

SSCRG Achievements in 2010/11

Sarcoma Centre and Network Clinical Leads Workshop
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Overview

- Who are the SSCRG?
- What data do we have?
- What have we done with the data?
 - Data briefings
 - Specialisation of bone cancer treatment
 - Co-morbidities
 - Rare sarcomas
- Where next?



Site Specific Clinical Reference Group - Who are they?

Chair (and surgeon) – Rob Grimer

Pathology – Nick Athansou, Chas Mangham

Surgery – Lynda Wyld

Oncology – Rob Turner, Martin Robinson, Michael Leahy

Radiology – Julia Fairbairn

Nursing – Lynn Field, Gloria Tilt

Patients and Voluntary Sector – Roger Wilson, Mike Francis, Ann Scott

Cancer Registry – Sally Vernon, Matthew Francis

NCIN – Di Riley, Nicky Coombes, Linda Dutton

National Cancer Action Team – Stephen Parsons

Information Centre – Alison Roe, James Salt

Cancer Networks – Karen Metcalf

Peer Review – Lisa Cunnington



West Midlands Cancer Intelligence Unit

Lead registry for Bone and Soft Tissue Sarcoma, based at University of Birmingham



Matthew Francis,
Data Development
Manager



Gill Lawrence,
Director



Sally Vernon,
Deputy Director



James Brown,
Information Analyst



Yuen Wong,
Sarcoma Analyst

What data do we have?

Cancer Registry Data

- Data from all 8 of the English cancer registries
- Historical data goes back in time until 1979
- Latest data from 2008
- Population based
- Data items cover key information about:
 - The patient: age, sex, postcode, date of death
 - The tumour: site, morphology...
 - Some treatment data
- Path labs and death certificates have historically been the main source of data, although many registries now collect a wide range of sources.



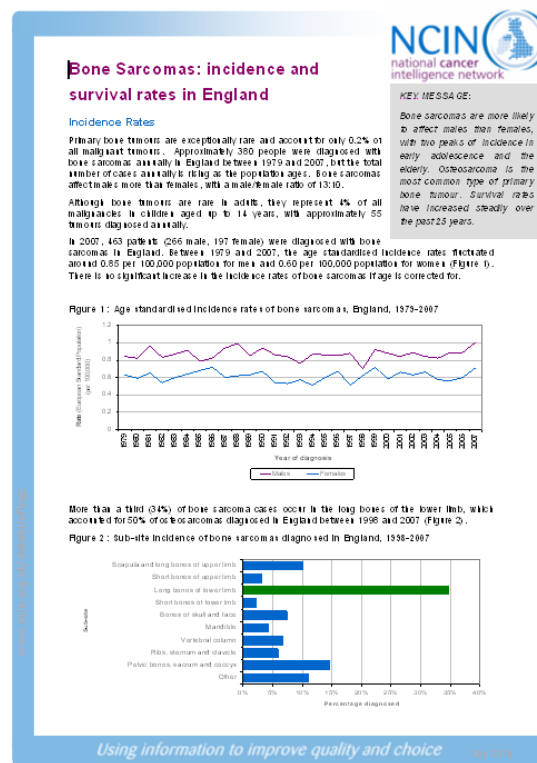
What data do we have?

Hospital Episode Statistics

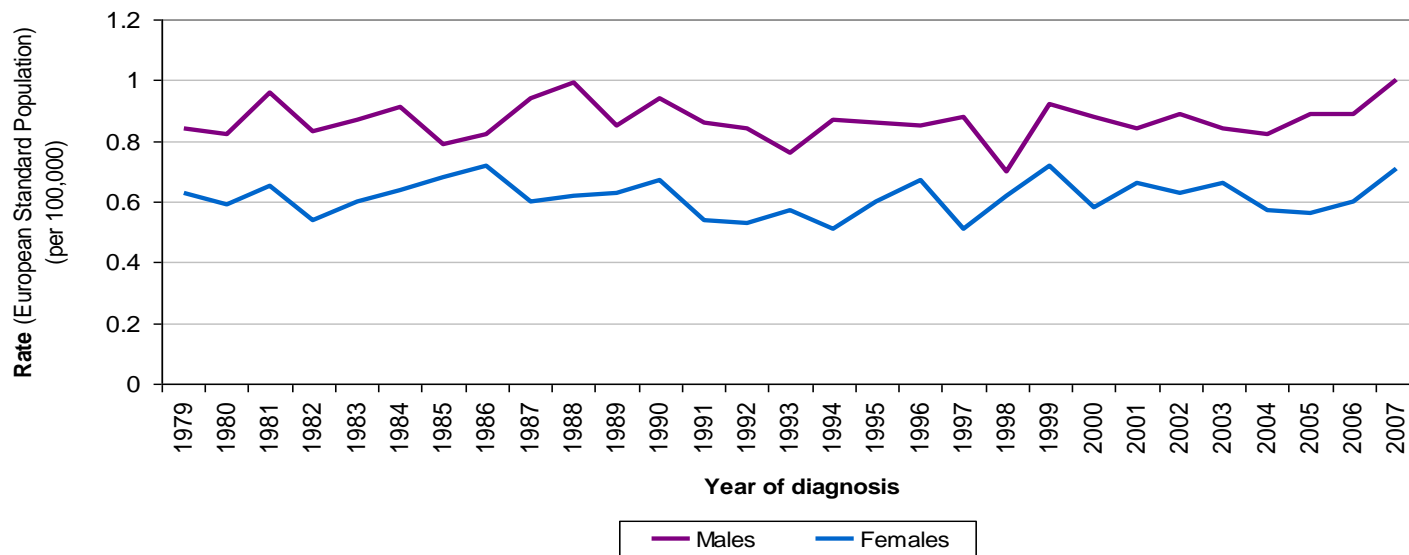
- Data from all NHS hospitals in England
- Cover the financial years 1997/98 – 2009/10
- Data items cover key information about:
 - The patient: age, sex, postcode, date of death
 - Their admissions into hospital
 - When, where, diagnosis, operation, treating surgeon
- Data don't cover tumour pathology, or date of death.
- Only NHS patients – private patients or patients not seen in hospital excluded.

