Public Health England

National Cancer Intelligence Network

The role of NCIN and the SSCRG work programmes

NCIN Haematological Cancers Workshop, 30th September 2014

Lucy Elliss-Brookes, Analytical Programme Manager, NCIN

Public Health England

The Health & Social Care Act 2012: two new organisations from April 2013

NHS England

- “The purpose of NHS England is to use the £80bn commissioning budget to secure the best possible outcomes for patients”
- To ensure the whole commissioning architecture is in place; will also commission some services directly

Public Health England (PHE)

- Information & Intelligence to support public and local Public Health (PH) making healthier choices
- National Leadership to PH, supporting national policy
- Development of PH workforce
- A civil service function, not NHS

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Providers of information

Health & Social Care Information Centre (HSCIC)

National Audits

Office for National Statistics (ONS)

PHE including Health Intelligence Networks

UK and Ireland Cancer Registries

NHS England Business Intelligence Teams

Information intermediaries

- e.g. Dr Foster, Cancer Research UK, Macmillan Cancer Support, Incisive Health

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PHE Chief Knowledge Office (CKO): Knowledge and Intelligence

National Cancer Registration Service (NCRS)

8 regional Knowledge and Intelligence Teams (KITs)

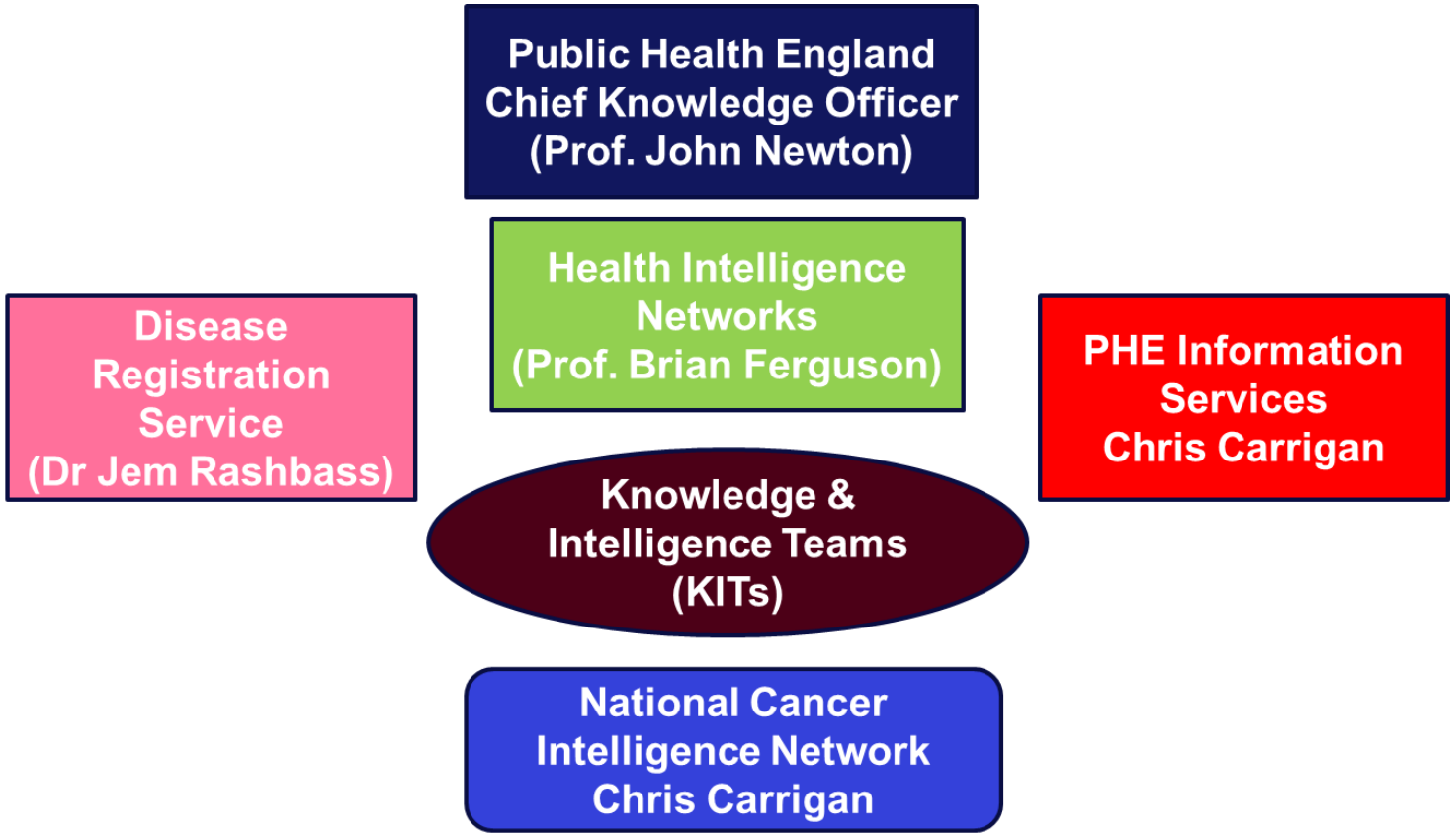
- SSCRG Work Programmes
- Local contribution
- Non cancer work

