Northern Ireland Cancer Registry

Peer Review 2018

A Review of the Northern Ireland Cancer Registry 2018

Authors

Dr Liesbet van Eycken, Director of the Belgian Cancer Registry

Professor Donna Fitzsimons, Head of School of Nursing and Midwifery, Queen's University Belfast

Dr Brid Farrell, Assistant Director of Service Development, Safety and Quality, Public Health Agency

Mrs Janine McCann, Northern Ireland Cancer Research Forum

Professor David S Morrison (Chair), Director of the Scottish Cancer Registry

Acknowledgements

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Executive Summary

An expert panel carried out a review of the Northern Ireland Cancer Registry (NICR) in the summer of 2018 at the request of the Public Health Agency. The purpose of this review was principally to assist and support the NICR so that it will continue to provide a high quality service to contribute to cancer control in Northern Ireland. The review used the National Cancer Peer Review Programme template to structure its approach and set its recommendations against its terms of reference (ToR). However, the recommendations extend beyond these Terms of Reference. A site visit on 4th and 5th June 2018 included discussions with members of the NICR staff and presentations to illustrate the work of the registry.

The Northern Ireland Cancer Registry was established in 1994 and is funded from the Public Health Agency. The NICR is an electronic registry that is notified of new cancers through a range of datasets. Northern Ireland is a population of 1.8 million whose population of over-65 year olds is projected to increase by 65% by mid-2041. The numbers of new cancers are therefore expected to increase concomitantly. With cancer survival also increasing, the number of people living with cancer in Northern Ireland will continue to increase. Thus, the need for robust cancer information systems and the workload for collecting and reporting it will continue to rise in the foreseeable future.

The 2008 review of the NICR identified a lack of a legislative mandate for a cancer registry in Northern Ireland as being a risk. While some progress has been made drafting legislature, the absence of a functioning Northern Ireland government since January 2017 means that this welcome objective remains missing.

The NICR provides a range of stakeholders with timely information on cancer but we recommend that it explores its further potential. The one-off quality improvement reports should be repeated regularly to encourage a cycle of improvement. Plans are required to indicate how information on systemic anti-cancer therapy and radiotherapy will be integrated into the NICR.

The NICR is considering expanding its registration to other conditions, such as coronary heart disease and stroke. The review panel did not reach a consensus on whether such a development would be beneficial nor, indeed, whether it was beyond its remit to comment in any detail. We recommend a risk analysis to assess the strengths, weaknesses, opportunities and threats of this proposal.

While acknowledging the high quality data that the NICR produces, the panel recommended an option appraisal of adding, or moving to, the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3); and detailing plans for future assessments of its data quality.

With respect to data sources and processing, the panel endorsed the continued use of a variety of databases, with feedback to help to improve the quality of the data that are being supplied. We recommend that a minimum dataset be described. This may be a part of the legislative framework described above.

The overall view of the review panel was that the NICR is a well-run cancer registry that provides high quality information on cancer occurrence and outcomes to all the appropriate audiences. It has benefitted greatly from the excellent leadership of Dr Anna Gavin since it was established. The review panel did not find any immediate risks or concerns in the NICR, but its recommendations

reflect a greater need for preparedness as we can anticipate information technology, service demands and personnel will change in the future.

Terms of Reference, as set out by the Public Health Agency, and recommendations

Note that the recommendations of the Review Panel extend beyond these Terms of Reference and further commentary is included in the body of this report. Timescales: ST, short term; MT, medium term; LT, long term. Further commentary beyond these recommendations is provided in the main body of this report.

1 Adherence to governance, ethical and data security requirements;

1.1 We recommend that Standard Operating Procedures (SOPs) be developed for the deliverables associated with these posts (Director, IT Manager, Tumour Verification Officers) and consideration given to a detailed succession plan that secures the longevity of the expert human resources on which the success of the NICR is heavily dependent. These SOPs should include all processing and storage of cancer registry data. (Recommendation 3.3.1) *MT*

1.2 We recommend that an option appraisal paper should be produced to help decide which future IT platform should be used for the NICR. This should include consideration of how Queen's University Belfast might provide support for the implementation and ongoing running of the IT system. (Recommendation 3.3.3) *MT*

1.3 Irrespective of the outcome of this options appraisal, we recommend that the NICR invests £60k to update the current IT system onto SQL server format. (Recommendation 3.3.4) *ST*

1.4 We recommend that a legislative mandate for having a cancer registry in Northern Ireland is obtained as soon as possible. (Recommendation 3.3.6) *ST*

2 The production of outputs which contribute to monitoring overall cancer burden within N. Ireland;

3 Data flows, timelines, completeness of data outputs and other registry processes when benchmarked with other registries;

3.1 A review and option appraisal of the advantages and disadvantages of moving from ICD-10 to ICD-O-3 either as an additional set of variables or as an alternative to ICD-10. (recommendation 5.3.1) *MT*

3.2 We recommend that the NICR produces plans for future data quality assessments. (Recommendation 5.3.2) *MT*

3.3 We recommend enhancing the current (or trying to establish a) mandated minimum cancer dataset similar to the Cancer Services and Outcomes Dataset in England to ensure complete and high quality registration. A further close collaboration and partnership of the NICR with the Northern Ireland Cancer Network (NICaN) and Clinical Reference Groups is needed to facilitate and improve this pathway. Endorsement and initiatives from the qualified authorities could help as well as legislative initiatives for the NICR (described elsewhere in this report). (Recommendation 6.3.2) *MT*

4 Provision of information to assist stakeholders, including the N. Ireland Cancer Network (NICaN), in service planning and development, quality improvement and audit;

