

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

February 2017

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 a number of 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 nation-specific 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 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.

Year 1 priorities

Profiling 'Transforming Cancer Follow Up' populations: By identifying and flagging Transforming Cancer Follow Up (TCFU) patients in NICR datasets, a profile of these patients will be produced to determine how well they reflect the total cancer patient case mix. Work has begun with breast cancer patients, exploring 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 comparing these groups. Work is also ongoing to define how SDA is coded and recorded across Trusts to establish protocols for routine submission of SDA data to the NICR. During 2017, each of these elements will be further developed. An important next step will also be to identify which cancer types to prioritise for further TCFU profiling. An interim report will be delivered in early 2017 and posters/papers submitted to conferences, including the PHE Cancer Data and Outcomes Conference in June 2017.

Profiling cancer populations within the new Primary Care Federations: By extracting patient data and aggregating based on designated GP practice, a profile of people living with cancer within each federation will be produced. To date, the work has produced incidence and prevalence figures for breast, prostate colorectal, lung cancer and all cancers ex. NMSC, and determined whether incidence in each Federation is higher, lower or similar to the NI average. Priorities in early 2017 will be to produce mortality and survival rates by Federation, deliver an interim report and to consult primary care colleagues about further useful analyses of NICR data by Federation.

Identifying breast cancer recurrences and metastases: Drawing on data collected from hospital notes and other sources, information on breast cancer recurrences will be reported on. A cohort of breast cancer patients has been followed up for recurrence over a period of four years to investigate the characteristics of women with recurrence/ progression (stage, type of progression/metastases) compared to the breast cancer population. A working procedure for recording tumour relapse is also in development and is currently being consulted on (for breast cancer). This work will align with the Macmillan-NCRAS development of a proxy to identify recurrence, second cancer and metastatic disease, with the potential of testing the Macmillan-NCRAS algorithm. For metastatic breast cancer, the NICR will explore methods to distinguish different mets which have different survival outcomes and service needs (e.g. liver and/or brain vs. bone mets). This could in future inform NI wide acute oncology services.

Consequences of cancer and its treatment: The partnership gives Northern Ireland an opportunity to lead the way in investigating the consequences of cancer treatment. The NICR will draw on hospital activity data and – where possible – primary care data to explore and test the prevalence and severity of known consequences. To date, areas of investigation have included:

- Consequences of pelvic radiotherapy (RT), to complement and expand upon work already underway between the Northern Ireland Cancer Network and NICR, which seeks to explore and quantify certain consequences of pelvic RT for lower GI cancers
- Premature death among adults who have had cancer as children (article published Sept 2016)

Potential priorities for Year 2

Priorities for Year 2 of the partnership will be subject to discussion and agreement in early 2017, but are likely to include long-term conditions among people living with cancer and the cost of cancer. Further information about these projects and new priorities will be provided in future updates of the work plan as it develops.

To find out more and key contact

Dr Colm Burns – Macmillan Evidence Officer, Northern Ireland cburns@macmillan.org.uk