Macmillan-NCIN work plan
Understanding the cancer population
Summary of work plan
November 2012

The purpose of this document
To provide an overview of the Macmillan-NCIN work plan, including its overall aims and short term priorities.

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. The 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.

Objectives

- To provide high quality information on health and its determinants to decision makers who can make changes to improve the lives of the cancer population
- To describe quantitatively the disease burden of cancer across the whole of the cancer pathway and to develop a strategic approach that will pave the way for large scale analysis across cancer types.
- To identify key and develop new routine 'cancer population statistics'.
- To understand the needs of the cancer population, the health and social impacts of cancer (including cancer recurrence and metastatic disease) and the consequences of its treatment.
- To understand the 'cost of cancer'. Understanding the cost of providing pathways and model the cost of optimal pathways of care.
- To understand the linkages between clinical outcomes, patient experience and PROMs (patient reported outcome measures).
- To scope data requirements for social care and identify potential sources for the development of these datasets (including the extent of provision and cost of providing social care).
- To continue to develop relationships across UK nations and to access data and influence the range and depth of data collection and quality of recording, understanding what data is available and what the gaps are.

Priorities over the short term

Build a greater understanding of the cancer population across the UK

Initial analysis will use national cancer datasets to analyse the cancer population. The analysis will explore the number of people 'living with cancer' and their characteristics. Where possible this will include analysis by cancer type, age, gender, locality, ethnicity, deprivation, stage, time since diagnosis, care pathways, hospital utilisation and comorbidity This initial stage of the work plan is also likely to focus 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.

The Macmillan-NCIN work plan will also undertake work which will help inform the expansion of a pilot called 'Routes from Diagnosis' (RfD), as part of Macmillan's Routes from Diagnosis Programme. RfD is an approach which enables us to map the cancer journey, at a population level, from diagnosis through to death or survivorship describing the 'routes' or survivorship outcome pathways that patients experience i.e. survival times as well as the incidence and prevalence of cancer and non-related cancer morbidities. The approach also provides visibility of the burden of disease on the health care system e.g. the length of time patients spend in a health care setting, when the interaction with health care services is taking place and how much this costs. The RfD programme will also apply the analysis at a local level enabling local service development teams to understand their local population and redesign the cancer pathway appropriately. It will also provide high quality information that will inform decision makers, so that they can improve the lives of the cancer population. See here to find out more about the RfD programme.

Scoping of future projects

The work plan involves "cutting edge" analysis and use of new datasets. Some of the aspirations and projects are not currently routinely produced or feasible, therefore these will either initially need to be scoped or put "on hold" until datasets become available. It will be important for the work plan to be flexible to be able to review, reprioritise and identify new projects on a regular basis in response to the changing environment.

In order to improve our understanding of the cancer population; we need to build our knowledge. This will involve scoping data and analyses in the following areas:

- Routine statistics – including the need for prevalence and median survival analysis
- Recurrence
- Consequences of treatment
- Patient experience and Patient Reported Outcome Measures
- UK nations analyses – identify opportunities for new analyses and compare data
- Cost of patient pathway
- Social care

For each this will involve:

- Building an understand what is currently known
- Identifying other survivorship work being done nationally and locally, and working with partners where relevant
- Identifying what datasets can be used and are needed
- Identifying what analysis could be done
- Identify opportunities
- Identify the barriers/gaps

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

To find out more and key contacts
If you have an interest in finding out more about the work plan or a specific project, or are working in a related area and would like to share you insights, please do get in touch.

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