4.1	We recommend that the NICR establishes a leadership position in the ongoing discussions about new Northern Ireland health IT systems (eg. NIPACS, ENCOMPASS) and any relevant associated planning groups. (Recommendation 3.3.5) *ST*
4.2	We recommend that the roles of the HSC, PHA and NICR in quality improvement of cancer services are defined in a strategic report. This is likely to require consultation to develop a clear, shared approach. (Recommendation 4.4.1) *MT*
4.3	NICR should lead a review of the funding structure for audits so that a programme of re-audits can be ensured. (Recommendation 4.4.3) *MT*
4.4	We recommend that a plan is needed on how to integrate chemotherapy (SACT) and radiotherapy data more fully into the registry (not only for case ascertainment but for the detailed treatment data they contain) and plan for output. (Recommendation 4.4.4) *MT*
4.5	We recommend that efforts are made to improve participation of clinicians through the Cancer Patient Pathway System (CaPPS). We all agreed that feedback to providers on the quality of source data may improve participation and quality of the data. Feedback only however does not seem enough to assure a complete data set. (Recommendation 6.3.1) *MT*
4.6	Explore and introduce the access to new HSC systems such as the LIM's and ENCOMPASS. Explore and document the complementarity and need for these data. (Recommendation 6.3.5) *MT*
5	**Contributions to national and international efforts to monitor cancer incidence and treatment outcomes;**
6	**Training and education at general population, undergraduate, postgraduate and with professionals who undertake cancer investigation and treatment;**
7	**Undertaking original research.**
7.1	We recommend that a robust strategy is developed to help prioritise multiple research requests from funders. (Recommendation 3.3.7) *MT*

The Review Team was also requested in the Terms of Reference to review the resources required by the NICR to deliver its key functions, and if indicated, advise on the totality of resources required by the Registry to deliver these functions in the future (based upon a transparent analysis of costs and overheads along with any potential efficiencies that could be achieved).

Overall the financial governance of the NICR was viewed as somewhat cumbersome by the Review Team. The funding arrangements of the Registry are not secure and are agreed on a yearly basis only by the Public Health agency (PHA); this presents substantial vulnerability and compromises future planning. It is also a concern that much of the Registry innovation and development is dependent on securing external research income and the Review Team felt that this has the potential to distract the Registry team from their primary focus and may place undue pressure on a team that are otherwise performing well.

The Review Team noted a very efficient deployment of the available resources and believe the productivity of staff should be commended.

Future funding. We recommend a review of funding arrangements for the NICR with an option appraisal paper. NICR should quantify the additional workload associated with the increasing incidence of cancer described in Sections 2.3 and 2.4 and make a case for further investment by the Public Health Agency (Recommendation 3.3.2) *ST*

1   Introduction

The Northern Ireland Cancer Registry (NICR) invited a panel of reviewers to carry out a peer-review of it in 2018. Regular peer-review has been part of cancer registries in other parts of the world. The membership of the review panel was chosen by the NICR itself and comprised individuals with experience of running cancer registries, a senior academic, a senior public health physician and a lay representative. The primary purpose of the review was to support the NICR by identifying how it might best prepare itself for future challenges. However, should any failings be identified, it is also a responsibility of a peer review group to indicate risks and urgent remedial actions.

The review process is described in detail in subsequent chapters but the structure of this report follows that of the (now obsolete) National Cancer Peer Review Programme template.

A late draft of this report was provided to the NICR for factual checking but commentary and recommendations were not provided prior to the report being published. We expect that the NICR will consider our recommendations and provide the Public Health Agency and Queen's University Belfast with a written response. We accept that this may include refutation, with justification, of some of our recommendations.

2. Context

2.1 The Northern Ireland Cancer Registry (NICR)

The NICR was established in 1994 to provide information on cancers occurring in the Northern Ireland population for the purposes of research, education, planning and evaluation of services. It is a population based register and provides information relating to the diagnosis and treatment of cancer and named pre-malignant conditions.

Following the Review of Public Administration in 2008, funding for the registry moved from the Department of Health to the Public Health Agency (PHA) and is operationalised through a service level agreement between the PHA and Queens University, Belfast where the NICR is hosted. The registry is supported by a Steering Group which advises the Director and the Steering Group on matters related to the Registry and its outputs and a Council, appointed by the Steering Group.

The NICR receives notifications of cancer diagnoses electronically from a number of sources (see Chapter 6).

The NICR has produced 27 reports on a range of topics including survival, cancer incidence and prevalence trends as well as a publication on All Ireland Statistics and an All Ireland Cancer Atlas. www.qub.ac.uk/research-centres/nicr/Publications Additionally NICR generates on average 15-20 peer reviewed publications annually. It is responsible for the production of the official cancer statistics for Northern Ireland and produces factsheets annuals for each of the major cancers.

2.2 The 2018 Peer Review

This Peer Review, undertaken in 2018, consisted of a site visit in June 2018 where the Peer Review team met key staff from NICR, heard presentations by registry staff on IT issues, data quality, Statistics, Audits/Research and Macmillan/ biobank/ Prostate Cancer UK funded research. The structure of the review was based on NHS guidance, which although now somewhat historical, has not been formally superseded.[1]

The 2008 Peer Review highlighted several areas of good practice and some concerns with NICR. Areas of good practice included high levels of engagement with stakeholders, strong governance arrangements, extensive outputs from the registry, proactive approaches to improve data quality and evidence of research collaboration. Concerns raised at that time related to NICR's activities not being covered by any legislation such as the equivalent of the English Section 60 of the Health and Social care Act (2001) leaving it vulnerable to legal challenges under common law and the need to consider redesign and renegotiate with Trusts to improve access to Trust held data.

A Bill on secondary use of data in Northern Ireland received Royal Assent in 2016. However in the absence of an Assembly the regulations have yet to be drafted, consulted on and receive final approval. Cancer Registration is expected to be itemised as a part of this legislation.

