



## **Patient Information news issued April 2008**

### **Audit**

A single audit application was made to GAIN based on the two previously submitted. The outcome is awaited. There is application material attached, outlining much of what the project will entail (Appendix 1 - [blue](#)).

### **Cancer Services Framework**

The Patient Information standard was submitted to the project team on 29 February. It has since been through the Editorial process and is now being passed on to external quality assurance.

The language has been amended to reflect the audience for the framework including the public. The timescales and scope have been amended having considered other initiatives and monitoring capacity. (See Appendix 2 - [purple](#)).

### **Information Pathways**

The two information pathways being developed are progressing well.

There are areas within both information pathways that are being worked on *outside* of each main group. It is therefore likely that the pathways will be developed to a certain stage with some areas continuing to be 'under development'. Where this is the case, the rest of the pathway will be agreed and moved towards implementation.

#### **- Generic information**

The information pathways work started without a 'generic' information pathway being in place for information that is the same regardless of the cancer tumour site, e.g. general finance and benefits advice information, help and support for carers, travel insurance.

Much of the early feedback gathered from patients was about these topics so they have been included within the two pathways being developed.

This has meant that the two groups i.e. Breast and Lung, have had to work through a lot of material that future groups will not have to do. This material can then be used within all subsequent tumour-specific pathways.

#### **- Breast cancer information pathway**

It is expected that the majority of the breast pathway will be populated with existing resources and agreed among the working group in time for the Regional Breast Group meeting on 13 May. If the regional group are happy with the pathway, it will then be circulated wider – including this group – for feedback on its content.

## **- Lung cancer information pathway**

The lung information group next meets on 29 April where it will be able to consider a proposed pathway of existing resources. Again, there will be some areas where the material needs developed from scratch – the pathway will be progressed as far as possible using existing resources, with some areas remaining ‘under development’ until a later date.

The Belfast Trust may be developing a ‘pack’ for lung cancer patients using charitable funding. This pack will reflect the content of the information pathway for lung cancer.

## **- Future information pathway choices**

The decision on how to put tumour sites in order for the development of their information pathways will be made based on the considerations listed in the Patient Information standard, namely:

- (i) National work in developing information pathways – the first 5 national pathways being developed are Bowel, Breast, Gynae, Lung, Prostate (see below).
- (ii) The number of patients diagnosed within each tumour site.
- (iii) The availability of meaningful public and patient involvement for each tumour site.
- (iv) The tumour site having an established regional group/clinical network.
- (v) The tumour site having specialist healthcare staff available to participate in the work, e.g. Clinical Nurse Specialist.

## **National information pathways**

Work is underway in England to consolidate the different networks’ information pathways for each tumour site and to develop nationally agreed pathways. Part of this arrangement is that the Department of Health (DH) is working with the various charities to pay for PDF versions of their publications. This would mean that the likes of Cancerbackup material could be printed within the network without having to pay Cancerbackup for supplies of the resources.

I have been taking part in the workshops to develop parts of the pathway that the English networks’ pathways did not cover, e.g. signs and symptoms, remission and follow up. I would hope that we can eventually use the national pathways as a basis for our work here – adapting them to suit.

## **Information Prescriptions**

In England, information prescriptions are to be given to everyone with a long-term condition or social care need, in consultation with their health or social care professional. They will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.

Clearly the work in developing information pathways for people affected by cancer will be instrumental in developing information prescriptions. It is therefore important that any work in Northern Ireland is compatible with the potential that Information Prescriptions may be adopted here.

One of the characteristics of information prescriptions that immediately grabs my attention is that they actively signpost people to *other* sources for information. While this happens in some areas of provision, I think that our previous discussions (about partnership working between providers and intentional referral to other providers) are particularly relevant here.

It will be helpful to see the results of the launch of information prescriptions in England – in the meantime there is lots of material and a write up of the pilots in England available at [www.informationprescription.info](http://www.informationprescription.info) including three cancer pilots:

1. County Durham Primary Care Trust - Macmillan Cancer Information and Support Centre

This pilot is based at the Macmillan Cancer Information and Support Centre, and will develop information prescriptions for people with cancer, delivering the prescriptions through GPs and district nurses.

