



The National Cancer Intelligence Network

Sarcoma Work Programme

British Sarcoma Group, February 2010

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Overview

- What is the NCIN?
- What data do we have?
- Initial analysis
- Future work plan
- How you can help



The National Cancer Intelligence Network



*Using information to improve
quality and choice*

- Launched June 2008
- Data collection, national data, analysis, supporting audit and research
- Cancer registries, health service researches, clinical champions...
- Under auspices of National Cancer Research Institute

Lead Cancer Registries



- Each Registry takes a lead on one (or more) cancer sites
- Initially 11 cancer sites chosen
- West Midlands is the lead for
 - Breast
 - Sarcoma

West Midlands Cancer Intelligence Unit



Lead registry for Bone and Soft Tissue Sarcoma



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What data do we have?

- Cancer Registry data
- Hospital Episode Statistics
- Other data sources

Cancer Registry Data



- Data from all 8 of the English cancer registries
- Historical data goes back in time until 1979
- Population based
- Data items cover key information about:
 - The patient: age, sex, postcode, date of death
 - The tumour: site, morphology, stage...
 - Some treatment data



Cancer Registry Data



- Cancer registries all strive to collect at least the minimum cancer data set
... and strive to code in a consistent and standardised way
- However, data completeness, coding and quality vary between registries and over time.
- Path labs and death certificates have historically been the main source of data, although many registries now collect a wide range of sources.



Hospital Episode Statistics



- Data from all NHS hospitals in England
- Cover the financial years 1997/98 – 2005/06
- Data items cover key information about:
 - The patient: age, sex, postcode, date of death
 - Their admissions into hospital
 - When, where, diagnosis, operation, treating surgeon
- Data don't cover tumour pathology, or date of death.
- Only NHS patients – private patients or patients not seen in hospital excluded.

HESonline™
HOSPITAL EPISODE STATISTICS

Data Linkage



**Cancer
Registry
Data**



**Hospital
Episode
Statistics**

First time we have had national linked data

Linking the data sets together increases the power of both!

Other Data Sources



The WMCIU



**or at least
YOUR DATA!**

- With more data sources we can
 - link data sources together
 - Analyse more variables
 - Do data quality checks on data we already have
- Do you have a database you can share with us?

