Manchester Cancer

Children's Pathway Board

Constitution

July 2014

Review date: July 2015

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1. 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.

In general, Manchester Cancer Pathway Boards directly replace the network site specific groups that were in place under the old cancer network. In children's cancer however there was previously a Children's Cancer Network Coordinating Group (CCNCG) administered by the specialised commissioners rather than the cancer network and chaired by a specialised commissioner. This group has ceased to meet but the Greater Manchester children's cancer service continues to be configured in the same way and overseen by the Primary Treatment Centre. While the Manchester Cancer Pathway Board has begun meeting, there have been no discussions with regard to it taking on the full role and constitution of the CCNCG.

As such, this is a transitional constitution document based on the Pathway Board's terms of reference and the peer review documentation of the Primary Treatment Centre. In July 2015 every Manchester Cancer Pathway Board will publish a full constitution alongside its annual report and work plan for the year ahead and we hope to have the Children's Pathway Board's position clarified by this time.

2. CONFIGURATION

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

2.1 PTC configuration of MDTs (Measure 14-7A-101)

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).

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 patients 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 Children's Hospital are multiprofessional 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 MDTs

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

2.2 Shared care configuration (Measure 14-7A-102)

Paediatric oncology services are provided by the designated Principal Treatment Centre, Royal Manchester Children's Hospital, providing tertiary care for children with leukaemia and solid tumours. The catchment area of Royal Manchester Children's Hospital includes Greater Manchester and Cheshire Cancer Network and Lancashire and South Cumbria Cancer Network covering a population of 4.6 million.

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

The configuration of paediatric oncology services was described within the North West Specialised Commissioning Group's IOG implementation summary (December 2007) which was subsequently approved by the Department of Health in 2008.

2.3 Medical Cover Arrangements (Measure 14-7A-107)

The PTC's role in medical cover has been agreed. It will provide 24 hour advice to the POSCUs via 24 hours consultant haematology/oncology on call rota at RMCH PTC.

It is policy that the On-call rota for the oncology/haematology service at Royal Manchester Children's Hospital ensures the following:

- it should be staffed wholly by named consultants, each of whom is a paediatric oncologist employed at the PTC and providing inpatient care as a part of their timetable during normal working hours
- it provides 24/7 cover
- the on-call individual should be available for giving advice to enquiring clinicians regarding paediatric oncology patients being managed anywhere in the Children's Cancer Network, whether in hospital or in the community
- the on-call individual should be available to attend hospital facilities of the PTC when required
- there should be a minimum of five individual consultants

The oncology/haematology service at the Royal Manchester Children's Hospital provides resident 24/7 cover at a minimum of ST3 level.

2.4 Oncology and chemotherapy training programme (Measure 14-7A-108)

It is policy that staff who are not on the authorised list of chemotherapy administration may administer chemotherapy only as part of their training and assessment, in the presence of authorised staff.

There is a chemotherapy administration course and competency programme provided by the PTC for all staff in the CCN undertaking chemotherapy administration, including agreed part of the programme for medical staff and the low risk training programme.

2.5 Training and qualifications for staff in the 24-hour Telephone Advice Service (Measure 14-7A-109)

Ward 84 at the PTC provides a 24 hour telephone advice service for patients and their carers. Advice is available via the ward 24 hours a day, 7 days a week, every day of the year.

The single point of contact for patients/carers is Tel: 0161 701 7489 and this is distributed to parents with the discharge information together with instructions outlining the steps to follow if their chid is unwell. The contact person for each shift is an identified member of senior nursing staff on the inpatient ward or within the Day Case Unit of the PTC, who administer the staff rota. It is this staff members' responsibility to contact the consultant on call if and when necessary. The consultant on-call will be available to provide advice 24/7 to staff, parents and carers as required.

Information and instructions are available for nursing staff to assist in telephone assessment of the unwell child. The identified nurse undertaking the assessment and providing advice is a registered nurse who has worked within paediatric oncology for a minimum of two years and is IV and chemotherapy competent. The nurse in charge of the ward, resident medical staff and consultant staff are also available to give advice to staff, parents/carers and patients.

3. LEADERSHIP

3.1 Chemotherapy leadership (Measure 14-7A-110)

It has previously been agreed, in consultation with the lead cancer clinician of the Manchester Children's Hospital, that Bernadette Brennan is the single named head of service for chemotherapy for the PTC.

This named individual has a regular involvement in the use of chemotherapy in paediatric haematology and oncology as part of their list of responsibilities or work plan as well as their specific duties as head of service.

The responsibilities of the Chemotherapy Head of Service for the PTC are outlined below, as required by the Children's Cancer Measures. These responsibilities have been agreed.

- To form the PTC Paediatric Chemotherapy Group (PCG) with appropriate representation
- To chair the PTC Paediatric Chemotherapy Group
- To co-ordinate issues for the safe delivery of chemotherapy in accordance to the Manual of Cancer Services 2008: Children's Cancer Measures
- To oversee the development of appropriate guidelines and policies in accordance with the Manual of Cancer Services 2008: Children's Cancer Measures
- To ensure representation and liaison with the PTC Medicines Advisory Committee (MAC)
- To liaise with the regional bodies and their relevant groups regarding Chemotherapy issues
- To oversee the development of electronic chemotherapy prescribing systems for Paediatric Haematology and Oncology throughout the region
- To develop a comprehensive chemotherapy library of 1st and 2nd line chemotherapy treatments for use in Paediatric Haematology and Oncology and to ensure that these are approved by MAC for clinical use
- To agree appropriate funding arrangements with the CCGs for the TVCN for Paediatric chemotherapy services

3.2 Regional leadership (Measure 14-7A-103)

There is no longer either a formal Children's Cancer Network or a CCNCG. The Manchester Cancer Pathway Board is led by Dr Bernadette Brennan, who is also the lead for the PTC at RMCH. She has dedicated time through Manchester Cancer to carry out this role in line with the Pathway Director role description.

3.3 The Pathway Board Terms of Reference (Measure 14-7A-105)

The Pathway Board has adopted the generic Terms of Reference.

