

# **Sarcoma Cancer Pathway Board**

## Annual Report 2015/16

Pathway Clinical Director: James Wylie  
Pathway Manager: Rebecca Price

**Version 1.0**

## Executive summary

The Greater Manchester and Oswestry Sarcoma Service (GMOSS) is based primarily around three Hospitals, namely Manchester Royal Infirmary (MRI) which is part of Central Manchester University Hospitals Foundation Trust (CMFT), Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust (RJAH), and The Christie NHS Foundation Trust.

The vision of the pathway board is to provide a seamless service with improved outcome for patients. Work of the pathway Board has been hindered through 2015 as we awaited publication of the Service Specification for Sarcoma by NHS England (now expected 2016). This will set out the requirements for a compliant commissioned sarcoma service and has built in performance measures. A decision was taken by the Board to await this publication and then convene to discuss how GMOSS would react to these requirements. Unfortunately this publication has been delayed and is still awaited.

### Key achievements

Improved data collection at GMOSS MDT, including:

- Improved data capture on Somerset Cancer Registry (SCR)
- Improved performance recording COSD data
- Improved capture of stage at MDT (72% improved to 80%) and performance status (improved to 80%) for new patient diagnoses
- Improved quality of MDT annotations by the introduction of pre-population of radiology review text
- On-going pilot to explore possibility of collecting more meaningful data at time of MDT

Improved performance against 2 week wait referral target for referrals to CMFT.

Three service user representatives have been fully inducted and are now able to participate as a member of the Pathway board. All three members attended the extra-ordinary Sarcoma pathway Board Meetings and were fully informed and engaged prior to and within the meeting.

Completion of a customised patient experience survey applied across all 3 GMOSS sites.

Convened two extra-ordinary meeting to highlight immediate concerns in regard to the CMFT diagnostic/resection service, which developed as a result of one planned and one threatened resignation. As a result of these meetings a satisfactory plan was put in place to offer a robust immediate solution to the problem and in addition plans were discussed to develop succession strategies to prevent this problem occurring again.

## Key Challenges

- **Data quality** – Data quality remains a significant challenge. Current systems are not providing robust data outputs and are unlikely to meet the needs of the new Service Specification. SCR functionality is not well suited to such data capture and there is difficulty with data capture across three hospital sites. RJAH have developed a database to supplement SCR with the intention of improving the capture of data relating to management plans at the time of MDT discussion.
- **Performance – Manchester Cancer Sarcoma Pathway Board** is reviewing existing care pathways in light of the draft Service Specification for Sarcoma (final version expected in 2016).
- **Capture of number of surgical procedures on SCR** – the issue that all surgeons are not using SCR to record procedures persists leading to inaccurate surgical resection data. The proposal to capture more data on the database at Oswestry should address some of these issues.

## Objectives for the coming year

The focus of the board for the coming year is as follows:

- Await publication of the Service Specification for Sarcoma By NHS England (expected 2016). Benchmark present GMOSS service against this and identify areas of poor compliance. Work with local service providers, site-specific Pathway Boards/MDTs and commissioners to re-design site specific pathways.
- Continue to progress data collection across GMOSS in order to accurately collect the outcome measures mandated in the Service Specification (pending final version).

## 1. Introduction – the Pathway Board and its vision

This is the annual report of the Manchester Cancer Sarcoma Pathway Board for 2015/16.

This annual report is designed to:

- Provide a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard it is the key document for the Board.
- Provide an overview to the hospital trust CEOs and other interested parties about the current situation across Manchester Cancer in this particular cancer area
- Meet the requirements of the National Cancer Peer Review Programme
- Be openly published on the external facing website.

This annual report outlines how the Pathway Board has contributed in 2015/16 to the achievement of Manchester Cancer's four overarching objectives:

- Improving outcomes, with a focus on survival
- Improving patient experience
- Increasing research and clinical innovation
- Delivering compliant and high quality services

### 1.1. Vision

The vision of the pathway board is to provide a seamless service with improved outcome for patients. In order to do so the members agreed the following will be undertaken during 2015/16 to have a more informed understanding of patient outcomes;

*To explore end of treatment summaries for Sarcoma patients at the end of anti-cancer therapies.*

*To explore the support of Manchester User Involvement team to review of patient information given on treatment, side effects and late effects*

*To engage in the living with and beyond post treatment audit and share a list of late effects of treatment.*

