NCIN Sarcoma Workshop
The Past, Present and Future

West Midlands Cancer Intelligence Unit Update

22 March 2012

West Midlands Cancer Intelligence Unit

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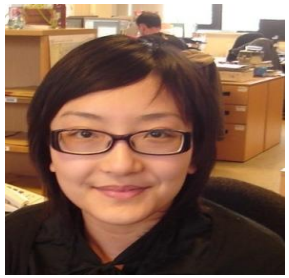
Overview

- Leavers and Joiners

- West Midlands Cancer Intelligence Unit Lead Registry Work
  - 2011/2012
  - Planned
  - Ongoing

Leavers and Joiners

Yuen Kwun Wong
August 2011



Sally Vernon
November 2011

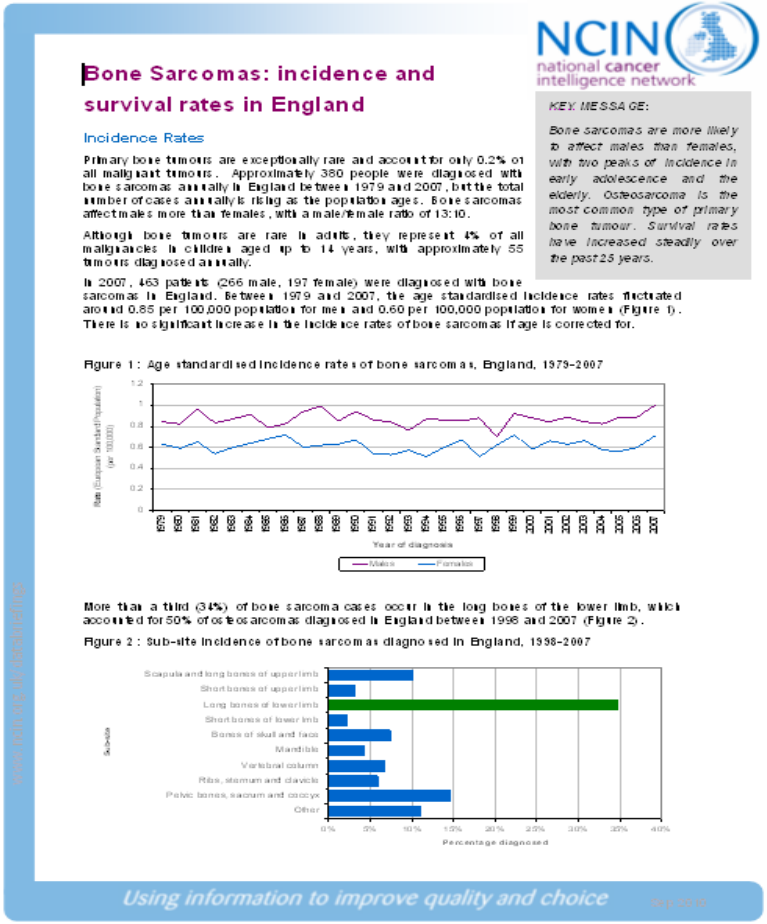
Sarcoma Analyst
Nicola Dennis
March 2012

WMCIU – Lead registry work

- All analyses undertaken in collaboration with the NCIN Site Specific Clinical Reference Group for sarcoma

Data Briefings

- Published on NCIN website
  - Provide basic information on
    - Incidence
    - Survival
    - Age profiles



Bone Sarcomas: incidence and survival rates in England

Incidence Rates

Primary bone tumours are exceptionally rare and account for only 0.2% of all malignant tumours. Approximately 380 people were diagnosed with bone sarcomas annually in England between 1979 and 2007, but the total number of cases annually is rising as the population ages. Bone sarcomas affect males more than females, with a male/female ratio of 13:10.

Although bone tumours are rare in adults, they represent 4% of all malignancies in children aged up to 14 years, with approximately 55 tumours diagnosed annually.

KEY MESSAGE:

Bone sarcomas are more likely to affect males than females, with two peaks of incidence in early adolescence and the elderly. Osteosarcoma is the most common type of primary bone tumour. Survival rates have increased steadily over the past 25 years.

In 2007, 463 patients (266 male, 197 female) were diagnosed with bone sarcomas in England. Between 1979 and 2007, the age standardised incidence rates fluctuated around 0.85 per 100,000 population for men and 0.60 per 100,000 population for women (Figure 1). There is no significant increase in the incidence rates of bone sarcomas if age is corrected for.

Figure 1: Age standardised incidence rates of bone sarcomas, England, 1979-2007

More than a third (34%) of bone sarcoma cases occur in the long bones of the lower limb, which accounted for 50% of osteosarcomas diagnosed in England between 1998 and 2007 (Figure 2).

