

**NICaN Patient Information Forum
Thursday 29th November 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, Belfast Trust	Heather Monteverde, Macmillan
Liz Henderson, NICaN/Belfast Trust	Lesley Munro, Macmillan
Bryan Irwin, Cancer Lifeline	Danny Sinclair, NICaN
Liddean McStravog, Cancer Lifeline	Jill Willis, SE Trust
Cherith Semple, SE Trust	Margaret McManus, Macmillan Support & Information Centre
Sally Campalani, Belfast Trust	Caroline Hughes, Action Cancer
Oliver Molloy, Cancer Choices	Breige O'Kane, NILSG

Apologies:

Fidelma Connor, Oncology Liaison nurse,
North and West Locality /Cancer Centre
Maureen Clarke, Angels of Hope
Mick McAtavey, Citizens Advice Bureau
Lorna Nevin, NICaN
Roy McMullan, Oesophageal Patients' Association
Jenny Kelly, Men Against Cancer/BCH Urology
Kate Ferguson, Brainwaves NI
Liz Osborne, CLIC Sargent

1. Welcome and Introductions

No notes recorded.

2. Notes from previous meeting – 25 September 2007

These were agreed among those present.

3. Network Patient Information update

3(i) A new website has been set up by a working group of the Equality Unit of the Scottish government containing **information in Polish** (see Appendix 1).

3(ii) **New disability discrimination regulations** have been put in place from 31 October 2007 to protect people diagnosed with cancer. The Equality Commission have been developing an awareness campaign for these regulations (see Appendix 2).

3(iii) GetWellUK are developing **an online map showing free and low-cost complementary therapy services in the UK** (and so are seeking information from providers of complementary therapies about their services). Ms Sinclair

noted that while information had not been provided by GetWell UK outlining quality criteria for services being included on the map, the company is operating a pilot project to integrate complementary medicine into the NHS. The pilot was announced and is funded by DHSSPSNI.

It was noted that there would be a need for a robust disclaimer, and a need for an editorial board and robust process for developing and maintaining the information that is published on the website. (See Appendix 3).

3 (iv) Ms Monteverde updated the forum about the **benefits advisor services** – Altnagelvin has been operating for most of this year (with positive evaluation), a second CAB advisor has been appointed for the Royal (covering adults and children patients at the Royal), the Belfast City Hospital service will be running within the next few weeks with a limited referral initially. This is through the drop in service at the Macmillan Support and Information Centre or from a referral through Social Work. The Royal service will provide outreach to the Mater in the new year.

Media is being used to generate interest with a view to there eventually being a service like this for all cancer units. At the moment, Macmillan is funding these 'at risk' i.e. with no guarantee that the costs will be picked up in the future from within the statutory sector.

3 (v) Patient Information pathways for Breast and Lung

Ms Sinclair has met with individual patients and carers, and support groups, to discuss their information experience, identifying lots of good practice and also some areas for improvement.

The development of patient information pathways has been well received, as long as they will meet individual needs. Several 'process issues' (rather than Patient Information issues) have been fed back either to Cancer Services Framework team or to the NICaN service improvement lead.

Further engagement has been encouraged in terms of ongoing development work.

Groups have been convened to agree themes and recommended resources for information provision to sit alongside the 'care pathway'. For breast, this is a group of breastcare nurses (including Ulster Independent Clinic UIC) and patients through the PPI forum. For lung, this is a group of lung nurses, and lung patient and carer, alongside AHP representation, Information Manager for BCH, Information and Support Radiographer, BCH.

Areas for outsourcing expertise have been identified by both groups, e.g. Palliative Care, Primary Care, Allied Health Professions, Chemotherapy, Radiotherapy, etc. In some cases, the information is not provided by the subject expert, but at the previous stage, e.g. we are looking into the information that the Outpatients clinic nurse would like the patient to have received from their GP or from the appointments office.

Clinical nurse specialists within each tumour site have undertaken mapping of their current information provision. We then had workshops to consider the patient journey which highlighted that each group needed time to explore what that journey meant in

terms of information needs. The patient/carer representation at the workshops was crucial in raising issues that might otherwise have been missed.

The time was well spent, resulting in groups who are enthusiastic to develop the pathways, outlining the stages of the patient journey, the core and additional information to be offered at each, with signposting to agreed further information/services/resources.

The next stages are:

For breast, each Trust and UIC exploring particular elements of the patient journey, identifying suitable resources to meet information needs. The group will reconvene in the new year to explore and agree these resources, assessment of information need and delivery of information.

For lung, the group will reconvene at the end of January to identify and agree information needs at each stage of the journey, and to explore and agree the resources.