*To explore the temporary adoption of the North Wales Cancer Network Excel based database to collate patient outcome data.*

*To aim to re-run patient experience survey to identify areas for improvement.*

## 1.2. Membership

Name	Title and Organisation	Capacity on Group	Deputy
Dr James Wylie	Consultant Clinical Oncologist, The Christie	Chairman. Data lead. Lead Clinical Oncologist	Mr Jonathan Gregory*
Mr Jonathan Gregory*	Consultant Orthopaedic Oncological Surgeon , CMFT	Chairman GMOSS MDT. Surgery and data lead	Mr Ashok Paul
Mr Paul Cool	Consultant Orthopaedic Oncological Surgeon , RJAH	RJAH sarcoma and diagnostic lead. Early diagnosis lead	Miss G Cribb
Dr Mike Leahy	Consultant Medical Oncologist, The Christie	Lead Medical Oncologist. Research lead	Dr Laura Horsley
Mr Ashok Paul	Consultant Orthopaedic Oncological Surgeon , CMFT	CMFT sarcoma and diagnostic lead	Mr J Gregory*
Mr David Mowatt	Consultant Plastic and Reconstructive Surgeon, Christie	Onco-plastic lead. Living with and beyond cancer lead	
Dr Anand Kirwadi	Consultant Musculo-skeletal Radiologist, CMFT	Lead Radiologist	Dr R Lalam
Sister Caroline Pemberton	Sarcoma CNS, RJAH	Lead CNS	Jane Evans
Dr Patrick Shenjere	Consultant Histopathologist, Christie	Lead Histopathologist	Prof A Freemont
Miss Maxine Cumbo	Physiotherapist, The Christie	Lead Physiotherapist Responsible for user issues and information for patients and carers	Ann Buchan/Helen Murray/Caroline Pemberton
Miss Rebecca Price	Manchester cancer	Sarcoma Pathway Manager	
Mr Damian Heron	Director North Wales Cancer Network		
Ann Buchan	Sarcoma CNS	Patient Experience	Helen Murray
Lucie Francis	Macmillan User Involvement Manager	Patient Experience	Tanya Humphries

\* now left GMOSS

## 1.3. Meetings

3 meetings have taken place during June 2015 to June 2016, below are meeting dates and links to the minutes of meetings.

10th June 2015

[https://manchestercancer.org/services/sarcoma/10\\_june\\_\\_sarcoma\\_pathway\\_board\\_minutes\\_final/](https://manchestercancer.org/services/sarcoma/10_june__sarcoma_pathway_board_minutes_final/)

13th March 2016

*To be uploaded*

18th May 2016

*To be uploaded*

*Note 1.*

*Meetings in August 2015 November 2015 and February 2016 were arranged but cancelled pending publication of Sarcoma Specification (unfortunately publication delayed and now expected 2016).*

*Note 2.*

*Following the creation of the Sarcoma Board there was wide interest for membership within the core GMOSS group. However, several members have failed to attend any of the meetings and have not expressed any particular explanation for this to the Chair.*

*These individuals do not hold designated roles on the Board and if attendance remains poor it may be necessary to write to these individuals to ask if they wish to continue to remain a member and emphasise the requirement for regular attendance as detailed in the ToR.*

*Please refer to appendix 1 for attendance register for all the meetings above.*

## 2. Summary of delivery against 2015/16 plan

No	Objective	Alignment with Provider Board objectives	Status Green = achieved Amber = partially achieved Red = not achieved
1	Explore end of treatment summaries for sarcoma patients at the end of anti-cancer therapies. Explore the opportunity to host Health and wellbeing clinics.	Improving & standardising high quality care across the whole service	Red
2	Engage in the living with and beyond post treatment audit and share a list of late effects of treatment. Following this; <ul style="list-style-type: none"> <li>- Generate awareness of the specialist palliative care role and referral</li> <li>- Generate awareness of the pain and symptom control guidelines</li> </ul>	Improving & standardising high quality care across the whole service / Improving patient experience	Red
3	Explore the support of Manchester User Involvement team to review of patient information given on treatment, side effects and late effects	Improving patient experience	Amber
4	Explore the temporary adoption of the North Wales Cancer Network Excel based database to collate patient outcome data.	Improving & standardising high quality care across the whole service	Amber

### 3. Improving outcomes, with a focus on survival

#### 3.1 Information

##### Nationally agreed Clinical Indicators/Lines of Enquiry (G1-22, Sar 1-3)

The Sarcoma Board have serious concerns regarding the quality of the data presented here. Extraction from multiple sources – SCR, Open Exeter, clinician databases have been utilised in an attempt to improve data quality / accuracy. Despite this the Board feel this data remains incomplete.

