

Sarcoma Pathway Board

Annual Report 2013/14

Pathway Clinical Director: James Wylie
Pathway Manager: Hodan Noor

Version 0.1 18/7/2014

Executive summary

The Sarcoma Advisory Group (SAG) was in existence supported by Greater Manchester and Cheshire Cancer Network. Due to the reconfigurations of Networks' nationally the former SAG was dissolved and a **Greater Manchester and Oswestry Sarcoma service (GMOSS)** Pathway board was formed. The board is informed by **NICE Improving Outcomes Guidance (IOG)** for people with Sarcoma 2006 and Improving Supportive and Palliative Care for adults with cancer (2011). The service delivery follows the **National Specifications** set out in the document B12/S(HSS)/a for primary malignant bone tumours service (adults and adolescents) and B12/S/a for soft tissue sarcoma (adult).

According to Cancer Research UK, **bone sarcoma accounts for 0.2% of all deaths** from cancer, in 2011, there were 263 deaths from bone sarcoma in the UK. The crude mortality rate shows that there are 5 bone sarcoma deaths for every million males in the UK, and 3 for every million females.

Around **3,300 people were diagnosed with soft tissue** sarcoma in 2010 in the UK, that's around 9 people every day. In the UK in 2010, around 1,700 males and around 1,600 females were diagnosed with soft tissue sarcoma. The five year survival rate stands at 56%. For children, survival rates for soft tissue sarcoma have doubled since the late 1960s. **Almost 7 in 10 children now survive their disease for at least five years.** Today more than **5 in 10 teenagers and young adults** survive their soft tissue sarcoma for at least five years. Survival is higher in young women (68%) than young men (55%).

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 (RJA), and The Christie NHS Foundation Trust.

The Challenge

key challenge from the previous Sarcoma Advisory Group was to address the barriers in **improving data collections**, this has improved some way by the implementation of Somerset Cancer Registry in April 2013 and a single MDT meetings' since September 2013. The next 12 months focuses on improving data quality by agreeing a data set above and **beyond the national standard** requirement to be collected per site and reporting annually.

The 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 2014/15 to have a more informed understanding of patient outcomes;

- Measure **clinically meaningful outcomes** and compare to international centres of excellence going above and beyond national standards.
- Audit existing **primary care knowledge** of sarcoma pathways and provide education and awareness programme to improve early diagnoses and outcome for patients.
- **Engage with Living With and beyond and palliative care board** work programmes to support patient journey.

Introduction

2013/14 was a transitional year for cancer services in Greater Manchester and East Cheshire. The Greater Manchester and Cheshire Cancer Network ceased to exist in March 2013 when cancer networks nationally were amalgamated into strategic clinical networks as part of the NHS reorganisation. In Greater Manchester this coincided with the creation of Manchester Cancer, an integrated cancer system for Greater Manchester and East Cheshire.

Twenty Manchester Cancer Pathway Clinical Directors were appointed in late 2013 and took up their roles on 1st January 2014. They spent the first months in post forming their Pathway Boards, multi-professional clinical groups from across the region. These pathway Boards are now formed and most had their first meeting in April/May of 2014.

As such, this is a transitional annual report. It outlines the current configuration of services, the progress in forming the Pathway Board, the data on outcomes and experience that the Board took into account when setting its objectives, and what those objectives are for 2014/15 and beyond. In July 2015 every Manchester Cancer Pathway Board will publish a full annual report, outlining the work of its first full year and its progress against those objectives.

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.

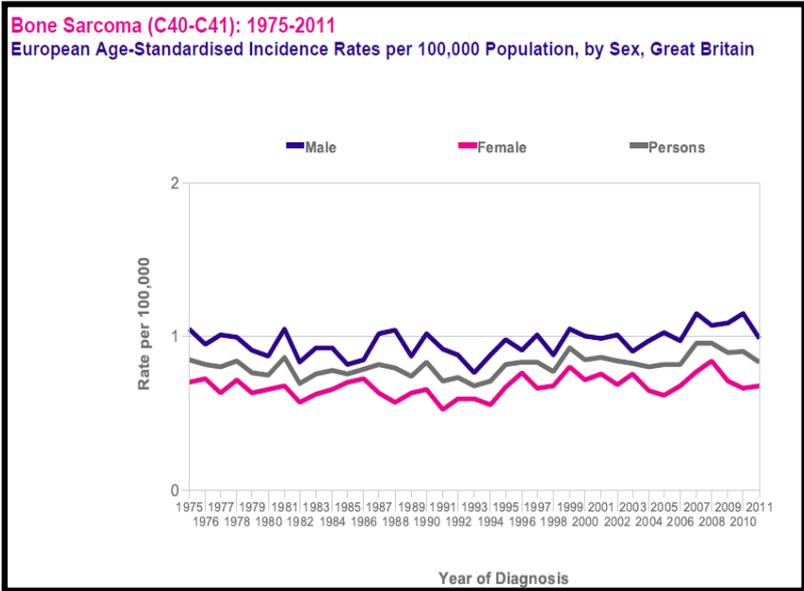
1. General overview

Greater Manchester and Oswestry Sarcoma service (GMOSS) Pathway board is informed by NICE Improving Outcomes Guidance (IOG) for people with Sarcoma 2006 and Improving Supportive and Palliative Care for adults with cancer (2011).

The national peer review measure supports the development of the pathway board and set the standards required for assessment (January 2014 version 1.1). The service delivery follows the National Specifications set out in the document B12/S(HSS)/a for primary malignant bone tumours service (adults and adolescents) and B12/S/a for soft tissue sarcoma (adult).

