



Macmillan-NCIN work plan Understanding the cancer population

Update of work plan
November 2014

Background

The development of robust data analysis is a crucial component of understanding the two million people currently living with cancer in the UK and to inform our understanding of the cancer survivorship population. People surviving cancer will have very different levels of need and these needs are likely to change over time and depend on the type of cancer and treatment they have had. To make personalised care a reality, we need to understand the needs of the two million, the health, social and economic impacts of cancer and the consequences of its treatment.

Macmillan Cancer Supports' ambition is to reach and improve the lives of everyone affected by cancer and inspire millions to do the same. We do that by providing medical, practical, emotional or financial support and pushing for better cancer care. Public Health England's National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working 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.

With the two million people in the UK living with cancer now predicted to increase to four million by 2030, these are very challenging ambitions. 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 achieve the best possible outcomes.

To help achieve this Macmillan and the NCIN are working in partnership and have developed a Macmillan-NCIN work plan. As part of the work plan, both parties are funding two data fellows over three years who will build a programme of work to develop and apply the analysis of large scale data sets to the survivorship intelligence agenda. The analysts are jointly badged Macmillan-NCIN Data Fellows.

The Macmillan-NCIN work plan

Vision

"Macmillan Cancer Support and the National Cancer Intelligence Network are working to:

- use data and information to push the boundaries of understanding of the whole cancer population, now and in the future, of the impact and costs of cancer and it's treatment on patients, the wider community and the NHS, and
- work to enable wider health and social care services to extend the usage of this information to improve the care, experience and outcomes for patients by designing, testing and implementing better models of delivery"

Why now?

We already know a lot about people living with cancer. In order to reach and improve the lives of everyone living with cancer now and in the future, commissioners, providers and decision makers need to fully understand in this challenging economic climate the current numbers, needs and experiences of people living with cancer. We need to increase the granularity of our understanding so that we have the best intelligence to most effectively target and ensure the best outcomes for people living with cancer.

Work streams

A number of work streams will be prioritised over the course of the partnership all underpinned by the desire to increase analysis and reporting for all four nations of the UK at a national (UK), nation and local level where possible.

- Segmenting the cancer population: Cancer Prevalence
- Routes from Diagnosis
- Developing routine survivorship stats
- Patient Outcomes and Experience
- Costing

- Social Care

Specific projects within the work streams will be prioritised over the course of the partnership.

Current priorities

Build a greater understanding of the cancer population across the UK

Initial analysis is using national cancer datasets to analyse the cancer population. The analysis explores the number of people 'living with cancer' and their characteristics. Where possible this includes analysis by cancer type, age, gender, locality, ethnicity, deprivation, stage, time since diagnosis, care pathways, hospital utilisation and comorbidity. The initial stage of the work plan also focuses on specific areas of analysis including NHS costings, hospital outpatient activity (follow-ups) and second cancers. The depth of our understanding, and the analysis that supports this, will be developed as knowledge expands and new datasets become available.

Current analytical projects

Cancer prevalence – There is little granular information on the cancer survivor population. Our work uses patient-level data to quantify a united picture of need across the cancer population for the whole of UK, which is essential to understand the full burden of disease. The first stage of this work looks at people diagnosed with cancer in the UK between 1991 and 2010 (1993 in N Ireland) using the National Cancer Data Repository (NCDR). We identify people alive with cancer at the end of this period (i.e. 20-year prevalence) and then explore the characteristics of this population such as cancer types, UK and UK nations, new NHS and PHE localities, sex, deprivations and age at diagnosis as well as the attained age. Work on all cancers has been published [here](#) and detailed 20-year prevalence by cancer type and sub-geographical areas will be published soon.

The third phase of this work will collate further data for the whole of the UK back to 1985 where available. It will model prior to 1985 (1993 in N Ireland) to enable new estimates of the total number of people living with cancer – total prevalence. We will also produce breakdowns of the data similar to those noted above.

Costing the patient pathway – Evidence on the economic burden of cancer is limited due to the lack of reliable data on cost of care. In partnership with Imperial College London a new dataset for England is being developed which links patients in the National Cancer Data Repository (NCDR) with data on hospital activity (Inpatient HES) and NHS costs (National Schedule of Reference Cost). This dataset will enable us to build a better understanding of the cost of patient pathways. Next steps include adding more hospital activity data (e.g Outpatient HES), quality assurance of the dataset and cost analysis. NCIN is support the Macmillan funded project led by Imperial College London.

Understanding progressive cancer – Historically there has been limited national information on progressive cancers (recurrence, second cancers and metastatic disease), as data on these have not been routinely collected. The study assesses the quality of routine national datasets for analysing progressive cancer, and determines how these data can be used to develop a methodology to identify cancer progression. There are a number of national datasets which, when linked, can inform our understanding of how cancers progress after the first diagnosis. Initial analysis includes second cancers, hospital activity and treatment analysis with a focus on specific cancers types.

Other ongoing projects

- Analysis across the UK nations
- Linking outcomes and experience
- Follow-ups

More information about these projects and new priorities will be provided in future updates of the work plan as it develops.

To find out more and key contacts

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