



# The National Cancer Intelligence Network:

Capturing data for patient benefit

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**Dr Gill Lawrence**

West Midlands Cancer Intelligence Unit

**Mr Rob Grimer**

Birmingham Royal Orthopaedic Hospital

Tel: 0121 415 8129 Fax: 0121 414 7714

e-mail: [gill.lawrence@wmciu.nhs.uk](mailto:gill.lawrence@wmciu.nhs.uk)

# National Cancer Intelligence Network



- A National Cancer Intelligence Network has been established as part of the Cancer Reform Strategy

- launched 18 June 2008



- Each UK cancer registry will take the lead for specific cancers

- The WMCIU is the nominated lead registry for:

- breast cancer
- bone and soft tissue sarcoma



- NCIN National Site Specific Clinical Reference Groups

- established for each cancer site
- first joint meeting 11 March 2009
- sarcoma NSSCRG 18 May 2009
- NCIN conference 25 June 2009

# National Cancer Intelligence Network

## Core Objectives



- Enable use of existing cancer information to support **commissioning** and the implementation of **Improving Outcomes Guidance**
- Exploit information to drive improvements in **standards of care** and **clinical outcomes**
- Enable use of cancer information to support **audit** and **research**
- Promote efficient and effective **data collection**
- Provide common **data repository** for cancer datasets
- Produce **expert analyses**, based on robust methodologies, to **monitor patterns of cancer care**
- Provide effective **dissemination** of findings to healthcare professionals, managers and the general public

# NCIN National Site Specific Clinical Reference Groups - Terms of Ref



- Identify and prioritise **clinical outcome measures**
- Identify **key variables** that contribute to achieving high standards in these outcome measures
- Establish what is **already known** about clinical outcomes for sarcoma in UK and international variations
- Develop and collect a **core data set**:
  - linkage of relevant data sources, peer review, PROMs
  - case ascertainment, data completeness, timeliness
- Advise NCIN on **priorities** for sarcoma:
  - analyses, audits, research activity, publications, press releases
  - service improvement initiatives, bids for additional resources
- Build **links**:
  - NCRI Sarcoma Clinical Study Group
  - voluntary sector – Sarcoma UK, Bone Cancer Research Trust

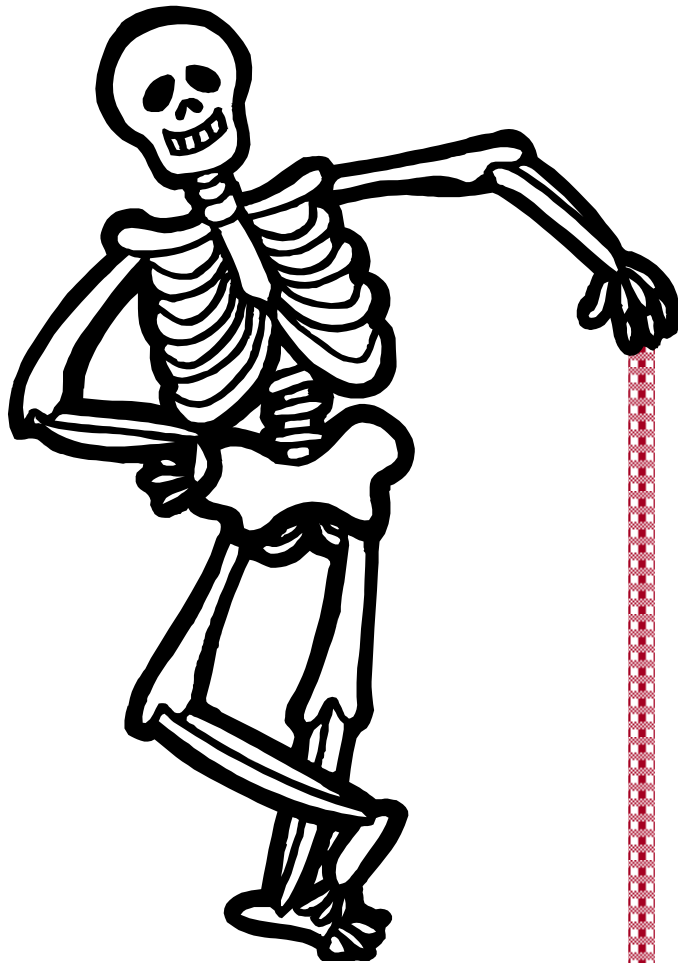
# Sarcoma NSSCRG - Membership



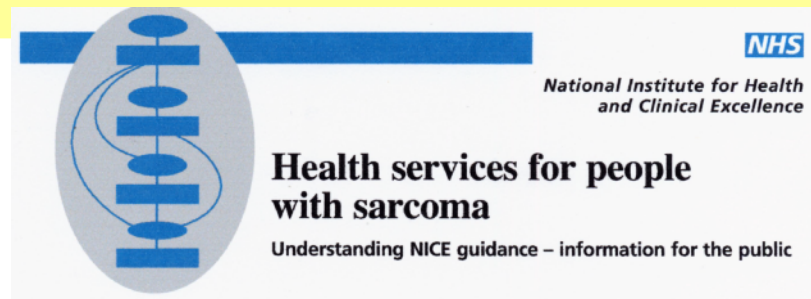
- Chair – Rob Grimer (surgical oncologist)
- Lead cancer registry – WMCIU – Sally Vernon
- Surgery – Andrew Hayes, Lee Jeys
- Radiology – Julia Fairbairn
- Pathology – Nick Athanasou, Chas Mangham
- Oncology – Rob Turner, Martin Robinson
- Cancer network – Pan Birmingham – Karen Metcalf
- Voluntary sector – Roger Wilson, Mike Francis
- Patient representative – Terri Johnson
- National team – Stephen Parsons (peer review)
- Cross links:
  - Children & Young Adults – Jeremy Whelan
  - CNS, gynae, upper GI (GIST)
  - Scotland, Wales



# Bone and Soft Tissue Sarcoma



What would  
we like to  
know?



- Are patients referred to a **specialist treatment centre** for diagnosis & management?
- Is care supervised by a specialised **sarcoma MDT**?
- Are diagnoses reviewed by a **specialist sarcoma pathologist** and/or **radiologist** who are part of a sarcoma MDT team?
- Does the MDT manage
  - at least **100** new patients with **soft tissue sarcoma** per year
  - at least **50** new **bone sarcoma** patients per year?
- Are resections done by **surgeons** who are MDT members and have tumour site-specific experience?
- Are **chemotherapy** and **radiotherapy** carried out at designated centres by appropriate specialists?
- Are patients informed of relevant **clinical trials** and supported to enter them?
- Do the MDTs participate in **national audit, data collection & training**?