Figure 2: Sub-site incidence of bone sarcomas diagnosed in England, 1998-2007

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Data briefings

- Completed 3 x data briefings
  - Estimated incidence of bone sarcomas of the facial skeleton
    - Current ICD-10 codes not detailed!
  - Estimated incidence of bone sarcomas of the base of skull, vertebral column and sacrum
    - Current ICD-10 codes not detailed!
  - Co-morbidities of patients with bone sarcoma

Data briefings

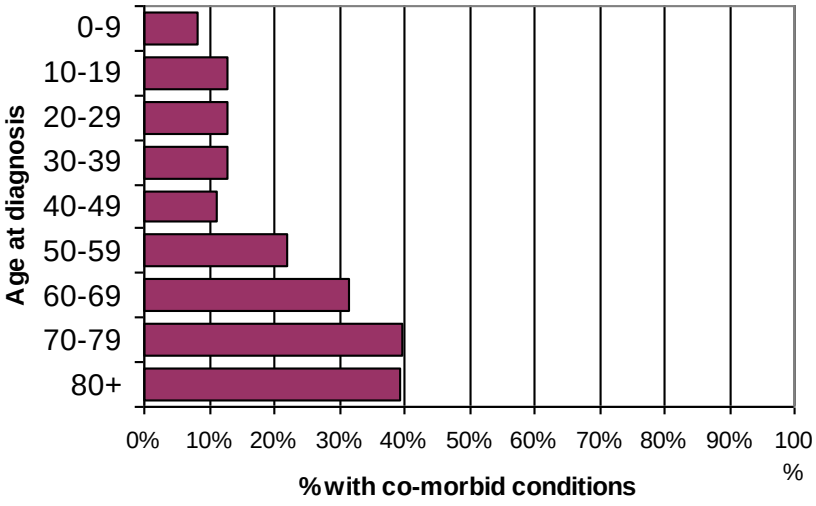
Co-morbidities of patients with bone sarcoma

- Charlson co-morbidity Index
  - Predicts 10 year mortality
  - Derived from HES data
- Patients admitted to hospital with cancer
  - HES record created
  - All other conditions recorded
  - Compared to table containing co-morbid conditions – assigned score 1, 2, 3 or 6!
  - All scores are summed to find the overall Index

Data briefings

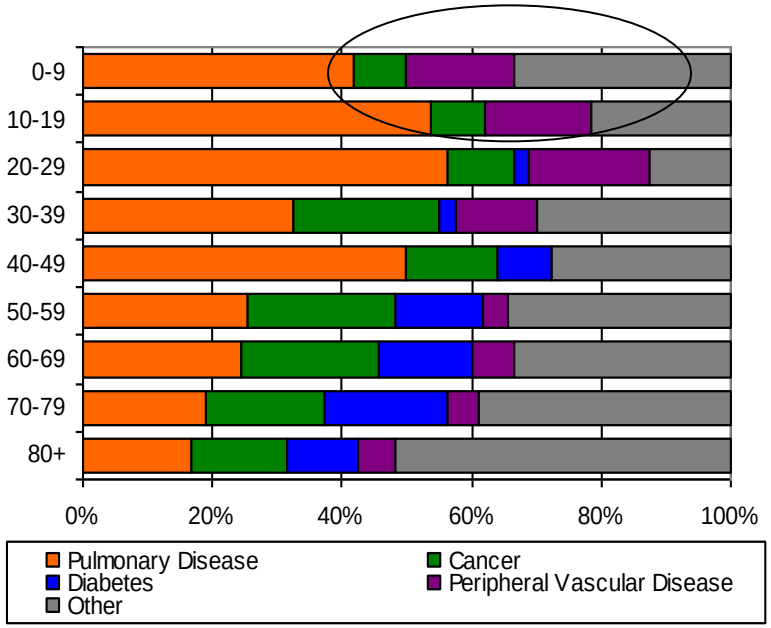
Co-morbidities of patients with bone sarcoma

- Proportion of bone sarcoma patients with co-morbid conditions
- Not only what proportion of patients had co-morbidity



- But also what the conditions were:

Limitation of method – children with peripheral vascular disease?

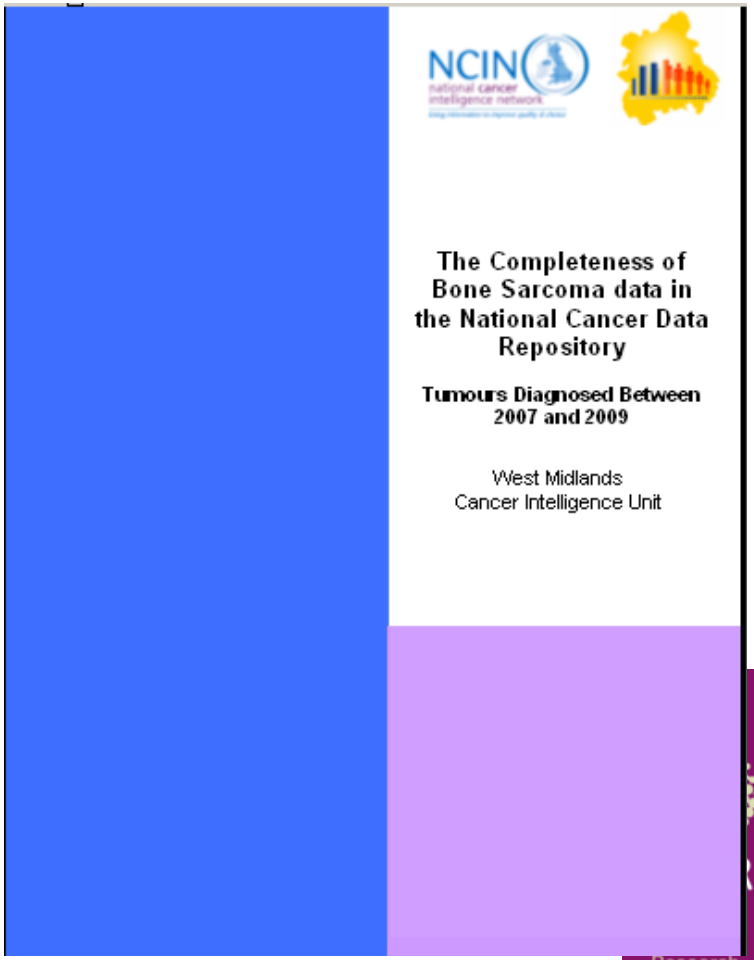


Co-morbidities

- Send us your data and we can calculate Charlson co-morbidity scores
  - (We can also append correct NHS numbers, find vital status, cause of death and much more…….)