These terms of reference were agreed on XXXXX 2014 by XXXXX, Pathway Clinical Director for Manchester 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 all of hospital trusts that are involved in the delivery of children's cancer care in Greater Manchester. 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 Greater Manchester 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 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.

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 Greater Manchester 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 Greater Manchester's cancer commissioners and 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 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 two 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.

2.5 Pathway Board Membership (Measure 14-7A-104)

PATHWAY BOARD MEMBER	PROFESSION/SPECIALITY	TRUST/ORGANISATION
Dr Bernadette Brennan	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	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

4. PATHWAYS AND 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.

4.1 Clinical guidelines (Measure 14-7A-111), Chemotherapy guidelines (Measure 14-7A-112) and agreed chemotherapy regimens (Measure 14-7A-113)

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Diagnosis and Staging Protocol

Introduction

All suspected cancers are referred to the PTC for initial diagnosis and assessment. It is recognised that some cases will have had some initial investigations at the POSCU/district general hospital and may have had a biopsy of for example a neck node demonstrating lymphoma.

All results will be communicated verbally to the patient as applicable and their parents by the Consultant Haematologist/Oncologist the patient is admitted under and her/his medical team. The results will also be communicated in the patient's permanent record of the diagnosis, treatment options and plan

Acute Leukaemias - Initial investigations

- FBC and blood film,
- CXR
- Biochemical profile

Further details of the investigations and assessment are detailed in the following protocols depending on the leukaemia type:

HAEMATOLOGY PROTOCOLS	
	UKALL 2003
	ALL R3
	AML 17
	Relapsed AML 2001/01
LK 2006 10	**Interfant 06**
	EsPhALL
	Management of MDS
	Management of CML

Non CNS Solid Malignant Tumours- Initial investigations

- FBC and blood film
- CXR
- Biochemical profile
- Tumour Markers
- Coagulation profile
- U/S of primary site
- CT/MRI primary site

Further details of the investigations and assessment are detailed in the following protocols depending on the tumour type :

LT 2004 09	**SIOPEL 4 – HIGH RISK HEPATOBLASTOMA**
LT 2007 03	**SIOPEL 6 – STANDARD RISK HEPATOBLASTOMA**
Pfizer Study	**IRINOTECAN with TEMOZOLOMIDE – Phase 11**
NB 2000 09	**UNRESECTABLE NEUROBLASTOMA**
NB 2002 06	**HIGH RISK NEUROBLASTOMA**
LCH 2006 02	**HLH-2004**
GC 2005 04	**GERM CELL (GC-3)**
NHL 2000 06	**ALCL – ANAPLASTIC LARGE CELL LYMPHOMA**
NHL 2004 08	**EURO – LB 02**
	GUIDELINES FOR B cell NHL
	HODGKINS GUIDELINES –Lymphocyte Predominant
HD 2007 10	**EuroNet PHL-C1 (Classical Hodgkin's)**
STS 2006 04	**RMS 2005 – Non-Metastatic Rhabdomyosarcoma**
STS 2006 03	**EpSSG – NRSTS 2005 – Localised Non-Rhabdomyosarcoma**
ET 2000 03	**EURO EWINGS 99**
RB 2005 11	**RETINOBLASTOMA**
WT 2002 01	**SIOP WILMS**
OS 2005 10	**EURAMOS - OSTEOSARCOMA**

Paediatric Endocrine Tumour Guidelines
October 2005
Guidelines on the management of adrenocortical tumours (ACT) and adrenocortical carcinoma (ACT)
June 2007 version 2.0
Guidelines for the investigation and management of nasopharyngeal carcinoma
June 2007 version 3.0

Guidelines for the Investigation and Management of Melanoma
March 2004 / Version 2

Metastatic Rhabdomyosarcoma (RMS) – Treatment Recommendations
26/01/2010 - Version 3.0

CNS tumours - Initial investigations

- CT scan
- MRI head and spine
- Tumour markers

Further details of the investigations and assessment are detailed in the following protocols depending on the tumour type:

SIOP CNS GERM CELL GUIDEINES 09/03/06	
MEDULLOBLASTOMA FOLLOWING CLOSURE OF HIT-SIOP PNET 4 - GUIDELINES	
RELAPSED EPENDYMOMA	
LOW GRADE GLIOMA 2	
CNS 2007 04	**TEMOZOLOMIDE WITH RADIOTHERPY IN DIFFUSE PONTINE GLIOMA**
CNS 2007 09	**INFANT EPENDYMOMA**

Guidelines for the treatment of High Risk Medulloblastoma for children more than 3 years old
March 2010

Revised neuro-radiological guidelines
January 2009

High Grade Glioma
22nd November 2007 Version 2.0

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Leukaemias

The management of the individual acute (ALL and AML) leukaemias are covered comprehensively in the following protocols which also gives guidance on the indications for bone marrow transplantation.

HAEMATOLOGY PROTOCOLS	
	UKALL 2003
	AML 17
LK 2006 10	**Interfant 06**
	EsPhALL

Management of the chronic leukaemia CML is covered in the following treatment guidance

Guidelines for the Management of Chronic Myeloid Leukaemia in Children

August 2005/Version 1

Download (PDF 108kb)

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Lymphoma and Reticulo-Endothelial Malignancy

The management of individual lymphomas is covered comprehensively in the following protocols

	NHL 2000 06	**ALCL – ANAPLASTIC LARGE CELL LYMPHOMA**
	NHL 2004 08	**EURO – LB 02**
		GUIDELINES FOR B cell NHL
		HODGKINS GUIDELINES –Lymphocyte Predominant
HD 2007 10		**EuroNet PHL-C1 (Classical Hodgkin's)**

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- CNS Tumours

The management of individual CNS tumours is covered comprehensively in the following protocols

Guidelines for the treatment of High Risk Medulloblastoma for children more

than 3 years old

March 2010

Download (PDF 717 KB)

High Grade Glioma
22nd November 2007 Version 2.0
Download (Word 162kb)
Guidelines for the management of medulloblastoma following closure of the HIT-SIOP PNET 4 study.
February 2007
Download (Word 202kb)
Guidelines for the management of intracranial meningioma in children and young people