##### G1 Number of new cases managed per year (brackets indicate source of data)

Provider	Number of new cases
CMFT	65 (SCR)
RJAH	134 (RJAH data)
Christie	117 - 5 Operations (SCR) 35 chemotherapy (SCR) 77 RXT
Total GMOSS	316

##### G2 Number of newly diagnosed patients per year

Provider	Number of new cases
CMFT	71 (SCR)
RJAH	72 (SCR)
Christie	88 (SCR)
Other	22 (SCR)
Total	253 (SCR)

CMFT is being wrongly recorded as the diagnosing site for some cases leading to inaccuracy with this data. Above figures are taken based on institution patient first seen. The cases listed as other were probably managed by RJAH / Christie

##### G3 Patients (from #G2) aged 70+

Diagnosing Organisation	Total Diagnoses
GMOSS	94

##### G4 Patients (from #G2) with recorded ethnicity

Diagnosing Organisation	Total Diagnoses
GMOSS	76

**G5 Patients (from #G2) with recorded ethnicity which is not White British**  
Data not available

**G6 Patients (from #G2) who are income deprived**  
Data not available

**G7 Patients (from #G2) who are male**

Diagnosing Organisation	Total Diagnoses
GMOSS	145

**G8 Peer review. Does the specialist team have full membership?**  
The specialist team has full membership and details can be seen in the GMOSS MDT Operational Policy and the MDT attendance record in this annual report.

**G9 Proportion of peer review indicators met.**  
Refer to CQUINS site

**G10 Are there immediate risks?**  
No. Refer to CQUINS site

**G11 Are there serious concerns?**  
No. Refer to CQUINS site

**G12 Patients surveyed and % reporting being given the name of a CNS**  
Local patient survey 39/41 (95%) patients reported being aware of the name of their CNS / Keyworker.

**G13 & G15 Number of urgent GP referrals for suspected cancer and Urgent GP referrals for suspected cancer seen within 2 weeks calendar year 2015**

Provider	Number of urgent GP referrals (2 week wait) for suspected cancer, 2015		Performance
	Number of referrals	Number seen within 2 weeks	
CMFT	203	192	95%
RJAH *	283 (215 English, 68 Welsh)	215 English 63 Welsh	100% for English patients 93% for Welsh patients
Christie**	0	0	
Total GMOSS	486	470	97%

\* until 01/04/16 NHS Wales did not have a target for Urgent GP referrals for suspected cancer to be seen within 2 weeks. RJAH endeavoured to provide equal access to both Welsh and English patients despite the absence of a target for Welsh patients.

\*\* Christie do not accept 2 ww referrals from GPs.

**G14 Estimated proportion of tumours with emergency presentations**

Data not available (no A&E at RJAH or Christie; No data on inter-hospital transfers).

**G16 Treatment within 62 days of urgent GP referral for suspected cancer**

Data extracted from Open Exeter, only data from CMFT obtained.

First Seen Organisation	Total Treatments	Within 62 Days	Performance
CMFT	12.5	2	84%
RJAH			

The table above highlights the 62 day performance as reported on the National Cancer Waiting Times Open Exeter system which is what the service profile is looking at. However, this performance following reallocation of breaches is 65.7%.

**G17 Urgent GP referrals for suspected cancer diagnosed with cancer (Conversion Rate)**

Site	Number of Sarcoma Cancers following a 2ww referral	Number of 2ww referrals (Suspected Sarcomas)	Conversion Rate
CMFT	17	203	8%
RJAH	19	283	7%

**G18 Cases treated that are urgent GP referrals for suspected cancer (Detection Rate)**

Site	Number of Sarcoma Cancers following a 2ww referral	Number of sarcoma cases managed	Detection rate
CMFT	17	65	26%
RJAH	19		

**G19**

**First treatment began within 31 days of decision to treat**

Provider	Number of first treatments within 31 days of decision to treat, 2014/15	
	Number of treatments	Number of treatments beginning within 31 days of decision to treat
CMFT	34	34
RJAH	Data not available	Data not available
Christie	Data not available	Data not available
Total	Data not available	Data not available

**Indicator Sar1: Patients attending trust within the timeframe and % first or only**

We do not have access to HES data so will be unable to generate this indicator

**Indicator Sar2: Percentage of patients receiving surgical treatment**

The data extracted directly from SCR is felt to be inaccurate. CMFT high cost form and RJAH database felt to be more accurate representation of surgical activity. No data provided by Christie hospital and only 5 cases entered onto SCR by surgical team at the Christie.