Data completeness reports

- Completeness of data items in the national dataset for:
  - Bone sarcoma tumours
  - Soft tissue sarcoma tumour
- Excellent at collecting info about patients and tumours
- Staging – only 2% complete



Soft tissue sarcoma completeness report – variations in coding

Morphology	88903	88003	91403	88503	88323	89303	88013	88113	91203	89903	88513	88303	89363	
Description	Leiomyosarcoma, NOS	Sarcoma, NOS	Kaposi's sarcoma	Liposarcoma, NOS	Dermatofibrosarcoma	Endometrial stromal sarcoma	Spindle cell sarcoma	Fibromyxosarcoma	Haemangiosarcoma	Mesenchymoma, malignant	Liposarcoma, well differentiated	Fibrous histiocytoma, malignant	Gastrointestinal stromal sarcoma	5 Most common types
ECRIC	21%	12%	3%	5%	5%	3%	5%	4%	2%	7%	2%	2%	0%	**50%**
NWCIS	18%	13%	5%	5%	6%	1%	4%	4%	5%	4%	4%	2%	1%	**52%**
NYCRIS	17%	14%	2%	5%	6%	2%	4%	3%	3%	2%	7%	1%	5%	**49%**
OCIU	17%	12%	2%	12%	3%	3%	4%	3%	2%	7%	4%	3%	0%	**53%**
SWCIS	17%	12%	3%	7%	4%	3%	4%	5%	4%	5%	2%	3%	0%	**47%**
Thames	14%	10%	12%	5%	6%	12%	4%	3%	3%	0%	1%	3%	0%	**53%**
Trent	19%	11%	4%	2%	6%	3%	2%	5%	4%	6%	3%	2%	0%	**48%**
WMCIU	17%	6%	3%	3%	4%	1%	8%	2%	6%	0%	5%	8%	8%	**46%**
Grand Total	**17%**	**11%**	**5%**	**5%**	**5%**	**5%**	**4%**	**4%**	**4%**	**3%**	**3%**	**3%**	**1%**	**44%**

- Sarcoma NOS; Checked a random sample of pathology reports held within the West Midlands
- Half could be assigned a more detailed morphology code
- Registries missing opportunity to record more detailed information

Soft Tissue Sarcomas in England

- With the aid of pathologists, identified sarcoma related morphology codes
- Extracted all tumours with a diagnosis of any sarcoma morphology code
- Current dataset covers diagnosis years 1985 to 2009
- Separated bone sarcomas from soft tissue sarcomas (using ICD-10 site codes)

Questions

- How many soft tissue sarcomas diagnosed annually?
  - We have identified the relevant morphology codes
- How do the rates vary by sarcoma type?
  - Required further analysis!

How do the rates vary by sarcoma type?

- Over 100 sarcoma morphology codes
- We can't report on all of them separately
  - Incidence of <5 cases annually!

- Therefore……
  - We require a sensible method for grouping sarcoma morphology codes

Solution

- Literature review of international studies
  - SEER
  - Austrian data
  - Scandinavian data
  - No general agreement in methods
- Generated high level groups

Solution (cont.)

- For each group considered 5 elements
  - How many cases diagnosed annually?
  - How did incidence rates vary?
  - Were the age profiles similar?
  - Were the survival curves similar?
  - Were the cancer sites similar?

Results

Identified 22 sarcoma “groups” for reporting incidence and survival

…including

Title	Sub-sections	Morphologies to include
Leiomyosarcoma		Leiomyosarcoma, NOS
		Epithelioid leiomyosarcoma
		Myxoid leiomyosarcoma
		Smooth muscle tumour (malignant)
Liposarcomas	Liposarcoma NOS / rare	Liposarcoma, NOS; fibroliposarcoma
		Mixed liposarcoma
		Fibroblastic liposarcoma
		Angiomyoliposarcoma
	Well differentiated liposarcoma	Liposarcoma, well differentiated
	Myxoid liposarcoma	Myxoid Liposarcoma; myxoliposarcoma
		Round cell liposarcoma
	Pleomorphic Liposarcoma	Pleomorphic liposarcoma
		Dedifferentiated liposarcoma

