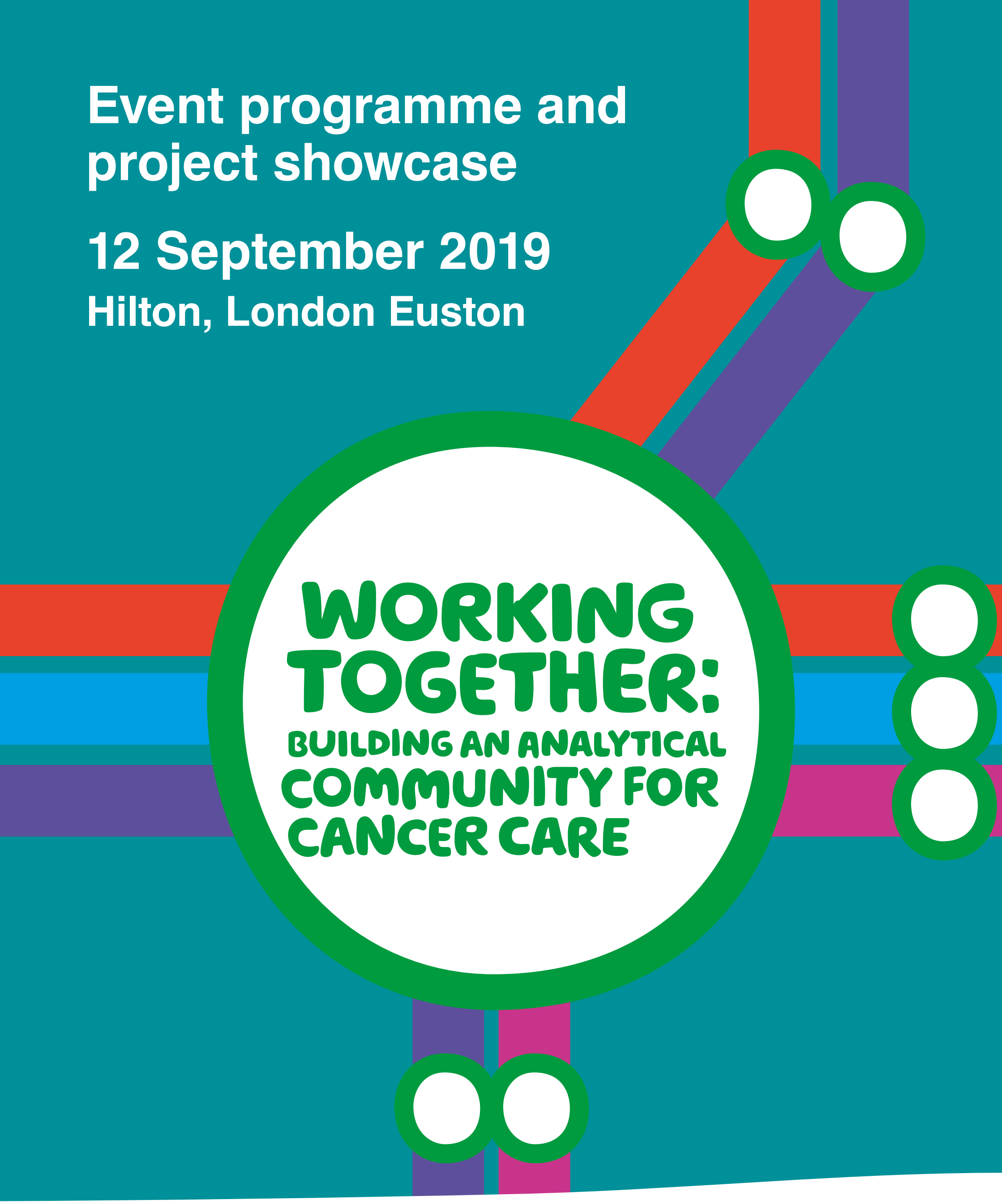
Event programme and project showcase

12 September 2019
Hilton, London Euston



WORKING TOGETHER: BUILDING AN ANALYTICAL COMMUNITY FOR CANCER CARE

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

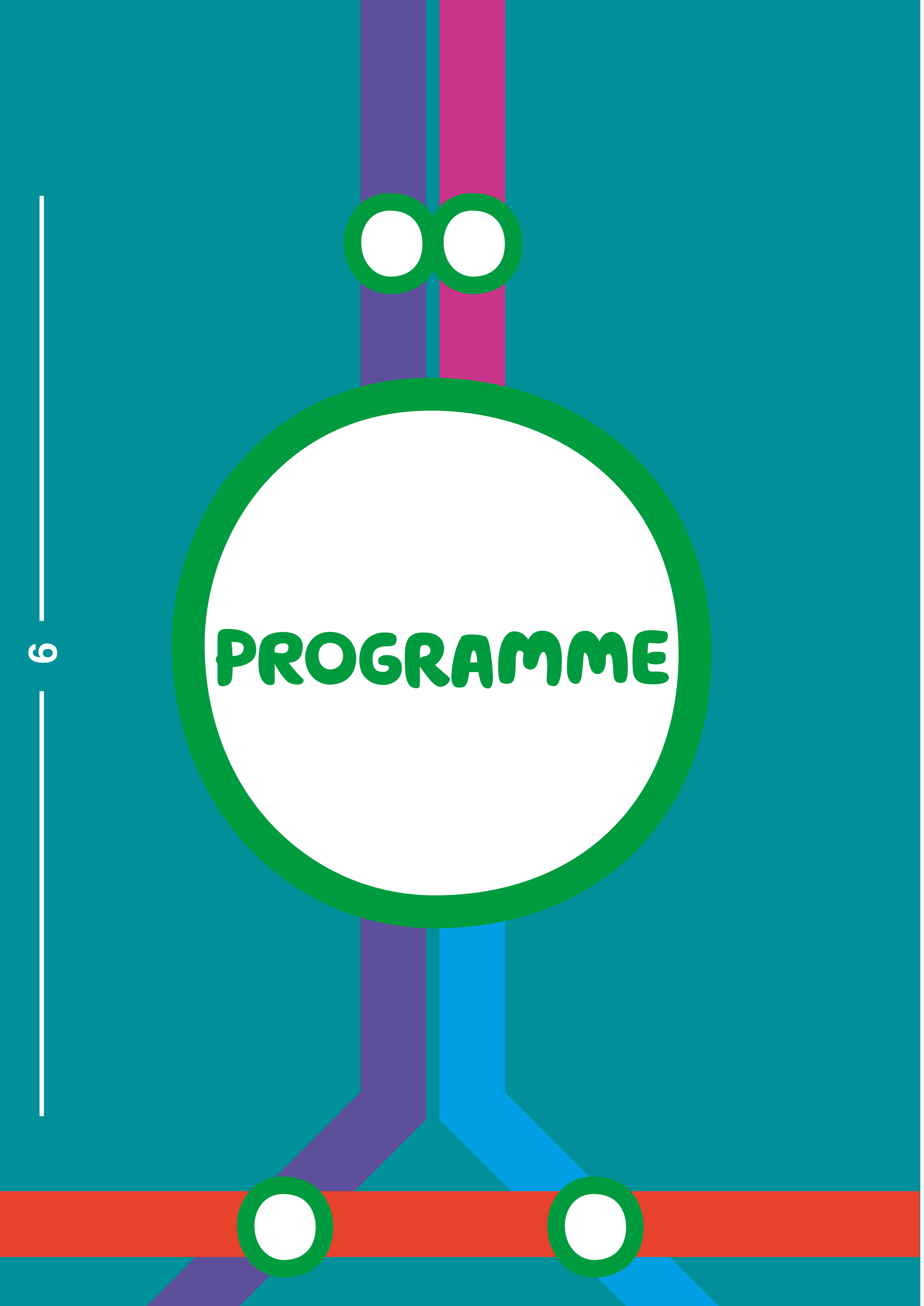
If you have any questions about the event, please contact
Becky Gorringe rgorringe@macmillan.org.uk or 020 7840 7897.

Event objectives

- Build a shared sense of the cancer analytical community in the public and third sector.
- Identify approaches to working through barriers, building and sharing knowledge, skills and expertise.
- Showcase innovative analysis being undertaken within organisations and partnerships.

Contents

*these projects demonstrate an innovative methodology and will be presented in the 'rapid fire' presentation session at the event.



PROGRAMME

10.00 – 10.10

Open of event, welcome and aims of the day

Julie Flynn, Senior Evidence Manager – Data and Influencing, Macmillan Cancer Support

10.10 – 10.30

Building an analytical community (part 1)

Start to meet delegates from across the community and gather insight on expectations for the day, experience and key areas of interest.

10.30 – 11.30

The bigger picture (part 1)

Macmillan Cancer Support, Cancer Research UK, the Cancer Alliance Data, Evidence and Analysis Service (CADEAS) and the Cancer Registries in England, Scotland, Northern Ireland and Wales will present about their strategy, partnership working and influence in wider improvements to cancer care. This session will include a Q&A and table discussion around the benefits of organisations working together across the cancer data community, how this currently impacts the way you work and could impact the way you work in the future.

Presentations will be given by the following:

- Julie Flynn,
  Senior Evidence Manager – Data and Influencing, Macmillan Cancer Support
- Rebecca Crallan,
  Head of Cancer Intelligence, Cancer Research UK
- Gabrielle Emanuel,
  Cancer Information Analyst, National Cancer Registration and Analysis Service (NCRAS)
- Amy McKeon,
  Principal Information Analyst, NHS National Services Scotland's Information Services Division (ISD)
- Victoria Cairnduff,
  Post-doctoral Researcher, Northern Ireland Cancer Registry (NICR) at Queen's University Belfast
- Lucy Young,
  Senior Analyst, Cancer Alliance, Data, Evidence and Analysis Service (CADEAS), NHS England/Public Health England

11.30 – 11.40

Break

11.40 – 11.55

Building an analytical community (part 2)

Consider initial thoughts on some of the barriers to working effectively in cancer data analysis, as identified by the community. An opportunity to fully explore the issues, current ways of working and ideas for how to respond in the future will be explored in the next session.

11.55 – 13.00

Overcoming barriers

Following on from the previous session, there will be an opportunity to continue to discuss these barriers in more detail. Full questions will be provided on the day. Topics include: sharing of skills, knowledge and expertise, ways of working between organisations, maintaining consistent and positive clinical engagement, setting achievable and well-defined objectives and creating a sustainable framework for long-term projects. This session will include an opportunity to synthesise and share learning.

13.00 – 13.40

Lunch

13.40 – 13.45

Welcome back!

13.45 – 14.15

The bigger picture (part 2) Health Foundation and Association of Professional Health Analysts (AphA): Investing in Analytics & Analysts

Ellen Coughlan, Programme Manager in Analytical Capability from The Health Foundation and Paul Stroner, Co-founder and CEO from the Association of Professional Health Analysts (AphA). Ellen will focus on the Health Foundation's work in improving analytical capability within the system. Paul will speak on behalf of the AphA, who work in partnership with The Health Foundation, describing the work they do to support analysts.

14.15 – 14.50

Innovative methodologies

3-minute 'rapid fire' presentations on projects that have displayed an innovative methodology, followed by discussion around applying learning and a vote!

The following presentations will be given:

1 *What explains patients feeling supported emotionally and psychologically during their cancer treatment? Analysis of data from the Scotland Cancer Patient Experience Survey 2017-2018*. Sonja Kummer, Senior Strategic Data Analyst, Macmillan Cancer Support.

2 *Geographical variation in ovarian cancer treatment in England*. Hira Naveed, Data & Research Analyst, Cancer Research UK.

3 *Get Data Out*. Charlotte Eversfield, Cancer Data Analyst, National Cancer Registration and Analysis Service (NCRAS).

4 *Scottish Routes from Diagnosis (SRfD)*. Claire LeBlanc on behalf of Macmillan Cancer Support and NHS National Services Scotland's Information Services Division (ISD)

5 *Investigating characteristics of women with Breast Cancer Recurrence in NI*. Victoria Cairnduff, Post-doctoral Researcher, Northern Ireland Cancer Registry (NICR) at Queen's University Belfast.

6 *Analysis of median pathway length by patient demographics, cancer stage and route to diagnosis for colorectal, lung and prostate cancers (2013-2017)*. Fazaan Dasu, Analyst, Cancer Alliance Data, Evidence and Analysis Service (CADEAS), NHS England/Public Health England.

7 *Exploring variation in early diagnosis and treatment using Cancer Stats 2*. Steve Scott, Head of Informatics, RM Partners West London Cancer Alliance.

14.50 – 15.00

Break

15.00 – 15.30

Using data to identify and reduce variation –Breast One Stop Clinics in South East London

Graham Roberts, Head of Informatics, and Justine States, Cancer Improvement Manager, South East London Accountable Cancer Network at Guy’s and St Thomas’ NHS Foundation Trust London.

Graham and Justine will present an example where cancer data analysis has been used to influence practice, behaviour and an ongoing work programme. This session will include a Q&A and table discussion.