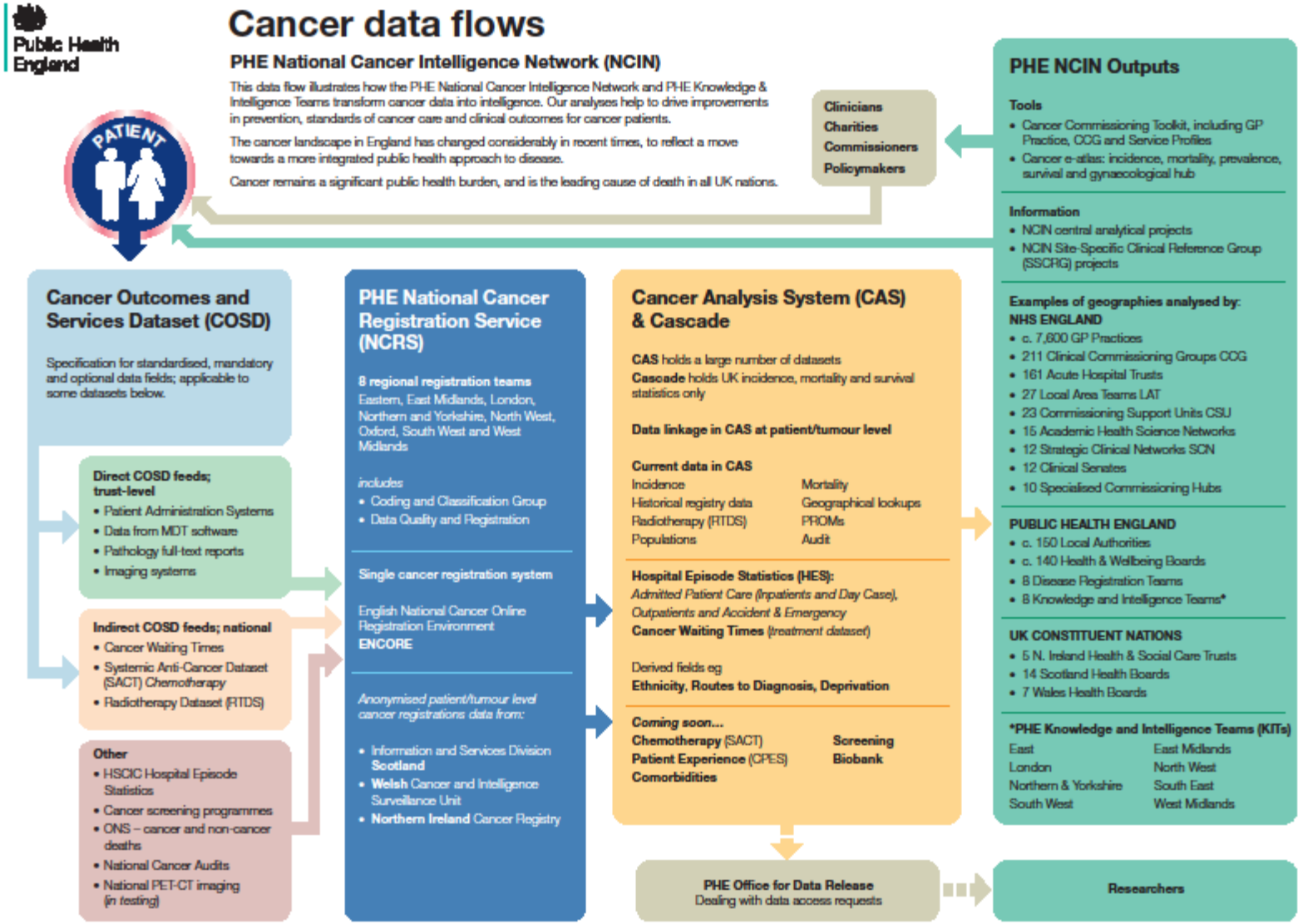
5 Health Intelligence Networks (HINs):

- Mental Health, Maternal & Child Health, Cardiovascular & Diabetes, End of Life, Cancer (NCIN)

Public Health England

PHE ‘intelligence structures’




Public Health England
Cancer data flows
PHE National Cancer Intelligence Network (NCIN)
This data flow illustrates how the PHE National Cancer Intelligence Network and PHE Knowledge & Intelligence Teams transform cancer data into intelligence. Our analyses help to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.
The cancer landscape in England has changed considerably in recent times, to reflect a move towards a more integrated public health approach to disease.
Cancer remains a significant public health burden, and is the leading cause of death in all UK nations.
PATIENT
Clinicians
Charities
Commissioners
Policymakers
PHE NCIN Outputs
Tools
Cancer Commissioning Toolkit, including GP Practice, CCG and Service Profiles
Cancer e-atlas: incidence, mortality, prevalence, survival and gynaecological hub
Information
NCIN central analytical projects
NCIN Site-Specific Clinical Reference Group (SSCRG) projects
Examples of geographies analysed by:
NHS ENGLAND
c. 7,600 GP Practices
211 Clinical Commissioning Groups CCG
161 Acute Hospital Trusts
27 Local Area Teams LAT
23 Commissioning Support Units CSU
15 Academic Health Science Networks
12 Strategic Clinical Networks SCN
12 Clinical Senates
10 Specialised Commissioning Hubs
PUBLIC HEALTH ENGLAND
c. 150 Local Authorities
c. 140 Health & Wellbeing Boards
8 Disease Registration Teams
8 Knowledge and Intelligence Teams*
UK CONSTITUENT NATIONS
5 N. Ireland Health & Social Care Trusts
14 Scotland Health Boards
7 Wales Health Boards
*PHE Knowledge and Intelligence Teams (KITs)
East
East Midlands
London
North West
Northern & Yorkshire
South East
South West
West Midlands
Cancer Outcomes and Services Dataset (COSD)
Specification for standardised, mandatory and optional data fields; applicable to some datasets below.
Direct COSD feeds; trust-level
Patient Administration Systems
Data from MDT software
Pathology full-text reports
Imaging systems
Indirect COSD feeds; national
Cancer Waiting Times
Systemic Anti-Cancer Dataset (SACT) Chemotherapy
Radiotherapy Dataset (RTDS)
Other
HSCIC Hospital Episode Statistics
Cancer screening programmes
ONS – cancer and non-cancer deaths
National Cancer Audits
National PET-CT imaging (in testing)
PHE National Cancer Registration Service (NCRS)
8 regional registration teams
Eastern, East Midlands, London, Northern and Yorkshire, North West, Oxford, South West and West Midlands
includes
Coding and Classification Group
Data Quality and Registration
Single cancer registration system
English National Cancer Online Registration Environment
ENCORE
Anonymised patient/tumour level cancer registrations data from:
Information and Services Division Scotland
Welsh Cancer and Intelligence Surveillance Unit
Northern Ireland Cancer Registry
Cancer Analysis System (CAS) & Cascade
CAS holds a large number of datasets
Cascade holds UK incidence, mortality and survival statistics only
Data linkage in CAS at patient/tumour level
Current data in CAS
Incidence
Mortality
Historical registry data
Geographical lookups
Radiotherapy (RTDS)
PROMs
Populations
Audit
Hospital Episode Statistics (HES):
Admitted Patient Care (Inpatients and Day Case), Outpatients and Accident & Emergency
Cancer Waiting Times (treatment dataset)
Derived fields eg
Ethnicity, Routes to Diagnosis, Deprivation
Coming soon...
Chemotherapy (SACT)
Screening
Patient Experience (CPES)
Biobank
Comorbidities
PHE Office for Data Release
Dealing with data access requests
Researchers