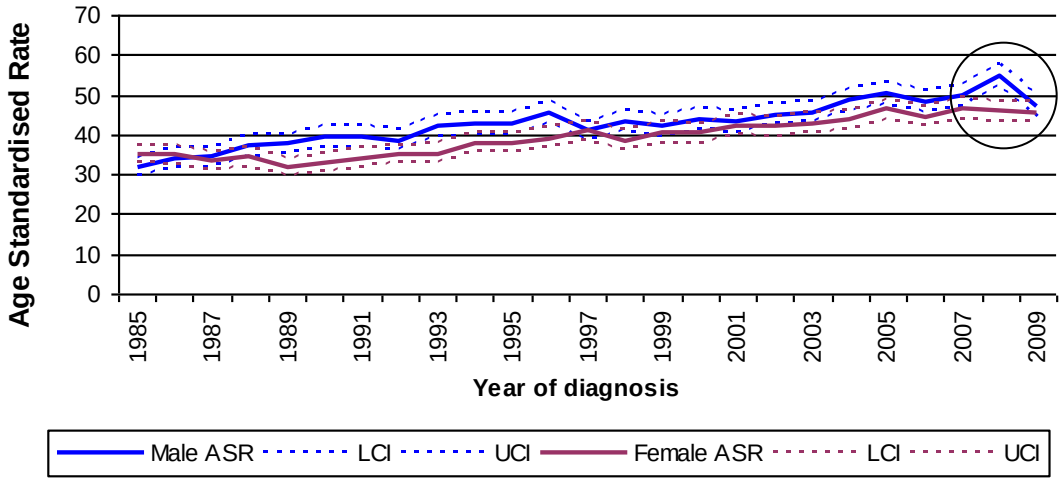
…including

Title	Sub-sections	Morphologies to include
Rhabdomyo sarcoma	Embryonal RMS	Embryonal RMS
	Alveolar RMS	Alveolar RMS
	Pleomorphic RMS	Pleomorphic RMS
	Other RMS grouped	RMS NOS
		Mixed type RMS
		Spindle cell RMS
		RMS with ganglionic differentiation
Haemangio sarcoma	Angiosarcoma	Haemangiosarcoma, Angiosarcoma of soft tissue
		Lymphangiosarcoma
	Haemangioendothelioma	Haemangioendothelioma
		Epithelioid hemangioendothelioma
…….	…….	……

….and more!

Soft Tissue Sarcomas in England – Preliminary results

- 2,794 sarcomas diagnosed in 2009
- Age standardised rate of 48 per million persons



- Improved diagnosis and reporting!

Soft Tissue Sarcomas in England By anatomical site

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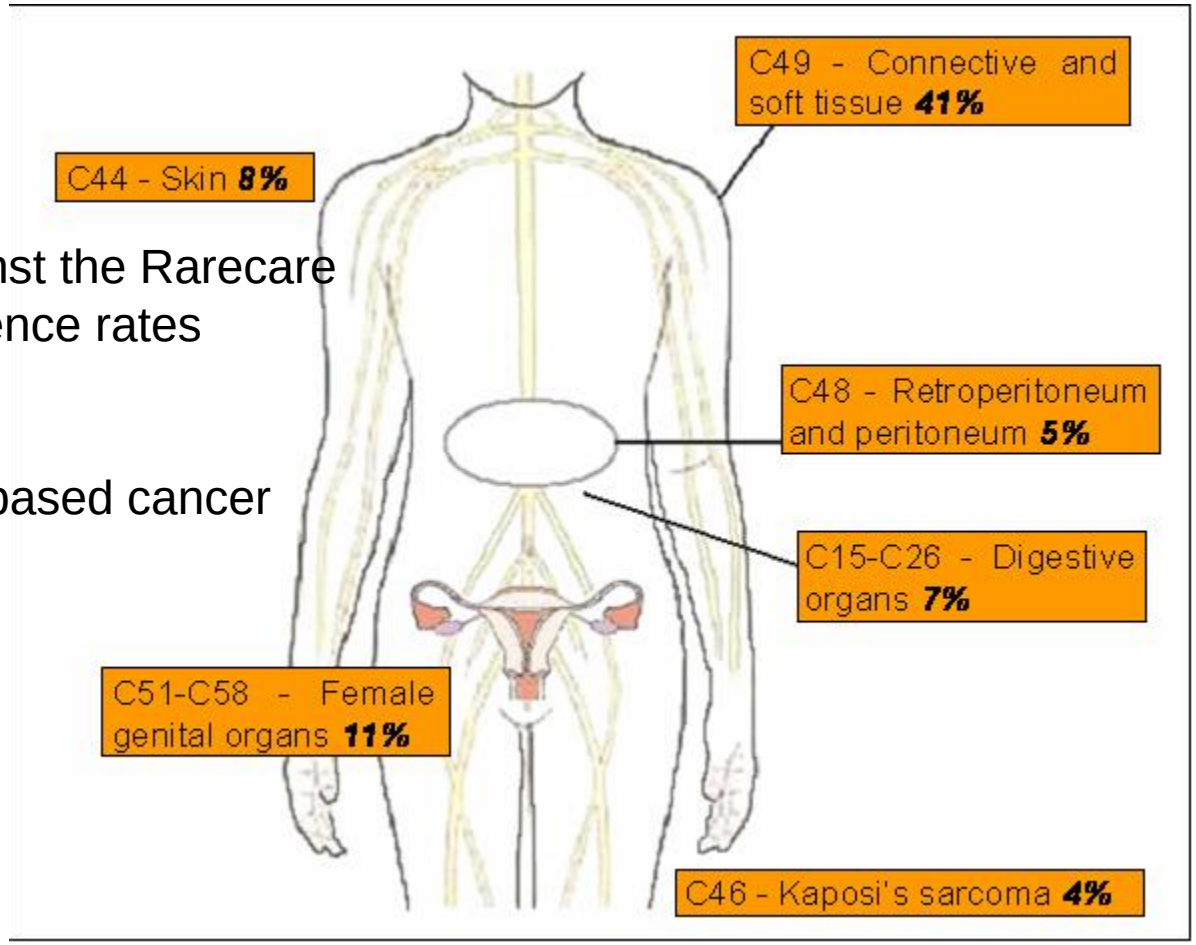
Validated against the Rarecare sarcoma incidence rates

Europe wide

76 population based cancer registries



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Soft Tissue Sarcomas in England – Preliminary results