15.30 – 15.50

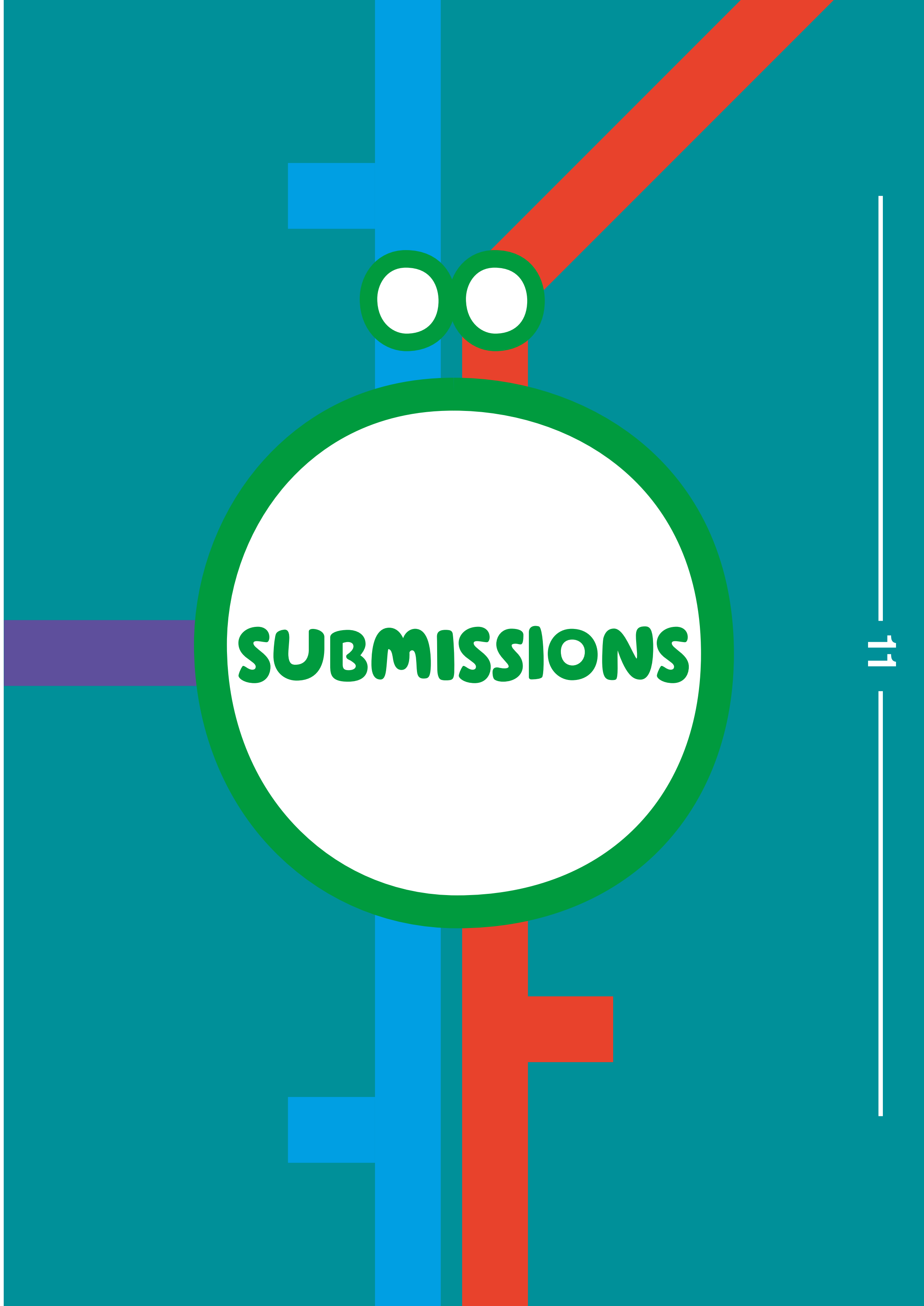
Maintaining momentum: generating and prioritising ideas

Opportunity to share feedback and ideas for staying connected with the community.

15.50 – 16.00

Event roundup

Julie Flynn, Senior Evidence Manager – Data and Influencing, Macmillan Cancer Support



SUBMISSIONS

Project theme Cancer population

R scripts to streamline and enhance work

Project background

Cancer data in the population is created twice each year to communicate cancer burden to health professionals and the public. ~140 graphs of four different types are created.

The new method produces rapid robust outputs. Firstly a standard set of graphs is output, secondly the input is flexible enough to produce adhoc reports, ready for external publication.

Who has worked on the project?

CRUK: Christine Delon, Katie Connor, (Lydia Maher, Roisin Connon, Emily Maxwell)

What did the project involve?

Creating R scripts.

What are the results?

- Fast, robust, flexible graphs to communicate, cancer burden.
- Less time spent working on graphs freeing up more time for other analyses.

How are the findings being implemented?

Streamlining publication process so UK data can be published within 6 months of receiving raw data.

Submitted by

Cancer Research UK

Project theme Diagnosis/ Cancer population

Secondary Care Diagnostic Interval

Project background

For the majority of cancer patients, the length of the diagnostic pathway is unknown. Only those on a specific pathway (TWW) are monitored and for this group of patients. Operational standards have not been met since 2014 (CWT 62-day target). Quantifying pathway length is important for all cancer patients to understand variation, investigate which factors lead to longer pathways and is the first step in identifying which patients may benefit most from an expedited pathway.

Who has worked on the project?

Clare Pearson & Jess Fraser, CRUK-PHE partnership.

What did the project involve?

Innovative linking of routine health datasets to cancer registrations (diagnosed in 2014-2015).

We calculated the Secondary Care Diagnostic Interval (SCDI) by identifying first relevant interaction in secondary care in the 6 months before diagnosis and calculating time to diagnosis.

Variation of the SCDI by various socio-demographic and disease factors was explored using descriptive analysis and regression (for lung and colorectal) which investigated associations with longer SCDIs.

What are the results?

SCDIs were calculated for over 95% of all patients in 25 sites. The median SCDI (days) was shortest for acute lymphoblastic leukaemia (ALL) (2) and longest for kidney (45). Patients diagnosed via routine GP referrals and outpatient routes had the longest SCDIs, as did those with high comorbidity scores. Early stage patients had longer SCDIs than later stage disease. There were differing patterns by site by age, sex and ethnicity and no variation by deprivation.

We also demonstrated variation by cancer alliance.

How are the findings being implemented?

An online tool is available to view/ download data, **http://www.ncin.org.uk/about_ncin/scdi**, along with lists of diagnostic codes used to identify relevant diagnostic procedures in Hospital Episode Statistics (HES) and Diagnostic Imaging Datasets (DID).

This project has provided evidence to support policy drives of CRUK – a recent CRUK blog highlighted the work and urged the NHS to commit to change.

https://scienceblog.cancerresearchuk.org/2019/06/30/the-first-complete-picture-of-how-long-it-takes-to-diagnose-cancer-in-england/

We hope that this project enables further work investigating diagnostic pathways.

Submitted by

Cancer Research UK

East of England Cancer Alliance Quarterly Sustainability and Transformation Partnerships (STPs) Intelligence Data Packs

Project background

The newly formed Informatics Team at the East of England Cancer Alliance received many requests for data and information from their stakeholders, many of which were similar. It was felt that a Data Pack covering the key Cancer standards as well as population health data would be well received and address common queries. A comprehensive pack of validated data was compiled that contains signposts to data links sources.

Who has worked on the project?

Macmillan Senior Programme Manager and Information Manager with input from STP Programme Managers.

What did the project involve? Exploring validated cancer datasets, identifying data that supports the delivery and evaluation of the transformation projects that STP stakeholders are delivering. The first report was produced for quarter one 2019, using the latest available data.

What are the results?

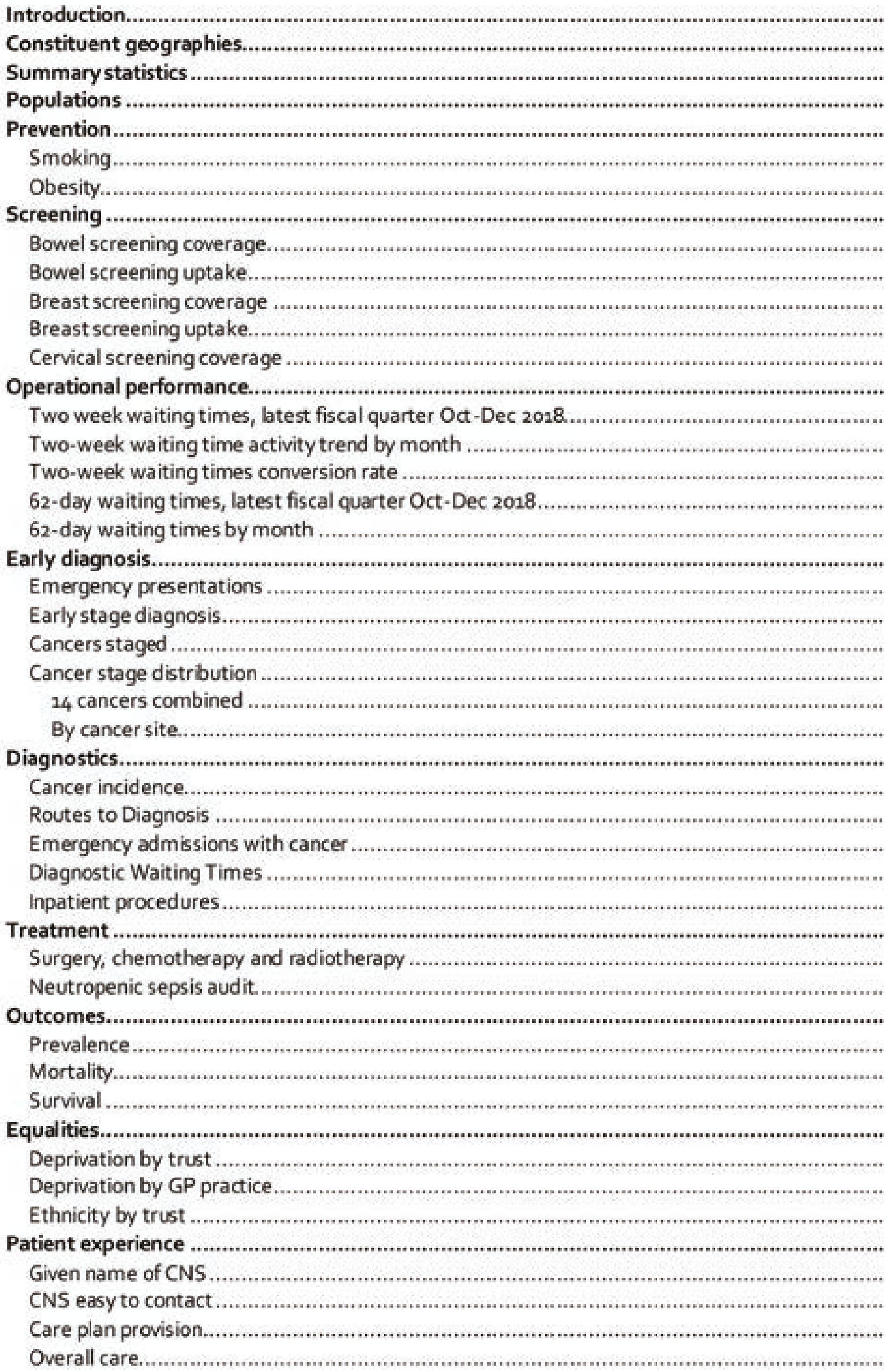
Six seperate data packs, one for each STP, so that local variation can be identified across the cancer pathway-from prevention through to outcomes and living with and beyond cancer. The pack contains a range of visualisations and data tables, as well as intelligence highlighting key messages from the data. A copy of the contents page is provided on the next page:

How are the findings being implemented?

The data packs have been distributed STP stakeholders to use in their systems. Feedback and suggestions for the next version have been collated and discussed.

Submitted by

East of England Cancer Alliance



- **Introduction**
- **Constituent geographies**
- **Summary statistics**
- **Populations**
- **Prevention**
  - Smoking
  - Obesity
- **Screening**
  - Bowel screening coverage
  - Bowel screening uptake
  - Breast screening coverage
  - Breast screening uptake
  - Cervical screening coverage
- **Operational performance**
  - Two week waiting times, latest fiscal quarter Oct-Dec 2018
  - Two-week waiting time activity trend by month
  - Two-week waiting times conversion rate
  - 62-day waiting times, latest fiscal quarter Oct-Dec 2018
  - 62-day waiting times by month
- **Early diagnosis**
  - Emergency presentations
  - Early stage diagnosis
  - Cancers staged
  - Cancer stage distribution
    - 14 cancers combined
    - By cancer site
- **Diagnostics**
  - Cancer incidence
  - Routes to Diagnosis
  - Emergency admissions with cancer
  - Diagnostic Waiting Times
  - Inpatient procedures
- **Treatment**
  - Surgery, chemotherapy and radiotherapy
  - Neutropenic sepsis audit
- **Outcomes**
  - Prevalence
  - Mortality
  - Survival
- **Equalities**
  - Deprivation by trust
  - Deprivation by GP practice
  - Ethnicity by trust
- **Patient experience**
  - Given name of CNS
  - CNS easy to contact
  - Care plan provision
  - Overall care

Project theme Cancer population

Estimating the number of people living with treatable but not curable cancer in England using the cancer registry*

Project background

We hypothesised that there is an important group within the cancer population who have cancer that is very unlikely to be eradicated completely but can be treated to slow the progression of the cancer, prolong life and control symptoms. They could be described as living with treatable but not curable (TbNC) cancer. This population are increasingly critical as more treatments are developed that gradually prolong survival but that are not able to completely eradicate the disease. Understanding the size of this population will be essential for influencing decision makers and service designers to recognise the group and provide services for them.

Who has worked on the project?

The project team has included Rachel White at Macmillan and Macmillan-NCRAS analysts Fintan Stanley, Jennifer Than and Jo Pethick. Others from Macmillan (e.g. Gregory Fallica and Professor Jane Maher) and NCRAS (e.g. Luke Hounsome and James Charnock) were also involved. In addition, over 20 oncologists, haematologists and specialist nurses providing a clinical perspective. Further support come from others across Macmillan including the media, specialist advisory, strategy and policy teams.

What did the project involve?

A set of search criteria to identify TbNC in the cancer registry and linked data sets in England were developed through repeated iterations of analysis and clinical feedback.

What are the results?

These rules first identified the population in the cancer registry who have specific cancer types and stages at diagnosis that we have categorised as TbNC from the point of diagnosis. Additional people who have TbNC cancer at diagnosis or who develop it post-diagnosis were identified. This was based on showing signs of metastatic disease or disease modifying or palliative treatment. These were searched for in the chemotherapy, radiotherapy, hospital episodes and cancer waiting times data sets.

How are the findings being implemented?

