

Children's Cancer Pathway Board

Annual Report 2013/14

Pathway Clinical Director: Bernadette Brennan
Pathway Manager: Melissa Wright

Executive summary

Cancer in children and young people is rare with only 1,600 children each year in the UK developing cancer. Cancer in children tends to occur in different parts of the body to adults and as such respond differently to treatment and have a higher cure rate.

Outcomes for children in Greater Manchester reflect this with survival rates at 1-, 3- and 5-year on par or above the national average.

Paediatric Cancer services are specially commissioned with the support of the Clinical Reference Group which has developed services specifications for the delivery of paediatric oncology.

Locally Greater Manchester hosts one of 21 Principal Treatment Centres (PTC) and works closely with shared care units across the Strategic Clinical Network Region and there is a Key Worker policy (via the CNS) in place.

All clinical guidelines to support the delivery of care within the PTC are updated regularly and there are work programmes to support its three MDT's and the PTC core measures.

Recruitment into clinical trials for children is good and exceeds targets set by the Clinical Research Network. The focus for the Pathway Board this year will be to ensure relationships are established with all key stakeholders across the pathway and across wider regional remit of children's cancer. This will allow the Board to take a comprehensive view and to ensure that there is equity across the service provision.

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

National context

NHS England is working with a range of stakeholders at a national level to determine the outcomes expected for specialised services. This will be achieved through the development of clinical strategies set out within five national Programmes of Care (PoC) which group together the nationally agreed range of specialised services. These strategies will enable the commissioning of services to be based on clear evidence and ensure that they are cost effective and patient focused.

The direct specialised commissioning function of NHS England is supported by a devolved clinical leadership model. Clinical Reference Groups (CRGs) covering all nationally agreed specialised services, draw membership from each of the geographical areas covered by the 12 Senates. They are responsible for preparing national specialised service level strategy and developing specialised service contract products such as specifications and policies.

CRGs bring together clinicians, commissioners, and Public Health experts with the patients and carers who use the relevant services. Members are volunteers who have a particular interest, knowledge or experience of a specific area of specialised healthcare and wish to contribute to its development.

The Paediatric Cancer Services CRG has prepared two service specifications for Retinoblastoma service and Paediatric Oncology. These service specifications are important in clearly defining what NHS England expects to be in place for providers to offer evidence-based, safe and effective services. They have been developed by specialised clinicians, commissioners, expert patients and public health representatives to describe core and developmental service standards. Core standards are those that any reasonable provider of safe and effective services should be able to demonstrate, with developmental standards being those that really stretch services over time to provide excellence in the field.

Incidence

Cancer in children and young people are rare. In the UK, only 1 in every 500 children under 15 develops cancer, and this would equate to 1,600 children each year (Macmillan 2012).

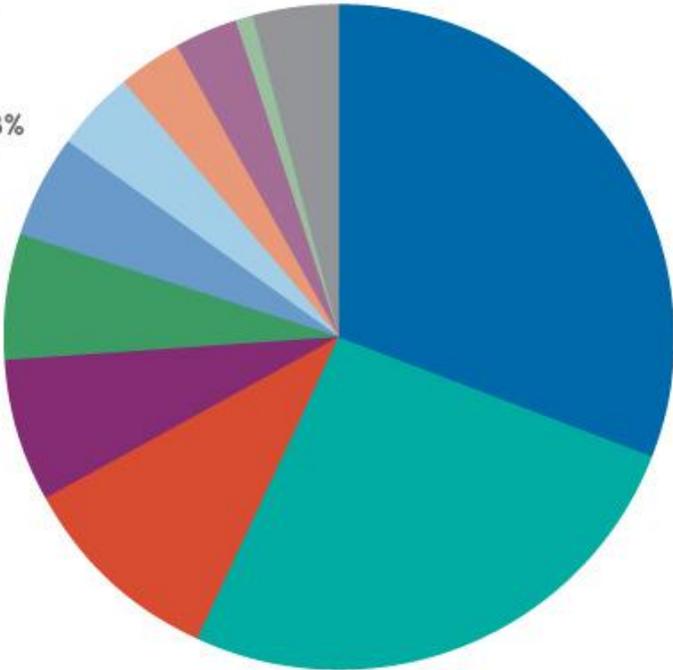
Children's cancers can be quite different from cancers affecting adults. They tend to occur in different parts of the body to adult cancers. They also look different under the microscope and respond differently to treatment.

Cure rates for children are much higher than for most adult cancers. The survival rate for children's cancer has more than doubled since the 1960s and there have been huge improvements in cancer treatments for children in the past 50 years. On average, 82% (over 8 in 10) of all children can now be completely cured. For some types of children's cancer, the cure rate is much higher.

Figure 1. Incident rates of cancer in children

Types of cancer in children

- Leukaemias **31%**
- Brain and spinal tumours **26%**
- Lymphomas **10%**
- Soft tissue sarcomas **7%**
- Neuroblastoma **6%**
- Kidney tumours **5%**
- Bone tumours **4%**
- Germ cell tumours **3%**
- Retinoblastoma **3%**
- Liver tumours **2%**
- Other **4%**