2.1 National incident and mortality rates

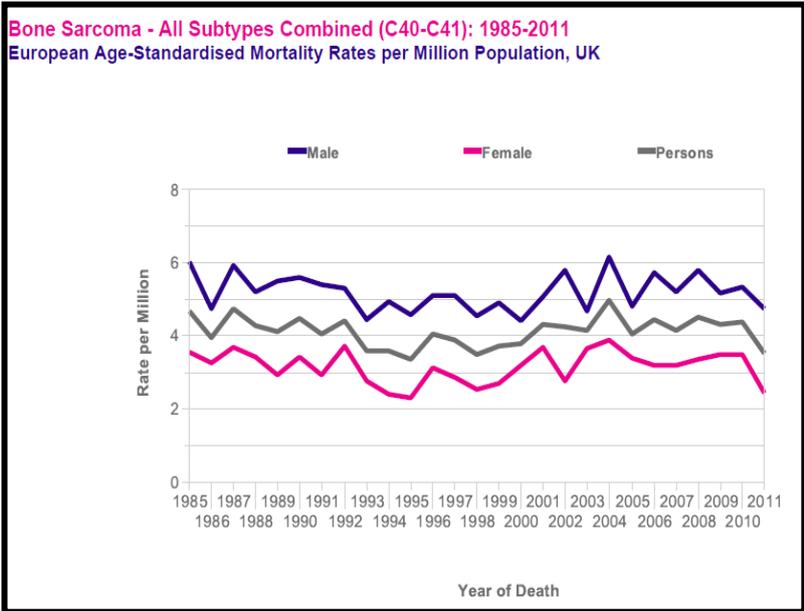
According to Cancer Research UK 559 people in the UK were diagnosed with bone sarcoma in 2011. There were 263 deaths from bone sarcoma in 2011. 56% of adult bone sarcoma patients (58% of men and 54% of women) in England survived their cancer for five years or more in 2001-2005.



Bone sarcoma (all subtypes combined) incidence rates have remained relatively stable overall in Great Britain since the mid-1970s, though this includes a decrease followed by an increase.

These increases probably reflect improved diagnostic techniques and reporting rather than a true increase in incidence.

Charts prepared by Cancer Research UK



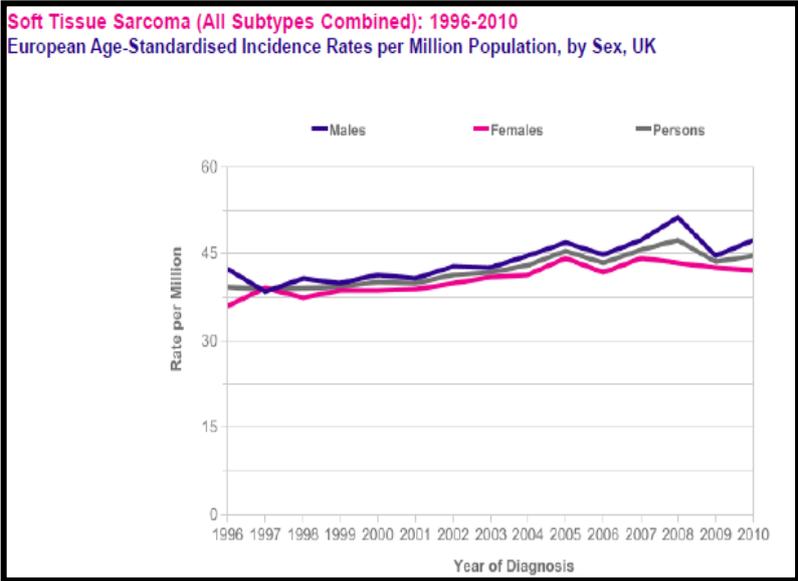
Bone sarcoma accounts for 0.2% of all deaths from cancer, 0.2% of male deaths from cancer, and 0.1% of all female cancer deaths.

In 2011, there were 263 deaths from bone sarcoma in the UK. The crude mortality rate shows that there are 5 bone sarcoma deaths for every million males in the UK, and 3 for every million females.

Charts prepared by Cancer Research UK

Bone sarcoma mortality rates have remained stable overall for all of the broad age groups in the UK since the mid-1980s, though in most age groups the trend includes significant fluctuations.

According to Cancer Research UK around 3,300 people were diagnosed with soft tissue sarcoma in 2010 in the UK, that's around 9 people every day. In the UK in 2010, around 1,700 males and around 1,600 females were diagnosed with soft tissue sarcoma.



Soft tissue sarcoma survival rates have improved in the last 25 years. In the mid-1980s 48% of people survived their disease for at least five years, now it's 56%. For children, survival rates for soft tissue sarcoma have doubled since the late 1960s. Almost 7 in 10 children now survive their disease for at least five years. Today more than 5 in 10 teenagers and young adults survive their

Charts prepared by Cancer Research UK

soft tissue sarcoma for at least five years. Survival is higher in young women (68%) than young men (55%).

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2. Background to the Greater Manchester and Oswestry Sarcoma Service Pathway Board

The Sarcoma Advisory Group (SAG) was in existence supported by Greater Manchester and Cheshire Cancer Network. Due to the reconfigurations of Networks' nationally the former SAG was dissolved and a Greater Manchester and Oswestry Sarcoma service (GMOSS) Pathway board was formed.

In principal the basis of the old SAG is the same as the pathway board with members drawn from the MDT Lead Clinicians from each specialist and local team, and clinical support services involved in tumour management along the patient care pathway.

The purpose of the board is to ensure that services for patients with suspected or diagnosed with Sarcoma cancer are being delivered in accordance with NICE Improving Outcomes Guidance, Peer Review Cancer Quality Measures and create an opportunity to further develop standards of care.

3. Configuration of services

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.

At present GMOSS provide specialist care for patients including Teenage and young adult (TYA) with all types and stages of soft tissue and bone sarcoma residing in Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network (GMLSCSCN) and in parts of Greater Midland Cancer Network (GMCN), and North Wales.

The present service covers a population of approximately 4 million residents:

Greater Manchester and Cheshire ~ 3.2m

Greater Midlands ~160,000

North Wales ~ 675,000

(GMLSCSCN) TYA ~ 109,000

Diagnostic and treatment of Sarcoma

Diagnostic services are provided at MRI (soft tissue only) and RJAH Hospitals (bone and soft tissue). Core resection services are based at MRI (soft tissue only) and RJAH Hospitals (bone and soft tissue). The Christie Hospital provides specialist care with onco-plastic support, a retroperitoneal resection service, chemotherapy and radiotherapy services. GIST patients requiring systemic treatment are managed at The Christie.

The Manchester Royal Infirmary Hospital (MRI) is part of the Central Manchester University Hospitals NHS Foundation Trust and is located in Manchester City centre. It is a large University Teaching Hospital offering all major specialties with a large Orthopaedic Department. It has specialist oncological orthopaedic, pathology and radiology services in sarcoma management and provides the sole soft tissue diagnostic service and the principle soft tissue resection service for extremity sarcomas in Greater Manchester. CMFT has one of only two supra-regional neurofibromatosis centres which work closely with the MDT in the management of patients with suspected malignant peripheral nerve sheath tumours.