June 2007 version 1.0

	SIOP CNS GERM CELL GUIDEINES 09/03/06
CNS 2001 04	RELAPSED EPENDYMOMA
CNS 2004 03	LOW GRADE GLIOMA 2
CNS 2005 03	Phase 11 – HIGH DOSE METHOTREXATE
CNS 2007 04	TEMOZOLOMIDE WITH RADIOTHERPY IN DIFFUSE PONTINE GLIOMA
CNS 2007 09	INFANT EPENDYMOMA

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Sympathetic Nervous system Tumours

The management of the individual Sympathetic Nervous system Tumours

is covered comprehensively in the following protocols

12	**NB 2000 09**	**UNRESECTABLE NEUROBLASTOMA**	**09/02/07**
13	**NB 2002 06**	**HIGH RISK NEUROBLASTOMA**	
14	**NB 2006 05**	**TVD – PHASE 11**	**06/10/09**

Guidelines for Therapy of Patients with Relapsed High Risk Neuroblastoma Following High Dose Myeloablative Therapy
February 2010
Download (PDF 38kb)
Unresectable Localised Neuroblastoma Study
9th February 2007
Download (Word 34.5kb)
UKCCSG Infant Neuroblastoma Study (UKCCSG NB 9903)
June 2004
Download (PDF 19.4kb)

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Retinoblastoma

The management of the individual RetinoblastomaTumours

is covered comprehensively in the following protocols

Retinoblastoma Group
- Guidelines for the management of children with Intraocular Retinoblastoma I Chemotherapy
Version 2 - October 2008
Download (PDF 218kb)
- Guidelines for the management of children with Intraocular Retinoblastoma II Second line Chemotherapy
January 2008
Download (PDF 138kb)

34	**RB 2005 11**	**RETINOBLASTOMA**	**27/07/09**

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Renal Tumours

The management of the individual Renal Tumours

is covered comprehensively in the following protocols

STS 2006 03	**EpSSG – NRSTS 2005 – Localised Non-Rhabdomyosarcoma- For Malignant Rhabdoid tumoursof the Kidney**
WT 2002 01	**SIOP WILMS**

Renal Tumours Group
Best Practice Document for Wilms tumour surveillance in at-risk individuals
April 2005
Download (PDF 154kb)

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Liver Tumours

The management of the individual Liver Tumours

is covered comprehensively in the following protocols

LT 2004 09	**SIOPEL 4 – HIGH RISK HEPATOBLASTOMA**	**20/08/09**
LT 2007 03	**SIOPEL 6 – STANDARD RISK HEPATOBLASTOMA**	

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- Malignant Bone and Soft Tissue Tumours

The management of the individual Malignant Bone and Soft Tissue Tumours

is covered comprehensively in the following protocols

STS 2006 04	**RMS 2005 – Non-Metastatic Rhabdomyosarcoma**
STS 2006 03	**EpSSG – NRSTS 2005 – Localised Non-Rhabdomyosarcoma**
ET 2000 03	**EURO EWINGS 99**
OS 2005 10	**EURAMOS - OSTEOSARCOMA**
B020924	**BERNIE- metastatic RMS 2009**

Central Manchester University Hospitals NHS
NHS Foundation Trust

Measure 14-7A-111 The Clinical Management Protocol- any other maligancies

The management of the individual Tumours not covered by measure 09-7A-115 to 09-7A-122 i.e.

Rare Tumours is covered comprehensively in the following protocols/Guidelines

Rare Tumours Group
Guidelines for the Management of Melanotic Neuroectodermal Tumour of Infancy
August 2004/ Version 1
Download (PDF 161kb)
Guidelines for the management of intracranial meningioma in children and young people
June 2007 version 1.0
Download (Word 361kb)
Guidelines on the management of adrenocortical tumours (ACT) and adrenocortical carcinoma (ACT)
June 2007 version 2.0
Download (Word 452kb)
Paediatric Endocrine Tumour Guidelines(Please note that the ACT guidelines contained in this document have been updated - see Version 2.0 June 2007 above)
October 05
Download (PDF 3.8mb)
Guidelines for the investigation and management of nasopharyngeal carcinoma
June 2007 version 3.0
Download (Word 877kb)
Guidelines for the Investigation and Management of Melanoma
March 2004 / Version 2
Download (PDF 70 kb)
Pancreatic Tumours
June 2003/ Version 1
Download (PDF 169kb)

4.2 Guidelines for psychosocial assessment (Measure 14-7A-114)

Children's Cancer Clinical and Supportive Care Protocols
7A-114 – Psychosocial Assessment Guidelines

Scope of the Guidelines

This document provides guidance for the implementation of Psychosocial Needs Assessments for Children and Young People with Cancer and their families/carers who are under the care of the designated Principal Treatment Centre (PTC), Central Manchester University Hospitals NHS Foundation Trust (CMFT) and the Paediatric Oncology Shared Care Unit (POSCU), which are part of the Greater Manchester and Cheshire Cancer Network and the Lancashire and South Cumbria Cancer Network. The policy is for children up to the age of 16. A separate protocol is provided for the 16 – 24-year-old (TYA) age group by the Young Oncology Unit at the Christie Hospital, Manchester.

Guidance **(Cancer Measures, 2008)**
09 - 7A - 141 The Children's Cancer Network (CCN), in consultation with the Multi Disciplinary Team (MDT), should agree CCN-wide guidelines for psychosocial assessment of patients and carers.

Definition

The NICE Improving Outcomes Guidance for Children and Young People with Cancer (2005) defines psychosocial care as the psychological and social supportive care for a child or young person and his/her family during active cancer therapy, long-term follow-up and palliative care, as well as for families after bereavement, and includes respite care.

This guidance follows the recommendations that;

- All families should be offered the advice and support of a social worker
- They should have access to expert psychological support
- There should be a structured psychosocial assessment at significant points throughout the care pathway
- Assessment of information needs should be included
- There should be access to neuropsychological services for cognitive assessment, particularly for those with CNS tumours
- Appropriate training and support should be provided to all members of the MDT
- All families should be offered benefit advice

The guidelines set out the expected standard required to ensure a high-quality and consistent approach to assessment of psychosocial support needs of children, young people with cancer and their families. Improving Outcomes Guidance (IOG 2005) and the Children's Cancer Network Co-ordinating Group (CCCNG, 2008) agree that support needs are highly individual and will change at different stages along the patient pathway. The provision of psychosocial care is complex and requires multi-professional collaboration to be effective.

