Public Health England

National Cancer Intelligence Network

Cancer Information in the NHS: sources and uses of data

Mick Peake
Clinical Lead, National Cancer Intelligence Network

Data Drivers

- Government
  - A spotlight on the role of data and transparency
- Commissioning
  - NHS Outcomes Framework
- Regulation
  - New regulation framework (CQC & Monitor)
- The ‘public’, patients and families
  - (e.g. ‘Friends and family test’)

Public Health England

Providers of information in the new NHS

- Main sources/providers
  - Health & Social Care Information Centre (HSCIC)
  - National Audits
  - ONS
  - PHE (Civil Service)- Cancer Registries
  - NHS England Business Intelligence Teams (ATS/CSU)
- Information Intermediaries (e.g. CRUK, Dr Foster, MacMillan)

Public Health England

Public Health England

Cancer functions in Public Health England

- Prevention (smoking; obesity; HPV vaccination, etc.)
- Screening and its QA
- Environmental aetiology (including cluster analyses)
- Public Awareness Campaigns (Be Clear on Cancer Campaigns) – links with Local Authorities and Health & Well Being Boards
- Cancer Intelligence:
  - Registration
  - Analysis
  - Reporting

Public Health England

Public Health England: Emerging 'Intelligence' Structures

Public Health England Chief Knowledge Officer Prof. John Newton

Knowledge and Intelligence & Health Intelligence Networks (Peter Bradley)

Disease Registration Service Dr Jem Rashbass

Office for Data Release Chris Carrigan

National Cancer Intelligence Network Chris Carrigan

Knowledge & Intelligence Teams (NCIN)

Public Health England

Public Health England

Knowledge Directorate

- National Cancer Registration Service
- Analytical workforce from 8 registries moved into regional Knowledge and Intelligence Teams (KITs)
  - SSCRG Lead Area Work Programmes
  - Local contribution
- Health Intelligence Networks (HINs):
  - Mental Health, Maternal & Child Health, Cardiovascular & Diabetes, End of Life, **NCIN**

