

What the NCIN is doing for Less Common cancers...

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To be covered today.....

- What is “Less Common”
- What do we already know
- What are we planning
 - Inputs
 - Process
 - Outputs
- Questions

What is “Less Common”?

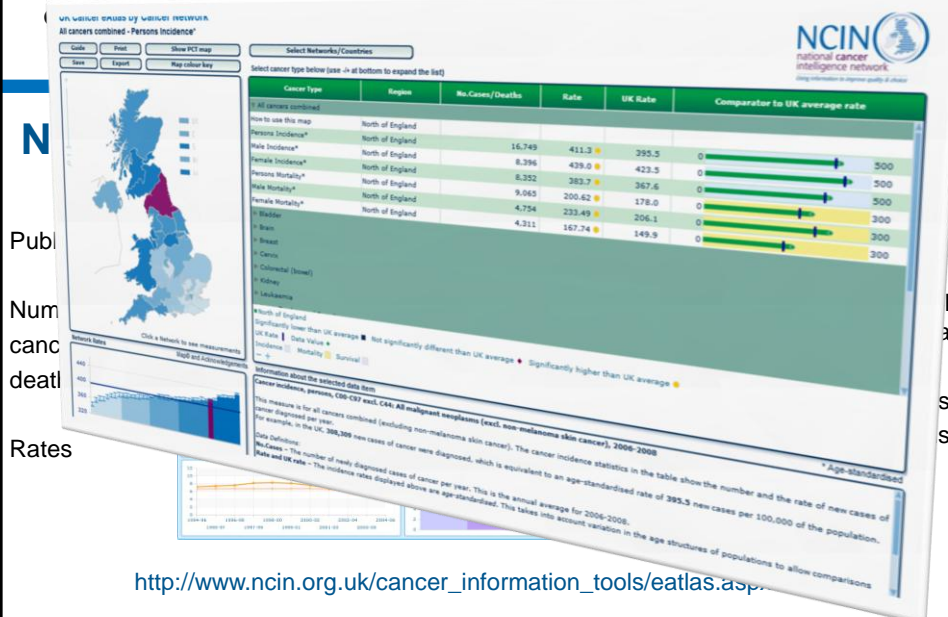
What is “Less Common”?

- “Common” (just under half)
 - Breast, Colorectal, Lung & Prostate
 - 30,000 – 40,000 each
- “Less Common” (just over half)
 - All other cancers
 - 10,000 or fewer

What do we already know?



Published sources which have statistics



Published sources and tools which have statistics on less common cancers

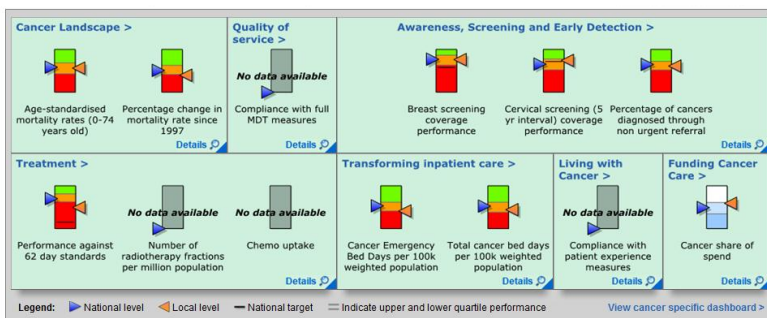


Cancer Commissioning Toolkit

http://www.ncin.org.uk/cancer_information_tools/cct.aspx

Key information for commissioners, but Charities can have access too.

14 cancer types



Published sources and tools which have statistics on less common cancers



NCIN Statistical reports

Usually statistics for 22 cancer types

<http://www.ncin.org.uk/publications/reports/default.aspx>

Examples:

- UK incidence & mortality
- Cancer survival
- Incidence by Deprivation
- Prevalence
- Cancer by Ethnicity