(vi) NICaN PPI Signposting group – it is intended that the signposting handbook will be launched in January. The group will be considering how best to distribute the handbooks and plan to reserve some copies for an evaluation study of the book's effectiveness in directing people affected by cancer to existing services.

(vii) The integration of the CAPriCORN and NICaN websites. The successful tender applicant will shortly be decided. Funding requires completion before the end of March. The intention is the creation of a flexible site with good training of NICaN personnel for dynamic use.

4. Cancer Services Framework and a standard for Patient Information

The Department of Health are seeking to address standards of care within cancer services. These standards will affect how services are developed over the next 3-5 years.

Currently, the standards being drafted for Cancer services include

- 3 Supportive & Palliative Care,
- 5 cancer prevention,
- 1 multidisciplinary teams
- 1 patient information
- and
- various tumour site specific, e.g. lung, skin, ...

Additional themes have been identified and are being considered/taken forward. The contact for the framework is Bridget Tourish. There is a dedicated section on NICaN website. The whole framework will be put out for consultation April – August.

Drafting the standard:

A standard was drafted based on the feedback received from PPI forum and current NICaN patient information development work. The draft was circulated for comment to this group.

Comments from this exercise, and from the discussions had at the Cancer Services Framework workshop held on 12 October have been considered, and the standard re-drafted. The Patient Information section on the NICaN website encourages users to email requests for and provide feedback on the latest draft.

It is acknowledged that confidence in the current draft depends upon awareness of and understanding of the Cancer Services Collaborative 'Improvement Partnership' approach to developing patient information.

Members were asked to take time at the meeting to consider and agree the standard for submission to the Cancer Services Framework project team.

Particular issues include how to ensure that the standard is being met – taking account of job roles and organisational and sectoral boundaries.

Performance Indicators should have both a measurable baseline level of care to be achieved within the first year of the framework and further expected levels to be achieved over the lifetime of the framework. One of the challenges is writing the standard to be able to establish the baseline appropriately in terms of information provision / uptake / understanding.

Ms Sinclair agreed to circulate the re-drafted standard to ensure that forum members' comments had been captured (see Appendix 4). It was noted that the template was difficult to work with. It was suggested that an introduction may be useful to support the standard being presented within a dictated template.

5. Patient Information Strategy for the network

Carried forward for future discussion by the forum (and see Any other business).

6. Audit

Ms Sinclair and Ms McManus explained to the group that it had been intended to discuss (at this meeting) the prospective submission of a Patient Information Audit proposal to the Guidelines and Audit Implementation Network (GAIN).

Having made an initial enquiry about making a submission to GAIN, an opportunity to draft a proposal for an audit commencing within 07/08 and present it to GAIN was offered.

Ms Sinclair and Ms McManus availed of this opportunity, drafting a proposal (see Appendix 5) and presenting it to GAIN. The outcome from the proposal will be notified in the new year.

7. Any other business

It was suggested that the Review of Public Administration (RPA) and its effect on Patient Information should be considered at the next forum meeting.

8. Meeting close and date of next meeting

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

31 January 2008; 10am-12noon, venue to be confirmed.

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.

Appendix 1

<http://www.polishinformationplus.co.uk/index.aspx>

As part of the work of the Translation, Interpreting and Communication Support Implementation Group (TICSIG) - a working group of the Equality Unit of the Scottish Government - a pilot website has been set up to explore the feasibility of creating a central resource of translated information in a range of languages about public services.

The website contains information in Polish which has been collected from NHS boards, local authorities and voluntary sector organisations. It also contains information produced in England which is equally relevant in Scotland, as well as a small amount of information produced in other countries which is currently being used in Scotland.

I would like to invite you to look at this site and use it in your work. You can comment on your experience of the website from the link on the home page *Send us your comments*.

Appendix 2

Know your rights

From 31 October 2007, new disability discrimination regulations have been put in place to protect people diagnosed with cancer, MS, HIV or mental health conditions socially, in education and at work.

To ensure everyone knows where they stand, the Equality Commission NI has developed a website www.youarenowcovered.org It explains everything you need to know, whether you are diagnosed with a disability, or are an employer or service or education provider.

Know your rights visit www.youarenowcovered.org

The Equality Commission for NI - helping stop discrimination!

Appendix 3

GetWellUK Complementary Therapy services information

www.getwelluk.org is a map showing free and low-cost complementary therapy services in the UK. There are hundreds of services nationwide providing affordable complementary services both in the public and voluntary sectors. This is the first register of its kind-focusing only on free and low-cost. Our goal is to raise the visibility of complementary therapies to decision makers, healthcare professionals and NHS patients.

This is a two-stage process. In this, the first stage, we're gathering information: We're putting the services on the map. We've already got 160 mapped. We're getting in touch with people (like you who provide or direct people towards complementary therapies) to get details and get as many of them as possible on the map.