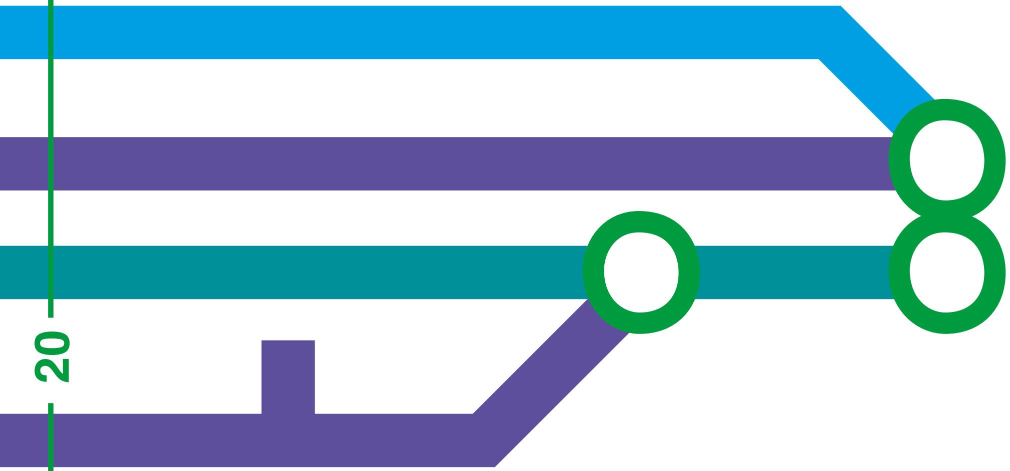
The search criteria are being applied to the registry data to create estimates of the size of the TbNC group. Macmillan and NCRAS aim to use the findings to help transform perceptions of cancer and influence the health and social care system so that people with TbNC cancer are better recognised and supported. The findings will also help inform the development of Macmillan's services and interventions that provide support for this group.

Submitted by

Macmillan Cancer Support

Project theme Cancer population

What explains patients feeling supported emotionally and psychologically during their cancer treatment? Analysis of data from the Scotland Cancer Patient Experience Survey 2017-2018



Project background

Guidelines recommend that basic psychological support should be offered by all health and social care professionals responsible for patient care. We examined which patient-perceived cancer care experiences may contribute to individuals feeling supported emotionally and psychologically by HCPs during their cancer treatment.

Who has worked on the project?

Dr Sonja Kummer
(Macmillan Cancer Support)
Dr Taha Itani
(Macmillan Cancer Support)

What did the project involve?

Secondary data analysis from the 2018 Scotland Cancer Patient Experience Survey using cross-sectional data from N=5,001 individuals with cancer.

What are the results?

Findings showed that only 55% felt that they had been supported emotionally and psychologically by healthcare professionals (HCPs) during their cancer treatment. Preliminary results, using chi-square testing, indicate that certain patient-perceived cancer care experiences, such as the ‘GP did everything they could to support you while you were having treatment’ [X^2(1, N=4546)=643.51, p=<0.0001], having been ‘given a care plan’ [X^2(1, N=4365)=521.63, p=<0.0001] or having ‘been given enough care and support from health and social services’ [X^2(1, N=3415)=878.09, p=<0.0001] significantly contribute to individuals feeling supported emotionally and psychologically during their cancer treatment.

How are the findings being implemented?

These preliminary findings highlight the importance of making patients feel adequately supported emotionally and psychologically during their cancer treatment. Nevertheless, further analyses, using regression models, will need to be conducted to determine which patient-perceived cancer care experiences contribute most to individuals feeling supported emotionally and psychologically by HCPs during their cancer treatment and account for variation by socio-demographic and clinical characteristics prior to informing any service development.

Submitted by

Macmillan Cancer Support

Project theme Cancer population

Scottish Cancer Registry and Intelligence Service (SCRIS)

Project background

Following a review of the existing Scottish Cancer Registry (SCR), NHS National Services Scotland and the Innovative Healthcare Delivery Programme (IHDP) are collaborating to modernise the SCR and create the Scottish Cancer Registry and Intelligence Service (SCRIS), which will help move us along the path to establishing the wider Scottish Cancer Intelligence Framework.

Who has worked on the project?

Led by NHS National Services Scotland in collaboration with IHDP.

What did the project involve?

Four main aims:

1. Providing easier access to timely, linked national cancer data for clinicians and other NHS staff (e.g. service planners and analysts) through a secure cancer 'dashboard'
2. Incorporate data not currently available nationally (including chemotherapy and radiotherapy)
3. Enhance the existing SCR by increasing efficiency, data sources and completeness
4. Introduce a wraparound analytical service to Boards and Networks to help make better use of these data supporting service planning and improvement.

What are the results?

1. Dashboard has been developed and available to all NHS staff in Scotland since May 2019.
2. NSS has connected to local chemotherapy data by data virtualisation technology. NSS are working with local chemotherapy data experts to reconcile differences in local coding for a 'national' view of the data. Due to the complexity of this, reconciliation is being done incrementally by each tumour group in turn.
3. NSS have agreed with Public Health England the supply of standardised Scottish radiotherapy data for inclusion in the SCR and for secondary analysis. Data systems are currently being built.
4. Additional routine data feeds (cancer waiting times, outpatients and prescribing) to assist with the cancer registration process have been established. Inclusion of cancer waiting times data in particular has improved SCR efficiency by providing earlier notification of some registrations.

How are the findings being implemented?

- Dashboard in active use and supported by analytical service.
- Enhanced SCR is now BAU.
- SACT reconciliation forming basis of national clinical reference group for standardising classification of new chemotherapy treatment.

Submitted by

NHS National Services Scotland's Information Services Division (ISD)

Project theme Cancer population

Cancer Survival Official Statistics: Cancer survival by stage

Project background

The stage at which cancer is diagnosed can inform the treatment choices for patients. However, high-quality staging data was not consistently recorded across England before 2012 diagnoses, preventing the production of reliable estimates of survival by stage.

Following a report from the Public Accounts Committee in the House of Commons (**https://publications.parliament.uk/pa/cm201011/cmselect/cmpubacc/667/66702.htm**), a 70% target for stage completeness was set for 2012 diagnoses onwards. The collection and recording of staging data across England has increased to over 85% for 2017 diagnoses.

An Office for National Statistics (ONS) consultation in 2012 (**https://webarchive.nationalarchives.gov.uk/20160108013314/**, **http:/www.ons.gov.uk/ons/about-ons/get-involved/consultations-and-user-surveys/consultations/cancer-statistics-consultation/index.html**) also found increasing interest in understanding cancer survival by stage of disease at diagnosis to help quantify patient outcomes by stage that can be compared to other jurisdictions.

Who has worked on the project?

PHE: John Broggio, Kwok Wong, Carolynn Gildea, Marta Emmett, Sophie Finnigan
ONS: Sarah Caul, Sophie John, Lorna Ushaw

What did the project involve?

This work resulted from the collaboration between Public Health England (PHE) and ONS, which started in June 2016 and is ongoing in the production of all cancer survival Official Statistics.

What are the results?

Results will be presented on 1.3m tumours to illustrate the range and pattern of survival by stage according to tumour grouping, sex and survival time. These analyses are reported as official statistics, due to be published in Summer 2019; results cannot be provided ahead of publication. A previous version is published at **https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/ nationalestimatesforpatientsfollowedupto2017.**

How are the findings being implemented?

We are now able to present robust 1- and 5-year age-standardised net survival by stage of disease for common cancer groupings based on diagnoses from all of England, which helps explain how outcomes vary by stage at diagnosis and cancer site for cancer patients. These survival estimates can help inform the planning of preventative, diagnostic and therapeutic services to improve patient outcomes.

Submitted by

National Cancer Registration and Analysis Service (NCRAS)

Project theme Cancer population

Get Data Out*

Project background

The Get Data Out programme within the National Cancer Registration and Analysis Service (NCRAS) publishes in-depth, open data for small groups of cancer patients in such a way that ensures patient anonymity is maintained.

Who has worked on the project?

NCRAS analysts Sally Vernon, Charlie Turner and Charlotte Eversfield, and project manager Sophie Morris.

What did the project involve?

Get Data Out routinely publishes key statistics about small groups of cancer patients. The grouping process can be imagined as a branching tree where patients with a particular cancer type are partitioned by meaningful characteristics, such as year of diagnosis, age or stage. These characteristics are seen to be meaningful as patients in different groups will generally experience different patient pathways and outcomes. If at any point a group contains fewer than 100 patients, it will not be divided any further. Statistics are calculated for the groups of patients rather than for individuals, so even if the statistic is small, re-identification of an individual will not be possible as they will be in a group of around 100 other patients with the same characteristics. Because patients have been grouped together in this way, the anonymisation standard has been ‘designed in’, and the data can be released openly and safely without risks to patient confidentiality.

What are the results?

As at August 2019, statistics for incidence, routes to diagnosis, treatment and survival have been published for five cancer sites: brain, ovary, pancreas, prostate and testis. Get Data Out aims to publish routine statistics for all cancer sites.

How are the findings being implemented?

All Get Data Out data releases are available on the CancerData website. Charities including Target Ovarian Cancer, Brainstrust and Pancreatic Cancer UK have used the data in reports and interactive tools. We hope that by releasing detailed data like this we can help researchers, the public and patients discover more about cancer.

Submitted by

National Cancer Registration and Analysis Service (NCRAS)

Use of a Cancer Dashboard to inform and drive cancer improvements

Project background

RM Partners has a well-established informatics service and has continued to develop and iterate its approach to ensure Cancer Informatics is used as a driver to inform priorities in improving outcomes and experience of cancer patients.

A key driver of this has been the development of a Cancer Dashboard covering the West London population which is used to draw out key metrics. This is then used as the headline tool to inform discussions throughout the Cancer Alliance governance structure including discussions around areas of priority.

Who has worked on the project?

RM Partners informatics team with input from governance structure within Cancer Alliance.

What did the project involve?

The key to this approach has been developing a cancer informatics resource over a number of years with expertise in the source of cancer data and producing comparable metrics.

In additional the dashboard has been developed in conjunction through the RMP governance structure meaning that it has evolved based on clinical, operational and patient input.

What are the results?

RM Partners West London Cancer Alliance utilises dashboard and other informatics outputs to inform it's priorities to improve cancer services across its population.

This has a been a key factor in the success of the Alliances, including being the only Alliance nationally to meet the 62 day standard in 2018/19 and continuing to show improvement in the proportion of patients diagnosed at early stage.

A screenshot of the latest front page of the dashboard is included overleaf.

How are the findings being implemented?

Continual development of headline Cancer Dashboard as well as development of tumour specific dashboards. The approach has also been widely shared with other Cancer Alliances and CADEAS.

Submitted by

RM Partners West London Cancer Alliance

Cancer Scorecard – May 2019

Domain	Measure	Benchmark	Period	North West London STP	South West London STP	**RM Partners overall**	Change since last period	Providers/ sites meeting standard	CCGs meeting standard	England average	Ranking against other Alliances
Best Practice Care	1. 2 week wait: Urgent suspected cancer GP referral to 1st seen (Population)	93%	Q4 2018/19	93.4%	96.8%	**94.7%**	-0.1%	8/10	10/14		
	2. 2 week wait Breast symptomatic referral to 1st seen (Population)	93%	Q4 2018/19	92.9%	96.8%	**94.8%**	+1.0%	8/8	9/14		
	3. 62 day: Urgent suspected cancer GP referral to 1st treatment (Population)	85%	Q4 2018/19	84.5%	85.6%	**85.0%**	-2.2%	5/10	6/14		1/19
	4. 62 day: Screening referral to 1st treatment (Population)	90%	Q4 2018/19	78.8%	80.0%	**79.5%**	-7.5%	2/8	2/14		
	5. Bowel screening coverage (60-74 year olds)	60%	June 2018	47.7%	54.4%	**50.5%**	+0.3%		0/14	59.8%	18/19
	6. Breast screening coverage (50-70 year olds)	70%	June 2018	64.8%	69.0%	**66.6%**	+1.4%		5/14	71.9%	18/19
	7. Cervical screening coverage (25-64 year olds)	80%	June 2018	60.8%	68.5%	**64.0%**	-0.5%		0/14	71.5%	19/19
Positive experience	8. NCPES - Q2 – How do you feel about the time you had to wait for your 1st appointment?	England average	NCPES 2017 - Admissions Q1 2017/18	80.1%	82.0%	**81.4%**	+1.8%	4/10		84.2%	
	9. NCPES – Q9 – How do you feel about the way you were told you had cancer.			82.8%	82.7%	**82.7%**	+0.6%	6/10		84.7%	
	10. NCPES – Q59 – Overall, how would you rate your care?			8.54	8.81	**8.73**	+0.07	2/10		8.80	
Best Clinical Outcomes	11. Proportion of cancers stage 1 or 2 (Taskforce definition)	England average	2017	54.5%	57.1%	**55.7%**	+1.9%		12/14	53.6%	
	12. Proportion of cancers stage 1 or 2 (CCG IAF definition)	England average	2017	51.6%	54.8%	**53.1%**	+2.4%		10/14	52.2%	2/19
	13. Proportion of patients diagnosed via an emergency (population based)	England average	July 2017 to June 2018	19.5%	15.5%	**17.7%**	-1.8%		8/14	18.8%	2/19
	14. 1 year cancer survival index	England average (95% CI)	2016	74.9%	75.2%	**75.0%**	+-0.7%		11/14	72.8%	1/19
Quality of life	15. Proportion of patients receiving a Holistic Needs Assessment around diagnosis	70%	Q3 2018/19	65.2%	63.2%	**64.1%**	+1.4%	4/10			
	16. Proportion of patients receiving an End of Treatment Summary at end of treatment	70%	Q3 2018/19	17.1%	25.5%	**21.7%**	+2.1%	0/10			
Data quality	17. % completeness of stage at diagnosis – COSD level 2	70%	2017	54.7%	66.3%	**60.1%**	-1.1%	3/10		57.4%	
	17. % completeness of performance status – COSD level 2	70%	2017	48.7%	58.4%	**53.1%**	-12.6%	4/10		48.3%	

Project theme Cancer Population / Living with and Beyond Cancer

23-Year Cancer Prevalence Dashboard for London

Project background

People living with cancer have 60% more A&E attendances, 97% more emergency admissions and 50% more contact with their GPs 15 months after diagnosis than a population of similar age, sex and locality; 70% have another long-term condition. There is increasing need for health systems to respond to rising cancer incidence and improving cancer survival and plan services accordingly.