Data briefings

- Published on NCIN website
- Provide basic information on
 - Incidence
 - Survival
 - Common cancer sites
 - Types of sarcoma
 - Age profiles
- Brief, high level, with “Key Facts”

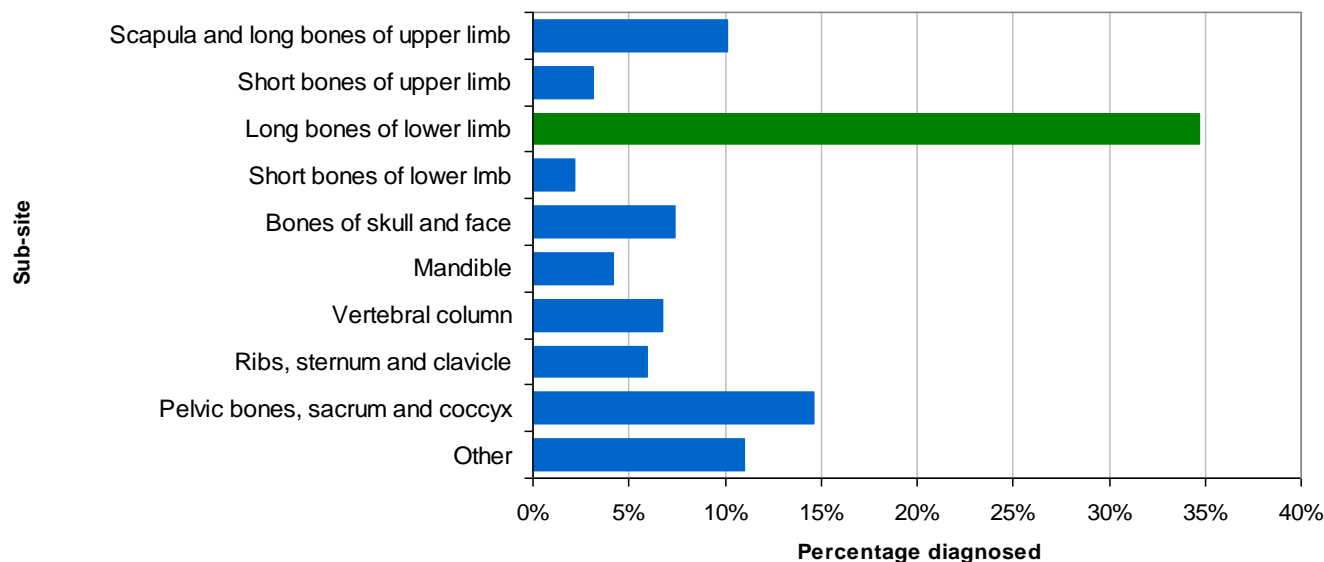


Bone data briefing



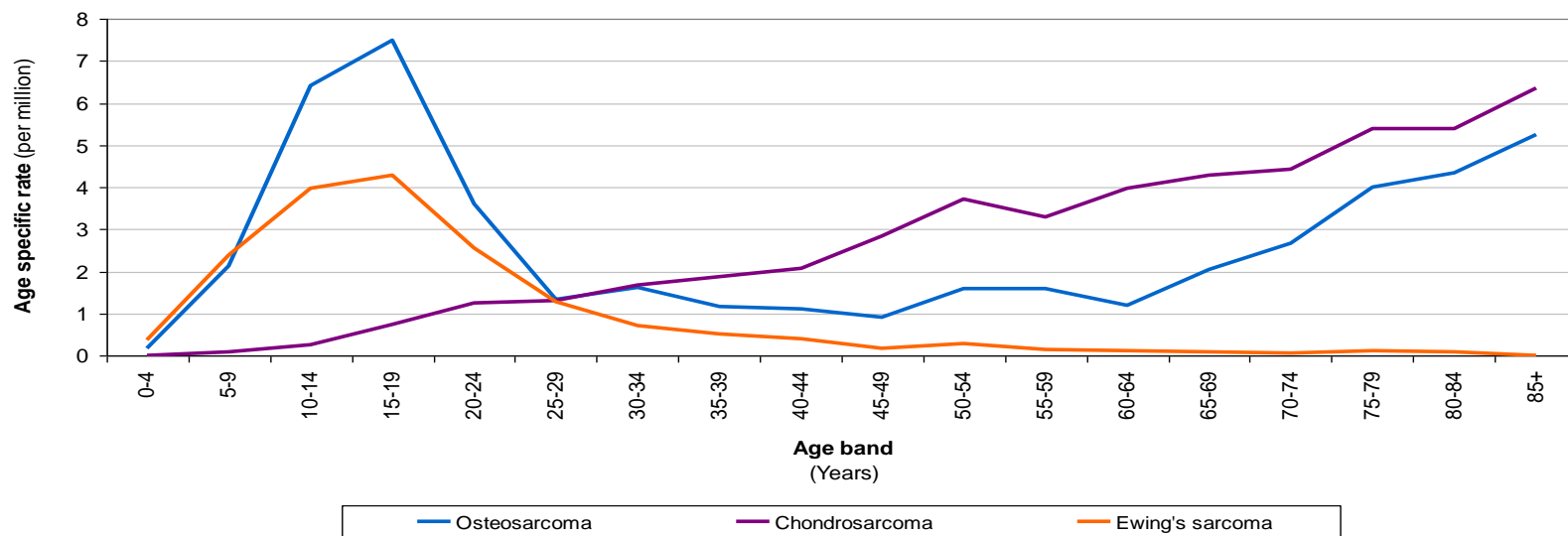
- Age-standardised incidence has not increased over time
- Bone sarcomas more common in males than females