From locality data sources:

CMFT	57 primary procedures for soft tissue sarcoma
RJAH	134 procedures for soft tissue sarcoma or primary malignant bone tumours
Christie	5 cases SCR no local data submitted (considered an under estimate)
From SCR extraction GMOSS total	90 operations, 64 for malignant diagnoses.

**Indicator Sar3: Percentage with stage recorded at cancer registry**

Number of diagnosed sarcoma cases with a valid TNM stage recorded

**Staging Completeness**

Diagnosing Organisation	Total Diagnoses	With Complete Stage	Staging Completeness (%)
All Sites	254	201	79.8%

**Performance Status Completeness**

Diagnosing Organisation	Total Diagnoses	With Complete PS	PS Completeness (%)
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All Sites	254	205	80.7%
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This indicator details the number of diagnosed malignant cancers with a valid Performance status recorded.

**G20 Patients surveyed and % reporting always being treated with respect and dignity**

37/40 patients in local audit reported always being treated with respect and dignity, 3/40 patients reported being treated with respect and dignity most of the time.

**G21 Number of viable survey questions and % of those questions scoring red – not applicable**

**G22 Number of viable survey questions and % of those questions scoring green – not applicable**

**3.2. Progress**

The poor data collection across GMOSS continues to be a major obstacle. Until accurate data can be collected across GMOSS it remains challenging to benchmark local services against national criteria. It was suggested that we could employ an Excel based database that is used in N.Wales. However, on further discussion there was not unanimous support for this.

**3.3. Challenges**

The Sarcoma Board remain committed to collecting better quality data collection across GMOSS sites. A new system of collecting data directly from the MDT discussions has been piloted since April 2016 and we await a report on this. The CWP portal at Christie which utilises web forms to collect patient data is another option but the Outcomes Group at Christie are overwhelmed with such requests and this can not be progressed at this time.

## 4. Improving patient experience

### 4.1. Information

Macmillan in partnership with Manchester Cancer have funded a team to facilitate a User Involvement Programme of work that will establish a structure and platform for people affected by cancer to influence and steer the design of cancer services locally.

Key objectives of the User Involvement team working across Manchester Cancer up to March 2017:

- To ensure at least one person affected by cancer on each Pathway Board representing the wider community and where there is already one, to recruit another.
- For People Affected by Cancer to be fully involved and treated as equals.
- To recruit patients and carers to form a wider community of people affected by cancer involved at different levels through coproducing a menu of opportunities.
- To develop a robust UI strategy for Greater Manchester & East Cheshire, coproduced with people affected by cancer.

### Northwest Sarcoma Group

The group meets five times per annum and is run by a GMOSS CNS and physiotherapist. It is an opportunity for past and present sarcoma patients/carers to come together and normally involve an agreed external speaker.

### Local Patient Surveys

A sarcoma patient experience survey was completed in April 2016 which was distributed across the 3 trusts within GMOSS (CMFT, RJAH and Christie) and includes patients diagnosed and treated within 2015. The results of the survey were highlighted to the Board where it was agreed that they highlighted a number of areas of good practice:

### 4.2. Progress

#### User Involvement Programme

Key developments with User Involvement at the Sarcoma Board are detailed below:

- 3 SURs attended the extra-ordinary Sarcoma pathway Board Meetings and were fully informed and engaged prior to and within the meeting. SURs then fed back to the User Involvement Steering Group through a progress report. Although previously SURs have not had the opportunity to attend a Sarcoma Pathway Board meeting due to inactivity of the Board, when the extra-ordinary meeting was called, people affected by cancer were engaged with and involved in discussions from the outset, in line with the coproduction model of involvement set out in the Manchester Cancer User Involvement Charter.

