Impact of COSD on Cancer Registration

NCIN Sarcoma Workshop

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The UK's National Cancer Registration System

- 8 'regional' English cancer registers + Wales, Scotland, N Ireland [& Eire]

  record all malignant (invasive and *in situ)* and some benign cancers in their residents

- Core data
  Surve
  ac
  each year
- WMCIU holds the second largest regional register and fifth largest European register

BUT
this is all changing in 2013

- In 2013 the regional cancer registries are moving to a single cancer registration database for England

ENCORE

- From 1 January 2013 there will be a new cancer registration dataset

COSD

Data sources - patient-level data

National Feeds

Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

National PET-CT imaging

National cancer audits - Lung, Head and Neck, Upper GI and Colorectal

Hospital Episode Statistics (HES)

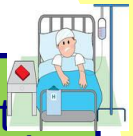
Encore

Local Feeds

Data from MDT software systems

Pathology full-text reports

Local imaging systems



Patient Administration Systems

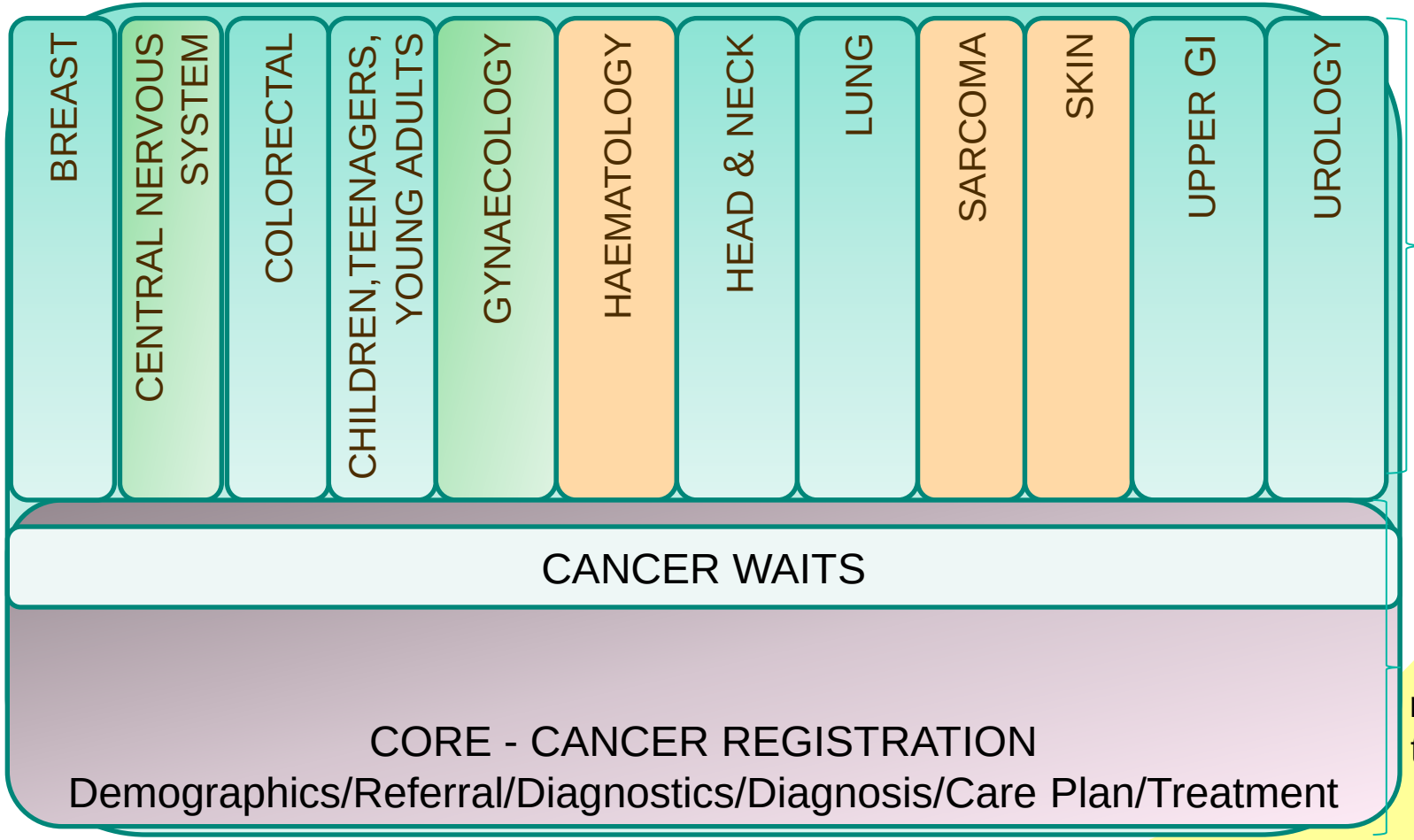
Local clinical data systems

National Pilots

Recurrent/ Metastatic Breast Pilot

CRUK Stratified Medicine

COSD – Mandatory from 1 January 2013



What's different about the COSD?

- Complete patient pathway
  - Referral details for all cases
  - All treatments
  - Includes palliative and supportive care
- Additional core data items including
  - Involvement of Clinical Nurse Specialist
  - Duration of symptoms
    - Mandatory for Children,Teenagers,Young Adults (CTYA), Optional for others
    - Year/Month/Day as appropriate or available
- All registerable conditions including
  - In situ bladder, in situ melanoma, benign brain tumours
- Includes recurrences
  - Breast cancers to start with
- Site specific data
  - Key site specific clinical items – patient management
  - Site specific stage
  - Stage components of RCPath datasets

COSD Dataset

Data Item Name	Suggested System/Source
Primary Diagnosis (ICD)	
Multidisciplinary Team Discussion Date (Cancer)	
Cancer Care Plan Intent	
Performance Status (Adult)	
