



Title	<b>Guidance for HSC staff on the provision of information to people affected by cancer</b>	
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## **NICaN Guidance for HSC staff on the provision of information to people affected by cancer**

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## Section 1 General information

### 1. Purpose

This Guidance has been developed **to support the implementation of information pathways** across cancer health and social care (HSC) services.

### 2. Scope

This Guidance relates to all HSC staff. It is **not** limited to specialist cancer services and staff.

People receive health and social care services, directly related to their cancer investigations, diagnosis or otherwise, in various settings and from a wide range of HSC staff. Staff could be asked directly for cancer-related information or could identify a need for cancer-related information in their patient/client.

In this Guidance, 'information' means both clinical and non-clinical information. It is used to describe 'permanent' information for example, leaflets, booklets, web-based material, audio-visual material.

This Guidance should be read and implemented in conjunction with the Trust policy on informed consent.

### 3. Aims/objectives

- To improve patient safety and patient/carer experience
- To help HSC Trusts achieve and evidence their delivery of patient information-related elements of patient safety alerts e.g. National Patient Safety Agency (NPSA)
- To help HSC Trusts achieve and evidence their delivery of the patient information standard in the Service Framework for Cancer Prevention, Treatment and Care
- To help HSC Trusts achieve and evidence their delivery of the patient information-related measures in Peer Review
- To help Service managers understand their responsibility in supporting the implementation of cancer information pathways
- To help staff understand their responsibilities to provide information to people affected by cancer
- To help staff use information pathways as a tool to do so.

## **4. Roles and responsibilities:**

### **4a. HSC Trust leads for cancer patient information**

Each HSC Trust has nominated a lead for cancer patient information.

The main role of the Cancer Information Lead is to provide advice to Trust managers on the implementation of network-agreed information pathways in the Trust, in line with the Service Framework for Cancer Prevention, Treatment and Care. Information pathways are explained in Section 2 (from page 6).

The role crosses several boundaries, notably between specialist and non-specialist cancer services, and between primary, secondary and tertiary care. The Cancer Information Lead is a resource and guide who communicates with those who have service responsibility to people affected by cancer.

Each Trust's Cancer Information Lead nomination is outlined in Appendix 3.

### **4b. The NICaN Regional Coordinator for Patient Information**

The NICaN Regional Coordinator for Patient Information coordinates the work of groups developing information pathways and supports the work of Trust Cancer Information Leads.

### **4c. Staff providing specialist and non-specialist cancer care**

The main roles of staff relevant to this Guidance are to provide appropriate information to patients in line with cancer information pathways and to record such provision as evidence for audit.

## 5. Context

**Patients and carers cannot express preferences about care and make choices on involvement in decision making unless they have access to appropriate and timely information. Many patients report, however, that they receive inadequate information from health and social care professionals.**

**Information materials of high quality should be available in places where patients can access them readily, with patients being offered them at key stages in the patient pathway.**

National Institute for Clinical Excellence<sup>i</sup>

**While good face to face communication skills are vital, patients also need access to other sources of information. Studies have shown that some patients only remember one tenth of what they were told during a consultation. Face to face communication needs to be backed up with high quality, accurate information that the patient can return to in their own time.**

NHS<sup>ii</sup>

Surveys have consistently shown nine out of ten people diagnosed with cancer want to receive information about their disease, its diagnosis, treatment options, side effects, and clinical outcome. It can enable them to feel informed and subsequently empowered to make their own choices, rather than having these imposed on them.

Studies have revealed that patients who are well-informed, experience less anxiety, and are more likely to cope with their illness than those who are ill-informed or uninformed.<sup>iii iv v</sup>

There is evidence that leaflets specific to a condition are read by patients<sup>vi</sup> and evidence that patients receiving written information are more satisfied with the information they are given<sup>vii</sup>.

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<sup>i</sup> Improving Supportive and Palliative Care for Adults with Cancer, National Institute for Clinical Excellence, 2004

<sup>ii</sup> NHS Cancer Plan, 2000

<sup>iii</sup> The Quality of Life. Fallowfield L. London Human Horizons Series Souvenir Press 1990

<sup>iv</sup> Information needs of cancer patients in the west of Scotland Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, Fallowfield L. BMJ 1996 313 724-726

<sup>v</sup> How much truth and to whom? Respecting the autonomy of cancer patients when talking with their families-ethical theory and patients' view. Benson J, Britten N. BMJ 1996 313 729-731

<sup>vi</sup> Edwards, M. (1990) "Satisfying Patients' Needs for Surgical Information". British Journal of Surgery vol. 77. pp 463-5

Mayberry, J. (1988) "Information Booklets for Patients with Inflammatory Bowel Disease" International Disability Studies. Vol. 10 pp 179-80

<sup>vii</sup> Mayberry, J. (1988) "Information Booklets for Patients with Inflammatory Bowel Disease" International Disability Studies. Vol. 10 pp 179-80

Cancer has become a chronic disease that people live with for a number of years. Many of these people have an ongoing need for care, rehabilitation, information and support. This might include information about the long-term side-effects of treatment and other 'survivorship issues' that can help an individual regain a sense of normality in their lives e.g. sexuality, fertility, financial issues, employment, and sources of support such as counselling and support groups.