Bone data briefing



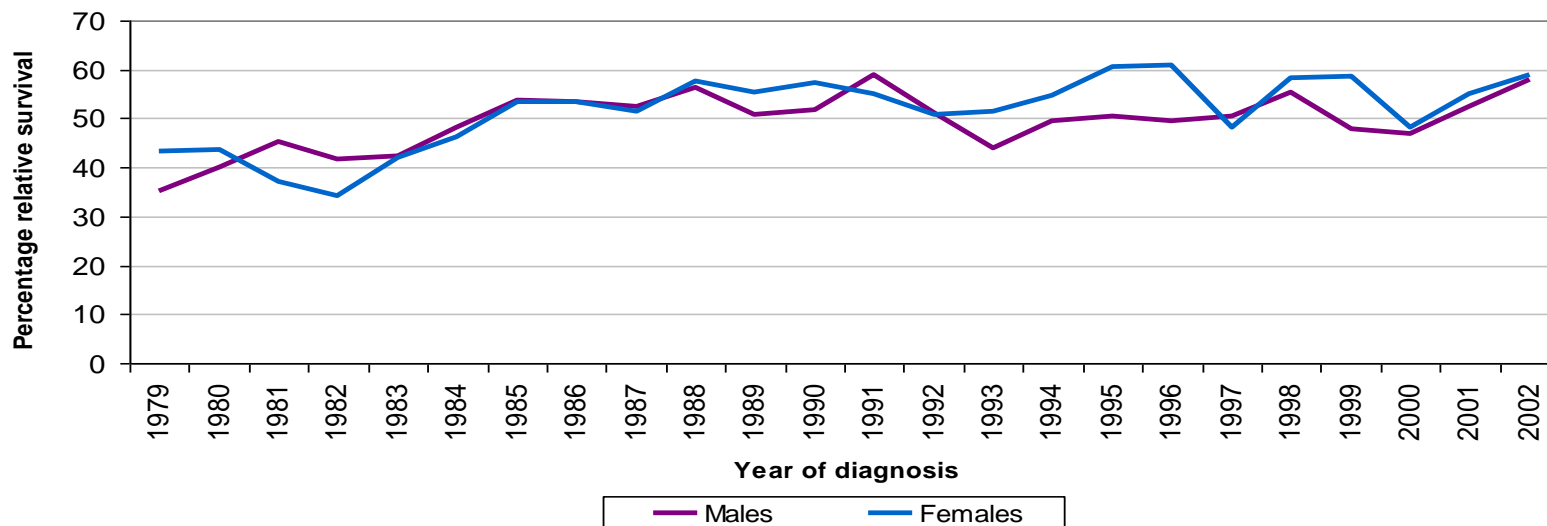
- Long bones of the leg are the most common site for primary bone cancer
- But they are only a third of all bone cancers.

Bone data briefing



- Age profile varies with the type of sarcoma
- Ewings and Osteosarcoma in the young
- Chondrosarcoma in the old

Bone data briefing

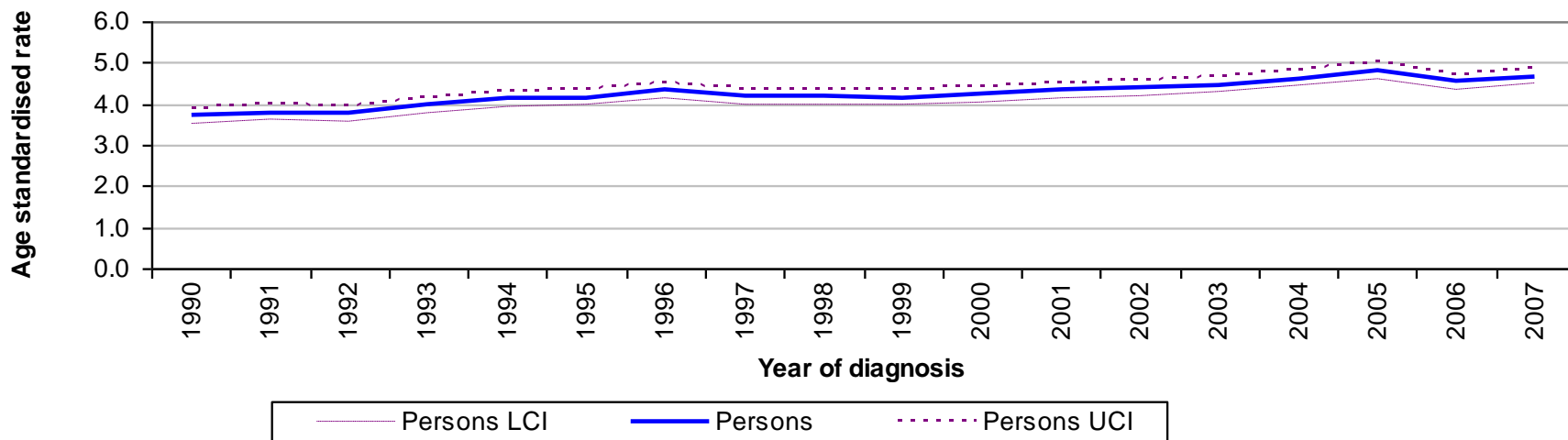


- 5 year Survival has increased since the early 80s
- But has levelled off recently.
- Survival is still only around 50%

Soft Tissue data briefing

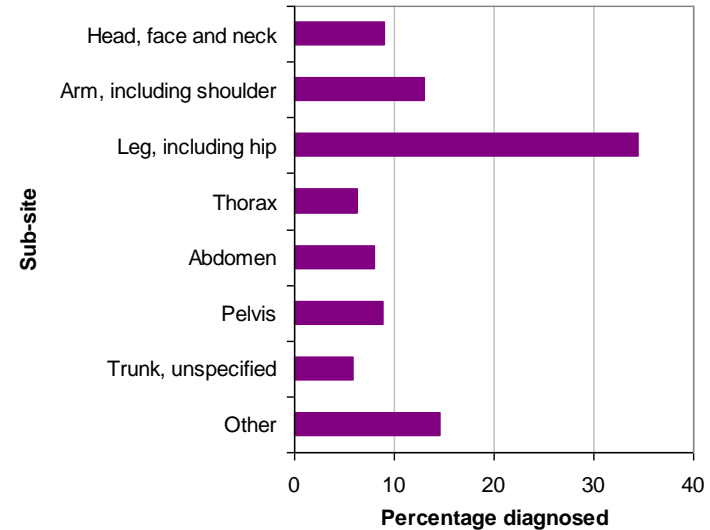
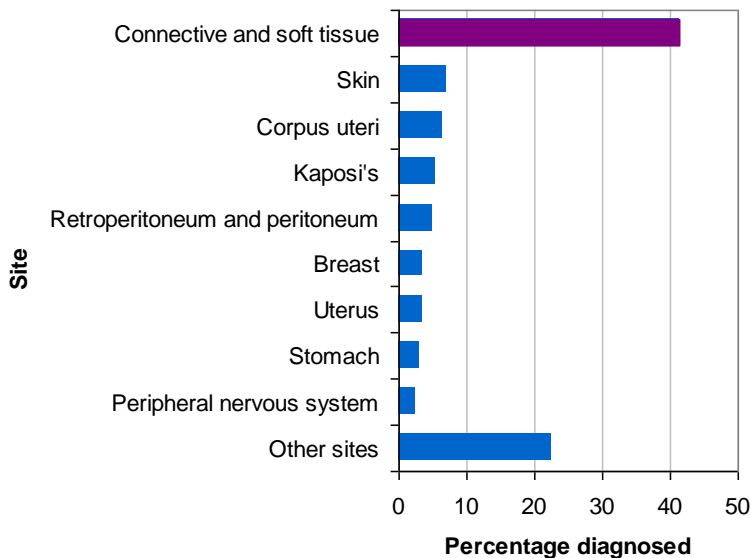
- Hard to decide which cancer sites to count as ‘soft tissue sarcomas’ for head line figures
 - Which morphologies to include – tumours such as Kaposi’s
 - Which behaviours to include – malignant or malignant and uncertain
 - Which sites to include – skin cancers often excluded from stats
- Worked with Site Specific Clinical Reference Group
- Have a consistent definition that can be used
- Defined by morphology, not site
 - Increased numbers more representative of true incidence
- Looking at Soft Tissue Sarcomas as a group is limited – need to pick the right definitions to answer the questions being asked