TNM Stage Grouping (Final Pre Treatment)	
Site Code (Of Imaging)	
Procedure Date (Cancer Imaging)	
Imaging Code (Nicip)	
Cancer Imaging Modality	
Imaging Anatomical Site	
Consultant Code	
Care Professional Main Specialty Code	
Procedure Date	
Primary Procedure (Opcs)	
Procedure (Opcs)	
Investigation Result Date	
Service Report Identifier	
Service Report Status	
Care Professional Code (Pathology Test Requested By)	
Organisation Site Code (Pathology Test Requested By)	
Cancer Treatment Event Type	
Treatment Start Date (Cancer)	
Cancer Treatment Modality	
Organisation Site Code (Provider Treatment Start Date (Cancer)	

MDT

Radiology

PAS

Pathology

National Feeds – datasets and other sources e.g. CWT, RTDS, SACT, (ONS)

How will data reach the registries?

- Multiple Trust systems (MDT, PAS, Path, RIS)
  - Separate files for MDT, PAS, Path, RIS
  - Compiled by registries into a full patient record
- Method of transmission
  - Agreed with registries –
    - Data Transfer Agreements
  - Secure transmission - nhs.net
  - Aim towards XML
  - Path data extracted from path reports by registries
- Minimising duplication of data flows

Sarcoma specific data items

Sarcoma Specific Data Items		
Data item No.	**Data Item Section**	**Data Item Name**
SA11000	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SITE (BONE)**
SA11010	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SUBSITE (BONE)**
SA11080	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SITE (SOFT TISSUE)**
SA11090	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SUBSITE (SOFT TISSUE)**
SA11025	SARCOMA - DIAGNOSIS	**MULTIFOCAL OR SYNCHRONOUS TUMOUR INDICATOR**
SA11200	SARCOMA - PATHOLOGY	**INVESTIGATION RESULT DATE**
SA11210	SARCOMA - PATHOLOGY	**SERVICE REPORT IDENTIFIER**
SA11120	SARCOMA - PATHOLOGY	**HISTOPATHOLOGICAL TUMOUR GRADE**
SA11170	SARCOMA - PATHOLOGY	**GENETIC CONFIRMATION INDICATOR**
SA11130	SARCOMA - PATHOLOGY - BONE	**EXTENT OF LOCAL SPREAD (BONE)**
SA11140	SARCOMA - PATHOLOGY - BONE	**TUMOUR NECROSIS**
SA11160	SARCOMA - PATHOLOGY - BONE	**TISSUE TYPE AT NEAREST MARGIN**
SA11100	SARCOMA - PATHOLOGY - SOFT TISSUE	**TUMOUR DEPTH**

