



Public Health  
England

# Sarcoma Site Specific Clinical Reference Group – Update

22<sup>nd</sup> January 2015

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Knowledge and Intelligence Team (West Midlands)

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# 2014/2015 work programme update

- **Priority areas**

- **Primarily dashboards and indicators**

- **Sarcoma and radiotherapy**

what do we want to investigate?

- **SSCRG Initiated work**

- **Uterine leiomyosarcoma**

Do not have information on morcellation

- **Thoracic metastases and SACT**

Still waiting for access to SACT data

- **Long term outcome of RPS**

Circulated for comments – complete (?!)

- **GISTs**

Currently collecting mutation data

- **Teenage and young adult sarcomas**

Waiting for access to 2013 registrations



# Priority areas

## Dashboards and indicators

- Sarcoma service profiles
- CCG Outcomes indicator set
- Specialist commissioning dashboards

## Radiotherapy

- ? No agreed work stream defined
  - Proposed detailed lit review of what treatment would be – **do we need this?**
  - Is there a specific element we would like to investigate – **currently don't have information on size of tumour at diagnosis**



# Priority areas

- Specialist commissioning dashboards

	1996-2012		
Alternative anatomical group2	Patients diagnosed	Patients still alive (01/01/2013)	% still alive
Bone and articular cartilage	6,734	3,602	53%
Bowel	1,329	546	41%
Brain & Central Nervous System	2,069	908	44%
Breast	1,515	954	63%
Connective tissue	18,406	9,101	49%
Gynaecological	4,343	1,782	41%
Head and Neck	774	398	51%
Kaposi's sarcoma	1,894	1,368	72%
Lung	589	115	20%
Male genitalia	623	422	68%
Other	5,237	1,656	32%
Skin	3,860	3,052	79%
Upper Gastro-intestinal	1,561	785	50%
Urological	812	278	34%
<b>Grand Total</b>	<b>49,746</b>	<b>24,967</b>	<b>50%</b>

ors?

- Pulling together a profile of prevalence stats to support commissioning



# Priority areas

- PHE Specialised commissioning High Spend – want a set of indicators and metrics at SCN/Trust level
- Originally planned as CCG Outcomes Indicator set
- These are not for CCT:
  - Fingertips has been proposed
  - Could be a platform for CRG stats as well as requirements for specialised commissioning
- A single dashboard of dashboards and profiles
- Contain information:
  - At a national level
  - Strategic clinical level
  - Sarcoma hospital Trust level



# Priority areas

e.g.

Indicator	What geographic level can these be generated?			Original work stream
	Hospital Trust	Strategic Clinical Network	National	
Proportion of patients diagnosed via emergency route	X	X	X	CCG Indicator set
Proportion of patients with record of stage IV disease at diagnosis	X	X	X	CCG Indicator set
Size of population survivors		X	X	NHS England CRG
Demographics of sarcoma survivor population		X	X	NHS England CRG
What treatment have the sarcoma survivor population received		X	X	NHS England CRG
Does proportion with Stage IV vary with distance from specialist centre	X			PHE Specialised Commissioning
Stage at diagnosis by deprivation quintile	X	X	X	PHE Specialised Commissioning
Proportion of patients with stage IV diagnosis	X	X	X	PHE Specialised Commissioning
Trends in terms of centre caseload for the last 5 years	X	X		PHE Specialised Commissioning
Treatment modality for each tumour type	X	X		PHE Specialised Commissioning
1-year outcomes	X	X	X	PHE Specialised Commissioning
5-year outcomes	X	X	X	PHE Specialised Commissioning

