

# BUILDING A SURVIVORSHIP DATASET IN MANCHESTER

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## Building a pseudonymised, linked, cross-setting dataset covering the Breast and Lung Cancer pathways in Manchester

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### Background

In 2009 Macmillan Cancer Support worked with Monitor Group and a number of City of Manchester partners to develop an understanding of the current baseline of service use across the secondary care cancer pathway, specifically in relation to breast and lung cancers. The evidence provided by this work provided a catalyst for Macmillan-sponsored service re-design and also identified a need to better understand the needs of people living with and beyond cancer. This programme of work became known as 'Routes from Diagnosis'.<sup>1</sup>

Routes from Diagnosis (RfD) links and analyses routinely collected cancer registry and HES data to map the cancer journey for whole cohorts of patients over up to 7 years

after diagnosis. This approach brings together information on survival, morbidities and demographics, painting a detailed picture of survivorship.

The Routes from Diagnosis methodology has already been used by the North Trent Cancer Network in the redesign of colorectal cancer treatment pathways. In 2014, the RfD methodology was replicated and extended in the City of Manchester to provide evidence at a population level describing breast and lung cancer survivorship in the City of Manchester. Findings from this work can inform service re-design programmes, such as the Macmillan Cancer Improvement Partnership.

There are eight key data flows in the data extraction process with no personal confidential information leaving NHS computer systems



### Applying Routes from Diagnosis to the City of Manchester

#### Overview

This project has brought together a cross-sector team of over 60 individuals across Macmillan, local NHS and third-sector healthcare providers, commissioners, Public Health England and the private sector in order to create a pseudonymised, cross-setting of care, patient-level database by linking local providers' routinely collected data.

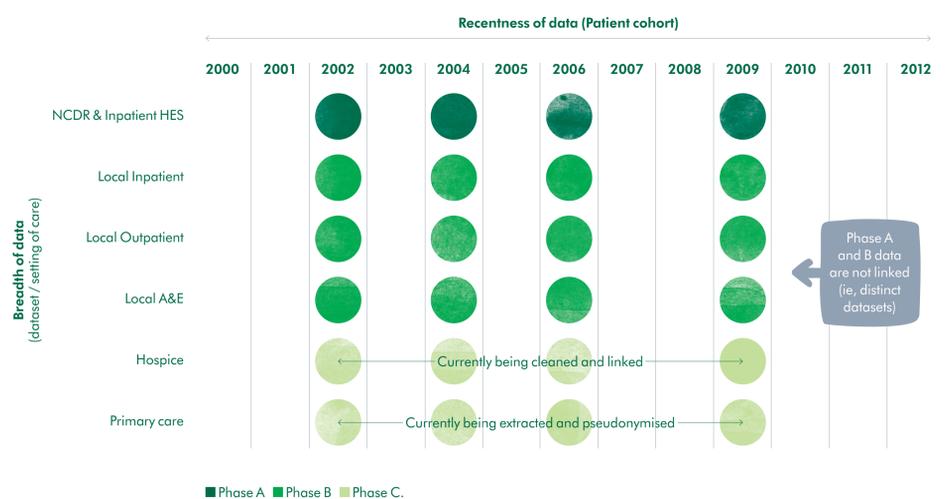
The dataset covers all breast and lung cancer patients diagnosed in cohort years 2002, 2004, 2006 and 2009 (lung only), who were resident in the City of Manchester (North, Central and South Manchester NHS Clinical Commissioning Groups) at diagnosis. Currently it captures pre- and post-diagnosis interactions in accident & emergency, outpatient and inpatient care providers in the City. Palliative care activity is currently being linked to the dataset and primary care data extraction is ongoing. Data providers include University Hospital of South Manchester NHS Foundation Trust, The Christie NHS Foundation Trust, Central Manchester NHS Foundation Trust, Pennine Acute Hospitals NHS Trust, St. Ann's Hospice and consenting GP practices within the City of Manchester.

#### Learnings and Impact

Our experience on this programme of work has highlighted several of the ongoing challenges faced by researchers in this field; these have been documented previously elsewhere.<sup>2</sup> However, this project has demonstrated that even in what have been very challenging times for the healthcare community, it is possible for local stakeholders to partner to share and analyse data to improve patient outcomes.

Outputs from the analysis have identified areas for service redesign interventions to improve the outcomes and delivery of cancer care services in the City of Manchester, supplementing

**Figure B: Recentness and breadth of data**



the other work-streams that Macmillan is pursuing in the area. This information has the potential to also help the Macmillan Cancer Improvement Partnership to understand their local population as part of the pathway and service redesign process, providing insight as to what is happening to cancer patients, and highlighting where changes can be made to ensure the most effective and cost-efficient care pathways are developed and co-created between the acute and non-acute sector.

#### References:

- <sup>1</sup> Routes from Diagnosis, Macmillan Cancer Support, 2014
- <sup>2</sup> Mapping cancer patients' routes from diagnosis in Manchester, Macmillan Cancer Support & Greater Manchester Academic Health Science Network, blog posted 29 January 2015. Available at: <https://aforce4change.wordpress.com/>