## 2. University Hospitals Birmingham NHS Foundation Trust - Queen Elizabeth Hospital

This pilot site is developing information prescriptions for people with cancer in the field of non surgical oncology. It is based on the hospital site, and information prescriptions will be delivered by clinicians.

## 3. Mid Trent Cancer Network, Nottingham University Hospitals NHS Trust

Piloting in a range of areas covered by the Mid Trent Cancer Network, information prescriptions are being developed for people with cancer. Information prescriptions will be delivered by clinical nurse specialists, and focus on palliative care, head and neck, lung and gynaecological cancers.

## **Signposting**

The signposting handbook launch took place on 26 February. This event was well attended and the handbook has been well received. There are some suggestions on how the handbook might be developed in the future.

The signposting group met this week to discuss evaluation of the handbook to inform its future development. This evaluation relies on the enthusiasm of those who offer the handbook out. We need people who get the handbook to be encouraged to complete the tear off slip in the book which signifies their interest in taking part in a short postal/email/online questionnaire.

Through the development of the information pathways it is hoped to have the handbook considered an essential item to offer every person affected by cancer. The group are applying for another Macmillan grant to fund the second year of the handbook. It is hoped that Trusts will pick up the costs of printing the handbook once it is featured within adopted information pathways.

In the meantime, funding has been secured via the 4 health boards for another 10,000 copies. This funding was conditional in the handbooks being purchased before the end of March.

The only amendment that was made before ordering the additional handbooks was the title being changed to 'Voluntary sector cancer services for patients, carers, families and friends'. This was to address comments that have been received that the original title implied a comprehensive list of services i.e. including NHS services. It is a few pages in that the reader is told the handbook does not include NHS services.

You will see both versions of the handbook title across the network.

Please remember to notify me if there are any changes to your service. This will be reflected on the new website, and collected up in anticipation of reviewing the handbook content.

### **- Handbook distribution**

As most of the feedback from patients indicated that the best time to receive the handbook was at diagnosis, Trusts are being asked to supply the number of diagnoses that take place in their clinics. This information will be used to ensure proportionate distribution of the handbook between Trusts.

It is expected that each Trust can then manage their supply appropriately, including making sure that their staff know how they can replenish their supplies.

## **Network website**

All of the material from the existing NICaN and CAPriCORN sites has been moved over to the new NICaN website – [www.cancerni.net](http://www.cancerni.net). The NICaN team are being trained later this month on use of the website. Following that, there will be an opportunity for forum members to provide feedback on the website by way of a questionnaire (“testing”).

Further to previous discussions among forum members, it is recognised that making full use of the website could benefit from additional staffing.

There are various other options available that would allow improved use of the site.

For example, the Press Offices within network organisations will be offered the potential to submit their press stories directly to the website. The NICaN team will retain editorial control as to whether the submitted story is published on the site or not. The same can apply for Events that network members may wish to add.

This would increase ownership of the website among us as a network. Its success relies on use and participation from us all.

## **Terms of reference**

Having now met several times and gained some understanding of the context of patient information across the network, it would be useful to develop and agree Terms of Reference for this group. With potential formal roles in network initiatives, it would be useful to have Terms of Reference agreed by the group.

Draft Terms of Reference will be circulated for future discussion by this forum.

## **Membership of forum**

Since the last meeting I have contacted Trust nursing and other disciplines about membership of this forum. I will follow this up again before the next meeting.

## **PiF conference (Manchester)**

Margaret McManus and I attended the PiF conference ‘Producing Effective Information for Patients; the key issues’ in March. This conference was very useful in highlighting practice elsewhere that would be entirely reasonable here and now, and some practice that we might consider aspirational!

It may be useful to share some of what we learned at the next meeting.

## **Readers panel**

At the PiF conference, one initiative that was described to us was a Trust involving a readers panel of 30-40 people in considering new information leaflets that the Trust produces.

I have suggested to Janis McCulla that this may be a useful activity to set up with PPI forum members to review existing leaflets as well as proposed new ones. This would improve the robustness of selecting particular resources for the information pathways.

