



# Patient Information

## Regional audit

### Report and recommendations



Health and  
Social Care



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

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# 1. Executive Summary

**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.**

Improving Supportive and Palliative Care for Adults with Cancer,  
National Institute for Clinical Excellence, 2004

The 'patient information standard' in the DHSSPS Service Framework for Cancer Prevention, Treatment and Care aims to address the provision of quality written information to support patients throughout their cancer journey.

This regional audit was carried out during 2009. It sought to provide a baseline upon which to assess the effectiveness of NICaN patient information development work and the 'patient information standard'.

This audit highlights areas for improvement in:

- (i) meeting patients' written information needs,
- (ii) appropriately documenting such provision, and
- (iii) the availability of good quality information materials in formats to meet individual needs.

## **Findings: information provision**

Patients primarily reported having been offered or receiving *verbal information* rather than written information.

In many of the indicators measured in this audit, patients reported a better 'information experience' than was recorded in their case notes.

Where documentation of information provision did exist, this was often found in different sets of notes, making audit cumbersome and likely making information coordination for an individual patient very difficult.

## **Findings: information quality**

The main areas for improvement were the availability of alternative formats and clarity about the currency of leaflets.

Varying responses to subjective aspects of information quality, e.g. suitability of language, confirmed the need to involve patients during the design of information.

## **Other learning**

During the focus groups, some areas for improvement were suggested which were not information-specific. The Clinical Improvement Nurse also learned of areas of good practice during this project. These suggestions and learning have been forwarded to the NICaN Lead Nurses group for their consideration.

### **Recommendations: information provision**

1. Information provision should be prioritised as a core quality marker. Trusts should actively engage in supporting the provision of individually tailored information in line with regionally agreed cancer information pathways. Funding should be identified in budgets.
2. Communication is a core competency within the Knowledge and Skills Framework (KSF). Each staff member's training needs on information provision should be assessed and addressed at their KSF appraisal
3. Staff should 'guide' patients when providing written information to help patients understand the content of the resources they are given
4. Each person diagnosed with cancer should have access to a specialist nurse or other suitable advocate who will act as their key worker and who will signpost and translate appropriate information at key points throughout the course of the illness
5. Information should be more readily available in formats to suit individual needs
6. Information provision should be recorded in case notes
7. Recording should be in a single patient record to enable coordination of provision
8. The various components of this audit should be separated for any re-audit.

### **Recommendations: information quality**

1. Trusts should actively engage in supporting the sourcing and development of quality information materials that meet their patients' needs. Funding should be identified within budgets.
2. Trusts should improve adherence to their styleguides by staff who produce information
3. HSC staff and charities should use the NHS Toolkit for Patient Information as a resource when producing information
4. Information providers should use the NHS Toolkit for Patient Information as a resource to help them appraise the quality of information
5. A Readers Panel should be developed to help address the subjective quality criteria of information design
6. Where there is not already a policy in place, organisations involved in creating and/or sourcing patient information should develop and implement a policy for this.
7. Samples from the same providers should be re-audited using only the objective questions in the audit tool.

## 2. Acknowledgements

**The Patient Information Regional Audit Project Team would like to recognise the valuable contribution made by the following people and groups throughout the duration of the project:**

- The NICaN Patient Audit Panel, recruited and trained by Janis McCulla, Nicola Porter, Debbie Schofield and Danny Sinclair.
- The project steering group (see Appendix for full list) and leads – Margaret McManus, Alison Porter, Anne Quinn and Danny Sinclair.
- The project's Clinical Improvement Nurses, Eimer McGeown and Shauna Mooney and Audit Facilitator, Raymond Haffey.
- The Guidelines and Audit Implementation Network for funding, guidance and practical help.
- The managers and staff of breast, colorectal and chemotherapy services who facilitated and contributed to data collection.
- The charities who took the opportunity to have their information audited, particularly those who have responded to their results report.

Special thanks are due to the patients who completed the questionnaires and took part in the focus groups.

## 3. Introduction

**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.**

Improving Supportive and Palliative Care for Adults with Cancer,  
National Institute for Clinical Excellence, 2004

Cancer is one of the main causes of ill health, disability and death in Northern Ireland. Around 4,318 men and 4,414 women are diagnosed with cancer in Northern Ireland every year<sup>1</sup>.

Around one in every four cancers recorded are non-melanoma skin cancers. These are rarely fatal. Apart from this cancer type the most common male cancers are prostate, lung and colorectal. In women the most common cancers are breast, colorectal and lung .

Almost two out of every three cancers are diagnosed in people aged 65 and over. On average, one in three of the population will develop a cancer by the age of 75 years. By 2025 it is predicted that there will be an increase of between 30-54% in all cancers due to population growth and ageing.

Improved access, diagnosis and treatment means that more and more people are living longer with cancer. Almost two out of every three people diagnosed with cancer are alive one year after their diagnosis. Almost one in two people (45.7%) are alive 5 years after diagnosis. 55,000 people in Northern Ireland today are living with cancer. 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.

The draft Service Framework for Cancer Prevention, Treatment and Care (Department of Health, Social Services and Public Safety, DHSSPS, 2009) includes standards that aim to improve the person's experience of care. The Service Framework 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).

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<sup>1</sup> The information in this section is based on Northern Ireland Cancer Registry data from 1993-2004 unless otherwise stated. The data are for adults only.

## Patient information

**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 Cancer Plan, 2000

The 'patient information standard' in the draft Service Framework for Cancer Prevention, Treatment and Care aims to address one of the issues that patients say impact on their care experience, namely the provision of quality written<sup>2</sup> information to support them throughout their cancer journey.