2.3 Northern Ireland Demographics

The Northern Ireland population (at 30 June 2016) is estimated to be 1.862 million, an increase of 10,500 people (0.6 per cent) since mid-2015. Population growth in the same period for the rest of the UK was estimated at 0.8 per cent. [2]

Population Projections

NISRA estimates that the population of Northern Ireland is projected to increase by 4.2 per cent to reach 1.940 million by mid-2026; rising again to 1.966 million by mid-2031 (an increase of 5.6 per cent from mid-2016)[3] - Figure 1. By mid-2041 it is projected to increase to 2.003 million (an average annual rate of growth of 0.3 per cent).

Figure 1. Estimated and projected population, mid-1991 to mid-2041 (non-zero y-axis). Reproduced from NISRA Statistical bulletin.
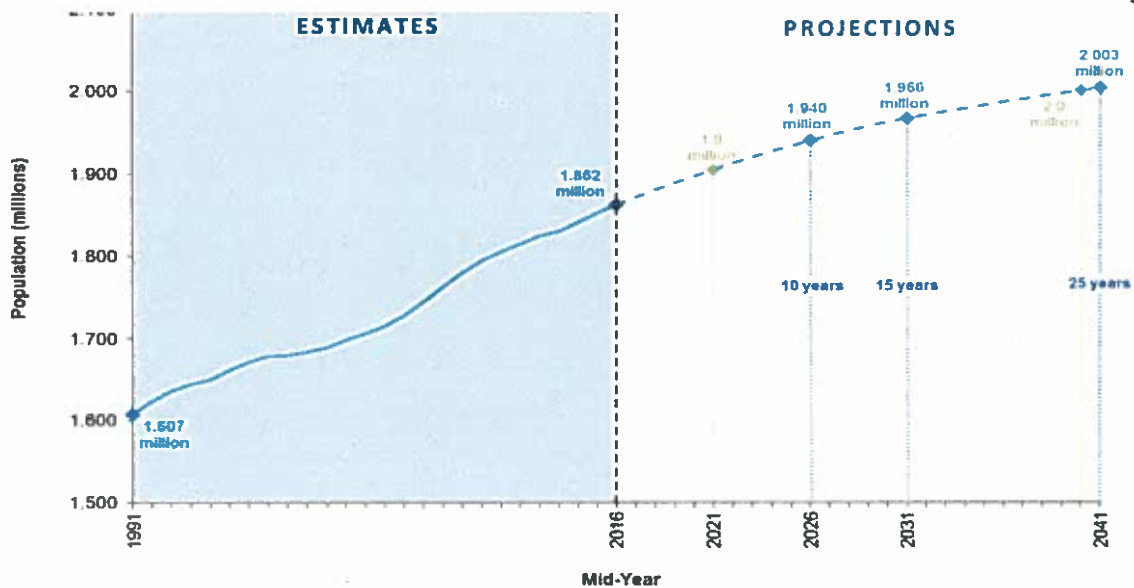
The population aged 65 and over is projected to increase by 65.1 per cent to 491,700 people from mid-2016 to mid-2041, with the result that almost one in four people (24.5 per cent) will be in this age category. The population aged 85 and over is projected to increase by 127.2 per cent to reach 82,800 people over the same period, which will see their share of the population doubling from 2.0 per cent to 4.1 per cent. This is relevant to the work of the NICR as cancer is more common with increasing age, with over 60% of cancers occurring in those ages over 65.

2.4 Epidemiology of Cancer in Northern Ireland

Cancer incidence

Between 2007 and 2016 the number of incident cancer cases (excluding NMSC) increased from 4,044 to 4,629 among men (15%) and 3,885 to 4,817 among women (24%) - Figure 2. This rise is largely due to increasing numbers of older people in the population.

Cancer incidence is higher in the most deprived communities in Northern Ireland though this varies significantly by cancer site. In 2015 deaths due to malignant neoplasms accounted for 28% of all deaths.

The incidence of cancer is expected to rise by 25% for men and by 24% for women by 2020 to 5,443 and 5,285 cases per year respectively.   By 2035 the number of cases per year is projected to be 7,181 male and 6,967 female cases, a 65% rise among men and a 63% rise among women.

Cancer prevalence

Over 58,000 people living in Northern Ireland were diagnosed with cancer within the last 23 years (with 'cancer prevalence' being defined as the number of living people who have ever had a cancer diagnosis since the beginning of 1993 to 2015, excluding the common easily treated non melanoma skin cancer (NMSC). By 2020, it is estimated that almost one in two people will be diagnosed with cancer at some point in their lives.

Cancer survival

The five-year net survival from cancer in NI has improved, increasing from 38.3% to 53.1% for men and from 48.0% to 56.4% for women, when we compare patients diagnosed from 1993 to 2000 to those diagnosed from 2006 to 2010.

Figure 2. Incidence of cancer (excluding NMSC) in Northern Ireland, by year.
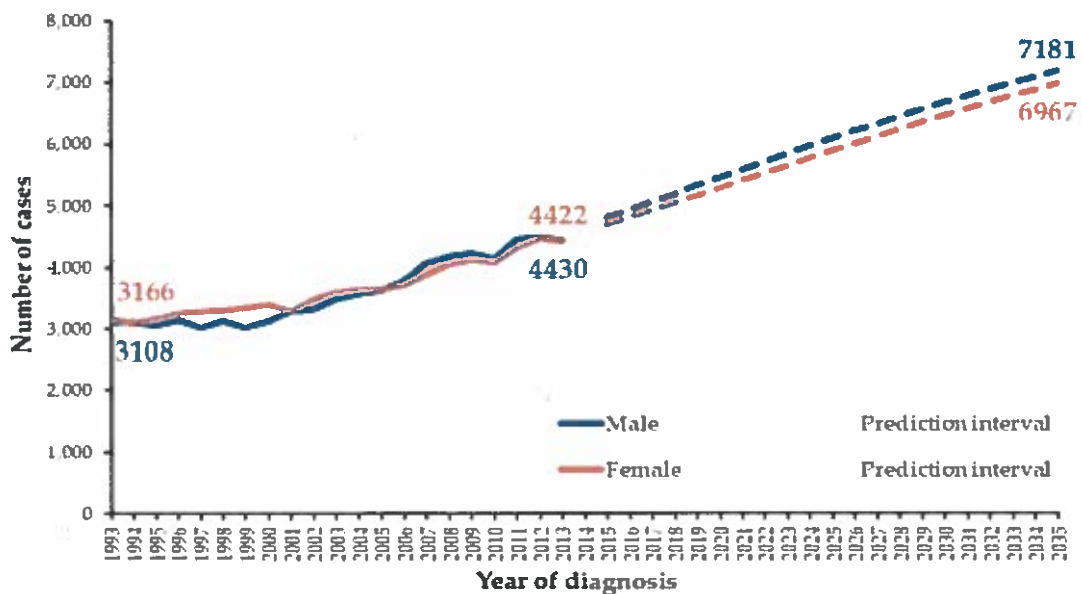
2.5 Cancer Policy in Northern Ireland

