

Macmillan-ISD Scottish Cancer Pathways Project

February 2017

Background

Given that there are almost 220,000 people living with and after cancer in Scotland and this number is predicted to rise to 360,000 by 2030, the development of robust research and data analysis is crucial to further our understanding of the cancer population. 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 reach and improve the lives of everyone affected by cancer and to inspire millions to do the same. We provide medical, practical, emotional and financial support, and push for 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 particularly 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 affected by cancer to get the care which best fits their individual needs and to achieve the best possible outcomes.

The Partnership

Building on the existing Macmillan-National Cancer Registry and Analytical Service (NCRAS) partnership Macmillan and NHS National Services Scotland's Information Services Division (ISD) are now in an analytical partnership to carry out a programme of work, 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 began in July 2015, and is now entering its next phase of work that extends through June 2018. The first year of the partnership focused on setting up foundations, and mapped

Scotland's complex health and social care integration agenda, projects, and datasets in a Landscape Paper.

Why now?

To reach and improve the lives of everyone living with cancer now and in the future, we need to increase the granularity of our understanding of the needs of people living with cancer. Commissioners, providers and decision makers need to fully understand, in this challenging economic climate, the numbers, needs and experiences of people living with cancer.

The Macmillan –NCRAS partnership has delivered some UK-wide work, yet 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, as well as a need for improved representation of the national contexts. Dedicated analytical capacity in national registries – including the Scottish Cancer Registry – will help address this.

2016-2018 Priorities

Completion and Publication of Survival by Deprivation: Survival analysis by deprivation, sex and cancer site have already been produced for the most common 20 cancers in Scotland (2013 incidence). Where cancer types demonstrate statistically significant variation between the most deprived and least deprived for 1 year survival, 5 year survival, and/or sex, multivariate analysis is being carried out. This work sheds some light on reasons and contributing factors to the variation, such as stage at diagnosis, access and use of screening programmes, and co-morbidities. *Published February 2017.*

Sub-national and Local Cancer Intelligence (LCI) Scotland: An externally available tool, LCI will allow data to be accessed at the Network, Health Board and Local Authority level. It will be developed in 2017 and likely cover prevalence, incidence, mortality, survival, patient experience, population, death, place of death, and stage at diagnosis. Macmillan and ISD will explore the feasibility of what data can be utilised and made available across Scotland's Health and Social Care Partnerships, and potentially at the locality level.

Scottish Routes from Diagnosis (SRfD): This work will develop a survivorship outcome framework using the English RfD as a foundation rather than a replicable framework. A 2017 priority, the analysis will explore the cancer population per survival and outcome pathways. It will explore these 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.

Progressive Cancers: This work will collaborate with the Macmillan-NCRAS Progressive Cancers development of a proxy algorithm aiming to identify recurrence, metastatic disease, and secondary cancers in routine national datasets. Helping to test and refine the breast cancer algorithm on Scottish datasets will help to improve our understanding of progressive cancers in the Scottish population.

During the next two years, work will also begin on developing longer term objectives, namely **Costs of Cancer Across the Pathway** and **Consequences of Treatment**, both of which will require further refinement and the availability and accessibility of particular datasets.

What's Next

February 2017 sees the full report on survival analysis by deprivation, sex, and cancer site, with briefings on the 6 cancer sites showing significant differences in survival between the most and least deprived. Development of the SRfD is currently underway.

To find out more and key contact

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