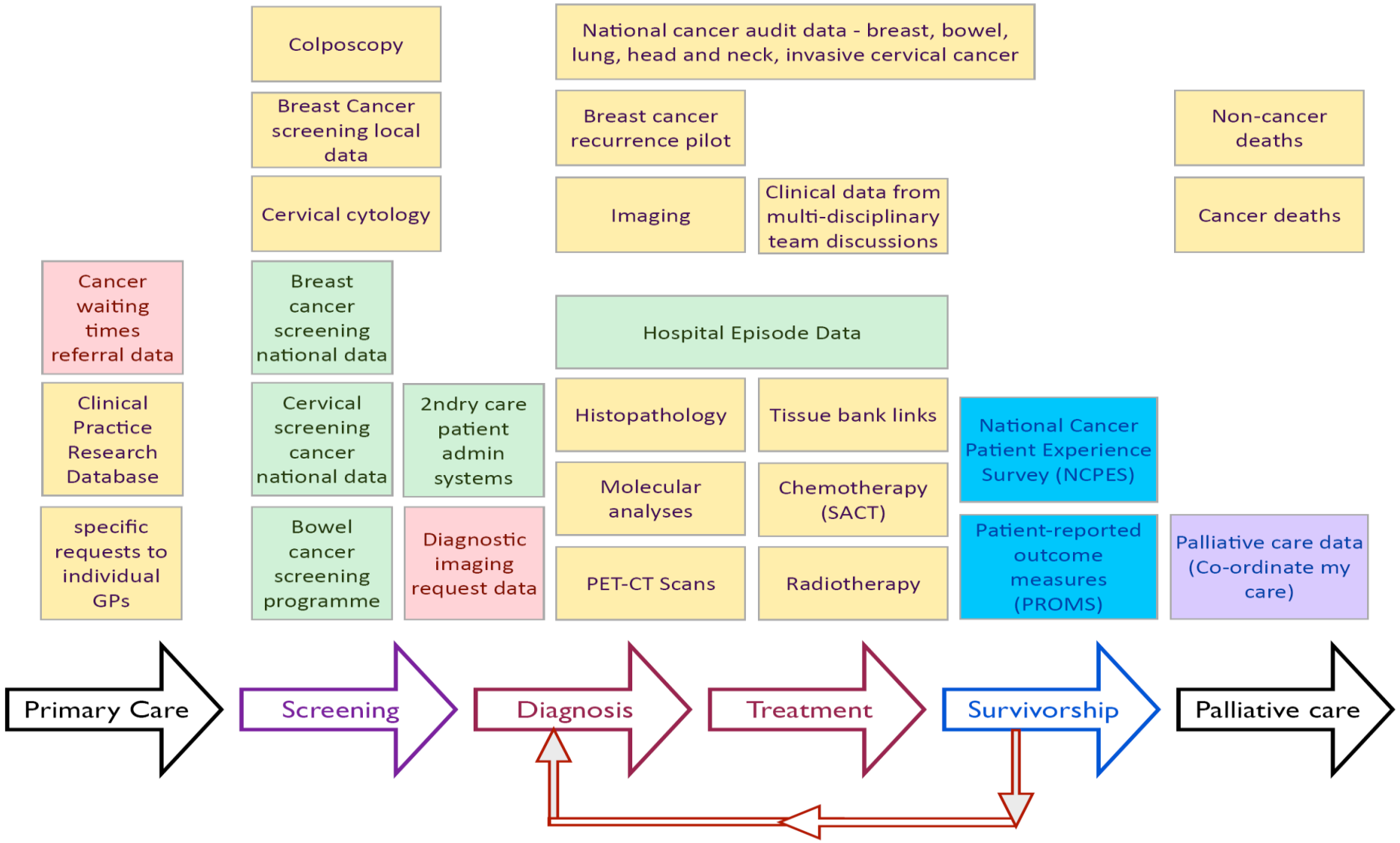
Public Health England

The English National Cancer Registration System

- Comprehensive data collection and quality assurance over the entire cancer care pathway on all patients treated in England
- Single national system across England
- Routine electronic sources in registry practice
- Single integrated workforce – split off from the analytical work force
- Director of Disease Registration
- Evolving operational links with hospital leads
- Pan-England roll-out completed September 2013

Public Health England

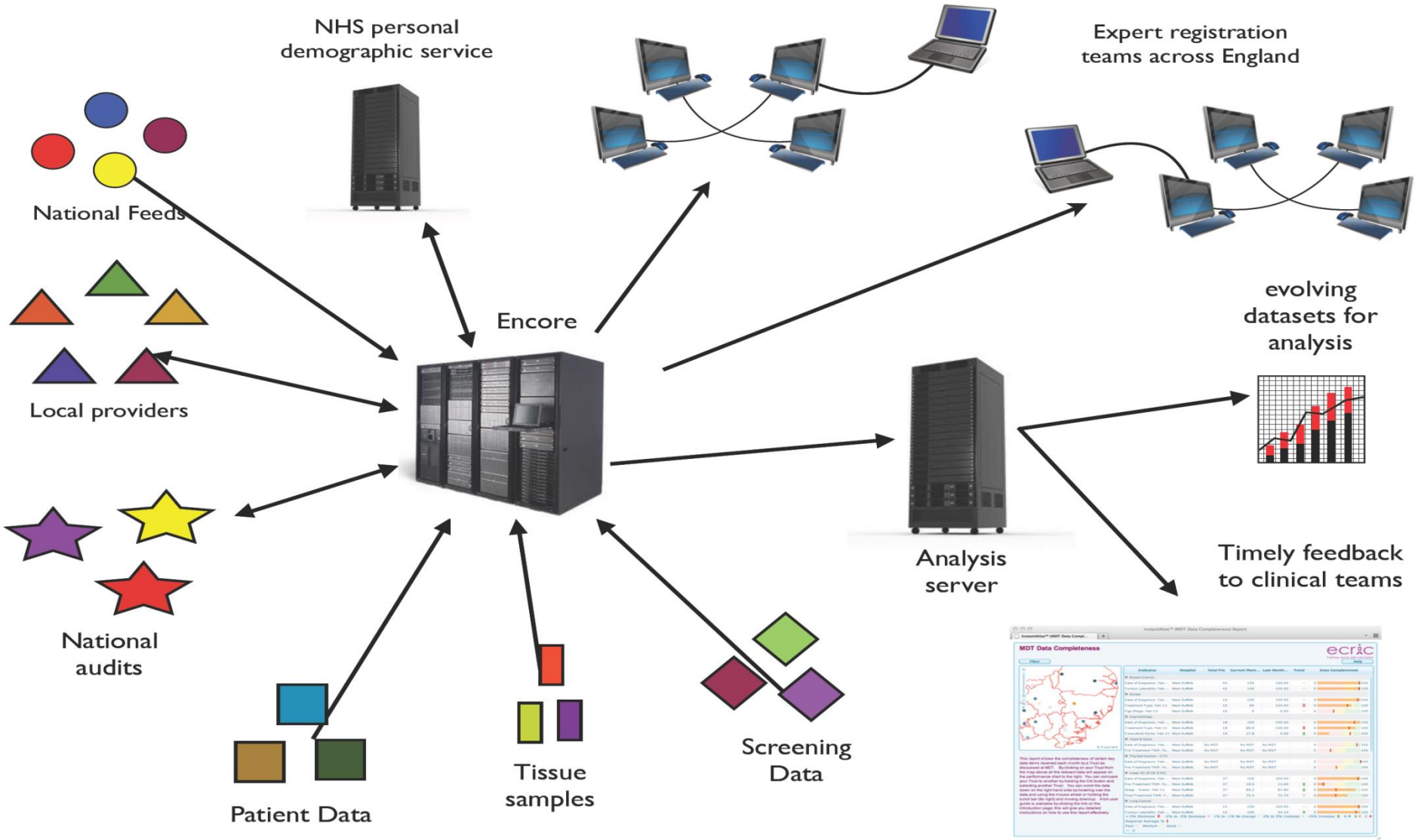
National Cancer Registration Service: Data Sources