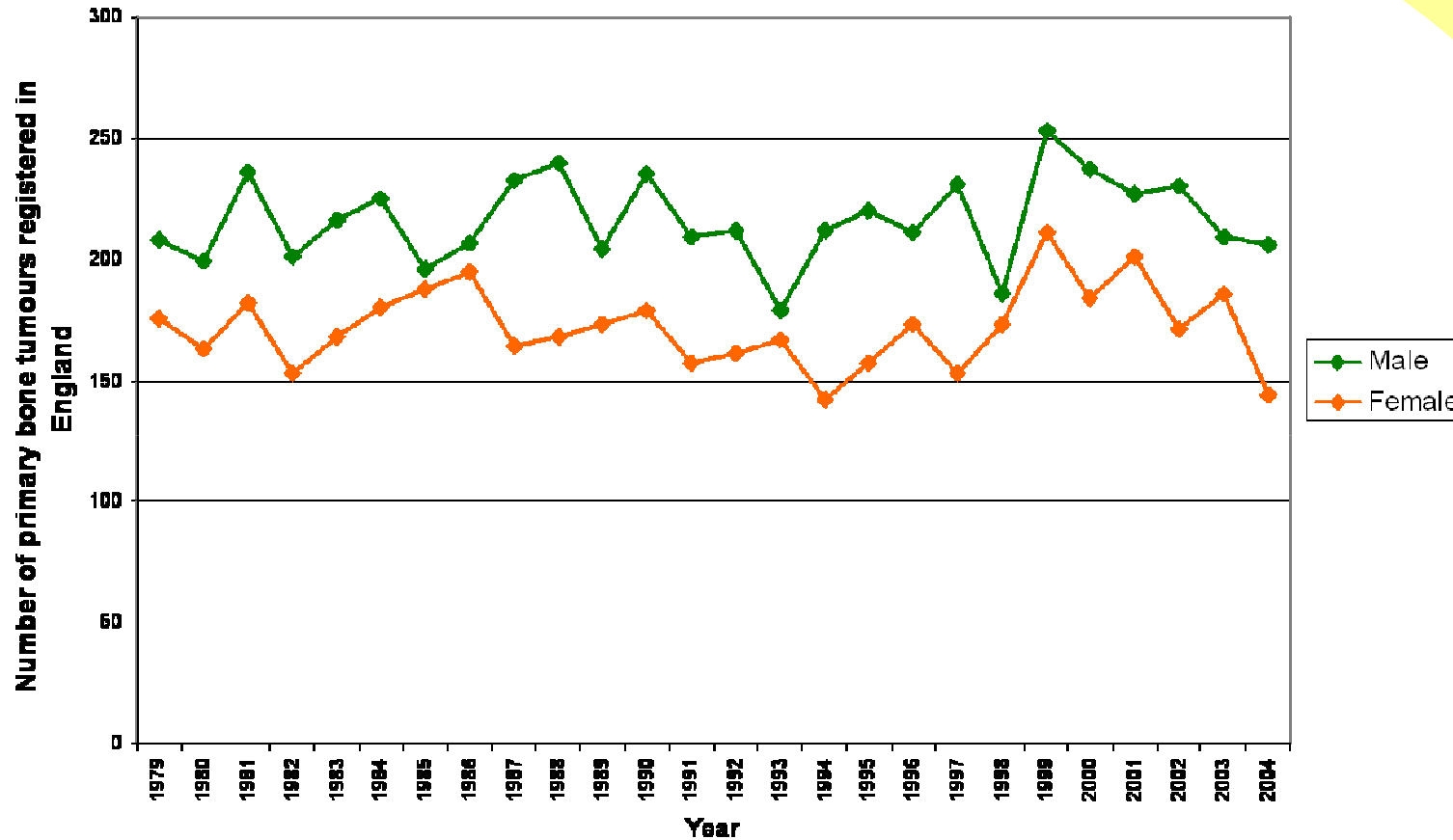


What analysis have we done?

- Initial Analysis – mostly bone
- Location of treatment
- Spinal and Sacral Tumours



Trends over time