The Service Framework for Cancer Prevention, Treatment and Care<sup>viii</sup> includes standards that aim to improve the patient experience. It builds on several other regional policy documents that address patient information, including Cancer Services: Investing in the future (Campbell Report, 1996) and The Cancer Control Programme (DHSSPS 2006).

The Framework is expected to be launched during 2010 and Health and Social Care (HSC) Trusts will be required to actively monitor performance against framework standards. This includes a specific standard on the provision of information.

**All people affected by cancer should be offered good information to support them throughout their cancer journey. This information should be tailored to their needs both in content and the way in which it is given.**

(Draft) DHSSPS, 2010<sup>viii</sup>

In recent years, there has been development work undertaken by Northern Ireland's cancer services to regionally agree high quality information for people affected by cancer. This guidance aims to help HSC staff understand how they can improve patient experience through making use of such work.

## 6. Consent

The DHSSPS report on its Regional Audit of Consent in 2007 states that, "Seeking consent is a process of providing information, discussion and decision making. Consent for a (procedure or) treatment must be based on the patient having the information they need to make a valid decision. They can be given the information to read, and have time to discuss it with their family, carers or healthcare professionals before giving consent to the treatment.

As patients and staff move between different Health & Social Care (HSC) organisations throughout Northern Ireland it is important that ... the information used across the HSC is standardised"<sup>ix</sup>.

Staff must adhere to their Trust's policy on seeking informed consent and should consult NICaN information pathways to see if regional information for the test/investigation or treatment has been agreed.

<sup>viii</sup> Draft Service Framework for Cancer Prevention, Treatment and Care, DHSSPS, 2009

<sup>ix</sup> Good Practice in Consent: Consent for Examination, Treatment or Care. Belfast, DHSSPS 2003

## Section 2 Information Pathways

### 7. What is an information pathway?

Staff and patients across N.Ireland have been working to agree the minimum information to be offered to people affected by cancer. This work informs regional 'information pathways'.

An information pathway is an agreed set of information topics and written information resources, set against stages of the cancer journey.

Information topics are put on the pathway at the earliest point at which they may be useful for the patient/carer. The information resources have been identified as offering clear, accurate and well written information.

An information pathway is not an exhaustive list of all possible information that a patient/carer could need. It does not preclude staff from using their judgement and offering further information. It does however enable a streamlined, regionally agreed standard of provision. Written resources should be used to complement verbal information rather than replace it.

Information pathways are published at [www.cancerni.net/infopathways](http://www.cancerni.net/infopathways).

### 8. Which information pathway should staff use?

The NI Cancer Network has developed a 'generic' information pathway, featuring those topics and written resources that do not need to be differentiated between different types of cancer. This includes information topics relevant to people with advanced cancer.

Members of the cancer network are working progressively by tumour type to tailor the generic information pathway for each cancer type, by supplementing it with tumour-specific topics and information resources.

- **If the appropriate tumour-specific information pathway is available, staff should use it.**
- **If the appropriate tumour-specific information pathway is not available yet, staff should use the generic information pathway.**  
(In the meantime, reputable sources for tumour-specific information to supplement the generic information pathway include Macmillan/Cancerbackup and Cancer Research UK).

Staff with any queries about tumour-specific information should direct them to Trust specialist staff for those cancer types in the first instance. If the Trust has a cancer information manager, they may be able to help. See Appendix 4. The NICaN Regional Coordinator for Patient Information may also be able to help.

## **9. Where can staff find information pathways?**

All agreed information pathways are published on the NICaN website at [www.cancerni.net/infopathways](http://www.cancerni.net/infopathways).

Those which are under development are also highlighted at this webpage.

### **Section 3 Providing information**

## **10. The interaction between information provider and recipient**

There are a number of steps involved in a basic interaction between an information provider and the patient/carer. This includes selecting or sourcing information in alternative formats as needed.

These steps are outlined in Appendix 1.

See section 11 below for reference to complex interactions.

## **11. Skills development in information provision**

Education and training on information provision is a developing area in NI.

There are already several learning resources which are available publicly for anyone to undertake. These are outlined in Appendix 2 and can be accessed from the NICaN website at:

[www.cancerni.net/patientinformationskills](http://www.cancerni.net/patientinformationskills).

Communication is a core competency within the Knowledge and Skills Framework (KSF). Each staff member's training needs on information provision, particularly complex interactions, should be assessed and addressed at their KSF appraisal.

## **12. Recording information provision**

It is important that the Trust is able to evidence that information has been offered.

Each information pathway includes a form to record information provision on. An example recording form is available at [www.cancerni.net/infopathways](http://www.cancerni.net/infopathways).

