



**Northern & Yorkshire Cancer Registry &
Information Service (NYCRIS)**

Communication and Engagement Strategy

March 2007

	Contents	Page
1	Introduction.....	3
2	Aim.....	3
3	What is cancer registration?	4
4	Background.....	6
5	Our Stakeholders.....	7
6	Working Together.....	8
7	Implementation.....	9
8	Conclusion.....	13
	Stakeholder Consultation	Appendix 1

1 Introduction

The purpose of this Communication and Engagement Strategy is to outline the aims of effective communication and how this will be undertaken by the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS).

NYCRIS is undergoing significant change; partly because of an on-going plan of cancer registry modernisation (which all cancer registries are working towards), and partly because of senior managerial changes and governance arrangements within NYCRIS (following retirements in spring 2006).

In summer 2006, a stakeholder consultation exercise was carried out by NYCRIS in conjunction with our partners. For information, a summary of the critical themes from this exercise is attached at appendix 1.

As an organisation, NYCRIS is committed to working closely with all our partners and stakeholders and is keen to develop different ways of doing this and communicating effectively.

This strategy will look at:

- Why we have a strategy
- Whom we seek to involve and engage
- What we hope to achieve
- How we will go about this

2 Aim

This NYCRIS Communication & Engagement Strategy has the following aims:

- To communicate more effectively with stakeholders
- To develop more proactive engagement
- To develop ways of supporting closer working with partners

3 What is Cancer Registration?

Cancer registries have a long-term role in monitoring trends in the patterns of cancer in the population. Registries are able to provide population-based data to monitor changes in cancer incidence or survival over long time periods. Indeed, UK cancer registries have been collecting cancer data for more than 40 years on every new diagnosis of cancer occurring in their populations. Information is also co-ordinated nationally for England & Wales by the Office of National Statistics (ONS).

The UK is known for one of the most comprehensive cancer registration systems anywhere in the world. There are 11 cancer registries in the UK covering populations of between 1.65 and 13.8 million people, ensuring that there is complete national coverage of population-based cancer data.

All registries seek to provide timely, comparable, high quality data. To do this, registries collect information on each new cancer diagnosis (specifically, condition considered to be registerable) within their populations. Information is collected from hospitals, hospices, private hospitals, screening programmes, other cancer registries, general practices, nursing homes, and death certificates. This can include multiple sources of information from one source such as hospital Patient Administration System (PAS) data, radiotherapy, pathology and medical records.

As the use of electronic data becomes more commonplace within the NHS, it is likely that other new sources of electronically available data will be accessed, for example, electronic patient records (EPR). NYCRIS is keen to ensure that as much automation takes place as can be harnessed in order to both exploit the data and maintain the NYCRIS reputation for good quality data.

Registries collect a common minimum dataset of information. Within England, this dataset is being extended to comply with the new National Cancer Dataset, which cancer registries are actively working towards.

NYCRIS works collaboratively with other registries, Public Health Observatories (PHOs) and external researchers (for example, within the NHS and academia) on shared projects relating to

analysis and research. Collaborative working with our data providers plays a large part in changing our registration processes.

It is important to note that information collected by NYCRIS complies with Caldecott Guardian principles.

Cancer registration information has a wide variety of uses, working in partnership with other local organisations such as cancer networks. In providing reliable, population-based data on cancer incidence, prevalence and survival rates, registries have a key role in implementing and monitoring national plans, for example, NHS Cancer Plan (Department of Health, 2000).

Information collected by registries also enables:

- Cancer incidence, prevalence and survival monitoring (time trend analysis among different social groups/areas)
- Evaluation of cancer prevention and screening programmes (for example, breast screening)
- Evaluation of quality and outcomes of cancer care via comparative data analysis
- Supporting cancer genetics services for those with a higher likelihood of developing cancer
- Investigative analysis (in conjunction with partner NHS organisations) to determine differences in for example, cancer survival among social groups, contributing to local programmes to reduce health inequalities in health outcomes

4 Background: What is NYCRIS?

NYCRIS was established in 1996 when the existing Yorkshire Cancer Organisation merged with its Northern counterpart. The service is now based in Leeds. It is responsible for the collection, analysis, interpretation and dissemination of population-based cancer data. It also has a collaborative research programme, information requests service and genetic enquiry service.