The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust (RJAH) is a dedicated specialist orthopaedic hospital based near the Welsh border in Oswestry. It is funded by the National Specialist Commissioning Group (NSCG) to provide a diagnostic and treatment service for suspected bone sarcomas and in addition provides a diagnostic and resection service for soft tissue sarcomas. It is the designated referral centre for patients with confirmed or suspected sarcomas residing in North Wales and has a specialist oncological orthopaedic, pathology and radiology services in sarcoma management.

The Christie NHS Foundation Trust is a tertiary cancer centre located in Withington 2 miles from MRI. It is a centre of excellence for cancer treatment providing specialist surgical oncology, medical and clinical oncology, pathology and radiology. There are also specialist facilities and expertise for teenage and young adults with cancer. In terms of sarcoma, specialists in onco-plastics offer a resection service for soft tissue sarcomas arising from the scalp, head and neck (excluding oral cavity, pharynx, larynx), trunk, axilla and groin, as well as a reconstruction service following larger resections. There is also a dedicated retroperitoneal service. Dedicated radiotherapy and chemotherapy services are based here. The structure of the service is designed to reflect the operational requirements of the sarcoma units and the necessity to fulfil national guidance, such as are set out in the Manual of Cancer Services and the Improving Outcomes Guidance for Sarcoma.

This service is complex, reflecting:

- The complexities of managing all types of sarcoma
- The large number of patients seen
- The geographical split between the NHS Trusts
- The need to maintain clear and effective working relationships with a large number of partners, across a large population area

GMOSS has a **large team of clinicians**, radiologists, pathologists, specialist nurses and allied healthcare professionals (including physiotherapists, dieticians, occupational therapists) caring for patients across the three Trusts. This multidisciplinary team working is coordinated by separate MDT coordinators at Christie and MRI. The service has also developed a network of site-specific extended multidisciplinary teams to offer sarcoma specific treatment for tumours arising at sites other than the limbs or trunk.

The core service comprises of the following specialists;

- Five sarcoma surgeons
- Two medical oncologist
- Two clinical oncologists
- One dedicated TYA oncologist
- Three musculo-skeletal radiologists
- Five specialist sarcoma pathologists (SSP"s)
- One clinical nurse specialists (CNS) at each site all with a special interest in sarcoma.

The sarcoma service screens and recruits patients to clinical trials and is assisted by a dedicated clinical trials nurse and a data manager based at The Christie.

A core weekly multi-disciplinary team meeting (MDT) between the sites is held where all confirmed new, highly suspected or recurrent sarcoma cases are discussed to formulate a management plan. At present the meeting alternates between MRI and Christie.

The Host Trust for the multidisciplinary team (MDT) is Central Manchester University Hospitals NHS Foundation Trust (CMFT) and the host network is Greater Manchester and Cheshire Cancer Network.

Core curative resection services for soft tissue sarcomas are based at MRI and RJAH. Patients needing onco-plastic support for resection/reconstruction are referred to the onco-plastic team at Christie.

Bone diagnostic and treatment services are based at RJAH which is an NSCG agreed site for this.

Retroperitoneal sarcomas are referred to the Christie retroperitoneal service for discussion between the Christie pelvic team (responsible for the retroperitoneal resection service) and the non-surgical core members of GMOSS MDT.

All new or relapsed patients with proven or suspicious sarcoma are discussed at a weekly multi-disciplinary meeting (MDT) which is hosted at MRI on Wednesday afternoons 3.30-5.30. RJAH and Christie video-conference with this meeting.

Patients with extremity/trunk soft tissue sarcoma and bone sarcomas referred to RJAH from Manchester Cancer are all discussed at the GMOSS MDT. All bone surgery is done at RJAH and most soft tissue resections will take place at RJAH.

4. Clinical guidelines

The GMOSS Pathway Board has only been in place since spring 2014 and has not yet had the opportunity to review its clinical guidelines and patient pathways. As such, the guidelines created by the previous cancer network group have been adopted until such time as they can be reviewed and updated in the coming year.

All of the relevant documentation remains on the legacy website of the old cancer network www.gmccn.nhs.uk and will be migrated to the Manchester Cancer website over the coming months www.manchestercancer.org.

A full list of active current guidelines and their renewal dates will be produced for the updated constitution of July 2015.

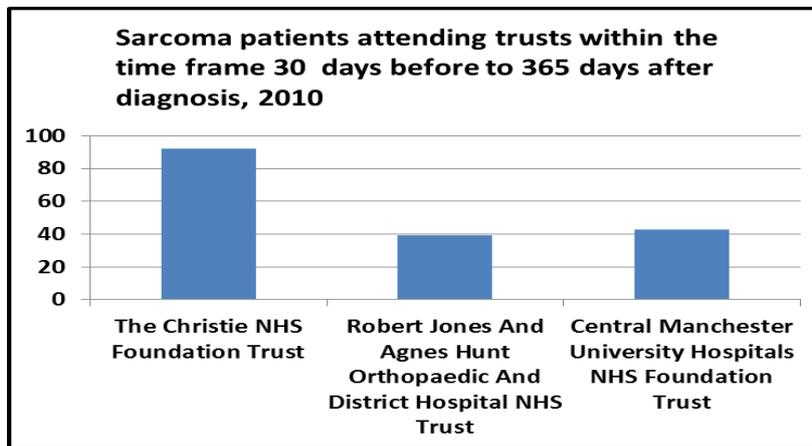
5. Clinical information and outcomes

Clinical Lines of enquiry

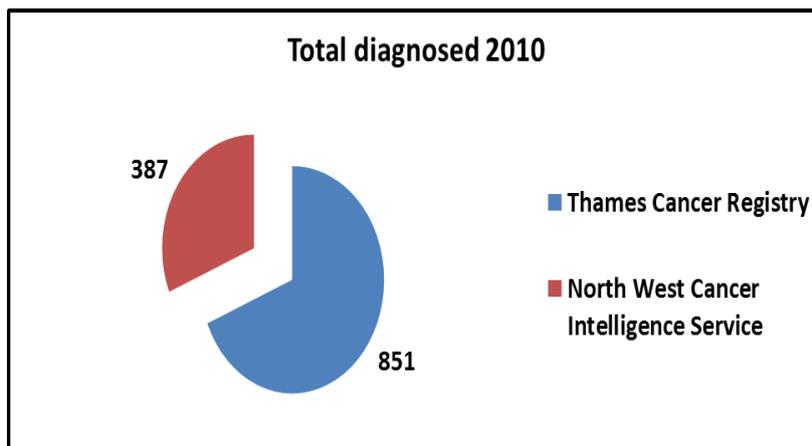
In 2008 the SHA introduced clinical lines of enquiry to increase the focus in clinical outcomes to improve patient journey, discussions at a national level developed the following measures for sarcoma;