Public Health England

NCRS – ENCORE

(English National Cancer Online Registration Environment)



Public Health England

National Cancer Audits

- New contracts for National Lung and Colo-rectal cancer audits awarded December 2014:
    - Lung Cancer – RCP with NCRS
    - Colo-rectal Cancer – RCS with the HSC Information Centre
- Contract for Head & Neck Cancer Audits not awarded
- Upper GI Cancer audit ongoing – contract until 2016
- New Prostate Cancer Audit began 2014
- Breast cancer audit likely to be commissioned in 2015

Public Health England

National Cancer Audits

NPCA
National Prostate Cancer Audit

RCS
ADVANCING SURGICAL STANDARDS

- New model for national cancer audits
  - Partnership between NCRS and professional bodies
- Information governance and data QA managed by NCRS
  - Near-real-time data collection from MDTs
  - Data set largely collected as part of routine flows
- Continuous feedback to clinicians and MDTs
- NCRS produces linked audit datasets for analysis

Public Health England

Who do we produce intelligence for?

- Clinicians & Clinical Teams
- NHS England (e.g. specialist commissioning)
- Clinical Commissioning Groups
- Health Care Providers
- NICE
- CQC
- Research Community
- National Statistics
- International Cancer Benchmarking Partnership
- Patients and the public
- Pharmaceutical Industry

Feeding back: examples

Public Health England

- E Atlas
- Reports and data briefings
- Cancer Commissioning Toolkit
- Service & GP Profiles
- COSD portal – Clinical Headline Indicators

Cancer Service Profiles for Lung Cancer

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NCIN national cancer intelligence network
Using information to improve quality & choice
NHS
National Cancer Action Team
Part of the National Cancer Programme

NHS Acute Trust

Select Trust/MDT

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Size	1	Number of newly diagnosed lung cancer patients per year, 2010 [experimental] (1)										
	2	Number of NLCA patients - lung cancer										
	3	Number of NLCA patients - mesothelioma										
Demographics (based on newly diagnosed patients, 2010)	4	Patients (from #1) aged 70+										
	5	Patients (from #1) with recorded ethnicity										
	6	Patients (from #5) with recorded ethnicity which is not White-British										
	7	Patients (from #1) who are Income Deprived (2)										
	8	Male patients (from #1)										
	9	Number and proportion of patients (from #2) with a stage assigned										
	10	Number and proportion of patients, excluding SCLC, with stage I or II assigned										
	11	Number and proportion of patients, excluding SCLC, with a stage IIIA assigned										
	12	Number and proportion of patients, excluding SCLC, with a stage IIIB and IV assigned										
	13	Proportion of patients (from #2) with a Performance Status assigned										
Waiting times	27	Urgent GP referrals for suspected cancer diagnosed with cancer [experimental]	103	25%	21%	30%	24%	4%		46%	CWT	2011/12
	28	Cases treated that are urgent GP referrals with suspected cancer [experimental]	34	25%	19%	33%	39%	0%		76%	CWT	2011/12
	29	Q2 2012/13: First treatment began within 31 days of decision to treat	14	100%	78%	100%	99%	91%		100%	CWT	2012/13 Q2
Practice	30	No. and proportion of patients (from #2) receiving surgery, chemotherapy and/or radiotherapy	174	53%	47%	58%	60%	36%		100%	NLCA	2011
	31	No. and proportion resected of patients (from #2) excluding confirmed SCLC	50	17%	13%	22%	16%	0%		38%	NLCA	2011
	32	No. and proportion resected of patients (from #2) with confirmed NSCLC	48	26%	20%	33%	21%	0%		45%	NLCA	2011
	33	No. and proportion resected of patients (from #2), excluding confirmed SCLC ,with stage I and II disease	40	48%	38%	59%	53%	0%		100%	NLCA	2011
	34	No. and proportion of patients (from #2) with confirmed SCLC receiving chemotherapy	27	68%	52%	80%	68%	0%		100%	NLCA	2011
	35	No. and prop. of patients (from #2) with stage IIIB/IV, PS 0-1 excl. conf. SCLC, receiving chemotherapy	28	58%	44%	71%	55%	0%		100%	NLCA	2011
Outcomes and Recovery	36	First outpatient appointments and proportion of all outpatient appointments	23,053	41%	41%	41%	32%	15%		68%	PBR SUS	2011/12
	37	NLCA: Median survival in days and adjusted hazard ratio for mortality	176	0.95	0.82	1.11	1.0	0.57		1.49	NLCA	2011
	38	NLCA: Proportion of patients surviving at one year and adjusted odds ratio of surviving 1 year	34%	1.43	0.97	2.11	1.0	0.40		2.67	NLCA	2011
Patient Experience - CPES (4)	39	Patients surveyed & % reporting always being treated with respect & dignity (6)	13	n/a			83%	66%		100%	CPES	2011/12
	40	Number of survey questions and % of those questions scoring red and green (7) — % Red	0	n/a				0%		78%	CPES	2011/12
	41	Number of survey questions and % of those questions scoring red and green (7) — % Green		n/a				0%		69%	CPES	2011/12