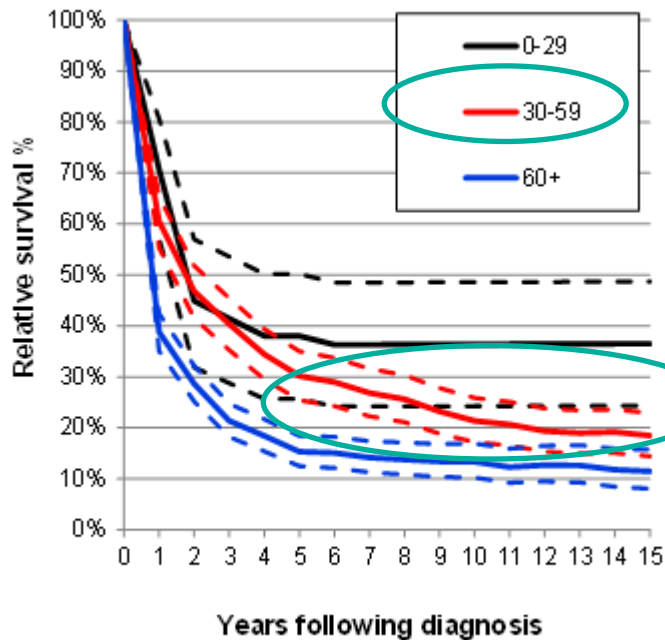
- What indicators should sit in here?



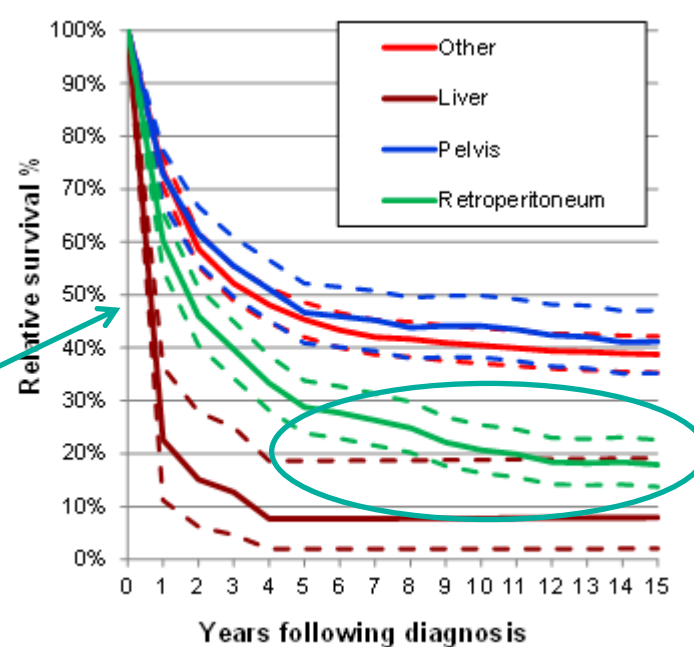
# Long term outcome of RPS

Question: what is the optimal follow up period for patients with retroperitoneal sarcoma?

RPS 5-Year RS



30-59 – all IA sites





# Long term outcome of RPS

- No information on stage at diagnosis
- No information on recurrence
- We do know where these patients were treated
- Analyses to be extended on 15/16 work programme
- Requirement for national commissioning
  - Where were patients treated surgically?
  - Variation in outcomes by treatment centre?
  - Readmissions/bed stays??
  - Coding issues – rectified through COSD OPCS4 Z-codes?
  - Or extend analyses to include all intra-abdominal tumours (excl stomach)





# GISTs/GIST registry

- True incidence of GIST not known for certain
- Collecting mutation data
- Act as audit to ensure that all GISTs now correctly coded
- Mutation – treatment and outcomes



# Teenage and young adult sarcomas

- In collaboration with KITNW
- Report on:
  - Incidence
  - Survival
  - Treatment – place of treatment, outcomes,
- Waiting for 2013 registry data (mid February 2015)
  - Up to date
  - Use in conjunction with SACT data



# Other sarcoma outputs

## SSCRG

### **Breast cancer and angiosarcoma** – data briefing circulated

- Collaboration between breast and sarcoma SSCRGs 15/16?

## Requests

- **Charity** – children with osteosarcoma and Ewing sarcoma/bone sarcoma/all soft tissue sarcoma – incidence and survival for bone sarcoma awareness week
- **Clinician** – chondrosarcoma incidence and survival over 20 year period
- **Clinician** – no. of extremity soft tissue sarcomas diagnosed in each UK country between 1996 and 2010



# Other sarcoma outputs

## Publications

- Gynaecological sarcoma incidence and survival rates – **accepted International Journal of Gynaecological Cancer**
- Identifying Stage IV Sarcoma Using HES data – **accepted Cancer Investigation**
- Bone and soft tissue sarcoma routes to diagnosis – submitted?
- Synovial sarcoma – outcome and the effect of age and socioeconomic status  
- currently in progress