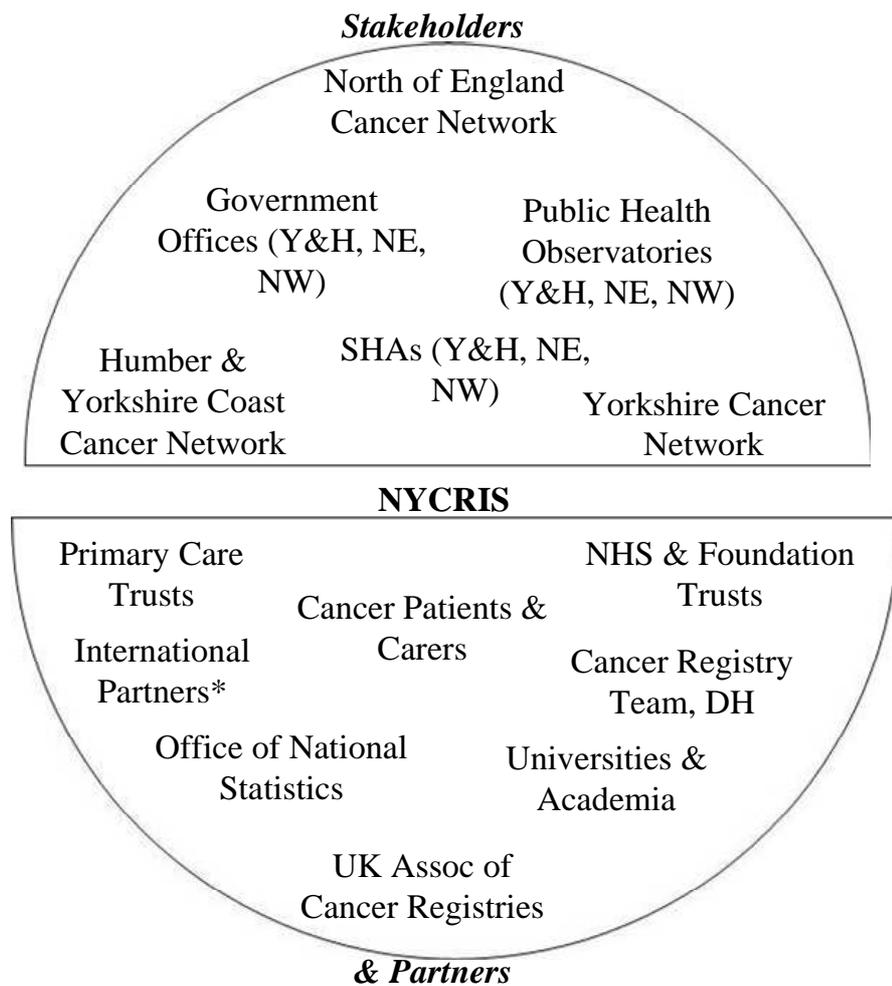
NYCRIS covers an area with a population of approximately 6.6 million and registers information on 50,000 new cancer patients annually. The service operates on a budget of £1.57m, allocated centrally from the Department of Health through the office of the Yorkshire & Humber Regional Director of Public Health (RDPH). The RDPH oversees the service and its performance on behalf of Strategic Health Authority (SHA) North East and North Cumbria parts of SHA North West.

NYCRIS is hosted by Leeds Teaching Hospitals NHS Trust and has established a single steering group for the purposes of clear governance. The NYCRIS Steering Group met for the first time in March 2007.

NYCRIS employs just under 50 Full Time Equivalents, with a further 6 field staff employed by local NHS Trusts and based in hospitals across the geographical patch. NYCRIS staff collect information on every new diagnosis of cancer annually within the NYCRIS area. Data is collected from a variety of sources including hospitals by registration staff. Data is processed and checked to ensure validity and completeness and a process of clinical data linkage and consolidation.

5 Our Stakeholders

NYCRIS works with a variety of stakeholders, including the following:



Key

Y&H Yorkshire & the Humber

NE North East

NW North West

* Includes European Network of Cancer Registries (ENCR) & International Association of Cancer Registries (IACR)

6 Working Together

NYCRIS is keen to work with all our stakeholders in developing a workable programme to meet the needs of both individual organisations and NYCRIS. Working together will help to ensure that cancer care may be improved, performance will be developed and health outcomes will improve.