This policy also supports the introduction of a Key Worker approach (More Than My Illness, 2009). The Key Worker role may be carried out by a number of practitioners from different disciplines. To ensure consistency and clarity, this role and the associated responsibilities will be clearly articulated and written information made available to families to ensure expectations are met. The Key Worker role is currently undertaken by the Macmillan Specialist Practitioners.

Guideline statements

The multi-professional approach taken for the assessment of children and young people with cancer ensures that various domains are assessed by those with the most appropriate skills and reduces repetition for families. A summary of specific additional needs identified in these assessments (e.g. those requiring referral on) is presented at the psychosocial MDT meeting.

The psychosocial MDT is responsible for agreeing an action plan for supporting the additional psychosocial needs of the patient and the family/carer.

Frequency of psychosocial assessment

IOG 2005 stipulates that assessments must be structured and must be carried out at significant points during the care pathway, in particular:

- At diagnosis
- During treatment
- At end of treatment
- During long-term follow-up
- At any point where there is significant change or challenge to health and well-being, or when concern is expressed by the family or by other members of the wider MDT
- At relapse
- At the start of and during palliative care
- At bereavement

Assessments should be carried out in ***partnership*** with the patient, their family and other relevant carers, and should be experienced by families as building on previous discussions (rather than a repeated information-gathering exercise). Copies of the assessment should be available upon request to the family.

What should be included in the assessment?

IOG 2005 stipulates that, as a minimum, the following issues need to be considered:

- Information needs
    - Information is provided from diagnosis and throughout the cancer journey
    - Must be in different formats in terms of, e.g. language, age, disability
    - Leaflets/booklets are ratified by the MDT as suitable (e.g. factually correct, up to date, age appropriate)
    - We have a parents' support group (run by parents, facilitated by the Macmillan team) which meets once a month and provides information and social support direct to parents.

- Coping skills

    - These are assessed at the time of diagnosis.
    - Initial history taking and clinical assessments will gather significant past family experiences; wider family and friendship support networks; previous family members diagnosed with cancer; and other current significant issues affecting the family.
    - Future service improvements include the introduction of a tool to aid holistic needs assessment[1]. This will help teams:
        - facilitate a more consistent approach;
        - identify people who need help;
        - provide families with an opportunity to think about their needs with a health professional and to make a plan about how best to meet these;
        - help families self-manage their child's condition; and
        - help teams target support and care efforts and work more efficiently, by making appropriate and informed decisions.

- Practical support issues

    - Families often face many practical issues during the cancer pathway – e.g. increased travel costs/living away from home/being unable to work, etc
    - Many families will not ask for support, so it is vital that MDT members develop excellent professional relationships with the child/young person and family to ensure open communication of non-clinical pressures
    - The social workers formally assess practical needs and work with the child/young person and family to resolve such issues

- Social and cultural circumstances
    - Assessing the following is vital to improve the patient and family's cancer journey and ensure the appropriate support is in place:
    - Language/method of communication (children or other family members should not be used as interpreters)
    - Religion – so that patient and family's cultural and religious beliefs are respected
    - Any safeguarding issues/vulnerable adult issues
    - Any other health needs in the patient or other family member

- Education-related issues

    - Each child of nursery or school age who is diagnosed with cancer is entitled to an individual education plan

[1] (*Holistic Needs Assessment for people with cancer*, NCAT 2011)

- Children/young people can experience cognitive, behavioural, emotional and personality changes, whether due to brain/other CNS tumours or as a consequence of radiotherapy or chemotherapy treatment.
- Cognitive assessments by clinical psychologists with expertise in neuropsychology are recommended by government guidelines (IOG 2005, IOG 2006). They can guide schooling and help patients and families adjust to these changes.
- Neuropsychological testing will become a central part of determining health status in all CCLG CNS tumour trials.
- The Macmillan specialist practitioner will liaise with and visit a patient's school to ensure information is given and support is in place and to encourage the patient's continued attendance when well enough.
- The Macmillan specialist practitioner, together with the Oncology Unit teacher, will co-ordinate home tuition if required.
- The Oncology Unit has its own teacher and school room available during term time. The teacher will liaise with a patient's school and acquire curriculum work to ensure continuity of the patient's education (this can include negotiating the completion of exams in the hospital setting).

- Employment issues

  - One parent may become the main carer for the child/young person, which may affect their employment situation and financial capacity
  - The social worker will undertake a financial assessment at key points in the cancer journey. S/he will also apply for grants to support families
  - The key worker will send employer support letters (employers are more likely to be supportive with a greater understanding of the carer's needs)
  - The social worker will apply for DLA for the child/young person and carer's allowance

- Level 4 psychological support

Tier 4 psychological support is based around the template of 'tiered care' as now adopted in NICE (2004) Guidelines on Improving Supportive and Palliative Care for Adults with Cancer. The table below outlines the different tiers for support that have been adapted for the Psychosocial Care Pathway at RMCH.

Level	Oncology care professionals	Assessment	Intervention
1	The whole oncology psychosocial care team	Recognition of psychological needs	Effective information-giving, compassionate communication and general psychological support
2	Professionals with additional expertise, such as senior nursing staff, play specialists	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals such as Specialist Counsellors and Clinical Psychologists.	Assessed for psychological distress and diagnosis of some psychotherapy	Counselling and specific psychological interventions such as anxiety management and solution focussed therapy, delivered according to an explicit theoretical framework
4	Mental health specialists such as clinical psychologists, psychotherapists and psychiatrists	Mental health specialists assess complex psychological problems providing a specialist formulation/diagnosis to inform intervention.	Specialist psychological and psychiatric interventions delivered by mental health specialists to manage moderate to severe mental health problems e.g. CBT.
5	Psychosocial care co-ordinators such as consultant clinical psychologists	Management of psychosocial pathway for the whole oncology psychosocial care team	Includes supervision, management, clinical governance, quality assurance, research and teaching functions, staff support

