



Mid year report – Patient Information

This report updates on regional work in patient information since the Annual Report to March 2009.

The aim of our patient information work is to identify or develop and regionally agree information to be offered to patients. This information should be good quality, not only to support patients and carers, but to support HSC governance.

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 same quality criteria for patient information that is referred to in NHS Litigation Authority Risk Management Standards.

1.0 Peer Review

1.1 The Peer Review measure that relates to patient information states:

The MDT should provide patients and carers with written material which includes:

- information specific to that MDT about local provision of the services offering the treatment for that cancer site;
- information about patient involvement groups and patient self-help groups;
- information about the services offering psychological, social and spiritual/cultural support, if available;
- information specific to the MDT's cancer site or group of cancers about the disease and its treatment options (including names and functions/roles of the team treating them).

Compliance: The written (visual and audio if used - see note below) material.

Notes: It is recommended that it is available in languages and formats understandable by patients including local ethnic minorities and people with disabilities. This may necessitate the provision of visual and audio material. For the purpose of self-assessment the team should confirm the written information which is routinely offered to patients.

1.2 Regional patient information pathways are being used to identify the information available to patients on many of the subjects listed. MDTs need to

supplement this with their local information. See also '8.0 Signposting handbook' below.

1.3 Consultation record templates (developed during the national work on patient information) have been highlighted to NI colleagues coordinating Peer Review. These are now being adapted for use here.

2.0 Information pathways

2.1 Generic cancer information pathway including advanced cancer

Through a subgroup nominated by the NICaN Supportive & Palliative Care Network, we have developed an information pathway 'component' for people affected by advanced cancer. This has been signed off by the S&PC Network. It has been incorporated into the generic information pathway which was developed mainly by the lung cancer information pathway working group. This creates a more comprehensive generic information pathway that can be tailored for all tumour-specific information pathways.

2.2 Breast cancer information pathway

Breast cancer nurse specialists are currently reviewing the regional Breast cancer information pathway and helping to design a recording tool to enable staff to evidence the information they provide. The reviewed pathway will reflect the generic information pathway described above.

2.3 Lung cancer information pathway

Belfast HSC Trust will be piloting the use of an information folder to deliver the lung cancer information pathway. The aim of the folder is to help patients navigate and revisit the information they have been provided with. The pilot will include an evaluation to assess the effectiveness of this approach.

2.4 Colorectal cancers information pathway(s)

The colorectal cancers information pathway(s) work continues. This work has demonstrated an opportunity to develop regional patient information leaflets for the various colorectal surgery procedures.

2.5 Prostate cancer information pathway

The prostate cancer information pathway work continues. Group members are currently appraising the quality of existing leaflets in use across the region, and some which have been included in the national information pathway.

2.6 Gynaecological cancer information pathway

The regional NICaN Gynaecological Cancers Network will be asked at their meeting this month to nominate a working group to develop a regional patient information pathway for at least one gynaecological cancer.

2.7 Haematological cancers information

Work is underway to understand the information needs of people affected by haematological cancers. This has been undertaken by Janis McCulla and John Curran, PPI representative on the regional Haematology network group. A subgroup of the regional network group are collating the information that is currently provided. National work should be available in the next few months which could help inform this work.

2.8 Oesophageal cancer information

Members of the regional Upper GI cancers network group and the Oesophageal Patients Association NI have indicated an interest in developing information for people affected by oesophageal cancer. Initial meetings have taken place, however there are capacity issues about supporting an information pathway's development at this time and national work should be available in the next few months which could help inform any work in this area.

3.0 Tests and investigations

3.1 Our work, particularly the work of the colorectal cancers information group, has identified that there are several variations of information leaflet for any single type of cancer test or investigation. The existing leaflets vary in quality. The number of variations also causes duplication of effort to review them. Several appear out of date.

It has become clear that this work should be undertaken through specialist groups for the type of test/investigation, e.g. endoscopy, radiology.