The framework is expected to be launched during 2010 and Health and Social Care (HSC) Trusts will be required to actively monitor this provision.

In recent years, there has therefore been increasing attention across Northern Ireland's cancer services to developing and providing written information to patients.

This audit was carried out during 2009. It aimed to provide a baseline upon which to assess in the future the effectiveness of this work and the 'patient information standard'.

It captured data about the provision of both written and verbal information. This was to acknowledge the provision of verbal information at a time when there is much development work being done on the availability and provision of written information. The recommendations arising from this audit, however, concentrate on written information. Future re-audit should therefore be based around this.

In many of the indicators measured in this audit, patients reported a better 'information experience' than was recorded in the case notes. This audit highlights areas for improvement in:

- (iv) meeting patients' written information needs,
- (v) documenting such provision, and
- (vi) being able to source good quality information materials in formats to meet individual needs.

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<sup>2</sup> Written information is used to describe 'permanent' information for example, leaflets, booklets, web-based material, audio-visual material.

# Report layout

This report includes the following sections:

## **Audit approach**

This outlines the standard and quality indicators used during the audit, firstly on the provision of information to patients, and then the quality of information leaflets.

## **Findings**

These sections outline the main findings, firstly on the provision of information to patients, and then the quality of information leaflets. Focus group findings from the patient and staff focus groups are interspersed throughout.

## **Recommendations**

Recommendations are outlined in this report aimed at improving access to, and quality of information for people affected by cancer. Both statutory and voluntary sector organisations could help address these recommendations.

## **Appendices**

This section includes items that are referred to in the report. The audit tools are included so that they can be accessed easily for re-audit.

## **Focus group findings**

These are interspersed throughout this report, highlighted in pale blue. Patients were recruited for mixed focus groups (breast and colorectal) using an Expression of Interest form with their questionnaire. This was followed up by a phone call from the project's Clinical Improvement Nurse towards the end of the questionnaire data collection period. There were small numbers of patients at the focus groups however they provided valuable qualitative data through elaborating on their cancer experience. Where they highlighted issues that are not specific to patient information, these have been indicated to the appropriate NICaN team members.

Staff focus groups were carried out with breast and colorectal cancer staff, often with the same issues being raised by staff as had been raised by patients.

## 4. Standard and quality indicators

The following standard was translated into quality indicators using the NHS Toolkit for Producing Patient Information Version 2.0 (2003), the Macmillan Information Materials Guide 2003, NICaN information pathways and Royal National Institute for the Blind 'See It Right' guidelines.

### Standard

All people affected by cancer should be offered good information to support them throughout their cancer journey. This information should be tailored to the needs of the person both in content and the way in which it is given (Draft Service Framework for Cancer Prevention, Treatment and Care, NICaN/DHSSPSNI, 2007).

### Quality indicators

This list is not an exhaustive set of possible quality indicators for the standard above – it reflects the agreed scope of the audit project.

A. All patients should be offered:

1. written information about any tests and investigations they are going to have (including staging tests)
2. written information about how they can get more information about the tests and investigations if they need it (including staging tests)
3. written information about how to get to the facility where the tests and investigations are going to be carried out
4. written information about the type of cancer they have been diagnosed with
5. written information about the treatment options for that type of cancer
6. written information about their prognosis
7. timely written information about the support and information available to them from their healthcare team and from any appropriate charities/voluntary organisations
8. written contact details for their key worker / nurse
9. timely information about financial help they could be entitled to and how they can get help with their finances
10. information about what members of their health and social care team can offer
11. information about spiritual support that is available within the hospital (e.g. hospital Chaplain's details).

B. Patients being offered surgery should be offered written information to include:

1. its benefits
2. its risks
3. its side-effects
4. any alternatives
5. the aim of it
6. how it works
7. the effectiveness of that type of surgery
8. how their appearance may be affected by it
9. emotional support with changes in appearance because of surgery (e.g. counselling, nurse support)
10. practical help with changes in appearance because of their surgery (e.g. prostheses, clothing ranges and fitting services)
11. how to get to the facility where their surgery is being carried out
12. information to prepare them, including what to expect when they arrive.

C. Patients being offered chemotherapy should be offered written information to include:

1. its benefits
2. its risks
3. its side-effects
4. any alternatives
5. the aim of it
6. how it works
7. the effectiveness of that type of chemotherapy
8. how their appearance may be affected by it
9. emotional support with changes in appearance because of chemotherapy (e.g. counselling, nurse support)
10. practical help with changes in appearance because of their chemotherapy (e.g. wig-fitting, headwear and fitting services)
11. how to get to the facility where their chemotherapy will be administered
12. information to prepare them for their chemotherapy treatment, including what to expect when they arrive.

D. Each written patient information resource should:

1. show the date when it was developed and when it needs to be reviewed
2. show who published it (e.g. HSC Trust)
3. be clear in its title and/or introduction what it is about and who it is aimed at
4. include contact details or general signposting for further information for the reader. General signposting might be 'Ask your GP if you need further information'
5. be grammatically correct
6. use text at size 12 or above, (i.e. a minimum x-height of 2mm) and in a 'sans serif' font (e.g. Arial)
7. state that it is available in different formats, e.g. Braille, audio version, different languages
8. have enough contrast between the text and the background to allow easy reading (paper weight, colour of ink and background, ...)
9. not include text laid over images
10. be relevant and sufficiently comprehensive for the reader
11. be well laid out
12. include appropriate images to illustrate the written text
13. include language that is easy to understand. Where unfamiliar or complicated terms are used, these should be explained.

These quality indicators were separated into two strands for audit:

- (i) provision of information to patients; and
- (ii) quality of information leaflets.

## 5. Strand 1:

### Provision of information to patients







































































