The Campbell Report, Cancer Services - Investing for the Future, published in 1996, signalled a major re-organisation of cancer care and recommended a new joined-up model for cancer services, based on a regional Cancer Centre and supporting Cancer Units. This included four 'spokes' (in Antrim Area Hospital, Craigavon Area Hospital, the Ulster Hospital and Altnagelvin Hospital) linked through a managed clinical network to the Northern Ireland Cancer Centre (NICC) located in Belfast (the 'hub'). The Campbell Report also recommended that the oncology outpatient and chemotherapy service for the 'common' cancers, namely breast, colorectal, lung and prostate, be delivered in the four 'spoke' hospitals. Patients with all other primary tumours were to travel centrally for treatment decisions and chemotherapy. All patients, regardless of primary tumour, requiring radiotherapy were to travel to Belfast, the NICC being the sole radiotherapy provider.   This pattern of services remained unchanged until 2016 when the North West Cancer Centre (NWCC) opened. The opening of NWCC changed the pathways for patients requiring radiotherapy from the north west of Northern Ireland from Belfast to Altnagelvin Hospital. This cancer Centre also treats patients from the north west of Ireland (Donegal, Sligo etc).

2.6 Northern Ireland Cancer Network

The Northern Ireland Cancer Network (NICAN) was established in 2004 and consists of a partnership of HSCNI organisations, academic, charity, cancer specialists and service users working in collaboration to deliver safe and effective care, improve cancer clinical outcomes and enhance patients and carers experience and quality of life. It is part of the Health and Social Care Board and works across HSC organisational boundaries. NICaN facilitates a network of groups called Clinical Reference Groups (CRGs) who look at particular cancers (e.g. Breast, Lung), or a particular service area (e.g. radiotherapy) for service planning/redesign, quality monitoring, service improvement and evaluation. NICR staff attend NICAN Board meetings and all the CRG groups.

3. Organisation and Management

3.1 Description of the organisation and management of the NICR

The Northern Ireland Cancer Registry Operational Plan dated 2018-19, effectively outlines the registry purpose, methodology, quality assurance mechanisms and key performance indicators.

The Registry sits as a separate unit within the Centre of Public Health which is part of the School of Medicine and Dentistry and Biomedical Sciences in the Faculty of Medicine Life and Health Sciences of Queen's University Belfast. The NICR is almost entirely funded by the Public Health Agency via funding agreed annually and allocated/recognised as a grant by the University. However in order to capture data and function effectively the Registry also relies heavily on strong links and data transfer with the HSCNI through each of the 5 HSC Trusts in NI and the Business Services Organisation.

3.2 Commentary

The Review Team were in agreement that the organisational arrangements pertaining to the NICR were generally sound and that there were robust procedures in place to enable the successful achievement of key objectives. Importantly, the Operational Plan also details a candid analysis of the inherent challenges and issues of concern going forward for the Registry which in turn demonstrates a transparent, reflective and problem-solving approach from the team. These characteristics are the hallmarks of good governance and as such testify to the strong and visible leadership that the NICR has enjoyed for the past decades. The skills and dedication of the wider team were also evident and it is clear that despite some challenging circumstances in terms of infrastructure etc staff morale and collegiality are key assets to the Registry.

The Registry noted that identifiable data can only be obtained with supportive legislation and involvement in direct patient care, as it would not be feasible to obtain informed consent. Since 2016, progress has not been made with legislation to support the NICR because the Northern Ireland parliament has been suspended.

There is a variety of disparate stakeholders within the NICR structure and it was the judgement of the Review Team that this has the potential to be disruptive.

Overall the financial governance of the NICR was viewed as somewhat cumbersome by the Review Team. The funding arrangements of the Registry are not secure and are agreed on a yearly basis only by the Public Health agency (PHA); this presents substantial vulnerability and compromises future planning. It is also a concern that much of the Registry innovation and development is dependent on securing external research income and the Review Team felt that this has the potential to distract the Registry team from their primary focus and may place undue pressure on a team that are otherwise performing well.

While strongly commending the skill and dedication of NICR team, the Review Team are concerned about succession planning. It would seem that there are several bespoke roles within the Registry that are highly dependent on legacy knowledge of the system at an individual level. These posts include the role of Director, IT Manager and Tumour Verification Officers.

At an infrastructure level there are also some concerns noted. Firstly the IT system dates back to more than two decades ago when NICR was established. As such it requires substantial additional investment to achieve maximum contemporary functionality and to ensure the system becomes future-proofed. The Mull House Building in which the Registry Staff work also requires modernisation to ensure that basic work place standards in relation to space, ventilation, noise and data security are addressed.

