

Macmillan Cancer Support and PHE National Cancer Registration and Analysis Service analysis partnership

June 2018

Background

Given that there are almost 2 million people living with a cancer diagnosis in Englandⁱ and this number is predicted to rise to 3.4 million by 2030ⁱⁱ, the development of robust research and data analysis is crucial to further our understanding of the cancer population and is critical to informing and delivering initiatives and change.

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. 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 cancer. This includes the health, social and economic impacts of cancer and the consequences of its treatment. This must be in the context of understanding people's experience of care and their long-term quality of life.

The Partnership

The focus of this partnership between Macmillan and Public Health England's National Cancer Registration and Analysis Service (NCRAS) is to deliver insightful analysis of routinely collected data describing people living with a cancer diagnosis in England. This is through the development and application of conventional and innovative approaches and statistical techniques.

The partnership began in 2012 in recognition of the significant amount of additional analyses that both parties have been interested in taking forward but that neither organisation would otherwise be able to progress.

2017-2019 Priorities

Identifying and counting people living with treatable but not curable cancer within the NCRAS linked data sets: As treatments improve, people are increasingly living longer after a cancer diagnosis. A considerable number of people have cancer that cannot be cured, but their cancer burden can be reduced and thus their symptoms alleviated by treatments which may also prolong life. This is a complex group of people, living with different cancers, prognoses and treatments. There is no marker for people with treatable but not curable cancer in the cancer registry or in linked routinely collected datasets. Therefore, in this project, we will build a search criterion to identify people who are likely to be living with treatable but not curable cancer in the NCRAS linked datasets. The search criterion will be a set of rules and surrogate markers based on what is currently collected. The search criterion will allow the estimation of how many people have treatable but not curable cancer and their population characteristics. This will be the foundation of any future work on treatable but not curable cancer. This will feed into an academic paper.

Cancer Prevalence Project: Between 2013 and 2018 the partnership has produced a wealth of data describing the numbers of people living with cancer across the UK. This provides detailed information on local regions, cancer types, age groups and deprivation quintiles. All the data files and a technical report on modelling complete prevalence can be found at:

http://www.ncin.org.uk/about_ncin/segmentation. We currently have an academic paper in

preparation about complete prevalence and are developing Standard Operating Procedure with the United Kingdom and Ireland Association of Cancer Registries. The most recent work has been a collaboration between Macmillan, NCRAS and Transforming Cancer Services Team for London, NHS to describe the number of people living up to 21 years post a cancer diagnosis in 2015 in England. The data is presented by local area, cancer type, time since diagnosis, age, deprivation, ethnicity (10 year), or stage at diagnosis (4 year).

Local Cancer Intelligence (LCI) England: lci.macmillan.org.uk/England - LCI England is an online tool combining local cancer population (CCG) data with insight from Macmillan and other sources. CCG data will soon also be available grouped by Cancer Alliance. It has been designed to help commissioners and other users of cancer data provide evidence to plan services and influence decisions. The tool is mobile friendly, allowing users to view headlines and charts on the go, with the ability to filter and manipulate the charts. The partnership with PHE NCRAS, has provided data on the numbers of people diagnosed with cancer (incidence), the number of people living with cancer (prevalence), and the number of cancer deaths (mortality) in each CCG of England. We will soon add information on 1-year survival.

Length of stay in the first-year post diagnosis: Length-of-stay refers to the total time spent in hospital during the first year following a cancer diagnosis. This work found that cancer patients in England who were diagnosed in 2014 spent 5.3 million days in hospital receiving treatment in the first year of diagnosis and almost 10,000 people made 50 or more trips – the equivalent of once a week. This analysis is currently being developed into an academic paper.

Emergency admission towards end of life: This research shows that on average, around 22,000 (35%) of those who die each year from one of eight common types of cancer have five or more emergency visits in the last year of their life. More than 3,000 (5%) of these patients have more than 10 emergency visits in their final 12 months. We have published detailed information on emergency admissions between diagnosis and death (up to 3 years) split by, deprivation, sex, route to diagnosis, age at death, rural/urban classification and cause of death - <http://www.ncin.org.uk/view?rid=3533>

Linkage of the English Cancer Patient Experience Survey to cancer registration data: Working with Cancer Research UK and NCRAS we developed a methodⁱⁱⁱ to link the datasets to allow researchers to understand how differences in patient experience impact the cancer information in the registry and the hospital activity statistics.

To find out more and key contact(s)

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ⁱ Macmillan-NCRAS partnership. 2017. Updated UK Complete Cancer Prevalence for 2013 Workbook for UK nations and UK combined. <http://www.ncin.org.uk/view?rid=3415>

ⁱⁱ Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 2012; 107:1195-1202. (Scenario 1 presented here) and share in England based on Maddams J., Thames Cancer Registry, personal communication. See also Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547.

ⁱⁱⁱ http://www.ncin.org.uk/cancer_information_tools/cancer_patient_experience