Children Teenagers Young Adults Specific Data Items		
Data item No.	**Data Item Section**	**Data Item Name**
CT6470	OSTEOSARCOMA and EWINGS	**SARCOMA TUMOUR SITE (BONE)**
CT6440	OSTEOSARCOMA and EWINGS	**SARCOMA TUMOUR SUBSITE (BONE)**
CT6380	RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**SARCOMA TUMOUR SITE (SOFT TISSUE OTHER THAN RHABDOMYOSARCOMA)**
CT6390	RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**SARCOMA TUMOUR SUBSITE (SOFT TISSUE) OTHER THAN RHABDOMYOSARCOMA**
CT6350	RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**IRS POST SURGICAL GROUP**
CT6360	RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**CYTOGENETICS FOR ALVEOLAR RHABDOMYOSARCOMA**
CT6370	RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**RHABDOMYOSARCOMA SITE PROGNOSIS CODE**
CT6400	OSTEOSARCOMA	**PRIMARY TUMOUR SIZE (Radiological)**
CT6410	OSTEOSARCOMA	**EXTENT OF NECROSIS AFTER CHEMOTHERAPY**
CT6420	OSTEOSARCOMA	**SARCOMA SURGICAL MARGIN ADEQUACY**
CT6450	EWINGS	**TUMOUR VOLUME AT DIAGNOSIS**
CT6460	EWINGS	**CYTOGENETICS FOR EWINGS SARCOMA**

Why is COSD important? –
Bone cancer data completeness 2007-2009

	% Complete	Registry							
	Data item	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Patient details	Sex	100%	100%	100%	100%	100%	100%	100%	100%
	Age at diagnosis	100%	97%	100%	100%	100%	100%	100%	100%
	NHS number	98%	100%	100%	100%	100%	98%	99%	99%
	Ethnicity	54%	95%	62%	85%	91%	86%	91%	93%
Tumour details	Morphology	94%	70%	99%	82%	86%	94%	94%	99%
	Morphology coding system (ICDM 3)	61%	45%	69%	0%	0%	0%	0%	100%
	Laterality	89%	79%	99%	80%	88%	95%	93%	100%
	Detailed Site Code	92%	73%	97%	87%	93%	84%	89%	97%
Diagnosis information	Basis of diagnosis	90%	78%	95%	82%	86%	91%	87%	97%
	Cases registered from more than a death certificate	100%	99%	100%	100%	100%	99%	97%	100%
	Diagnosis dates	95%	96%	100%	100%	100%	98%	100%	97%
Treatment data	Surgery	44%	44%	74%	62%	54%	75%	47%	65%
	Radiotherapy	12%	20%	20%	19%	10%	12%	5%	10%
	Chemotherapy	34%	29%	38%	16%	38%	29%	37%	38%
	Neo-adjuvant therapy	0%	0%	0%	0%	0%	0%	0%	23%
Death data	Cause of death	100%	99%	100%	100%	100%	99%	96%	99%
	Place of death	100%	98%	98%	46%	44%	65%	98%	92%
Staging data	Tumour size	20%	0%	0%	0%	7%	11%	0%	47%
	T component	1%	0%	0%	0%	1%	1%	0%	1%
	Nodes examined	1%	0%	1%	0%	3%	1%	0%	3%
	Nodes positive	1%	3%	4%	0%	1%	0%	0%	3%
	N component	1%	0%	0%	0%	1%	0%	0%	1%
	Metastases ("Yes" or "No")	0%	0%	12%	1%	7%	68%	0%	10%
	M component	0%	0%	0%	1%	7%	0%	0%	0%
	Grade	34%	20%	22%	26%	32%	5%	0%	63%
	TNM stage	1%	0%	1%	1%	7%	0%	0%	2%