Five-year cancer prevalence by cancer site, England, 31st December 2006

Cancer site	Males			Females			Persons		
	No. of patients	standardised proportion	95% confidence interval	No. of patients	standardised proportion	95% confidence interval	No. of patients	standardised proportion	95% confidence interval
C00-C14 & C30-C32: Head and neck	13,852	48.9	48.0 - 49.7	5,388	18.7	18.2 - 19.3	19,240	33.9	32.8 - 35.0
C15: Oesophagus	4,652	16.0	15.5 - 16.5	2,307	6.3	6.0 - 6.6	6,959	10.9	10.6 - 11.1
C16: Stomach	5,092	16.8	16.3 - 17.3	2,622	6.8	6.5 - 7.1	7,714	11.4	11.1 - 11.6
C18-C20: Colorectum	42,096	138.6	137.2 - 139.9	33,214	87.6	86.6 - 88.6	75,310	116.7	115.9 - 117.6
C22: Liver	1,099	3.9	3.7 - 4.1	279	1.8	1.8 - 1.9	1,678	2.8	2.8 - 2.9
C25: Pancreas	1,565	5.4	5.2 - 5.7	1,540	4.5	4.3 - 4.8	3,105	5.0	4.8 - 5.1
C33-C34: Trachea, bronchus and lung	13,656	45.5	44.7 - 46.2	10,669	31.0	30.3 - 31.6	24,325	37.4	37.0 - 37.9
C43: Malignant melanoma	13,497	48.3	47.5 - 49.1	17,561	58.4	57.5 - 59.3	31,058	55.2	54.5 - 55.8
C45: Mesothelioma	1,330	4.5	4.2 - 4.7	320	0.9	0.8 - 1.1	1,650	2.6	2.5 - 2.7
C50: Breast	937	3.1	2.9 - 3.3	147,807	480.1	477.6 - 482.6	148,744	251.7	250.4 - 253.0
C53: Cervix uteri				9,233	30.6	30.4 - 30.7			
C54-C55: Uterus				19,569	60.9	60.1 - 61.6			
C56: Ovary				13,005	43.6	42.8 - 44.3			
C61: Prostate	108,243	347.8	345.8 - 349.9						
C62: Testis	7,751	30.6	29.9 - 31.3						
C64-C66 & C68: Kidney	6,567	21.0	20.2 - 21.8	5,263	16.2	15.7 - 16.7	11,830	23.1	22.7 - 23.5
C67: Bladder	16,248	51.7	50.9 - 52.6	5,106	12.7	12.3 - 13.0	21,354	39.0	38.6 - 39.5
C70-C72: Brain and other parts of CNS	3,007	11.9	11.5 - 12.4	2,172	8.5	8.1 - 8.8	5,179	10.2	9.9 - 10.5
C81: Hodgkin disease	2,939	11.5	11.1 - 12.0	2,236	8.5	8.2 - 8.9	5,175	10.0	9.7 - 10.3
C82-C85 & C86: Non-Hodgkin lymphoma	12,898	45.6	44.8 - 46.4	11,309	34.4	33.7 - 35.1	24,207	39.7	39.2 - 40.2
C88 & C89: Myeloma	4,277	14.5	14.1 - 14.9	3,404	9.6	9.3 - 10.0	7,681	11.9	11.6 - 12.1
C91-C95: Leukaemia	8,225	28.8	28.1 - 29.5	5,762	18.7	18.3 - 19.2	14,017	23.9	23.5 - 24.4
Other Malignant Neoplasms*	12,555	45.5	44.7 - 46.3	17,901	57.9	57.0 - 58.8	30,456	51.8	51.2 - 52.4
C00-C97 excl. C44: All malignant neoplasms (incl. Non-melanoma skin cancer)	222,535	651.0	647.9 - 654.1	216,524	577.0	573.4 - 580.6	539,059	861.5	858.0 - 865.0

*Age-standardised proportion to the European Standard Population. Crude and age-standardised proportions are shown per 100,000 population.
*All other malignant neoplasms includes the following ICD-10 codes: C17, C21, C23-C24, C26, C27-C31, C40-C42, C47-C52, C57-C59, C60, C63, C69, C73-C80, C83.

