Macmillan Cancer Support and Public Health Wales
Welsh Cancer Intelligence and Surveillance Unit (WCISU)
Analytical Partnership
June 2018

Background

There is an estimated 130,000 people living with and beyond cancer in Wales and this number is expected to rise to 220,000 by 2030. 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.   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.

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

The Welsh Cancer Intelligence & Surveillance Unit (WCISU) is the National Cancer Registry for Wales and its primary role is to record, store and report on all incidence of cancer for the resident population of Wales wherever they are treated. In April 2017, using the long-running partnership with Public Health England's National Cancer Registration and Analysis Service (NCRAS, formerly NCIN) as a blueprint, Macmillan and WCISU entered into a partnership 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. The work of the partnership feeds into the UK-wide work streams underway with NCRAS as well as delivers more local analysis to utilise unique datasets, answer nation-specific questions and test innovative analysis.

Macmillan and WCISU use data to improve the understanding of the impact and costs of cancer and its treatment across the primary, secondary and tertiary pathways in Wales. The partnership aims to deliver insightful analysis of Welsh cancer data to support improved design, testing and implementation of better models of care, and to identify gaps and opportunities to deliver world class data collection and analysis for improved outcomes for people living with and beyond cancer.

Partnership projects 2017-2019

Landscaping paper

 The partnership commenced with a review of data availability and the potential to link and analyse data on clinical outcomes and patient experience across primary, secondary and tertiary care in Wales. The paper provided insight into unique characteristics of cancer data in Wales, highlighted gaps in availability between Wales and other UK nations and informed opportunities for analysis considering the partnership's objectives.

Understanding the local cancer population in Wales

GP Cluster Profiles – cancer incidence and prevalence: This first data product from the partnership is an online dashboard which provides information about cancer incidence and prevalence at GP Cluster level, Health Board and All Wales by sex, age, stage at diagnosis, deprivation and rurality. Developed with input from a range of end-users, the use of the dashboard will be closely reviewed to ensure the information it provides is both accessible and useful to those designing services for patients.

Cancer and comorbidities: Comorbid diseases are chronic illnesses existing alongside other medical conditions and can increase the risk of cancer and make the treatment of cancer more difficult. The second phase of the local GP Cluster analysis will explore what diseases cancer patients had prior to diagnosis. It is anticipated that this data will also be available via the GP Cluster dashboard and followed closely to determine the impact on service development and patient experience.

Routes at diagnosis

Building on work pioneered in England, Macmillan and WCISU want to learn more about the needs of people currently living with cancer in Wales, and to distinguish between groups of people with ongoing health and support needs after cancer treatment. The analysis will link data held by the Cancer Registry with Hospital Episode Statistics, to allow us to understand the cancer journey from pathways of diagnosis through the first-year post-diagnosis, describing the needs patients and the health outcomes they experience.

Future priorities: Using data to drive improvements in end of life experience

Improved planning in the earlier stage of cancer can lead to fewer hospital admissions and deaths in hospital. It is anticipated that future work will explore the profile of hospital admissions in the last year of life to target service development and improve the experience of those at end of life.

What's next and key contact

The GP cluster dashboard will be launched over the summer of 2018. If you want to find out more about the Wales work plan or a specific project, or are working in a related area and would like to share your insights, please contact:

Adele Oddy, Evidence Officer for Wales, Macmillan Cancer Support aoddy@macmillan.org.uk