### Northwest Sarcoma Group

In 2015 there were a wide range of subjects covered including:

- February 2015 - Christmas meal which gave members the opportunity to socialise and catch up with other members.
- March 2015- June Robson was the guest speaker and gave a talk on mindfulness and sarcoma
- May 2015- Maxine Cumbo (sarcoma physiotherapist) was the guest speaker who gave us a talk on exercise in cancer and Helen Murray lead a discussion on patients opinions on wound care following sarcoma surgery
- September 2015- June Robson facilitated an informal group discussion on 'what helped me through and what made it harder'
- November 2015- Research led by Mr. Gregory and conducted by 2 MSc students from the University of Manchester was discussed, the research is exploring patient experience and psychological issues around the time of diagnosis and treatment for sarcoma. Pat Jones Macmillan lead Cancer Nurse discussed patient and user involvement and Elisabeth Islam talked about PanBe- a wellbeing project being launched in February.

### **Local patient surveys**

The results of the survey have shown a number of areas of good practice:

- 39/45 reported that they had been given details on how to contact their clinical nurse specialist and no one found it difficult to get hold of their CNS
- 4/45 said the Clinical Nurse Specialist was not present when they were given their diagnosis
- 37/42 were happy with who was present for their cancer diagnosis
- 42/45 felt their diagnosis was delivered sensitively
- 45/45 of the patients surveyed felt that they were given enough privacy when discussing treatment with the doctors and nurses
- 44/45 were given the opportunity to ask questions
- 45/45 felt that they were involved in decision making about their treatment/care.
- 43/43 had their pain well managed when an inpatient
- 30/31 felt there were no problems with the transfer of care between the hospitals
- 28/42 Received a copy of their clinic letter 8/42 couldn't remember

### **4.3. Challenges**

#### **User Involvement Programme**

The key challenge for the User Involvement Manager has been in working to maintain engagement and manage concerns of those people affected by sarcoma who would like to get involvement in influencing and improving sarcoma services through the Board but have been unable to as meetings have not taken place. However, these people affected by cancer have been fully involved in the wider user involvement programme of work such as the Steering Group, focus groups and small communities and are ready to support the Sarcoma Board as and when, going forward.

#### **Northwest Sarcoma Group**

This continues to be a successful interaction but wider membership from patients remains a challenge.

### **Local patient surveys**

#### **Areas for improvement identified in the survey included**

- 8/45 would have liked information on financial help
- 7/44 would have liked to know they could get free prescriptions
- 5/45 would have liked information about support/self-help groups with people with sarcoma
- 24/43 received a visit from the specialist nurse when an inpatient on the ward, 3/43 couldn't remember
- 9/42 did not receive a phone call from the specialist nurse when they went home
- 8/45 report they were not given written information about the type of cancer they had
- 36/45 completely understood the explanation of what was wrong with them, 9/45 understood most of it

It has been acknowledged that compared to 2014 there has been an improvement in patients being offered / receiving a copy of their clinic letters. Many points of good practice have been maintained. Information regarding free prescriptions and patients receiving a visit from their CNS whilst an inpatient remain areas for improvement.

## 5. Increasing research and innovative practice

### 5.1. Information

The Sarcoma Board remain committed to contributing to local, national and international research trials

