

# Regional Patient Information Project

## Annual Report 2009/10

### 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 as a vital element of 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, 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.

In 2009, the Health Minister launched a guide for staff on the DHSSPS’s ‘5 Standards’ of patient and client experience. This includes a standard on communication where demonstration of it will be achieved when “patients and clients report that they have been provided with clear, correct information using language they understand”. The 2009/10 Priorities for Action included a target to ensure that Trusts embed this work into their policies and procedures.

Trust preparations during 2009/10 for ‘Peer Review’ encouraged a focus on patient information. Multidisciplinary teams delivering cancer services for the four peer reviewed tumour sites were able to reflect upon and promote the information that they offer their patients, putting in place systems to ensure that patient information offered and given could be recorded in the patient notes.

Some of the other achievements in year have included the completion of a GAIN funded regional patient information audit to provide a baseline of current information provision in two tumour sites (breast and colorectal) with a view to identifying those areas where we can strengthen provision in the future. A number of scoping studies designed to identify the information needs of patients and carers have also been developed. A number of additional tumour information pathways have been developed with further pathways under development.

NICaN patient information work supports HSC to deliver on the information agenda. As such our aim is to develop a system of coordinated information and signposting for people affected by cancer, based on quality, equity and partnership. Our vision is that this system is developed and implemented successfully across the region to meet the individual needs of people affected by cancer.

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For information that has not been quality-assured nationally as part of the National Cancer Action Team's work, we use the NHS Toolkit for Patient Information to appraise content quality and the HSC Styleguide to appraise format quality. The NHS toolkit includes the quality criteria for information that is referred to in NHS Litigation Authority Risk Management Standards.

The focus for the year ahead will include strategy development to build upon and ensure sustainability of the development work that has been undertaken to date. This report summarises regional work on patient information during the year April 2009 to March 2010. It includes achievements by groups from across the network, including working groups that sit outside the Forum itself.

## **2.0 Network audit**

GAIN funding was secured by SHSCT and NICA Patient Information Forum for a regional audit of patient information in May 2008. One strand of the audit focused on the information experiences of people with breast cancer and colorectal cancers. The other used a patient audit panel approach whereby patients audited and rated information using a pre-agreed set of quality criteria. The audit has been completed and a regional report agreed by the audit's multidisciplinary steering group. Each Trust has been provided with their results.

In an effort to improve the recording of information provision to support future audit, a number of nurses in Southern HSC Trust are piloting a draft information recording form.

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## **3.0 Research and development**

Several pieces of NICaN work have involved efforts to understand the information needs of people affected by cancer.

The information needs of people living with and beyond cancer have been explored through the network's "Beyond cancer" work (as discussed in foreword of the full NICaN Annual Report 2009/10).

A scoping study of the information and support needs of people affected by cancer has been carried out, initially for people in SHSCT area, and then for the rest of the region. The reports from these scoping studies are expected soon. A further scoping study, "Coordination of community services for people affected by cancer in North Belfast" includes discussion of the information needs in this specific area.

A separate interest group for patient information research has met several times during 2009/10 with the aim to identify (or develop) and evaluate the effectiveness of a patient information decision aid.

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

## **4.0 Patient and carer feedback and involvement**

Patient and carer involvement continues to be instrumental in the development of NICaN information pathways and resources. Through membership on working groups and consultation on all development work, Patient & Public Involvement Forum members help ensure that the work is patient-centred.

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

During 2009/10, Patient & Public Involvement Forum members played an integral role in the development of the second edition of the NICaN 'Signposting handbook' (Cancer services for patients, carers, families and friends).

The patient information audit steering group included patient members and the audit tools themselves were developed with patient and carer involvement. The audit represented the first project for the patient audit panel formed which was formed in March 2009.

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### 5.0 Key achievements during 2009/10