- Percentage of patient diagnosed with a sarcoma seen at a specialist centre
- Percentage of patients diagnosed with a sarcoma receive surgical treatment
- Percentage of patients with a recorded stage
- Readmission rates within 30 days of surgery

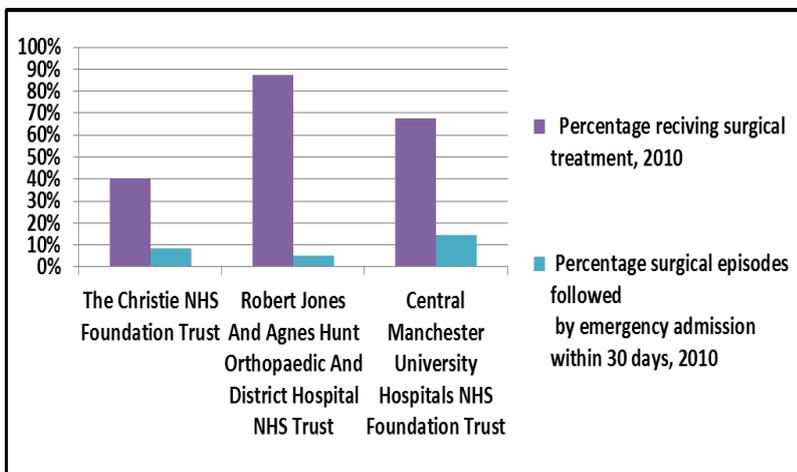
Below are the results from the NCIN matrix report 2013/14



53% of patients attended Christie of which 25% attended Central Manchester with the remainder 22% to Robert Jones and Agnes Hunt.



1.8% of patients had staging recorded in the North West cancer intelligence register, no staging data was report on the Thames Cancer Registry.



Central Manchester had a higher readmission rate in 2010.

Somerset activity and indicators 2013/14

GMOSS MDT Activity and Indicators - 2013/14	
GMOSS Indicator	Total
No of Patients Discussed at GMOSS MDT	482
Tumour Statuses	
- Primary	178
- Recurrence	35
- Metastatic	21
- Benign	25
- Other Tumour Site	3
- Unknown	207
- Non Cancer	7
- Missing	6
Types of Tumour	
- Sarcoma	76
- Chondrosarcoma	18
- Leiomyosarcoma	16
- Liposarcoma	16
- Gastrointestinal stromal tumour, NOS	11
- Ewings sarcoma	10
- Myxoid liposarcoma	10
- Spindle cell sarcoma	10
- Synovial sarcoma	9
- Osteosarcoma	8
- Others	46
Total Operations (Diagnosed during 2013/14)	
61	
Christies	1
Robert Jones and Agnes Hunt	21
University Hospital of South Manchester	2
Salford Royal	1
Royal Orthopaedic Hospital	1
Central Manchester University hospitals	33

A snap shot data report from the host organisation was requested to identify gaps in recording and interrogate Somerset reporting functionality.

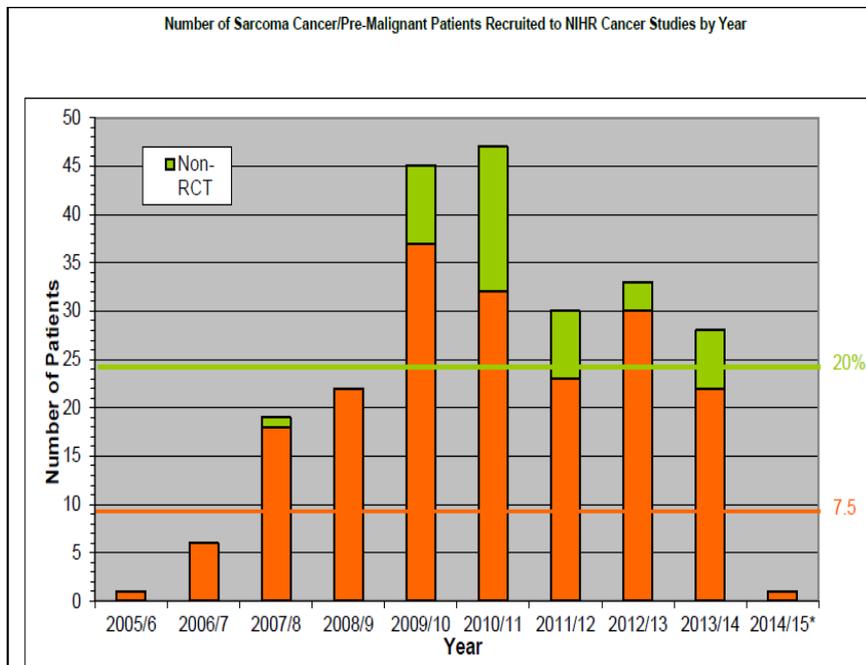
This data identified the gaps in recording activity and provided a baseline to measure against identified improvements in the work programme for 2014/15.

6. Patient experience

Analysis of the results of the national cancer patient experience survey at a pathway level across Greater Manchester has been made available to Pathway Boards and this will continue to be the case in future years.

The results of the national survey are limited by the absence of data in cancer types or in particular institutions where low numbers of people are surveyed. As such, regional groups have tended to rely on patient experience data gleaned in different ways by different teams across the area. Improving patient experience is one of the key outcomes of the Manchester Cancer Provider Board and as such we are committed to supporting Pathway Boards to meaningfully measure it across the system from 2014 onwards.

7. Research and clinical trials



Performance on the projected recruitment targets have improved in comparison from 2012/13 to 2013/14 year the set RCT and non-RCT 2013/14.

This data is scheduled to be discussed at the second pathway board meeting due to held on September and agree there the regularity of reviewing clinical trials uptake.

8. The Pathway Board

8.1. Formation of the Board

The principle of Manchester Cancer Pathway Boards is that they should be professionally and institutionally representative, yet small and manageable in size. To help Pathway Clinical Directors form institutionally representative Boards the Manchester Cancer central team sought nominations from trusts for their representative(s) on 16 of the 20 Pathway Boards. Nominations were not sought for Children's, Sarcoma, Palliative Care and Early Diagnosis as alternative arrangements were necessary in these areas.