- Most common sarcoma types:
- Leiomyosarcoma (22%)
- Sarcoma NOS (18%)
- Liposarcoma, NOS (6%)

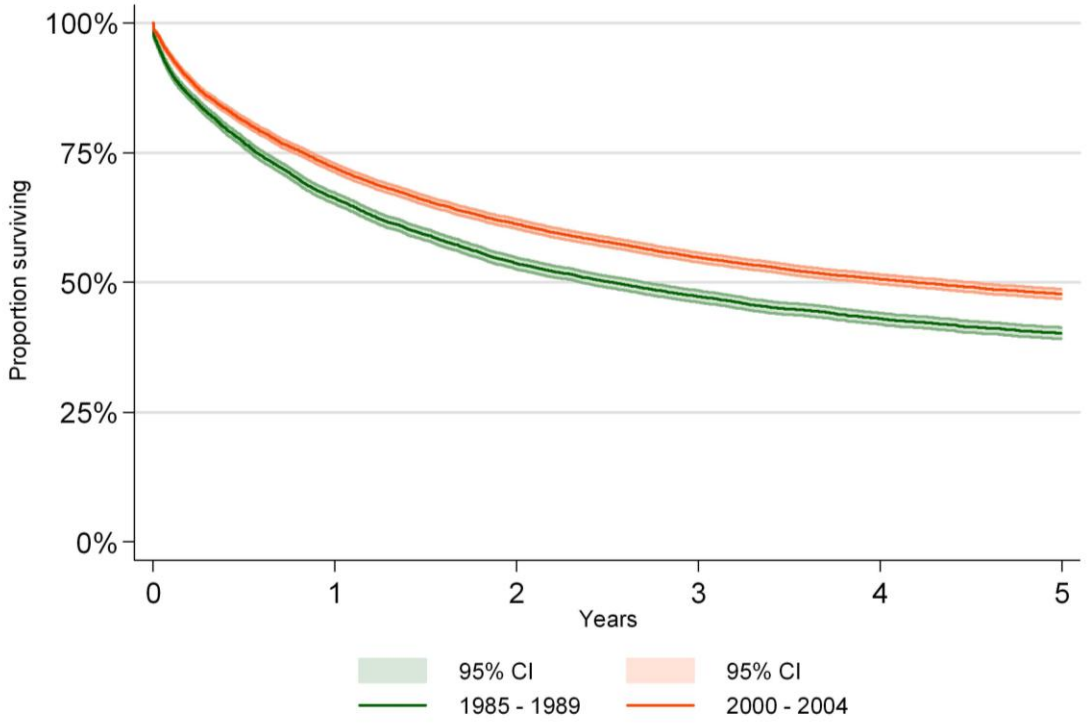
……..

- Embryonal rhabdomyosarcoma and Ewing's sarcoma/Pnet most common diagnoses patients under 10

- Kaposi's sarcoma and dermatofibrosarcoma: 20-29

Soft Tissue Sarcomas in England – Preliminary results

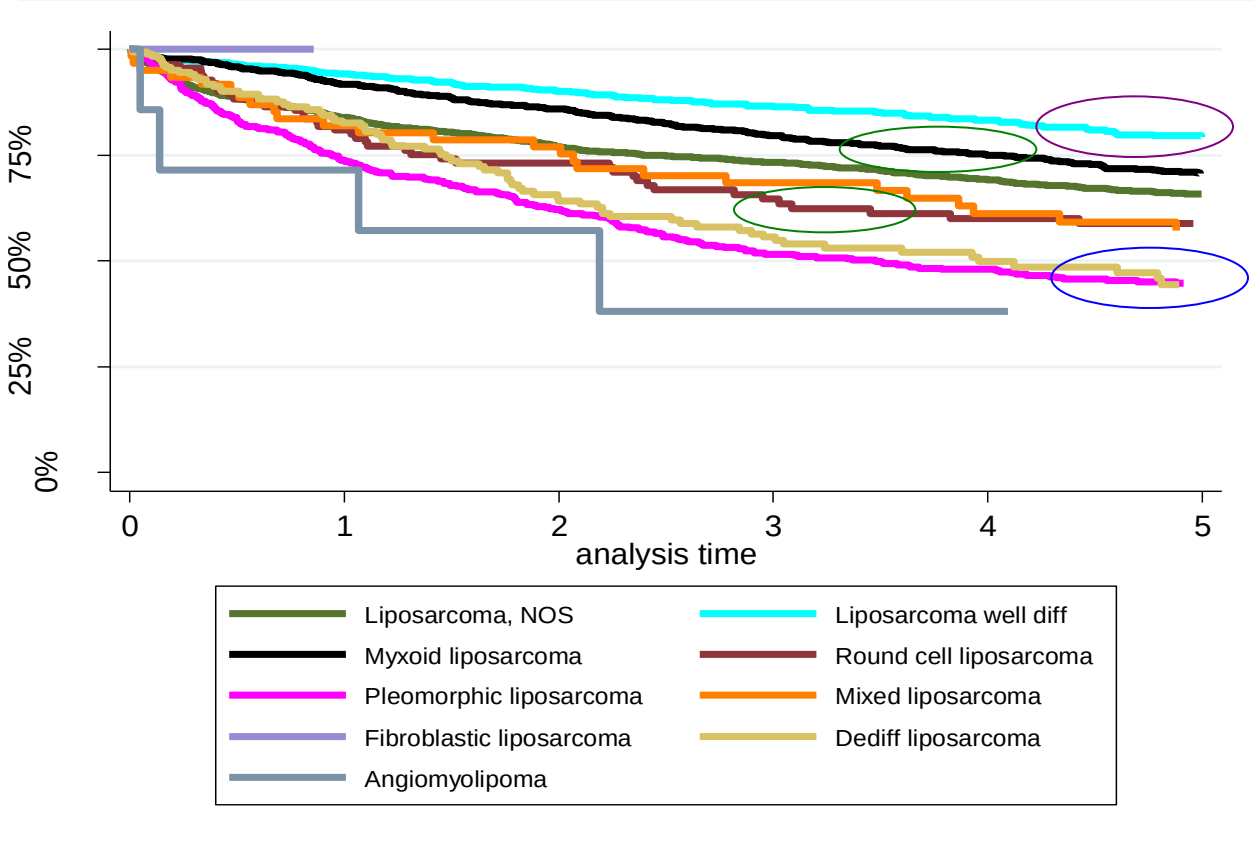
- Five year survival rates have improved since 1985 (excluding dermatofibrosarcoma)



