

Regional Patient Information Project

Annual Report 2008/09

1.0 Introduction

Providing written information is an essential component for meeting patient safety and Trust governance requirements. For consent to be valid, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention in question.

There is growing recognition of information on a range of issues as a vital element of the overall patient experience. NICE guidance for the supportive and palliative care for adults with cancer states that “Good quality information should be available free of charge to help people affected by cancer make decisions about their care”.

In 2007, as part of the work to develop the Service Framework for Cancer, the NICaN Patient & Public Involvement Forum agreed that information and communication is an important area for improvement.

In 2007 NICaN employed a Regional Coordinator for Patient Information to lead on ensuring the provision of, and access to, high quality, consistent and up-to-date information across the network. A regional Patient Information Forum was established in September 2007 with members spanning health, social care, charities and the voluntary sector.

The announcement made by Cancerbackup (merged with Macmillan Cancer Support) that all their booklets are free to healthcare professionals was received positively during the year.

This report summarises regional work in patient information during the year April 2008 to March 2009. This report includes achievements by groups from across the network, including working groups that sit outside the Forum itself.

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2.0 Forum meetings schedule and attendance

The table below summarises the dates and attendance at regional Patient Information Forum meetings during the 08/09 year. Ms Sally Campalani has provided a link between the Patient Information Forum and her nurse colleagues within each of the four other Trusts' management teams.

Date	BHSCT	NHSCT	SEHSC	SHSCT	WHSCT	Voluntary sector / Charities represented
04/08	Meeting cancelled, email update circulated					
05/08	✓	✓	✓	✓	✓	Cancer Lifeline, CLIC Sargent, IA, Macmillan, Marie Curie, NI Hospice, OPANI, UCF
09/08	✓	✓	✓	✓	✓	Cancer Choices, Macmillan, NILSG, UCF
11/08	✓	✓	✓	✓	✓	Cancer Choices, IA, Macmillan, Macmillan/CAB welfare rights, NILSG, OPANI
02/09	✓	✓	✓	✓	✓	Action Cancer, IA, Macmillan, Macmillan/CAB welfare rights, NI Hospice, OPANI, UCF

✓ - organisation represented at the meeting

3.0 Network audit

GAIN funding was secured for a regional audit of patient information in May 2008. The audit's multidisciplinary steering group met in September 2008 to design the audit. Data collection commenced in February 2009. The audit results are anticipated to be ready for review by the steering group in Autumn 2009 and publishing thereafter. One strand of the audit focuses on the information experiences of people with breast cancer and colorectal cancers. The other uses a patient audit panel approach whereby patients rate the information using a pre-agreed set of quality criteria. The patient audit panel was established as an initiative of the NICaN Patient and Public Partnership forum.

4.0 Research and development

A stakeholder workshop was held in Southern Health and Social Care Trust in January 2009. Service providers for people in the SHSCT area from both the statutory and voluntary/charities sectors were invited to identify the area's information service development needs. This exercise represented the first part of a phased exercise which is expected to be continued across the region during 2009.

The network Patient Information Forum offers a mechanism through which Research reports can be disseminated to patient information providers across the region.

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5.0 Patient and carer feedback and involvement

Patients and/or carers involvement during 2008/09 has included visits to support groups at the outset of information pathways development work, membership on working groups and consultation on all development work through the Patient & Public Involvement Forum.

Patients and their carers are represented on the Regional Patient Information Forum, making a valuable contribution to the group's discussions.

Patient & Public Involvement Forum members have played an integral role to the development of the NICaN website and the ongoing development of the 'Signposting handbook' (Cancer services for patients, carers, families and friends).

The patient information audit steering group includes patient members and the audit tools themselves have been developed with patient and carer involvement. The audit represents the first project for the patient audit panel formed which was formed in March 2009.

6.0 Key achievements during 2008/09

- A standard for patient information was developed for the Services Framework for Cancer Prevention, Treatment and Care.
- An information pathway for breast cancer was developed (endorsed by the regional breast cancer network in September 2008).
- An information pathway for lung cancer was developed (endorsed by the regional lung cancer network in December 2008).
- The following lung cancer leaflets were developed (endorsed by the regional lung cancer network in December 2008).
 - Bronchoscopy
 - PET/CT Scan
 - MRI Scan
 - Mediastinoscopy
 - Bone scan
 - CT-guided biopsy
 - Lung surgery
 - Follow up arrangements
 - Useful websites
- The new network website was launched with a 700+ page 'Information and Support' section, including independently quality assured content from the Macmillan Cancer Support Repository Project. 'Information and Support' has been the most popular section of the website.