8.2. Membership

The board was formed from the former Sarcoma Advisory Group members and the service leaders in Sarcoma. The first meeting was held on the 25th of June at which point the membership lead roles and Terms of Reference was discussed and agreed. Invitations have been sent to the identified patients by the Chair and confirmation to be received by September 2014.

Name	Role & Trust	Leads
Dr JP Wylie	Chairman. Clinical Oncologist representative, Christie FT	Data lead
Mr D Mowatt	Reconstructive surgical representative Christie FT	Living with and Beyond Cancer Lead
Dr P Shenjere	Soft tissue pathology representative Christie FT	
Dr M Leahy	Medical Oncologist/research and TYA representative Christie FT	Research Lead
Mr P Cool	RJAH surgical representative and MDT Chairman, RJAH FT	Early diagnoses
Miss G Cribb	Surgical representation, RJAH FT	
Dr C Mangham	Bone pathology representative RJAH FT	
Dr R Lalam	Bone radiologist representative RJAH FT	
Mr A Paul	Surgical representative , CMFT	
Mr J Gregory	Surgical representative , CMFT	Data Lead
Dr N Winn	Soft tissue radiology r representative, CMFT	
Miss Maxine Cumbo	Physiotherapy representative, CMFT	Physiotherapy Lead
Proff A.Freemont	Soft Tissue pathology CMFT	
Mr Damian Heron	Director of North Wales Cancer Network	
Caroline Pemberton	Sarcoma CNS RJAH FT	Nursing Lead
Jane Evans	Sarcoma CNS RJAH FT	Nursing Lead

8.3. Meetings

The first board meeting was held in 25th June 2014, key priorities for this meeting were to discuss the Term of Reference and work programme for the future.

The board focused the development of a work programme from the requirements of National Specifications, Sarcoma clinical lines of enquiry and a snap shot activity Somerset data report from 2013/14.

Based on the above information the board agreed to (1) develop a joint data set above and beyond the national standard requirement and a robust mechanism for recording and report (2) Audit diagnostic pathways (3) increase primary care awareness to improve patient outcome.

9. Progress and challenges to date

The pathway board is fairly new in its formation; however a programme of work has been defined in the first meeting by all providers.

Furthermore, key challenge from the previous Sarcoma Advisory Group was to address the barriers in improving data collections, this has improved some way by the implementation of Somerset Cancer Registry in April 2013 and a single MDT meetings' since September 2013. The next 12 months focuses on improving data quality by agreeing a data set above and beyond the national standard requirement to be collected per site and reporting annually.

10. Vision and objectives

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 2014/15 to have a more informed understanding of patient outcomes;

- Measure clinically meaningful outcomes and compare to international centres of excellence going above and beyond national standards.
- Audit existing primary care knowledge of sarcoma pathways and provide education and awareness programme to improve early diagnoses and outcome for patients.

Please refer to appendix 4 for the detailed annual plan

11. Appendix 1 – Pathway Board Terms of Reference

Greater Manchester and Oswestry Sarcoma Pathway Board Terms of Reference

These terms of reference were agreed on 25th June 2014 by James Wylie, Pathway Clinical Director for sarcoma, and Mr David Shackley, Medical Director of Greater Manchester Cancer Services, on behalf of the Greater Manchester Cancer Services Provider Board. The terms of reference will be subject to future review.

1. The Pathway Board

- 1.1. Manchester Cancer and Oswestry Pathway Board is a cancer care specific board with responsibility to improve cancer outcomes and patient experience for local people across Greater Manchester, areas of Cheshire and those geographical areas covered by the Greater Manchester and Oswestry Cancer Service (GMOSS). These terms of reference are in addition to those previously outlined by the Sarcoma Advisory Group in the constitution documentation of GMOSS.
- 1.2. The Pathway Board is led by a Pathway Clinical Director and is formed of a multidisciplinary team of clinicians and other staff from all of hospital trusts that are involved in the delivery of sarcoma care in Greater Manchester and Oswestry. The Pathway Board also has membership and active participation from patient representatives.
- 1.3. Manchester Cancer and Oswestry Pathway Board reports into and is ultimately governed and held to account by the Greater Manchester Cancer Services Provider Board.

2. Manchester Cancer Provider Board

- 2.1. Manchester Cancer Provider Board is responsible for the service and clinical delivery arm of Manchester Cancer, Greater Manchester's integrated cancer system. Manchester Cancer has two other arms: research and education (see appendix for the structure of Manchester Cancer).
- 2.2. The Provider Board is independently chaired and consists of the Chief Executive Officers of the ten acute hospital trusts in the Greater Manchester area:
 - Bolton NHS Foundation Trust
 - Central Manchester University Hospitals NHS Foundation Trust
 - East Cheshire NHS Trust
 - Pennine Acute NHS Trust
 - Salford Royal NHS Foundation Trust
 - Stockport NHS Foundation Trust

- Tameside Hospital NHS Foundation Trust
- The Christie NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust;
- Wrightington, Wigan and Leigh NHS Foundation Trust;

2.3. The Provider Board regularly invites representatives of commissioners, the Strategic Clinical Network, and Manchester Cancer to its meetings.

3. Purpose of the Pathway Board

3.1. The purpose of the Pathway Board is to improve cancer care for patients on the Greater Manchester and Oswestry Sarcoma cancer pathway. Specifically, the Pathway Board aims to save more lives, put patients at the centre of care, and improve patient experience. The Board will represent the interests of local people with cancer, respecting their wider needs and concerns. It is the primary source of clinical opinion on this pathway for the Greater Manchester Cancer Services Provider Board and Greater Manchester's cancer commissioners.

3.2. The Pathway Board will gain a robust understanding of the key opportunities to improve outcomes and experience working in partnership with Oswestry Sarcoma providers by gathering and reviewing intelligence about the Sarcoma cancer pathway. It will ensure that objectives are set, with a supporting work programme that drives improvements in clinical care and patient experience.

3.3. The Pathway Board will also promote equality of access, choice and quality of care for all patients within Greater Manchester, irrespective of their individual circumstances. The Board will also work with cancer commissioners to provide expert opinion on the design of any commissioning pathways, metrics and specifications.

4. Role of the Pathway Board

The role of Manchester Cancer and Oswestry pathway Board is to:

4.1. Represent the Greater Manchester Cancer Services professional and patient community for sarcoma.

4.2. As a minimum promote an IOG compliant service achieving high compliance with the nationally agreed Sarcoma Measures.

