

Macmillan – NHS Scotland’s Information Services Division (ISD) Scottish Cancer Pathways Partnership

June 2018

Background

The development of robust research and data analysis is crucial to further our understanding of the cancer population, particularly as there were almost 220,000 people living with and after cancer in Scotland in 2015 and this number is predicted to rise to 360,000 by 2030. People surviving cancer will have different levels of need, with these needs changing over time and being dependent on the type of cancer experienced and treatment undergone.

Macmillan Cancer Support’s ambition is to help everyone with cancer live life as fully as they can. We provide medical, practical, emotional and financial support for people at the times they need us the most. better cancer care. To realise our ambition, 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.

In this context, and with the current system unlikely to be able to cope with the projected increase in health and social care service use, we need an improved understanding of post-diagnosis pathways for cancer patients to better plan support and services. The collection and analysis of high quality data is critical to informing and delivering initiatives and change, which will enable people living with cancer to get the care which best fits their individual needs and to achieve the best possible outcomes.

The Partnership

Macmillan and NHS National Services Scotland’s Information Services Division (ISD) are working together to carry out a programme of work through an analytical partnership called Scottish Cancer Pathways.

The Scottish Cancer Registry, which sits within ISD, collates and analyses information on cancer patients and the services they receive and, based on this, reports cancer incidence, prevalence and survival. In addition, ISD develop patient level activity data into information and intelligence to support the delivery and planning of health and social care services.

The Macmillan-ISD Scottish Cancer Pathways work plan

Macmillan and ISD are working in partnership to:

- deliver insights of Scotland cancer data to support improved models of care, and identify gaps and opportunities to deliver world class data collection and analysis and improve outcomes for people living with cancer
- participate in similar initiatives and partnerships in the other nations by providing Scotland-specific analysis for UK-wide use of evidence

The Macmillan-ISD partnership, begun in July 2015, is now coming to the end of the 2016-2018 workplan, with its new phase of work starting this summer and extending through June 2020. To date the partnership focused on setting up foundations, mapping Scotland’s data and health and social care agenda in a

Landscape Paper, and publishing a technical report and non-technical briefs on [deprivation and cancer survival](#) (Feb 2017). A newer project, Scottish Routes from Diagnosis, has begun and will continue into the next partnership period.

Why now?

The devolved health and social care functions across the UK means we need to have nation-specific analysis that draws on the datasets available in each nation and allows for the devolved socio-political contexts. Therefore, we now have partnerships with the cancer registries in each nation of the UK: National Cancer Registry and Analysis Service (NCRAS) in England; the Northern Ireland Cancer Registry (NICR); NHS Scotland's Information Services Division (ISD); and the Welsh Cancer Intelligence and Surveillance Unit (WCISU). Such dedicated analytical capacity in the national registries will help Macmillan to take advantage of unique datasets in each nation, and to tailor Macmillan services to the local cancer population, understand needs and influence the different systems.

2018-2020 Priorities

Local Cancer Intelligence (LCI) Scotland: An externally available tool, LCI will allow data to be accessed at the national, Network, Health Board and Local Authority level. It's being developed in 2018 and will provide data on prevalence, incidence, mortality, patient experience, and deprivation.

Scottish Routes from Diagnosis (SRfD): This work is developing a survivorship outcome framework using the English RfD as a foundation rather than a replicable framework. Begun in 2017, the framework maps patient pathway experiences, describes survivorship morbidity and health outcomes, and identifies relationships of how patient characteristics influences the diversity of outcomes within and between cancer sites. It explores outcome groups according to co-morbidities and other long term conditions, inpatient activity, unscheduled care, pharmacy, palliative and end of life care, and mental health. When social and primary care data is available, it will be linked into this work as well. Initial publication will begin late 2018.

Health Board Profiles: Using net survival for the 20 most commonly diagnosed cancers in Scotland to explore variations, multivariate analysis will then investigate the drivers behind any variation. This will be contextualised by sociodemographic and case mix backgrounds, and further profiles to be developed in partnership with health boards. A primary aim of this work will be facilitating collaborative learning across Scotland.

Rural and remote outcomes: This work will explore variations in outcomes according to the urban / rural index, and further explore cancer pathways – particularly in terms of access, travel time, and technology – for people living in more remote areas. Investigating implications of time and cost according to these pathways will help to inform further service and support development.

What's Next

Late 2018 will see the publication of the first chapters from SRfD, and our work with the Health Boards will be ongoing. Check the Macmillan website for Scotland's LCI tool later in 2018.

To find out more and key contact

Dr Kelly Shiell-Davis, Senior Evidence Officer, Macmillan Cancer Support, ksdavis@macmillan.org.uk