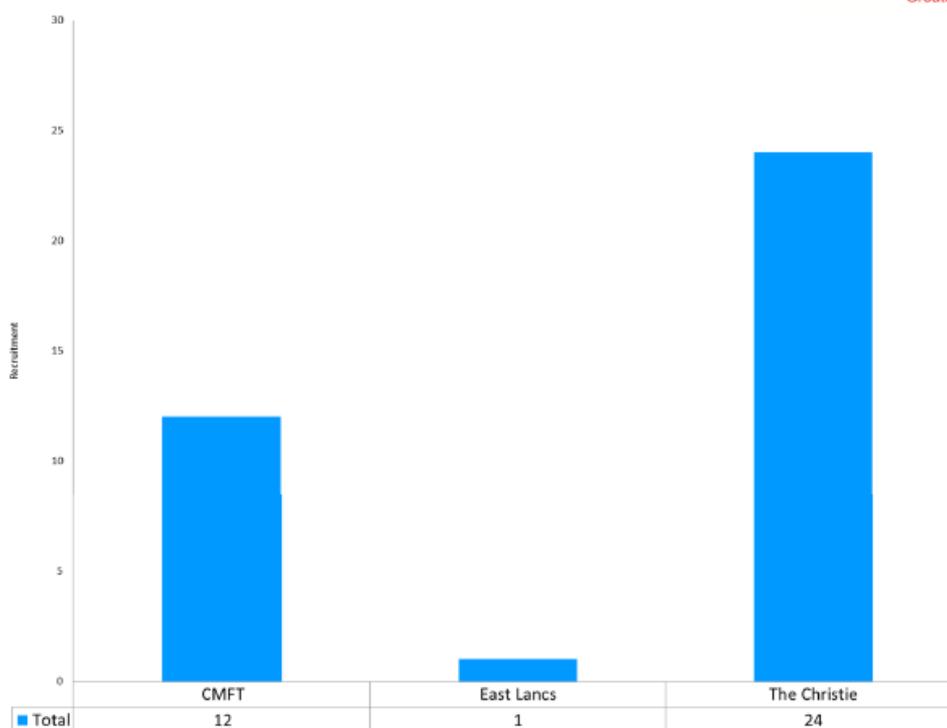
### 5.2. Progress

**Table 1: National (England) Analysis by LCRN's May 2015 Clinical Research Network Greater Manchester**

Design Type	Acronym	CRN Population source ONS (millions)															Grand Total
		East Midlands	Eastern	Greater Manchester	Kent, Surrey & Sussex	NEast & N Cumbria	North Thames	North West Coast	North West London	South London	South West Peninsula	Valley & SMids	Wessex	West Midlands	West of England	Yorkshire & Humber	
		4.4	3.3	2.9	4.5	3.3	5.4	3.7	2	3.1	2.2	2.7	2.7	5.6	2.4	5.3	
<b>Interventional</b>	A study of selumetinib in patients with Kaposi's sarcoma (SCART)				1											1	
	Axi-ST5			1			1				3					5	
	CASPS			2			1			2				1		6	
	CREATE (EORTC 90101)						2									2	
	EORTC-1202-STBSG							1		1						2	
	Euro Ewing 2012	1	3	10			6	2		3		3	1	2		32	
	LINES: Eurosarc Trial of Linsitinib in advanced Ewing Sarcoma											1				1	
	MEMOS: A Eurosarc Study of Mifamurtide in advanced osteosarcoma											2				2	
	PARAGON		1	4				2		5						14	
	rEECur	1		4			4	3		1					3	16	
	STRASS (EORTC 62092-22092)									1				2		3	
	STS 2006 03 (NRSTS)			2		1	2	1		5	2		1	1	5	20	
	STS 2006 04 RMS 2005 (ESSG1)	4	3	3		1	7	2		3		3	5	3	6	40	
<b>Interventional Total</b>		<b>6</b>	<b>7</b>	<b>26</b>	<b>1</b>	<b>2</b>	<b>23</b>	<b>11</b>	<b>24</b>	<b>11</b>	<b>1</b>	<b>10</b>	<b>5</b>	<b>17</b>	<b>144</b>		
<b>Observational</b>	BRIGHTLIGHT: The 2012 TYA Cancer Cohort Study	5	4	1	2	3	9	5		6	2			2	2	7	
	Ewings Genotype													14		14	
	ISKS study									15						15	
	Optimisation of Circulating Tumour Cell Detection in Bone Sarcomas					5	2									7	
	Pharmacokinetic variation and toxicity in Ewing's sarcoma			10		1		1		1		1			1	15	
	PIRS									4						4	
	PREDICT (Sarcoma)												9			9	
	Profiling and culturing of neuroblastoma and soft tissue sarcoma cells									1						1	
<b>Observational Total</b>		<b>5</b>	<b>4</b>	<b>11</b>	<b>2</b>	<b>9</b>	<b>11</b>	<b>6</b>	<b>27</b>	<b>2</b>	<b>1</b>	<b>25</b>	<b>2</b>	<b>8</b>	<b>113</b>		
<b>Grand Total</b>		<b>11</b>	<b>11</b>	<b>37</b>	<b>3</b>	<b>11</b>	<b>34</b>	<b>17</b>	<b>51</b>	<b>2</b>	<b>12</b>	<b>1</b>	<b>35</b>	<b>7</b>	<b>25</b>	<b>257</b>	