- NICA Patient Information Forum agreed information for people affected by *any* cancer, creating the 'NICA Generic Information Pathway'. This is available for use now by all cancer information providers and provides the groundwork for all tumour-specific information pathways. Trust information leads are prioritising the implementation of 'core' items from the generic information pathway across all tumour sites over the next two - three years to ensure that all patients are offered this as a minimum.
- The NICA Supportive & Palliative Care Network agreed information for people affected by advanced cancer and end-of-life issues. This has been incorporated into the NICA Generic Information Pathway and therefore now features in all tumour-specific information pathways.
- Breast, colorectal, gynaecological and lung cancer multidisciplinary teams carried out patient surveys for Peer Review to understand how well these patients' information needs were met. Teams delivering services for these tumour sites were able to reflect upon and promote the information that they offer their patients, putting in place systems to ensure that information offered and given could be recorded in the patient notes.
- An information pathway for colorectal cancers was developed (being consulted on at time of publishing this report).
- The following regional colorectal cancer leaflets were developed (being consulted on at time of publishing this report).
  - Bowel surgery leaflets (left hemicolectomy, right hemicolectomy, sigmoid colectomy, total colectomy, Hartmann's procedure, panproctocolectomy, anterior resection, abdominoperineal resection, general surgery leaflet for tailoring)
  - Colonic stenting
  - Help minimise the risk of parastomal hernia following surgery
  - What happens next (follow up arrangements)
  - Who will be looking after me?

Development of these leaflets saw the introduction by NICA of additional techniques to improve information usability, e.g. card sorting by patients (this allows patients to objectively consider and shape the order in which content is presented).

- The following regional endoscopy leaflets were developed (being consulted on at time of publishing this report)
  - Colonoscopy
  - Flexible sigmoidoscopy
  - Endoscopic Retrograde Cholangiopancreatography (ERCP)
  - Gastroscopy / Oesophagogastroduodenoscopy (OGD).

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- Patient & Public Involvement members facilitated a patient feedback exercise to identify how well existing chemotherapy information meets patients' needs. Improvement work is now being carried out through NICaN chemotherapy nurses group.
- Patient groups for prostate, haematological and oesophageal cancers facilitated patient feedback exercises to ascertain information needs of these groups and to recruit individuals to contribute to NICaN information pathways development work for these tumour sites.
- Working groups were established to develop information pathways in 2010/11 for ovarian and prostate cancers, lymphoma and myeloma.
- Macmillan Information Services were set up in the Ulster Hospital and Royal Victoria Hospital.
- The 'Signposting handbook' was revised to include a new section on HSC care as well as ten additional organisations. 11,000 copies of the handbook were provided to HSC Trusts, with a further 3,000 available to voluntary sector cancer support organisations. Summaries of services and posters highlighting availability of the handbook have been developed for use by information providers.
- The network website has a 700+ page 'Information and Support' section, including independently quality assured content from the Macmillan Cancer Support Repository Project. During the year, the patient information content has been updated to reflect changes such as benefits rates etc. 'Information and Support' remains the most popular section of the website.
- Belfast HSC Trust staff agreed to pilot a patient information folder for people affected by lung cancer. Macmillan Support & Information Centre volunteers prepared the packs for use by Belfast lung cancer nurse specialists and social workers. The first packs will be distributed to patients during 2010/11.
- NICaN Patient Information Forum hosted two 'Appraising the quality of information' workshops for cancer information providers.
- A patient information presentation was delivered to Allied Health Professionals at the NICaN Stakeholder Event for AHPs interested in Oncology and Palliative Care.
- A presentation about NICaN's information pathways project and a patient information teaching session was delivered to nurses studying specialist practice at Queens University Belfast.

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- The Macmillan Support & Information Centre (MSIC) facilitated a mail-out to all Northern Ireland GPs advising them of the MSIC, NICaN website and information pathways as resources for them and their patients.
- The Patient Information Forum participated in a workshop resulting in mission and vision statements for NICaN patient information. Members have since started work to develop a cancer patient information strategy. This has included agreeing meaningful objectives for the region.
- A scoping study of the information and support needs of people affected by cancer has been carried out, initially for people in SHSCT area, and then for the rest of the region. Data collection and analysis are complete and the reports from these scoping studies are expected soon.

### 6.0 Key challenges for 2010/11

The main challenge in terms of patient information is that of project sustainability. The patient information coordinator post is fixed term, funded by Macmillan Cancer Support until July 2011. While the project has made considerable achievements in terms of the development of tumour information pathways, audit and research, the task of *implementation* of the pathways is only now getting underway in earnest. Not only is there still considerable work to be done to support the implementation of the existing pathways, but there is a need to develop pathways for the remaining tumour sites not yet scheduled in the programme (e.g. leukaemia, head and neck, brain and central nervous system, remaining urology and gynaecological cancers).