The Review Team also noted a very efficient deployment of the available resources and believe the productivity of staff should be commended. An example of this is that a team of 7.2 (Whole Time Equivalent) Tumour Verification Officers in NI compares very favourably to the Scottish Registry where a team of 27 TVOs undertakes a similar role in a population that is approximately double the size of Northern Ireland. In particular the contribution of the Registry to the work of the Northern Ireland BioBank was highlighted as a significant additional investment and the substantial resource implications for the Registry were noted. There is an impressive volume of high quality outputs from the Registry noted by the Reviewers who also appreciate the significant pressure that can be exerted by having multiple research requests and the divisive influence these may have on the team. There was clear evidence that the outputs of the Registry are valued by the community in Northern Ireland and that the impact of Registry data on the health and wellbeing of the Northern Ireland population more widely is being effectively exploited.

3.3 Recommendations

The panel recommends the following:

3.3.1 Standard Operating Procedures (SOPs). We recommend that SOPs be developed for the deliverables associated with these posts (Director, IT Manager, Tumour Verification Officers) and consideration given to a detailed succession plan that secures the longevity of the expert human resources on which the success of the NICR is heavily dependent. These SOPs should include all processing and storage of cancer registry data.

3.3.2 Future funding. We recommend a review of funding arrangements for the NICR with an option appraisal paper. NICR should quantify the additional workload associated with the increasing incidence of cancer described in Sections 2.3 and 2.4 and make a case for further investment by the Public Health Agency.

3.3.3 IT platform. We recommend that an option appraisal paper should be produced to help decide which future IT platform should be used for the NICR. This should include consideration of how Queen's University Belfast might provide support for the implementation and ongoing running of the IT system.

3.3.4 Irrespective of the outcome of this options appraisal, we recommend that the NICR invests £60k to update the current IT system onto SQL server format.

3.3.5 Influence on Northern Ireland IT developments. We recommend that the NICR establishes a leadership position in the ongoing discussions about new Northern Ireland health IT systems (eg. NIPACS, ENCOMPASS) and any relevant associated planning groups.

3.3.6 Legislature. We recommend that a legislative mandate for having a cancer registry in Northern Ireland is obtained as soon as possible.

3.3.7 Prioritisation of projects. We recommend that a robust strategy is developed to help prioritise multiple research requests from funders.

4. Uses of information

4.1 The roles of a cancer registry

Population-based cancer registries provide the most reliable and complete information about cancer occurrence. The purpose of cancer registries is to provide a key basis for cancer control in a population – that is, to reduce the incidence, morbidity and mortality from cancer.[4] We reviewed the uses of information by the NICR in light of this framework. Annually, following the launch of official statistics by the Registry, summary bulletins updated with information on cancer incidence, prevalence and survival are produced for the major cancer sites. These are available on the NICR website and are sent to clinicians via the NICaN clinical groups.

In addition, occasional reports on particular cancers documenting care and outcomes are produced auditing performance over time since 1996. The registry also provides information to enable quality checks for the screening services (breast, colorectal and cervical cancers). Reports have also been produced on cancer in children and young adults. Survival data allow inferences to be made about the performance of the overall service, provide opportunities for international and time trend comparisons as well as enabling the raising of questions about differences in case mix if unexplained variations are observed.

The registry also provides information for clinical genetics services and responds to approximately 200 requests for information annually; these include investigation of alleged clusters, parliamentary questions and media queries. Since 2017, some requests for information incur administrative recovery fees.

The registry is actively engaged in research and supports the work of external researchers. This work results in papers for peer review.

4.2 Evidence reviewed

The review group considered a number of examples of outputs from the NICR. We considered information available on its website, www.qub.ac.uk/research-centres/nicr, printed materials and a presentation given at our visit. These included general reports; audits; All Ireland reports in collaboration with the National Cancer Registry, Ireland; commissioned reports; infographics; newsletters; factsheets; Macmillan and NICR Partnership outputs; research; and pathology BioBank outputs (see Appendix for further details).

4.3 Commentary

The panel acknowledged the wide range of audiences to which the NICR data was presented. These respond to needs for information on cancer prevention, early detection and treatment. We were mindful that the potential range of outputs is almost unlimited and that, on balance, the NICR provides a good range of high quality outputs from its data.

The panel discussed the potential to expand the NICR's capacity to provide more data to health services for quality improvement, but we did not reach a consensus on whether the NICR should lead this work or if HSC (Health and Social Care in Northern Ireland) should do so.

NICR contains much of the main information which forms the basis for audits. They have been single reports and not part of cyclical quality improvement processes. Part of the reason for this has been that funding has not been continuous.

Data on Systemic Anti-Cancer Therapy (SACT) and radiotherapy are used to complete the Registry records. The panel was not clear about whether there were plans to integrate more treatment data and what the format of outputs from this work would be. There is an increasing expectation that registries can report on variations on treatment and outcomes for cancer.

We were told that there are plans to extend the NICR to register other chronic diseases, such as coronary heart disease and stroke. Such plans would bring with them additional staff and infrastructure that would help to improve continuity planning. NICR felt that many of the skills used to register cancers could be applied to other conditions. The panel did not reach a consensus on whether extending registration to other diseases was within its remit for the NICR review nor on whether it should be supported. Such a development might have mixed effects. While it would bring additional resources, these might be short-term and not secure. At the same time, existing resources – specifically, the time and skills of registry staff - may be drawn into setting up new non-cancer registries.

NICR has links with the Northern Ireland Cancer Network (NICaN). This involves working with over 14 site-specific groups to understand changes in clinical practice and coding and to help ensure that outputs from NICR are clinically relevant.

4.4 Recommendations

The panel recommends the following:

4.4.1 Quality improvement. We recommend that the roles of the HSC, PHA and NICR in quality improvement of cancer services are defined in a strategic report. This is likely to require consultation to develop a clear, shared approach.

4.4.2 Extension of the registry beyond cancer. We recognise that there are opportunities and risks to this aim. We recommend that a risk analysis is carried out to fully assess the strengths, weaknesses, opportunities and threats of such an approach. Our principal concern would be if such a development diverted existing resources in setting it up while failing to provide the long-term investment in staff and other resources that are anticipated.