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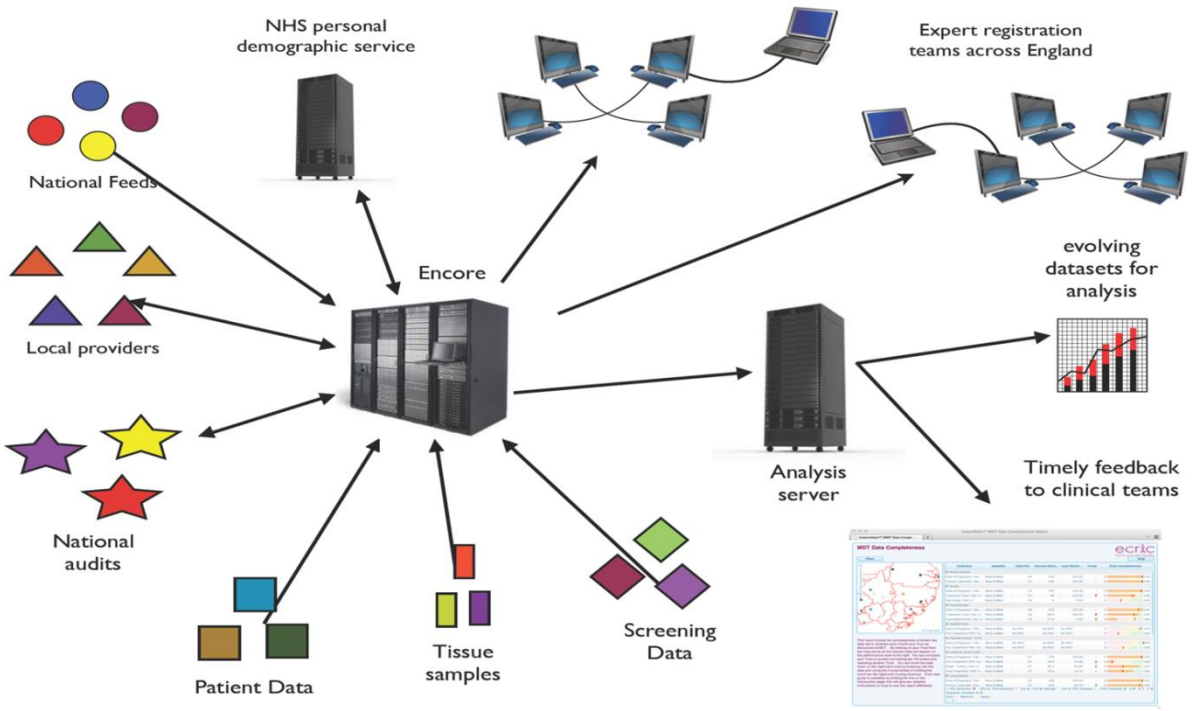
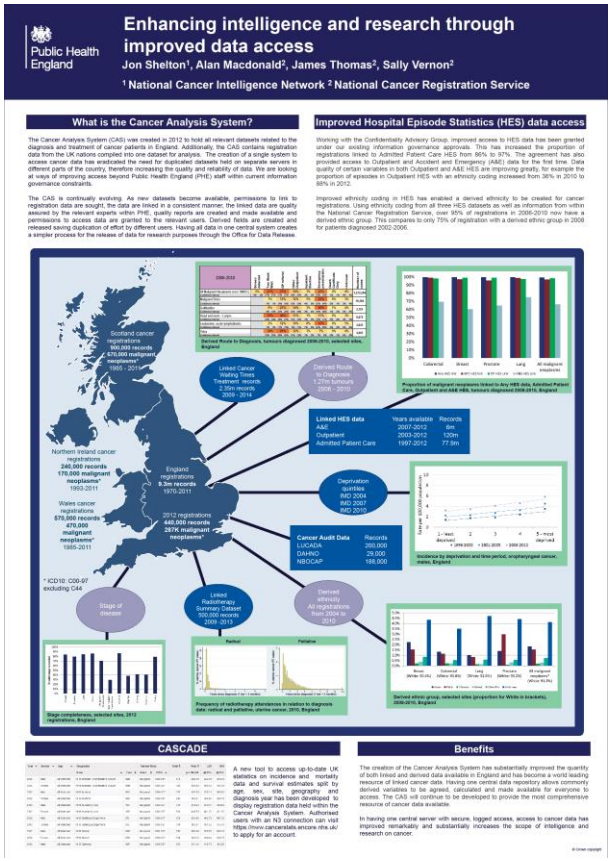
Encore (English National Cancer Online Registration Environment) and CAS (Cancer Analysis System)





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NCIN central analysis work programme

NCIN Analysis Work Programme

October 2014

NCIN central analytical team

RAGU rating:

R	Significant risk to project
A	Some risk to project
G	Project on track
U	Under consideration

Key to colour coding:

Consideration	Doing
Scoping	Write-up or QA
Proposal/Plan	Publication prep
Agreement	Communication