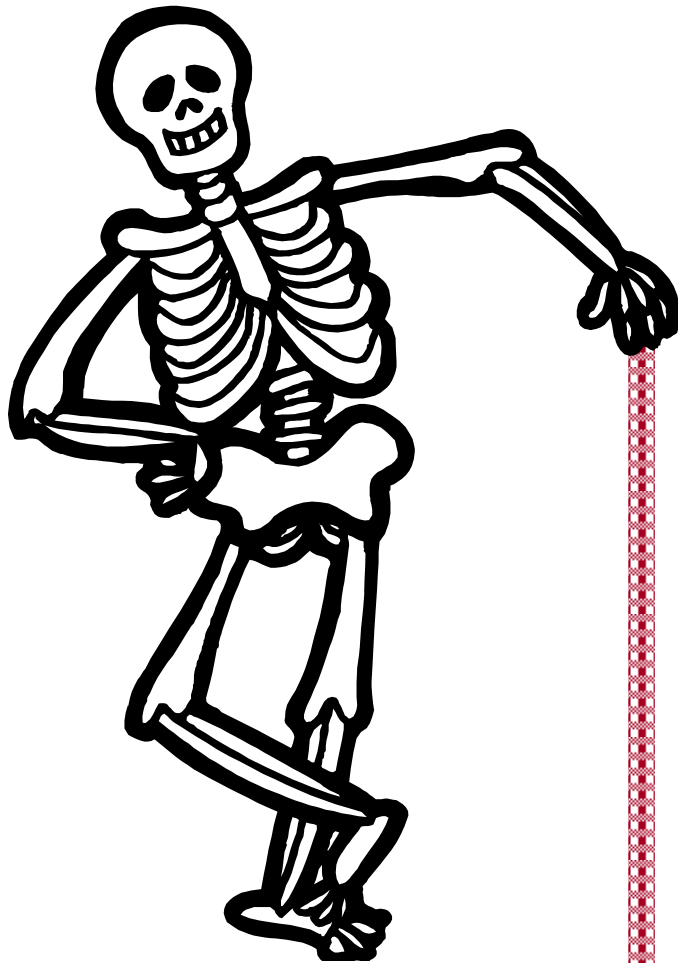
# Outcome measures



IOG Chapter	Measure
3	% patients referred to sarcoma MDT before first definitive treatment
	% patients undergoing pre-operative diagnostic biopsy (excl retroperitoneal sarcoma)
	% patients undergoing pre-operative scan (MRI or CT)
4	Time taken from GP referral to definitive diagnosis
	Attendance of site specific pathologists at MDT
5	Number of patients managed by sarcoma MDT
	Every patient is managed by appropriate MDT
	Participation by individual specialists at MDT
6 and 7	Compliance with national waiting times pathways
	Compliance with national referral pathways
	Compliance with radiotherapy regimens
	Compliance with chemotherapy regimens
	5 year survival data
	3 year local recurrence data
	Stage specific survival and recurrence data
6	Amputation rate in patients treated with curative intent
	Chemotherapy-related toxic deaths
7	% patients with GIST receiving Imatinib