Incidence data from 1979 – 2004 analysed for trends
Beware coding changes as well as genuine trends!

Geographical variation



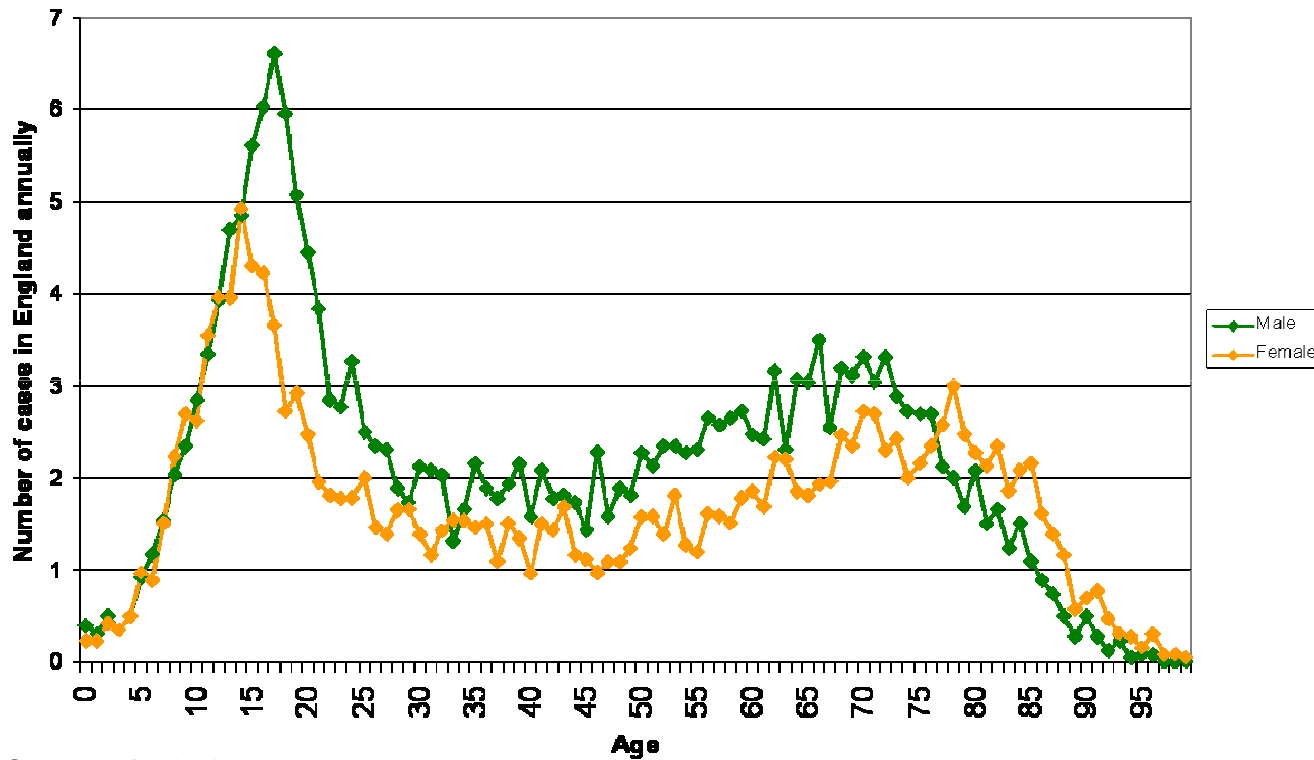
Bone Sarcoma Rates - 1979 - 2004 by Registry