Psychosocial MDT Meeting

The PTC will hold a weekly psychosocial MDT meeting. The purpose of this meeting is:

- To discuss patients' and families' psychosocial needs
- To agree appropriate action plans
- To act as the final common referral pathway for psychosocial support

Attendees at the Psychosocial MDT will include:

- Clinical Psychologists
- Play Specialists
- Physiotherapists
- School teachers

- Social work team
- Specialist Practitioners

Neuro-psychosocial MDT

The PTC will hold a weekly neuro-psychosocial MDT meeting. The purpose of this meeting is:

- To discuss patients with a new diagnosis of malignant brain tumours who are to receive ongoing chemotherapy treatment
- To discuss patients attending the out patient clinic for review or treatment
- To discuss patients with brain tumours who are currently receiving radiotherapy treatment at the Christie Hospital
- To discuss patients' and families' psychosocial needs
- To agree appropriate action plans
- To act as the final common referral pathway for psychosocial support

Attendees at the neuro-psychosocial MDT will include:

- Consultant oncologist
- Clinical Psychologists
- Neurosurgical specialist practitioners
- Nursing representative from the Paediatric Oncology out patients department
- Physiotherapists
- Social work team
- Specialist Practitioners

Access to Specialist Social Work (CMFT)

Children and young people (0 – 16 years) are referred to the regional specialist social work team at the point of a cancer diagnosis. A social worker will make contact within one week of referral to them. The family have to give consent to support from CLIC Sargent and a signed data protection form is required (Data Protection Act 1998) prior to a service. An assessment based on the Common Assessment Framework (DCSF 2004, CWDC 2007), which focuses on psychosocial need, is completed in partnership with the child/young person and family within 14 working days and a care plan agreed. These are formally reviewed at key points in the treatment journey and at points of significant familial change (see **Frequency of Assessment**). The assessment is completed in partnership with the child/young person and family, and a copy of the assessment is available to them upon request.

Referral Process

Referrals are accepted from:

- Psychosocial MDT meetings
- Social work attendance at ward rounds (main source of referrals)
- Individual referral from consultants/ward staff/specialist practitioners
- Self-referral by families
- Neurosurgical specialist practitioners

When to refer:

- Definite cancer diagnosis. (Allocation of patients takes place at the weekly meeting of the oncology social work team, Tuesday afternoon)

Social workers will assist in particular with the following:

- Child protection concerns
- Financial emergencies
- High levels of family stress/conflict
- Bereavement support
- Liaison with a range of agencies and service providers on behalf of the child/young person and their family – e.g. benefits agency, housing providers, employers.

Youth worker

Each young person aged 13+ will be introduced to the youth worker, who provides support on an individual or group work basis, based on need. The youth worker has a vital role to play in identifying and providing direct emotional support to individual young people during their treatment pathway, inpatient stays on the oncology unit and on completion of treatment. The youth worker is collaborative in her/his approach, working together with key members of the MDT. Supervision is provided by the CLIC Sargent Team Manager.

Access to Clinical Psychology Service

When a child, parent and/or family is experiencing considerable and intense emotional/behavioural distress and is referred to the clinical psychologist, an in-depth psychological assessment will be conducted. This will determine the therapeutic intervention required. A cognitive/neurological psychological assessment may also be indicated. Access to neuropsychological services for cognitive assessment will be provided, when appropriate, for all patients particularly those with CNS tumours, and also to guide schooling and career decisions.

If the MDT determines that a child/young person or family is presenting with psychological difficulties which are more complex (i.e. moderate to severe anxiety or depression) and such difficulties have not responded to interventions made by other members of the MDT, a referral can be made to the Clinical Psychologist for Paediatric Oncology.

Referrals are made via telephone consultation or at the Psychosocial MDT meeting. A formal letter or referral form is necessary for all patients.

Clinical Psychology Referral process

Written/telephone referrals accepted from:

- Consultants
- Macmillan specialist practitioners
- Psychosocial MDT members
- Ward nursing staff
- Neurosurgery specialist practitioner

When to refer:

Referral is indicated in situations where any of the following apply:

- The child and/or family are expressing significant psychological distress/disorder beyond what would be expected of a family in that situation
- The psychological problem(s) are related to the child's medical condition and are having a significant negative impact upon the child's health, treatment or quality of life
- When psychological or psychiatric assessment is important for decision-making around paediatric care
- Where psychological/neuropsychological assessment and intervention will be beneficial in the CYP late-effects follow-up and survivorship.

Where referrers are uncertain about the appropriate timing or situation of a referral, the clinical psychologist should be contacted by phone in the paediatric psychosocial department or at a Psychosocial Team meeting.

The psychologist will assess the appropriateness of the referral and signpost to alternative services if necessary. If the referral is accepted, the psychologist will send an appointment to the family to attend their outpatient clinic for a formal psychological assessment. If the patient is on the ward, the psychologist will telephone the ward to arrange a suitable time to see the family and/or child/young person. The psychological assessment will vary according to the presenting difficulties, age and specific needs of the family.
The assessment would typically comprise of:

- Clinical interview
- Behavioural observations
- Standardised psychological/neuropsychological assessment measures
- Liaison with MDT members who know the family

The psychologist will collate the assessment outcomes to develop a formulation, which is shared with the family and the MDT, with the patient's consent. If required, an appropriate evidence-based psychological intervention (e.g. CBT, family therapy, narrative therapy, and solution-focused therapy) will be undertaken and, where appropriate, progress will be monitored with follow-up sessions. Referrers will be informed of intervention outcomes in a formal letter.

Access to paediatric neuropsychology

Referrals for neuropsychology should be made via the MDT meeting and recorded formally within the MDT minutes. Agreed referral criteria are:

<u>Inclusion criteria</u>

- Cerebral hemisphere tumours with a high risk of neuropsychological impairment
- Children with severe neurological complications following treatment/s
- Children who have received radiotherapy or proton therapy
- Children and young people up to 19 years (for some patients aged 16 – 18 it may be more appropriate for their needs to be met by the adult neuropsychology service. Patients in this group will be considered on a case-by-case basis.)