## **Keeping up to date on existing and new resources**

During the information pathways work, the Breast and Lung working groups were tasked with supplying a sample of each information resource they currently use.

These 'mapping' exercises suggested that the services could benefit from support in having up to date information about resources. For example, new resources were not always known about and out-of-date resources were turning up. Nb. the national information pathways work highlighted similar problems in English networks.

To support our services I would hope to act as a central point where notifications and samples of new resources could be sent. I could then use this when developing and maintaining the information pathways. The network website can also be used to host information about any new resources and to provide notifications to forum members when new resources are featured. I also wish to gather information about ordering resources.

Please consider how your organisation could keep me up to date with your information resources.

## **PI strategy**

As discussed at the January forum meeting, the first step in developing a strategy for patient information will be identifying stakeholders. This will require discussion among forum members to take it forward.

## **Next Patient Information forum meeting**

Tuesday 27 May 10am-12noon, Boardroom, Bush House, Antrim Area Hospital.

RSVP to Danny Sinclair [dsinclair@nican.n-i.nhs.uk](mailto:dsinclair@nican.n-i.nhs.uk).

**GUIDELINES & AUDIT IMPLEMENTATION NETWORK [GAIN]  
PROJECT PROPOSAL**

**Your Details: Project Lead**

Name: <b>Danny Sinclair</b>	Board / Trust <b>NI Cancer Network</b>
Project Title: <b>Audit of Cancer Patient information in Northern Ireland</b>	
Position / Job Title: <b>Regional Coordinator for Patient Information</b>	Specialty: <b>Cancer Patient Information</b>
Email: <b>dsinclair@nican.n-i.nhs.uk</b>	Tel: <b>07747 067 098 / 02890 699069 ext 5665</b>
Start date: <b>June 2008</b>	Completion date: <b>May 2009</b>

**Type of project (please tick).**

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

**Project Team**

<b>Name</b>	<b>Job Title</b>	<b>Specialty</b>	<b>Role within Project (data collection, Supervisor etc)</b>
Danny Sinclair	Regional Coordinator for Patient Information	NICaN	Joint project lead (tbc*)
Margaret McManus	Information Manager	Belfast City Hospital	Joint project lead (tbc*)
Alison Porter	Head of Cancer Services	SHSCT	Joint project lead (tbc*)
Anne Quinn	Effectiveness & Evaluation Manager	Corporate function, representing audit counterparts in other Trusts	Joint project lead (tbc*)
Wilma Boyd-Carson	Clinical Manager for Cancer	SESCT	Advisor
Sally Campalani	Directorate Nurse	Cancer services, BHSCT	Advisor
Eileen Deery	Lead Cancer Nurse	Cancer services, NHSCT	Advisor
Elizabeth England	Lead Cancer Nurse	Cancer services, WHSCT	Advisor
Medical & AHP reps	To be nominated by NICaN groups		Advisor
Primary Care rep	To be nominated by NICaN Primary Care group		Advisor
Patient representation	To be nominated by NICaN Patient & Public Involvement Forum/Coordinator	Patient & Public Involvement	Advisor

\*tbc – Following GAIN's request to re-submit a single application, the teams have been amalgamated. Roles within the team have not yet been decided – the 4 individuals listed above with Lead roles 'tbc' have scheduled a meeting on 4 April to further discuss this audit application including lead roles etc.

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

It is essential to understand the current range, quality and provision of information in Northern Ireland. This will be used to inform the development of a strategy to ensure that people affected by cancer have equitable access to high quality 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 in line with regionally agreed quality standards. The Cancer Service Framework project team has recognised the need for inclusion of a regional patient information standard in the framework and Trusts will be required to actively monitor this. This project will enable the development of a model for evaluating patient information provision for use across all disease sites. It helps understanding of the quality of the patient experience and seeks to extend active user-involvement into formal service evaluation.