Bone cancer – data completeness

Figure 4.2.3 Morphology completeness by cancer registry

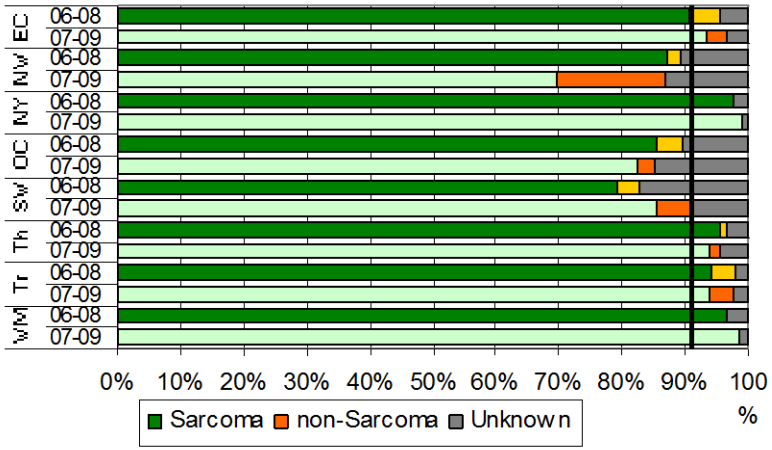


Figure 4.6.1 Tumour size completeness by cancer registry

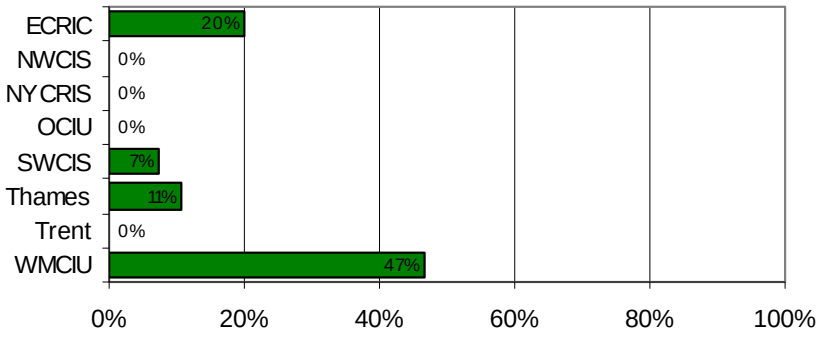


Figure 4.6.8 Grade completeness by cancer registry

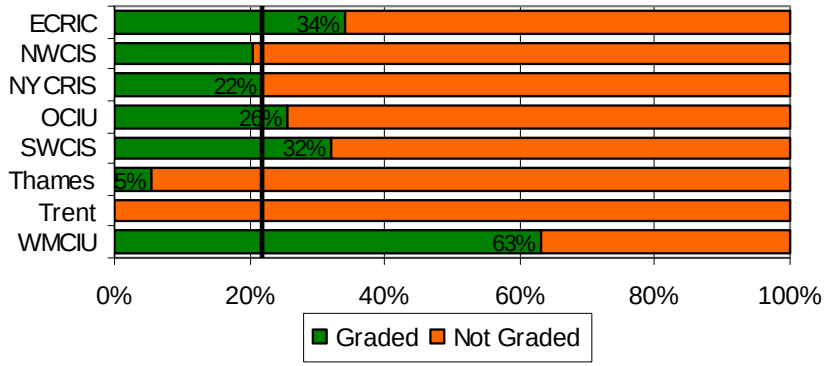
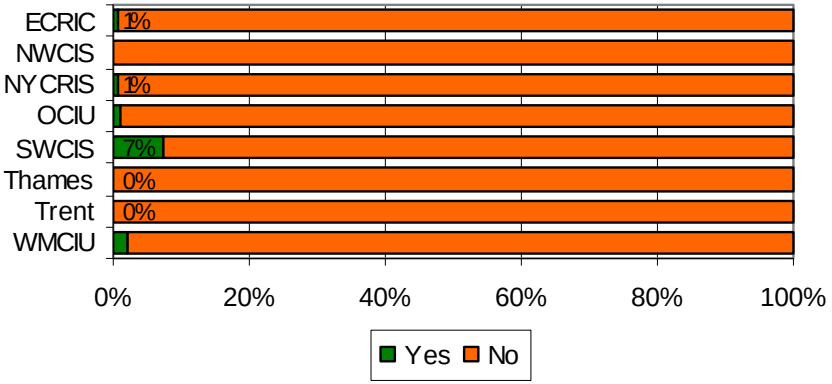