Analyse data from across England by region

Looking for possible coding variation as well as variation in incidence!

Age profiles



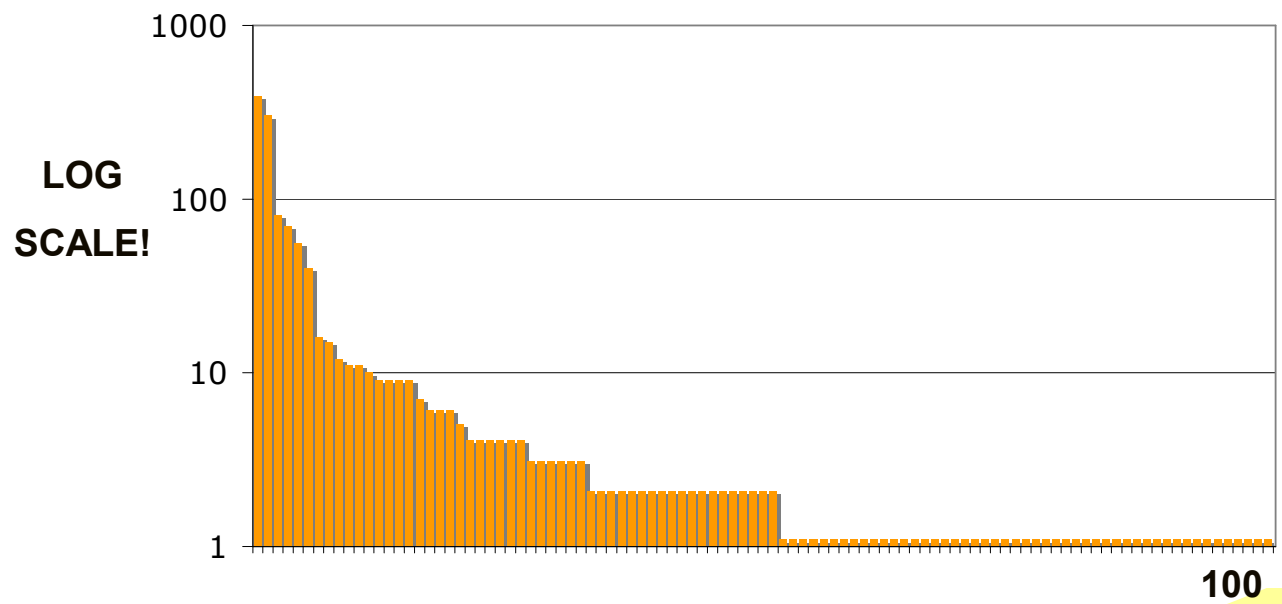
Bone Sarcoma 1979 - 2004

National data allows detailed age profiles to be seen



Trust Caseload - Bone

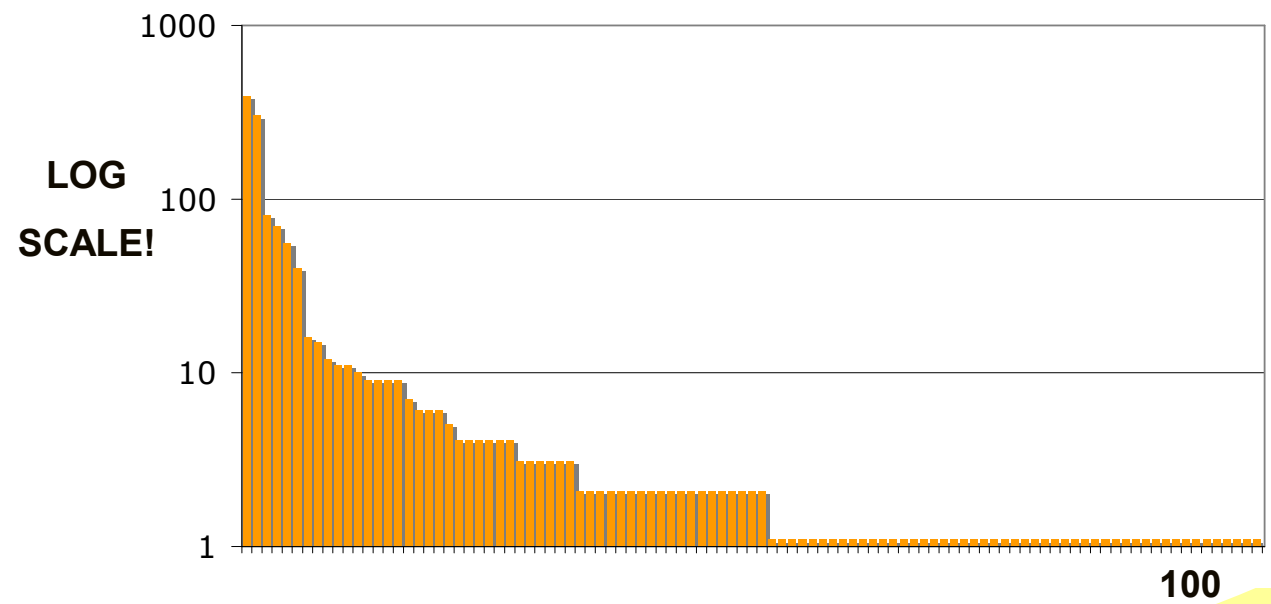
- For HES data from 1997/98 to 2004/05, 100 Trusts were identified performing a total of 1,218 surgical operations on patients with bone sarcoma
- On average 12 operations per Trust – but the profile is very different
- The highest caseload centre oversaw 396 operations - 33%
- Two very high caseload specialised Trusts