## How will this project improve safety/reduce risk?

- Patients will be enabled to make informed choices about their treatment and care and to contribute to their consent process in a meaningful way through equitable access to high quality, timely information. Informed consent has been identified as a priority area in the DHSSPS audit work programme and this project will embrace the recommendations in DHSSPS recent report on Consent.
- Reducing the risk of unnecessary anxiety and distress caused by poor quality information provision.
- Reducing the risk of patients not availing of support that is essential to their well-being (physical, financial, social and psychological) through not being aware of services e.g. social work and job roles e.g. dietician.
- This audit will allow for the identification of poor practice and use of inappropriate materials.

## Aims/Objectives of project

- To support the monitoring of the generic and tumour site specific information standards currently being developed through NICaN for the Cancer Services Framework.
- To establish an understanding of current information provision across statutory and voluntary organisations, including points of information provision.
- To inform the development of a patient information strategy for Northern Ireland.
- To support patient-centred care. This is through ensuring patients are offered appropriate information at the relevant times to support and give them control during anxious and debilitating times.
- To raise awareness of efforts to coordinate patient information provision across the region.

## Method for Data Collection (Audit Only)

Use of a standard check list during retrospective review of casenotes. The checklist will be based on topics identified in *Macmillan Information Materials Guide (2003) Appendix 15* (see attachments).

Focus groups/semi structured questionnaires to patients and patient information providers (e.g. clinical nurse specialist) to assess the provision of information.

Patient information literature review using DISCERN and NHS Toolkit standards (see attachments).

Nb: It is expected that this will be entirely compatible with information pathways developed locally (NICaN) and nationally (DH Cancer Action Team) – making this audit design suitable for long term use.

\* \* \* Start / Finish date for data collection \_\_\_\_August 08 \_\_\_\_ / \_\_\_\_May 09 \_\_\_\_

## Resources Required to Complete the Audit/Guidelines

1 half time Audit post for period of 12 months (1-2 month setup, 10 months data collection and report writing).  
Cost of post including employer's costs (Mid point, 07/08 rates) £15,255.

Associated Costs:

IT equipment (Laptop) and software licenses, postholder travel and subsistence expenses: £2,000.

Reimbursement to patient representation and hospitality for 13 focus groups: £2,000 **Total £19,255.**

### Notes:

The project needs a realistic timeframe that reflects the detailed planning needed for the audit, the lead-in time required to identify focus group participants and the organising of these focus groups. There is also a large volume of patient information literature to be reviewed.

We have not been able to source much information about other similar projects, however have used the following example to inform our expectation of the required timeframe.

12 months is consistent with the approach undertaken during *Evaluating the 'Cancerbackup Network Patient Information Project 2004-2006': users' experiences of patient information delivery across a cancer network (2006)*.

## Macmillan Information Materials Guide (2003)

### Information topics from the template cancer information pathway monitoring form (adapted from Appendix 15)

Pathway (stage)	(Information topics)
General concern about cancer and cancer prevention	<ul style="list-style-type: none"> <li>• Guidance on healthy living and cancer prevention</li> <li>• Information on early signs and symptoms of cancer</li> </ul>
Symptoms discovered	<ul style="list-style-type: none"> <li>• Reassurance and advice to seek help</li> <li>• Information concerning the signs and symptoms of cancer</li> </ul>
Goes to G.P./Routine Screening	<ul style="list-style-type: none"> <li>• Information about screening procedures/tests as required</li> </ul>
Referral to local hospital or cancer centre for further tests/results of screening investigations	<ul style="list-style-type: none"> <li>• How to get to the hospital and what to expect during investigations</li> <li>• When and how the results will be given</li> <li>• Psychological support for patient and carers/family</li> <li>• Signposting to the information and support network</li> </ul>
Receives diagnosis	<ul style="list-style-type: none"> <li>• Information about their cancer – treatment available and prognosis</li> <li>• Psychological support for patient and carers/family</li> <li>• Sign-posting to the information and support network</li> </ul>
Referral for treatment – sees oncologist/surgeon for diagnostic/treatment options discussion	<ul style="list-style-type: none"> <li>• Further investigations to stage the cancer</li> <li>• Treatment planning</li> <li>• How to get to the clinic and orientation to this environment</li> <li>• Information concerning further investigations and staging procedures and treatment planning phase</li> <li>• Staging information if appropriate</li> <li>• Sign-posting to the information and support network</li> <li>• Psychological support for patient and carers/family</li> </ul>
Treatment	<ul style="list-style-type: none"> <li>• End of treatment review</li> <li>• Cure/continuing treatment</li> <li>• Information on the aims of treatment, how it works and side effects, plus self-help techniques</li> <li>• Information on effectiveness of treatment and further treatment options</li> <li>• Referral to support available in primary care</li> <li>• Signposting to the information and support network</li> <li>• Psychological support for patient and carers/family</li> </ul>
Long-term monitoring and follow-up	<ul style="list-style-type: none"> <li>• Relapse</li> <li>• Continuing treatment</li> <li>• Palliative care</li> <li>• What now? information</li> <li>• Managing long-term side effects</li> <li>• Isolation at end of treatment and fear of recurrence</li> <li>• Signposting to training and information on self-help techniques and self-management/Expert Patient programmes</li> <li>• Signposting to primary care team, palliative care team, information and support network.</li> </ul>