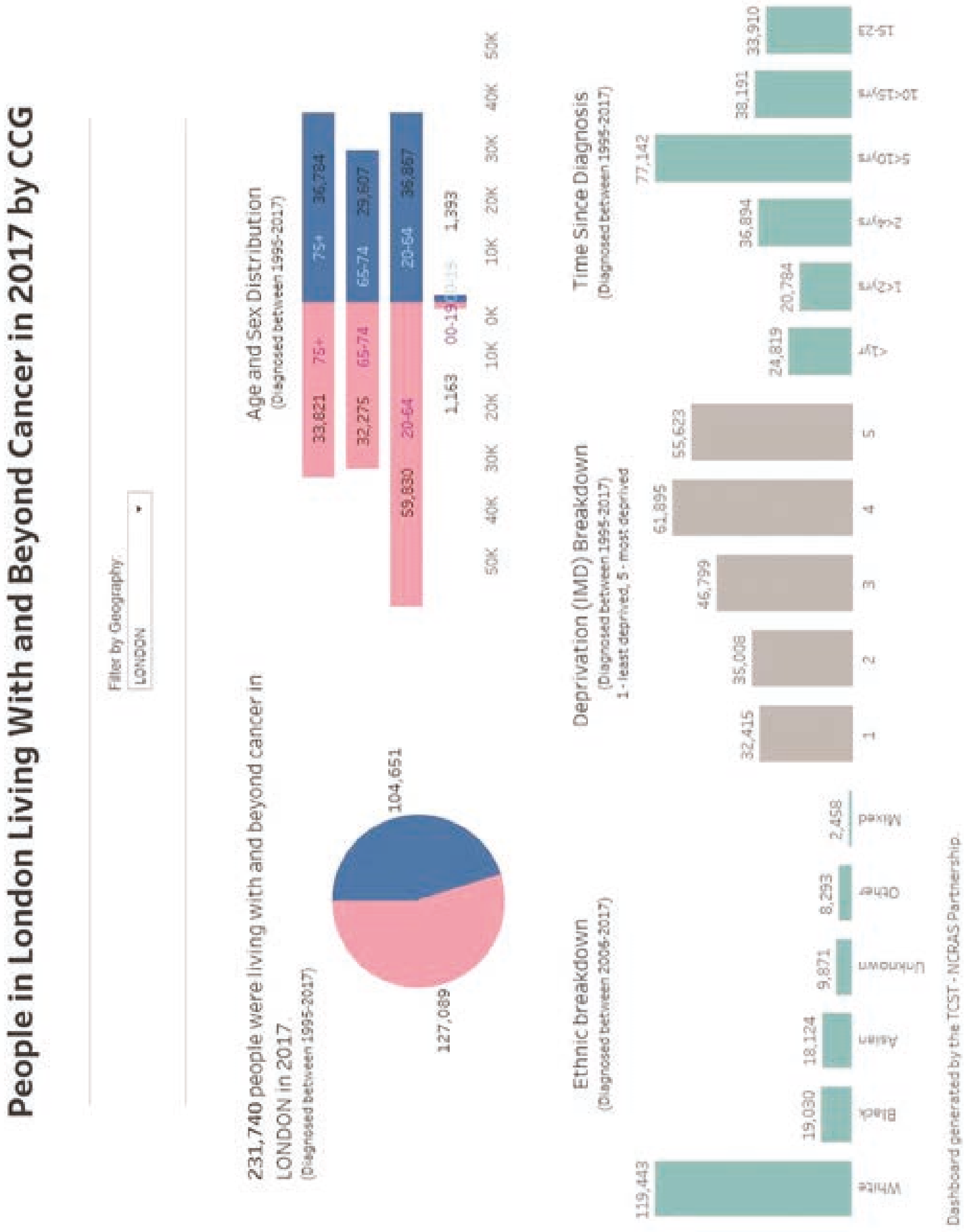
Understanding the prevalent cancer population is a crucial first-step toward this. The TCST-NCRAS Partnership previously published extended prevalence measures including prevalence of subsequent primary cancers and comparisons of GP cancer registers to the national cancer registry. For the first time, we have combined these measures in an interactive dashboard.

Who has worked on the project?

Lead: Amy Zalin (TCST-NCRAS Partnership)
Advisors: Sophie Jose (TCST-NCRAS), Liz Price & Jason Petit (TCST)
QA: Catherine Welham & Paul Clarke (NCRAS)

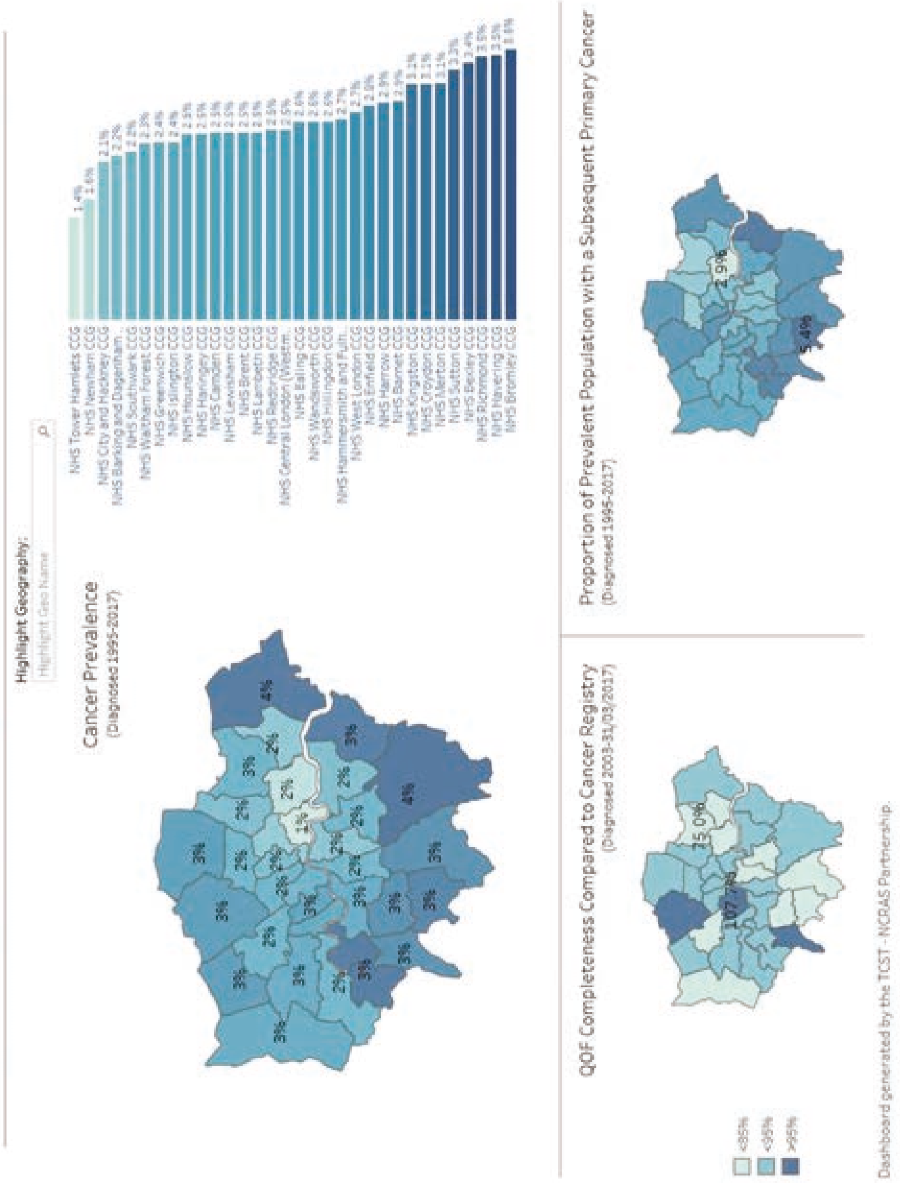
What did the project involve?

Using NCRAS data, cancer prevalence rates and counts were updated for London. Those diagnosed between 1995-2017 and alive on 31 December 2017 were included. The proportion of patients with subsequent primary cancers was calculated. Cancer prevalence counts were compared to the number of patients on GP-maintained cancer registration lists. This information has been presented through an interactive dashboard.



Dashboard generated by the TCST - NCRAS Partnership.

People in London Living With and Beyond Cancer in 2017 by CCG



Dashboard generated by the TCST - NCRAS Partnership.

What are the results?

There were 231,740 people living with a cancer diagnosis in London in 2017. Cancer prevalence varied across CCGs, from 3.6% in Bromley to 1.4% in Tower Hamlets. Prevalence is higher in women across all London geographies, and dramatically increases with age; prevalence in patients >75yrs was above 12% in all geographies. Approximately 4% of people living with cancer had more than one cancer diagnosis. Completeness of GP-held cancer registers ranged from 75%-108% across CCGs.

How are the findings being implemented?

STPs and CCGs are using the dashboard to understand the demographics of their local population living with cancer to inform service planning. For example, South East London STP have identified and are investigating demographic differences in their population who have gynaecological cancers.

Submitted by

Transforming Cancer Services Team Partnership, National Cancer Registration and Analysis Service (NCRAS)

Project theme Cancer Population

Cancer Registry enhancing datasets for primary care

Project background

The Northern Ireland Cancer Registry (NICR) has on three previous occasions provided feedback to primary care on cancer patients registered for each Practice. This enabled GPs to easily establish their cancer chronic disease registers as part of the 2004 contract. It also enabled the NICR to check data quality. In Northern Ireland the 350 General Practices have come together to form 17 Primary Care Federations (PCF). PCFs are not-for-profit healthcare provider organisations, with approximately 20 General Practices and 100,000 patients per Federation.

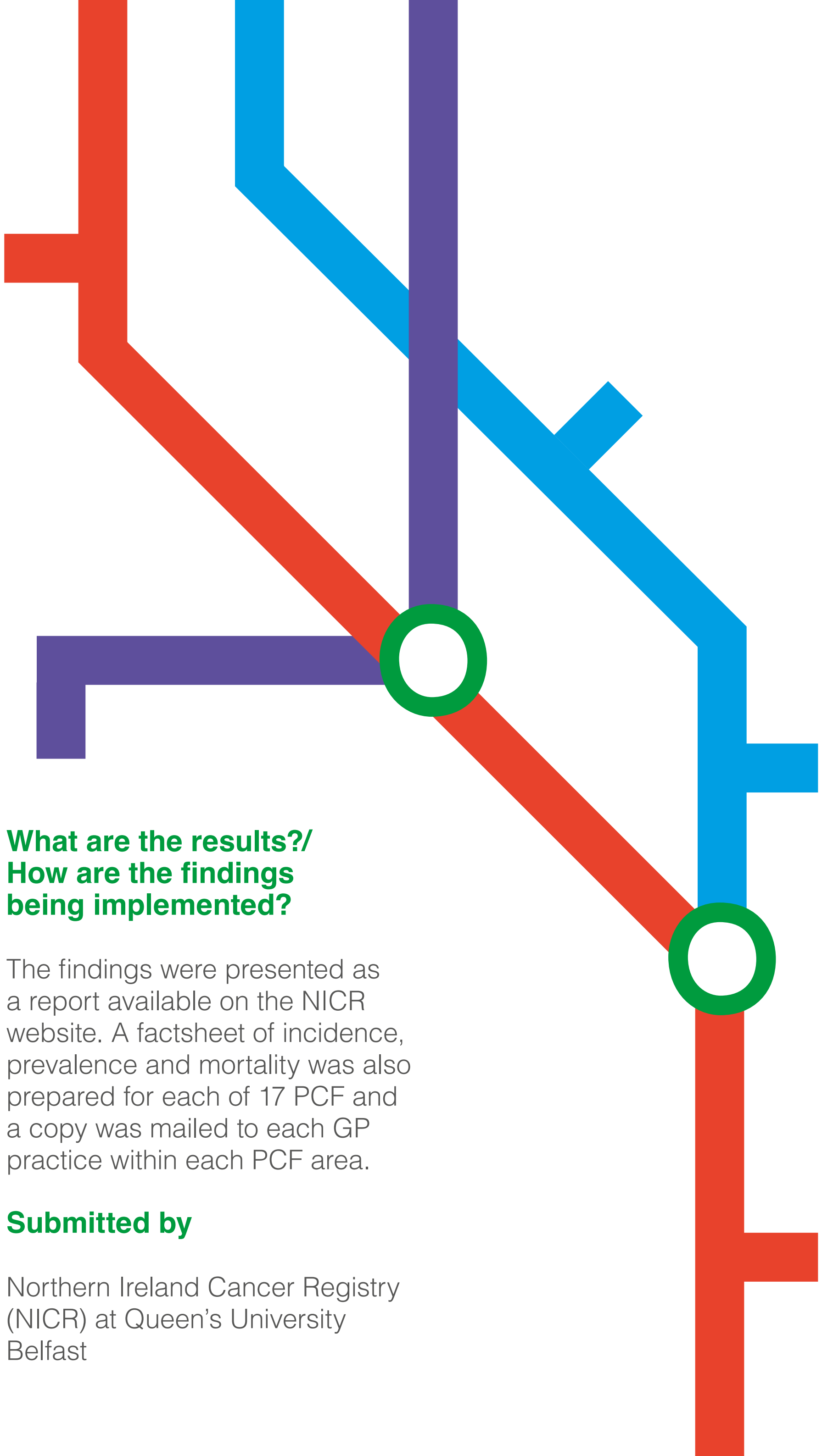
Part of the role of the newly formed PCFs will be an increased focus on caring for patients with chronic conditions (including cancer) within the primary care setting with, for example, the introduction of PCF based pharmacists and physiotherapists. This increased focus on chronic conditions together with increasing cancer incidence and survivorship will place increasing pressure on Primary care in Northern Ireland. The aim of this project was to report the incidence, prevalence and mortality of all cancers and of the main cancer sites for each PCF to support future service planning.

Who has worked on the project?

The Macmillan partnership funded researcher worked on this project with support from NICR IT staff.

What did the project involve?