# Bone and Soft Tissue Sarcoma



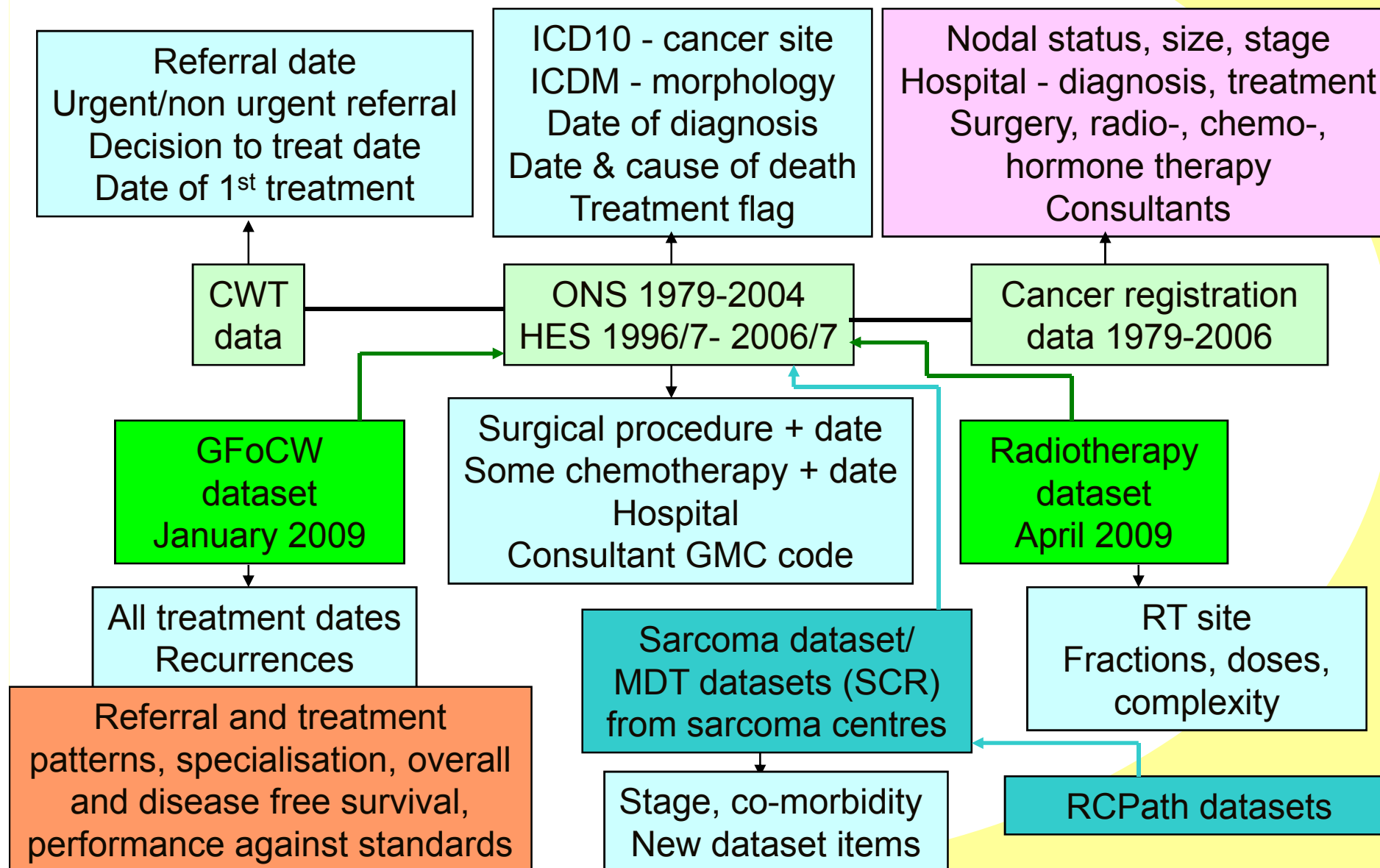
Dataset and  
database  
development

# Dataset development

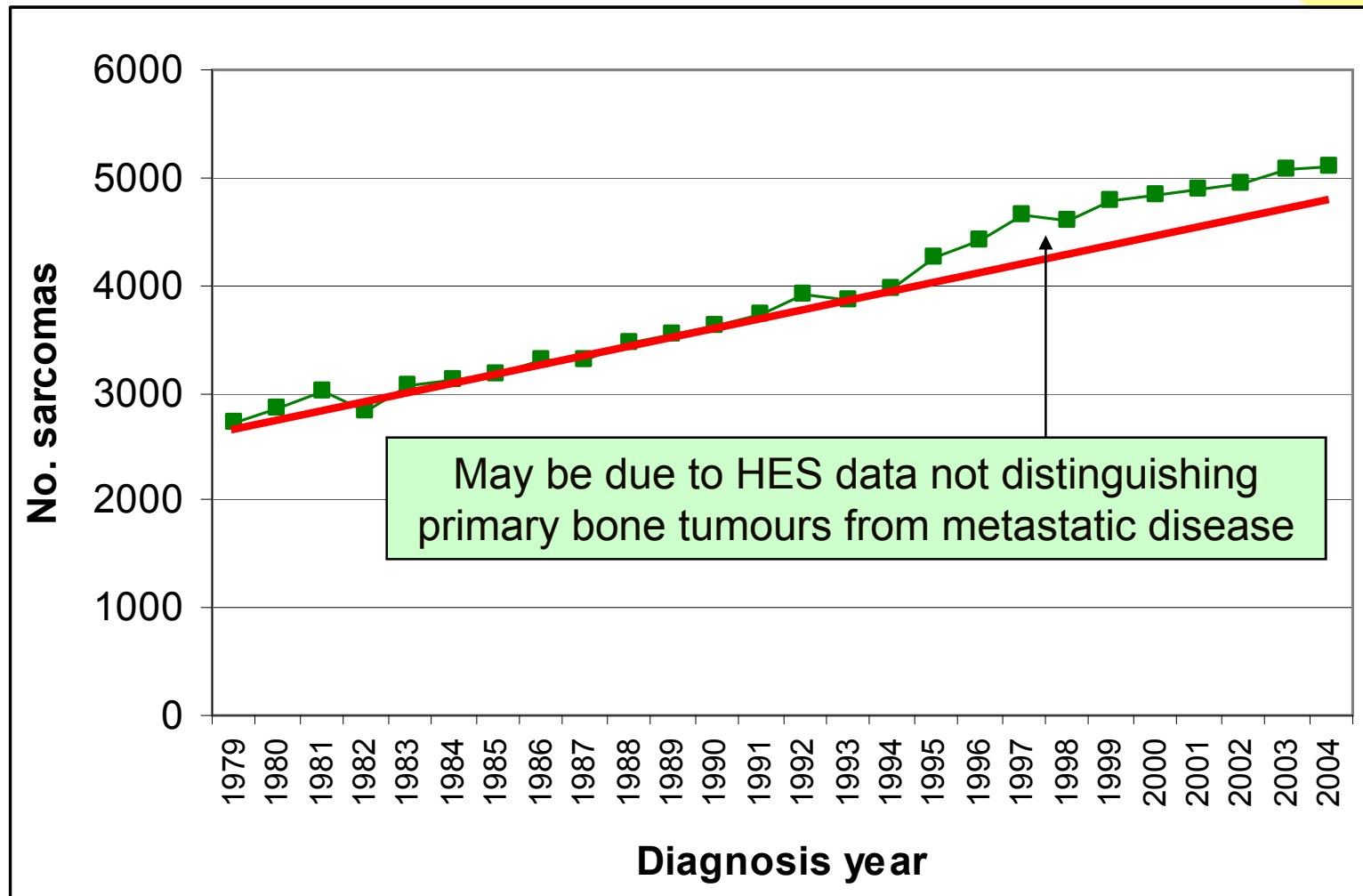


- Review National Cancer Dataset items
  - view as series of events
  - what, where, when, who?
- Additional imaging data items:
  - primary tumour or metastases (+site)
  - diagnostic imaging modality - updated
  - image-guided needle biopsy technique
- Additional surgical items:
  - margins – planned, closest, distance, material present
  - peri-osteal breach, cortex intact, further excision
- Other new items:
  - symptom duration, referral to key worker, complications, follow up
- Comparison with RCPATH datasets
  - SNOMED/WHO code lists
  - soft tissue sarcoma – draft published
  - bone – still awaited