Soft Tissue data briefing



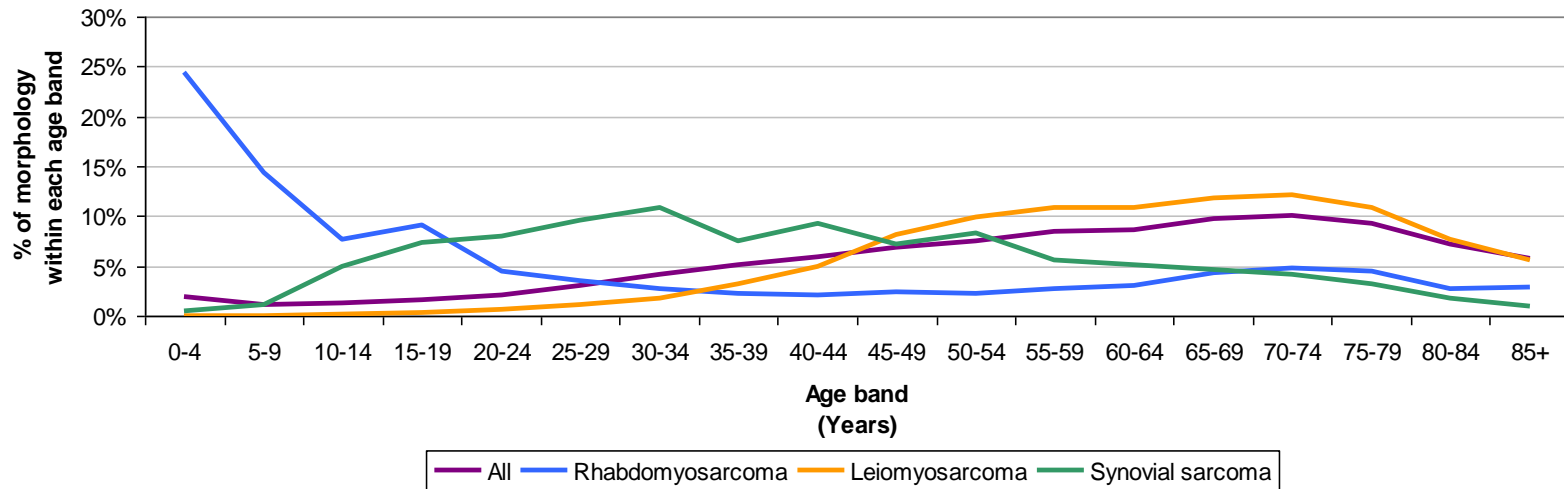
- Unlike bone, age-standardised incidence rising
- True increased incidence? Or better diagnosis, reporting and coding?

Soft Tissue data briefing



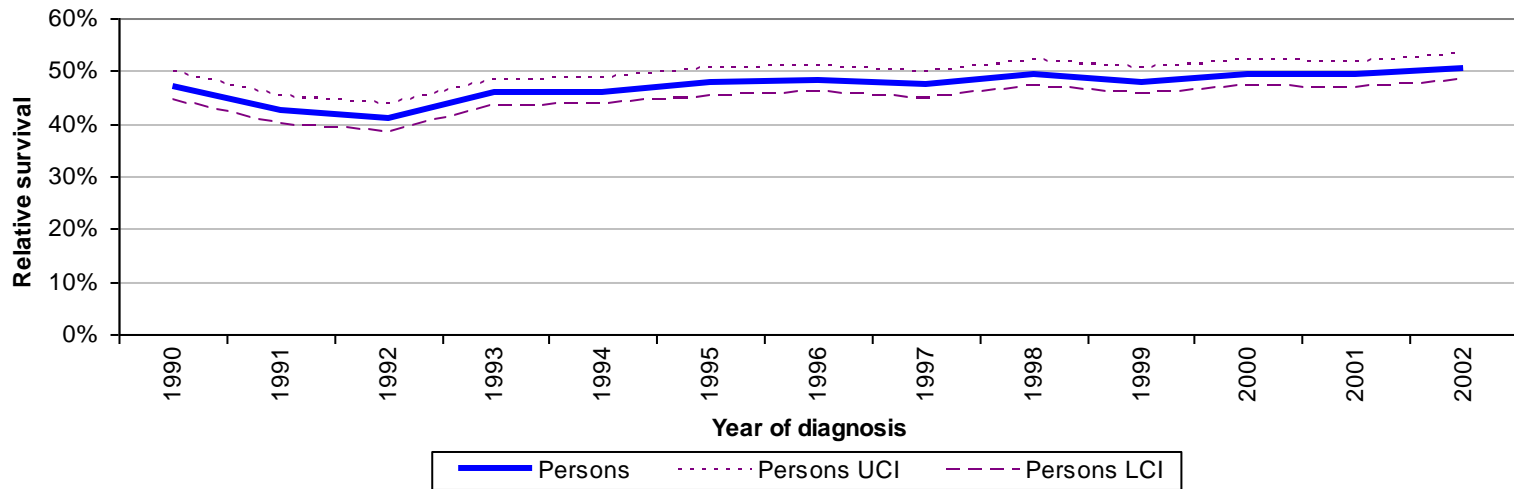
- C49, 'other connective and soft tissue' most common site
 - But less than half of all STS
- Sarcomas in the leg are the most common sub-site
 - But very diverse group of tumours.

Soft Tissue data briefing



- Like bone, age profile varies with type of sarcoma
- Rhabdomyosarcoma common in the young
- Leiomyosarcoma common in the elderly

Soft Tissue data briefing



- 5 year survival is around 50%
- This has not significantly changed since the 1990s
- But trend does appear to be upward
- Is the case mix changing?

Bone Cancer Specialisation:

- Were people treated by the specialist bone cancer centres?
- Were there factors that affected how likely they were to be seen by a specialist?
 - Age
 - Deprivation
 - Distance to specialist
 - Site of bone cancer
- Were they more likely to get surgery if they were seen by a specialist?