Cancer profiles (incidence prevalence and mortality) were calculated by PCF as place of care with patients assigned to PCFs using GP code at time of diagnosis and follow-up (31st December 2015).



What are the results?/ How are the findings being implemented?

The findings were presented as a report available on the NICR website. A factsheet of incidence, prevalence and mortality was also prepared for each of 17 PCF and a copy was mailed to each GP practice within each PCF area.

Submitted by

Northern Ireland Cancer Registry (NICR) at Queen's University Belfast

Project theme Cancer Population

Investigating characteristics of women with Breast Cancer recurrence in NI*

Project background

Knowledge about cancer recurrence at population level is important for service providers, patients, researchers and clinicians aiming to increase survival and provide best treatments for the population. However, little is currently known about the proportion and characteristics of women who go on to develop a recurrence following a diagnosis of invasive breast cancer. This project aims to report the proportion of women developing a breast cancer recurrence as well as providing information of women developing a recurrence compared with those who did not.

Who has worked on the project?

Both the Macmillan partnership funded officer and tumour verification officer have worked on this project with support from NICR IT staff.

What did the project involve?

The disease and socio-demographic characteristics of women (n=1,109) diagnosed with Invasive Breast Cancer (ICD10 C50; excluding stage IV) in 2009 were extracted from the NICR database. Electronic healthcare databases were used to follow up for disease recurrence to 2017 to collect additional information on hormone receptor status, sentinel node biopsy and axillary node clearance and treatment that are not routinely collected during the cancer registration process.

What are the results?

145 (13%) women diagnosed with Invasive Breast Cancer had a recurrence with a mean time to recurrence of 3.4 years (95% CI: 3.1-3.7 years).17% of recurrences were local/regional recurrence, 64% distant site(s) and 19% both local/regional and distant recurrence. A lower proportion of screening age women (50-70 years; 9.7%) and those over 80 years (10.4%) at diagnosis had a recurrence recorded when compared with other age groups (20-49 years; 20.2% and 70-79 years; 16.4%). A higher proportion of women (34.0%n=53) initially diagnosed with Stage III disease had a recurrence (Stage I; 6.0%, Stage II; 16.0% and Unknown Stage; 2.4%). In terms of hormone receptor status, 10.1% were triple negative and no differences were observed between those women who developed a recurrence and those who did not (12.5% vs 9.7%; $p=0.454$).

How are the findings being implemented?

The preliminary findings of this work have been presented to Clinicians through the Northern Ireland Cancer Network (NICan). It is hoped that this work will help inform the development of methodology to record recurrence using routine data collected for cancer registration and to identify women at higher risk of a recurrence of breast cancer in the future.

Submitted by

Northern Ireland Cancer Registry (NICR) at Queen's University Belfast

Supporting local health service decision-making in Wales with profiles of cancer incidence and prevalence at primary care cluster network level

Project background

In Wales, 60 Cluster Networks of GP practices and partner organisations support local health needs assessments to improve local primary care and other services. For the first time, we linked and analysed cancer registry and other data to profile the incidence and prevalence at Cluster Network level. This will support their health service planning, and to better understand the cancer burden across Wales.

This project was part of a partnership between Macmillan Cancer Support and the Welsh Cancer Intelligence and Surveillance Unit (WICISU), Public Health Wales. Funding was provided by Macmillan Cancer Support.

Who has worked on the project?

Welsh Cancer Intelligence & Surveillance Unit: Tamsin Long, Claire Wright, Dyfed Wyn Huws, Ceri White and Rebecca Thomas Macmillan Cancer Support: Kelly Shiell-Davis, Adele Oddy and David Egan.

What did the project involve?

We extracted Welsh Cancer Intelligence and Surveillance Unit cancer registry data from 2011 – 2015 for incidence, 1995 – 2015 for prevalence. We linked cases to Cluster Networks. Patients were assigned to area deprivation quintile (Welsh Index of Multiple Deprivation 2014) and a 2011 Rural Urban Classification category. We calculated Cluster Network incidence and proportion in each category by cancer type, sex, age band, area deprivation, rurality and stage at diagnosis. We calculated percentage prevalence for cases alive on 31 December 2015, with a diagnosis up to 21 years previously for Cluster Networks by cancer type, sex, age band, area deprivation and rurality.

What are the results?

The results of this analysis were presented in an interactive online dashboard.

There was wide variation in incidence and prevalence between Cluster Networks when considering sex, rurality, deprivation and stage at diagnosis. Cancer diagnosis were most common in the 75+ age group, with proportions ranging from 29% to 43%. However, two Cluster Networks in Cardiff were found to have high proportions of diagnoses in the youngest age group (0 – 49 years) at 15% and 17%.

Overall, more than a third of new cancer patients live in rural areas in Wales. Large variation in rurality between the Clusters highlights the challenge faced in planning cancer care and provision of services in rural areas.

One year prevalence ranged from 9% to 18% for men and 7% to 15% for women. However, 21 year percentage prevalence in women (23 to 36%) was higher than in men (18 to 31%).

How are the findings being implemented?

This work will prove useful for Cluster Networks to understand the overall burden of cancer and potential services needed by cancer patients in Wales. The interactive dashboard and key-messages were directly disseminated to the steering group and stake holders; published to the WCISU website to be accessed freely by the public; and promoted through traditional and social media.

Submitted by

Public Health Wales, Welsh Cancer and Intelligence Surveillance Unit (WICISU)

Project theme Cancer Population / Living with and Beyond Cancer

People with cancer living in deprived areas of Wales are more likely to have another serious condition at diagnosis than those in the least deprived areas

Project background

People diagnosed with cancer are living longer and whilst cancer survival is improving for many cancers, there is not the same parity for all social groups - older people and people living in more deprived areas often have more chronic health conditions. We examined the association between those other health conditions and cancer incidence, prevalence and survival for all Welsh patients, for the four most common cancers and all malignant cancer cases (excluding non-melanoma skin cancer).

Who has worked on the project?

Welsh Cancer Intelligence & Surveillance Unit (WICISU): Tamsin Long, Dyfed Wyn Huws, Julie Howe, Tomos Smith and Rebecca Thomas.

Macmillan Cancer Support: Kelly Shiell-Davis, Adele Oddy and David Egan.

What did the project involve?

We extracted data on all malignant cancer cases from the WCISU's population-based cancer registry for diagnosis periods 1995-2015. Cases were linked to a Cluster Network and to Patient Episode Database for Wales hospital data for the preceding year to establish pre-existing health conditions. From this, a Charlson score was calculated for each case - this is a validated score to predict risk of death and disease burden.

For incidence and prevalence, we calculated the proportion of patients with Charlson score 0, 1 and 2+, and proportions with each health condition examined. We calculated one-year net survival by Charlson score or condition. Where possible, analysis was by cancer type, age-band, area deprivation, rurality, sex and stage at diagnosis.

What are the results?

One in four people were already living with another serious condition. Patients diagnosed in more deprived areas of Wales were more likely to have an existing condition at diagnosis. Survival worsened as the severity or number of existing conditions increased.

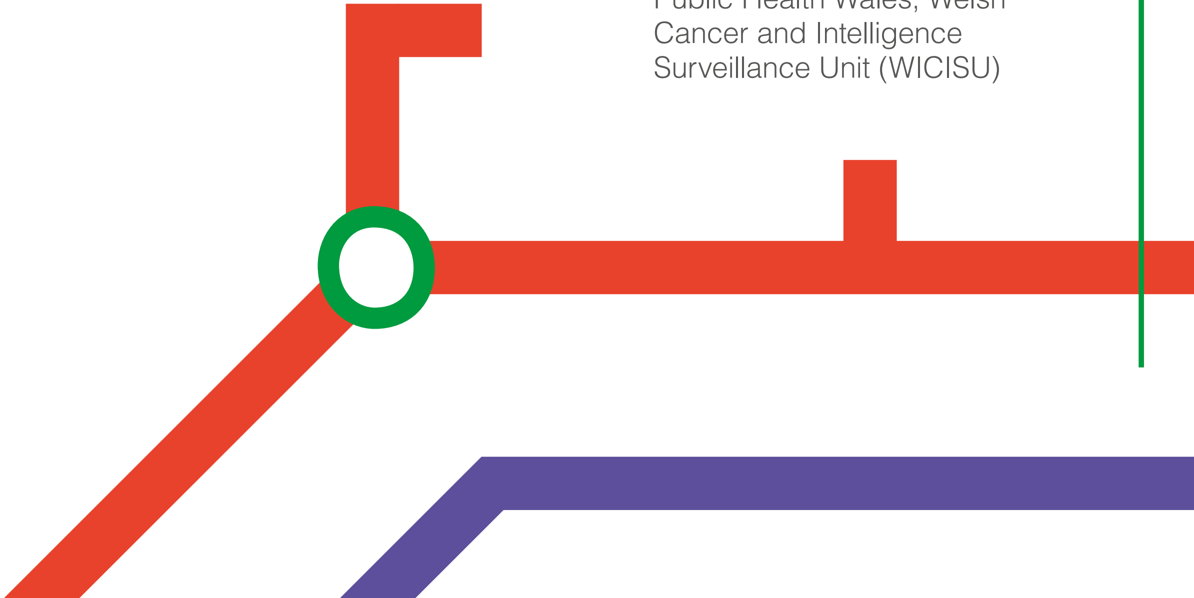
How are the findings being implemented?

This work will enable acute, primary and community care, and other organisations to understand the overall burden of ill health in the cancer population in Wales.

The interactive dashboard and key-messages were directly disseminated to the steering group and stake holders; published to the WCISU website to be accessed freely by the public; and promoted through traditional and social media.

Submitted by

Public Health Wales, Welsh Cancer and Intelligence Surveillance Unit (WICISU)



Project theme Prevention/Diagnosis

Cancer Awareness Measure Plus 2019

Project background

The Cancer Research UK Cancer Awareness Measure (CAM) has historically monitored public awareness of potential risk factors, possible signs and symptoms of cancer, cancer screening programmes, and attitudes towards seeing a doctor with a potential symptom in Great Britain (GB) since 2008. New for 2019, a range of additional measures and data collection has moved online enabling more frequent monitoring of changes over time.

Who has worked on the project?

The Health Evaluation and Research team in Cancer Intelligence at CRUK developed and adapted the CAM Plus. New items have been added to the survey, in consultation with academic experts and patients, that provide additional insight into the awareness, attitudes and behaviours of the GB population.

What did the project involve?

New questions were developed for the survey regarding cancer risk factors, screening (bowel and cervical), information seeking, and seeking medical attention. This process involved key stakeholders rating each item on importance for inclusion in the questionnaire and cognitive testing with members of the public.

What are the results?

The results will be analysed to explore differences by region in GB, groups of the population, and associations between knowledge, beliefs, and behaviours. The latest results will be available in autumn 2019 (contact **CAM@cancer.org.uk** for more information).

How are the findings being implemented?

CAM Plus allows CRUK to monitor and track trends in public awareness, attitudes and behaviour over time and crucially, explore socio-demographic differences within a GB representative sample. These findings enable CRUK to assess the short and long-term impact of national campaigns and identify priority areas.

Submitted by

Cancer Research UK

Project theme Diagnosis

Early Diagnosis Data Hub

Project background

Data relating to the early diagnosis of cancer is published by various organisations across the UK nations. We're using an R Shiny app to bring together and display in one place the latest data and trends relating to early diagnosis across the UK. It's provisionally for internal use, with a longer-term aim to make it externally available. Overall, it's to support the monitoring and understanding of the state of progress (or lack of) towards improving the early diagnosis of cancer (and ultimately our ambition that 3 in 4 people will survive their cancer for at least 10 years by 2034), and for helping respond to internal queries asking for the latest data or trends for use in our materials.

Who has worked on the project?

Taylor Sanders, Data and Research Analyst, Cancer Research UK.

What did the project involve?

The Early Diagnosis Data Hub was created using a package from R called Shiny and additional HTML and CSS. It pulls and presents data from a SQL Server database, Alteryx, the Fingertips API, and other Excel files. It includes data from England and other devolved nations (where available).

What are the results?

The Data Hub is an interactive web application that acts as a central hub for a number of datasets relating to Early Diagnosis, including incidence by stage, screening, and routes to diagnosis. The charts on the Data Hub allows users to see visually what is happening in the area of early diagnosis, which can be downloaded for use in presentations. The Data Hub is also used to answer common enquiries, including press enquiries, and requests for data.

Submitted by

Cancer Research UK

Analysis of median pathway length by patient demographics, cancer stage and route to diagnosis for colorectal, lung and prostate cancers (2013-2017)*

Project background

The Cancer Alliance Data Evidence and Analysis Service (CADEAS) has conducted analysis of the median pathway length for patients diagnosed with colorectal, lung and prostate cancers. The aim is to further Cancer Alliances' understanding of variation in median days for intervals of the patient pathway from referral to first treatment.

Who has worked on the project?

Lucy Young – Project Manager
Fazaan Dasu – Analytical Lead
CADEAS/NCRAS Analysts – Quality Assurance.

What did the project involve?

Using linked Cancer Registration, Cancer Care Plan and Cancer Waiting Times datasets, this analysis investigates the patient pathway and stratifies into four intervals; referral to first seen in secondary care, first seen in secondary care to cancer diagnosis, cancer diagnosis to first multi-disciplinary team (MDT) meeting, and first MDT meeting to treatment start.

The median time taken in the pathway has then been calculated and segmented by the following factors: year of diagnosis, sex, age at diagnosis, stage at diagnosis, ethnicity, income domain quintile and route to diagnosis.

What are the results?

The national reports highlight several key findings with variation displayed for most factors considered:

- Patients diagnosed with colorectal cancer have the longest median pathway and patients diagnosed with lung cancer have the shortest.
- Patients with stage 1 colorectal and lung cancers have longer median pathways than all other stages and patients diagnosed with stage 4 cancer have the shortest. The same pattern was not observed for prostate cancer.
- For each cancer type, there is statistically significant variation with at least one interval of the pathway being longer for patients of Black ethnicity compared with patients of White ethnicity, in 2017.

How are the findings being implemented?