# Database development

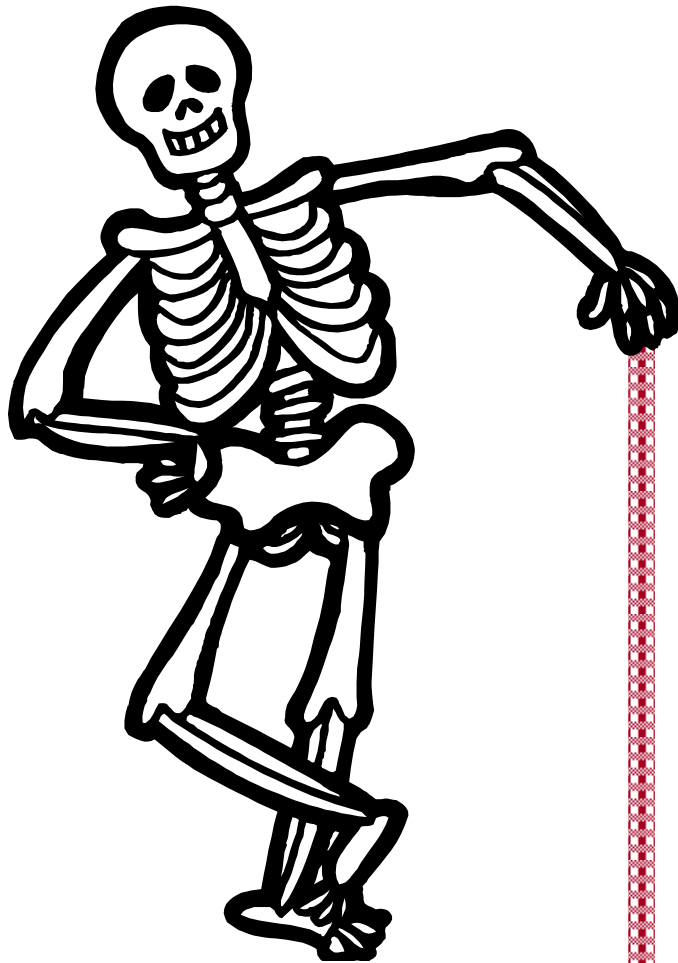


# ONS-HES data – initial analyses



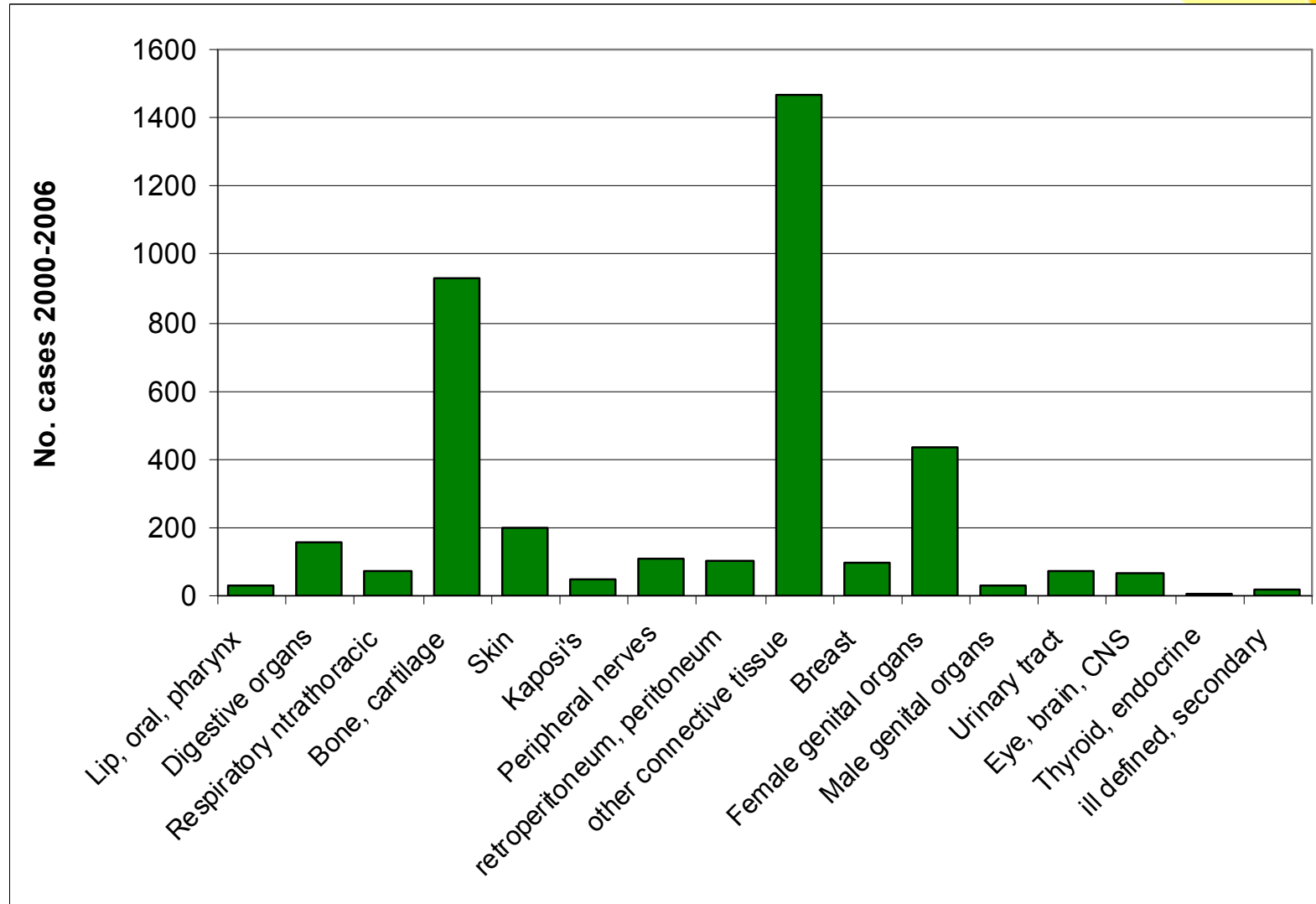


# Bone and Soft Tissue Sarcoma



Cancer  
registration  
data  
quality

# West Midlands cases 2000-2006

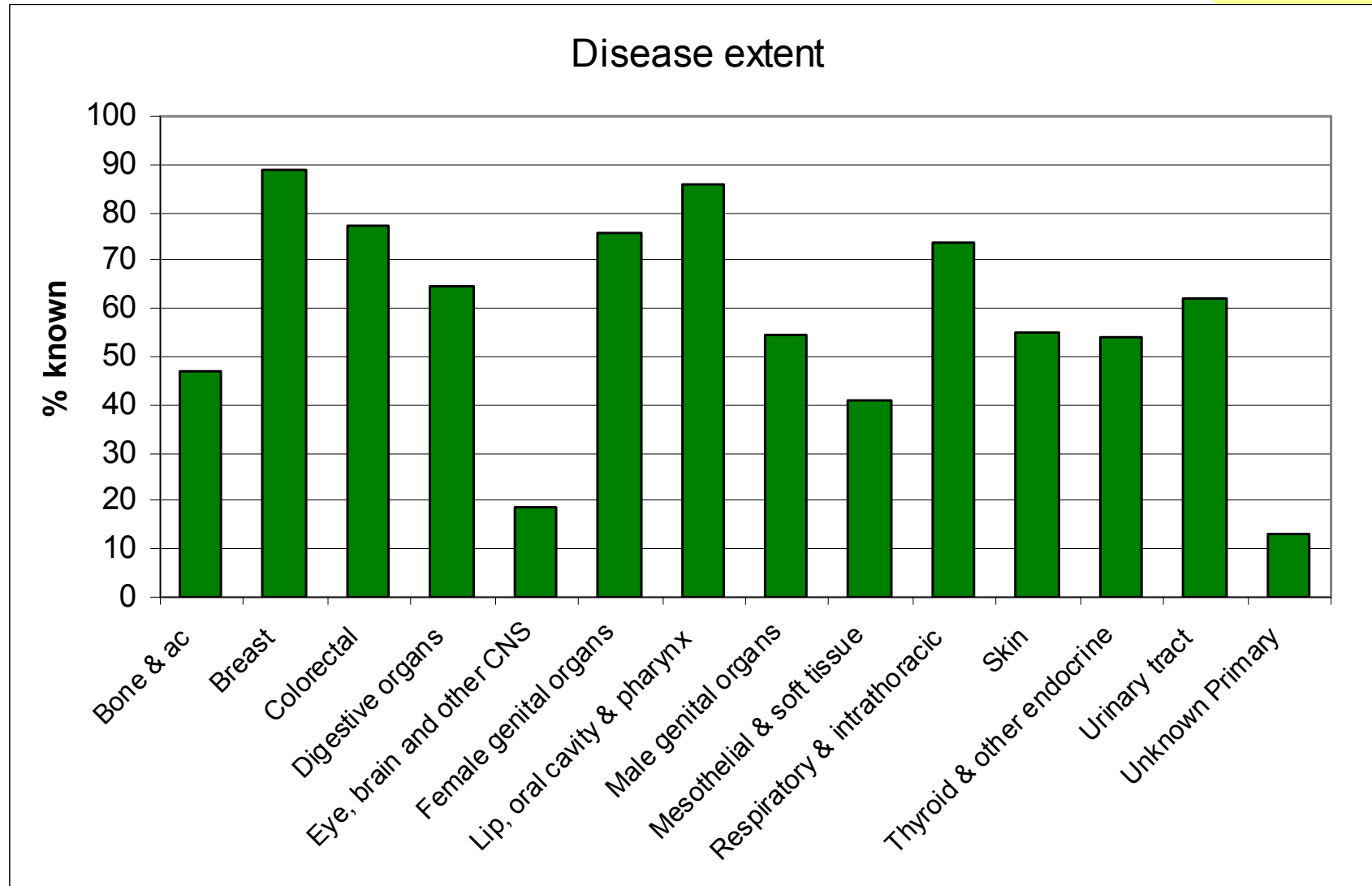


# Data completeness



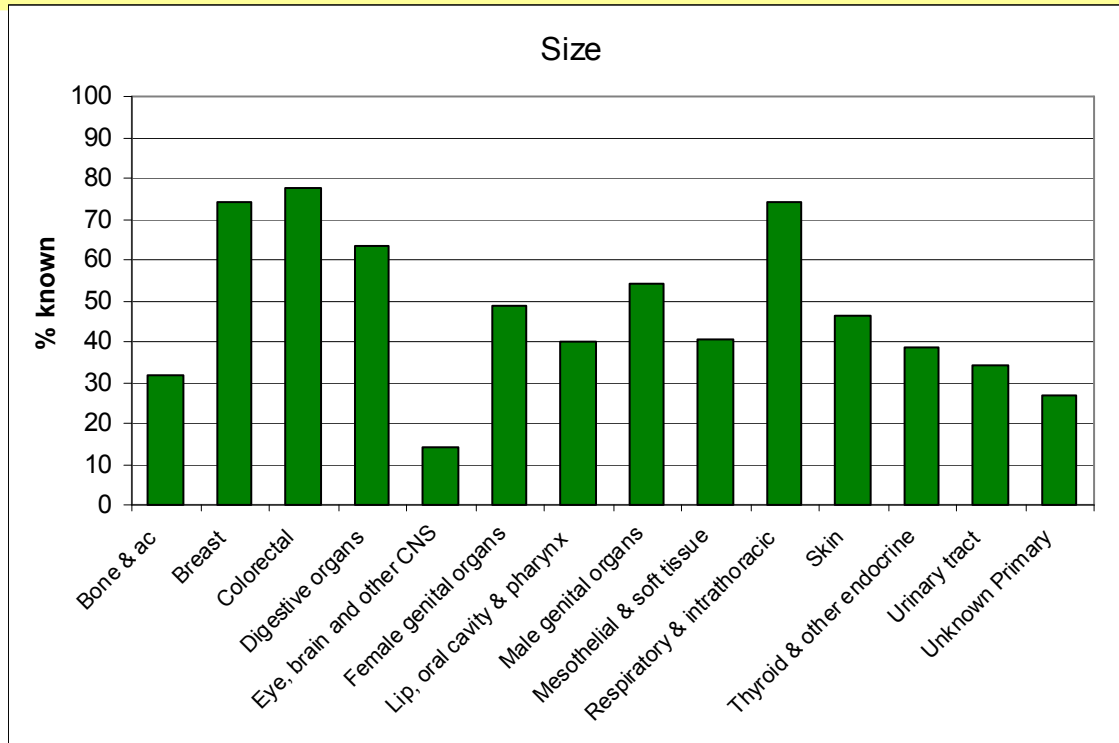
Clinically abstracted cases

# Data completeness

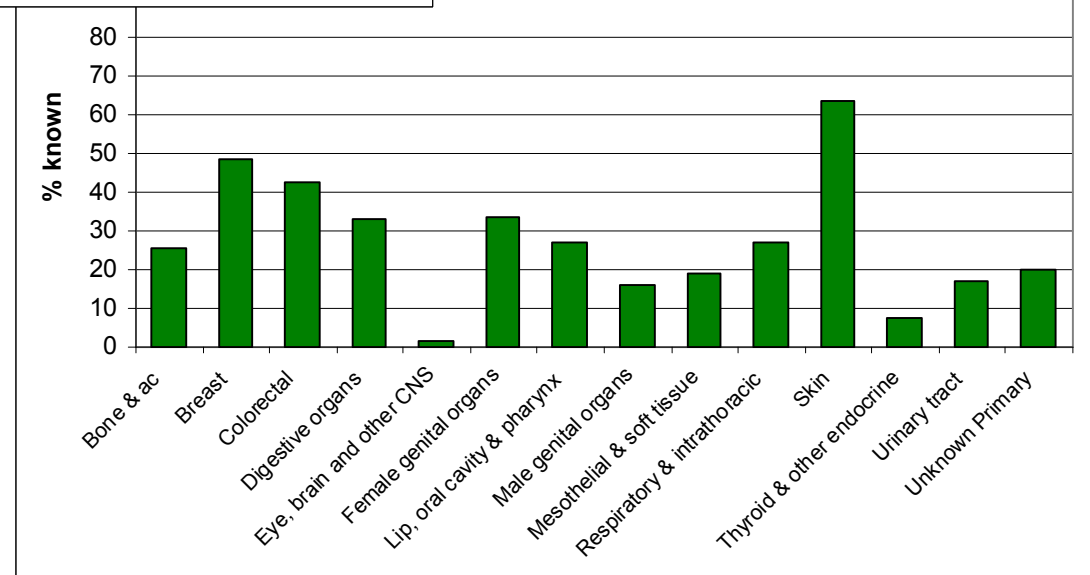




# Data completeness



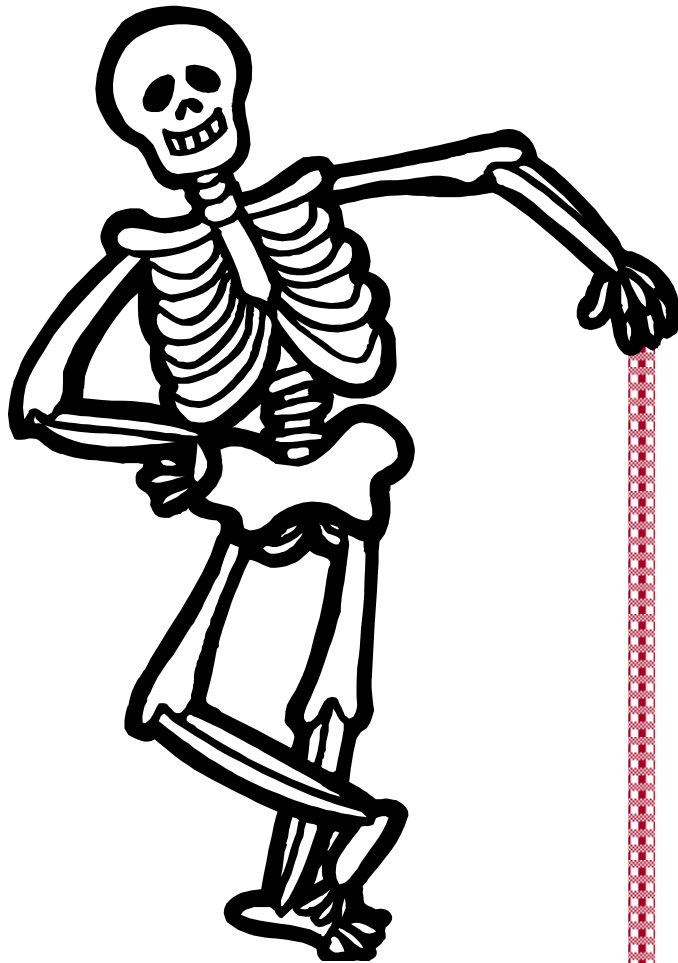
Excision margins



Clinically abstracted  
surgically treated  
cases



# Bone and Soft Tissue Sarcoma



Rare  
tumours



# GIST 1998-2003 124 cases

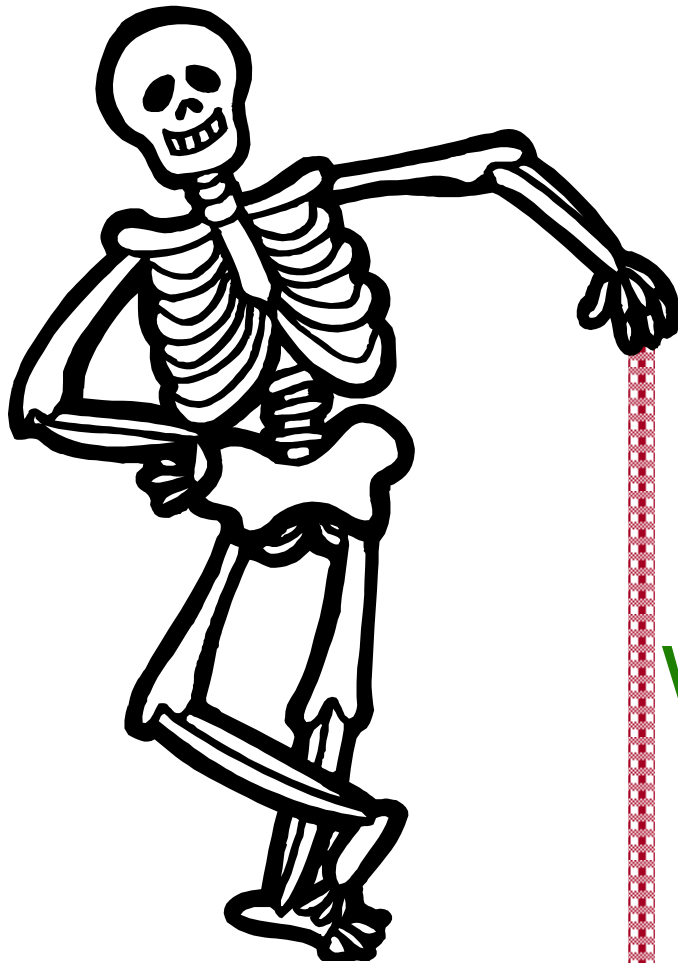