Area	Project title	RAGU	Status	Lead	Oct-14	Nov-14	Dec-14	Jan-15	Feb-15	Mar-15
CUP	CUP data briefings - age disparities (UK)	G	In progress	Claudia						
CUP	Registration questionnaire (UK)	G	In progress	Claudia		12-Nov	03-Dec			
General	Public facing data: tools update	A	In progress	Sean						
General	Cancer Patient Experience Survey	G	In progress	Lucy						
General	CCG Outcomes Indicator Set	G	In progress	Sean						
General	Cancer in GB and Ireland: similarities and differences (UK)	G	In progress	Eamonn			31-Dec			
General	Information Governance and data release	G	In progress	Sean						
General	Cancer Analysis System (CAS) development	G	In progress	Sean						
General	What cancer statistics are available... ? (update)	G	Agreed	Sam			09-Dec			
General	IOSC fourth annual report	G	In progress	LEB			09-Dec			
Inequalities	Older people and cancer	G	In progress	Laura			09-Dec			
Inequalities	NCEI report 2015	U	Undefined	Sam						
Methodology	Analysis of outpatient HES data	G	In progress	Sarah		12-Nov				
Methodology	Big HES data application	R	In progress	Sean						
Methodology	COSD level 4 conformance testing	U	In progress	tbc			31-Dec			
NAEDI	BCQC: breast screening and PPI data	G	In progress	Eamonn						
NAEDI	Routes to Diagnosis: variation by age and sex	G	In progress	Sam						
NAEDI	Emergency Presentations (proxy indicator in CCT)	R	In progress	Sam						
NAEDI	Routes to Diagnosis: Treatments H1	G	In progress	Claudia						
NAEDI	Impact of early diagnosis on survival H2	G	In progress	Bella						25-Mar
NAEDI	Routes to Diagnosis: Intervals	U	Undefined	Bella						
NAEDI	GP & CCG Profiles 2014 (refresh)	G	In progress	Sean						
Rarer cancers	Granular breakdown of rarer cancers (UK)	G	In progress	Sam						
Research	BioBank: adjudication of cancer outcomes (UK)	G	In progress	Eamonn						
Survivorship	Segmentation of 2 million (UK)	G	In progress	Sarah						
Survivorship	Progressive cancers	G	In progress	Lucy						
Survivorship	Costings (partnership project with Imperial)	G	In progress	Lucy						
Survivorship	Local Cancer Intelligence (UK)	G	In progress	Lucy						
Training	Understanding Cancer: regular statistics (UK)	G	In progress	Sam						
Treatment	Staging data 2012	G	In progress	Sean						
Treatment	Comorbidity: agreement of methodologies	G	In progress	Sean						
Treatment	Treatment dataset mapping	U	Undefined	Sean						
Treatment	Analysis of radiotherapy data	G	In progress	Sam						

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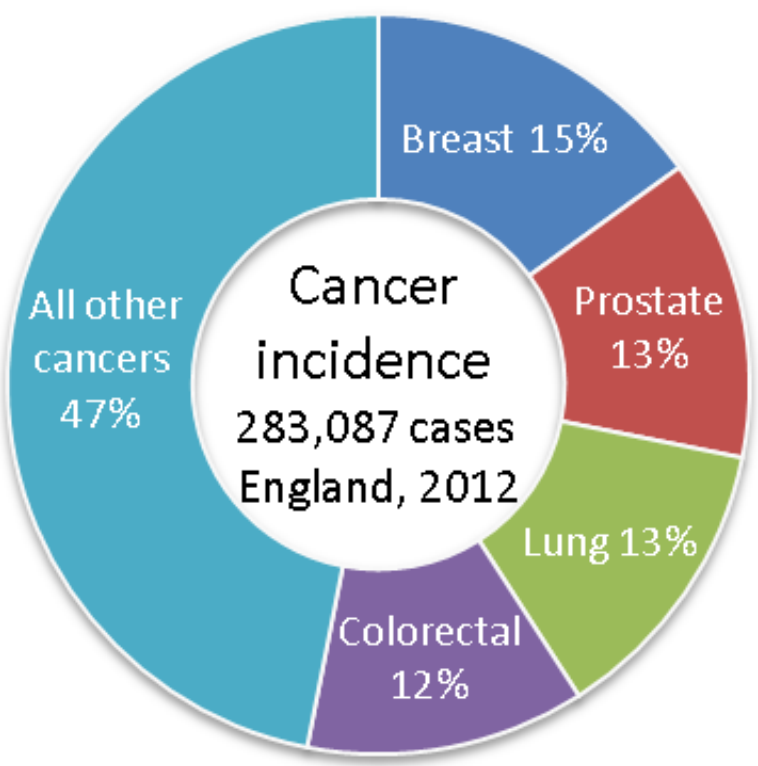
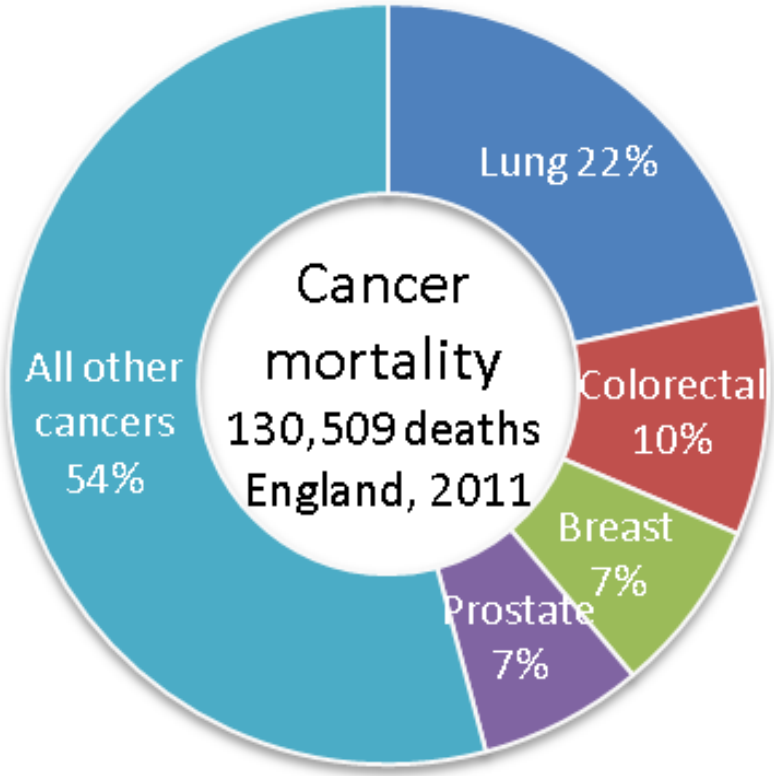
Rare and less common cancers