Mortality

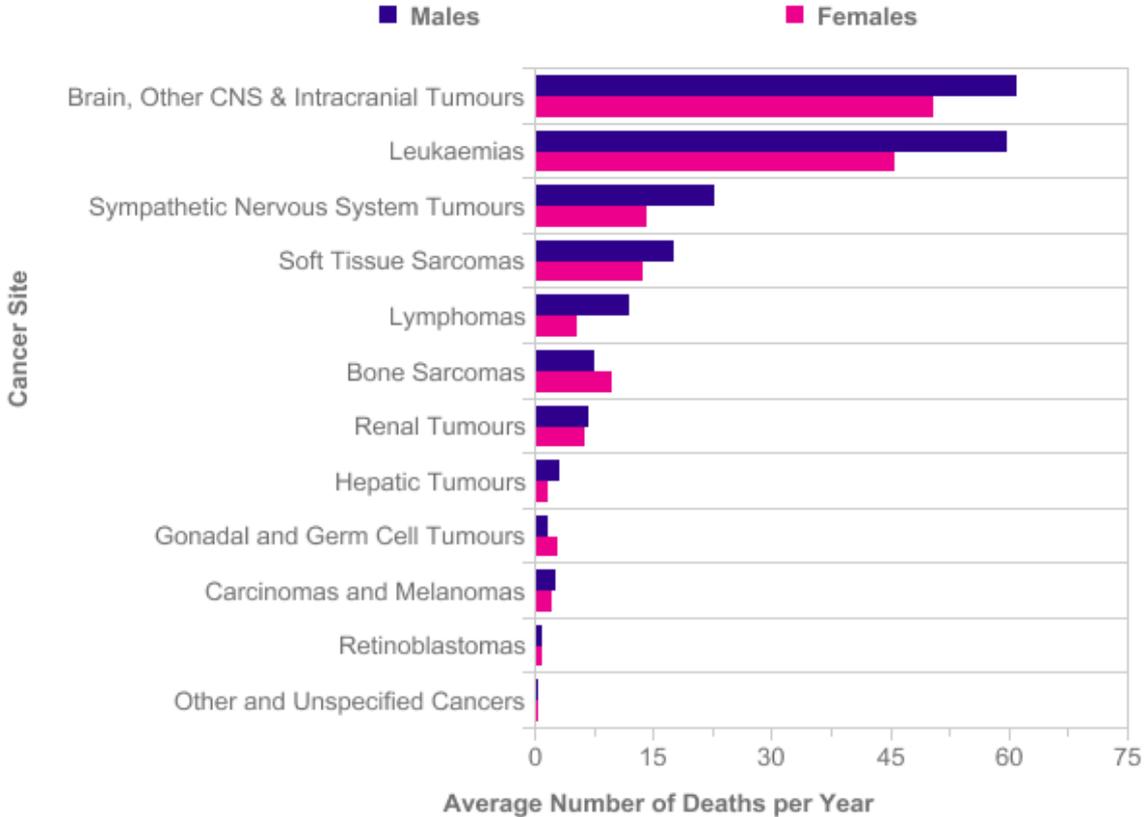
Cancer is the most common cause of death in children and accounts for less than a fifth of all deaths in boys and girls aged 1-14, 18% and 19%, respectively (ONS 2011). Despite this, deaths from cancer are still relatively rare in children aged 0-14 years, with less than one per cent of the total cancer deaths occurring in this age group. In 2009-2011, there was an average of 252 deaths per year from cancer (including benign, uncertain or unknown behaviour brain, other CNS and intracranial tumours) in children aged 0-14 in the UK

Table 1. All childhood cancers, average numbers of deaths per year, crude and age standardised mortality rates per million population, ages 0-14 2009-11

All Childhood Cancers: 2009-2011						
Average Number of New Deaths per Year, Crude and World Age-Standardised (AS) Mortality Rates per Million Population, Ages 0-14, UK						
		England	Wales	Scotland	Northern Ireland	UK
Male	Deaths	113	4	10	4	132
	Crude Rate	23.8	16.3	23.7	21.9	23.3
	AS Rate	23.6	15.6	24.2	22.7	23.3
Female	Deaths	101	5	9	5	120
	Crude Rate	22.3	18.5	21.6	28.9	22.3
	AS Rate	22.4	18.5	21.6	28.7	22.3
Persons	Deaths	215	9	19	9	252
	Crude Rate	23	17.4	22.7	25.3	22.8
	AS Rate	23	17	22.9	25.6	22.8

Childhood cancers are further classified into cancer type which takes the tumour's anatomical site and morphology into account. The three most common causes of cancer deaths in children are brain, other central nervous system (CNS) and intracranial tumours, leukaemia and sympathetic nervous system tumours. Although brain, other CNS and intracranial tumours rank second in incidence, they are the most common cause of deaths from cancer in childhood, accounting for around a third of all cancer deaths in boys and girls (31% and 33%, respectively). Certain types of brain tumours, such as primitive neuroectodermal tumours and atypical teratoid/rhabdoid tumours, have some of the lowest survival of all childhood cancers (Stiller 2007).

Figure 2. Childhood cancers by cancer type, average numbers of deaths per year, aged 0 - 14, Great Britain, 1996 - 2005