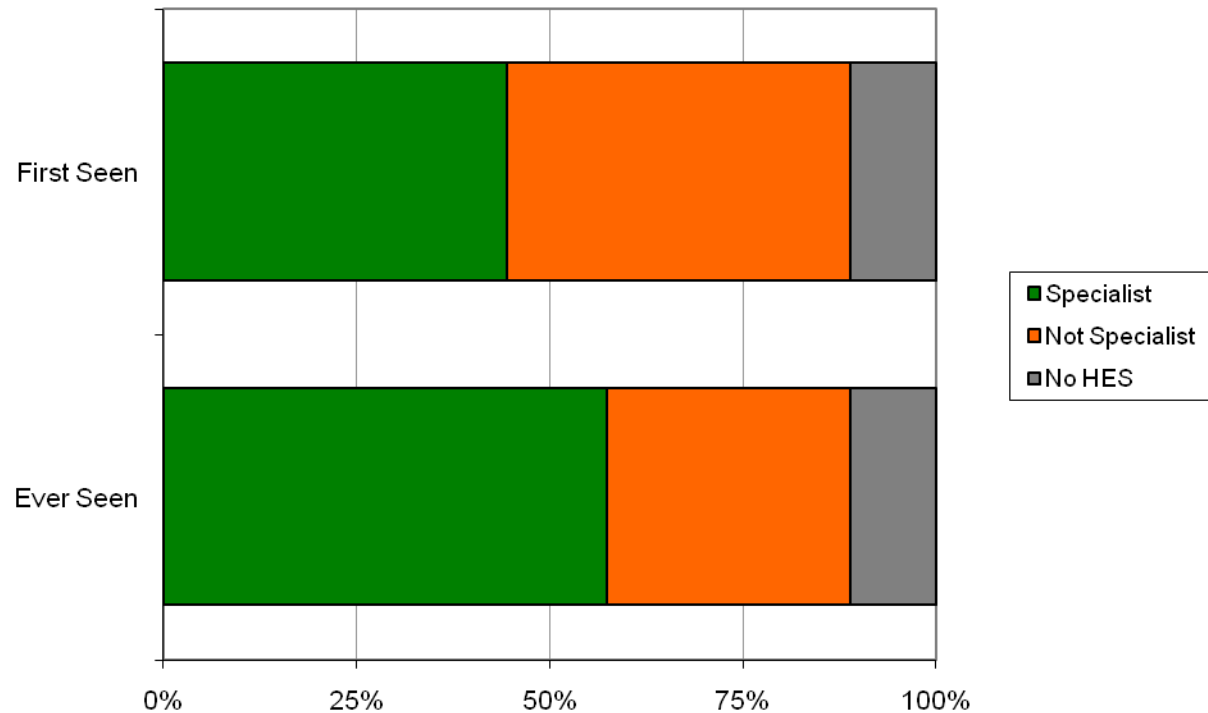
Bone Cancer Specialisation: Methodology

- Identified all primary bone cancers 2000-2007 using ICD 10 codes on registry data – 3,500 bone sarcomas
- Linked to HES data using NHS number and demographics
- Identified care episodes for cancer using ICD 10 codes on HES data.
- Identified surgical treatment from HES using OPCS 4 codes relating to orthopaedic surgery.
- HES data includes Trust of treatment code

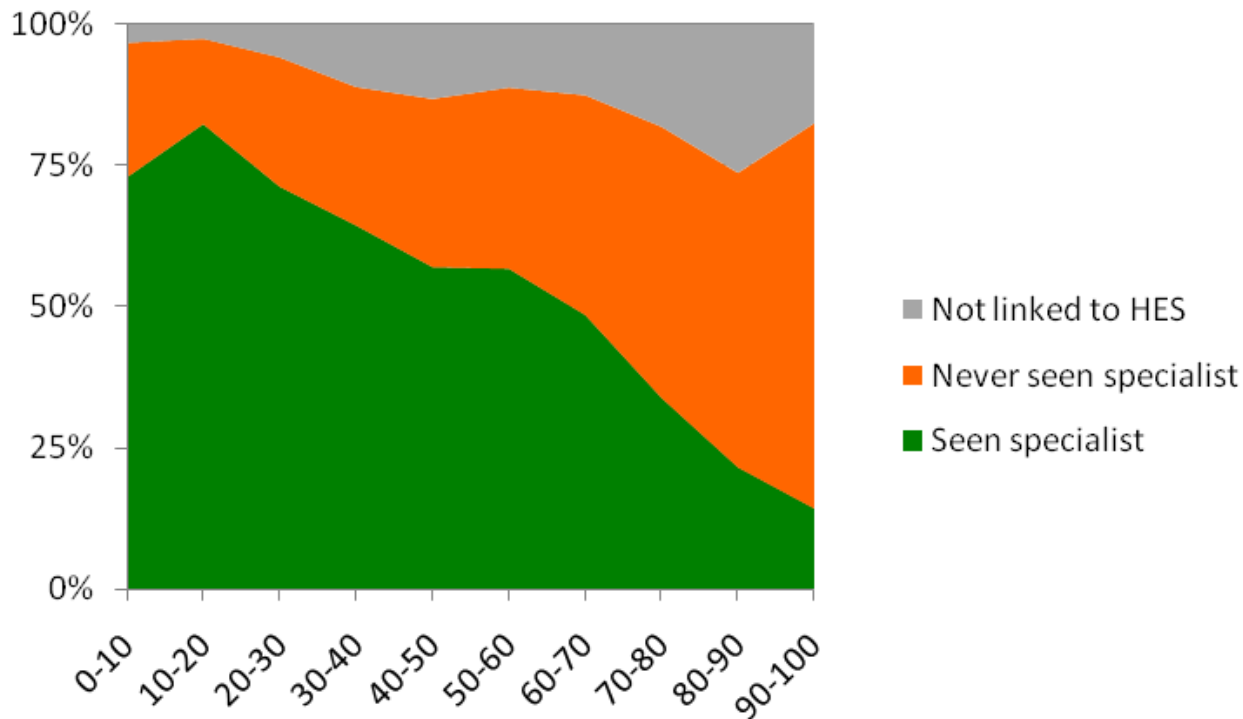
Bone Cancer Specialisation: Specialist centres

- Included the 5 specialist centres
 - GMOSS
 - London Sarcoma Service / RNOH
 - Oxford Sarcoma Service
 - Newcastle
 - ROH, Birmingham
- Included Bristol
 - Was working as specialist centre between 2000 – 2007
 - PCTs near Bristol clearly referring into Bristol in this period.