4.4.3 Audit. Audits should be cyclical and not one-off reports to facilitate continuous quality improvement. NICR should lead a review of the funding structure for audits so that a programme of re-audits can be ensured.

4.4.4 SACT and radiotherapy data: We recommend that a plan is needed on how to integrate these data more fully into the registry (not only for case ascertainment but for the detailed treatment data they contain) and plan for output.

5. Data quality

At the heart of all uses of cancer registry data are that its records provide complete and valid information on all cancers that occur in the population. Information should be reported in ways that are consistent with other registries so that fair comparisons can be made.

5.1 Evidence reviewed

We considered the following sources of information when assessing the quality of NICR data:

o   NICR relationships with all Ireland, UK and Ireland, European and worldwide cancer registries
o   The results of quality assessments, such as the ENCR self-completed short questionnaire UKIACR Key Performance Indicators[5]
o   A presentation by Sinéad Lardner at our visit, including the role of the Tumour Verification Officer in data quality assurance
o   A peer-reviewed evaluation of the completeness and accuracy of the NICR data[6]undertaken by the UK and Ireland Association of Cancer Registries[7]
o   A research paper comparing GP held data on cancer with that held by the NICR

NICR receives notification of cancers from sources using ICD-10 or SNOMED these are translated to ICD-O-3 by the registry for registration purposes as it latter is considered the definitive standard for cancer registries and includes topographical, histological and behavioural codings.[8] In most cases, there is little difference between the topographic codes in ICD-10 and ICD-O-3, although generally the former is updated more frequently and thus clinicians may be recording more current revisions than registries report.

In 2018, for the 2016 dataset, the screening data linkage to the NICR dataset was completed too late for NICR Performance Indicators due to IT and personnel issues. These issues were due to late verification of 2016 screening data but did not affect the official statistics. The Registry has excellent exchange with each of the three screening services as evidenced, for example, by the percentage of patients with full screening history in the previous three years 2013-15, 94% of cervical cancer aged 25-60 years, and 98% of bowel and breast cancer patients aged 60-69 years.

NICR is recognised producer of Official Statistics of cancer in Northern Ireland. Staff liaise with NISRA regarding routine production of Official Statistics to ensure regulations are met.

5.2 Commentary

The Director of the NICR is a member, and at the time of our visit, Chair, of the UKIACR. She is also an elected member of the European Network of Cancer Registries' Steering Committee. The NICR is

a member of the World Health Organisation's International Association of Cancer Registries. These professional connections help to ensure that the NICR maintains consistent practices in recording and reporting cancer incidence and outcomes with other international cancer registries. The UKIACR 2018 Performance Indicators report compares the timeliness, quality and completeness of the UK and Ireland cancer registries. NICR met or exceeded targets for the proportion of cases with staging completed (84.7% vs 81.9% in England and 67.2% in Scotland), low death certificate only rates and low zero day survivor rates. Indicators that were not reached or not in line with other registries comprised: Average of core patient information complete; and Diagnosing hospital known. In its commentary, the NICR noted that updating the PRAXIS cancer registration system, coding errors in the General Register's System death certificates and late provision of PAS hospital records had resulted in delays to processing the 2016 incidence data (the latest incidence year to be reported). Among other comments, they noted that ethnicity remains poorly completed within their data.

Kearney and others' validation of the NICR case ascertainment validated registration data by asking GPs to confirm details. Just under a third of GPs (29%) took part. Of over 17,000 individuals, only two records differed with respect to benign/malignant status and two with respect to date of diagnosis. A further 15 individuals were identified by GPs who were not in the NICR. Thus, the registry was found to be 99.9% complete.

5.3 Recommendations

We recommend the following:

5.3.1 International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3). A review and option appraisal of the advantages and disadvantages of moving from ICD-10 to ICD-O-3 either as an additional set of variables or as an alternative to ICD-10.

5.3.2 Quality assessment. We recommend that the NICR produces plans for future data quality assessments.

6. Data sources and processing

6.1 Sources and evidence reviewed

NICR uses a wide range of electronic data sources, including hospital Patient Administration Systems (PAS), pathology laboratory, COIS/RISOH, CaPPS (MDT), the ARIA system for Radiotherapy, General Register Office (GRO)(death certificates), Business Services Organisation, Quality Assurance Reference Centre (screening) and GP records - Figure 3. [9,10] The NICR also access other HSCNI systems eg 3 radiology systems to view imaging reports/data, oncology annotations (free text notes), labcentre etc. These assist with confirming/refuting registration made electronically and also add value in terms of data/registration quality

These sources provide the primary cancer notification (mainly from PAS, pathology and GRO) , besides the (pre-)malignant cancer diagnoses, relevant data about stage of the disease, treatment (e.g. surgical procedures, radiotherapy, systemic treatment), comorbidities, causes of death, primary care data, demographic details and prescription data. Generally, 85% have a pathology diagnosis, Death Certificate Initiated cases account for 1.8 % cases, and Death Certificate Only 0.4 %.