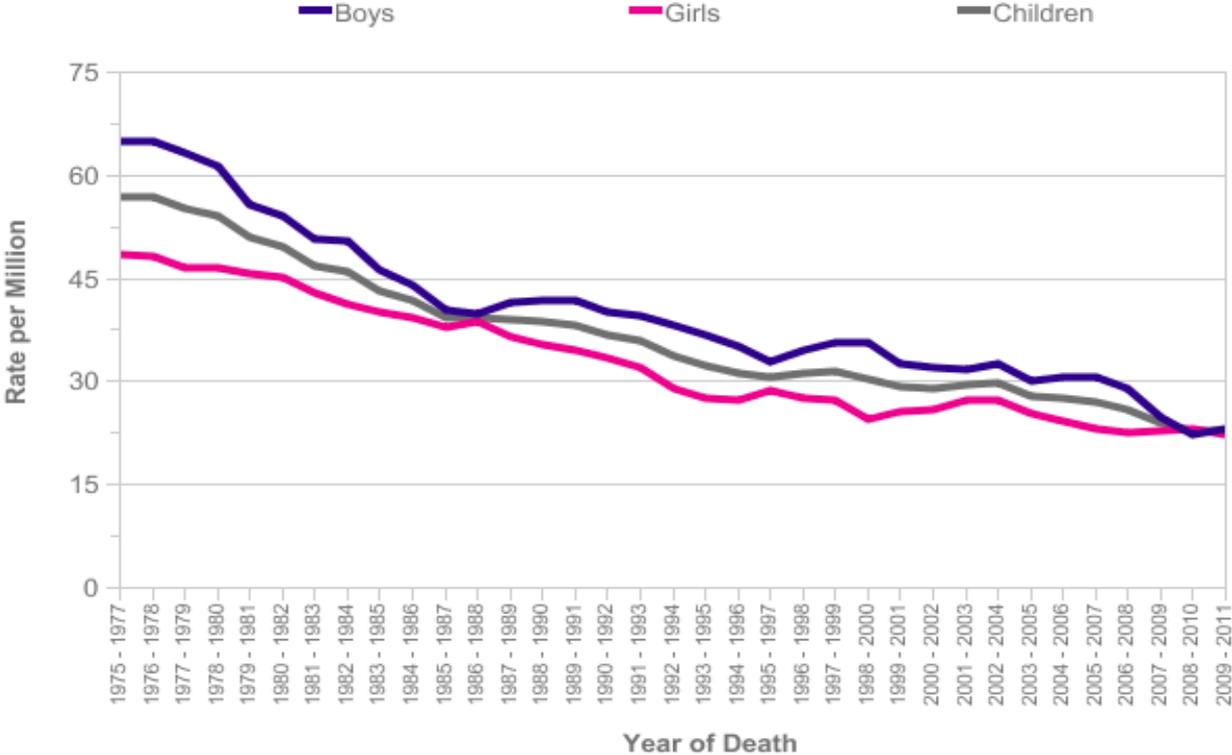


Cancer Research UK

Trends

Mortality rates for childhood cancer (including all benign, uncertain and unknown behaviour brain, other CNS and intracranial tumours) have decreased overall in the UK since the mid-1970s. In males aged 0-14, age standardised mortality rates decreased by 64% between 1975-1977 and 2009-2011. The decline is slightly less for females aged 0-14, with rates decreasing by 54% between 1975-1977 and 2009-2011. This downward trend is true for all cancer types, but to varying amounts. Over the last decade (between 2000-2002 and 2009-2011), age standardised mortality rates have decreased by 27% in males aged 0-14, but remained stable in females aged 0-14 (ONS 2013).

Figure 3. All childhood cancers, age standardised mortality rates per million population aged 0 -14, UK, 1975 - 2011



Cancer Research UK

2. Background to the pathway/cross-cutting area

Summarise, if known, some of the details of the previous cancer network group: the former chair, the last meeting date and the work plan at the time of the group’s closure. If appropriate outline the successes of the previous group, the challenges it faced, and note the Pathway Board’s commitment to redouble efforts to bring about change/improvement.

The configuration of Paediatric oncology is different than that of other tumour groups. Specialist services are delivered by The Royal Manchester Children’s Hospital (RMCH), at Central Manchester University Hospital Trust, and this role identifies them as the Primary Treatment Centre (PTC).

The work programme for Paediatric Oncology can be found in the appendix. Some of the key achievements 2013 -14 include no delays in patient diagnosis and treatment, no breaches of Cancer Waiting Targets and there were no refusal/transfer of new cancers to neighbouring PTCs. All major tumour resections were performed by two oncological surgeons and there was an extension to the ward treatment room and drug preparation room.

The parent's, carers and patients experience survey had an 83% response rate which is significantly higher than national averages and response rates for some adult tumour sites. There has also been continued recruitment of patients into clinical trials with a projection of the highest recruitment by the PTC since 2004/5 and on-going participation in CLIC Sargent keyworker role national project. In addition the Teenage Cancer Trust has supported the development of facilities for teenagers.

A number of policies/guidance/protocols have been updated/ratified to support Improving Outcomes Guidance. There have also been appointments of an MDT Co-ordinator to free up time for Paediatric Cancer Services Quality Manager Appointment of 2 additional Oncology Consultants as well as an appointment of a further WTE Dietician, to ensure compliance for dietetic support and the appointment of 0.5 WTE Occupational Therapist.

There have been a number of challenges to the service last year these include the facilitation of extra inpatient treatment of children from other PTCs in view of successful Christie/RMCH Supraregional Proton radiotherapy bid. There has also been patient/carer dissatisfaction with management of unwell patients in PED in relation to waiting times

It has been a challenge to provide education to nursing staff to develop specialist knowledge and expertise as there is no designated education practitioner. There is also a lack of local university first degree level specialist courses for nurses. The nursing establishment allows safe staffing levels but is not compliant with the Measure. It has been difficult to deliver required nurse training to POSCUS as Chemotherapy Trainer has Trust wide role and there is no designated paediatric oncology teacher/practitioner and the Oncology Outreach Nurse establishment does not meet Improving Outcomes Guidance.

3. Configuration of services

The provision of paediatric oncology care in the UK is divided by the Children's Cancer and Leukaemia Group (CCLG) among 21 specialist centres. The Royal Manchester Children's Hospital (RMCH), at Central Manchester University Hospitals NHS Foundation Trust is the specialist centre which co-ordinates care for the Manchester Cancer and Lancashire and South Cumbria Cancer Networks. These cover a total population of 4.6 million and are served by the following organisations:

North West Sector

Wrightington, Wigan and Leigh NHS Trust
Royal Bolton Hospital NHS Foundation Trust
Salford Royal Foundation Trust

North East Sector

Pennine Acute Hospitals NHS Trust
Central Manchester University Hospitals NHS Foundation Trust

South Sector

Trafford Healthcare NHS Trust
Tameside Acute NHS Trust
Stockport NHS Foundation Trust
University Hospital of South Manchester NHS Foundation Trust
East Cheshire NHS Foundation Trust
Mid Cheshire NHS Foundation Trust
The Christie NHS Foundation Trust

Lancashire/Cumbria Cancer Network

East Lancashire Hospitals NHS Trust
Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust
Lancashire Teaching Hospitals NHS Trusts
University Hospitals of Morecambe Bay NHS Trust

Royal Manchester Children's Hospital has been designated as the Principal Treatment Centre (PTC) for Paediatric Oncology (0-16yrs) and radiotherapy is provided at The Christie NHS Foundation Trust. In line with the Children's Cancer Measures, RMCH is the PTC for paediatric patients requiring diagnostics and treatment for potential oncological disease and hosts the Multidisciplinary Team Meetings (MDT).