4.3. Identify specific opportunities for improving outcomes and patient experience and convert these into agreed objectives and a prioritised programme of work.

4.4. Gain approval from Greater Manchester's cancer commissioners and the Manchester Cancer Provider Board for the programme of work and provide regular reporting on progress.

- 4.5. Design and implement new services for patients where these progress the objectives of commissioners and Manchester Cancer, can be resourced, and have been shown to provide improvements in outcomes that matter to patients.
- 4.6. Ensure that diagnosis and treatment guidelines are agreed and followed by all teams in provider trusts, and are annually reviewed.
- 4.7. Ensure that all providers working within the pathway collect the pathway dataset measures to a high standard of data quality and that this data is shared transparently amongst the Pathway Board and beyond.
- 4.8. Promote and develop research and innovation in the pathway, and have agreed objectives in this area.
- 4.9. Monitor performance and improvements in outcomes and patient experience via a pathway scorecard, understanding variation to identify areas for action.
- 4.10. Escalate any clinical concerns through provider trusts.
- 4.11. Highlight any key issues that cannot be resolved within the Pathway Board itself to the Medical Director of Manchester Cancer for assistance.
- 4.12. Ensure that decisions, work programmes, and scorecards involve clearly demonstrable patient participation.
- 4.13. Share best practices with other Pathway Boards within Manchester Cancer.
- 4.14. Contribute to cross-cutting initiatives (e.g. work streams in living with and beyond cancer and early diagnosis).
- 4.15. Discuss opportunities for improved education and training related to the pathway and implement new educational initiatives.
- 4.16. Develop an annual report of outcomes and patient experience, including an overview of progress, difficulties, peer review data and all relevant key documentation. This report will be published in July of each year and will be the key document for circulation to the Provider Board. A template for this report is available so that all Pathway Boards complete the report in a similar manner.

5. Membership principles

- 5.1. All member organisations of Manchester Cancer will have at least one representative on the Pathway Board unless they do not wish to be represented.
- 5.2. Provider trusts not part of Manchester Cancer can be represented on the Pathway Board if they have links to the Greater Manchester sarcoma pathway.
- 5.3. All specialties and professions involved in the delivery of the pathway will be represented.

- 5.4. The Board will have at least one patient or carer representative within its membership
- 5.5. One professional member of the Pathway Board will act as a Patient Advocate, offering support to the patient and carer representative(s).
- 5.6. The Board will have named leads for:
- Early diagnosis
 - Pathology
 - Radiology
 - Surgery
 - Oncology
 - Specialist nursing
 - Living with and beyond cancer ('survivorship')
 - Research
 - Data collection (clinical outcomes/experience and research input).
- 5.7. It is possible for an individual to hold more than one of these posts. The Pathway Clinical Director is responsible for their fair appointment and holding them to account.
- 5.8. These named leads will link with wider Manchester Cancer Boards for these areas where they exist.
- 5.9. All members will be expected to attend regular meetings of the Pathway Board to ensure consistency of discussions and decision-making (meeting dates for the whole year will be set annually to allow members to make arrangements for their attendance).
- 5.10. A register of attendance will be kept: members should aim to attend at least 5 of the 6 meetings annually and an individual's membership of the Pathway Board will be reviewed in the event of frequent non-attendance.
- 5.11. Each member will have a named deputy who will attend on the rare occasions that the member of the Board cannot.

6. Frequency of meetings

- 6.1. The Manchester Cancer and Oswestry Pathway Board will meet every two months.

7. Quorum

- 7.1. Quorum will be the Pathway Clinical Director plus five members of the Pathway Board or their named deputies.