CADEAS has published reports enabling Cancer Alliances to identify variation in pathway lengths by patient demographics, CCG, and diagnosis trust. Cancer Alliances can investigate whether the variations are justified, facilitate discussion to implement local strategies to reduce variation and address health inequalities, and to identify and share best practice for faster diagnosis and improving patient experience.

Submitted by

The Cancer Alliance Data, Evidence and Analysis Service, NHS England/Public Health England

Exploring variation in early diagnosis and treatment using Cancer Stats 2*

Project background

A key ambition for England and individual Cancer Alliances is to diagnosis 75% of cancer patients at stage 1 or 2 by 2028. Within West London the baseline position was 55% for patient diagnosed in 2017. Additionally there is a national ambition that 55,000 more cancer patients will survive more than 5 years for which it is important to make improvements in both early diagnosis and treatment of cancer.

In order to plan initiatives to work towards it is essential to have a clear tumour baseline position and also to understand the variation within our Cancer Alliance.

Who has worked on the project?

RM Partners informatics team with input from governance structure within Cancer Alliance as well as tumour specific pathway groups.

What did the project involve?

The RM Partners informatics team has started to utilise Cancer Stats 2 to access data relating to patients diagnosed between January 2013 and March 2018 (6.25 years).

In particular the team has looked at the proportion of patients diagnosed at stage 1 or 2 by CCG within West London, and compared these to the England rates against a range of demographics including:- age-band, ethnicity, deprivation quintile and gender.

Additionally treatments rates are being were reviewed by stage and demographic to understand variation in treatments.

What are the results?

The outputs of this work are driving and informing initiatives within the Cancer Alliances including location of pilots to achieve maximum impact. Examples include location of one of our low-dose CT pilots in the area with the latest stage lung cancer patients, and our symptomatic FIT pilot being trialled in the CCG in West London with the latest stage colorectal cancer patients.

In additional treatment variation work has started to inform pathway specific discussions on treatment access across the Cancer Alliance.

Overleaf are two examples of this work. A comparison of early stage for colorectal cancer by age-band for West London, showing patients under 50 with later stage disease (figure 1) and active treatment rates for stage 4 lung cancer patients by age-band comparing West London to England as whole showing higher treatment rates across all age bands (figure 2).

How are the findings being implemented?

This work is continually evolving based on ongoing discussions through the Cancer Alliance governance structure as well as informing priorities to improve early diagnosis and survival within West London population.

Additionally this work is being actively shared with other Alliances, as well as the National Cancer programme to both share the approach which could be replicated in other areas and also illustrate variation which could inform national policy.

Submitted by

RM Partners West London Cancer Alliance

Figure 1

Graph showing proportion of colorectal cancer patients with known stage diagnosed at stage 1 or 2 by age-band between 2013 and March 2018 West London vs England

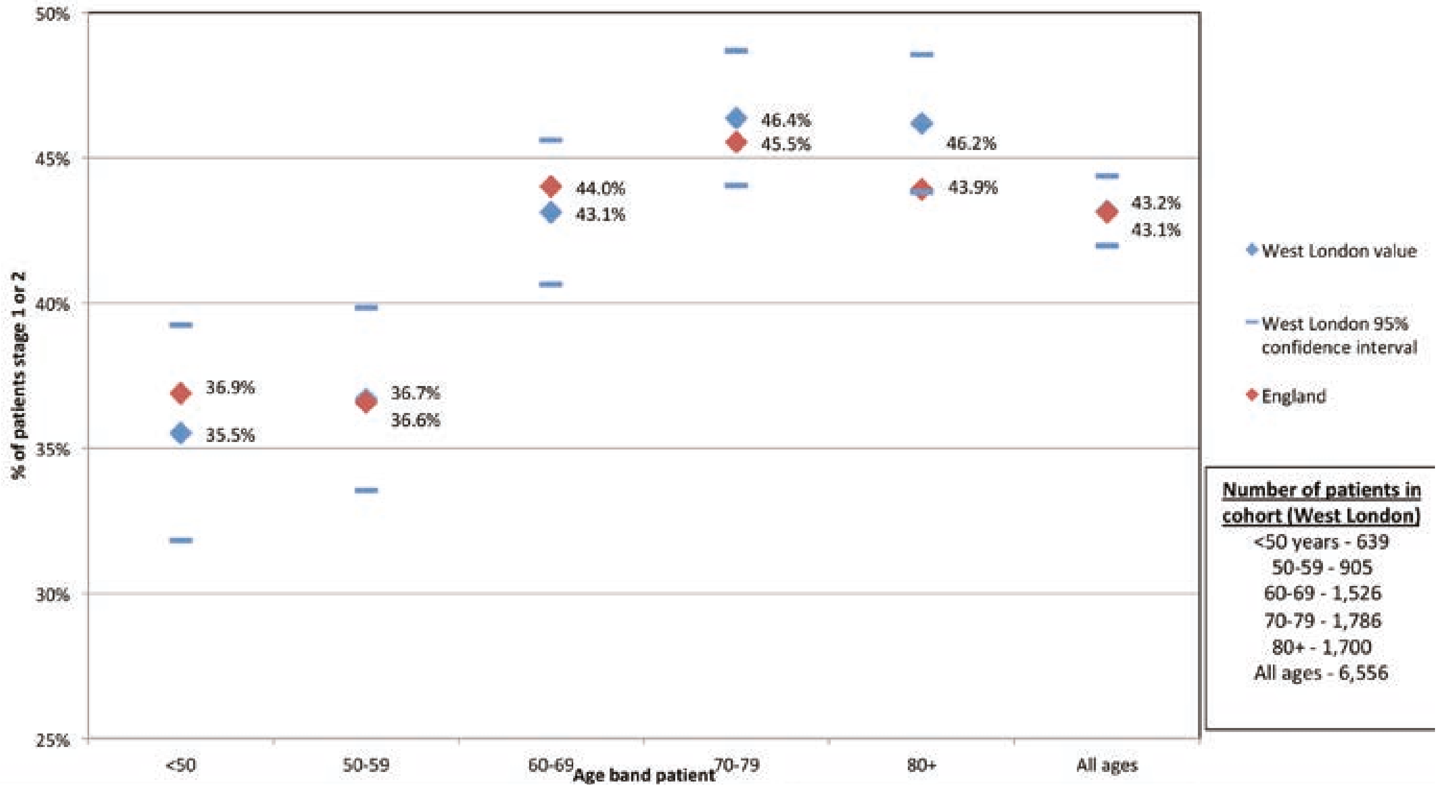
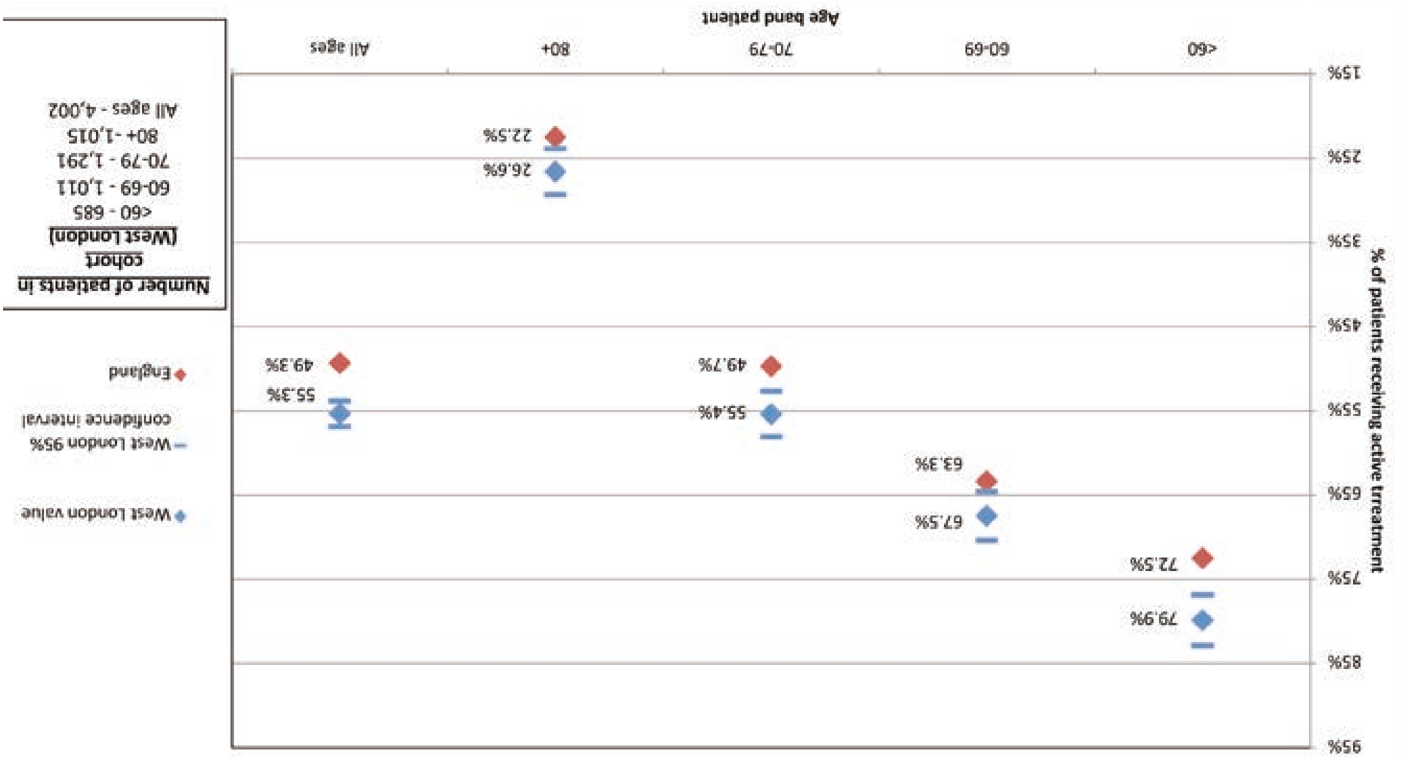


Figure 2

Graph showing proportion of lung cancer patients diagnosed at stage 4, by age-band between 2013 and March 2018 who had active treatment (Surgery, chemotherapy or radiotherapy) - West London overall vs England



Geographical variation in ovarian cancer treatment in England*

Project background

Data from the International Cancer Benchmarking Partnership (ICBP) has shown that survival for ovarian cancer in the UK is lower than in other high-income countries, and this difference is widest in older women. There is also marked regional variation in survival which is higher in ovarian cancer than in four other common cancers (breast, colorectal, lung, and prostate).

Who has worked on the project?

Cancer Research UK: Ewa Zotow, Hira Naveed and Rosie Hinchliffe.

What did the project involve?

This study used data from multiple combined population-wide datasets (obtained from the National Cancer Registration and Analysis Service) to explore geographical variation in access to ovarian cancer treatment across Cancer Alliances (CAs) in England. We controlled for differences in population characteristics (stage at diagnosis, age, deprivation quintile, performance status, route to diagnosis, and ethnicity) that may affect the rates of different treatments.

What are the results?

We found substantial geographical variation after adjusting for the case-mix variables, suggesting that regional disparities in access to treatment cannot be fully accounted for by the differences in the population characteristics across CAs. The CAs with higher rates of surgery and chemotherapy (NICE-recommended treatment) tended to have lower rates of no recorded treatment, and vice versa. Older patients (above 75) showed similar geographical variation but were significantly more likely to have no recorded treatment (43% vs 22% in whole sample). Older age, emergency diagnostic route and poorer performance status were the strongest predictors of having no recorded treatment.

How are the findings being implemented?

We envision that the findings will lead to further investigation into the underlying causes of the discrepancies in treatment across England, particularly in high-risk groups such as older women. This research calls for a nation-wide clinical audit for ovarian cancer in England and Wales – already ongoing for several cancer sites – which was recommended by England's Chief Medical Officer in a 2014 annual report.

Submitted by

Cancer Research UK and National Cancer Registration and Analysis Service (NCRAS) – partnership project

8

Project theme Treatment (follow up)

Transforming Cancer Follow-up

Project background

In recent years there has been increased interest in new models of cancer follow-up due to the pressure that increasing cancer survivorship places on the healthcare system. A self-directed aftercare (SDA) programme which initially focused on patients diagnosed with breast cancer was established in N.Ireland (NI) in 2013. This study aimed to investigate the characteristics of breast cancer patients who were assigned to the SDA programme with comparisons to the total population of patients diagnosed with breast cancer in NI.

Who has worked on the project?

Both the Macmillan partnership funded officer and tumour verification officer have worked on this project with support guidance from HSC Trust staff who were involved in the development in the new model of follow-up.

What did the project involve?

Data on the disease and socio-demographic characteristics for invasive breast cancer patients (ICD-10 C50) assigned to the SDA programme between 2013 and 2015 were extracted from the Northern Ireland Cancer Registry database. Chi-square analysis was carried out to investigate statistical differences in disease and socio-demographic characteristics between patients assigned to the SDA programme and all patients diagnosed with breast cancer over the same time period.

What are the results?

Preliminary findings have shown that a higher proportion of patients on the SDA programme (n=1365) were diagnosed at stage I and II (93%) when compared with average of all patients (73%) diagnosed with breast cancer in Northern Ireland between 2010 and 2014. The patients on SDA were also more likely to be younger with 77% patients aged less than 70 years at diagnosis when compared with 68% of total breast cancer population. No significant differences in receipt of SDA were observed across deprivation quintiles.

How are the findings being implemented?

The preliminary findings of this work have been presented to Clinicians through the Northern Ireland Cancer Network (NICan). It is hoped that this work will help inform future service planning.

