

## 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”?

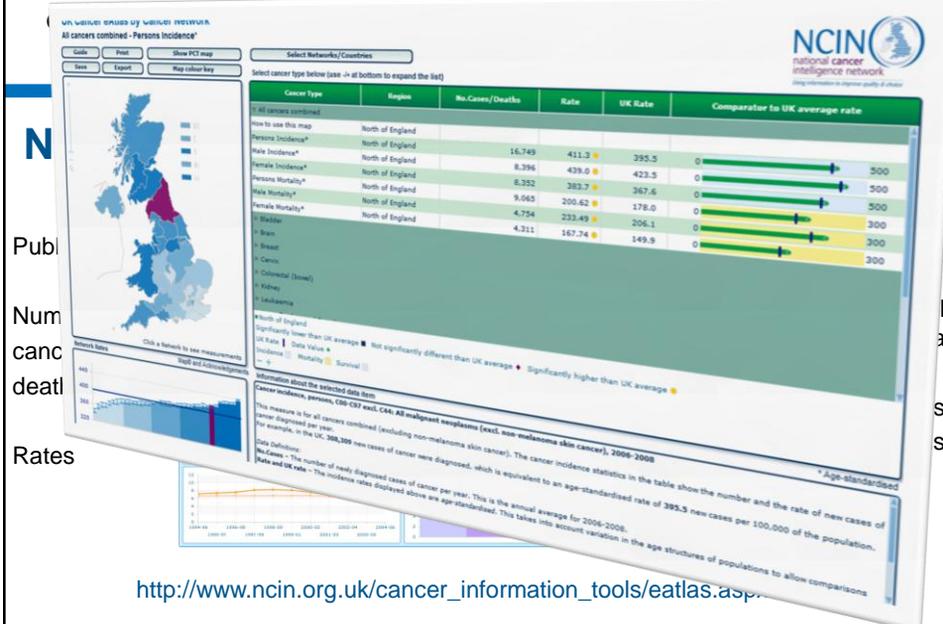
## What is “Less Common”?

- “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



The screenshot shows the EAtlas tool interface with the following data table:

Cancer Type	Region	No. Cases/Deaths	Rate	UK Rate	Comparator to UK average rate
All cancers combined	North of England				
Persons Incidence*	North of England			395.5	0
Male Incidence*	North of England	16,749	411.3	422.5	0
Female Incidence*	North of England	8,396	352.7	367.6	0
Persons Mortality*	North of England	8,352	200.62	178.0	0
Male Mortality*	North of England	9,040	233.49	206.1	0
Female Mortality*	North of England	4,754	167.74	149.9	0

Additional information from the screenshot:

- UK Rate:** 395.5 (Age-standardised)
- UK Rate - Incidence:** 422.5
- UK Rate - Mortality:** 178.0
- UK Rate - Survival:** 206.1
- UK Rate - All malignant neoplasms (excl. non-melanoma skin cancer):** 300

Information about the selected data item:  
 Cancer incidence, persons, C00-C97 excl. C44: All malignant neoplasms (excl. non-melanoma skin cancer). The cancer incidence statistics in the table show the number and the rate of new cases of cancer diagnosed per year. This is the annual average for 2006-2008. For example, in the UK, 395,300 new cases of cancer were diagnosed, which is equivalent to an age-standardised rate of 395.5 new cases per 100,000 of the population. This takes into account variation in the age structures of populations to allow comparisons.

[http://www.ncin.org.uk/cancer\\_information\\_tools/eatlas.asp](http://www.ncin.org.uk/cancer_information_tools/eatlas.asp)

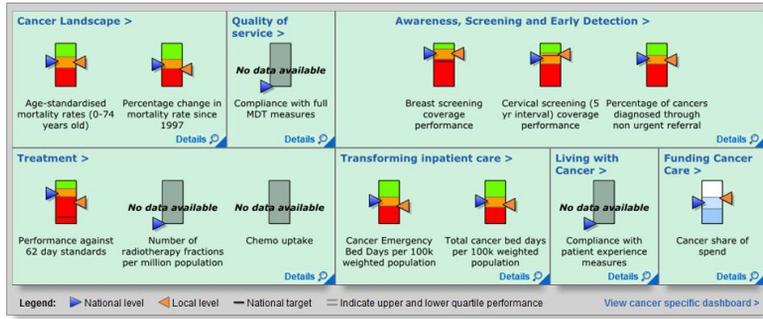
Published sources and tools which have statistics on less common cancers