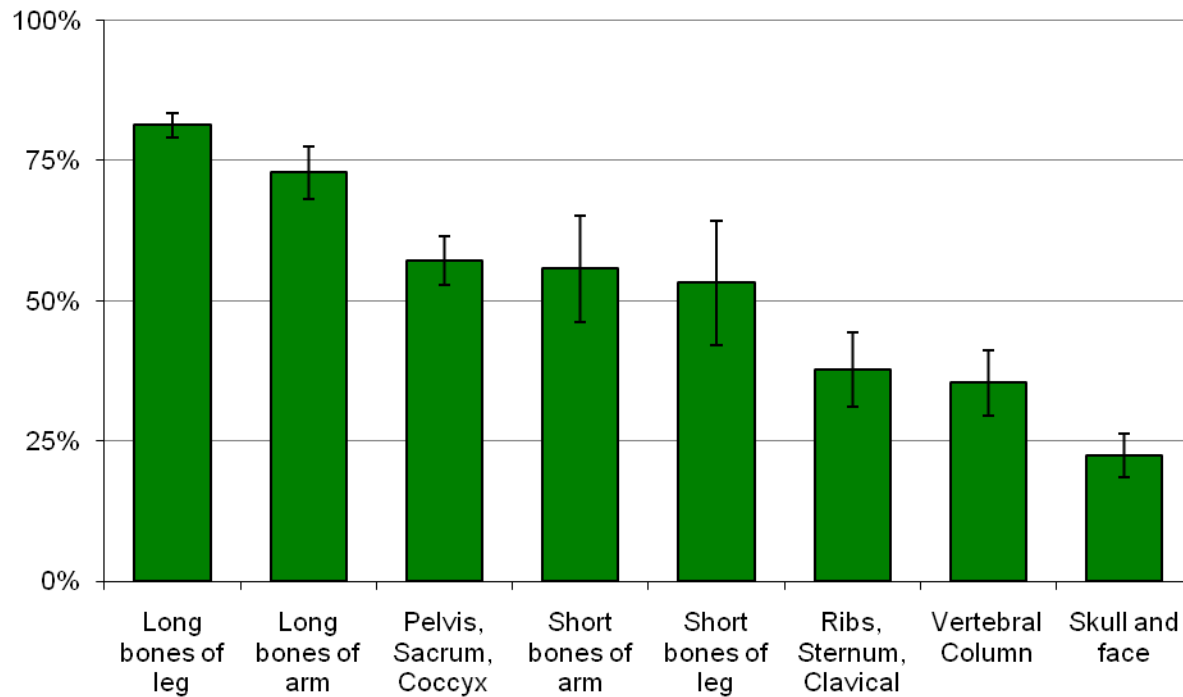
Bone Cancer Specialisation: Specialist centres



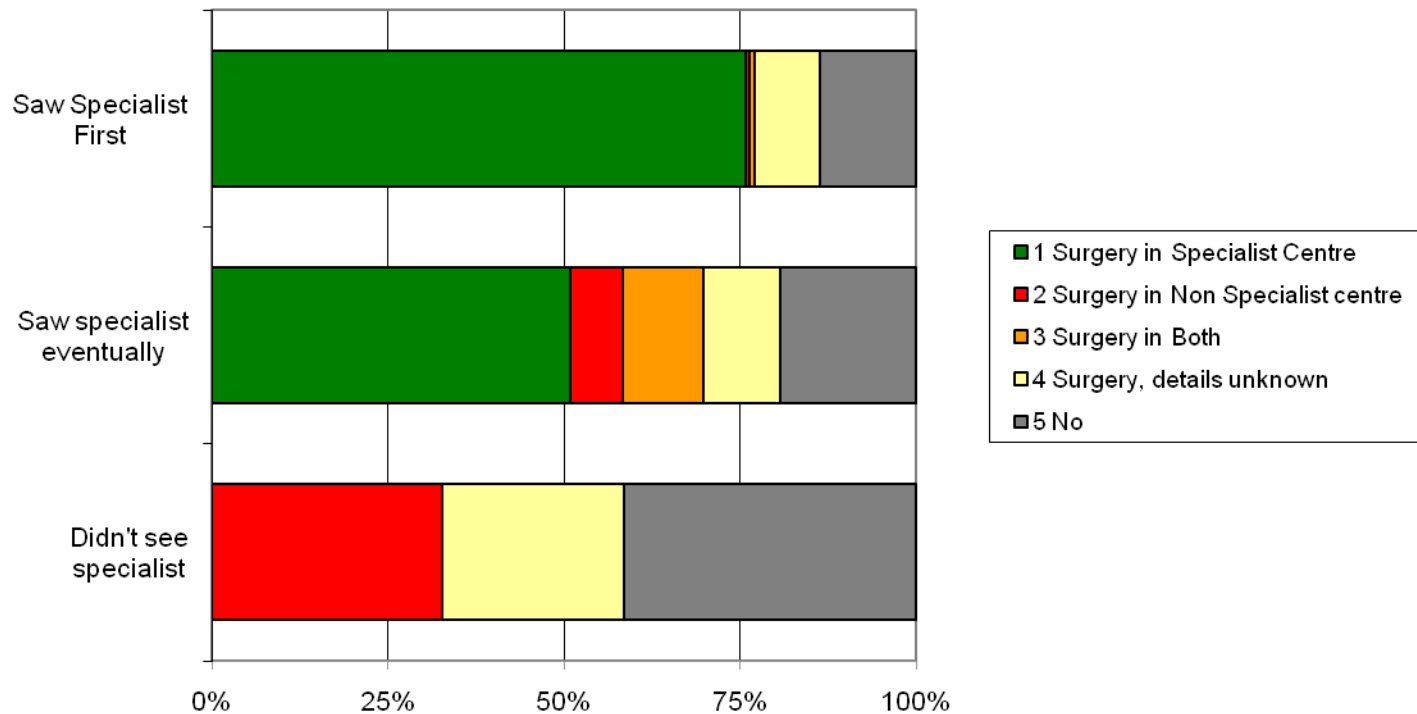
Bone Cancer Specialisation: Specialist centres - Age