Notes: (1) Large differences between indicators #1 and #2 are likely to indicate a large fraction of patients referred to or from the trust (2) Based on patient postcode and uses the Index of Multiple Deprivation (IMD) 2010; (3) Peer Review (NCPR) source - IV=Internal Verification, PR=Peer Review, SA=Self-Assessment; Amn=Amnesty; (4) The immediate risks or serious concerns may now have been resolved or have an action plan in place for resolution; (5) CNS = Clinical Nurse Specialist; (6) value = total number of survey respondents for tumour group. (7) Based on scoring method used by the Department of Health - red/green scores given for survey questions where the trust was in the lowest or highest 20% of all trusts. Questions with lower than 20 respondents were not given a score. Italic value displayed = the total number of viable survey questions, used as the denominator to calculate the % of red/greens for the trust; (8) CPES = Cancer Patient Experience Survey.
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England median

Lowest in England | 25th | 75th | Highest in England

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Sp... T...	14	Peer review: Does the specialist team have full membership? (3)										2010/11
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Thro... pat...	18	Number and proportion of patients (from #2) seen by CNS (5)										2010/11
												2011
												2011
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Specialist Team

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	22	Number and proportion of patients (from #2) with confirmed NSCLC who are diagnosed NOS										
	23	Number and proportion of patients (from #2) with histological confirmation of diagnosis										
	24	Estimated proportion of tumours with emergency presentations [experimental]										
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Specialist Team	14	Peer review: Does the specialist team have full membership? (3)	SA	Yes							NCPR	2010/11
	15	Peer review: Proportion of peer review indicators met	SA	85%			89%				NCPR	2010/11
	16	Peer review: are there immediate risks? (4)	SA	No							NCPR	2010/11
	17	Peer review: are there serious concerns? (4)	SA	No							NCPR	2010/11
	18	Number and proportion of patients (from #2) seen by CNS (5)	206	63%	57%	68%	79%	0%		100%	NLCA	2011

Practice	30	No. and proportion of patients (from #2) receiving surgery, chemotherapy and/or radiotherapy
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	40	Number of survey questions and % of those questions scoring red and green (7) — % Red
	41	% Green

Public Health England

National Cancer Intelligence Network

Cancer Commissioning Toolkit

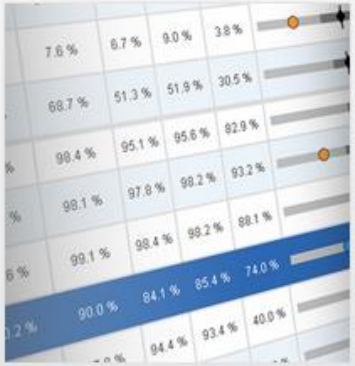
Kath Yates

Home | Dashboards | Comparisons | Profiles | Charts | Background | Updates

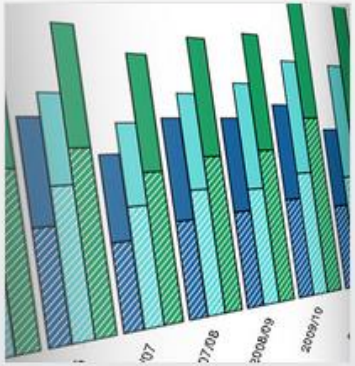
Home

Dashboards
Making the data count
View a snapshot of data by organisation group to support quality, services & outcomes.

Comparisons
Comparative reporting of data
Compare your organisation/service, establish baselines & identify issues.



Profiles
Improving outcomes
Understanding variation of both patient experience & service deilvery using data indicators.