All staff providing information should record what they have provided, and should file this in the patient's/client's case note.

## Section 4 Monitoring and review

### 13. Monitoring:

The Trust will regularly and robustly monitor their implementation of this Guidance.

### 14. Review:

This Guidance will be reviewed in .....

## Appendices (overleaf)

### **Appendix 1 The information interaction**

(based on Macmillan Cancer Support, Managing Cancer Information Materials 3<sup>rd</sup> edition)

### **Appendix 2 – Skills development learning resources**

### **Appendix 3 – Cancer Information Leads as at August 2010**

### **Appendix 4 HSC Information postholders as at August 2010**

## Appendix 1 The information interaction

(based on Macmillan Cancer Support, Managing Cancer Information Materials 3<sup>rd</sup> edition)

<b>Beginning</b>	<ol style="list-style-type: none"> <li>1. Be approachable</li> <li>2. Use open body language and eye contact</li> <li>3. Listen to the person's concerns</li> <li>4. Try not to interrupt, but be ready to speak when they are finished</li> </ol>
<b>Explore the content of the enquiry</b>	<ol style="list-style-type: none"> <li>1. Use open questions to tease out information needs</li> <li>2. Consider topics included on the information pathway</li> <li>3. The person's real issue of concern may not always be their opening question</li> <li>4. Establish any information they have previously received on the topic</li> <li>5. Reflect back what they have said</li> </ol>
<b>Clarify and summarise</b>	<ol style="list-style-type: none"> <li>1. Clarify the question to ensure you have interpreted their needs correctly</li> <li>2. Describe and agree together what they need</li> <li>3. If there are a range of issues, consider prioritising some– do this with the person and check that they are happy to do so</li> </ol>
<b>Guide enquirer through range of options appropriate to them and their query</b>  These options may be you providing information yourself, or you signposting them somewhere else	<ol style="list-style-type: none"> <li>1. Consider resources listed in the information pathway.             <ul style="list-style-type: none"> <li>– Published leaflets</li> <li>– Non-print resources, e.g. CD</li> <li>– Guided internet search</li> <li>– Listening support</li> <li>– Counselling</li> <li>– Signposting to specialist services</li> </ul> </li> <li>2. Consider the person's information capacity. Do they need information in another language, an 'alternative format' or at a higher/lower literacy level? Remember you may have a statutory duty here (you can ask your Equality Manager for more information about this)</li> <li>3. Go through the benefits and limitations of the options</li> <li>4. Do not overwhelm the person</li> <li>5. Agree and provide the information materials</li> <li>6. If you don't know the answer to their question, signpost the person to an appropriate source. Do not risk giving wrong information</li> <li>7. Offer the person written details of any websites or organisations and any resources you do not have to hand</li> </ol>
<b>Identify how to end and clarify enquirer's choices</b>	<ol style="list-style-type: none"> <li>1. Consider putting a timeframe on the end of the enquiry, e.g. "During the next five minutes or so, we'll go through what we've just discussed, then I'll leave you to look through the information".</li> <li>2. Check you have answered their question(s)</li> <li>3. Confirm options and close the enquiry, e.g. "I think I have given you all of the information you have asked for, but let me know if there is anything else you need"</li> <li>4. Ensure the person knows how they can get more information</li> <li>5. Record the information you offered and whether the person took it up</li> </ol>

## Appendix 2 – Skills development learning resources

(available from [www.cancerni.net/patientinformation](http://www.cancerni.net/patientinformation))

- Macmillan Cancer Support course on Information Giving.
- Beverley Van Der Molen, Continuing Professional Development module - Providing Patient Information: Assessing information needs of cancer patients.
- Social Care Institute for Excellence courses on Communication. Please note that the course on Providing Information and Explaining offers transferable learning. You do not have to be a social worker to learn from this course.
- ‘Giving information to patients’ article in Nursing Standard. This is an article which encourages reflection on aspects of information giving and signposts to other resources. Caress, A. (2003) Giving information to patients. Nursing Standard 17(43) 47-54.

## Appendix 3 – Cancer Information Leads as at August 2010

Belfast HSC Trust	Sally Campalani, Senior Nurse, Cancer Services
Northern HSC Trust	Eileen Deery, Lead Cancer Nurse
South Eastern HSC Trust	Wilma Boyd-Carson, Clinical Manager for Cancer Services
Southern HSC Trust	Edel Corr, Patient Support Manager
Western HSC Trust	Elizabeth England, Lead Cancer Nurse

## Appendix 4 - HSC Information postholders as at August 2010

Belfast City Hospital Royal Hospitals and Mater Hospital SE HSC Trust Information and Support Radiographers	Margaret McManus Angela Small Karen Kelly - consult Belfast City Hospital Radiotherapy Department
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### Links

Information Pathways

[www.cancerni.net/infopathways](http://www.cancerni.net/infopathways)