**Table 2: Local Recruitment by Trusts May 2015 Clinical Research Network Greater Manchester**

# Local (GM) recruitment by Trust's



**Table 3: Local GM Analysis by Trusts May 2015 Clinical Research Network Greater**

## Christie

Name	DOG	Total 15/16	Total recruited	Status	Target
CASPS	11 dog09 37	1	7	Open	6
Announce	15 dog09 64	1	1	Open	15
GEMCAS	14 dog09 60	1	1	Open	6
AB science 4030	08 dog09 20	2	9	Open	6
AB science 11002	15 dog09 54	1	1	Open	6
AXI STS	09 dog09 29	1	16	Closed	12
CREATE	13 dog09 45	3	7	Open (2 cohorts)	6
EORTC QOL	13 dog09 53	4	4	On hold	6
RECURR	14 dog09 56	4	4	Open	
PK 2013	13 dog09 52	7	7	Open	
EE 2012	13 dog09 46	9	16	Open	
Brightlights	12 dog10 11	1	61	Closed	
MISTS	10 radio96	6	13	Open	15

## CMFT

Study number	Total 15/16	Total Recruited	Closing date	Target
142640 - Genetics of Multiple Cancers Study (GeMCoS)	2	4	Open	4

## Local (GM) analysis by Trust's



Clinical Research Network  
Greater Manchester

Study Design	Acronym	CMFT	East Lancs	The Christie	Grand Total
<b>Interventional</b>	Axi-STS			1	1
	CASPS			2	2
	Euro Ewing 2012	3		7	10
	PARAGON			4	4
	rEECur	1		3	4
	STS 2006 03 (NRSTS)	1		1	2
	STS 2006 04 RMS 2005 (ESSG1)	3			3
	<b>Interventional Total</b>		<b>8</b>		<b>18</b>
<b>Observational</b>	BRIGHTLIGHT: The 2012 TYA Cancer Cohort Study		1		1
	Pharmacokinetic variation and toxicity in Ewing's sarcoma	4		6	10
<b>Observational Total</b>		<b>4</b>	<b>1</b>	<b>6</b>	<b>11</b>
<b>Grand Total</b>		<b>12</b>	<b>1</b>	<b>24</b>	<b>37</b>

### 5.3 Challenges

Sarcoma is a rare cancer and the portfolio is therefore much reduced compared to commoner cancers. However, we remain committed to maintain recruitment to trials and maintain our accrual at a level similar to other larger sarcoma services.

## 6. Delivering compliant and high quality services

### 6.1 Information

Data provided here was extracted from Somerset Cancer Registry unless otherwise indicated.

### 6.2 Progress

The MDT occurs on a Wednesday and is a major job plan commitment for all Consultants involved.

**Total Number of Discussions for C40, C49 and D Codes (D codes used by GMOSS MDT to cover desmoid fibromatosis, GCT of bone, miscellaneous complex benign)**

Primary Diagnosis	Total Discussions
C40	83
C49	363
D Codes	46
<b>Total</b>	<b>492</b>

### Treatment by primary modality

Data quality on SCR relating to this measure is variable.

#### Extraction from SCR

**Surgery** – 90 surgical procedures recorded (STS, Bone and complex benign – fibromatosis/ GCT of bone) 64 of which were for malignant diagnoses.

Surgeon	No of Operations
Gregory CMFT /RJAH	33
Paul CMFT	25
Mowatt Christie	5
Kosutic Christie	0
Cribb RJAH	12
Cool RJAH	15
<b>Total</b>	<b>90</b>

Comparison against the High cost form for CMFT and the Oswestry database shows that not all procedures have been captured.

CMFT data 57 operations for STS (49 primary resections) in 2015

Oswestry data 134 operations for STS and bone sarcoma in 2015

5 cases recorded by Christie is an under representation of workload and is due to procedures not being entered on to SCR.

**Chemotherapy** - Number of patients receiving neoadjuvant or adjuvant therapy SCR extraction 35

**Radiotherapy** - . Number of patients receiving either neoadjuvant or adjuvant radiotherapy SCR extraction 15

Locality database at Christie hospital – 77 cases planned for conventional / IMRT

**Total Number of Patients treated with Palliative Care Intent**

There were 37 patients with a recorded Care Plan Intent of Non Curative at diagnosis.

**Performance against waiting time targets**

It has not been possible to obtain GMOSS wide data for performance against targets as data is collected separately by member trusts. Data presented is from Open Exeter extractions.