Once we've got 500 services mapped, the second stage will be a full, nation-wide PR campaign. Our aim is to show decision makers and the media that there is a genuine need and want for free or affordable complementary therapies. We hope this map will make them visible and get the NHS to fund complementary therapies for all patients.

If you work in, or know of, a statutory/public or voluntary complementary therapy service, we'd love to hear about it. The details we need to put the service on the map are below. You can call me at 020 73835577 to find out more or to give me the information over the phone. Or email nichola@getwelluk.com. If you don't have all the information, fill in what you have, send it to me and I'll follow up with a call to get the rest of the details.

Nichola Lenehan, Mapping Project Manager, telephone 020 73835577

Name of organisation
Address of service (no PO boxes)
Postcode
Phone
Website
Email (for clients)
Organisation type (charity, hospital service, etc)
Client group (women, older people, etc)
Therapies offered (acupuncture, osteopathy, etc)
Cost of treatment
Project description/goal of organisation
Funded by (big lottery, NHS, etc)
Clinical (independent) audit Y/N
Languages spoken (other than English)
Contact person (not for the website, just for us to contact you)
Contact phone/email (for us, not for the website)
Accessible building Y/N
Accessible toilet Y/N

About GetWell UK

Get Well UK makes it possible for GPs to confidently refer their patients to complementary therapists, by providing information, support and a team of highly skilled and qualified practitioners. With NHS funding this service is free to patients. We believe that complementary medicine can play an important role in improving health and well-being and want to ensure that many more people have access to effective healthcare, not just people who can afford to pay for it privately.

Northern Ireland. Paul Goggins MP, when he was Health Minister for Northern Ireland, announced a new fund to pilot the integration of complementary medicine into the NHS. He said that these therapies should be made available to all people, not just people who can afford to pay privately - sentiments that we share. Get Well UK is operating the pilot project until 1 March 2008. The service is available to patients registered with a GP practice at The Arches Centre, East Belfast or Shantallow Health Centre, Derry.

Appendix 4

DRAFT standard for Patient Information Version 6 (29/11/2007)

<p>Overarching standard:</p> <p>Individuals affected by cancer will have timely and equitable access to supportive information-giving throughout their journey. This information will be appropriate, high quality and tailored to their individual needs both in terms of content and delivery.</p> <p>Holistic Community Impact – Living with cancer Supportive information giving (PI) Throughout the whole patient journey F2f communication – delivery</p>	
<p>Rationale</p> <p>Information needs to be of high quality to inform, support and reassure patients and carers. This means it must meet the needs of the target group and be evidence-based, balanced, regularly updated, culturally sensitive, available in a variety of formats and composed in plain language. Service users and experts must be involved in its design and development (Improving supportive and palliative care for adults with cancer, NICE, 2004).</p> <p>Paragraph here about effect (via Margaret) <i>Information pathways will be developed for each tumour site, e.g. breast, lung. These will include assessing the patient's and their caregivers' needs for information and will outline what must be offered to the patient at particular times in their cancer journey. Health and social care professionals in partnership with patients and the public will develop, quality assure and maintain the information and the pathways.</i></p> <p>A regional approach to developing these pathways and putting them into practice will enable the delivery of information to an agreed standard across Northern Ireland.</p> <ul style="list-style-type: none"> • Regional Cancer Framework - A Cancer Control Programme for Northern Ireland (DHSSPSNI). • Improving Supportive and Palliative Care for Adults with Cancer (NICE, 2004). • The NHS Cancer Plan, Providing a patient centred service (Chapter 4). • National Audit Office report February 2005. • Tackling cancer: improving the patient journey. Department of Health England (2006) • Information needs and experiences: An audit of UK cancer patients (2006). (Cancer Research UK Psychosocial Oncology Group, University of Sussex). 	
<p>Quality Dimensions</p>	<p>Responsibility for delivery/ implementation</p>
<p>Information pathways will be developed for each tumour site with action plans in place for their regular review and update.</p>	<p>Network regional groups in partnership with patients and the public.</p>
<p>Service providers will demonstrate a commitment to ensuring that information provision is integral to care, including financial and human resource support.</p>	<p>Service providers across all sectors.</p>
<p>All staff should be trained, equipped and supported in the delivery of information appropriate to their level.</p>	<p>All information providers, including those roles where it is not considered the postholder's</p>