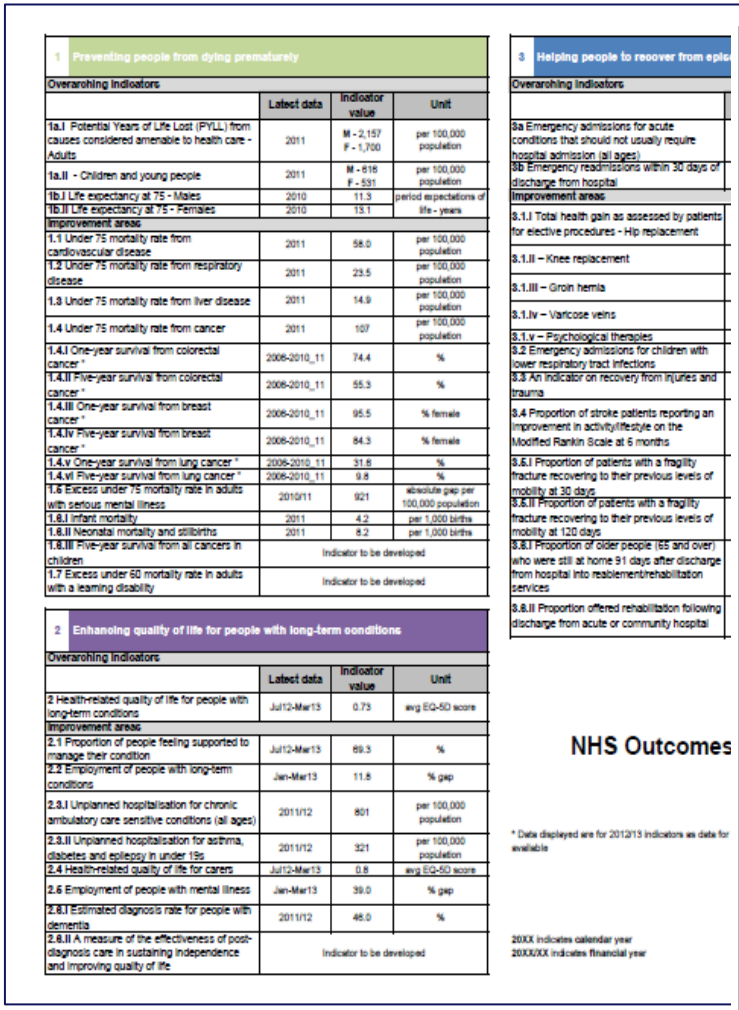


Charts
Increase the value of data
View or download trends to benchmark along the patient pathway by accessing in depth data.

Background

Help

NHS Outcome Framework 2013/14 Dashboard



1 Preventing people from dying prematurely

Overarching indicators

	Latest data	Indicator value	Unit
1a.i Potential Years of Life Lost (PYLL) from causes considered amenable to health care - Adults	2011	M - 2,157 F - 1,700	per 100,000 population
1a.ii - Children and young people	2011	M - 616 F - 531	per 100,000 population
1b.i Life expectancy at 75 - Males	2010	11.3	period expectations of life - years
1b.ii Life expectancy at 75 - Females	2010	13.1	
Improvement areas			
1.1 Under 75 mortality rate from cardiovascular disease	2011	58.0	per 100,000 population
1.2 Under 75 mortality rate from respiratory disease	2011	23.5	per 100,000 population
1.3 Under 75 mortality rate from liver disease	2011	14.9	per 100,000 population
1.4 Under 75 mortality rate from cancer	2011	107	per 100,000 population
1.4.i One-year survival from colorectal cancer *	2006-2010_11	74.4	%
1.4.ii Five-year survival from colorectal cancer *	2006-2010_11	55.3	%
1.4.iii One-year survival from breast cancer *	2006-2010_11	95.5	% female
1.4.iv Five-year survival from breast cancer *	2006-2010_11	84.3	% female
1.4.v One-year survival from lung cancer *	2006-2010_11	31.8	%
1.4.vi Five-year survival from lung cancer *	2006-2010_11	9.8	%
1.6 Excess under 75 mortality rate in adults with serious mental illness	2010/11	921	absolute gap per 100,000 population
1.8.i Infant mortality	2011	4.2	per 1,000 births
1.8.ii Neonatal mortality and stillbirths	2011	8.2	per 1,000 births
1.8.iii Five-year survival from all cancers in children	Indicator to be developed		
1.7 Excess under 60 mortality rate in adults with a learning disability	Indicator to be developed		

2 Enhancing quality of life for people with long-term conditions

Overarching indicators

	Latest data	Indicator value	Unit
2 Health-related quality of life for people with long-term conditions	Jul12-Mar13	0.73	avg EQ-5D score
Improvement areas			
2.1 Proportion of people feeling supported to manage their condition	Jul12-Mar13	69.3	%
2.2 Employment of people with long-term conditions	Jan-Mar13	11.8	% gap
2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (all ages)	2011/12	801	per 100,000 population
2.3.ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s	2011/12	321	per 100,000 population
2.4 Health-related quality of life for carers	Jul12-Mar13	0.8	avg EQ-5D score
2.6 Employment of people with mental illness	Jan-Mar13	39.0	% gap
2.8.i Estimated diagnosis rate for people with dementia	2011/12	46.0	%
2.8.ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life	Indicator to be developed		

3 Helping people to recover from epis

Overarching indicators

3a Emergency admissions for acute conditions that should not usually require hospital admission (all ages)

3b Emergency readmissions within 30 days of discharge from hospital

Improvement areas

3.1.i Total health gain as assessed by patients for elective procedures - Hip replacement

3.1.ii – Knee replacement

3.1.iii – Groin hernia

3.1.iv – Varicose veins

3.1.v – Psychological therapies

3.2 Emergency admissions for children with lower respiratory tract infections

3.3 An indicator on recovery from injuries and trauma

3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months

3.5.i Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 30 days

3.5.ii Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 120 days

3.8.i Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services

3.8.ii Proportion offered rehabilitation following discharge from acute or community hospital

