

UK-WIDE ANALYTICAL PARTNERSHIPS

WE ARE
MACMILLAN.
CANCER SUPPORT

Developing the cancer survivorship evidence base through UK-wide analytical partnerships

Authors: K Shiell-Davis¹, V Cairnduff², D Huws³, D Brewster⁴, L Hounsoms², J Charnock¹, C Burns¹, J Evans¹, J Flynn¹, H McCannell¹

1. Macmillan Cancer Support; 2. Northern Ireland Cancer Registry, Queen's University Belfast; 3. Welsh Cancer Intelligence and Surveillance Unit (WCISU), Health Intelligence Division, Public Health Wales; 4. Scottish Cancer Registry, Information Services Division (ISD) in the Public Health & Intelligence Unit of NHS National Services Scotland; 5. National Cancer Registration and Analysis Service (NCRAS), Public Health England.

Background

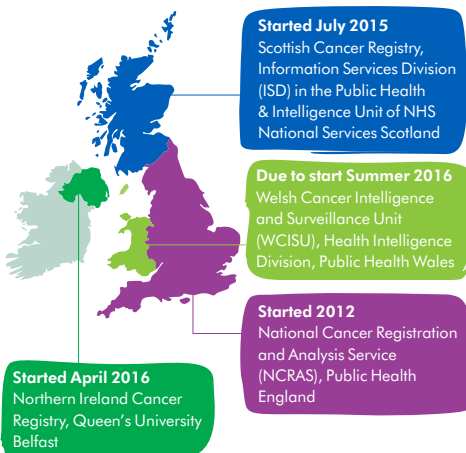
The number of people living with cancer in the UK has risen dramatically and is predicted to rise further. In this context, and with budgets tightening, we need an improved understanding of post-diagnosis pathways for cancer patients to better plan support and services.

Despite devolved health and social care functions across the UK there is also demand from devolved nations, the UK and international organisations for UK-wide and nation comparative data. Through analytical partnerships across the UK we aim to increase the focus on the post-diagnosis phases of the Cancer Pathway.

Methods

Building on previous investment, Macmillan Cancer Support is now working to develop the survivorship evidence base in partnership with cancer intelligence functions across the UK.

Figure 1: Macmillan analytical partnerships across the UK



We are working with partners who, with the correct safeguards and permissions in place, are increasingly able to derive impactful insight through an expanding array of cancer datasets. These datasets can be linked to other health, social care, socioeconomic and environmental data within and between UK nations to paint a picture of the whole cancer pathway.

Results

Macmillan focuses on UK-wide analysis, where possible, and nation-specific analysis to utilise unique datasets, answer nation-specific questions, maximise advocacy, and test innovative analysis.

We aim to identify opportunities to deliver world class cancer data collection and analysis with a particular focus on post-diagnosis. This increased understanding will then support improved design, effective commissioning, testing and implementation of better models of care across the cancer pathway, to ultimately improve outcomes for people living with cancer.

We have agreed a set of broad objectives for our nation-specific work programme to facilitate alignment across the UK. Key common objectives include:

- To identify and access new data sources and improve the use of existing datasets relevant to cancer patients in each nation.
- To identify gaps in availability of cancer-specific and cancer-relevant data in each nation, particularly in other UK nations.
- To understand the potential to link and analyse data on clinical outcomes and patient experience across primary, secondary, community, and social care.
- To understand the needs and outcomes of the cancer population in each nation, the health and social impacts of cancer (including cancer recurrence and metastatic disease), and the consequences of treatment across the cancer journey.
- To assess the feasibility of adapting Macmillan's Routes from Diagnosis¹ approach in each nation, or developing a similar but tailored set of analysis to map the patient pathway.
- To align with Macmillan's regional and UK strategies, and with the National Strategies or Cancer Plans outlined by the devolved health functions in each nation.