Still only 50%!!

Example: liposarcoma

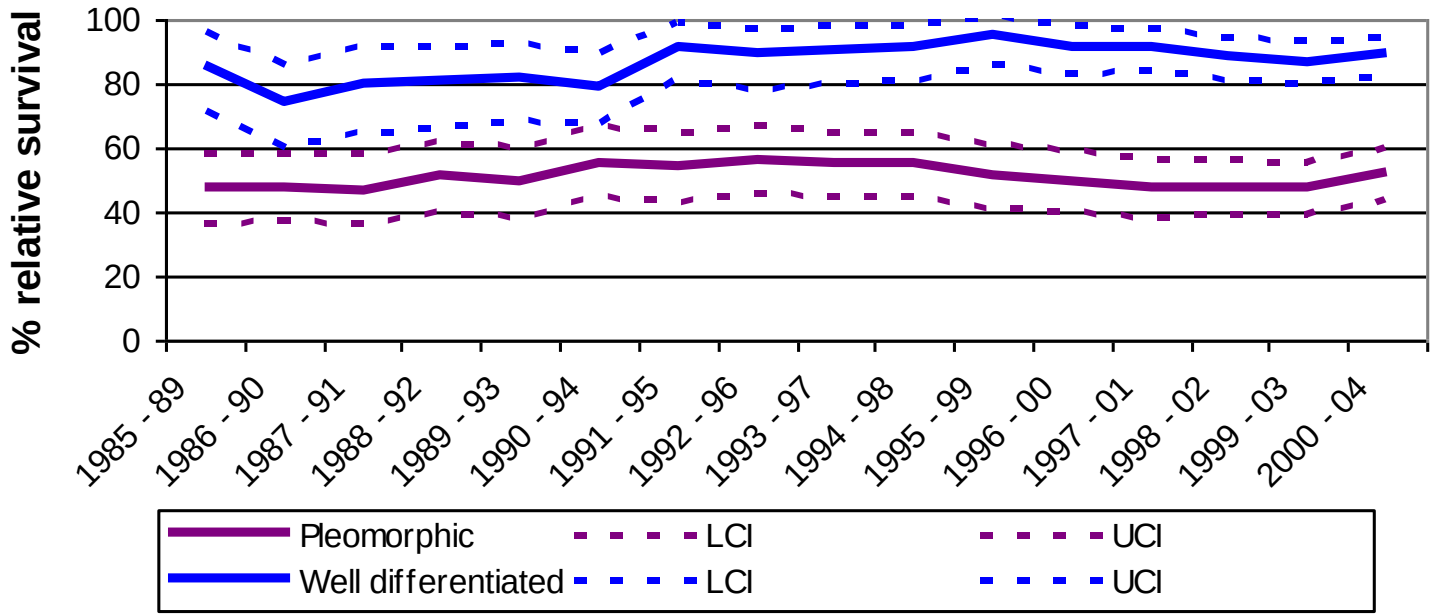
- Liposarcoma survival curves



1. Pleomorphic + dedifferentiated
2. Well-differentiated
3. Myxoid and round cell
4. NOS + all other variants

Soft tissue sarcomas in England -relative survival rates

- Five year relative survival rates
  - Pleomorphic and well-differentiated liposarcomas



Soft Tissue Sarcomas in England – Preliminary results

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All results to be published on the NCIN website

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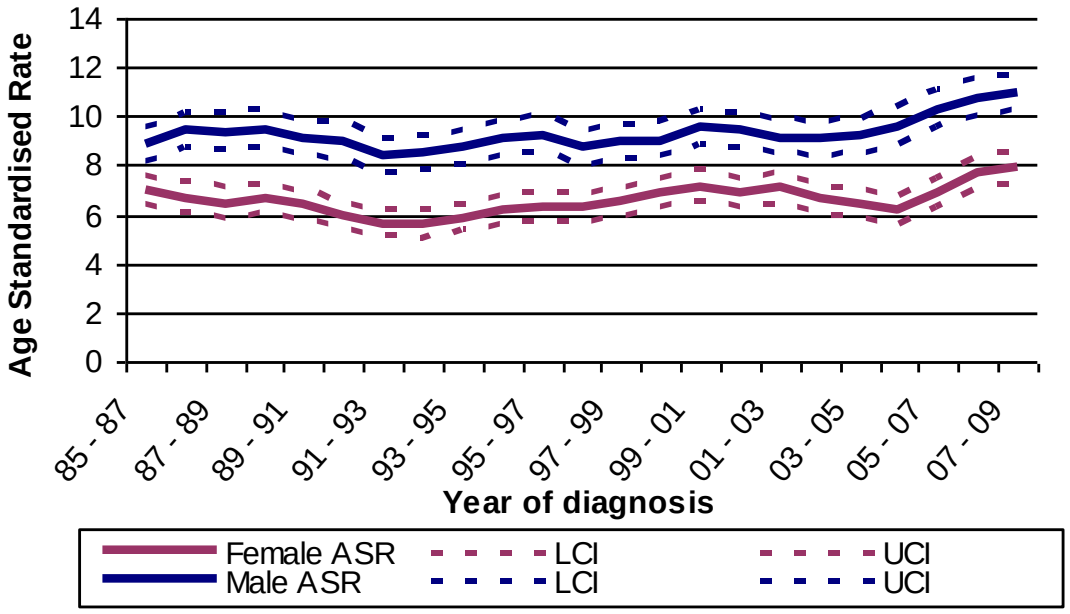
Bone Sarcoma – Incidence and Survival