NHS Outcomes

* Data displayed are for 2012/13 indicators as data for available

20XX indicates calendar year
20XX/XX indicates financial year

1 Preventing people from dying prematurely

Overarching indicators

	Latest data	Indicator value	Unit
1a.i Potential Years of Life Lost (PYLL) from causes considered amenable to health care - Adults	2011	M - 2,157 F - 1,700	per 100,000 population
1a.ii - Children and young people	2011	M - 616 F - 531	per 100,000 population
1b.i Life expectancy at 75 - Males	2010	11.3	period expectations of life - years
1b.ii Life expectancy at 75 - Females	2010	13.1	
Improvement areas			
1.1 Under 75 mortality rate from cardiovascular disease	2011	58.0	per 100,000 population
1.2 Under 75 mortality rate from respiratory disease	2011	23.5	per 100,000 population
1.3 Under 75 mortality rate from liver disease	2011	14.9	per 100,000 population
1.4 Under 75 mortality rate from cancer	2011	107	per 100,000 population
1.4.i One-year survival from colorectal cancer *	2006-2010_11	74.4	%
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1.4.iii One-year survival from breast cancer *	2006-2010_11	95.5	% female
1.4.iv Five-year survival from breast cancer *	2006-2010_11	84.3	% female
1.4.v One-year survival from lung cancer *	2006-2010_11	31.6	%
1.4.vi Five-year survival from lung cancer *	2006-2010_11	9.8	%
1.5 Excess under 75 mortality rate in adults with serious mental illness	2010/11	921	absolute gap per 100,000 population
1.6.i Infant mortality	2011	4.2	per 1,000 births
1.6.ii Neonatal mortality and stillbirths	2011	8.2	per 1,000 births
1.6.iii Five-year survival from all cancers in children	Indicator to be developed		

Clinical Commissioning Group Outcomes Indicator Set

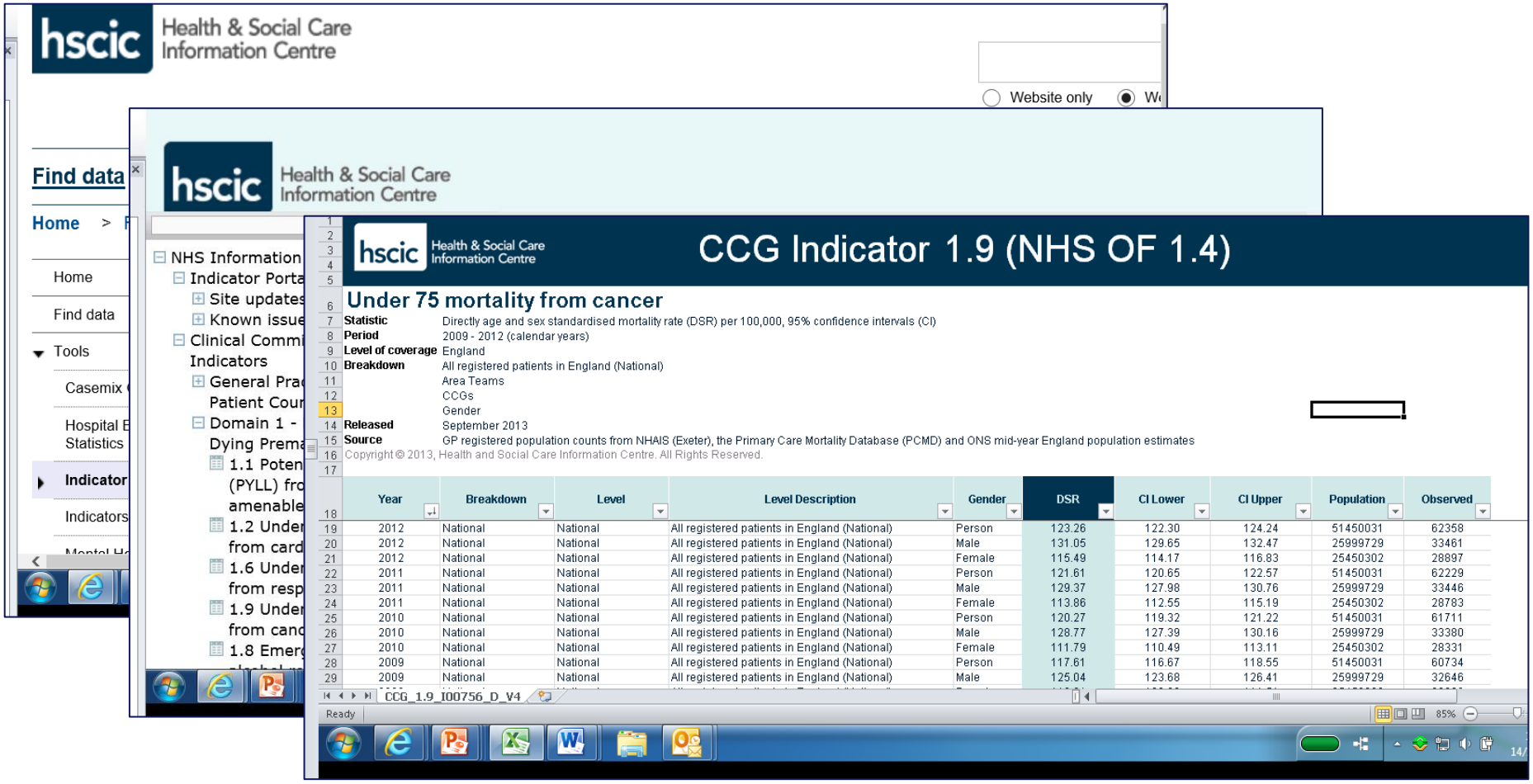
2013/14 under 75 mortality rate from cancer