Submitted by

Northern Ireland Cancer Registry (NICR) at Queen's University Belfast

Project theme Treatment/LWBC

East of England Cancer Alliance National Cancer Patient Experience Survey (NCPES) Analysis Workbook

Project background

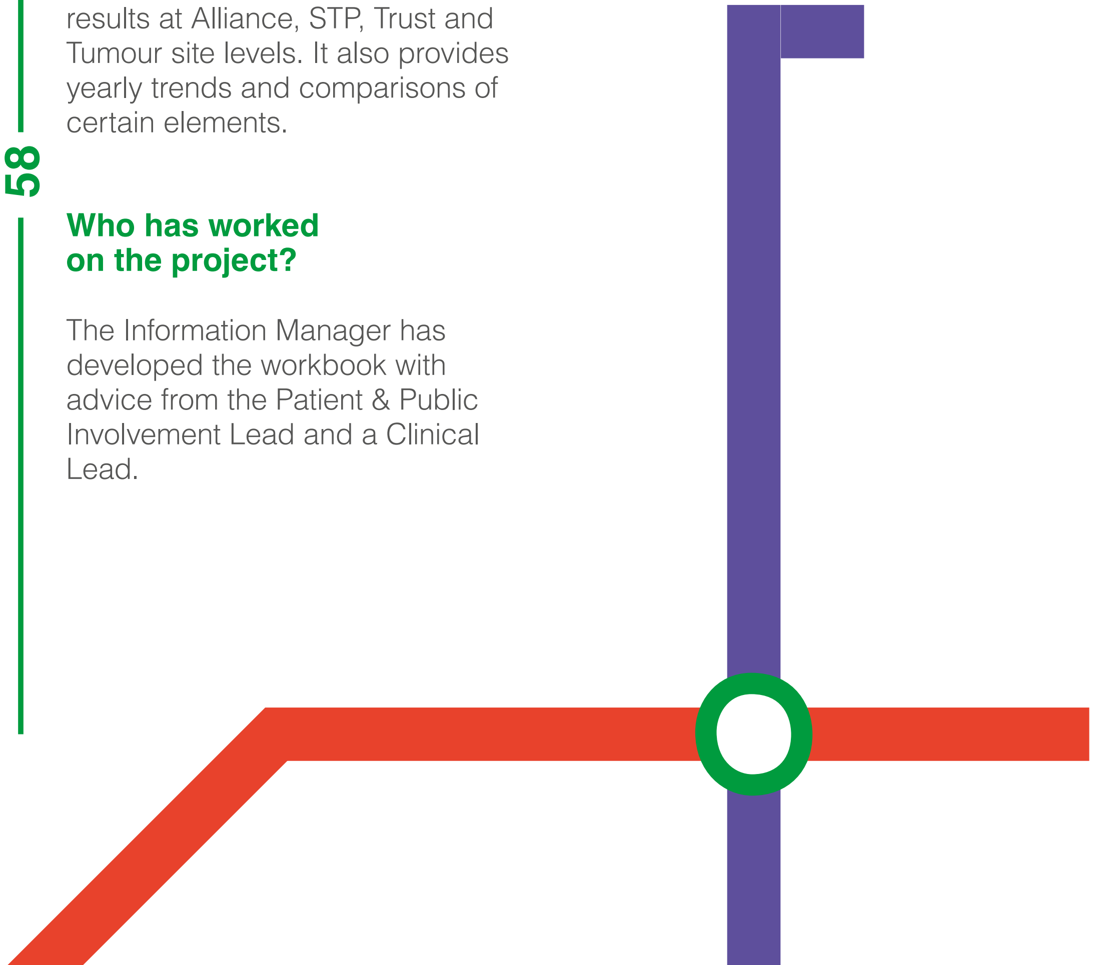
Annual NCPES results are provided by the national team at individual Trust level. STPs found it helpful to see the results of their Provider Trusts in one view which they use for planning and evaluation. This workbook provides the last three year's results at Alliance, STP, Trust and Tumour site levels. It also provides yearly trends and comparisons of certain elements.

Who has worked on the project?

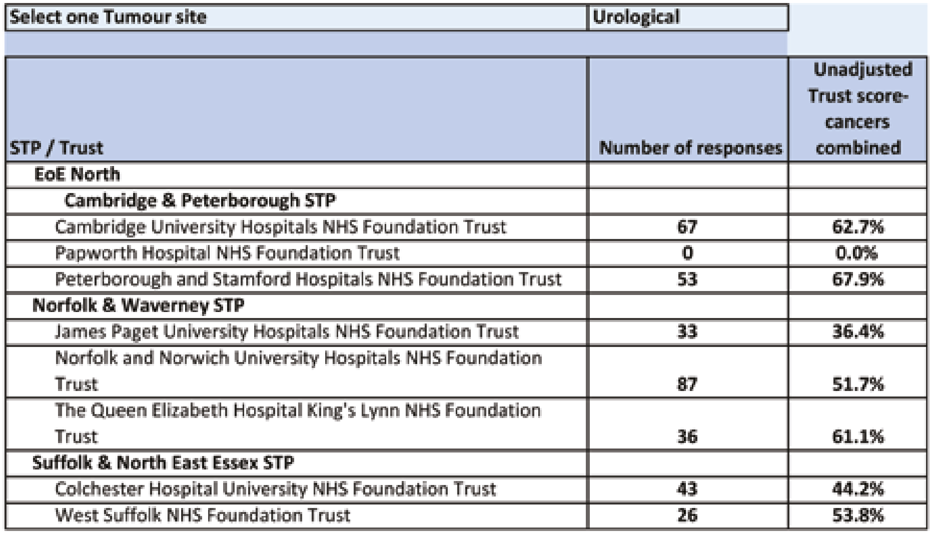
The Information Manager has developed the workbook with advice from the Patient & Public Involvement Lead and a Clinical Lead.

What did the project involve?

Analysing three years of CPES data for the STPs and Trusts in the Alliance footprint. Engineering the data to enable views which are not available in reports published online. These include:

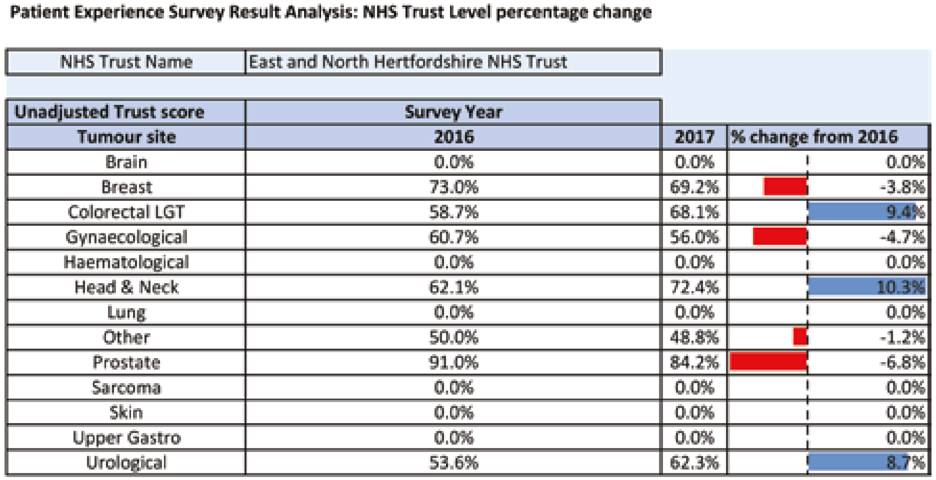


(1) Presentation of the questionnaire results grouped into Themes, views by Region, Trust, Year and Tumour site in tabular form with slicers;



Select one Tumour site	Urological	
STP / Trust	Number of responses	Unadjusted Trust score- cancers combined
EoE North		
Cambridge & Peterborough STP		
Cambridge University Hospitals NHS Foundation Trust	67	62.7%
Papworth Hospital NHS Foundation Trust	0	0.0%
Peterborough and Stamford Hospitals NHS Foundation Trust	53	67.9%
Norfolk & Waverney STP		
James Paget University Hospitals NHS Foundation Trust	33	36.4%
Norfolk and Norwich University Hospitals NHS Foundation Trust	87	51.7%
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	36	61.1%
Suffolk & North East Essex STP		
Colchester Hospital University NHS Foundation Trust	43	44.2%
West Suffolk NHS Foundation Trust	26	53.8%

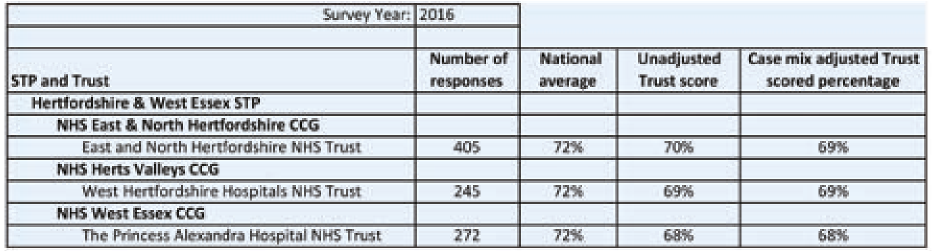
(2) Presentation of the questionnaire results grouped into Themes and Tumour sites showing the percentage change from the previous year with visualisations:



Patient Experience Survey Result Analysis: NHS Trust Level percentage change

NHS Trust Name	East and North Hertfordshire NHS Trust		
Unadjusted Trust score	Survey Year		
Tumour site	2016	2017	% change from 2016
Brain	0.0%	0.0%	0.0%
Breast	73.0%	69.2%	-3.8%
Colorectal LGT	58.7%	68.1%	9.4%
Gynaecological	60.7%	56.0%	-4.7%
Haematological	0.0%	0.0%	0.0%
Head & Neck	62.1%	72.4%	10.3%
Lung	0.0%	0.0%	0.0%
Other	50.0%	48.8%	-1.2%
Prostate	91.0%	84.2%	-6.8%
Sarcoma	0.0%	0.0%	0.0%
Skin	0.0%	0.0%	0.0%
Upper Gastro	0.0%	0.0%	0.0%
Urological	53.6%	62.3%	8.7%

(3) Case-mix adjusted Trust level results grouped into nationally defined ranges. In tabular form



Survey Year:	2016			
STP and Trust	Number of responses	National average	Unadjusted Trust score	Case mix adjusted Trust scored percentage
Hertfordshire & West Essex STP				
NHS East & North Hertfordshire CCG				
East and North Hertfordshire NHS Trust	405	72%	70%	69%
NHS Herts Valleys CCG				
West Hertfordshire Hospitals NHS Trust	245	72%	69%	69%
NHS West Essex CCG				
The Princess Alexandra Hospital NHS Trust	272	72%	68%	68%

How are the findings being implemented?

The workbook will be shared with Alliances and STPs via an established online portal (Kahootz). Trusts and the National Patient experience Team will be able to access it via the Cancer Alliance's public facing website. Awaiting 2018 data to complete and release the workbook.

Submitted by

East of England Cancer Alliance

Scottish Routes from Diagnosis (SRfD)*

Project background

Scottish Routes from Diagnosis (SRfD) is an ongoing project which focuses on improving the understanding of post-diagnosis pathways for people living with cancer and the services needed to support them.

Who has worked on the project?

SRfD is an output of Macmillan and the NHS Scotland's Information Services Division (ISD). A Clinical Advisory Group (CAG) and a Steering was formed to critically review, advise on, and sign off the definitions, as well as to inform and advise on the implementation, interpretation and future direction of the projects.

What did the project involve?

The aim of the project is to investigate the survivorship experiences of residents of Scotland diagnosed with breast, colorectal, lung or prostate cancer in 2007 and in 2012.

Alongside the approval and linkage of the required data was the development of 'Survivorship outcome groups' (OGs). Robust definitions of these groups are fundamental to the Scottish Routes from Diagnosis Project (SRfD) and are part of the comparative framework. One key aspiration in the creation of the survivorship outcome groups was the ability to produce definitions which could be applied across and well as within the cancer types.

The analysis into survivorship will explore the following areas:

- Investigating patient, tumour and treatment characteristics by cancer and survivorship outcome pathway group.
- Providing insights into the role of co-morbidities (pre and post diagnosis) on survivorship.
- Exploring end of life experience and cause of death in the cohorts.
- Exploring the role and variation of unscheduled care and other inpatient stays in cancer diagnosis and post-diagnosis.
- Examining the frequency and time interval of metastatic disease, previous and subsequent diagnoses of cancer.

Each area of exploration will be published as a Chapter available online and accompanied by storyboard mapping visualisations.

What are the results?

The outcome experiences of people diagnosed with different cancers can be very different. More people are surviving their cancer than ever before, with some recovering to a state of health that was very similar to their pre-diagnosis. Others, however, experience ongoing needs stemming from the effects of the cancer and its treatment. Most notably, more people are experiencing cancer as a long-term condition. Cancer in Scotland today presents a complex picture of different post-diagnosis pathways, with a wide variance in experience and accompanying needs.

How are the findings being implemented?

The results of the findings from SRfD can be used to further impact service development and planning as cancer care delivery begins to change and adapt to the reality of cancer in Scotland today. Data resulting from the project demonstrates that there is no one size fits all to address the variety, complexity and breadth of the needs of people living with and beyond cancer and that experiences of cancer may vary significantly even within the same cancer type.

Submitted by

Macmillan Cancer Support and NHS National Services Scotland's Information Services Division (ISD).

Scottish Routes from Diagnosis: Comorbidities

Project background

Scottish Routes from Diagnosis (SRfD) is an ongoing project by Macmillan and NHS Scotland's Information Services Division (ISD). Routinely collected national data are linked and analysed with the intention of delivering insights that support improved models of care and improve outcomes for people living with cancer. SRfD focuses on improving the understanding of post-diagnosis pathways for cancer patients and the services needed to support them. This aspect of the project focuses on the disease burden that cancer patients experience due to comorbidities..

Who has worked on the project?

ISD and Macmillan. Clinical support/advice is provided by a Clinical Advisory Group (CAG) and a Steering Group.

What did the project involve?

This is an ongoing project whose overall aim is to explore the experience of comorbidity in cancer patients at and beyond their cancer diagnosis. We intend to compare the comorbidity experiences across cohorts with the four most common cancers (colorectal, lung, prostate, and female breast cancer).

Changes in broad measures of comorbidity and disease burden such as time in hospital, community prescribing and Charlson score will be explored.

We have engaged with the CAG to elicit opinion on specific comorbidities which would likely be of interest, and why. This took the form of initial unstructured discussion followed by the development of an online survey to collate opinion from the group in a more formal and structured manner. The resulting clinical feedback allows us to explore how the prevalence of specific conditions, and their impact (e.g. contribution to hospital admissions) changes over time.

What are the results?