Source: ONS, Play and Terrence Cancer Prevalence, UK, 31st December 2006, NCIN, Cancer Registry and Metastatic Cancer Support, <http://www.ncin.org.uk/publications/default.aspx>

Published sources and tools which have statistics on less common cancers



NCIN specialised Analysis/Tools

<http://www.ncin.org.uk/publications/default.aspx>

- Routes to diagnosis
- Major resections
- Cancer in Men
- Cancer equalities portal
- Profiles e.g for GP practices

All Persons	Screen detected	Two Week Wait	GP referral	Other outpatient	Inpatient elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients	
Acute leukaemia		3%	17%	14%	4%	57%	0%	4%	100%	2,551	
Bladder		32%	28%	15%	2%	18%	0%	4%	100%	7,665	
Brain & CNS		1%	17%	14%	4%	58%	0%	6%	100%	4,147	
Breast	21%	42%	12%	9%	0%	4%	0%	12%	100%	34,232	
Cervix	14%	16%	25%	16%	2%	12%	0%	13%	100%	2,085	
Chronic leukaemia		10%	30%	12%	2%	30%	1%	16%	100%	2,869	
Colorectal		26%	24%	15%	4%	25%	1%	6%	100%	27,903	
Kidney		20%	29%	18%	1%	24%	1%	6%	100%	5,172	
Larynx		31%	32%	21%	1%	12%	0%	3%	100%	1,583	
Lung		22%	20%	13%	1%	38%	1%	5%	100%	29,420	
Melanoma		41%	29%	11%	1%	3%	0%	16%	100%	8,117	
Multiple myeloma		13%	27%	15%	1%	38%	0%	6%	100%	3,145	
Non-Hodgkin's lymphoma		16%	30%	17%	2%	28%	0%	7%	100%	7,777	
Oesophagus		25%	21%	17%	10%	21%	1%	4%	100%	6,001	
Oral		26%	28%	30%	1%	6%	0%	9%	100%	3,062	
Other		14%	25%	15%	2%	36%	1%	7%	100%	27,730	
Ovary		26%	22%	15%	1%	23%	1%	6%	100%	5,012	
Pancreas		13%	18%	12%	2%	47%	1%	6%	100%	5,989	
Prostate		20%	38%	16%	3%	9%	0%	14%	100%	28,362	
Stomach		17%	21%	16%	7%	32%	1%	5%	100%	5,841	
Testis		48%	14%	16%	2%	10%	0%	10%	100%	1,569	
Uterus		35%	31%	16%	1%	8%	0%	8%	100%	5,733	
Total		3%	25%	24%	14%	2%	23%	1%	8%	100%	225,965

Published sources and tools which have statistics on less common cancers

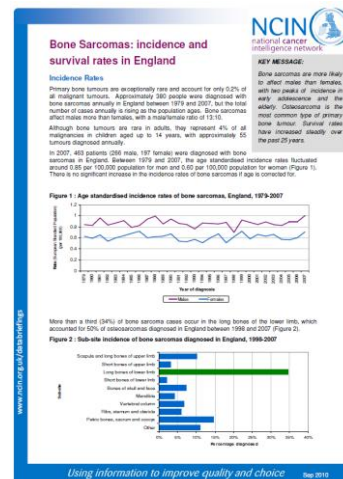


NCIN data briefing and the Site Specific Clinical Reference Groups (SSCRGs)

http://www.ncin.org.uk/publications/data_briefings/default.aspx

Example briefsheets:

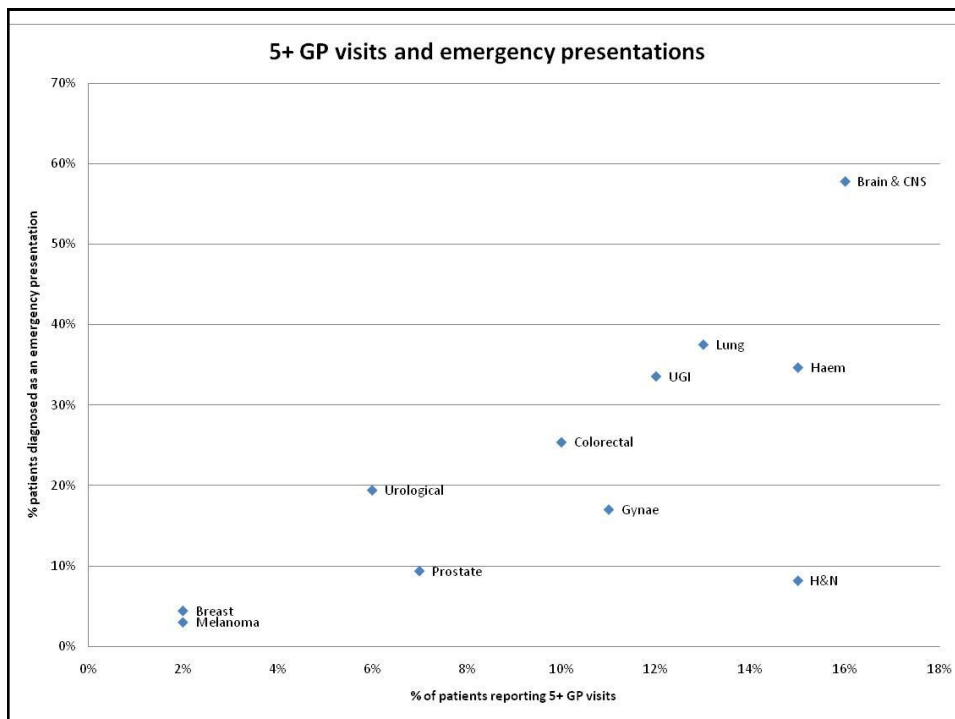
- Bone Sarcomas: incidence and survival rates
- Malignant Pleural Mesothelioma
- Route to Diagnosis
- Oral Cavity Cancer
- Geographic Variation in cancer of the lower oesophagus
- Geographic Variation in primary liver and gall bladder cancer



Pooling knowledge



- 40% of patients with less common cancers waited for over 3 months before seeking medical advice
 - [Rarer Cancers Foundation](#)
- Patients with rarer cancers visit their GP on three or more occasions prior to onward referral
 - [Patient Experience Survey \(2010\)](#)
- Patients diagnosed at Emergency have far poorer survival
 - [Routes to Diagnosis \(2010\)](#)



What are we planning?

Inputs, Process, Outputs

Inputs

- Cancer Outcomes and Services Dataset
 - Site-specific data items
 - Trust requirement to submit
- Systemic Anti-Cancer Therapy dataset
 - Chemotherapy
- Piloting augmented Brain data collection
- Piloting secondary Breast cancer

Process

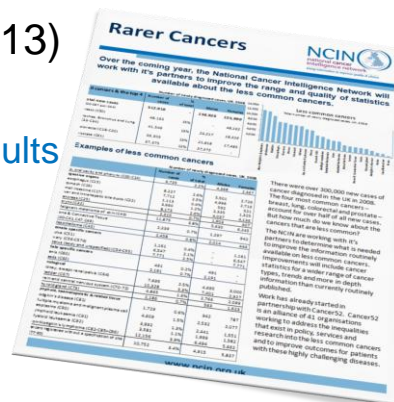


- Shift in Timeliness
 - 2008 completed in 18 months
 - 2009 completed in 15 months
 - 2010 due to be 12 months
- Single National System (ENCORE)
 - Already underway, complete by end 12/13
- Improved and Consistent Staging
 - National Staging Panel

National Work Programme



- National (central) analyses
- Site-specific analyses (13)
 - Children
 - Teenage and Young Adults
 - Plus 7 (less common) cancer-types



Outputs



- Rules and regulations - small numbers
- Statistics for rarer cancers
 - NCIN and Cancer 52 website
 - Trends in Incidence, Mortality and Survival for less common cancers
 - Compare with common cancers
- Information about CUPs

Outputs



- Earlier diagnosis
 - Extend Routes to Diagnosis (2006-2008)
 - Less common vs. Top-4?
- Experience of Care
 - Detailed analysis of PES (w. Macmillan)
- Profiles by cancer type?
 - Myeloma example at the C52 workshop **

And finally, the Future



- Completely different scenario
- Complexity and Depth
- Patient as the denominator
- Disease, time, characteristic
- Speciality-extensible
- Information Governance

So what is “Less Common”?



- Breast cancer in a young woman?
- Lung Cancer in a patient with a particular genetic type?
- Particular set of co-morbid conditions?

Some final thoughts for you and me....



- Targeted Investment
 - £1,000 from each Cancer52 member buys a full time analyst
- Prioritisation
 - Making sure that the less common cancers get fair coverage
- Can't do everything yet...!



What the NCIN is doing for less common cancers...

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