Behaviour:		Malignant	Uncertain	Total
		n ( % )	n ( % )	n ( % )
		67 ( 54.0 )	57 ( 46.0 )	124 ( 100 )
Gender				
	Male	39 ( 58.2 )	22 ( 38.6 )	61 ( 49.2 )
	Female	28 ( 41.8 )	35 ( 61.4 )	63 ( 50.8 )
Age Group				
	<50	15 ( 22.4 )	8 ( 14.0 )	23 ( 18.5 )
	50-59	12 ( 17.9 )	8 ( 14.0 )	20 ( 16.1 )
	60-69	15 ( 22.4 )	13 ( 22.8 )	28 ( 22.6 )
	70-79	15 ( 22.4 )	19 ( 33.3 )	34 ( 27.4 )
	80+	10 ( 14.9 )	9 ( 15.8 )	19 ( 15.3 )
Diagnosis Year				
	1998	10 ( 14.9 )	5 ( 8.8 )	15 ( 12.1 )
	1999	7 ( 10.4 )	11 ( 19.3 )	18 ( 14.5 )
	2000	10 ( 14.9 )	4 ( 7.0 )	14 ( 11.3 )
	2001	6 ( 9.0 )	11 ( 19.3 )	17 ( 13.7 )
	2002	21 ( 31.3 )	18 ( 31.6 )	39 ( 31.5 )
	2003	13 ( 19.4 )	8 ( 14.0 )	21 ( 16.9 )
Site (ICD10)				
	Oesophageal (C15)	1 ( 1.5 )		1 ( 0.8 )
	Stomach (C16)	32 ( 47.8 )		32 ( 25.8 )
	Small Intestine (C17)	19 ( 28.4 )		19 ( 15.3 )
	Colon (C18)	8 ( 11.9 )		8 ( 6.5 )
	Rectum (C20)	2 ( 3.0 )		2 ( 1.6 )
	Ill Defined Digestive (C269)	5 ( 7.5 )		5 ( 4.0 )
	Stomach (D371)		46 ( 80.7 )	46 ( 37.1 )
	Small Intestine (D372)		8 ( 14.0 )	8 ( 6.5 )
	Rectum (D375)		1 ( 1.8 )	1 ( 0.8 )
	Digestive Organ, unspecified (D379)		2 ( 3.5 )	2 ( 1.6 )
Histology (ICDO2)				
	Leiomyosarcoma (8890)	26 ( 38.8 )	20 ( 35.1 )	46 ( 37.1 )
	Mesenchymoma (8990)	41 ( 61.2 )	37 ( 64.9 )	78 ( 62.9 )

Incidence = 4 per million  
lower end of NICE guidance range  
– are GIST being misdiagnosed  
as benign tumours and thus  
not being registered?