Our Commitment

- i. Communication will be open
- ii. Consistent involvement with stakeholders
- iii. NYCRIS will maintain a transparent programme of communication and feedback

Who will lead this strategy?

NYCRIS is managed by a Senior Management Team (SMT):

- Professor David Forman, Acting Director
- Dr Colin Pollock, Acting Medical Director
- Nicola Easey, Senior Operational Manager
- Caroline Brook, Information Services Manager

Funding arrangements

NYCRIS will establish an internal budget to fund implementation of this strategy.

How can we help you?

NYCRIS will develop a structured programme of engagement with stakeholders and products relevant to stakeholder needs that will encompass the following objectives. The examples quoted below are proposals of areas for effective joint working and we welcome other suggestions from our stakeholders:

- Annual Joint Work Plan
Working with local Cancer Networks, providers and commissioners, agree a work programme to support the implementation of Improving Outcomes Guidance and local cancer care.
- Clinical Studies
Working with commissioners and providers, analyse trends in care pathways to support better clinical practice.
- Supported Learning Programme
Working with all stakeholders, hold training days to share learning & improve practice.
- Extending use of Cancer Information Service
Working with all stakeholders, assess effectiveness of treatments via analysis of treatments.
- Professional Analytical Support
Working with all stakeholders, undertake analysis of Trust activity data to aid robust purchasing by PCTs and Practice Based Commissioners.
- Joint Working
Working with PHOs and Cancer Networks, assist in trend spotting to improve care & support peer review process within Trusts.
- Developments
Working with new providers, develop programmes to support better public health monitoring for effective patient care.

7 Implementation

NYCRIS proposes to use a variety of methods to communicate regularly with our stakeholders, utilising these approaches:

Cancer Networks

- Stronger ties with Cancer Networks will be developed. It is proposed that each Cancer Network will have a specific SMT officer link. If welcomed by the Cancer Networks, it is

suggested that this key link officer will routinely attend Network executive/board meetings and link specifically with PCTs and trusts within that network, in addition to users and carers via Patient Involvement Groups. This will enable regular, consistent sharing of information and feedback between NYCRIS and its partners towards improving patient care.

- Maintaining stronger links with Cancer Networks will be assisted by annual 'top team' meetings held between NYCRIS and each Cancer Network, to evaluate progress and agree joint work objectives.
- Regular programme of meetings, presentations and visits with stakeholders out with the Cancer Networks, for example, NHS Trusts via Cancer Centre/Unit Board meetings.

Public Health Observatories

- The PHOs are represented on the NYCRIS Steering Group and consideration is being given to the development of joint appointments in the future
- Public Health Observatory Links – closer links to be developed with PHOs in Yorkshire and the Humber and the North East to share public health intelligence, for example, Public Health User Forum with meetings held across the NYCRIS area.
- Utilise the expertise in PHOs for the design, dissemination and evaluation of NYCRIS outputs.

General Practitioners & Consultants

- Clinical Engagement – specific programme to be developed to link with secondary care consultants and GPs. This may include representation and links with cancer site specific groups (within networks) and Specialist Commissioning Committees.

General Communication

- Development of NYCRIS Website. For many NYCRIS stakeholders, the NYCRIS website will be the 'first frontier', and hence enhancement of the website is a priority.
- Greater use of electronic communication – video conferencing (for meetings), emails, utilising the NYCRIS website to communicate.

- Proactive approach to production of Press Releases for example, new developments in cancer outcomes
- Taking opportunities to promote the work of NYCRIS, for example via stand exhibits at Open Days, conference poster presentations etc
- Review of NYCRIS routine external publications (eg fact sheets) & newsletters to ensure that they have impact both in terms of increased awareness of NYCRIS work but also in shaping cancer services development.
- Stakeholder Days – one to be held in Yorkshire for Yorkshire & Humber based networks, PCTs and other stakeholders and one to be held in the North East for North East based networks, PCTs and other stakeholders. These will provide the opportunity for NYCRIS to jointly develop an annual work plan and respond to feedback.

Internal Communications

It is important that NYCRIS' staff equally have the opportunity to benefit from the developments being planned, and ensure that the organisation as a whole can benefit from the ideas and experience of our staff.