<u>Exclusion criteria</u>

- Palliative care patients, unless specific neuropsychological concerns have a significant impact upon quality of life.

Discharge criteria

- Child/young person is neuropsychologically stable
- The child's needs are represented appropriately to other agreed agencies e.g. education.

Psychological support for siblings

The MDT provides sibling support through two sibling support groups. These groups are available to all siblings aged between 6 and 16 (younger group = 6 – 11, older group = 11+) after referral by oncology unit staff or parents. The groups, which are run by a play specialist together with play leaders and a health care assistant, each meet four times a year, sometimes for a day out at a theme park, for example, and sometimes meeting in a play environment at the hospital. The remit of the groups is to have fun, meet other children in a similar situation, share experiences, ask questions and take part in games and activities.

The MDT also has access to age-appropriate literature about the various conditions to support siblings and school friends about the child/young person's condition and treatment.

Siblings with psychological difficulties related to their brother or sister with cancer also have access to the clinical psychology service through a formal referral pathway.

Access to Paediatric Macmillan Specialist Practitioners/Key Workers

At diagnosis each child/young person and their family will be offered the support of one of the Macmillan Specialist Practitioner team who will undertake the role of K**ey Worker** in supporting, managing and co-ordinating their care.

Macmillan team referral process

New patients are identified on a daily basis (except weekends) through the hospital day process. Referrals are also accepted from

- Consultants/ward staff/clinic staff/BMTU
- Psychosocial team meetings
- Ward round
- Neurosurgical specialist practitioners

When to refer:

- At point of definite cancer diagnosis (allocation among team determined by geography)

Furthermore, staff can consult the Macmillan team regarding:

- Emotional support
- Sibling support
- School issues
- Families experiencing difficulty whilst awaiting a diagnosis
- Liaison with other health care professionals (hospital/community):
- Co-ordinating treatment at home
- At any point where there is a significant change to health and well-being, or when suggested by families, or other members of the wider MDT

- Relapse
- Symptom management in palliative care
- Bereavement support

The Macmillan specialist practitioner/Key Worker should be included in the initial consultation and be present when the diagnosis/prognosis and treatment plans are discussed with the child/young person and their family. This ensures the family have a contact that can explain and reiterate information. Psychosocial assessment is commenced at this time and built on throughout the formation of a positive working relationship. Assessment of needs would be an active and ongoing process.

The Macmillan specialist practitioner/Key Worker will identify and liaise with existing services involved and the available services in the community to ensure the child/young person and the family have structured, informed support provided in their local area.

Throughout their contacts, the Macmillan specialist practitioner/Key Worker will offer holistic support to the child/young person and family, either personally or by signposting to other services as deemed necessary.

Patients and families who require low-level interventions and support may receive this from either their Key Worker or their allocated social worker. Key Workers should be supported in the giving of psychosocial care by having access to clinical supervision.

Access to Oncology Physiotherapy

Referrals are accepted from:

- Medical staff
- Nursing staff (ward and clinic)
- Members of the oncology psychosocial team
- Parents/patients.

Patients may be treated in the following places:

- Oncology inpatient ward
- Oncology outpatient clinic
- Physiotherapy department/hydrotherapy pool
- Patient's own home
- Local hospices (Derian House, Francis House)
- Via access visits (to schools/nurseries/patient homes)

Reasons for referral:

- Respiratory symptoms
- Neurological symptoms
- Orthopaedic symptoms
- Delayed development
- Mobility problems
- Wheelchair assessments
- Orthotics assessments

- Lung function assessments pre- and post- transplant
- Post-surgery for Hickman line insertion, tumour removal or biopsy
- Provision of walking aids

Access to Hospital School

Referrals: teaching staff make contact with all children of school age (3 – 19 years) on the oncology unit and their parents/carers and teach them on the ward. With parental permission, they will contact a child's home school and, together with the child's class teaching, will produce a Learning Plan which covers what they will be taught while in hospital.
Doctors, nurses, specialist practitioners, physiotherapists, social workers, play specialists and parents/carers can all refer children, especially if school issues have been highlighted. This can be done either directly, by phone or email, or via the weekly oncology unit MDT psychosocial meeting or the weekly Bone Marrow Transplant Unit MDT meeting.

The priority for teaching will be:

- Long-stay pupils (parents with an illness/diagnosis which indicates a prolonged (three days or more) stay in hospital.
- Recurring admissions
- Day patients who attend hospital daily for treatment/therapy
- Pupils taking external examinations
- Pupils with special educational needs.

Bereavement support guidance

All families will have an identified key worker for bereavement follow-up. This role may be undertaken by either the family's social worker or Specialist Nurse as appropriate, and this will be documented.

Immediate follow-up – up to and immediately post the funeral.
If contact is not made after the funeral, a card/letter will be sent with the date of the next call and an offer of a visit/contact at any time.

Interim follow-up – within the first month, to discuss and assess bereavement support needs (e.g. home visits, bereavement group, local support, etc).

The above is the minimum level of support that all families should receive. Support in the longer term can be negotiated by those families who require it. They can be offered:

- Monthly visits for six months (where appropriate) then a reassessment of family needs
- Support to the first anniversary, if necessary
- If further support is still required, referrals will be made to local community support.

A bereavement service is held every year and all families who have had a child/young person die are invited.

References

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Acknowledgements

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4.3 Patient pathways (Measure 14-7A-115)

Central Manchester University Hospitals NHS
NHS Foundation Trust

Royal Manchester Children's Hospital

Initial Referral Protocol for Children with Suspected Cancer

Introduction

This protocol describes referral arrangements for children with signs and symptoms of malignancy in order to ensure that all children aged 0 to 16 years are referred promptly to the appropriate clinical team for assessment and diagnosis.

This guidance should be read in conjunction with the National Institute for Health and Clinical Excellence (NICE) 'Referral Guidelines for Suspected Cancer' (June 2005).

Referral

Children who present with symptoms and signs of cancer should be referred to a paediatrician at their local hospital (DGH or Paediatric Oncology Shared Care Unit) or a paediatric oncologist/haematologist at the Royal Manchester Children's Hospital if appropriate. If malignancy is suspected a request by telephone or fax for urgent paediatric assessment should be made within 24 hours.