Nilsson et al Cancer 2005 103: p821  
14.5 per million



# Bone and Soft Tissue Sarcoma



Cancer  
waiting times  
analyses

# West Midlands CWT data

1 January – 31 December 2007

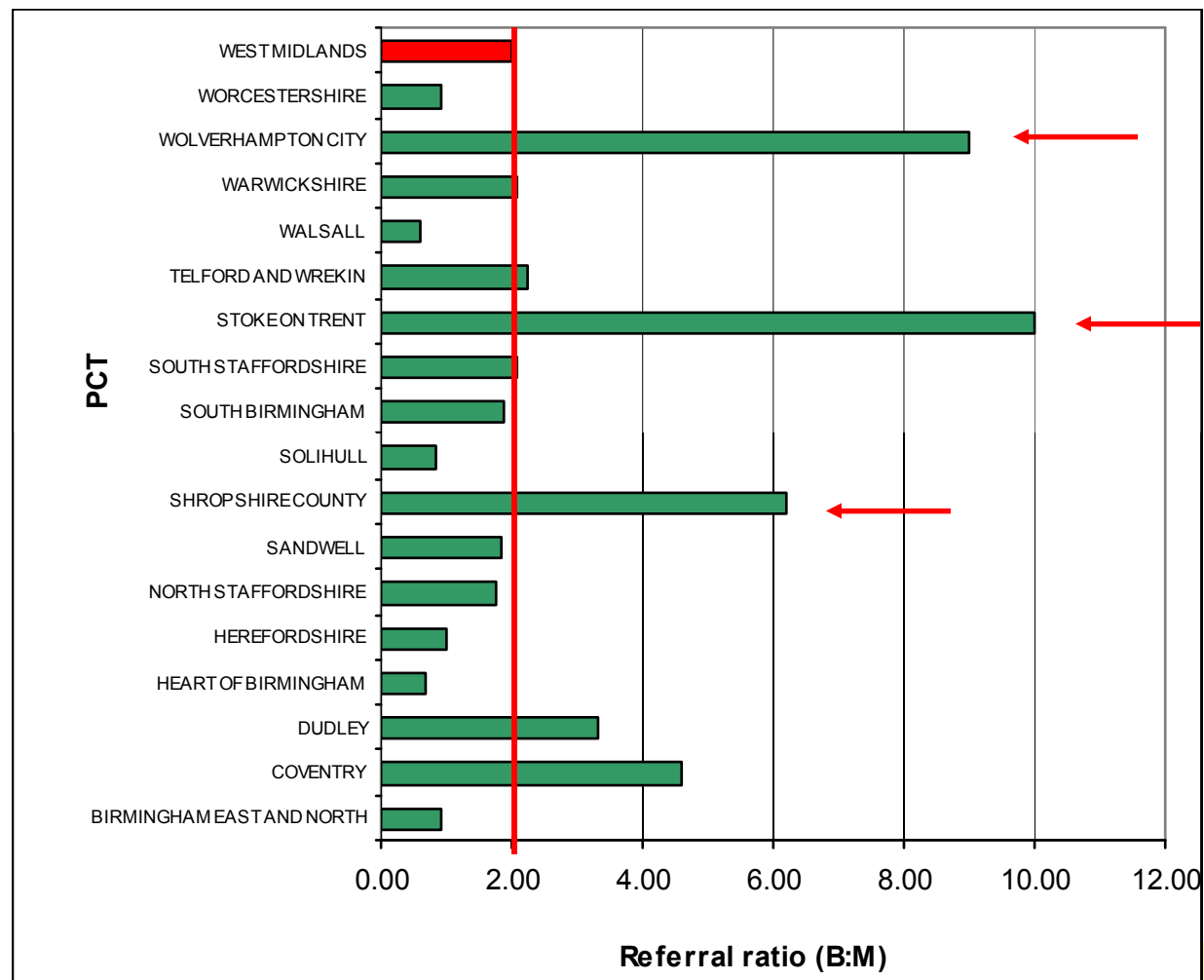


C40	Malignant neoplasm of bone and articular cartilage of limbs
C41	Malignant neoplasm of bone and articular cartilage other and unspecified sites
C46	Kaposi's sarcoma
C48	Malignant neoplasm of retroperitoneum and peritoneum
C49	Malignant neoplasm of connective and soft tissue

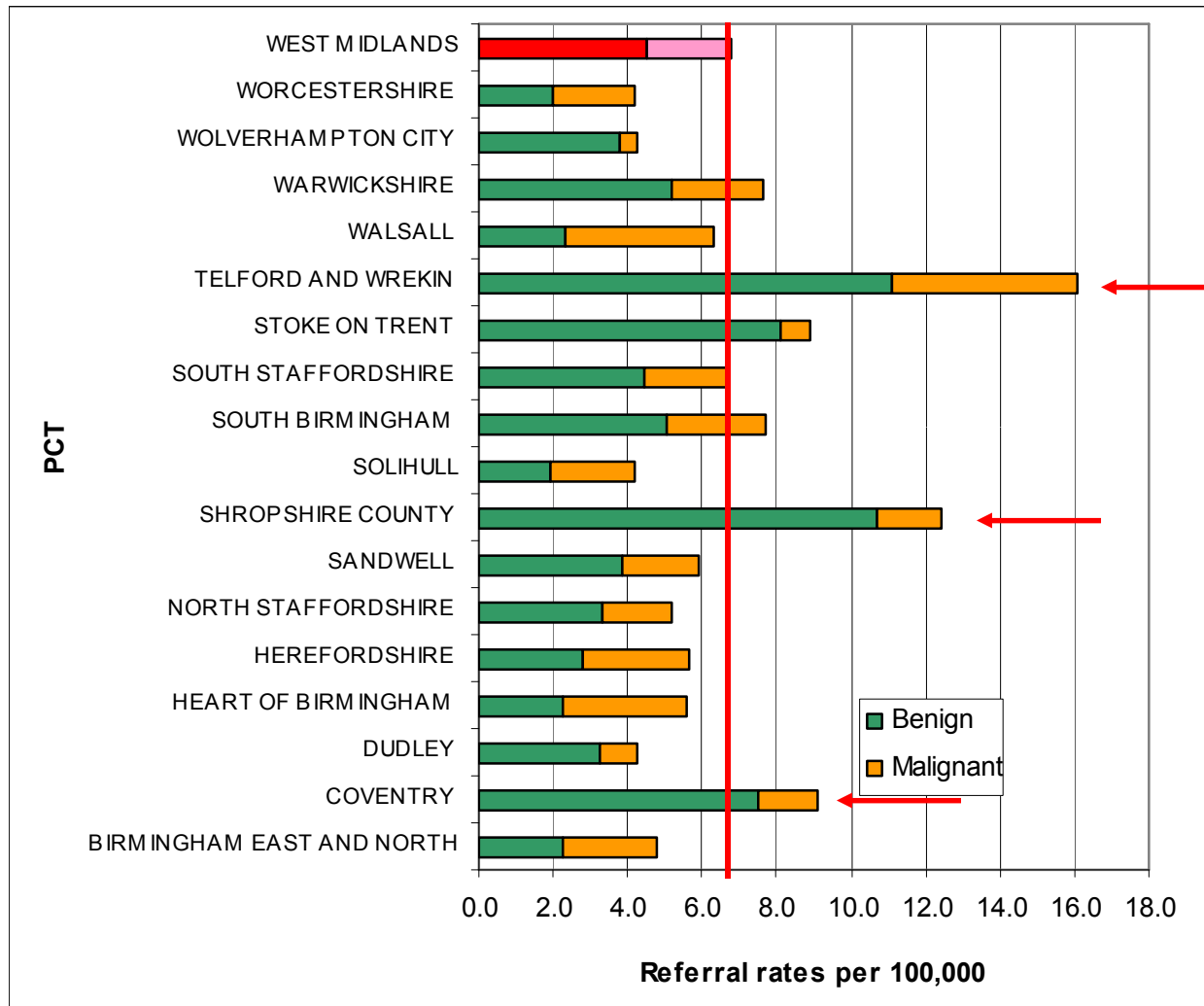
Referral type	"Benign"		"Malignant"		Total
	No.	%	No.	%	No.
Urgent referral	242	88	33	12	275