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- 11,000 copies of the 'Signposting handbook' were provided to HSC Trusts, with a further 5,000 provided to cancer support organisations.
- Funding was secured from Macmillan Cancer Support to pilot a patient information folder starting with lung cancer.
- Nominations were secured from each HSC Trust for leads for patient information.
- Developed links with nurse education at Queens University with a view to developing education/training on developing patient information-giving skills.
- A presentation about regional information pathways project and a patient information teaching session delivered to nurses studying specialist practice at Queens University Belfast.
- A presentation about regional information pathways project delivered to Macmillan professionals at the Macmillan professionals learning day in May 2008.
- Monthly Radiotherapy information evenings were piloted, positively evaluated and formally introduced in BHSCT for patients and families.
- An online tool was developed to automate access to up-to-date information about accommodation, laundry and taxi service providers in the vicinity of the Cancer Centre and each of the cancer units.
- Clinical trials patient information on the NICaN website was made local by NI Clinical Trials Unit. The unit has committed to using the Cancer Research UK clinical trials website to publish information for patients on clinical trials opportunities in Northern Ireland.

7.0 Key challenges for 2009/10

Challenges faced by the region include

- Ensuring effective communication and adequate support for the implementation of patient information pathways
- Delivering on an ambitious programme of developing more tumour-specific information pathways
- Investing in strategy development and implementation while achieving development goals.

For more information, contact

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Regional Patient Information Project Annual Work Plan 2009/10

Area	Ref	Task(s)	Lead	Timescale
1.0 Strategy development	1.1	Develop network patient information strategy	Danny Sinclair	By November 2009
2.0 Policy development	2.1	Preparatory work for implementation of Cancer Services Framework patient information standard	Trust Information Leads	By March 2010
	2.2	Develop policy for patient information items produced by NiCaN groups	Danny Sinclair	By November 2009
3.0 Development of information pathways	3.1	Complete development of colorectal cancers information pathways	Danny Sinclair	By December 2009
	3.2	Development of prostate cancer information pathway	Clinical lead TBC	By December 2009
	3.3	Development of coordinated Upper GI patient information	Clinical lead TBC	TBC
	3.4	Development of coordinated Haematological cancers information	Clinical lead TBC	TBC
4.0 Development of signposting information	4.1	Publish 2 nd edition of 'Signposting handbook'	Janis McCulla and Danny Sinclair	By September 2009
	4.2	Address sustainability of 'Signposting handbook'	Danny Sinclair and Trust Information Leads	By March 2010
	4.3	Update service directory on www.cancerni.net , addressing comprehensiveness, consistency and appropriateness of language	Danny Sinclair	Ongoing

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Area	Ref	Task(s)	Lead	Timescale
5.0 Pathways implementation	5.1	Establishment, leadership and support for Trust Information Leads	Danny Sinclair	Ongoing
	5.2	Set up of a communications structure for each Trust	Trust information leads Danny Sinclair	By October 2009 November 2009
	5.3	Patient information workshop for Allied Health Professionals	Danny Sinclair	Ongoing
	5.4	Engagement with new services and postholders including Ulster Hospital and Royal Victoria Hospital information postholders.	Danny Sinclair	Ongoing
	5.5	Implementation of information pathways in HSC Trusts including staff awareness and training	Trust Information Leads	Ongoing
6.0 Communication	6.1	Pilot exercise to raise awareness among Belfast GPs about patient information development work and services.	Danny Sinclair & Margaret McManus	By July 2009
	6.2	Patient information event(s) to raise awareness of patient information developments and strategy	Danny Sinclair and Trust Information Leads	December 2009
7.0 Audit	7.1	Review and publishing of patient information audit	Danny Sinclair	By October 2009
	7.2	Produce Trust improvement plans in response to audit report	Trust Information Leads	By end November 2009
8.0 Training & development	8.1	Develop patient information giving skills education/training	Sally Campalani	Ongoing