The Paediatric Oncology Shared Care Units (POSCU) which provide shared care at level 1 are Lancashire Teaching Hospital NHS Trust, East Lancashire NHS Foundation Trust and Blackpool, Fylde and Wyre NHS Trust

Children and young people with suspected cancer, leukaemia and haematological disease are admitted via referral from GP or secondary care for investigations, confirmation of diagnosis and preparation for treatment. RMCH provides on-going treatment and supportive care as required and admissions are therefore either 'elective' or 'non-elective'.

Children can be admitted for bone marrow transplantation for a range of malignant and non-malignant life threatening conditions.

There is a Key Worker policy. The clinical nurse specialist is the identified Key Worker within this Trust. The clinical nurse specialists attending the MDT assign one of 4 clinical nurse specialists as the Key Worker to each patient depending on their address in the region. CNS patient’s key worker is the Clinical Nurse Specialist in Neuro-oncology, initially funded by CLIC Sargent

The core MDT agrees and records individual patient treatment plans on the MDT proforma which is then uploaded to the Avon and Somerset Cancer Database.

RMCH provides regional oncology and haematology services, and a national and international Bone Marrow Transplant service. Patients outside the region are also accepted for the investigation of complex haematological disorders and Phase I and II trials in oncology.

The service provided by RMCH is for children and young people from 0 - 16 years, older patients receiving ongoing care will be transferred to the Young Oncology Unit at the Christie NHS Foundation Trust or adult services where appropriate.

The MDTs at Royal Manchester Childrens Hospital are multi-professional groups serving the population of the Greater Manchester and Cheshire Cancer Network and the South Cumbria and Lancashire Network. The combination of the two diagnostic and treatment MDTs and the Late Effects MDT provide a complete MDT care system for all patients.

Table 1. RMCH Paediatric Oncology MDT’s

Title of MDT	Category	Lead Clinician
Paediatric Oncology MDT	PTC Diagnostic and Treatment MDT	Dr Bernadette Brennan
Paediatric Leukaemia MDT	PTC Diagnostic and Treatment MDT	Dr John Grainger
Late Effects MDT	PTC Late Effects MDT	Dr Bernadette Brennan

4. Clinical guidelines

The Children’s Cancer Pathway Board has been in place since May 2014. Despite the Children’s Cancer Network and Co-ordination Group (CCNCG) not having held a meeting since 2012-13, guidelines that relate to this pathway area have been regularly updated in accordance with the requirements of the PTC.

All of the relevant documentation can now be found at www.manchestercancer.org/services/childrens/.

5. Clinical information and outcomes

Each MDT agrees to collect the same minimum dataset across the children's network CCN. This includes data items for cancer waiting times monitoring, including Going Further on Cancer Waits in accordance with DSCN 20/2008, to the specified timetable as specified in the National Contract for Acute services. All patients are tracked and 100% have been treated within the 31 day cancer wait time for paediatrics. All patients are also fully registered with The Children's Cancer Registration dataset. The table below is data provided by NHS England on individual Trusts' performance for 2 week wait for suspected children's cancer following a GP referral and identifies that most Trusts are meeting the target for this performance outcomes.

Table 3. 2 week wait performance for suspected cancer 2013-14 Q3 & Q4

Quarter 3		NUMBER OF PATIENTS SEEN				% WITHIN 14 DAYS		NUMBER OF PATIENTS SEEN BY A SPECIALIST				
PROVIDER	SUSPECTED T	TOTAL	WITHIN 14	AFTER 14 DAYS		WITHIN 14 DA	IN 15 TO 16	IN 17 TO 2	IN 22 TO 2	AFTER 28 DAYS		
EAST CHESHIRE NHS T	children's	6	6	0	100.00%	6	0	0	0	0		
MID CHESHIRE HOSPIT	children's	5	5	0	100.00%	5	0	0	0	0		
UNIVERSITY HOSPITAL	children's	4	4	0	100.00%	4	0	0	0	0		
CENTRAL MANCHESTE	children's	23	23	0	100.00%	23	0	0	0	0		
PENNINE ACUTE HOSP	children's	7	6	1	85.70%	6	0	0	1	0		
SALFORD ROYAL NHS	children's	14	14	0	100.00%	14	0	0	0	0		
STOCKPORT NHS FOU	children's	7	7	0	100.00%	7	0	0	0	0		
TAMESIDE HOSPITAL N	children's	8	8	0	100.00%	8	0	0	0	0		
UNIVERSITY HOSPITAL	children's	3	3	0	100.00%	3	0	0	0	0		
BLACKPOOL TEACHIN	children's	3	3	0	100.00%	3	0	0	0	0		
EAST LANCASHIRE HO	children's	29	25	4	86.20%	25	1	2	1	0		
LANCASHIRE TEACHIN	children's	25	24	1	96.00%	24	0	1	0	0		
Quarter 4		NUMBER OF PATIENTS SEEN				% WITHIN 14 DAYS		NUMBER OF PATIENTS SEEN BY A SPECIALIST				
PROVIDER	SUSPECTED T	TOTAL	WITHIN 14	AFTER 14 DAYS		WITHIN 14 DA	IN 15 TO 16	IN 17 TO 2	IN 22 TO 2	AFTER 28 DAYS		
EAST CHESHIRE NHS T	children's	5	5	0	100.00%	5	0	0	0	0		
MID CHESHIRE HOSPIT	children's	12	12	0	100.00%	12	0	0	0	0		
UNIVERSITY HOSPITAL	children's	3	2	1	66.70%	2	0	1	0	0		
CENTRAL MANCHESTE	children's	29	29	0	100.00%	29	0	0	0	0		
PENNINE ACUTE HOSP	children's	12	12	0	100.00%	12	0	0	0	0		
SALFORD ROYAL NHS	children's	7	6	1	85.70%	6	0	1	0	0		
STOCKPORT NHS FOU	children's	3	3	0	100.00%	3	0	0	0	0		
TAMESIDE HOSPITAL N	children's	7	7	0	100.00%	7	0	0	0	0		
UNIVERSITY HOSPITAL	children's	2	2	0	100.00%	2	0	0	0	0		
BLACKPOOL TEACHIN	children's	21	21	0	100.00%	21	0	0	0	0		
EAST LANCASHIRE HO	children's	19	19	0	100.00%	19	0	0	0	0		
LANCASHIRE TEACHIN	children's	24	22	2	91.70%	22	2	0	0	0		

Survival rates for patients with solid or Central Nervous System (CNS) tumours and leukaemia continue to be above or equal to the national average.