- 1 and 5 year survival from all cancers
- 1 and 5 year survival from breast, lung & colorectal cancers

2014/15 additional indicators for cancer

- cancers diagnosed via emergency routes
- 5 year survival - children
- cancer stage at diagnosis
- cancers detected at stage 1 or 2
- 1 and 5 yr survival for lung, breast and colorectal cancers

HSCIC Indicator Portal



Public Health England

Examples of the clinical value of new data

- Demonstration of variation
- Teasing out the causes of variation
- Demonstrating value of specialisation
- Building data into quality improvement
- Adding outcome data into Peer Review
- More meaningful regulation - CQC
- Providing robust evidence behind National Guidelines and Quality Standards (NICE)
- Supporting ‘intelligent commissioning’
- Supporting Clinical Trials

Public Health England

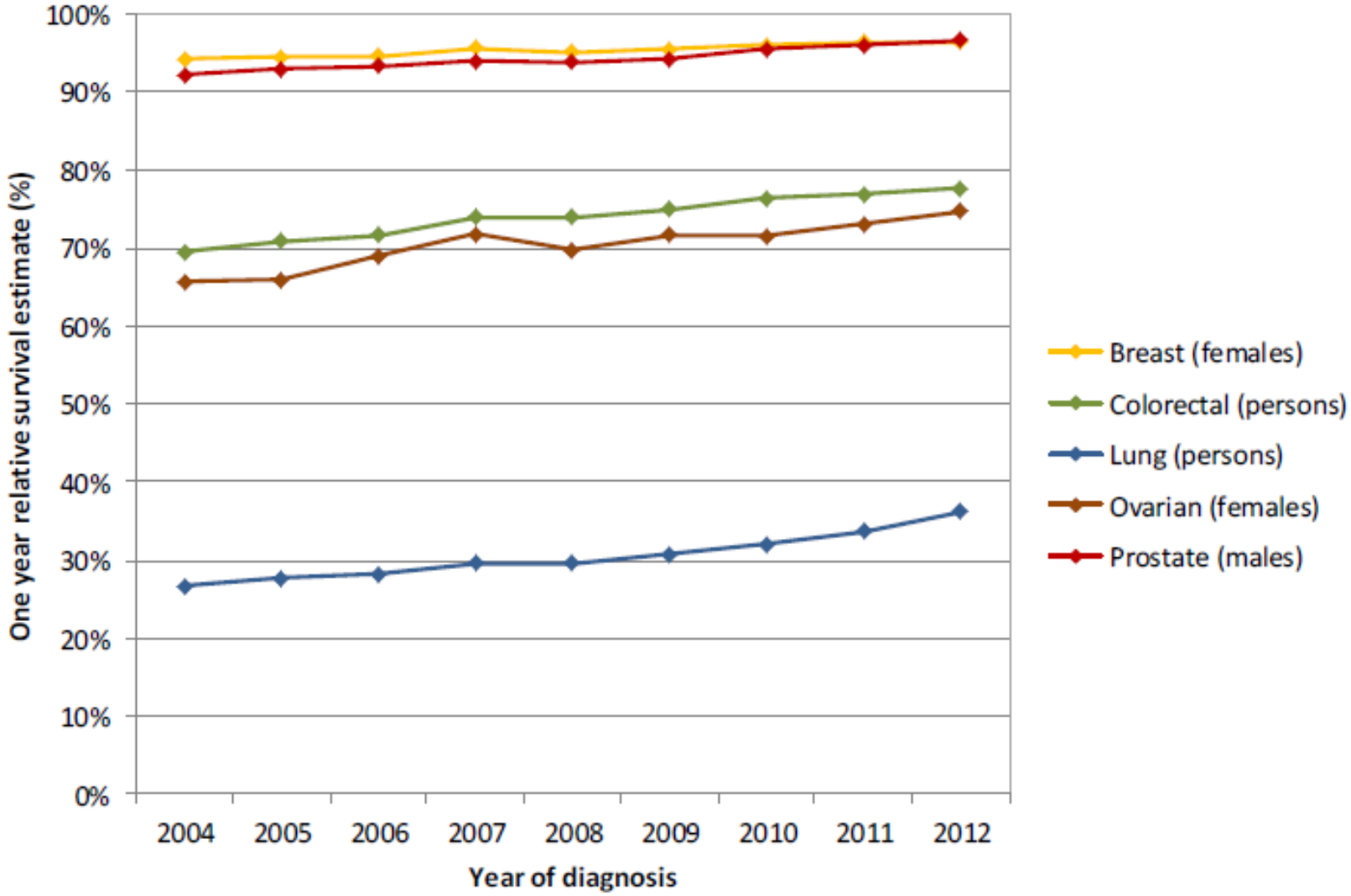
National Cancer Intelligence Network

