Scottish Routes from Diagnosis

Part of the Macmillan – ISD Scottish Cancer Pathways analytical partnership

The cancer story is changing. The combination of an ageing and growing population and more effective cancer treatment means that we now have unprecedented numbers of people living in the long term after a cancer diagnosis. This will only increase, with the approximate 2.5 million people living with cancer in the UK (as of 2015) projected to rise to 4 million by 2030. In many cases, cancer is becoming a condition that people live with for many years; people are now twice as likely to survive at least 10 years after being diagnosed with cancer than they were at the start of the 1970s. People living with and beyond cancer will have different intensities and complexities of need, with these needs fluctuating over time and being dependent on the type of cancer experienced and treatment undergone.

In this context, Macmillan and NHS Scotland’s Information Services Division (ISD) are working in partnership to use Scottish cancer, health, and other routinely collected data to deliver insights that support improved models of care and improve outcomes for people living with cancer. One project from the partnership’s workplan, Scottish Routes from Diagnosis, focuses on improving the understanding of post-diagnosis pathways for cancer patients and the services needed to support them.

**Background**
Scottish Routes from Diagnosis (SRfD) is a programme of work seeking to link and analyse routinely collected data to quantitatively describe survivorship experience of cancer patients in Scotland, both across and within cancers. It aims to be a powerful and robust approach that is an adapted framework of the English RfD.

Anonymised cancer registry data are linked to secondary care – and when possible, primary and social care data – at a patient and episode level to:

- Map patient pathway experiences – what happens to distinct groups of patients from diagnosis to death or on-going survivorship
- Describe survivorship morbidity and health outcomes, i.e. survival, incidence, cancer and non-cancer related co-morbidities, and mortality
- Identify relationships and further our understanding of how patient characteristics influence the diversity of outcomes within and between cancer sites

**Approach**
The first cohort of cancer sites for initial framework development are:

- Trachea, Bronchus & Lung Cancer (C33-C34)
- Female Breast Cancer (C50)
- Colorectal Cancer (C18-C20)
- Prostate Cancer (C61)

These four cancers make up over half of all cancers diagnosed in Scotland and enable more granular investigation. For the first cohort, a national extract of all cases diagnosed in 2007 (followed up for 10 years) and 2012 (followed up for 5 years) were taken.

By looking at two follow-up periods, we are able to look at longer term survival alongside more contemporary patient experiences that utilise more recently developed datasets. The relevant Public Benefits and Privacy Panel (PBPP) permissions were obtained.
The extracted cases are then allocated to one of four outcome pathway groups:

Outcome Group 1: Survive long-term with similar acute healthcare burden
Outcome Group 2: Survive long-term with increased acute healthcare burden
Outcome Group 3: Cancer as a continual part of life
Outcome Group 4: Limited Survival

In these definitions, changes in acute healthcare burden are identified by comparing the bed days in post-diagnosis to those in pre-diagnosis.

These groups are being investigated across a number of key themes. Due to the wide-ranging areas of interest, a multi-phased approach is being taken.

Phase 1
- Characteristics of the cohort by groupings
- Comorbidities
- Survival, cause of death, palliative and end of life
- In-patient, acute, and unscheduled care activity
- Multiple cancers and metastatic disease

Phase 2 is still for refinement and finalisation, but areas of interest are:
- Detection
- Mental Health
- Patient Experience
- Local/Glasgow health and social care application
- Palliative care and treatable but not curable cancer

Clinical Advisory Group
SRfD has established a Clinical Advisory Group (CAG) to provide clinical guidance over the course of the project. There are at least two specialists for each of the cancer sites in the first cohort of cancers: breast, colorectal, lung and prostate, and there is representation from primary care and specialist palliative care.

Outputs
The initial outputs of this work will be each chapter published separately, with Phase 1 chapters planned for publication throughout 2019 from February onwards. Academic publications will also stem from this framework, and consideration of a possible interactive element is underway.

To find out more or record your interest in the dissemination, please contact either Cheryl Denny, Principal Analyst (ISD) Cheryl.denny@nhs.net or Dr Kelly Shiell-Davis, Senior Evidence Officer (Macmillan) ksdavis@macmillan.org.uk.

This work uses data provided by patients and collected by the NHS as part of their care and support.

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