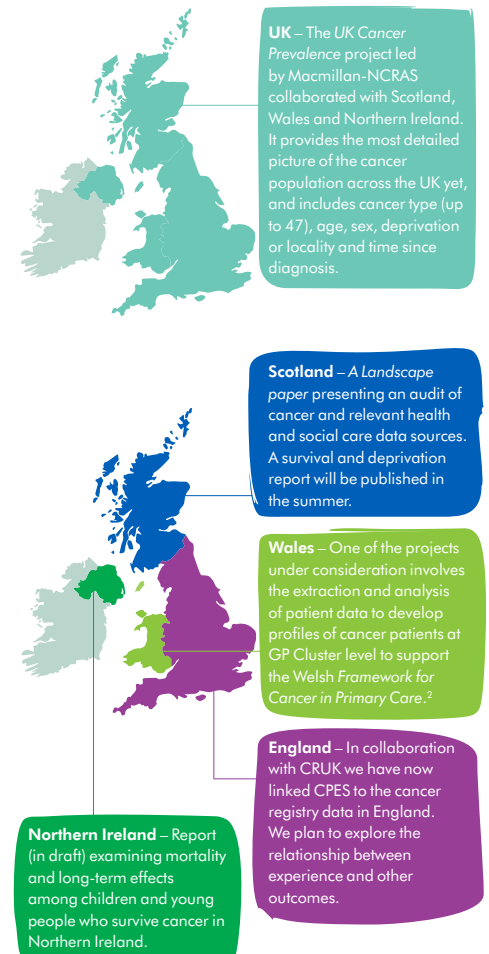
There are a number of datasets that we aim to explore or test for their feasibility of use to inform the survivorship evidence base as outlined in Table 1. All datasets would only be available within the secure environments of the cancer registries with the correct safeguards and permissions in place.

Table 1: Example datasets for exploration within analytical partnerships*

| England | Scotland |
|---|---|
| <p>Current:</p> <ul style="list-style-type: none"> Radiotherapy and Systematic Anti-Cancer Therapy dataset (SACT) Cancer Patient Experience Survey (CPES) <p>Forthcoming examples:</p> <ul style="list-style-type: none"> Digital imaging GP Prescribing dataset | <p>Current:</p> <ul style="list-style-type: none"> Outpatients (Appointments & Attendances) (SMR00) Costs Book/PLICs (Patient Level Information Costs) <p>Forthcoming:</p> <ul style="list-style-type: none"> Scottish Primary Care Information Resource (SPIRE) Health and Social Care Data Integration and Intelligence Project (HSCDIIP) |
| Wales | Northern Ireland |
| <p>Current:</p> <ul style="list-style-type: none"> Patient Episode Database for Wales (PEDW = hospital activity data) Primary Care GP dataset (SAIL) <p>Forthcoming:</p> <ul style="list-style-type: none"> Cancer Patient Experience Surveys (CPES) Radiotherapy and Systematic Anti-Cancer Therapy dataset (SACT) | <p>Current:</p> <ul style="list-style-type: none"> Transforming Cancer Follow Up Programme dataset (Breast cancer patients initially) Primary Care Federation Cancer Profiles <p>Forthcoming:</p> <ul style="list-style-type: none"> Identification of Breast cancer recurrences and metastases using existing audit datasets, and hospital discharge data |

* The table includes examples of current data current available, accessible and linked to cancer registry data as well as examples of potential forthcoming datasets in development or quality assurance phases, or which we aim to explore and assess feasibility of use in building the survivorship evidence base. Data is only available within secure environments of cancer registries using pseudonymised datasets.

Figure 2: Example outputs to date within analytical partnerships



Some examples of initial outputs are given in Figure 2. Macmillan's analytical partnerships will also work across nations, facilitating working groups and UK-wide forums to foster collaboration, comparative data (where possible) and learning, as well as promoting intellectual rigour.

Conclusion

By working collaboratively across the UK we hope to learn from each other, reduce duplication of effort and improve our understanding of the quality of life and also the functional, survival and experiential outcomes of people living after a cancer diagnosis. Thanks to Macmillan's investment, opportunities for innovative analysis to explore the needs of people living with cancer are numerous.



For more information please contact Kelly Shiell-Davis, at kdsdavis@macmillan.org.uk or evidence@macmillan.org.uk
Digital version of this poster available from macmillan.org.uk/analyticalpartnerships

Working together



References

- Macmillan Cancer Support. 2014. Routes from diagnosis: The most detailed map of cancer survivorship yet.
- Macmillan-sponsored Framework for Cancer in Primary Care is an ambitious five-year programme which aims to support GPs to diagnose cancer early and better integrate cancer care between primary, community and secondary care to support patients living with and beyond cancer.

June 2016