Table 4. 1-, 3- and 5-year survival rates for CNS tumours, Other solid tumours and Leukaemia

CNS tumours

	N	1-yr % survival (SE)	3-yr % survival (SE)	5-yr % survival (SE)	Log-rank test
Manchester	257	88 (2.0)	79 (2.6)	76 (2.8)	NS
All other centres	3673	84 (0.6)	75 (0.7)	72 (0.8)	

Other solid tumours

	N	1-yr % survival (SE)	3-yr % survival (SE)	5-yr % survival (SE)	Log-rank test
Manchester	433	92 (1.3)	82 (1.8)	78 (2.1)	NS
All other centres	5807	92 (0.4)	82 (0.5)	79 (0.6)	

Leukaemia

	N	1-yr % survival (SE)	3-yr % survival (SE)	5-yr % survival (SE)	Log-rank test
Manchester	334	93 (1.4)	89 (1.7)	85 (2.0)	NS
All other centres	4630	93 (0.4)	88 (0.5)	85 (0.6)	

6. Patient experience

All patients and parents are provided with a 'Going Home from the Oncology Unit' booklet.

This booklet covers:

- Contact numbers
- Parents checklist
- Outpatient clinic
- Medication
- Care of central venous line
- Infection
- Common Problems
- Personal Wellbeing
- Holidays
- Support Groups

Clear and comprehensive written information for patients is also offered on the following:

Information about childhood cancer, treatment, expected side effects and prognosis (CCLG/Cancer Backup parents' guide/CLIC Sargent specific booklets e.g. LRF childhood leukaemia booklets, parents' information sheets for specific treatment protocols).

RMCH has an Interpreting and Translation Service, which provides 24 hour telephone access to trained interpreters. The Hospital pays for this service and there is no cost to patients. Patients who need an interpreter contact the ward/outpatient department in advance of their visit to book the service they need. This included British Sign Language and lip speakers for the deaf.

Unlike in the care of adult patients with cancer there is currently no national survey undertaken for children with malignant disease. In order to self-assess our current performance the senior team within the oncology department at RMCH devised a questionnaire that attempted to mirror the question posed in the national survey for adults. However there is a fundamental difference between the two in the fact that the vast majority of respondents were parents or carers rather than the patients themselves.

The survey was undertaken in May and June 2013. It covered those patients who were diagnosed up to 2 years ago but remain on an ongoing treatment pathway.

The response rate of 83%, from 180 questionnaires, was excellent and overall the results were very good. The survey provided an opportunity to establish the experience of patients and carers going through treatment in more depth than the other methods used to collect patient and carer views as it focused specifically on the oncology/haematology service asking questions about the following areas:

- Treatment
- Hospital Facilities
- Discharge
- Accident and Emergency Admissions
- Information and Support
- Overall Parental satisfaction

Respondents were particularly positive regarding discussions about treatment, information and support provided, and overall parental satisfaction with 90% stating they would recommend the unit to others. Areas which require action to be undertaken include the provision of nutrition, accident and emergency admissions, facilities for teenagers and the promotion of the key worker role. The results were in line with the data collected from the patient tracker and Quality Car Rounds but provided more specific detail and what is required to improve the experience for patients and parents.

7. Research and clinical trials

Patients at RMCH have access to all Phase III clinical trials open in the UK. Recruitment to the NCRN portfolio trials exceeded the targets set by Greater Manchester Cancer Research Network. The MDT produces a report annually on clinical trials for discussion which is provided below.

- All available national portfolio trials are open at this PTC.
- Recruitment continues to be excellent year on year.
- No remedial measures are required this year.

Table 5. Oncology screening and recruitment data

Trial	2013									2014			Total for Apr2013 - Mar2014	Total number on trial
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar		
Phase III														
EuroEwings 99					1								1	39
EuroEwings 2012												1	1	1
EuroNet PHL-LP1												1	1	1
IMPORT				1	1	1				1		1	5	5
HR NB			1									1	2	32
SIOP CNS GCT II				1							1		2	2
SIOPEL 6													0	3
NRST 2005							1		1				2	20
RMS2005					1	1					2	1	5	36
CLIMB LDE225													0	0
Phase I/II														
Bernie					1								1	2
Herby													0	1
BEACON									1			1	2	2
VIT-0910													0	3

Table 6. Leukaemia screening and recruitment data

Trial	2013									2014			Total for Apr2013 - Mar2014	Total number on trial
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar		
Phase III														
ALLR3	1						1						2	23
Interfant-06								1					1	7
UKALL2011	1 (1 PD)	5	1	2 (1 PD)	1 (1 PD)	2 (2 PD)	1	1		1	3 (1 PD)	5 (2 CD)	23	34
Phase I/II														
AT9283 (Leukaemia)					1	(1 CD)							1	1
Dasatinib in Phil +ve ALL													0	0
PCV13 in ALL							1	1	2		4		9	9

8. Innovation in clinical practice

Manchester, with the partnership of the Christie NHS Trust and Royal Manchester Children's hospital, was successful in becoming one of two sites for Proton radiotherapy in the UK. This service will have enormous implications for the childhood cancer pathway in terms of activity, national profile and further innovative service development, but importantly will allow this therapy for the patients on the pathway locally rather than the current practice of travelling to the USA.