For more information, contact

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## Regional Patient Information Project Annual Work Plan 2010/11

Area	Ref	Task(s)	Lead	Timescale
<b>1.0 Development of strategy and structures</b>	1.1	Develop network patient information position paper for NiCaN Board and key stakeholders	Danny Sinclair	March 2011
	1.2	Identify individuals with responsibility for patient information within - each cancer MDT* and - each relevant Network Group* (* These exclude Children's and Young People's)	- MDT Leads - Network group chairs	See Group workplans
<b>2.0 Policy development</b>	2.1	Develop organisational guidelines on the provision of information for people affected by cancer	Danny Sinclair	July 2010
	2.2	Develop policy for patient information items produced by NiCaN groups	Danny Sinclair	September 2010
<b>3.0 Research and development</b>	3.1	Publish scoping study of information and support needs in Northern Ireland (Dr David Manning)	Danny Sinclair	September 2010
	3.2	Propose patient information research to Queens University Cancer Nursing Research Group	Danny Sinclair	June 2010

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<b>4.0 Development of information pathways and resources</b>	4.1	Develop information template for chemotherapy units including neutropenic sepsis symptom awareness	Caitlin McCoy, Fidelma Connor	December 2010
	4.2	Develop metastatic spinal cord compression information for people who are at risk of the condition, and for people who have been diagnosed with it	Joe O'Sullivan	March 2011
	4.3	Endorsement by regional group of colorectal cancers information pathway and leaflets	Colorectal Group	June 2010
	4.4	Develop prostate cancer information pathway	Urology Group	December 2010
	4.5	Develop ovarian cancer information pathway	Ian Harley	December 2010
	4.6	Develop oesophageal cancer information pathway	UGI Group	March 2011
	4.7	Develop myeloma information pathway	Philip Burnside	Ongoing
	4.8	Develop lymphoma information pathway	Philip Burnside	Ongoing
	4.9	Review lung cancer information pathway	Lung Group	December 2010
	4.10	Review breast cancer information pathway	Breast Group	September 2010
	4.11	Endorsement by Modernising Endoscopy Services group of endoscopy leaflets (four titles plus four aftercare titles)	Kourosh Khosraviani	June 2010
	4.12	Develop 'Information For You' resource	Danny Sinclair	August 2010
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<b>5.0 Development of signposting information</b>	5.1	Address sustainability of 'Signposting handbook'	Trust Information Leads	December 2010
	5.2	Update service directory on <a href="http://www.cancerni.net">www.cancerni.net</a> , addressing comprehensiveness, consistency and appropriateness of language	Danny Sinclair	Ongoing

<b>Area</b>	<b>Ref</b>	<b>Task(s)</b>	<b>Lead</b>	<b>Timescale</b>
<b>6.0 Pathways implementation</b>	6.1	Implement information pathways in HSC Trusts including staff awareness and training – please refer also to tumour group workplans where this is detailed	Trust Information Leads	Ongoing (phased)
	6.2	Provide support for Trust Information Leads and engage with Trust cancer information mechanisms (e.g. steering groups) to ensure and support the use of NICaN information pathways and resources	Danny Sinclair	Ongoing
	6.3	Pilot and evaluate the lung cancer information folder in Belfast HSC Trust	Sally Campalani	December 2010

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<b>7.0 Communication</b>	7.1	Patient information conference to raise awareness of NICA patient information work	Danny Sinclair and Janis McCulla	May 2010
	7.2	Create and raise awareness of a single point on the NICA website for access to NICA patient information work ( <a href="http://www.cancer.ni.net/patientinformation">www.cancer.ni.net/patientinformation</a> )	Danny Sinclair	May 2010
	7.3	Agree and document a process for NICA communicating patient information developments to HSC staff	Trust Information Leads	December 2010
<b>8.0 Audit</b>	8.1	Publish patient information audit	Danny Sinclair	May 2010
	8.2	Produce Trust patient information improvement plans	Trust Information Leads	After completion of Peer Review
	8.3	Agree mechanisms to monitor performance against patient information indicators in the Service Framework for Cancer	Trust Information Leads	March 2011
<b>9.0 Training &amp; development</b>	9.1	Develop content for patient information giving skills education/training	Sally Campalani	December 2010
	9.2	Deliver workshops for patient information providers "Providing information to people affected by cancer"	Margaret McManus	June, August and September 2010
	9.3	Raise awareness of existing patient information e-learning	Danny Sinclair	May 2010
	9.4	Patient information conference (see 6.1 above)	See 6.1	See 6.1
	9.5	Establish a Readers Panel	Danny Sinclair	June 2010