## Quick reference guide to the DISCERN criteria

A good quality publication about treatment choices will:

1. Have explicit aims
2. Achieve its aims
3. Be relevant to consumers
4. Make sources of information explicit
5. Make date of information explicit
6. Be balanced and unbiased
7. List additional sources of information
8. Refer to areas of uncertainty
9. Describe how treatment works
10. Describe the benefits of treatment
11. Describe the risks of treatment
12. Describe what would happen without treatment
13. Describe the effects of treatment choices on overall quality of life
14. Make it clear there may be more than one possible treatment choice
15. Provide support for shared decision-making

## **NHS Toolkit for producing patient information (Version 2.0, 2003)**

### **(a) Checklist for writing information about operations, treatments and investigations**

1. What is the leaflet about and who is it for?
2. What is the procedure?
3. Why are they having it? Give the benefits and alternatives where appropriate.
4. What preparation do they need or not need?
5. Do they need a general anaesthetic, sedation or local anaesthetic?
6. What happens when they arrive at the hospital or the clinic, and who will they meet?
7. Will they be asked to sign a consent form or is verbal consent needed?
8. What does the procedure involve? How long does it last? What does it feel like?
9. What happens after the procedure – pain control, nursing checks, stitches.
10. How long will they stay in hospital?
11. Do they need someone with them or any special equipment when they go home?
12. What care do they need at home?
13. What follow-up care is needed? Do they need to visit their doctor?
14. What can go wrong, what signs to look out for and what to do if something goes wrong.
15. When can they start their normal activities again, for example, driving, sport, sex or work?
16. Who can they contact if they have any more questions?
17. Tell people where they can find more information, for example, support groups and websites.

### **(b) Checklist for information about conditions and treatments**

1. What is the leaflet about, and who is it for?
2. What condition is being described?
3. What causes it? Or, if the cause is not known, say so.
4. Does anything increase the risk, for example, age, sex, ethnic origin or a family history of the condition?
5. What are the signs and symptoms?
6. Are there any tests or examinations needed to confirm the diagnosis?
7. What treatments are available? Give brief descriptions.
8. What are the side effects and the risks of getting treatment or not getting treatment?
9. What are the next steps?
10. What can patients do for themselves?
11. Are there other implications, for example, infecting other people?
12. Who can they contact if they have any more questions?
13. Say where the patient can find more information, for example, support groups and websites.

**(c) Checklist for writing information about services, for example, cardiac rehabilitation classes or a GP skin clinic**

1. Describe the service.
2. Start at the beginning where the patient would start, for example, a leaflet about transport might start with how to book it, with a phone number.
3. Who is eligible?
4. Details of how to access the service.
5. Is equipment or special clothing needed?
6. Where to go for it.
7. How to find it.
8. Are maps needed?
9. When is a service available?
10. Is there a waiting time?
11. How often do they need to attend?
12. Do they need to bring any documents?
13. Who to contact if they cannot attend.
14. What is or is not available, for example, transport.
15. Are interpreters needed?
16. Are any costs involved?
17. Are there any advantages or disadvantages that need to be explained?
18. Who to contact (phone number) and when, for example, from 9am to 5pm Monday to Friday.
19. Phone number, address and website of the organisation.