Malignant tumours	Urgent		Non-urgent		Total
	No.	%	No.	%	No.
Bone	2	13	14	88	16
Soft tissue sarcoma	31	30	74	70	105
<b>Total</b>	<b>33</b>	<b>27</b>	<b>88</b>	<b>73</b>	<b>121</b>

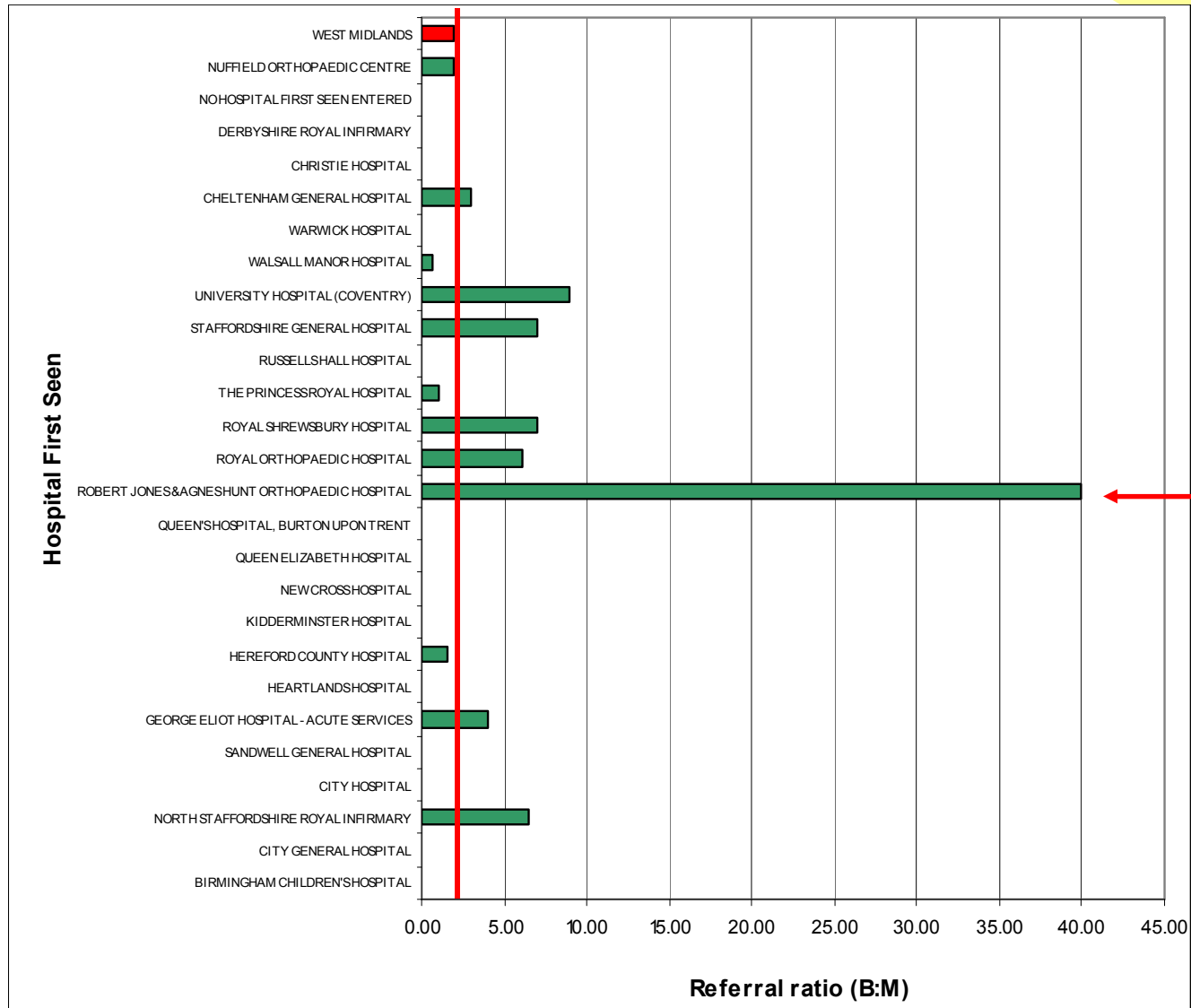
# PCT "Benign:Malignant" referral ratios



# PCT referral rates



# Trust "B:M" referral ratios



# Cancer Waiting Times targets



Only cases with a Decision to Treat Date (DTTD) and/or a First Definitive Treatment Date (FDTD) can be included in CWT calculations

Sarcoma type	62 day target - urgent cases			31 day target - urgent and non-urgent cases		
	Total eligible cases	Met 62 day target	% meeting 62 day target	Total eligible cases	Met 31 day target	% meeting 31 day target
Bone	2	1	50.0	16	15	93.8
Soft tissue sarcoma	31	25	80.6	105	100	95.2
<b>Total</b>	<b>33</b>	<b>26</b>	<b>78.8</b>	<b>121</b>	<b>115</b>	<b>95.0</b>

For 4 (13%) cases performance against 62 day target could not be calculated as they had no DTTD and/or FDTD

For 6 (5%) cases performance against 31 day target could not be calculated as they had no DTTD and/or FDTD

# Next steps



- To agree with the relevant professional bodies the ideal **core dataset** to be collected based on the NCDS and RCPATH datasets
- To create a **single register** collecting a consistent, high quality core dataset for all bone & soft tissue sarcomas diagnosed and treated in the UK
- To establish processes to **collect**, on a regular basis, all new cases identified by
  - regional cancer registries
  - specialist referral centres
- To **quality assure** the data for case completeness and accuracy and to ensure that diagnosis and treatment coding is consistent
- To define a set of **Key Performance Indicators** against which the quality of services can be monitored
- To appoint an **Sarcoma Analyst** within the WMCIU – interviews in May





# *Thank you*

- Berni Lee, Natasha Wood, Sam Hunt
- WMCIU cancer registration and data quality staff
- West Midlands cancer service providers