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Routes to Diagnosis

Routes to Diagnosis, a novel English methodology

LE Elliss-Brookes[1], S McPhail[1], A Ives[2], M Greenslade[2], J Shelton[1], S Hiom[3], M Richards[4]
1) National Cancer Intelligence Network, London 2) Public Health England Knowledge and Intelligence Team (South West), Bristol 3) Cancer Research UK, London 4) NHS England, London

Nationally, what didn't we know?
- How people come to get diagnosed with cancer
- Whether late diagnosis arises where patients have not gone through the screening or suspected cancer route

Nationally, what did we want to know?
- Can we use routinely available datasets to define the route to diagnosis for patients diagnosed with cancer?
- If so, how do routes differ by cancer site, age, sex, ethnicity, deprivation or geography?
- Are there differences in survival for different routes?

Method: Routes to Diagnosis uses routinely collected data sources to work backwards through patient pathways to examine the sequence of events that led to a cancer diagnosis. The methodology identifies over 70 individual pathways and then categorises patients into one of eight broad Routes (see table to right).

1. Registration records for cancers newly diagnosed in 2006 to 2008 (ICD-10 C00-C97 excluding C44) for England residents were extracted from the National Cancer Data Repository.

2. Records were linked at patient level to national datasets for inpatient and outpatient activity, Cancer Waiting Times (CWT) monitoring and breast, cervical and bowel cancer screening.

3. Hospital Episode Statistics (HES) data were used to categorise the Route for each cancer individually, **the algorithms described in the three flow diagrams below**.

4. Screening and CWT data were then examined with the Route potentially changing to either a Screening or Two Week Wait (urgent referral for suspected cancer) Route.

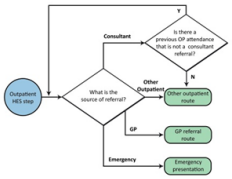
Route	Description
Screen Detected	Detected via the national breast, cervical or bowel screening programmes
Two Week Wait	Urgent GP referral with a suspicion of cancer
GP Referral	Routine and urgent GP referrals where the patient was not referred under the Two Week Wait referral route
Other Outpatient	An elective route starting with an outpatient appointment: either self-referral, consultant to consultant, other or unknown referral
Inpatient Elective	Where no earlier admission can be found prior to elective admission from a waiting list, booked or planned
Emergency Presentation	An emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral, emergency admission or attendance
Death Certificate Only	No data available from inpatient or Outpatient HES, CWT or screening and with a death certificate only diagnosis flagged by the cancer registry
Unknown	No data available from inpatient or Outpatient HES, CWT or screening

Figures A, B and C show the categorisation of each case into a Route using routine inpatient and outpatient activity data.

Figure A

Figure B

Figure C



Percentage of diagnoses by route 2006-2008	Screen detected	Two Week Wait	GP Referral	Other Outpatient	Inpatient Elective	Emergency presentation	Death Certificate Only	Unknown	Number of cases
All cancers	6%	26%	21%	10%	6%	24%	1%	6%	259,667
Breast	28%	46%	11%	5%	1%	6%	1%	3%	39,173
Central Nervous System		1%	10%	11%	7%	62%	1%	8%	11,697
Colorectal	2%	27%	26%	9%	5%	26%	1%	5%	83,416
Lung		14%	17%	10%	4%	35%	1%	8%	36,736
Melanoma		41%	27%	7%	3%	3%	1%	10%	10,466
Ovary		28%	28%	12%	4%	22%	1%	7%	6,926
Pancreas		11%	16%	6%	6%	60%	1%	6%	8,896

Rate for 12 month survival estimates by route and site, persons, 2006 - 2008	All routes	Screening	Two Week Wait	GP referral	Other outpatient	Inpatient elective	Emergency presentation	Unknown	Number of cases
Breast	97%	100%	98%	96%	92%	91%	84%	96%	39,173
Central Nervous System	33%		47%	54%	62%	65%	16%	50%	11,233
Colorectal	74%	93%	82%	82%	80%	64%	56%	73%	83,404
Lung	29%		46%	46%	44%	34%	12%	24%	52,522
Melanoma	97%		99%	98%	94%	96%	92%	99%	10,487
Ovary	78%		84%	81%	82%	81%	66%	68%	10,613
Pancreas	17%		19%	26%	33%	29%	3%	16%	10,591

Results: The percentage of patients diagnosed through each Route was broken down by cancer type, age, sex, deprivation, geography, ethnicity and year for 38 specific cancer types.

Relative survival estimates were calculated for 1, 3, 6, 9 and 12 month periods. Across all cancer types, one-year relative survival was significantly lower for Emergency Presentations.

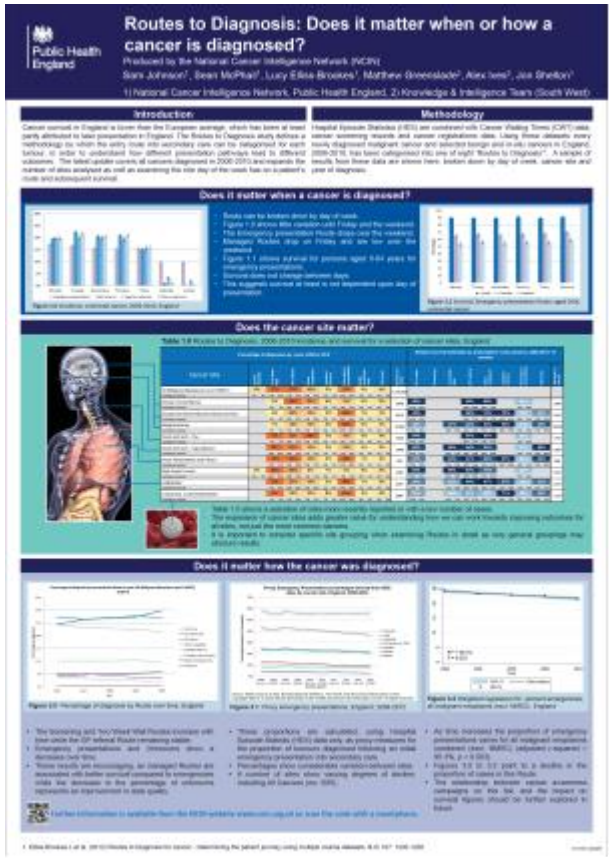
Conclusions: The small selection of results presented show that linked cancer registration and administrative data can be used to robustly categorise the route to a cancer diagnosis for all patients.