- All malignancies
- Osteosarcoma
- Chondrosarcoma
- Chordoma
- Ewing's sarcoma/Pnet

Bone Sarcoma Incidence

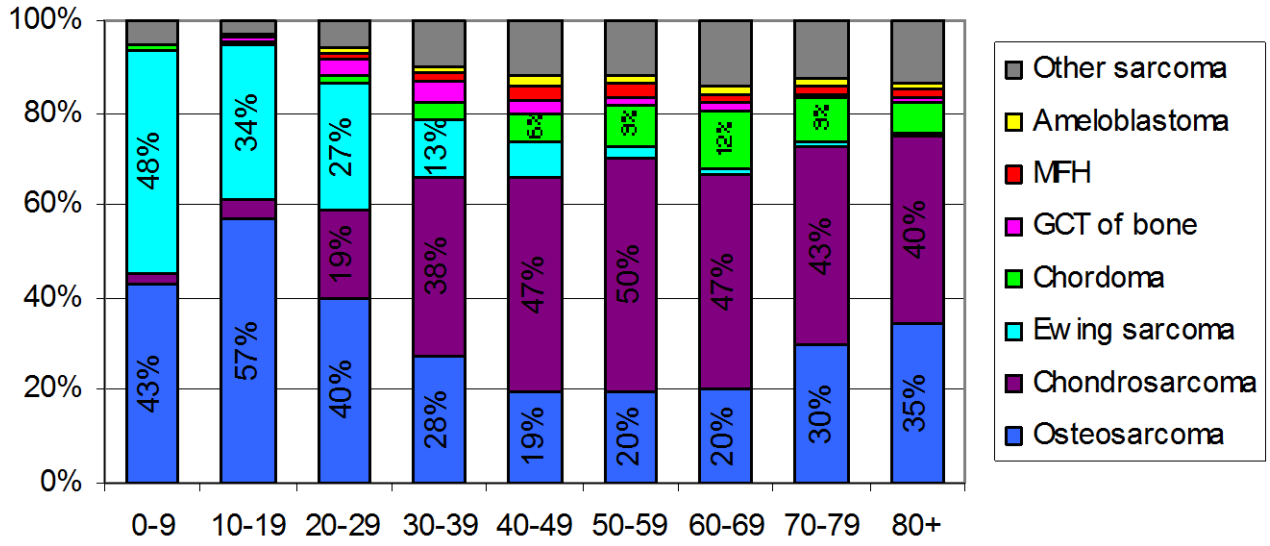
Age standardised rate 7.9 per million



- **Around 450 cases diagnosed annually**

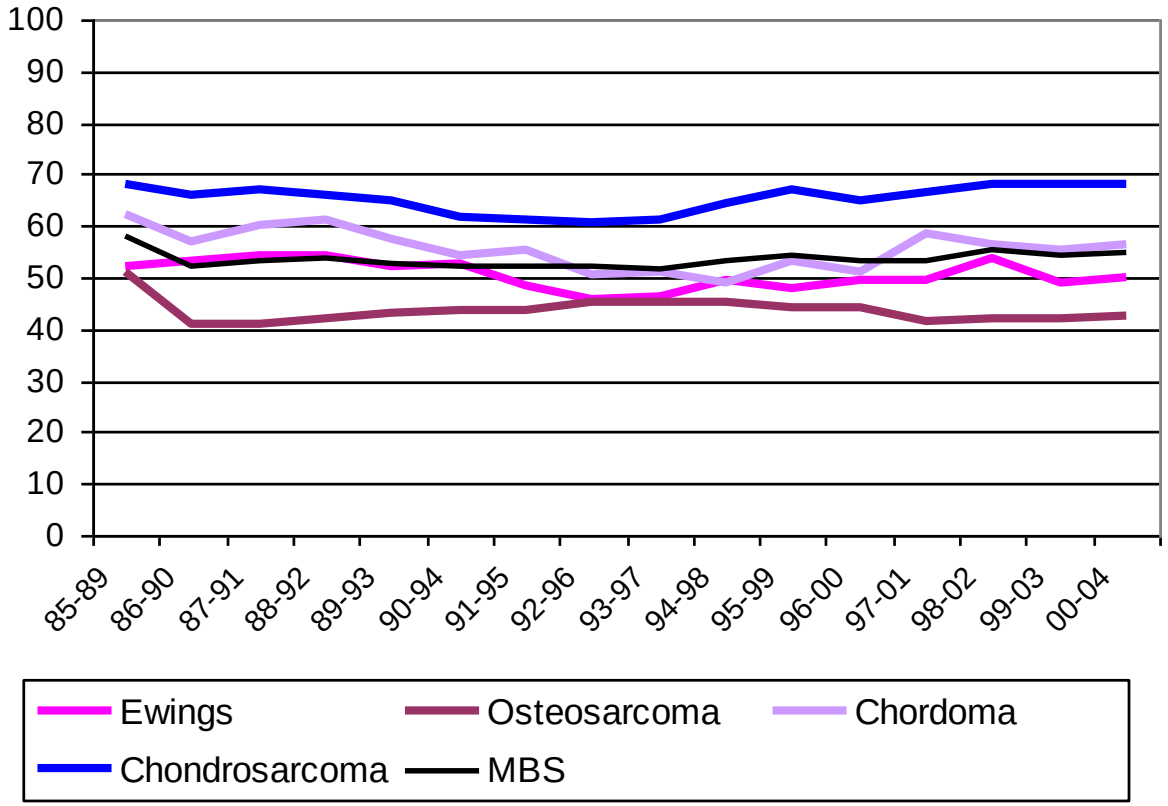
Variations in Histological Diagnosis by Age