31 day first treatments		
	Total Patients	Treated in Target
RJAH	Data not available	Data not available
CMFT	32	32
Christie	Data not available	Data not available

The number of patients who started subsequent treatment on a 31 day pathway, split by treatment type

31 Day Subsequent Treatment			
		Treated in Target	Performance
RJAH	Data Not Available	Data Not Available	
CMFT	15	14	93.3%
Christie	Data Not Available	Data Not Available	

The below table demonstrates the number of treatments for patients on a 62 day pathway, split by treatment type. Treatments not in whole numbers refer to the calculation of treatment allocation between trusts, and 0.5/treatment can be taken to mean 1 patient.

Trust	Total Patients	Treated in Target	Percentage Treated in Target
RJAH	Data Not Available	Data Not Available	
CMFT	12.5	10	84%
Christie	Data Not Available	Data Not Available	

**Indicator G18: Cases treated that are urgent GP referrals for suspected cancer (Detection Rate)**

<b>Site</b>	<b>Number of Sarcoma Cancers following a 2ww referral for suspected sarcoma</b>	<b>Number of sarcoma cancers managed</b>	<b>Detection rate</b>
CMFT	17	65	26%
RJAH	19		

This indicator looks at the proportion of new managed cancers that were “detected” via a Sarcoma 2 week wait referral.

**6.3.Challenges**

Once again the quality of data collection remains poor and inaccurate. The Board remain committed to improving this further.

The awaited publication of the Service Specification for Sarcoma should guide the Board further in terms of the type of data that will need to be collected and the measures against which GMOSS will be compared to.

## **6. Objectives for 2016/17**

The board have discussed below items as priorities for the coming year;

Continue to strive to collect more accurate data across the 3 GMOSS sites.

Await publication of Sarcoma Service Specification (expected 2016). Benchmark GMOSS services against this. Re-write site-specific pathways in line with Service Specification.

Streamline Board membership and review membership of individuals who were unable to attend >50% of meetings since Board convened.

Work to further engage with SURs in future Board meetings.

## 7. Appendix 1 – Pathway Board meeting attendance

### SARCOMA PATHWAY BOARD - Core members

#### ATTENDANCE

Name	Role & Trust	25/06/2014	08/10/2014	28/01/2015	10/06/2015	13/04/2016	18/05/2016
Dr JP Wylie	Chairman. Clinical oncologist representative, <b>Christie FT</b>	✓	✓	✓	✓	✓	✓
Mr D Mowatt	Reconstructive surgical representation <b>Christie FT</b>	✓	✓	✓	✓	✓	✓
Dr P Shenjere	Soft tissue Pathology representation	✓	✓	X	✓	✓	✓
Dr M Leahy	Medical oncologist/research and TYA representative <b>Christie FT</b>	✓	x	x	x	✓	
Mr P Cool	RJAH surgical representation and MDT	✓	✓	✓	x	✓	
Miss G Cribb	Surgical representation, <b>RJAH FT</b>	x	x	x	x	x	
Dr C Mangham	Bone pathology Representation <b>RJAH FT</b>	X	x	x	x	✓	
Dr R Lalam	Bone radiologist representation <b>RJAH FT</b>	X	x	x	x	✓	
Mr A Paul	surgical representation , <b>CMFT</b>	X	x	x	x	x	
Mr J Gregory	surgical representation , <b>CMFT</b>	✓	x	✓	✓		
Dr N Winn	Soft tissue Radiology rep, <b>CMFT</b>	✓	x	Replaced by Adnan	x	✓	
Miss Maxine Cumbo	Physiotherapy, <b>CMFT</b>	✓	✓	✓	✓	✓	✓
Proff A.Freemont	<b>Soft Tissue pathology CMFT</b>	X	x	x	x	x	
Mr Damian Heron	Director of North Wales Cancer Network	X	✓	x	✓	x	
Caroline Pemberton	Sarcoma CNS <b>RJAH FT</b>	✓	✓	✓	x	x	
Jane Evans	Sarcoma CNS <b>RJAH FT</b>	✓	x	x	x	x	
Ann Buchan	Sarcoma CNS Christie		✓	✓	x	x	
Helen Murray	Sarcoma CNS <b>MRI</b>	x	x	x	✓	✓	
Lucie Francis	User Involvement Manager	NA	NA	NA	NA	✓	✓
Bernie Delahoyde	Deputy Director of Operations	NA	NA	NA	NA	✓	✓
Rebecca Price	Manchester Cancer Pathway Manager	NA	NA	NA	NA	✓	✓