**(d) Checklist for writing information about medication for patients**

1. Explain that any information that is given in a leaflet should be read with any patient information leaflet provided by the manufacturer.
2. What medication are you describing and what is it for?
3. How is it given?
4. How often should it be given?
5. What should be avoided or added when taking a particular medication, for example, certain foods.
6. What are the side effects? Make sure that you mention that everyone is different so may react differently to medication.
7. What to do if medication is not given properly.
8. Remind patients to tell the clinician who prescribes the medication about any other medication they are taking.
9. Advice on storing medication out of the reach and sight of children, in the fridge and out of the sunlight.
10. Advice on where to get repeat prescriptions.
11. A contact number (of the pharmacy, specialist nurse, doctor or NHS Direct) for more information and to check on any concerns about side effects.

Appendix 2 – **Cancer Services Framework, Patient Information Standard**  
(after first Editorial process) – for information.

Overarching standard:

**All people affected by cancer should be offered good information to support them throughout their whole cancer journey. This information will be tailored to their individual needs both in terms of content and delivery.**

**Rationale:**

Evidence shows that people affected by cancer need good information to support and reassure them. Good information also allows people to make informed choices throughout their care journey. Currently not every person affected by cancer gets the information they need when they need it. There needs to be regional agreement on the key information points across the cancer journey to ensure that everyone gets the information they need. Work has already started on cancer information pathways for lung and breast cancers.

**Evidence:**

- 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).

**Responsibility for delivery / implementation**

Commissioners, Trust Chief Executives, senior operational and clinical teams within Trusts, Primary Secondary and Community Care staff, Voluntary providers.

**Quality Dimension**

**Safe and Effective** – Full and clear information improves understanding, reduces anxiety, helps people to prepare for what is ahead. It helps give people a sense of control, and helps people cope better with treatment

**Timely and Equitable** – Agreed information points across the cancer journey will mean that all people are offered the information when they need it.

**Efficient** – A regional approach reduces duplication in efforts to produce and review information resources, and allows for economies of scale in terms of purchasing and producing materials

**Patient-centred** - Information should be tailored to meet each person's needs.

<b>Performance Indicator</b>	<b>Data source</b>	<b>Expected Performance Level</b>	<b>Date to be achieved by</b>
For each tumour site, regionally agreed information pathways will be developed.	Northern Ireland Cancer Network (NICaN) records and website.	5 tumour sites	End of 2009.
Each Trust will have an identified person(s) with responsibility to support implementation of cancer information pathways.	Cancer Executive Team records at each Trust.	Further 4 tumour sites	End of 2010.
Evidence of improved adherence to cancer patient information pathways.	Annual audit of patient information provision.	All Trusts	January 2009.
		Annual improvement on baseline.	12 months after implementation of each pathway.

#### **Issues around implementation**

Service providers must demonstrate a commitment to the regional development of patient information and to ensuring that information provision is integral to care provision. This includes committing financial and human resource support.

This approach relies on the existence of regional groups for each tumour site and on meaningful public and patient involvement for each tumour site.

The groups developing cancer information pathways need to have regional coverage and meaningful involvement from all members.

A regionally accessible system for publishing and maintaining the information pathways is required.

A baseline assessment of information provision is required at or before implementation of each pathway.

Education and training programmes on assessment and delivery of information need to be made available to meet the identified information training needs of all service providers. All staff must be trained, equipped and supported in the delivery of information appropriate to their level.

Partnership working is needed between voluntary, independent and statutory service providers.

In selecting tumour sites for developing information pathways, the following will be considered by NICaN:

- (vi) National work in developing information pathways – the first 5 national pathways being developed are Bowel, Breast, Gynae, Lung, Prostate.
- (vii) The number of patients diagnosed within each tumour site.
- (viii) The availability of meaningful public and patient involvement for each tumour site.
- (ix) The tumour site having an established regional group/clinical network.
- (x) The tumour site having specialist healthcare staff available to participate in the work, e.g. Clinical Nurse Specialist.