The following contact points should be used;

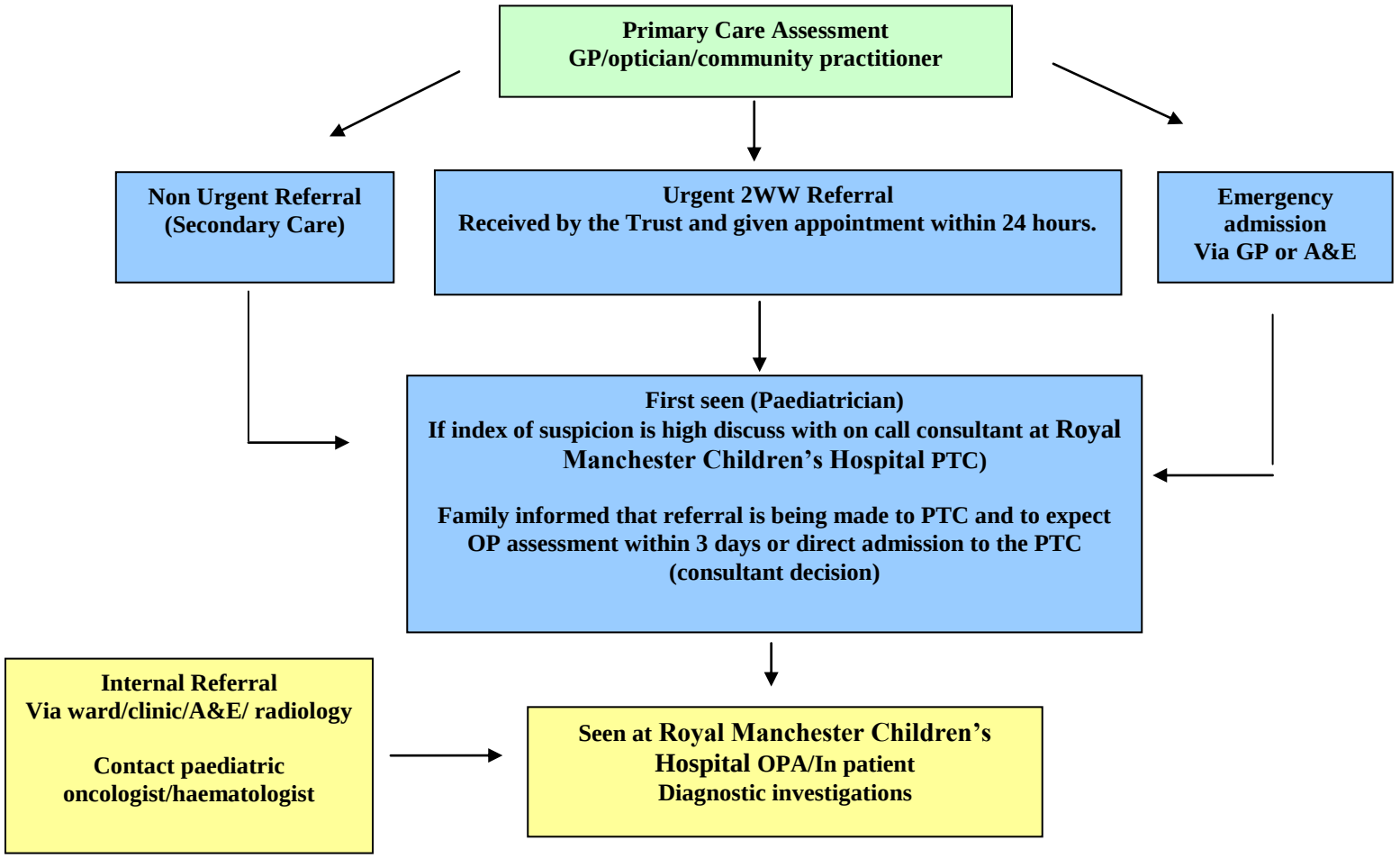
Local paediatrician:

- North Manchester General Hospital: 0161 795 4567
- Salford Royal NHS Foundation Trust 0161 789 7373
- Wythenshawe Hospital 0161 998 7070
- Trafford General Hospital 0161 748 4022
- Stepping Hill Hospital 0161 483 1010
- Tameside General Hospital 0161 331 6000
- Royal Oldham Hospital 0161 624 0420
- Fairfield General Hospital 0161 764 6081
- Royal Bolton Hospital 01204 390390
- Rochdale Infirmary 01706 377777
- Macclesfield District General 01625 421000
- Royal Albert Edward Infirmary, Wigan 01942 244000
- Royal Blackburn Hospital 01254 263555

Royal Manchester Children's Hospital, Principal Treatment Centre (PTC) (On call Consultant paediatric oncologist or haematologist via main switchboard Central Manchester University Hospitals NHS Foundation trust – 0161 276 1234)

For suspected brain tumours they are referred directly to Consultant neurosurgeon on call at Royal Manchester Children's Hospital, Principal Treatment Centre (PTC) (via main switchboard Central Manchester University Hospitals NHS Foundation trust – 0161 276 1234)

Royal Manchester Children's Hospital
Referral Flow Chart for Paediatric Suspected Cancer



Central Manchester University Hospitals NHS
NHS Foundation Trust

Appendix 1

SUSPECTED CHILDREN'S CANCER – REFERRAL FORM

Telephone: 0161 701 8419
Fax: 0161 701 8410

E-mail to: Heather.Houston@cmft.nhs.uk

REFERRER'S DETAILS			
Referring GP		**GP Code:**	
Registered GP			
GP Address & postcode			
GP Tel. No.			
GP Fax. No.			
Date seen by GP:		**Decision to refer date:**	

PATIENT DETAILS

Title & Surname		**Forename(s)**	
D.O.B.		**AGE:**	**Gender:** Male ☐ Female ☐
Address			
Postcode		***Tel. No. (day)**	**Mobile Tel.**
***Tel. No. (evening)**		**NHS No.**	**Hospital No.**

*** *N.B.* It is essential that you provide a current contact telephone number for the patient so that the Trust can contact the patient within 24-hours to arrange a convenient appointment.**