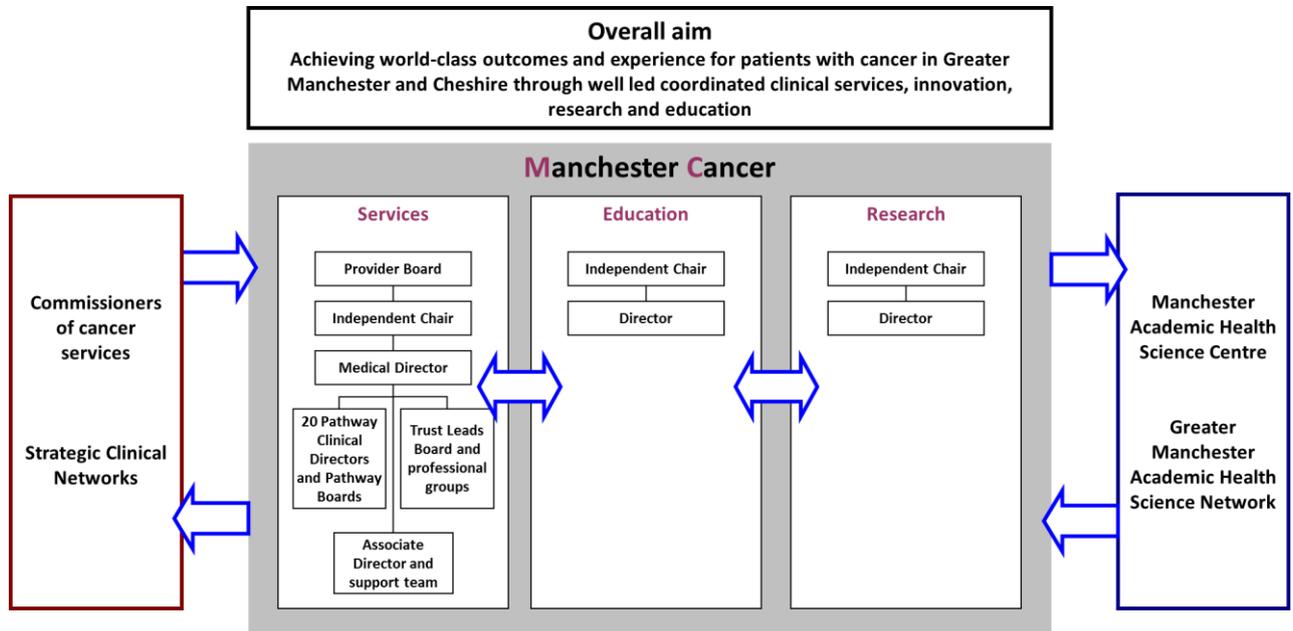
8. Communication and engagement

- 8.1. Accurate representative minutes will be taken at all meetings and these will be circulated and then validated at the next meeting of the Board.
- 8.2. All minutes, circulated papers and associated data outputs will be archived and stored by the Pathway Clinical Director and relevant Pathway Manager.
- 8.3. The Pathway Board will design, organise and host at least one open meeting per year for the wider clinical community and local people. This meeting or meetings will include:
 - An annual engagement event to account for its progress against its work programme objectives and to obtain input and feedback from the local professional community
 - An annual educational event for wider pathway professionals and interested others to allow new developments and learning to be disseminated across the system
- 8.4. Representatives from all sections of the Manchester Cancer professional body and Oswestry will be invited to these events, as well as patient and public representatives and voluntary sector partners.
- 8.5. An annual report will be created and circulated to the Medical Director of the Manchester Cancer Provider Board by 31st July of each calendar year.
- 8.6. The agendas, minutes and work programmes of the Pathway Board, as well as copies of papers from educational and engagement events, will be made available to all in an open and transparent manner through the Manchester Cancer website once this has been developed.

9. Administrative support

- 9.1. Administrative support will be provided by the relevant Pathway Manager with the support of the Manchester Cancer core team. Over the course of a year, an average of one day per week administrative support will be provided.

Appendix – Manchester Cancer structure



12. Appendix 2 – Pathway Board meeting attendance

Name	Role & Trust	25th June 2014
Dr JP Wylie	Chairman. Clinical oncologist representative, Christie FT	✓
Mr D Mowatt	Reconstructive surgical representation Christie FT	✓
Dr P Shenjere	Soft tissue Pathology representation Christie FT	✓
Dr M Leahy	Medical oncologist/research and TYA representative Christie FT	✓
Mr P Cool	RJAH surgical representation and MDT Chairman, RJAH FT	✓
Miss G Cribb	Surgical representation, RJAH FT	X
Dr C Mangham	Bone pathology Representation RJAH FT	X
Dr R Lalam	Bone radiologist representation RJAH FT	X
Mr A Paul	surgical representation , CMFT	X
Mr J Gregory	surgical representation , CMFT	✓
Dr N Winn	Soft tissue Radiology rep, CMFT	✓
Miss Maxine Cumbo	Physiotherapy, CMFT	✓
Proff A.Freemont	Soft Tissue pathology CMFT	X
Mr Damian Heron	Director of North Wales Cancer Network	X
Caroline Pemberton	Sarcoma CNS RJAH FT	✓
Jane Evans	Sarcoma CNS RJAH FT	✓

13. Appendix 3 – Pathway Board minutes to 31st July 2014

Minutes of the last meeting will be signed off at the next meeting in September.

Appendix 4 – Pathway Board Annual Plan 2014/15

Pathway Clinical Director:	Dr JP Wylie, Clinical Oncologist representative, Christie FT
Pathway Board Members:	Mr D Mowatt Reconstructive surgical representation Christie FT Dr P Shenjere Soft Tissue pathology representation Christie FT Dr M Leahy, Medical Oncologist/research and TYA representative Christie FT Mr P Cool , RJAH surgical representation and MDT Chairman, RJAH FT Miss G Cribb, Surgical representation, RJAH FT Dr C Mangham, Bone pathology representation RJAH FT Dr R Lalam , Bone radiologist representation RJAH FT Mr A Paul, surgical representation , CMFT Mr J Gregory, surgical representation , CMFT Dr N Winn, Soft Tissue Radiology representation, CMFT Miss Maxine Cumbo, Physiotherapy representation, CMFT Prof A.Freemont, Soft Tissue pathology CMFT Mr Damian Heron, Director of North Wales Cancer Network Caroline Pemberton, Sarcoma CNS RJAH FT Jane Evans, Sarcoma CNS RJAH FT
Pathway Manager:	Hodan Noor
Date agreed by Pathway Board:	
Date agreed by Medical Director:	
Review date:	

Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	Measure clinically meaningful outcomes and compare to international centres of excellence going above and beyond national standards.	Improve survival
2	Audit existing primary care knowledge of sarcoma pathways and provide education and awareness programme to improve early diagnoses and outcome for patients.	Improve survival and patient experience
3	Ensure patients are able to fully access all aspects of care pre, during and post treatment of Sarcoma.	Patient experience

Objective 1: Measure clinically meaningful outcomes and compare to international centres of excellence going above and beyond national standards

Objective:	<ul style="list-style-type: none"> • Review Somerset Cancer Registry (SCR) and re-assess whether it fulfils needs at the 3 centres • Identify measures outside of the national requirements to compare to international centres of excellence. • Adopt the RCPATH minimal data set
Rationale:	<p><i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i></p> <p>The Boards motivation is to deliver a high quality service which is comparable to other centres of excellence.</p> <p>To measure the quality of a service requires the definition of clinically meaningful outcomes which can then be easily collected and compared across different parts of the service and also compared with similar measures from internationally respected centres of excellence. These measures should, if necessary, go above those mandated by NICE and Clinical Reference Groups and could include nursing, pathology, physiotherapy, radiotherapy, oncology and surgery outcomes.</p> <p>At present data is collected by the host Trust of GMOSS via the SCR but it is unclear how well this is collected and how relevant this would be for future data collection. It is therefore intended to regularly review SCR and re-assess whether it is fit for purpose across the 3 centres. SCR functionality does have some limitations in relation to collecting outcome data as the main focus is performance. A snap shot data report from the host organisation has already been submitted and presented to the Board which identified significant gaps in recording activity and provided a baseline to measure against in the coming year.</p> <p><u>PLAN:</u></p> <p>Developing outcome measures data set above and beyond the national specification in order to compare performance with international centres of excellence is the ambition of the board.</p> <p>Agree how best to collect this data, hoping that it can be collected via SCR. A detailed review of SCR functionality will be performed.</p> <p>Adopt the pathology minimal data set across all centres to ensure consistent reporting.</p>
By (date):	<p><i>What is the target date for completion?</i></p> <p>Preliminary SCR review will be completed by 31st September 2014</p> <p>Agree new outcome measures by March 2015</p> <p>Confirm how best to collect this data by September 2015</p>
Board measure(s):	<p><i>Which of the Pathway Board's key measures will show it that the objective has been met?</i></p> <ul style="list-style-type: none"> • Board will publish agreed outcome measures • Future annual reports will include this data
Risks to success:	<p><i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i></p>

	<ul style="list-style-type: none"> Lack of consistent data management across all 3 sites. Data collection at present fragmented. No resource for single data collection. 3 surgical centres have initially agreed to collect their own data using the agreed outcome measures and there will be an annual presentation of the data.
Support required:	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i></p> <p>The board aims to utilise existing operational support of the Pathway Manager to facilitate the development s. Any proposals that require considerable changes to Trust data collection infrastructure will be share with the Provider Board to seek advice.</p>

Work programme		
Action	Resp.	By (date)
Set up virtual sub group to support the SCR review		Sept 2014
Identify key measure above and beyond national requirements		March 2015
Centre report on the agreed data set		Sep 2015
Discuss SCR review findings and develop proposal		March 2015
Present to the pathway board SCR findings and outcome measures		March 2015

Objective 2: Audit existing primary care knowledge of sarcoma pathways and provide education and awareness programme to improve early diagnoses and outcome for patients.