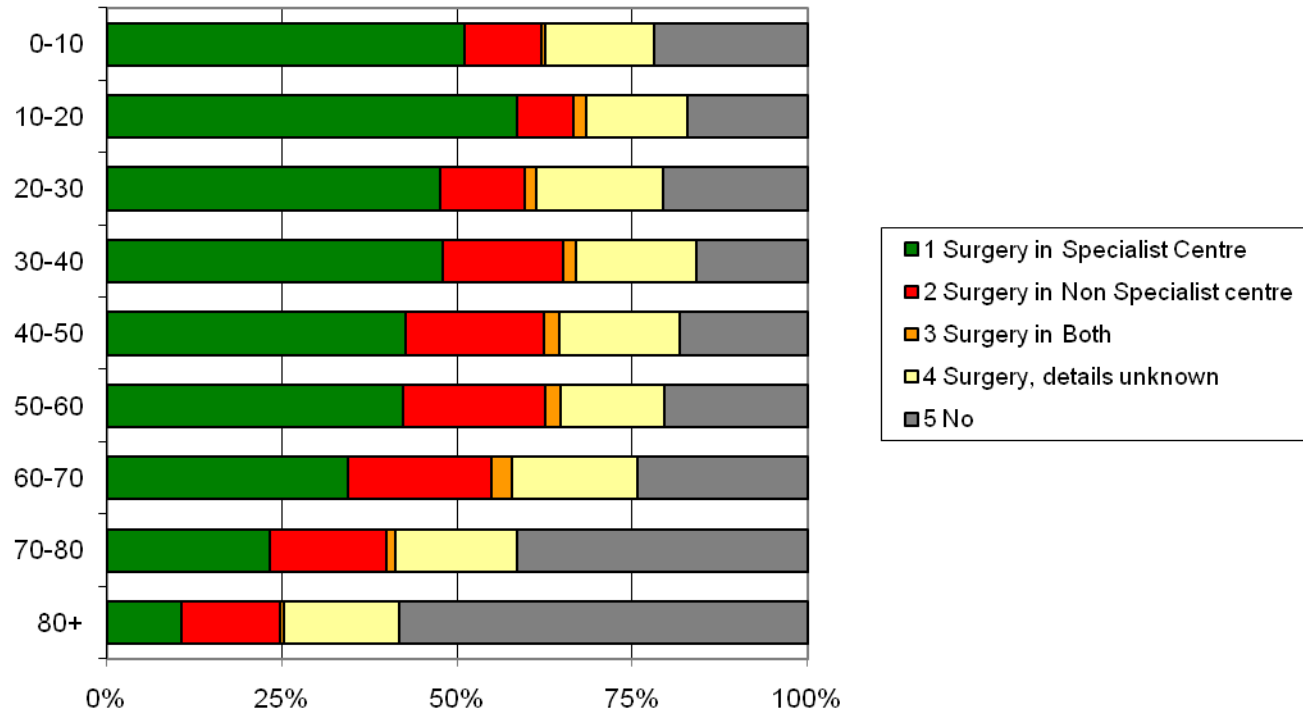
Bone Cancer Specialisation: Specialist centres - Site



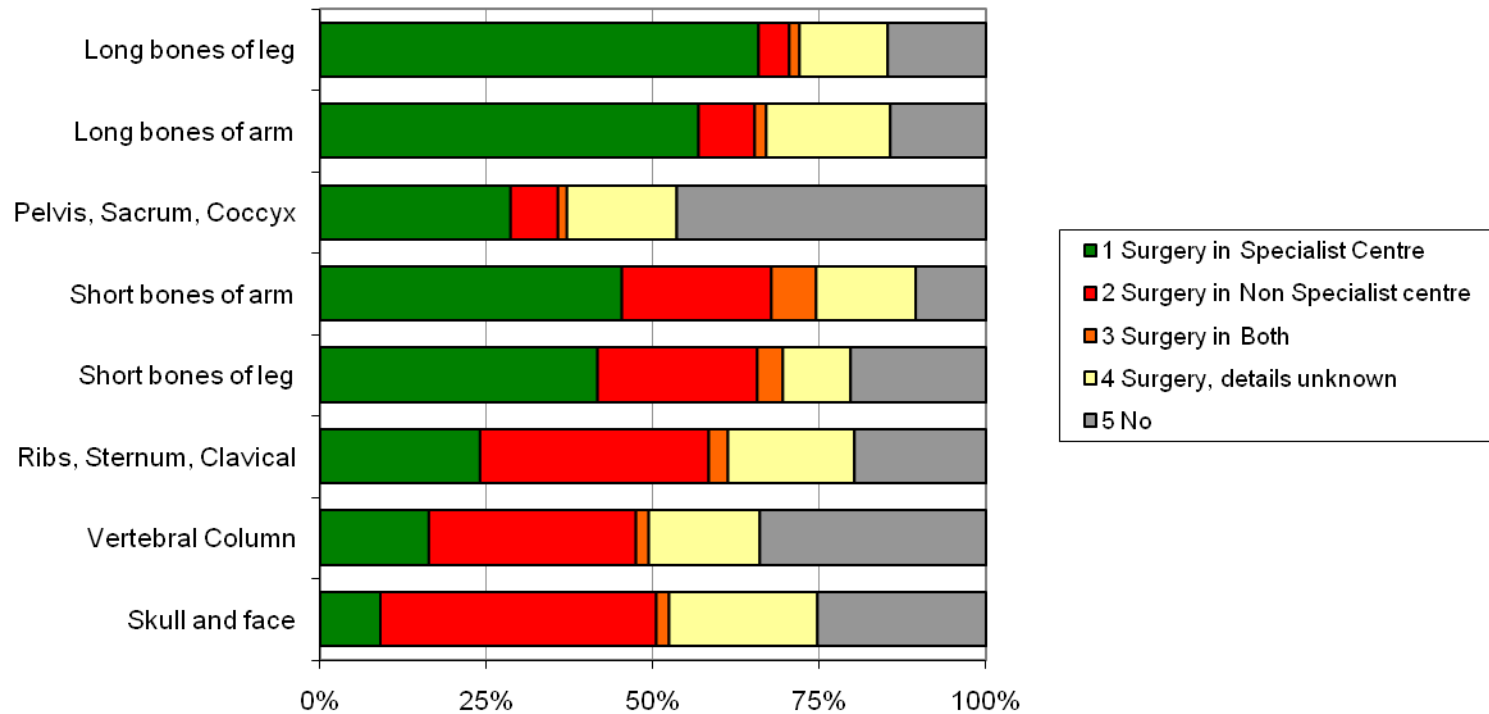
Bone Cancer Specialisation: Surgical Treatment



