

Macmillan & the N. Ireland Cancer Registry Analytical Partnership – Work Plan

April 2018

Background

The development of robust data analysis is a crucial component of understanding the estimated 63,000 people living with and beyond cancer in Northern Ireland in 2015 and to inform our understanding of the cancer survivorship population.

Macmillan Cancer Support's ambition is to reach and improve the lives of everyone affected by cancer and to inspire millions to do the same. We do that by providing medical, practical, emotional or financial support and pushing for better cancer care. To make this a reality, we need to understand the needs of people living with and beyond cancer, the health, social and economic impacts of cancer and the consequences of its treatment, alongside people's experience of care. The collection and analysis of high quality data is critical to informing and delivering initiatives and change which will enable people affected by cancer to get the care which best fits their individual needs and to achieve the best possible outcomes.

The N. Ireland Cancer Registry (NICR) collates and analyses information on cancer patients and the services they receive and, based on this, is able to report cancer incidence, prevalence and survival. One of its key outputs is evidence to help inform decision making around cancer services.

Public Health England's National Cancer Registration and Analysis Service (NCRAS) is an initiative working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Macmillan has had an analytical partnership with NCRAS for several years, funding two analysts to carry out a programme of work to develop and apply the analysis of large scale data sets to the survivorship intelligence agenda. In April 2016, Macmillan and the NICR began a similar partnership with a view to feeding regional analysis into the UK-wide work streams underway with NCRAS as well as delivering more local analysis to utilise unique datasets, answer nation-specific questions and test innovative analysis.

The Macmillan-NICR work plan

Vision

Through participation in Macmillan-NCRAS initiatives and nation-specific analysis in line with these initiatives, we aim to:

- Use data to improve the understanding of the impact and costs of cancer and its treatment across the whole of the cancer journey, and including the wider community and health and social care services in Northern Ireland, now and in the future;
- Identify opportunities to undertake world class data analysis to support improved design, testing and implementation of better models of care, ultimately improving outcomes for people living with and beyond cancer.

Why now?

We already know a lot about people living with cancer. In order to reach and improve the lives of everyone living with cancer now and in the future, commissioners, providers and decision makers need to fully understand, in this challenging economic climate, the numbers, needs and experiences of people living with cancer. We need to increase the granularity of our understanding so that we have the best intelligence to most effectively target and ensure the best outcomes for people living with cancer.

To this end, the Macmillan-NCRAS partnership has delivered some UK-wide work but there is a need to better ensure national contexts are fully and consistently represented in these projects. At the same time, there has been a widening gap between the levels of analysis and insight delivered around cancer survivorship in England compared to the other UK nations. Dedicated analytical capacity in national registries – including the NICR – will help to address this.

Work streams

A number of work streams will be prioritised over the course of the partnership all underpinned by the desire to (a) feed into the UK-wide initiatives within the Macmillan-NCRAS partnership and (b) answer cancer intelligence questions which are specifically important within Northern Ireland.

2016-2018 priorities

Profiling ‘Transforming Cancer Follow Up’ patients: By identifying and flagging Self-Directed Aftercare (SDA) breast cancer patients in NICR datasets, a profile of these patients has been produced to determine how well they reflect the total case mix of breast cancer patients. The work explored cancer type, age and stage at diagnosis for (a) those assigned to self-directed aftercare (SDA); (b) those re-entering the system post-SDA and; (c) the full breast cancer population, and compared these groups. The NICR will deliver a final report on the work undertaken, including reporting and interpretation of routine registration data (such as stage, age, deprivation score, form of breast cancer, etc.) and conclusions as to the effectiveness of the breast SDA pathway. An academic paper is also in development and a poster was presented at the PHE Cancer Data and Outcomes Conference in June 2017.

Profiling cancer populations within the new GP Federations: By extracting patient data and aggregating based on designated GP practice, the NICR has developed a profile of people living with cancer within each GP Federation. Delivered outputs include:

- Detailed factsheets (including registration data for incidence, prevalence, age/stage at diagnosis);
- One-page cancer profiles (highlighting the key features of each Federation’s cancer population);
- A central report identifying how cancer incidence and prevalence in each GP Federation differs from Northern Ireland trends, broken down by age group, gender, cancer type, time since diagnosis, stage at diagnosis, deprivation quintile, etc.

The usefulness of the current outputs will be gauged through liaison with the GP Federations with a view to incorporating feedback into further versions (e.g. to include screening uptake, emergency presentations).

Cancer data landscape in Northern Ireland: A report has been produced summarising the NICR’s current way of working, the data it holds and to which it has access, as well as external datasets to which NICR data could potentially be linked for public benefit.

2018-2020 priorities

Identifying breast cancer recurrences and metastases: Drawing on data collected from hospital notes and other sources, a cohort of breast cancer patients has been followed up for recurrence to investigate the characteristics of women with recurrence / progression (stage, type of progression/metastases) compared to the wider breast cancer population. The data will be used to explore changes in the diagnosis of breast cancer recurrence post ‘Transforming Cancer Follow Up’ and will also help inform the development of a method for routinely identifying and reporting breast cancer recurrence.

Acute Oncology data linkage: Northern Ireland’s regional Acute Oncology (AO) service was established in early 2016. By routinely coding the patients seen by each Trust’s AO service in NICR databases, and linking AO monitoring data to NICR data, the NICR will be able to profile the AO patient group, giving valuable insights about the characteristics of patients presenting to AO and about their cancer pathway before and after their contact(s) with AO.

Emergency admissions towards end of life: The NICR is using data from the Patient Administration System (PAS) to investigate the numbers of emergency admissions among people living with cancer in their last year of life in NI. This has been linked to NICR registration data to disaggregate those presenting as emergencies by age, gender, cancer type, deprivation quintile, rurality and discharge destination. The final report will deliver analysis for use in understanding the numbers and types of patients being admitted as emergencies at end of life, determining how many of these admissions are avoidable and influencing for system change accordingly in order to reduce avoidable emergency presentations.

To find out more and key contact

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