Figure 4.6.9 TNM value completeness by cancer registry



Why is COSD important? –
Soft tissue sarcoma data completeness 2007-2009

	% Complete Data item	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
Patient details	Sex	100%	100%	100%	100%	100%	100%	100%	100%
	Date of Birth	100%	96%	100%	100%	100%	100%	100%	100%
	NHS number	100%	99.6%	99.9%	99.8%	99.9%	98.2%	99.9%	99.8%
	Ethnicity	54%	86%	63%	83%	88%	82%	86%	89%
Tumour details	Morphology coding system (ICDM 3)	52%	35%	71%	0%	0%	0%	0%	100%
	Laterality	93%	83%	96%	91%	91%	94%	96%	99%
	Detailed Site Code	86%	80%	85%	79%	84%	71%	88%	85%
Diagnosis Information	Basis of diagnosis (histology)	95%	90%	97%	96%	96%	94%	95%	97%
	Cases registered from more than a death certificate	100%	98.5%	99.8%	99.7%	99.9%	99.2%	98.7%	100%
	Diagnosis dates	99%	97%	100%	100%	100%	98%	100%	96%
Treatment data	Surgery	67%	60%	75%	73%	73%	78%	47%	70%
	Radiotherapy	20%	15%	28%	14%	16%	15%	7%	26%
	Chemotherapy	20%	14%	20%	16%	16%	14%	17%	12%
	Neo-adjuvant therapy	0%	0%	0%	0%	0%	0%	0%	2%
Death data	Cause of death	100%	99%	100%	100%	99%	99%	95%	100%
	Place of death	100%	98%	97%	47%	47%	73%	100%	96%
Staging data	Tumour size	34%	1%	1%	2%	29%	12%	0%	47%
	T component	3%	0%	0%	1%	5%	3%	0%	12%
	Nodes examined	5%	0%	1%	1%	5%	5%	0%	6%
	Nodes positive	1%	1%	0%	0%	1%	1%	0%	2%
	N component	1%	0%	0%	6%	15%	2%	0%	7%
	Metastases ("Yes" or "No")	0%	0%	18%	3%	9%	61%	0%	16%
	M component	2%	1%	0%	4%	10%	1%	0%	8%
	Grade	44%	33%	34%	31%	51%	10%	2%	45%
	TNM stage	1%	1%	3%	3%	9%	0%	0%	8%