9. The Pathway Board

9.1. 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. Due to Central Manchester University Foundation Trust being the specialist centre for children's cancer, the members of the Children's Pathway Board are mainly representative of specialist working within the Royal Manchester Children's Hospital, with a representative from East Lancashire NHS Foundation Trust, one of the POSCU units, being invited to attend future meetings.

The Terms of Reference for the Board, was discussed at the first meeting and were agreed by members and can be found in the appendix.

9.2. Membership

The membership of the Pathway Board and the Clinical Subgroup is attached below, however the Pathway Board still requires patient/carer representation. This will be supported by Manchester Cancer who has been working with Macmillan Cancer Support to develop its approach to the involvement of people affected by cancer in its work. The outcome of this will be the development of a framework of the involvement of people affected by cancer which will be produced later in the summer. Manchester Cancer has also developed strong relationships with the Macmillan GP's and it is anticipated that this will support the recruitment of a primary care representative.

Table 7. Children’s Cancer Pathway Board representatives

Pathway Board Member	Profession/specialty	Trust/organisation
Dr Bernadette Brenn	Chair- Children’s Cancer Pathway Clinical Lead	RMCH
Dr Guy Makin	Senior Lecturer in Paediatric Oncology	RMCH
Dr John Grainger	Consultant Paediatric Haematologist	RMCH
Chris Lowe	Key Worker/Macmillan N	RMCH
Heather Houston	Paediatric Cancer Quality Manager	RMCH
Sue Crook	Modern Matron for Paediatric Oncology/Haematology	RMCH
Susan Kafka	Senior Clinical Pharmacist for Paediatric Oncology/Haematology	RMCH

9.3. Meetings

To date there has been one meeting. Meetings are scheduled every 4 months, with the next meeting is scheduled to take place on the 1st August, and as such there are no approved minutes.

10. Progress and challenges to date

Good Practice/Significant achievements for PTC/CCN

Patient satisfaction survey- Overall satisfaction was high with 61% of respondents rating the overall experience as excellent and 31% rating it as very good. 90% would recommend the unit to either friends or family,

2 new Paediatric Oncology Consultants have been appointed and started in the last year.

Consultant chemotherapy/treatment clinics

No delays in patient diagnosis and treatment

No breach of Cancer Targets for treatment

No refusal/transfer of cancer patients to neighbouring PTCs

All major tumour resection performed by 2 Oncology surgeons.

Continued to recruit patients into clinical trials with a projection of the highest recruitment by the PTC since 2004/5.

Well designed unit which facilitates good communication and good patient flows

Designated Teenage Facilities supported by Teenage Cancer Trust

Excellent junior medical cover which provides continuity of medical care

DVD following patient journey developed in response to 2011 – 2012 patient feedback identifying lack of age appropriate information

Participation in CLIC Sargent keyworker role national project

Improvement and extension to ward treatment room and drug preparation room

Appointment of MDT Co-ordinator to free up Paediatric Cancer Services Quality Manager

Validated self-assessment continues at a very high percentage at 97.2% in 2013/2014 assessment.

Challenges

Lack of compliance for nursing establishment within the context of children's cancer measures

Lack of compliance in the number available for 'other staff' within the context of the cancer measures.

Good Practice/Significant Achievements for diagnostic and late effects MDTs

100% achievement of the 31 day HSC cancer target throughout 2012/13

No refusal/transfer of new cancers to neighbouring PTCs

All new cancer patients are discussed at the MDT meeting

Patients have access to all Phase III clinical trials open in the UK

2 new members of Core Team, Paediatric Oncologists, one of whom is lead for neuro-oncology and has contributed significantly to the management of CNS tumours.

Recruitment to NCRN portfolio trails exceeded targets set by GMCN

All members have attended the Advanced Communication Course

100% Electronic data capture of MDT on the Avon and Somerset Cancer database

Increased personnel to support the operation of the MDT by appointment of dedicated MDT Co-ordinator, taking the role from the Paediatric Cancer Quality Manager.

Clear transition from follow up at RMCH to adult's late effects clinic at The Christie.

Strong service provided for patients for all late effects including endocrinology.

Clear pathway for referral to late effects MDT at end of treatment.

High level of patient satisfaction on patient surveys

Patients have access to all Phase III clinical treatment trials open in the UK which includes collection of follow up data and late effects outcomes

Self assessment continues to be excellent at 93 % and 100 % respectively

11. Vision and objectives

Outline here the agreed vision of the Pathway Board and introduce its objectives for 2014/15 and beyond. Append the latest version of the Board's 2014/15 annual plan.

- All childhood cancer patients have access in a timely manner to the childhood cancer pathway for diagnosis and treatment preventing perceived/real delays in this process
- All patients to have access to all available phase III therapeutic trials, and at relapse available phase II and I trials even if outside the PTC
- All patients to have an excellent patient experience on the pathway
- Improvement in outcome,- survival, quality of survival and the prevention/reduction of the late effects of treatment

• **Appendix 1 – Pathway Board Terms of Reference**

Children’s Cancer Pathway Board

Terms of Reference

These terms of reference were agreed on (*to be agreed at next meeting*) by Dr Bernadette Brennan, Pathway Clinical Director for Children’s Cancer, 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.

The Pathway Board

The Children’s Cancer Pathway Board is a cancer care specific board with responsibility to improve cancer outcomes and patient experience for local people across Greater Manchester and areas of Cheshire (a catchment population of 3.2 million). This area is synonymous with the old Greater Manchester and Cheshire Cancer Network area.

The Pathway Board is led by a Pathway Clinical Director and is formed of a multidisciplinary team of clinicians and other staff from Royal Manchester Children’s Hospital and representatives of Shared Care Units that are involved in the delivery of children’s cancer care in the North West region. The Pathway Board also has membership and active participation from primary care and patients representatives.

The Children’s Cancer Pathway Board reports into and is ultimately governed and held to account by the Greater Manchester Cancer Services Provider Board.