The methodology outlined allows for automation of analysis and is robust, with results aligning to several other studies. It is also broadly transferable to other countries, allowing international comparisons.

However it is not without its limitations. A small level of impact from background admissions will be present as the algorithm assumes patient activity prior to diagnosis is associated with the diagnosis itself. The method cannot be used to identify presenting symptoms (of cancer or any other illness).

The full methodology published in the British Journal of Cancer*, an information supplement and an Excel workbook containing all available results are available from the NCIN website: www.ncin.org.uk

* Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, Richards M (2012) Routes to Diagnosis for cancer- Determining the patient journey using multiple routine datasets. BJC 107: 1220-1226



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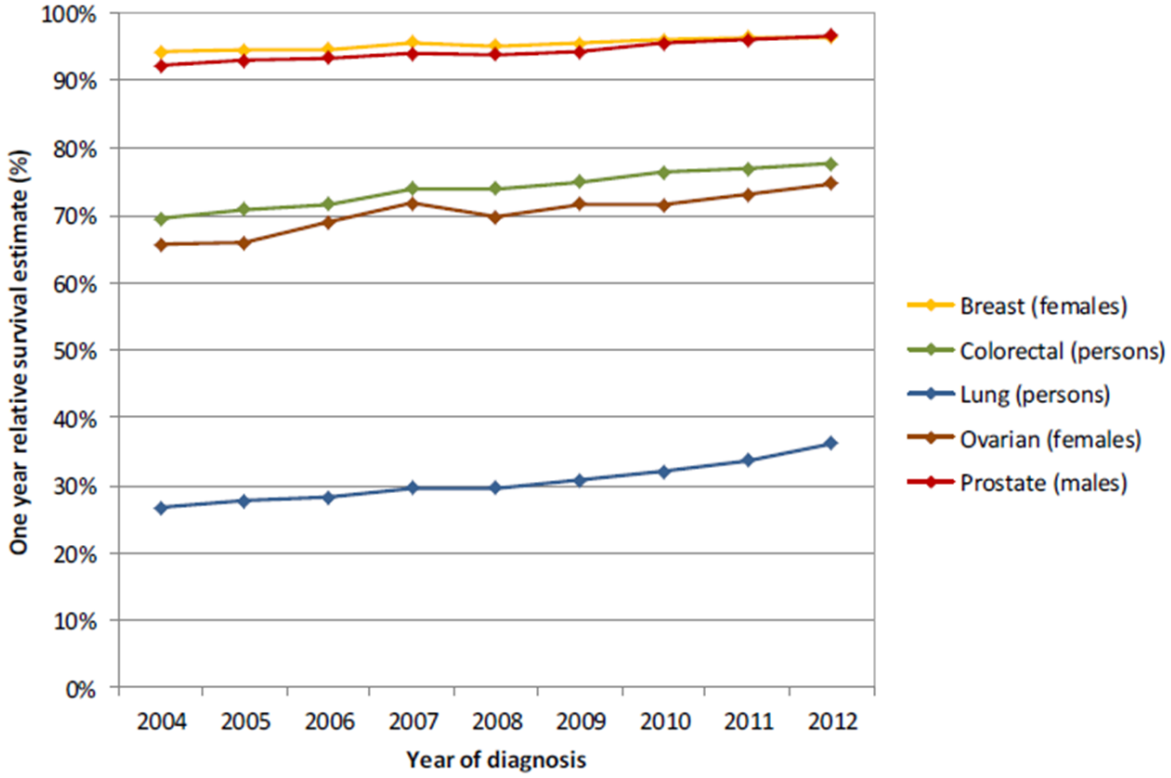
Cancer stage and survival

Figure 2, one-year survival, all stage, by year of diagnosis, not standardised by age



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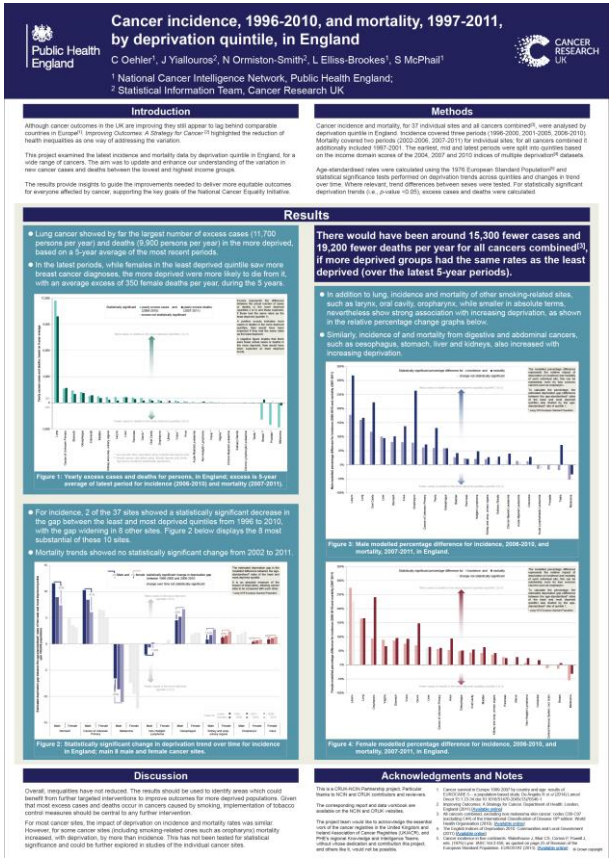
Inequalities



Cancer incidence, 1996-2010, and mortality, 1997-2011, by deprivation quintile, in England

C Oehler[1], J Yiallouros[2], N Ormiston-Smith[2], L Elliss-Brookes[1], S McPhail[1]

[1] National Cancer Intelligence Network, Public Health England;
[2] Statistical Information Team, Cancer Research UK

Public Health England

CANCER RESEARCH UK

Introduction

Although cancer outcomes in the UK are improving they still appear to lag behind comparable countries in Europe[1]. *Improving Outcomes: A Strategy for Cancer*[2] highlighted the reduction of health inequalities as one way of addressing the variation.