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	13,552	48.9	46.0 - 49.7	6,365	18.7	16.7 - 19.3	19,917	33.0	32.6 - 33.5
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	116.9 - 116.6
C22: Liver	1,099	3.9	3.7 - 4.1	679	1.8	1.8 - 1.9	1,678	2.5	2.6 - 2.5
C25: Pancreas	1,555	5.4	5.2 - 5.7	1,540	4.2	4.3 - 4.4	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	13,697	48.3	47.6 - 49.1	17,561	58.4	57.5 - 59.3	31,058	53.2	52.5 - 53.8
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				8,233	20.6	20.4 - 20.7			
C54-C55: Uterus				19,569	60.9	60.1 - 61.8			
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-C65 & C68: Kidney	8,967	31.0	30.2 - 31.8	5,263	16.2	15.7 - 16.7	14,230	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	6.5	6.1 - 6.8	5,179	10.2	9.9 - 10.5
C81: Hodgkin disease	2,939	11.5	11.1 - 12.0	2,236	6.5	6.2 - 6.9	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 - 15.0	3,404	9.6	9.3 - 10.0	7,681	11.9	11.6 - 12.1
C91-C95: Leukaemia	8,225	29.8	29.2 - 30.5	5,702	18.7	18.2 - 19.2	14,027	23.9	23.5 - 24.4
C96-C98: Multiple Myeloma	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	222,511	951.9	947.2 - 956.5	216,524	977.0	973.4 - 980.6	509,035	961.5	959.8 - 963.2

\*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 ICD10 codes: C17, C18, C23-C24, C26, C27-C31, C46-C48, C51-C52, C57-C59, C60, C63, C69, C73-C80, C87.  
 Source: ONS, Five and Ten-year Cancer Prevalence, UK, 31st December 2006, NCIN, Thames 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%	34,232	
Cervix	14%	16%	25%	16%	2%	12%	0%	13%	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%	100%	1,569		
Uterus	35%	31%	16%	1%	8%	0%	8%	100%	5,733	
<b>Total</b>	<b>3%</b>	<b>25%</b>	<b>24%</b>	<b>14%</b>	<b>2%</b>	<b>23%</b>	<b>1%</b>	<b>8%</b>	<b>100%</b>	<b>225,965</b>

## Published sources and tools which have statistics on less common cancers

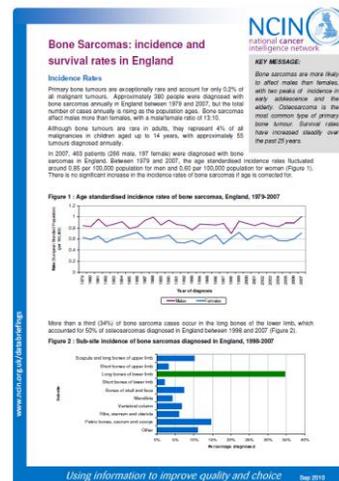


## NCIN data briefing and the Site Specific Clinical Reference Groups (SSCRGs)

[http://www.ncin.org.uk/publications/data\\_briefings/default.aspx](http://www.ncin.org.uk/publications/data_briefings/default.aspx)

Example briefsheets:

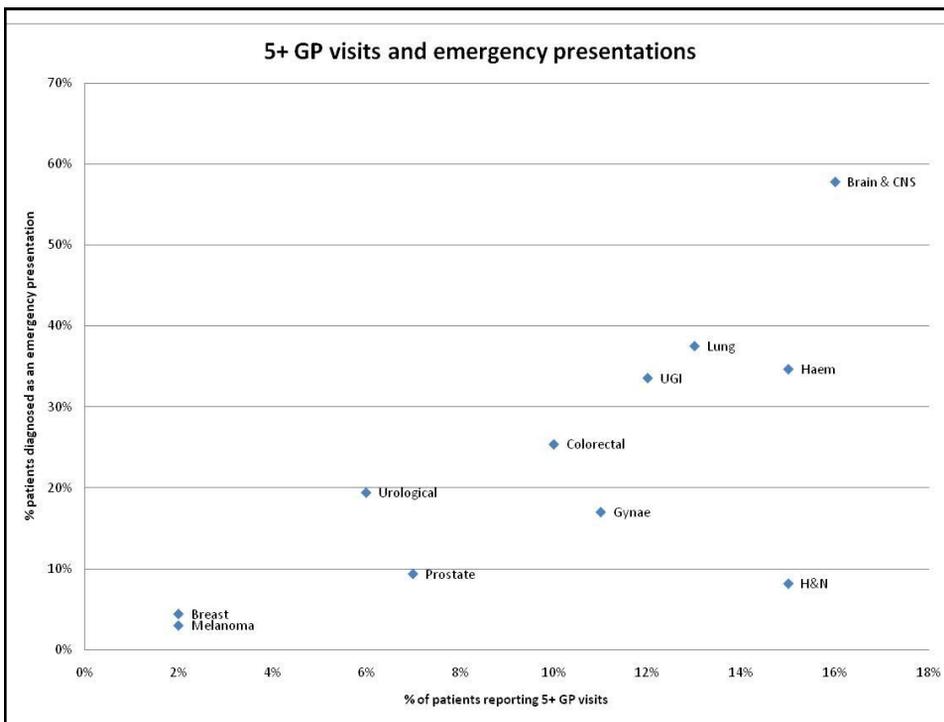
- Bone Sarcomas: incidence and survival rates
- Malignant Pleural Mesothelioma
- Route to Diagnosis
- Oral Cavity Cancer
- Geographic Variation in cancer of the lower oesophagus
- Geographic Variation in primary liver and gall bladder cancer



## 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



## 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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