Greater Manchester Cancer Services Provider Board

The Greater Manchester Cancer Services 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).

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;

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

Purpose of the Pathway Board

The purpose of the Pathway Board is to improve cancer care for patients on the North West region's children's 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 children living in the north west 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. (*not applicable*)

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

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.

Role of the Pathway Board

The role of the Children's Cancer Pathway Board is to:

Represent the North West Cancer Services professional and patient community for children's cancer.

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

Gain approval from the Greater Manchester Cancer Services Provider Board for the programme of work and provide regular reporting on progress.

Design and implement new services for patients where these progress the objectives of specialist commissioners and Greater Manchester Cancer Services, can be resourced, and have been shown to provide improvements in outcomes that matter to patients.

Ensure that diagnosis and treatment guidelines are agreed and followed by all teams in provider trusts, and are annually reviewed.

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.

Promote and develop research and innovation in the pathway, and have agreed objectives in this area.

Monitor performance and improvements in outcomes and patient experience via a pathway scorecard, understanding variation to identify areas for action.

Escalate any clinical concerns through provider trusts.

Highlight any key issues that cannot be resolved within the Pathway Board itself to the Medical Director of Greater Manchester Cancer Services for assistance.

Ensure that decisions, work programmes, and scorecards involve clearly demonstrable patient participation.

Share best practices with other Pathway Boards within Greater Manchester Cancer Services.

Contribute to cross-cutting initiatives (e.g. work streams in living with and beyond cancer and early diagnosis).

Discuss opportunities for improved education and training related to the pathway and implement new educational initiatives.

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.

Membership principles

All member organisations of Greater Manchester Cancer Services will have at least one representative on the Pathway Board unless they do not wish to be represented.

Provider trusts not part of Greater Manchester Cancer Services can be represented on the Pathway Board if they have links to the Greater Manchester children's cancer pathway.

All specialties and professions involved in the delivery of the pathway will be represented.

The Board will have at least one patient or carer representative within its membership

One professional member of the Pathway Board will act as a Patient Advocate, offering support to the patient and carer representative(s).

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).

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.

These named leads will link with wider Greater Manchester Cancer Services Boards for these areas where they exist.

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).

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.

Each member will have a named deputy who will attend on the rare occasions that the member of the Board cannot.

Frequency of meetings

The Children's Cancer Pathway Board will meet every four months.

Quorum

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

Communication and engagement

Accurate representative minutes will be taken at all meetings and these will be circulated and then validated at the next meeting of the Board.

All minutes, circulated papers and associated data outputs will be archived and stored by the Pathway Clinical Director and relevant Pathway Manager.

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

Representatives from all sections of the Greater Manchester Cancer Services professional body will be invited to these events, as well as patient and public representatives and voluntary sector partners.

An annual report will be created and circulated to the Medical Director of the Greater Manchester Cancer Services Provider Board by 31st July of each calendar year.

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 Greater Manchester Cancer Services website once this has been developed.

Administrative support

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

12. Appendix 2 – Pathway Board meeting attendance

Children's Cancer Attendance Sheet			
Pathway Board Member	Profession/specialty	Trust/organisation	Meeting dates 2014/15
			28th March
Dr Bernadette Brenn	Chair- Children's Cancer Pathway Clinical Lead	RMCH	
Dr Guy Makin	Senior Lecturer in Paediatric Oncology	RMCH	
Dr John Grainger	Consultant Paediatric Haematologist	RMCH	
Chris Lowe	Key Worker/Macmillan N	RMCH	
Heather Houston	Paediatric Cancer Quality Manager	RMCH	
Sue Crook	Modern Matron for Paediatric Oncology/Haematology	RMCH	
Susan Kafka	Senior Clinical Pharmacist for Paediatric Oncology/Haematology	RMCH	

13. Appendix 4 – Paediatric Oncology Work Programme 2013-14

Category	Aims	Action	Measure Number	Target Date	Progress to Date
Service Improvement and Development	Continue to support and develop POSCUs	<ul style="list-style-type: none"> Continue to work with Network to support RMCH in agreeing working arrangements. Continue to implement shared care pathways with Network and established POSCU centres 		August 2014	ALL POSCUS undergone validation
	Robust system in place to gain patient experience feedback which meets requirements of Cancer Measures to inform required service improvements	<ul style="list-style-type: none"> Work with the Trust PPI group and informatics to develop patient feedback electronic tools Review progress of CLIC Sargent Key Worker project. Continue participation in Improving Quality programme 		<ul style="list-style-type: none"> December 2013 Ongoing Ongoing 	
Facilities	Occupancy of oncology beds will be monitored to ensure guidance requirements are met.	Ongoing audit of oncology bed usage.	11-7B-113 11-7B-115	Ongoing	

	Effective and safe use of Ward treatment room and drug preparation room	Proposal for reconfiguration and extension of current rooms submitted.		September 2013	Work to commence 09/09/13
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Workforce	Nursing establishment will meet requirements of Cancer Measures and shortages will be addressed	<ul style="list-style-type: none"> • Modern Matron to attend agreed forum on daily basis to discuss workforce issues and escalate identified concerns • Further nursing workforce review undertaken by Divisional Lead Nurse for Education and Workforce in conjunction with Modern Matron awaiting consideration and outcome from senior management Team. • Submit proposal for Education Practitioner to deliver training within PTC to ensure nursing staff remain compliant with training requirements and maintain appropriately skilled workforce 	11-7B-125	Ongoing December 2013	Workforce paper submitted May 2013
Patient and carer feedback and Involvement	Ensure all patients and carers are aware of identity and role of key worker	<ul style="list-style-type: none"> • Notify all patients verbally and in writing via business card and information leaflet • Compile Ward notice board with support information for parents /carers including information on keyworker role • Include keyworker role within relevant education sessions delivered to nursing staff • Record keyworker name in medical and nursing notes • Audit representative sample of 15 patients regarding identity of keyworker • CLic Sargent Nurse Specialist will participate in national keyworker project 		October 2013 September 2013 Care of Child with Cancer Course – Sept 2013 September 2013 December 2013 Ongoing	
	Improve meals service and overall provision of nutrition to patients	<ul style="list-style-type: none"> • Utilise Improving Quality programme to identify issues and potential solutions • Participate in work being undertaken by 		December 2013	