Figure 3. Northern Ireland Cancer Registry – Method of Operation.
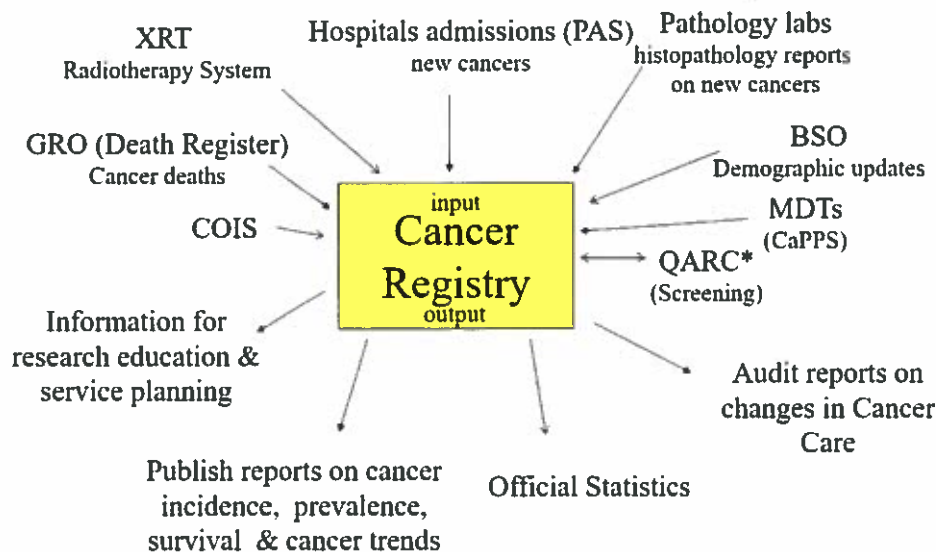
The NICR registers all invasive malignancies including non-melanoma skin cancer, all *in-situ* lesions, benign brain and testicular conditions, and neoplasms of uncertain or unknown behaviour. Recurrence data and clinical data have been collected by NICR firstly as part of a MacMillan funded project. Currently while processing each year's data NICR staff have collected recurrence information on breast cancer patients diagnosed from 2010 onwards and all other cancers diagnosed from 2014.

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Specific registers are created for some premalignant diseases or early diagnosis. Most of these registries were created within a research purpose context:

- o Barrett's Oesophagus (since 1993)
- o Colorectal polyps (since 2000)
- o Premalignant neoplasms of the cervix data available since 1993
- o Hydatidiform mole data available since 1993
- o Endometrial Hyperplasia (new)
- o Monoclonal Gammopathy of Undetermined Significance (MGUS) (new)
- o Prostate specific antigen (PSA) (since 1993)

PAS data are use to collect information on comorbidities.

The NICR also introduced the use of innovative techniques to capture clinically relevant data without increasing the manual work of the TVOs (Natural Language Processing - text recognition).

Data on pre-malignant disease have been used for research studies providing results highlighting genetic and lifestyle factors which increase the risk of malignant transformation.[11,12,13] The cervical datasets have been used to describe, for example, impacts of screening.

Pattern matching/regular expressions are used to help extract data from pathology and other free text sources. Pathology data are used to provide Gleason score for prostate but additional information (for example, on grade or TNM) could also be used.

Molecular pathology: data such as ER, PR, HER2, PSA biomarkers are currently routinely collected for cancer patients. The registry is liaising with the Northern Ireland Biobank and clinicians regarding what and how to record molecular markers in the future.

At the start of the registry, the NICR provided feedback on the volume of registrations received, monitored the levels of tumours notified form each source and checked if there is a change in notifications but do not routinely provide feedback to the source.   The NICR has, however, provided feedback on the completeness of various fields in the MDT, (Capps system) to the clinicians. This resulted in improvements in the various datasets received.

6.2 Commentary

An evaluation of these data sources and the ongoing actions for remedy (if needed), were thoroughly and clearly explained by the NICR collaborators during the presentations held on the 4th and 5th of June 2018. They are also commented upon and described in the action plan 2018-2019. The review committee agrees that it demonstrates clear insight, a critical and proactive attitude and full involvement from the NICR director and team.

According to the international literature, variety in information sources helps to improve completeness of the registration as well as helping to make data relevant and high quality. The high levels of utilisation of these data sources for years by the NICR is a real asset.

The Review Team is aware of the fact that availability of this large amount of treatment data cannot be assumed for a Cancer Registry in this era. It should therefore be safeguarded, further elaborated and treasured. The fact that Cancer Registry data are population based, makes them indispensable when evaluating quality of care and outcome measures in oncology, carrying out clinical audits or when assessing public health measures such as e.g. screening activities.

The complexity of cancer registry data means that there is a specific need for highly trained staff (tumour verification officers) to quality control, link, merge and validate the data. The existence of a very well trained and motivated team of Tumour Verification Officers (TVOs) was acknowledged by the review team. This very well trained team is small and highly specialised. Together, these may make the NICR vulnerable and at risk of losing specialisation when staff leave. It also emphasizes the particular needs and the duration (about 2 years) to train new staff.

Timely reporting of information on cancer incidence is one of the priorities for a cancer registry. The review team recognised that access to the variety of online data sources and especially the organisation of the TVO's work were exemplary for this aspect of their work.

The presence of longstanding and much-used rich data bases on pre-malignancies (e.g., Barrett's oesophagus, and colorectal polyps) and the historic PSA database are also considered to be unique. A structural plan (business plan) to manage and exploit these registries in the future is recommended.

The review team also expressed their concerns about the abrupt ending of access to COIS and the non-availability of Radiotherapy data for the most recent years. This may introduce a risk of incomplete treatment data in the NICR.

The panel recognises that GDPR compliance can hamper negotiations and the setup of new initiatives: NICR is well aware of that and seems ready to treat and overcome these issues.

The increasing incidence and the rising amount of available data (e.g. diagnostics, imaging, biomolecular and recurrence information), not only requires the appropriate staff equivalents (in numbers and training) but also analytical support and a sustainable model of funding in order to maintain timeliness and data validity which are crucial for the relevance of the data and its information.

6.3 Recommendations

We recommend the following:

6.3.1 CaPPS involvement. We recommend that efforts are made to improve participation of clinicians through the Cancer Patient Pathway System (CaPPS). We all agreed that feedback to providers on the quality of source data may improve participation and quality of the data. Feedback only does not seem enough to assure a complete data set.