- Osteosarcoma/Ewing's sarcoma most common diagnosis in children and teenagers



- Osteosarcoma and chondrosarcoma most common in elderly

Bone sarcoma - Survival



- **Different case mix**
- **Therefore separated by age at diagnosis and cancer site**

e.g. Osteosarcoma

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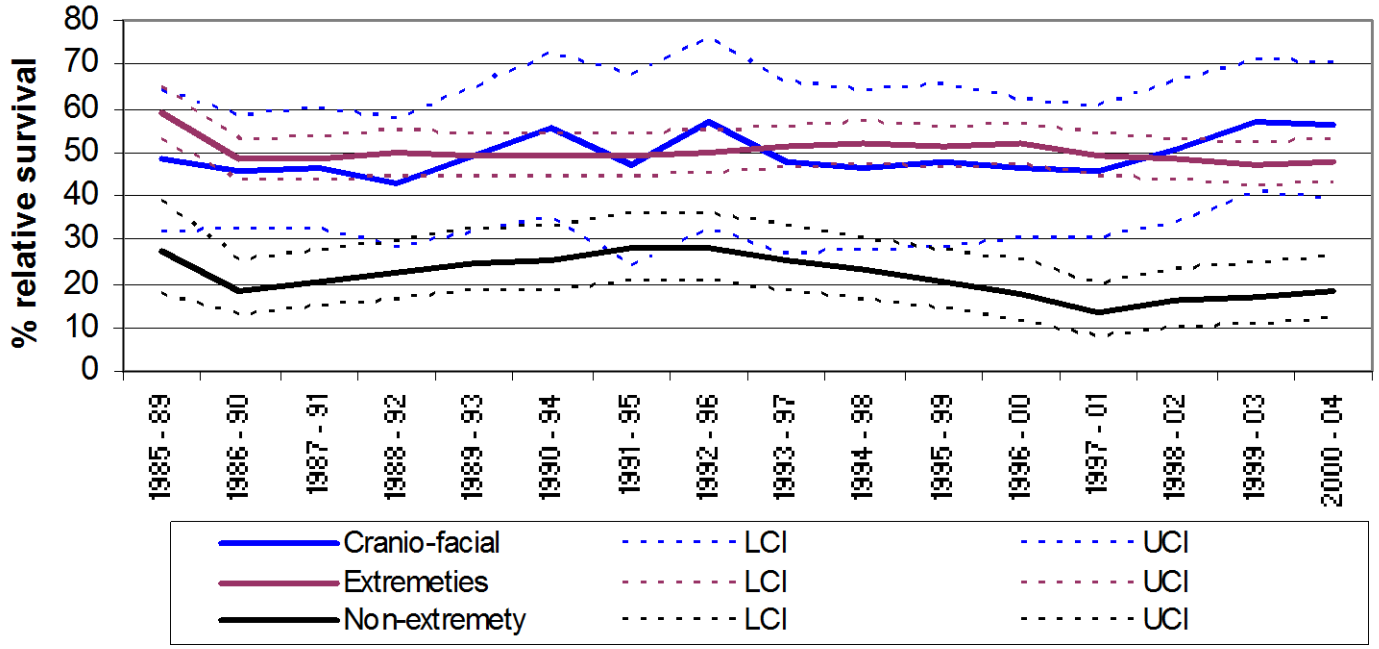
Osteosarcoma – Five Year Survival Rates by sub-site



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Ongoing
-2011/2012 Work Programme

- Bone cancer specialisation of treatment
  - Assess factors which affect whether patients are treated in a specialist centre
    - Age at diagnosis
    - Cancer site
    - Deprivation

Planned work

- Clinical indicators
  - Readmission rates – within 1 month following surgery
  - Improve staging data available
    - Liaising with specialist centres
  - Utilise radiotherapy data – assess proportion of patients receiving radtiotherapy

Specialist Services

- Review national cancer registry data and corresponding inpatient records (HES)
- Identify care pathways
  - Patients with retroperitoneal sarcomas
  - GISTs
  - Gynaecological sarcomas

Completeness

- Analyses the national cancer datasets against specialist centre databases:
  - Highlight discrepancies between tumour coding
  - Highlight discrepancies of treatment data in HES against specialist centre databases

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Thankyou

ANY QUESTIONS!

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