Preliminary analysis showed that 47% of breast patients, 83% of colorectal patients, 87% of lung patients and 54% of prostate patients experience other comorbidities in addition to their cancer diagnosis. Results based on clinical feedback are expected shortly.

How are the findings being implemented?

Increased knowledge of the prevalence and impact of comorbidity in people living with cancer (PLWC) will be used to inform service provision and planning for PLWC – both within Macmillan, and through engagement with other organisations more broadly within health and care services.

Submitted by

NHS National Services Scotland's Information Services Division (ISD)

Analysis of London Electronic Holistic Needs Assessment (E-HNA) results

Project background

Within London a number of providers have been recording Holistic Needs Assessments (HNA) using an Electronic System, either Macmillan's E-HNA tool or directly in a trusts Cancer Management system such as Somerset or Infoflex.

The information collected includes patients concerns as well as their cancer type and demographic details providing the opportunity to understand patient's needs across a population.

RM Partners has been providing informatics support for living with and beyond cancer (LWBC) projects across the 3 London Alliances with a number of years and as part of this support it was agreed that an analysis would be undertaken of Electronic Holistic Needs Assessments across London providers.

Who has worked on the project?

RMP informatics services, with support from Providers in London and project managers within the 3 London Alliances.

What did the project involve?

The audit has now been conducted for 3 years, with the initial audit conducted using the 2016 cohort of E-HNAs and the audit repeated using the cohorts from 2017 & 2018.

Trusts were asked to return their pseudo-annoymised returns to RM Partners informatics team. In the case of those using Macmillan's tool the data extracts had already been developed in the system so could be the extracted directly. For those using a Cancer Manager System custom extracts were developed.

This data was then collated and analysed into comparable metrics across London.

What are the results?

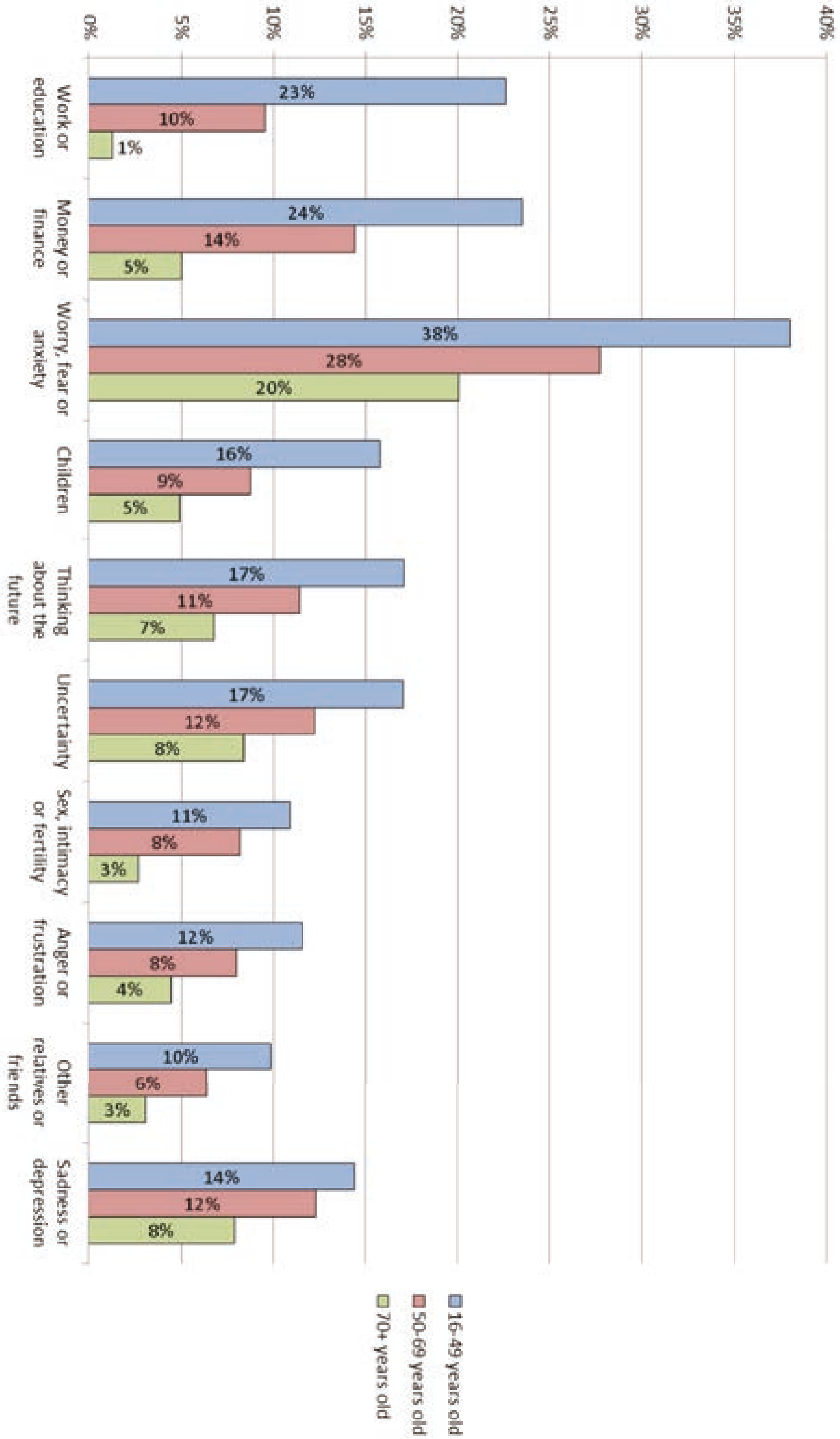
The most recent audit in 2018 included 11,808 E-HNA records from 11 providers across London.

This data has enabled a pan-London report to be produced including the following:

- Proportion of E-HNAs with a care plan record
- Number of concerns reported by tumour type
- Top concerns overall, and also individually by tumour type
- Concerns by age-band and gender
- Comparison of concerns at diagnosis and end of treatment
- Identification of the concerns with the largest variation by age or gender.

Overleaf is an example of one piece of analysis which shows the 10 concerns which were shown to have the greatest level of variation by age-band across London.

Graph showing the proportion of patients by age-band across London who reported concerns in e-HNA in 2018 (Ten concerns with biggest variation by age band)



How are the findings being implemented?

This analysis has been shared with all providers and Cancer Alliances within London and is informing discussions on both appropriate application of the Holistic Needs Assessment (e.g. care plan undertaken) and support service provision across London.

The long term vision of this work, would be all Holistic Needs Assessments across London are undertaken electronically and that this data could be used to identify the need and variation support service provision.

Submitted by

RM Partners West London
Cancer Alliance

Project theme End of life

Emergency Admissions in last year of life for people dying of cancer

Project background

Emergency admissions towards end-of-life may indicate gaps in routine cancer care. This project aimed to examine the demographic, disease and environmental characteristics of people dying with cancer admitted as an emergency in the last year of life to provide information to improve services.

Who has worked on the project?

Both the Macmillan partnership funded officer and tumour verification officer have worked on this project with support from NICR IT staff.

What did the project involve?

Data on all cancer deaths in Northern Ireland in 2015 were linked with hospital episodes relating to emergency admissions in the last year of life. Logistic Regression was carried out using “at least one emergency admission recorded” as the outcome variable.

What are the results?

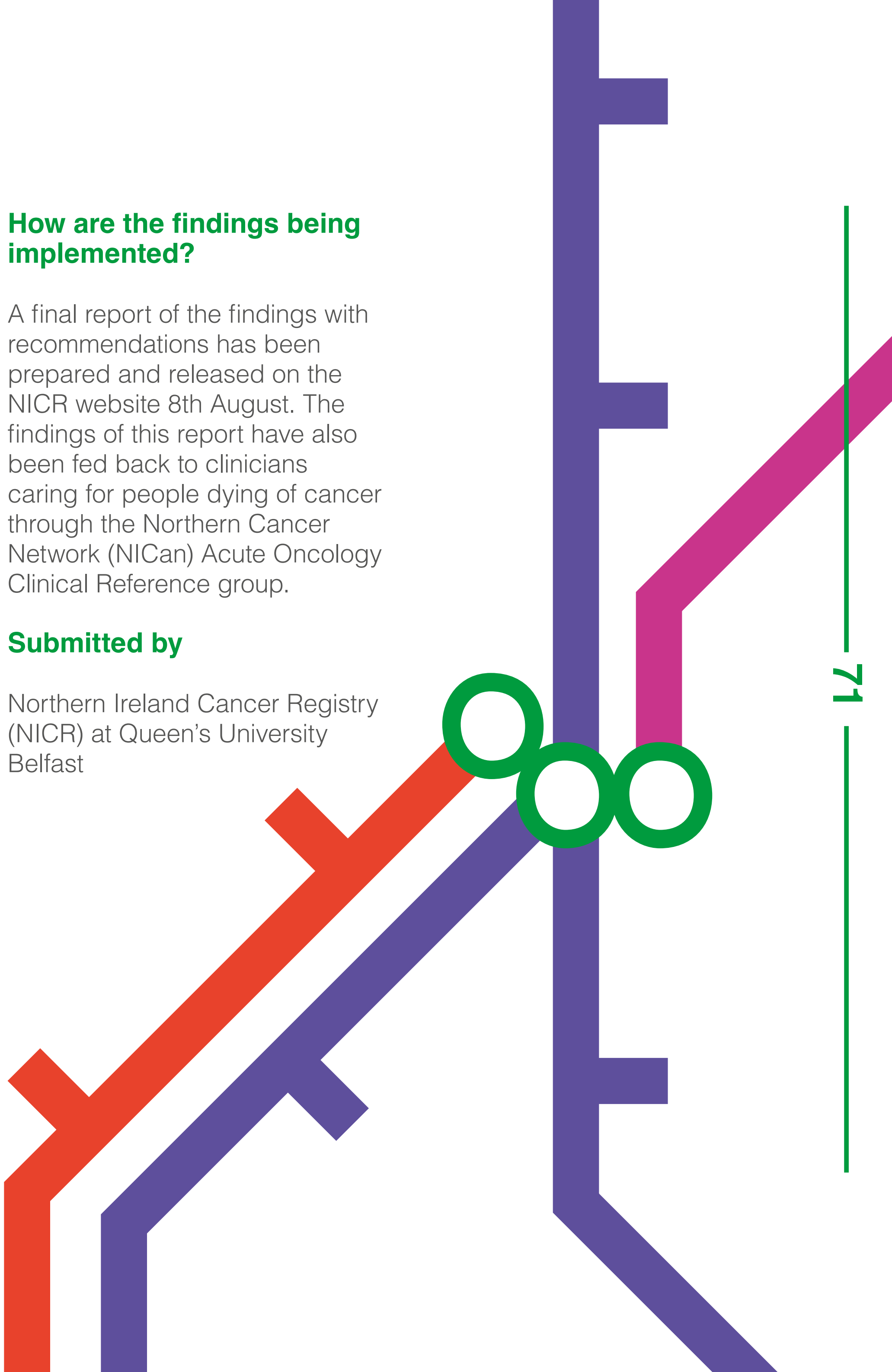
Of 4,224 people dying of cancer in Northern Ireland in 2015, 74.2%; (n=3,134) had at least one emergency admission is the last year of life recorded and 36.6% (n=1,546) in the last 28 days of life. Just over half (53%) occurred 5pm-9am Monday to Friday (likely reflects admission hours after attending the Emergency Department (ED) earlier). One in 9 (11%) occurred at the weekend, and 2% on public holidays. Late diagnosis was a feature with almost a quarter (1 in 4; 23%) being admitted as an emergency 1 to 3 months before diagnosis. Of those who had an emergency admission recorded in the last 28 days of life (n=1546) less than 1 in 5 (18%) died at home compared with 2 in 5 (43%) of those who did not have such an emergency admission (p<0.001).

How are the findings being implemented?

A final report of the findings with recommendations has been prepared and released on the NICR website 8th August. The findings of this report have also been fed back to clinicians caring for people dying of cancer through the Northern Cancer Network (NICan) Acute Oncology Clinical Reference group.

Submitted by

Northern Ireland Cancer Registry (NICR) at Queen’s University Belfast



Project theme End of life

End of life prescribing activity for cancer patients who die at home or in a nursing home: a population-based study of patients who died in July 2015

Project background

Current NICE guidelines recommend pain relief and symptom control drugs at the end of life. No studies have investigated the prescribing of drugs to control symptoms and anticipatory prescribing in cancer patients at the national level in England. Drugs for symptom control include drugs for pain; agitation and anxiety; breathlessness; nausea and vomiting; and noisy respiratory secretions. Anticipatory prescribing is used to treat these same symptoms, but consists of a supply of drugs within the patient's home to be administered by injection when distressing symptoms arise.

Who has worked on the project?

NCRAS: Gabrielle Emanuel, Dr. Katherine Henson, Prof. Karen Forbes, Dr. Luke Hounsome, Prof. Julia Verne

What did the project involve?

This project used dispensed prescriptions and mortality data linked to the cancer registration data to identify patterns in the prescribing of drugs for symptom control and anticipatory prescribing. Prescribing was analysed during the last four months of life in cancer patients who died in their own home or in a nursing home in July 2015. Prescribing patterns were assessed using proportions of all patients who died by location of death.

What are the results?

In the cohort, 94% of patients were prescribed drugs for symptom control and 65% received anticipatory prescribing during the end of life period. Over the four months to death, the proportion of patients receiving anticipatory prescribing increased from 3% three months before death to 53% in the same month as death. The increase for those prescribed symptom control drugs was 52% to 76%.

Differences in prescribing were seen by location of death: 67% of patients who died in their own home received anticipatory prescribing compared with 53% of those who died in a nursing home, with the largest difference seen in the same month as death (56% vs 38% respectively). Similarly, 77% of patients who died in their own home received symptom control drugs in the same month as death compared with 70% of those who died in a nursing home.

How are the findings being implemented?

The findings are being written up for publication in a peer-reviewed journal. This should draw attention to the differences in end of life prescribing between cancer patients who died in their own home and those who died in a nursing home and contribute to informing policy.

Submitted by

National Cancer Registration and Analysis Service (NCRAS)

Notes

Notes

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