6.3.2 Minimum dataset. We recommend enhancing the current (or trying to establish) a mandated minimum cancer dataset similar to the Cancer Services and Outcomes Dataset[14] in England to ensure complete and high quality registration. A further close collaboration and partnership of the NICR with the Northern Ireland Cancer Network (NICaN) and Clinical Reference Groups is needed to

facilitate and improve this pathway. Endorsement and initiatives from the qualified authorities could help as well as legislative initiatives for the NICR (described elsewhere in this report).

6.3.3 Access to data. Ensure continued access to datasets from Trusts in Northern Ireland and to COIS/RISOH.

6.3.4 Radiotherapy data. A plan is needed to renew availability of radiotherapy data.

6.3.5 Explore and introduce the access to new HSC systems such as the LIM's and ENCOMPASS. Explore and document the complementarity and need for these data.

Appendix 1: Summary of abbreviations

CaPPS	Cancer Patient Pathway System
COIS	Clinical Oncology Information System
CRGs	Clinical Reference Groups
ER	Oestrogen Receptor
GDPR	General Data Protection Regulation
GP	General Practice
GRO	General Register Office (for Death information)
HER2	Human Epidermal Growth Factor Receptor
HSC	Health and Social Care
ICD	International Classification of Disease
MDT	Multidisciplinary Team
NHS	National Health Service
NI	Northern Ireland
NICC	Northern Ireland Cancer Centre
NICaN	Northern Ireland Cancer Network
NICR	Northern Ireland Cancer Registry
NISRA	Northern Ireland Statistics and Research Agency
NMSC	Non Melanoma Skin Cancer
NWCC	North West Cancer Centre
PAS	Patient Administration Service
PHA	Public Health Agency
PR	Progesterone Receptor
PSA	Prostate Specific Antigen
QUB	Queens University Belfast
RISOH	Regional Information System for Oncology and Haematology
SACT	Systemic Anti-Cancer Therapy
SOP	Standard Operating Procedure
TVO	Tumour Verification Officer

UKIACR   UK and Ireland Association of Cancer Registry

Appendix 2: Evidence reviewed on uses of information.

- General reports
  - Survival of cancer patients 1993-2004
  - Living with and beyond cancer 2010
  - Cancer incidence trends 1993-2013 with projections to 2035
  - Cancer incidence by Local Government District 2008-2012
- Audits
  - Breast – (1) 1996 & 2001 (2) 2006 (3) 2012
  - Lung - (1) 1996 & 2001 (2) 2006 (3) 2014
  - Colorectal - (1) 1996 & 2001 (2) 2006
  - Prostate - (1) 1996 & 2001 (2) 2006
  - Oesophagus and Stomach – (1) 1996 & 2001 (2) 2005
  - Ovary and Cervix - (1) 1996 & 2001 (2) 2010
  - Pancreas - (1) 2001 (2) 2007
  - Melanoma – (2) 2006
  - Leukaemia & Lymphoma – (2) 2008
  - Bladder – (2) 2010 & 2011
  - Thyroid - (1) 2001/2 & 2004/5
  - PSA testing (in process)
- All Ireland reports in collaboration with National Cancer Registry, Ireland
  - All Ireland Cancer Atlas 1995-2007
  - Cancer in Ireland 1994-2004
  - All Ireland Statistics 1998-2000
  - All Ireland Statistics 1994-1996
  - Updated all Ireland Cancer Atlas (in process)
- Commissioned reports
  - Cancer referrals in NI
  - For DHSSPSNI
  - Review of oesophago-gastric surgical outcomes
  - For Belfast HSCT
  - Public attitudes towards cancer
  - For Public Health Agency
  - Why do cancer patients die in hospital
  - For Cancer Focus
- Infographics
  - Cancer in old age; cancer staging; cancer survival; colorectal cancer; and social deprivation.
- Newsletters
  - The latest NICR newsletter available on the website at the time of writing was Volume 23, August 2017.
- Factsheets
  - Cancer-specific factsheets summarise incidence, prevalence, mortality and survival by age, sex and socio-economic deprivation.
- Macmillan and NICR Partnership
  - Complete and summary reports on cancer incidence and prevalence have been created by GP Federation with an overall report covering the country.

- o A Cancer Data Landscape in Northern Ireland was produced in 2018, reviewing progress with 5 current and 2 future workstreams.
- Research
  - o Current research includes QUALYCARE-NI, International Cancer Benchmarking Partnership, Life After Prostate Cancer Diagnosis
  - o Past research includes the TEDI Project, Prostate Cancer UK and CONCORD-2 study
  - o Peer-reviewed publications number around 16 per year
- BioBank
  - o The NICR works closely with the pathology BioBank to provide information that links both databases for researchers.

Terms of Reference for Review of N. Ireland Cancer Registry 2018
4th and 5th June 2018

This advisory review is commissioned by the Public Health Agency to review and report on the work of the N. Ireland Cancer Registry (NICR) by assessing how effectively NICR systems facilitate:

1. Adherence to governance, ethical and data security requirements;
2. The production of outputs which contribute to monitoring overall cancer burden within N. Ireland;
3. Data flows, timelines, completeness of data outputs and other registry processes when benchmarked with other registries;
4. Provision of information to assist stakeholders, including the N. Ireland Cancer Network (NICaN), in service planning and development, quality improvement and audit;
5. Contributions to national and international efforts to monitor cancer incidence and treatment outcomes;
6. Training and education at general population, undergraduate, postgraduate and with professionals who undertake cancer investigation and treatment;
7. Undertaking original research.

The Review Team will review the resources required by the NICR to deliver its key functions, and if indicated, advise on the totality of resources required by the Registry to deliver these functions in the future (based upon a transparent analysis of costs and overheads along with any potential efficiencies that could be achieved).

[Members information removed as in the start]

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Northern Ireland Cancer Registry
Centre for Public Health
Queen's University Belfast
Mulhouse Building
Grosvenor Road
Belfast
BT12 6DP
Tel: +44 (0) 28 9097 6028
Email: nicr@qub.ac.uk
Web: www.qub.ac.uk/nicr