This project examined the latest incidence and mortality data by deprivation quintile in England, for a wide range of cancers. The aim was to update and enhance our understanding of the variation in new cancer cases and deaths between the lowest and highest income groups.

The results provide insights to guide the improvements needed to deliver more equitable outcomes for everyone affected by cancer, supporting the key goals of the National Cancer Equality Initiative.

Methods

Cancer incidence and mortality, for 37 individual sites and all cancers combined[3], were analysed by deprivation quintile in England. Incidence covered three periods (1996-2000, 2001-2005, 2006-2010). Mortality covered two periods (2002-2006, 2007-2011) for individual sites, for all cancers combined it additionally included 1997-2001. The earliest, mid and latest periods were split into quintiles based on the income domain scores of the 2004, 2007 and 2010 indices of multiple deprivation[4] datasets.

Age-standardised rates were calculated using the 1976 European Standard Population[5] and statistical significance tests performed on deprivation trends across quintiles and changes in trend over time. Where relevant, trend differences between sexes were tested. For statistically significant deprivation trends (i.e., *p*-value <0.05), excess cases and deaths were calculated

Results

- Lung cancer showed by far the largest number of excess cases (11,700 persons per year) and deaths (9,900 persons per year) in the more deprived, based on a 5-year average of the most recent periods.
- In the latest periods, while females in the least deprived quintile saw more breast cancer diagnoses, the more deprived were more likely to die from it, with an average excess of 350 female deaths per year, during the 5 years.

Figure 1: Yearly excess cases and deaths for persons, in England; excess is 5-year average of latest period for incidence (2006-2010) and mortality (2007-2011).

- For incidence, 2 of the 37 sites showed a statistically significant decrease in the gap between the least and most deprived quintiles from 1996 to 2010, with the gap widening in 8 other sites. Figure 2 below displays the 8 most substantial of those 10 sites.
- Mortality trends showed no statistically significant change from 2002 to 2011.

Figure 2: Statistically significant change in deprivation trend over time for incidence in England; main 8 male and female cancer sites.

There would have been around 15,300 fewer cases and 19,200 fewer deaths per year for all cancers combined[3], if more deprived groups had the same rates as the least deprived (over the latest 5-year periods).

- In addition to lung, incidence and mortality of other smoking-related sites, such as larynx, oral cavity, oropharynx, while smaller in absolute terms, nevertheless show strong association with increasing deprivation, as shown in the relative percentage change graphs below.
- Similarly, incidence of and mortality from digestive and abdominal cancers, such as oesophagus, stomach, liver and kidneys, also increased with increasing deprivation.

Figure 3: Male modelled percentage difference for incidence, 2006-2010, and mortality, 2007-2011, in England.

Figure 4: Female modelled percentage difference for incidence, 2006-2010, and mortality, 2007-2011, in England.

Discussion

Overall, inequalities have not reduced. The results should be used to identify areas which could benefit from further targeted interventions to improve outcomes for more deprived populations. Given that most excess cases and deaths occur in cancers caused by smoking, implementation of tobacco control measures should be central to any further intervention.

For most cancer sites, the impact of deprivation on incidence and mortality rates was similar. However, for some cancer sites (including smoking-related ones such as oropharynx) mortality increased, with deprivation, by more than incidence. This has not been tested for statistical significance and could be further explored in studies of the individual cancer sites.

Acknowledgments and Notes

This is a CRUK-NCIN Partnership project. Particular thanks to NCIN and CRUK contributors and reviewers.

The corresponding report and data workbook are available on the NCIN and CRUK websites.

The project team would like to acknowledge the essential work of the cancer registries in the United Kingdom and Ireland Association of Cancer Registries (UKACR), and the Office for National Statistics Cancer Registration Teams, without whose dedication and contribution this project, and others like it, would not be possible.

1 Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE-5 – a population-based study. Lancet Oncol. 2015 Jan;16(1):23-70. doi: 10.1016/S1470-2045(14)71159-3. Epub 2014 Dec 11.

2 Improving Outcomes: A Strategy for Cancer. Department of Health: London, January 2011. ISBN: 978-1-906254-77-8

3 All cancers combined excluding non-melanoma skin cancer (codes C00-C97 excluding C44) of the International Classification of Disease 10th edition World Health Organization (WHO), 1992. Available online

4 The English Indices of Deprivation 2010. Communities and Local Government (2011) Available online

5 Ahmad OB, Boschi-Pinto C, Lopez AD, Murray CJ, Lozano R, Inoue M. Age standardization of rates: a new WHO standard. Geneva: World Health Organization; 2001. (EIP/GPE/EBD). Available online

Tackling inequalities through cancer intelligence: key metrics to enable change

Lucy Elliss-Brookes [1], Jon Shelton [1], Sam Johnson [1], Joanne Rule [2]

1) National Cancer Intelligence Network, Public Health England, 2) National Cancer Equality Initiative

Public Health England

Background

In 2013, the National Cancer Equality Initiative (NCEI) and the National Cancer Intelligence Network (NCIN) published a baseline report "Cancer and Equality: key metrics" on cancer and equality groups. The purpose was to establish a series of metrics relating to equality groups and cancer which would provide a basis to measure change, whether positive or negative. The rationale was simple: it is impossible to tackle inequalities without data to inform activity and scrutinise progress.

The NCIN has pioneered the collection and analysis of meaningful cancer data, ensuring that data are routinely collected, analysed, interpreted and published for as many equality groups as viable.