<p>Objective:</p>	<p>The main driver for improving patient outcome is by improving early detection and diagnosis. This can be achieved by;</p> <ul style="list-style-type: none"> • Liaising with the prevention, early detection and screening Pathway Board • Providing primary care education on key tips for early detection yearly. • Ensure referral guidelines and proformas are up to date, accessible and easy to use.
<p>Rationale:</p>	<p><i>What was the Pathway Board’s motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i></p> <p>According to Sarcoma UK Charity outcomes for sarcoma can be improved through earlier diagnosis. The current average size of soft tissue sarcomas at diagnosis is 100mm. If soft tissue sarcomas can be diagnosed when <50mm, cure rates would improve by at least 20%.</p> <p>Sarcoma UK have developed a diagnostic tool in June 2014 which will be used as part of the education series and uploaded on line to encourage confidence in referring patients with suspected sarcoma.</p> <p>The rarity of sarcomas means that diagnostic pathways are often convoluted and slow leading to late diagnosis. We therefore wanted to audit primary care knowledge of current sarcoma diagnostic pathways to better understand any deficiencies and allow development of focused educational programmes.</p>
<p>By (date):</p>	<p><i>What is the target date for completion? If completion is expected beyond 2014/15 what progress is expected in year? If a phased approach is to be taken indicate this here.</i></p> <p>Audit existing knowledge of sarcoma prior to education sessions report finding by 31st March 2015.</p> <p>Engaging with the education series to Primary Care services and the annual programme will be delivered within this financial year.</p> <p>The reviewing of referral guidelines will also be completing by 31st March 2015.</p>
<p>Board measure(s):</p>	<p><i>Which of the Pathway Board’s key measures will show it that the objective has been met? What are the performance standards that will be expected?</i></p> <p>Below are the key performance indicators to assess the delivery of the board objectives this financial year;</p> <ul style="list-style-type: none"> • 1 GP education sessions per year across Greater Manchester and Cheshire areas annually and share Sarcoma UK diagnostic tool kit. • Compare GP knowledge through repeat audits pre and post education sessions • Reviewed guidelines and promoted the information to primary care services.

<p>Risks to success:</p>	<p><i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i> GP return rates with audit questionnaire Ability to engage with sufficient numbers of GPs through educational events</p>
<p>Support required:</p>	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i> The board aims to utilise existing operational support of the Pathway Manager to facilitate the development of this objective. Any proposals that require considerable changes to Trust infrastructure or require capacity will be share with the Provider Board to seek advice.</p>

<p>Work programme</p>		
<p>Action</p>	<p>Resp.</p>	<p>By (date)</p>
<p>Deliver GP education</p>		<p>2015</p>
<p>Identify needs of GP pre audit</p>		<p>Dec 2014</p>
<p>Share Sarcoma UK diagnostic tools</p>		<p>2015</p>

Objective 3: Ensure patients are able to fully access all aspects of care pre, during and post treatment of Sarcoma.

Objective:	To fully engage with the Living with and Beyond and Palliative Care service mapping to ensure full assessment of Sarcoma service delivery
Rationale:	<p><i>What was the Pathway Board’s motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i></p> <p>The National Cancer Survivorship Initiative (NCSI) developed a number of interventions (recovery package) to enable better outcomes for cancer survivors. The living with and Beyond Cancer pathway board plan to undertake a mapping of service provision based on the NCSI interventions and the board will engage in this assessment and take forward any recommendations from the mapping exercise to ensure improvements are made.</p> <p>The Palliative care Board also are undertaking a mapping of service provision to address generic and specialist palliative care service provision across all pathways include support for patient on the last days of life. The board will work closely by engaging with this mapping to identify its position and identify areas for improvement.</p>
By (date):	<p><i>What is the target date for completion? If completion is expected beyond 2014/15 what progress is expected in year? If a phased approach is to be taken indicate this here.</i></p> <ul style="list-style-type: none"> • A report on service provision post treatment and the level of engagement with the recovery package and palliative care including the last days of life.
Board measure(s):	<p><i>Which of the Pathway Board’s key measures will show it that the objective has been met? What are the performance standards that will be expected?</i></p> <p>The service by Palliative Care and Living with and Beyond Pathway Board, key measure is to fully engage and comply with the timeframe set for completions of information requested.</p>
Risks to success:	<p><i>What factors will hinder or prevent the Board’s ability to achieve the objective? How will these risks be mitigated?</i></p> <p>No risks identified</p>
Support required:	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i></p> <p>The board aims to utilise existing operational support of the Pathway Manager to facilitate the development of this objective. Any proposals that require considerable changes to Trust infrastructure or require capacity will be share with the Provider Board to seek advice.</p>

Work programme		
Action	Resp.	By (date)
Mapping of Sarcoma services against recovery package and palliative care support		Sept- January
Report on gaps and good practice		February

Appendix: Manchester Cancer Provider Board objectives

The Manchester Cancer Provider Board has identified the themes of its three key objectives. The precise wording of those objectives remains to be confirmed.

- 1. 1-year SURVIVAL:** Focus on improving 1-year pooled cancer overall survival rate, so that we halve the survival gap with the world's best (Sweden) for patients diagnosed in 2020, and approach their figures by 2025
- 2. Patient EXPERIENCE:** Achieve year-on-year improvement in patient experience aspiring to be the best performing conurbation in the National Cancer Patient Experience Survey
- 3. RESEARCH and INNOVATION:** Increase patient involvement in research (>40% by 2019) and be an international leader in developing innovation in clinical practice