Bone Cancer Specialisation: Surgical Treatment - Age



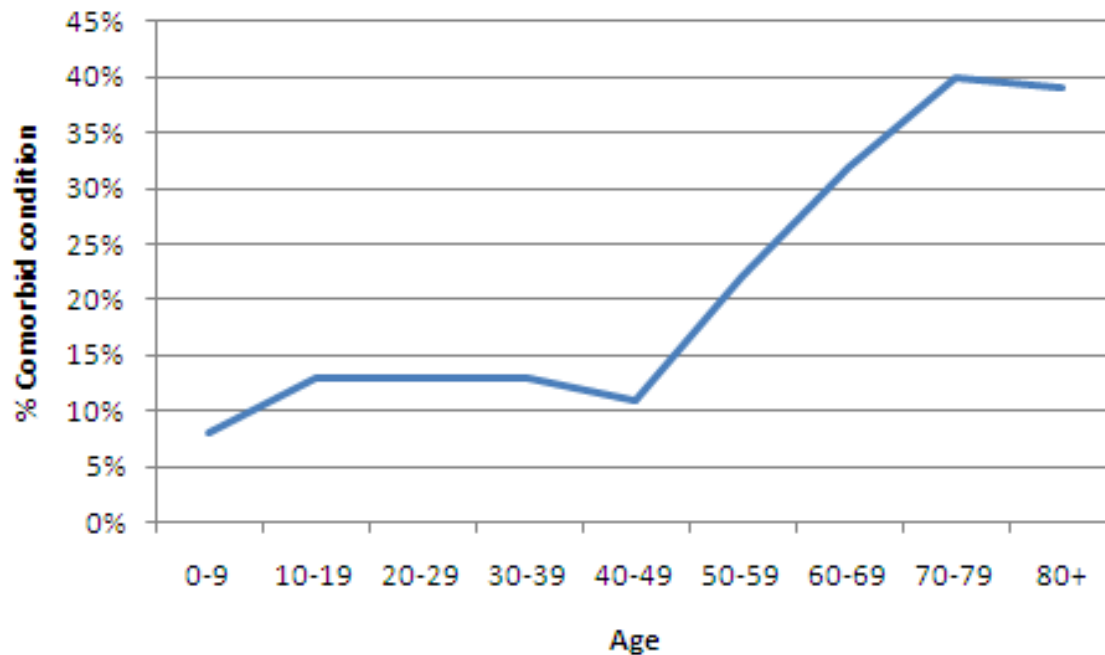
Bone Cancer Specialisation: Surgical Treatment - Site



Bone Cancer Specialisation: Future work

- Also looked at deprivation, distance to specialist centre, and changes over time
- Further data quality work
- Understand treatment in non-specialist centres
- Analysis of outcomes
 - 30 day mortality
 - 1 and 5 year survival
 - Infection rates?
- Improved analysis of predictive factors
 - Multivariate analysis
 - Other factors – which specialist centre, co-morbidity scores, rural/urban etc

Co morbidities: Bone Cancer



- Only have data on hospital admissions, so misses mild co-morbidities
- But allows us to use major co-morbidities as a confounding factor

Rare sarcomas

- National site codes don't give sub-site detail
- Audited West Midlands cases to find sub-site
- Extrapolated percentages by morphology to give a national estimate

Rare sarcomas: Facial sarcomas

Known to have different referral patterns to limb sarcomas

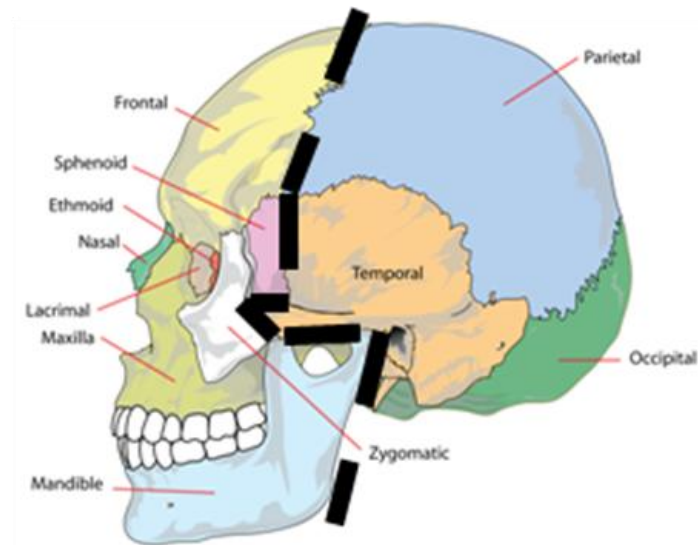
Plastic surgery support is important in these cases

Found:

25 cases annually in England

A crude rate of

0.5 cases per 1,000,000 population



Rare sarcomas: Vertebral column

Known to respond well to proton therapy

May be treated out of the country

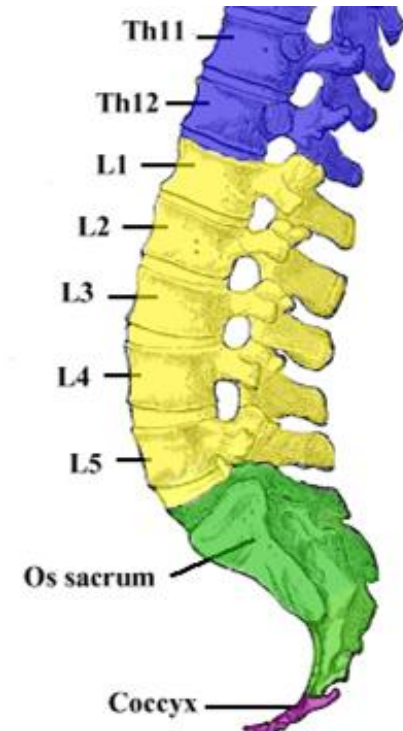
and contribute to demand for proton accelerator in England

Found:

38 cases annually in England

A crude rate of

0.6 cases per 1,000,000 population



Working together: Sharing and learning



- UKACR-NCIN conference June 2010
- British Sarcoma Group conference Feb 2010 and Feb 2011
- EMSOS conference May 2010
- Bone Cancer Research Trust
 - Patients and Supporters conference October 2010
 - Research and planning meeting Feb 2010



Four posters and three talks...

...and lots of learning and talking to people!



Working together: Information Requests

- WMCIU is the lead on all national sarcoma requests that come to the English Cancer Registries
- Mostly high level numbers of cases and deaths, incidence, mortality, survival

- Cancer Research UK
- Sarcoma UK
- Newcastle University



...and more!

Where next?

- 2008 national data arrived last week
- Want to work with clinicians around data quality issues
 - Audit our data and check it makes sense!
- Coming to the end of financial year 2010/11
 - Need to review last year's work programme and plan the next
- Important to work closely with clinicians, understand data quality issues and answer questions that can make a difference to our understanding of sarcoma
- So we need you to help with priorities for the work programme!