The availability and quality of data is improving, our knowledge of the disease and differences by equality groups is improving and our understanding of patient's experiences is evolving. This follow up report brings together updated information and intelligence and highlights where differences by equality groups exist so that we can work to reduce inequalities. It also shows what improved data quality will allow us to do in the future to improve our understanding further.

Methods

The metrics contained within the 2014 report provide an overview of national trends, providing insight for commissioners and providers alike and enable the NCEI to champion further action.

The ten chapters cover the spectrum of the cancer patient journey starting with basic epidemiological data such as incidence, mortality and one year survival. Further chapters cover the uptake of the cancer screening programmes; the completeness of data on ethnicity; a breakdown of Routes of Diagnosis; reporting on patient experience; radical treatment; stage at diagnosis and patient reported outcomes.

Data included in the report have been taken from a variety of different sources, including the Office for National Statistics, the Health and Social Care Information Centre, Cancer Patient Experience Survey and the Quality of life of cancer survivors in England. Basic epidemiology data (incidence, mortality and survival) are included to provide context. Some of the metrics highlight where differences within equality groups exist, whilst others show similarities between groups. Other metrics highlight current data gaps progress in filling them.

Ethnicity

Completeness of ethnicity recording by Trust, England, Admitted Patient Care Hospital Episode Statistics (HES) data for cancer registrations or people with a diagnosis of a neoplasm within HES, England, 2012

Deprivation

Cancer Patient Experience Survey by deprivation quintile, selected questions, England

Age

One year relative survival estimates by age group, selected sites, 2005-2009, England

Website

Sexuality

Differences in responses for heterosexual and non-heterosexual patients, Cancer Patient Experience Survey, 2013

Sex

Figure 1.4.3. Trends in age standardised rates, lung, England, 2002-2011

Cancer stage

Proportion of cancers staged by cancer site, cancers registered in 2012, selected sites (most common), England

Conclusions

Real progress has been made by hospital trusts in recording ethnicity which will enable us to have a much better understanding of cancer in relation to minority ethnic groups. Likewise, there has been a continued increase in the proportion of cancers with a recorded stage at diagnosis. This will lead to a vastly improved overview of differences in early diagnosis by all equality groups.

Whilst these improvements are positive, some trusts still have a long way to go to reach the levels of ethnicity coding required and the completeness of stage of disease is still below the benchmark of 70%.

Commissioners, clinicians, patients and local communities alike will want to see continued progress across the pathway from high quality data collection to intelligence on cancer by equality groups.

Find out more

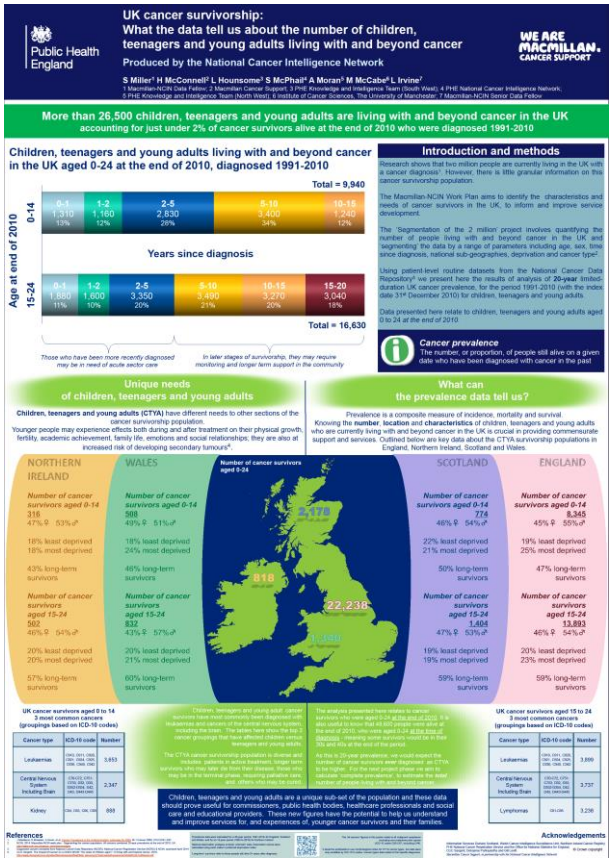
The report is updated on an annual basis; the latest version can be found on the equalities page of the NCIN website

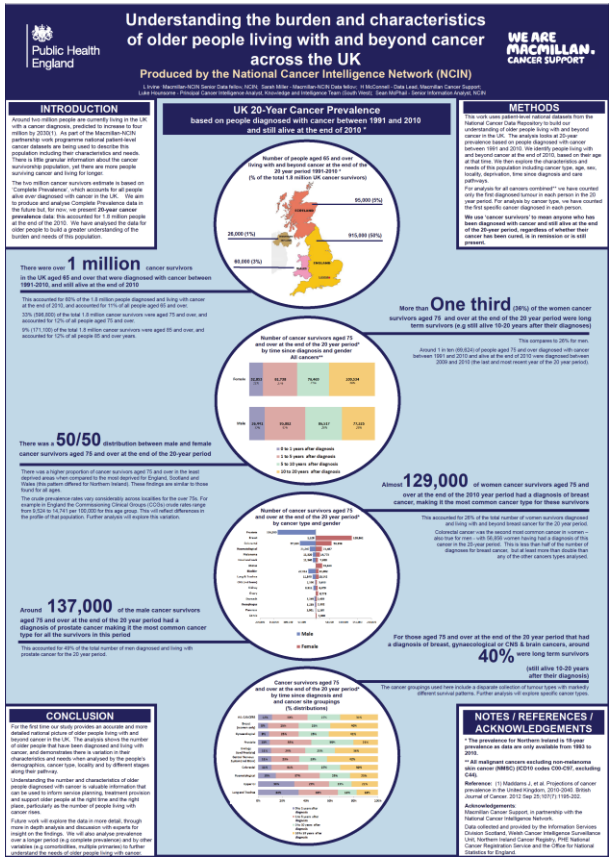
http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality

Produced by the National Cancer Intelligence Network

Public Health England

Older people, younger people





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National Cancer Intelligence Network

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