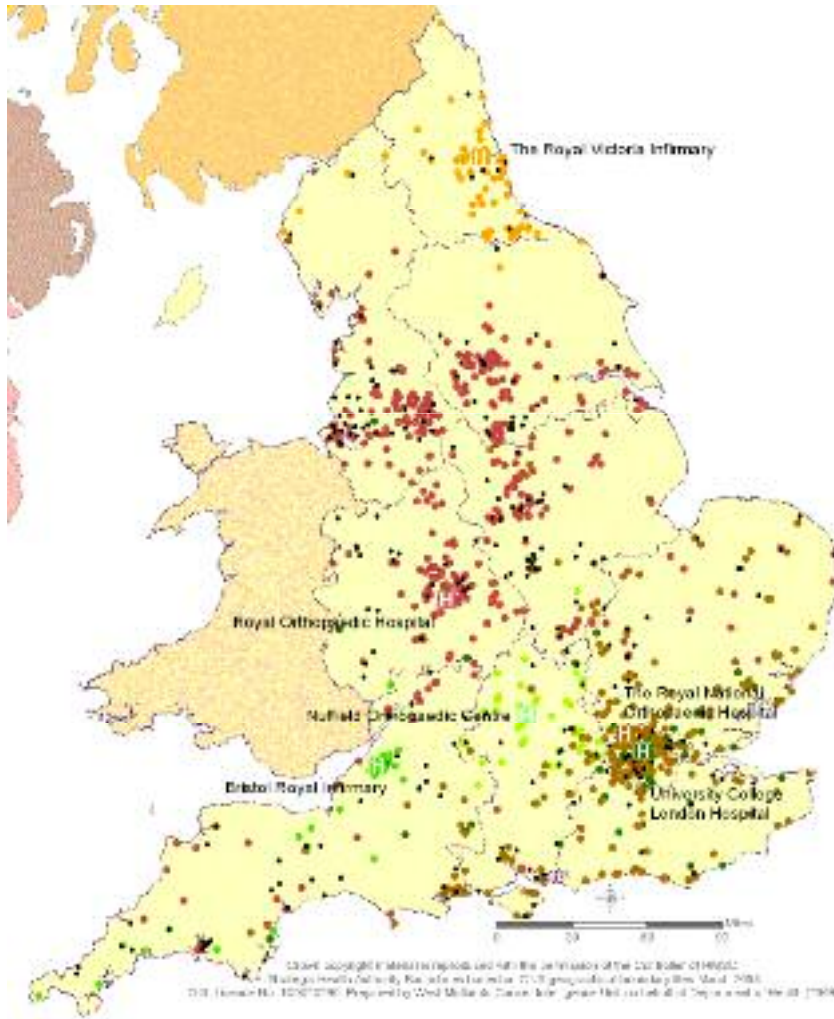


Trust Caseload - Bone

- Are these data correct?
- Are Trusts consistently coded over time?
- What operations were done in the low caseload Trusts? Were they emergency admissions?
- Is it best to look at most recent data only, even though numbers are small? Is our HES data too old?



Referral patterns (Bone)



- Two specialist centres treated the majority of patients from across England
- Patients in geographically isolated parts of England (the North, the South West) are more likely to be treated in a lower caseload centre
- In central England patients have a diverse three way referral pattern
- Referral patterns are changing over time – the operations in less specialised Trusts reduce



Spinal and Sacral Tumours

- Wanted estimate of base of skull, spinal and sacral tumours
 - Understand possible population who could benefit from proton therapy
- However, no codes for 'sacral', just for 'sacrum, coccyx and pelvis'
- No codes for 'base of skull', just 'skull'



Identifying Sacral Tumours

- WMCIU has full pathology reports etc for West Midlands tumours
- Surveyed 49 tumours coded to 'sacrum, coccyx or pelvis'
- Found subsite by morphology

Morphology	Sub-site			Grand Total	% relevant site
	Other	Pelvis	Sacrum		
Central osteosarcoma		1		1	0%
Chondroblastic osteosarcoma			1	1	100%
Chondrosarcoma	2	8	3	13	23%
Chordoma			6	6	100%
Ewing sarcoma		13	1	14	7%
Fibroblastic osteosarcoma		1		1	0%
Osteosarcoma	2	10		12	0%
Osteosarcoma in Paget disease			1	1	100%
Grand Total	4	33	12	49	25%



Spinal and Sacral Tumours

- Applied the estimates to national data
- Did similar survey for base of skull tumours
- Conclude:
 - Approx 30 spinal and sacral tumours annually in England
 - Approx 4 base of skull tumours annually in England
- National data provide the best way of estimating the incidence of very rare tumours



Spinal and Sacral Tumours

- Analysis based on very small numbers of tumours as rare condition
- Are our site codes fit for purpose?
- Can we influence international coding schemes?
- Do we need to collect more detailed sub sites so we don't need to estimate?



Future work:

Core epidemiology

- Define morphologies and sites for main sarcoma groupings
- Produce key epidemiological stats for these
 - Incidence, mortality, survival, prevalence
- Profile populations to understand effect of age, socio-economic status, sex etc on risk
- Long term outcomes – length of remission, recurrences
- Any correlations with other primary tumours



Future work: Data Quality

- Analysis of completeness of data
- Development of sarcoma dataset
- Pilot of central data collection
- Improved data quality process – direct feedback to surgeons
- Collection of more datasets eg Going Forward on Cancer Waits



Future work: Service Monitoring and Planning

- Length of patient pathway
- Surgeon caseload and specialisation
- Measures of IoG implementation
- Provide analysis to support NICE technology appraisals
- Treatment pathways for specific rare tumours
- Identification of key information needs



Future work: Communications

- Website
- NCIN publications
- Factsheets
- Nomograms



How can you help?

- Make suggestions for what should be on our work programme, and what we should prioritise
- Work with us on research projects
- Share data sets with us
 - do you have a database that collects more than basic HES data?
- Engage with data quality projects
 - check that the data we have on your patients looks correct to you!
- Sign up to read our reports and factsheets
 - and feed back to us about what is helpful!