3.2 Endoscopy

The Modernising Endoscopy Services project provides a timely opportunity to work towards regionally standardised information leaflets for some Endoscopy tests. Work is underway with the NI Nurse Endoscopy group to draft regional leaflets that can be tailored with local information e.g. contact details and patient preparation instructions. These are based on work originally done in SHSCT.

Ratification/endorsement of the leaflets, once agreed, will be sought from the Modernising Endoscopy Services project team.

3.3 Radiology

The Royal College of Radiologists provides templates for patient information leaflets. These do satisfy most of the NHS toolkit for patient information requirements.

A meeting was held with a Superintendent Radiologist to propose adapting these templates for use across the region. This was a positive meeting however it highlighted that there are a large number of radiological tests that would need considered and that the Trust systems for producing appointment letters may be difficult to change or could even be prohibitive.

I am working to investigate how this work can be progressed.

4.0 Network audit

4.1 The GAIN-funded regional audit of patient information is ongoing. 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 information leaflets using an agreed set of quality criteria. The patient audit panel was established as an initiative of the NICaN Patient and Public Involvement forum.

4.2 All breast and colorectal cancers patient questionnaires have been completed. The data collection has now moved to patient focus groups and staff focus groups.

4.3 The patient audit panel have completed their data collection on 32 leaflets from across HSC and our charities and voluntary sector.

4.4 The audit results are anticipated to be ready for review by the multidisciplinary steering group in January 2010 and publishing thereafter. This reflects a delay due to staffing changes part way through data collection.

5.0 Research and development

5.1 The phased scoping study of information and support services (started in SHSCT) continues. Individual discussions have been held with staff and patient surveys have been distributed in four Trusts. We continue working with the fifth Trust to enable it to be included. These discussions and surveys have also taken place across the region's charities and voluntary sector organisations.

5.2 Queens University Belfast colleagues are interested in opportunities for research in Patient Information. Dr David Manning, National Cancer Information Manager for the National Cancer Action Team has agreed to meet to explore opportunities for research that not only give us new knowledge in Northern Ireland, but that could also complement the evaluations commissioned through national work on 'Information Prescriptions'.

6.0 Trust information leads and policy for patient information

6.1 We are working with Trust-nominated information leads to develop a policy for HSC staff on the provision of information to people affected by cancer. This is to help service managers and their staff understand their

responsibilities, as well as to support them by providing guidance and tools that they can use. The intention is that this policy is implemented widely rather than only among cancer specialists.

6.2 We are also working with Trust information leads to develop a structured programme of awareness-raising and implementation for cancer information pathways.

6.3 Four of the five Trust-nominated cancer information leads have a cancer-specific remit for their Trust. The fifth Trust (SHSCT) has nominated its Patient Support Manager, Edel Corr. We are considering how Edel will link with SHSCT Cancer Management to deliver on this role.

7.0 Swine flu

7.1 We are developing regional information for people receiving chemotherapy. This is to highlight that there are similarities between some serious chemotherapy side effects and swine flu, and to advise the patient to contact their chemotherapy unit or the chemotherapy helpline if they have symptoms.

8.0 Signposting handbook

8.1 The handbook 'Cancer Services for Patients, Carers, Families and Friends', launched last year, is being reviewed. Feedback from patients and carers has been positive and any areas for improvement have been incorporated into the revised design.

8.2 Providing this handbook to patients contributes to many of the requirements of the Peer Review measure on patient information, e.g. psychological help, self-help and support organisations etc. The second edition will also contribute towards the measure in Peer Review that requires MDTs to give information about their team members' roles.

8.3 We need to identify recurrent funding for the handbook to make it sustainable. Previous 'one-off' funders have included Macmillan Cancer Support and the four health boards. Information will soon be available about the reviewed handbook's cost that will enable us to work to address its sustainability.

9.0 Website

9.1 Patient information on the NICaN website content has had its annual update to reflect changes in benefits rates for people affected by cancer.

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