NYCRIS proposes to utilise a number of methods to enhance internal communication with our staff:

- Staff Briefings
- Regular emails
- Effective intranet
- Individual staff discussions
- Staff Consultation and Awareness Sessions – highlighting to staff the work of NYCRIS with partners, and raising awareness of issues affecting the NHS (for example, outlining the impact of policy initiatives such as Payment by Results and Commissioning a Patient Led NHS (Department of Health, 2004 and 2005 respectively).

Communication & Evaluation

Once implemented, feedback in respect of this strategy will be regularly monitored to help evaluate the usefulness and effectiveness of the measures outlined, and to ensure that joint objectives are being met.

Measures will be considered in order to best evaluate outcomes and may include qualitative, quantitative and anecdotal outcomes. Examples of these may include:

- Productive meetings with stakeholders
- Numbers of comments received regarding strategy
- Numbers of stakeholders regularly attending events
- Numbers of requests for information
- Positive media coverage

Feedback will be collated and monitored on a quarterly basis (with performance reported to the NYCRIS SMT, NYCRIS Steering Group and our commissioners). Summary quarterly evaluation of feedback will also be shared with our stakeholders.

Proposed Timetable

The following draft timetable is proposed in respect of the implementation and monitoring of this strategy:

March 2007	Communication & Engagement Strategy ratified by NYCRIS Steering Group & commissioners
March 2007	Strategy to be shared with stakeholders
March 2007	Implementation of strategy commences
March/April 2007	Stakeholder Days to be held
April 2007	Closer ties with Cancer Networks implemented
April 2007 onwards	Other communication initiatives developed
June 2007	First quarterly monitoring of strategy feedback and evaluation produced & regularly reported to NYCRIS SMT, NYCRIS Steering Group & our stakeholders
January 2008	Review of strategy to ensure that it continues to meet needs of both our stakeholders and NYCRIS

8 Conclusion

NYCRIS enjoys a reputation for producing high quality cancer data provided by highly trained staff. In a society where access to information is available on demand and public expectations of the NHS are higher, it is essential that the services offered by NYCRIS are timely, effective, accessible, efficient and relevant to meeting both the needs of stakeholders and NYCRIS.

Whilst it is recognised that some stakeholders will welcome greater engagement and involvement, it is also acknowledged that increased levels of involvement may not be practical for all. Hence, it will be appropriate to clarify a level of engagement that will maximise efficiency and operational effectiveness where necessary.

NYCRIS is keen to ensure that it can respond effectively within a changing landscape, offering consistent, proactive engagement and welcomes the opportunity of playing its part in improving cancer prevention and patient care across the patch.

Nicola Easey
Senior Operations Manager
NYCRIS
March 2007

All comments in respect of this strategy, together with any suggestions you may have about working together are welcomed – please email nicola.easey@nycris.leedsth.nhs.uk or send to: Nicola Easey, Senior Operations Manager, NYCRIS, Arthington House, Cookridge Hospital, Hospital Lane, Leeds LS16 6QB.

Appendix 1

Summary Themes from Stakeholder Consultation (June-August 2006)

CONSTRUCTIVE CRITICAL THEMES

“It’s as though NYCRIS sees itself as being there because it has to be rather than being there because it has a real potential to impact on improvin~~g~~ patient cancer care” NYCRIS Stakeholder August 2006

NYCRIS is seen as old fashioned, introspective and reactive in its culture and approach to developing its working relationships.

It provides a high quality responsive service when approached,

But it is not seen as being proactive in helping commissioners, networks, and trusts set the cancer agenda.

NYCRIS needs more and varied ways of engaging with its stakeholders – not just relying on attending Network Information Group meetings and the Advisory Group.

It needs to market itself and its potential outputs.

Joint posts should be considered as one way of developing relationships with PHOs and Networks.

NYCRIS should consider tackling the timeliness issue by taking the approach of using ‘good enough’ data in real time but not threatening its major selling point of high quality data in the long term.

It must address the perception of its Leeds / Yorkshire-centric nature

The (existing) Advisory Group is not seen to be effective – ie not a two way process of engaging with stakeholders

NYCRIS needs to ask itself how its data can inform the performance management agenda for cancer services.