NATIONAL CANCER REGISTRY BOARD

STRATEGIC PLAN 2013-2016

BACKGROUND

With the appointment of a new National Cancer Registry Board, and the anticipated retirement of the current Director in 2014, the Board has decided to refresh and broaden its current strategic plan, to take into account the changing health services and research environment in Ireland. As part of this process the Board has carried out a wide consultation, including a survey of the views of a range of key bodies and individuals on the current and future role of the Registry.

Some key elements to emerge from this consultation were:

- Clinicians should have a greater role in advising the Registry, for instance though the establishment of an Advisory Committee.

- The Registry should have more engagement with clinicians and the public.

- The Registry should retain its autonomy as far as possible.

- Data collection and availability should be more timely.

- Registration of cancer should be mandatory.

- The routine dataset should be expanded to include, for instance, comorbidity, family history and risk factors.

- The Registry should attempt to provide follow-up information on patients.

- Data should be made as widely available as possible.

- Research using both registration data and additional data should be encouraged.

VISION

To provide cancer intelligence for the improvement of patient outcomes.

AIMS

1. To collect and confidentially store accurate, timely and comprehensive data through cancer registration and related research activities.

2. To provide official statistics on cancer incidence, and survival for Ireland.

3. To disseminate data and the results of analysis in a relevant and comprehensive manner.

4. To facilitate and undertake research on cancer.

5. To enable evaluation of health initiatives, including cancer awareness campaigns and cancer screening.

6. To ensure confidentiality of data held by the Registry.

7. To publish scientific reports and papers.

8. To link internationally.

9. To provide information for ad hoc queries.

10. To provide value for money.

CHALLENGES

The Board identified a number of key strategic challenges for the Registry.

1. To identify the optimum organisational setting for the Registry at a time of reorganisation and reform of public and health services.

2. To maintain and improve the quality of data and research output from the Registry at a time of change and financial restrictions within the health services.

3. To make the Registry more relevant to service planning and clinical practice to the ultimate benefit of cancer patients.

STRATEGIC OBJECTIVES

The Board has agreed a number of strategic objectives related to these challenges.

1. **Optimum setting for the Registry**

    a. Any arrangements should be sustainable and must allow the Registry to remain independent in its reporting of data.

    b. In consultation with the Minister for Health, his officials, management of the HSE and others, to agree a long-term configuration and governance arrangement for the Registry. These might include continuing as an autonomous agency of the Department of Health, integration with the Department of Health, integration with a health intelligence or public health agency, merging with the National Cancer Control Progamme or an academic partnership.

    c. To explore the possibilities of closer links with academic bodies within Ireland with a view to developing closer collaborations in research, data analysis and methodology, as well as enhancing the career possibilities of Registry researchers.

2. **Maintain and improve the quality of data and research output from the Registry**

    a. Build partnerships and capacity in health intelligence and cancer services research.

b. Increase the level of engagement with registries and other bodies in the rest of Europe and beyond.

c. Encourage wide participation and collaboration in research.

d. Keep the Registry at the forefront of registration and research development internationally.

e. Explore the potential of closer academic integration, while avoiding identification with any single academic institution.

3. Make the Registry more relevant to service planning and clinical practice

a. Establish processes of regular and effective engagement with clinicians and hospital groups to determine how the Registry might assist them, and they the Registry.

b. Provide regular outputs.

c. Explore methods of collecting data in a more timely way.

d. Examine the feasibility of extending the Registry dataset, particularly with regard to follow-up data.

e. Increase the visibility of the Registry and registration data to the public, to clinicians and in supporting planning, monitoring and evaluation of services.

f. Maximise social media to inform clinicians, managers, the media and the public on the work and outputs from the Registry.

g. Work toward greater availability and sharing of data across the cancer services and reduction of duplication in data collection and reporting.

h. Enhance public awareness of the Registry and its work.

STRATEGIC PLAN

1. Optimum setting for the Registry

a. Carry out an appraisal of the options available.

b. Initiate discussions with key individuals on the future governance arrangements for the Registry.

c. Appoint a new Registry Director with the skills and experience to lead and develop the Registry through this transitional phase and maximise the opportunities arising from any reconfiguration.

d. To initiate discussions with academic bodies within Ireland on the potential for collaboration at various levels, including shared posts, shared facilities and collaborative research programmes.

2. **Maintain and improve the quality of data**

a. Establish a cancer information committee in each hospital group to explore more efficient access to data and use of resources locally.

b. Improve data quality by benchmarking key performance indicators against other registries (e.g. UK).

c. Advocate for the Health Information Bill and for cancer registration to be made mandatory.

d. Work with

- hospital and HSE IT to increase the availability and quality of electronic data from histopathology, oncology, radiotherapy and similar systems;

- ESRI to improve access to HIPE data;

- Private health insurers to provide claims data.

e. Enhance the Registry website to improve access to data.

3. Maintain and improve research output from the Registry

a. Increase the output of peer-reviewed papers.

b. Increase success in research grant applications.

c. Encourage attendance of Registry staff to present research and analysis at clinical conferences.

d. Foster international collaborations.

e. Work with academic and research institutions to develop collaborative research both in Ireland and abroad.

4. Make the Registry more relevant to service planning and clinical practice

a. Establish a Clinical Advisory Group, in collaboration with the National Cancer Control Programme, to explore areas of mutual interest with the cancer clinical community, including more collaboration in data collection, additional data items and more focussed reporting and networking with clinicians and patients.

b. Consult with the Department of Health, National Cancer Control Programme, HSE and other relevant bodies on the type and content of outputs they would like to have from the Registry.

c. Develop the Registry's capacity in health economics and service assessment.

d. Develop capacity in data management linkage and analysis, in areas of relevance to planning, monitoring and evaluation of cancer services.

National Cancer Registry Board, 16 December 2013