Cancer survival in England by stage

www.ncin.org.uk

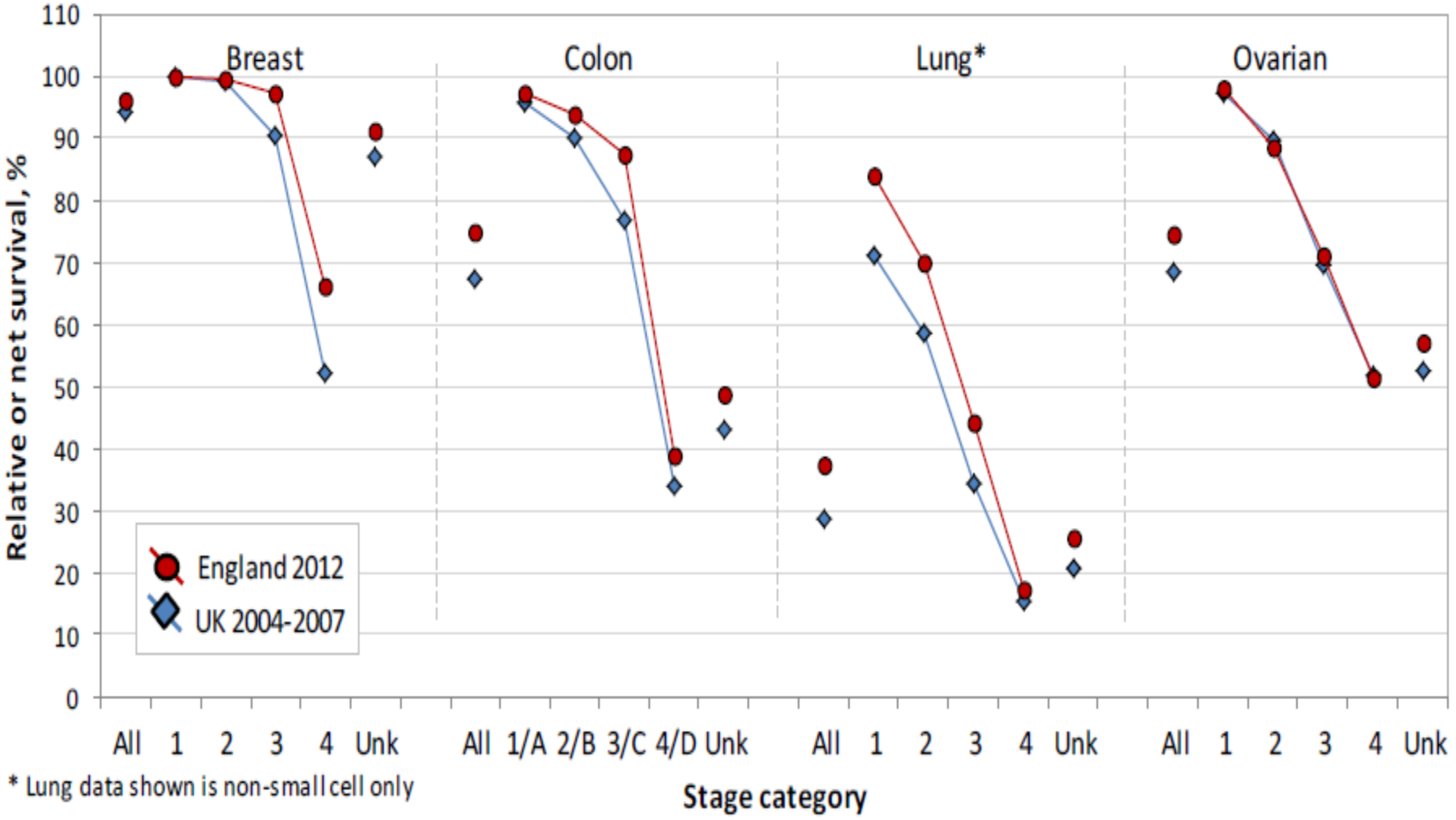
Public Health England

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



Public Health England

Figure 4 One-year relative/net survival, by stage, in the ICBP and England 2012 data



* Lung data shown is non-small cell only

Conclusions

- The quality and range of clinically relevant data on cancer is increasing rapidly
- The collection and intelligent use of data are at the heart of good clinical practice and commissioning
- We now have a large and expanding clinical community engaged with cancer data
- Feedback and ongoing interaction with clinicians is an essential part of the process – peer pressure is powerful
- There is a need to improve how information is used at a local level
- It is vital that we co-ordinate the work of the NCIN's SSCRGs and NHS England's CRGs