bush House, Antrim Area Hospital.

Attendance confirmation and apologies for this meeting should be notified at your earliest convenience -

Please email dsinclair@nican.n-i.nhs.uk or telephone 02890 565860.