		Sodexo and Facilities matron to improve food service			
	Improve parent /carers knowledge and understanding of unwell patient pathway	<ul style="list-style-type: none"> • Develop information leaflet on unwell patient pathway regarding process when attending Paediatric Emergency Department • Undertake audit of waiting times in PED for unwell patients over one month 		October 2013 December 2013	

14. Appendix 4 – Pathway Board Annual Plan 2014/15

Children’s Cancer Pathway Board Annual Plan 2014-15

Pathway Clinical Director:	Bernadette Brennan
Pathway Board Members:	 Pathway Board membership.xls
Pathway Manager:	Melissa Wright
Date agreed by Pathway Board:	1 st August 2014
Date agreed by Medical Director:	
Review date:	1 st August 2015

Summary of objectives

The Pathway Board should agree three to five objectives. Objectives should be specific, measurable, achievable, relevant and time-bound. The timeline for achievement of objectives can extend beyond 2014/15 but the Pathway Board should be clear on what progress will be made within the year.

The agreed objectives should be summarised here and expanded upon in the following pages. The summary should also outline the alignment of these objectives to those of the Manchester Cancer Provider Board outlined in the appendix.

No	Objective	Alignment with Provider Board objectives
1	To establish a strategic framework for Primary Treatment Centre (PTC)	1-year SURVIVAL
2	To develop robust systems to identify shortcomings in patient experience	Patient EXPERIENCE
3	To improve patient outcomes through recruitment into clinic research and trials	RESEARCH and INNOVATION
4	To increase timely access of new cancer patients to PTC	1-year SURVIVAL Patient EXPERIENCE

Objective 1: To establish a strategic framework for Primary Treatment Centre (PTC)

Objective:	To work within the Manchester Cancer and the Strategic Clinical Network Frameworks to develop the work programme of the Pathway Board
Rationale:	It will be important for the PTC to work within the framework of Manchester Cancer to ensure it is engaged with the wider aims and objectives for cancer services within Greater Manchester. Equally it will be important to engage with the SCN to ensure that work within the shared care units is implemented
By (date):	August 2015
Board measure(s):	
Risks to success:	Involvement/engagement of required stakeholders
Support required:	Manchester Cancer and the SCN to develop working relationships to support cancer services within wider geographical regions.

The programme of work through which the Pathway Board will achieve the objective should be outlined below. This can take whatever form the Pathway Board considers appropriate. Two suggested formats are provided.

Work programme		
Action	Resp.	By (date)
Representatives of Manchester Cancer to be identified with lead responsibilities	BB	August 2014
Recruitment of members to represent all of the pathway	BB/MW	December 2014
Recruitment of members to reflect POSCU's	BB	December 2014

Objective 2: To develop robust systems to identify shortcomings in patient experience

Objective:	To improve patients experience of care in line with local and national initiatives
Rationale:	Improve patients' experience of care and their ability to self-manage. To ensure that the specific requirements of children and their carers' are reflected in the delivery of services.
By (date):	On-going
Board measure(s):	Local patient experience surveys
Risks to success:	Slow process to implement outcomes across Trust Lack of patient representative
Support required:	Manchester Cancer will need to ensure that processes to assess and support the understanding of patient experience reflect e needs of children and their carers'.

The programme of work through which the Pathway Board will achieve the objective should be outlined below. This can take whatever form the Pathway Board considers appropriate. Two suggested formats are provided.

Work programme		
Action	Resp.	By (date)
Work with the Trust PPI group to develop patient feedback electronic tools	BB	February 2015
Review progress of CLIC Sargent Key Worker project	BB	February 2015
Investigate with POSCU's their methods of assessing patient experience	MW	December 2014
Develop a process of collating patient experience across PTC and POSCU's	MW/BB	February 2015
Continue participation in Improving Quality programme	BB	On-going

Objective 3: To improve patient outcomes through recruitment into clinic research and trials

Objective:	Enhance recruitment of patients to clinical trials
Rationale:	All patients should be offered the opportunity to participate as this improves their experience
By (date):	On-going
Board measure(s):	Regionally provided trial figures
Risks to success:	The risk to this objective will be lack of availability of appropriate trials. This will be mitigated by the research lead working with the Clinical Research Network to understand when trials will be available.
Support required:	The Clinical Research Network to provide data on trial activity

The programme of work through which the Pathway Board will achieve the objective should be outlined below. This can take whatever form the Pathway Board considers appropriate. Two suggested formats are provided.

Work programme		
Action	Resp.	By (date)
Regular presentation of figures at meetings	BB	On-going
Areas of low uptake to be discussed with lead clinicians	Research Lead	On-going
Work with the Clinical Research Network to reduce any identified imbalance	Research Lead	On-going

Objective 4: To increase timely access of new cancer patients to PTC

Objective:	This objective will identify any issues in regards to suspected cancer referrals via the 2 week wait process.
Rationale:	To provide consistency and equity of service and to assess whether education and engagement with primary care is required.
By (date):	1 year
Board measure(s):	2 week wait referrals
Risks to success:	Access to contemporaneous data
Support required:	Manchester Cancer will need to support the Pathway Board in engaging a GP representative to support the understanding of issues regarding HSC205 referrals.

The programme of work through which the Pathway Board will achieve the objective should be outlined below. This can take whatever form the Pathway Board considers appropriate. Two suggested formats are provided.

Work programme		
Action	Resp.	By (date)
To regularly review patients referred via 2 week wait and conversion rates in Greater Manchester	Pathway Board	On-going
To develop a process for identifying conversion rates for POSCU Trusts	MW	December 2014
To work with GP representative to identify any primary care education requirements regarding referral	Pathway Board	On-going

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