Most common soft tissue sarcoma variants

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%**

Soft tissue sarcoma – data completeness

Figure 4.6.9 TNM value completeness by registry

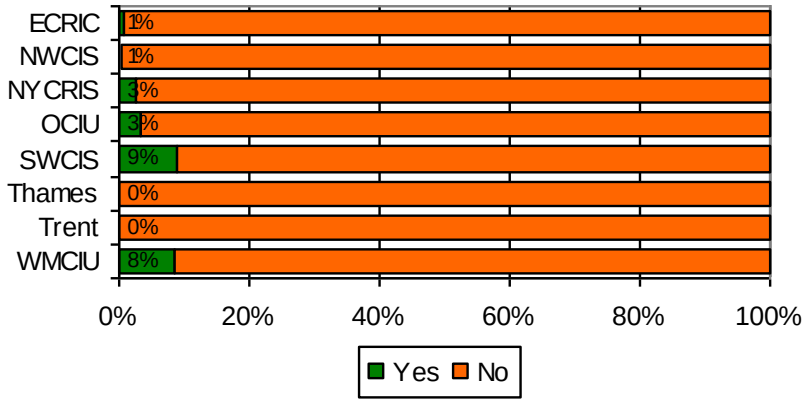


Figure 4.6.1 Tumour size completeness by registry

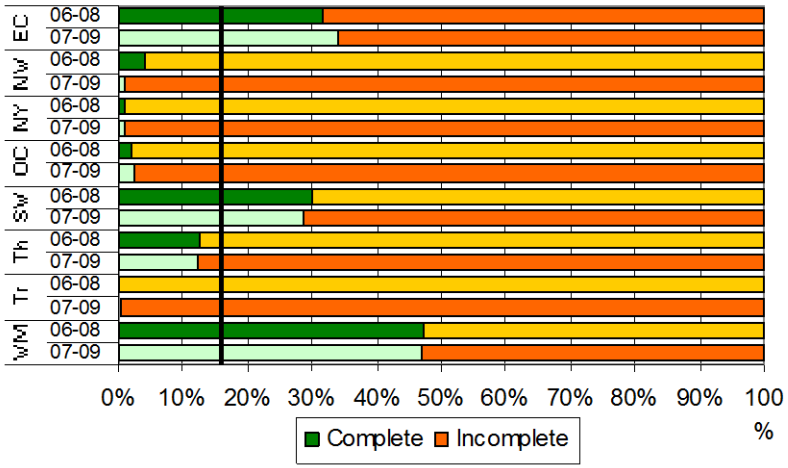
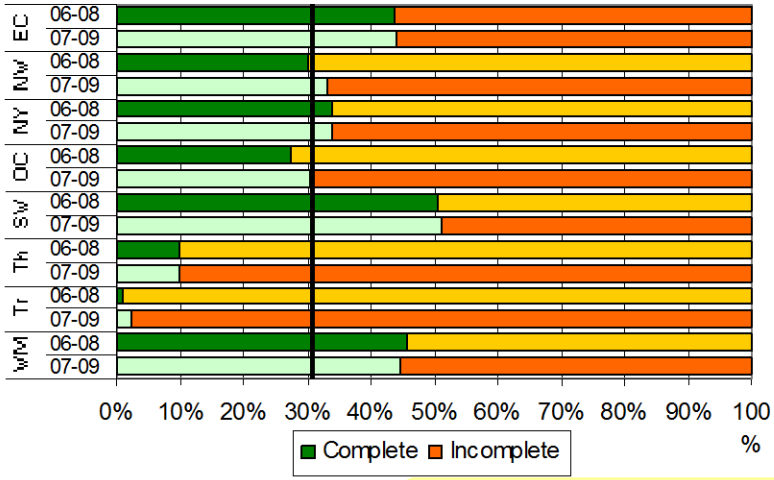
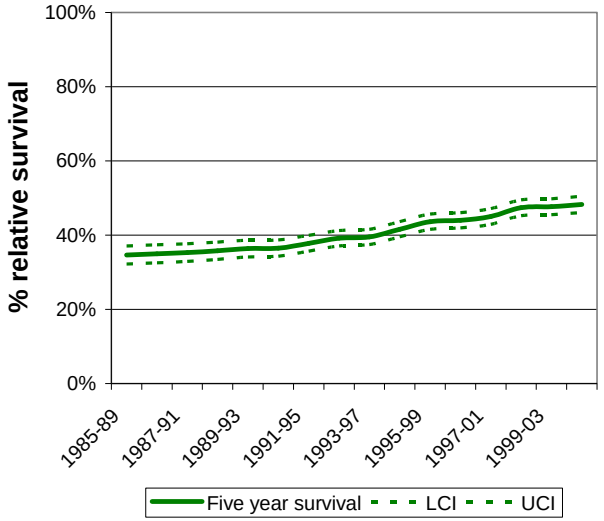
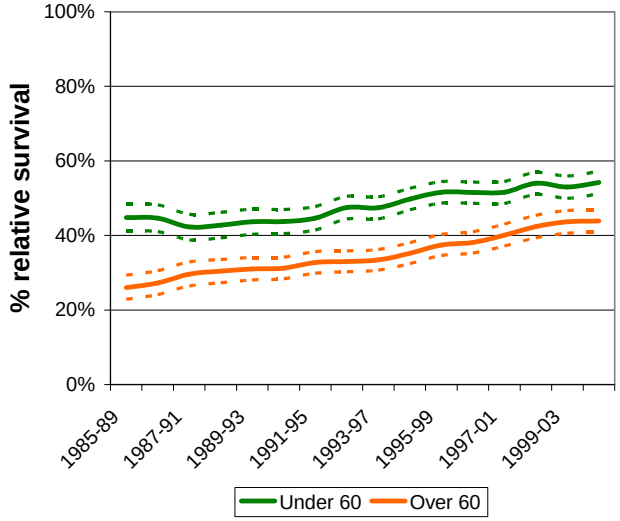