<p><i>Knowledgeable Confident Competent Signposting Safety</i> <i>Communication/terminology</i> <i>Guidance on assessing information need and on providing information will be disseminated to those identified in the pathways with responsibility for offering information to patients.</i></p>		<p>primary role. <i>Trusts, multi professional teams, Primary healthcare team inclusive of allied health professionals and social work, Voluntary Sector. Dissemination coordinated through NICaN Regional Coordinator for Patient Information.</i></p>	
<p>Patients should be provided with a record of the information offered, a copy of which will be maintained in their notes. <i>This would enable audit of adherence (but not outcomes) and fit in with Information Prescriptions and and potentially Patient Diary, if so developed.</i></p>		<p>All information providers within statutory sector, including those roles where it is not considered the postholder's primary role. <i>Trusts, multi professional teams, Primary healthcare team inclusive of allied health professionals and social work, Voluntary Sector.</i></p>	
<p>Performance Indicator</p>	<p>Data source for PI</p>	<p>Expected Performance Level</p>	<p>Date to be achieved by</p>
<p>Development of information pathways and review plans for each tumour site.</p>	<p>Network tumour group records.</p>	<p>4 tumour sites 8 tumour sites 13 tumour sites</p>	<p>End 2008 End 2009 End 2010</p>
<p>Evidence of implementation of pathways.</p>	<p>Trust records – information strategy and policy (s), implementation plan.</p>	<p><i>50% of sample 70% of newly 98% diagnosed within audit period.</i></p>	<p><i>6 months from 9 sign-off by 12 regional tumour group</i></p>
<p>Evidence of staff training in assessing information needs and delivering information effectively.</p>	<p>Training records/Staff survey</p>	<p>??</p>	<p>??</p>
<p>Evidence of information records being provided to patients and copy of same being maintained in the patient's case notes.</p>	<p>Audit of case notes/patient experience survey.</p>	<p>50% of sample 70% of newly 98% diagnosed within audit period.</p>	<p>6 months from 9 sign-off by 12 regional tumour group</p>
<p>Data source for performance indicator Network tumour group records. Audit of information record held in case note for patients diagnosed after implementation commences. Patient experience survey for patients diagnosed after implementation commences.</p>			

Appendix 5

GUIDELINES & AUDIT IMPLEMENTATION NETWORK [GAIN] PROJECT PROPOSAL

Your Details: Project Lead

Name: Danielle Sinclair	Board / Trust NICaN
Project Title Audit of Cancer Patient information in Northern Ireland	
Position / Job Title: Regional Patient Information Coordinator	Specialty: Cancer Patient Information
Email: dsinclair@nican.n-i.nhs.uk	Tel: 028 90565860
Start date March 2008	Completion date February 2009

Type of project (please tick).

- Clinical and social care regional audit project.
 Clinical and social care guideline development project.

Project Team

Name	Job Title	Specialty	Role within Project (data collection, Supervisor etc)
Danielle Sinclair	As above		Project joint lead
Margaret McManus	Information Manager	Cancer Patient Information	Project joint lead
Representatives from Cancer Centre and Units	Multi professional	Multi professional	Facilitate data collection and provide guidance to auditor post holder as part of the steering group.
Voluntary Sector Representation	Patient information/advocacy		Facilitate data collection and provide guidance to auditor post holder as part of the steering group.

Explain why you think that this is a priority area for action and how it contributes to regional priorities?

To inform the development of a strategy to ensure that cancer patients and those affected by cancer have access to high quality information across NI, it is essential to establish the current range and quality of existing information. Policy documents including Cancer Services: Investing in the future (Campbell Report, 1996) and Partnership in Caring (2000) highlighted the importance of accurate local information for patients with cancer and palliative care needs. The Cancer Control Programme (2006) recommends a strategy to ensure a coordinated approach to the provision of high quality, accessible and accurate information which is inline with regionally agreed quality standards. The Cancer Service Framework project team has recognised the need for inclusion of a patient information standard in the framework.

How will this project improve safety/reduce risk?

- Ensuring that all patients have equitable access to high quality information will enable them to make informed choices about their treatment and care.
- Reducing the risk of unnecessary anxiety and distress caused by poor quality information provision.
- This audit will allow for the identification of poor practice and inappropriate materials and will assist the drive for provision of a quality service.

Aims/Objectives of project

- To inform the development of a patient information strategy for Northern Ireland.
- Establish an understanding of current information provision across statutory and voluntary organisations, including points of information provision.
- Inform the development of information standards currently being developed through NICaN.
- Raise awareness of efforts to coordinate patient information provision across the region.

Method for Data Collection (Audit Only)

Qualitative evaluation using a standard check list and semi structured questionnaires to key stakeholders to assess the provision of information.

Start / Finish date for data collection _____ April 08 _____ / _____ July 08 _____

Resources Required to Complete the Audit/Guidelines

1 full time Audit post for period of 6 months (1 month setup, 3 ½ month data collection approximately 40 site visits, 1 ½ write up report). Cost of post including employers cost (Mid point) £13,289 – (Max Point) £14,385.
Associated Costs: IT equipment (Laptop) £600 and software licenses, travel and subsistence expenses.