Figure 4.6.8 Grade completeness by registry



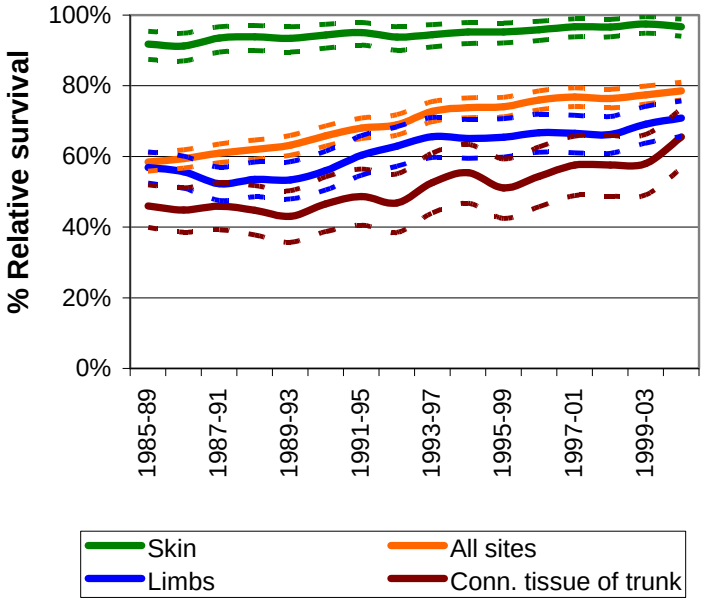
Why do we need staging data?

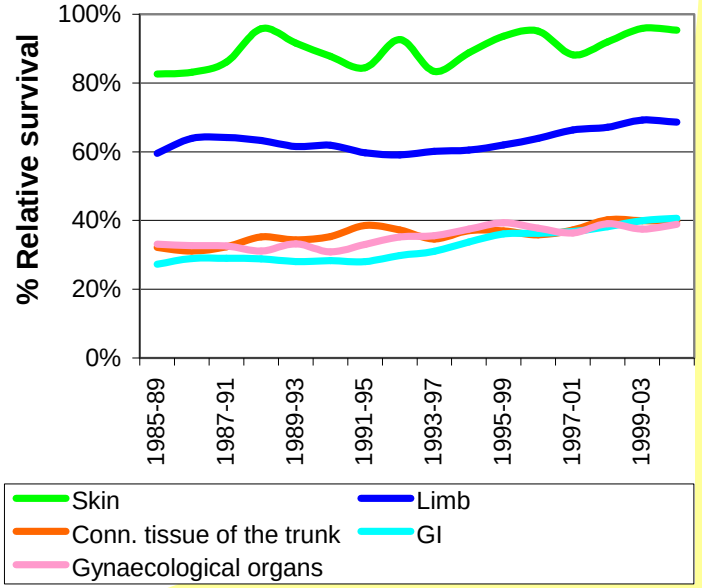




Leiomyosarcoma

Fibroblastic sarcoma





Thank you

- Matthew Francis
- Nicola Dennis