CULTURAL, MOBILITY, IMPAIRMENT ISSUES

What is the patient's preferred first language? ……..
Does the patient require Translation or Interpretation Services? YES ☐ NO ☐ ……
Please list any hearing or visual impairments requiring specialist help (Sign language, Braille, Loop Induction systems)
……

Is Disabled Access Required? YES ☐ NO ☐ Is transport required? YES ☐ NO ☐ ……

Ethnic Origin: …….. Religion: ……
Is the patient from overseas? YES ☐ NO ☐ Is the patient a temporary visitor? YES ☐ NO ☐

URGENT REFERRAL *(referral guidelines are provided below / attached to proforma)*

Diagnosis suspected:

Leukaemia YES ☐ NO ☐ Soft Tissue Sarcoma YES ☐ NO ☐

Brain Tumour	YES☐ NO☐	Bone Tumour	YES☐ NO☐
Lymphoma	YES☐ NO☐	Retinoblastoma	YES☐ NO☐
Neuroblastoma	YES☐ NO☐	Hepatoblastoma	YES☐ NO☐
Wilms' Tumour	YES☐ NO☐	Uncertain/other	YES☐ NO☐

Symptoms:

Fatigue/malaise/lethargy	YES☐ NO☐	Behavioral change	YES☐ NO☐
Bone pain	YES☐ NO☐	Deterioration in school performance	YES☐ NO☐
Headache	YES☐ NO☐	Haematuria	YES☐ NO☐
Vomiting/seizures	YES☐ NO☐		YES☐ NO☐

Examination:

Lymphadenopathy	YES☐ NO☐	Hepatomegaly	YES☐ NO☐
Soft tissue mass	YES☐ NO☐	Splenomegaly	YES☐ NO☐
Fever	YES☐ NO☐	Pallor/signs of anemia	YES☐ NO☐
Abdominal mass	YES☐ NO☐	Neurological signs	YES☐ NO☐
Other ……..	YES☐ NO☐		YES☐ NO☐

Any additional information

Is parent/guardian aware of the reason & urgency for referral & that they will be seen within 2 weeks? YES☐ NO☐

Referral Criteria: NICE – Clinical Guideline 27 (issued June, 2005)

Cancer in children and young people

General recommendations

Children and young people who present with symptoms and signs of cancer should be referred to a paediatrician or a specialist children's cancer service,.

Childhood cancer is rare and may present initially with symptoms and signs associated with common conditions. Therefore, in the case of a child or young person presenting several times (for example, three or more times) with the same problem, but with no clear diagnosis, urgent referral should be made.

The parent is usually the best observer of the child's or young person's symptoms. The primary healthcare professional should take note of parental insight and knowledge when considering urgent referral.

Persistent parental anxiety should be a sufficient reason for referral of a child or young person, even when the primary healthcare professional considers that the symptoms are most likely to have a benign cause.

Persistent back pain in a child or young person can be a symptom of cancer and is indication for an examination, investigation with a full blood count and blood film, and consideration of referral.

There are associations between Down's syndrome and leukaemia, between neurofibromatosis and CNS tumours, and between other rare syndromes and some cancers. The primary healthcare professional should be alert to the potential significance of unexplained symptoms in children or young people with such syndromes.

The primary healthcare professional should convey information to the parents and child/young person about the reason for referral and which service the child/young person is being referred to so that they know what to do and what will happen next.

The primary healthcare professional should establish good communication with the parents and child/young person in order to develop the supportive relationship that will be required during the further **management if the child/young person is found to have cancer.**

All new cases of childhood cancer are discussed at the weekly Paediatric/Leukaemia MDT (measure 09-7B-321)

Specific recommendations

Leukaemia (children of all ages)

Leukaemia usually presents with a relatively short history of weeks rather than months. The presence of one or more of the following symptoms and signs requires investigation with full blood count and blood film:

- pallor
- fatigue
- unexplained irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- persistent or unexplained bone pain

- unexplained bruising.

If the blood film or full blood count indicates leukaemia then an urgent referral should be made.

The presence of either of the following signs in a child or young person requires immediate referral:

- unexplained petechiae
- hepatosplenomegaly.

Lymphomas

Hodgkin's lymphoma presents typically with non-tender cervical and/or supraclavicular lymphadenopathy. Lymphadenopathy can also present at other sites. The natural history is long (months). Only a minority of patients have systemic symptoms (itching, night sweats, fever). Non-Hodgkin's lymphoma typically shows a more rapid progression of symptoms, and may present with lymphadenopathy, breathlessness, superior vena-caval obstruction or abdominal distension.

Lymphadenopathy is more frequently benign in younger children but urgent referral is advised if one or more of the following characteristics are present, particularly if there is no evidence of local infection:

- lymph nodes are non-tender, firm or hard
- lymph nodes are greater than 2 cm in size
- lymph nodes are progressively enlarging
- other features of general ill-health, fever or weight loss
- the axillary nodes are involved (in the absence of local infection or dermatitis)
- the supraclavicular nodes are involved.

The presence of hepatosplenomegaly requires immediate referral.

Shortness of breath is a symptom that can indicate chest involvement but may be confused with other conditions such as asthma. Shortness of breath in association with the above signs particularly if not responding to bronchodilators, is an indication for urgent referral.

A child or young person with a mediastinal or hilar mass on chest X-ray should be referred immediately.

Brain and CNS tumours

Children aged 2 years and older and young people

Persistent headache in a child or young person requires a neurological examination by the primary healthcare professional. An urgent referral should be made if the primary healthcare professional is unable to undertake an adequate examination. Referrals can be either to the PTC oncologist or neuro surgeon.

Headache and vomiting that cause early morning waking or occur on waking are classical signs of raised intracranial pressure, and an immediate referral should be made.

The presence of any of the following neurological symptoms and signs should prompt urgent or immediate referral:

- new-onset seizures
- cranial nerve abnormalities

- visual disturbances
- gait abnormalities
- motor or sensory signs
- unexplained deteriorating school performance or developmental milestones
- unexplained behavioural and/or mood changes.

A child or young person with a reduced level of consciousness requires emergency admission.

Children < 2 years

In children aged younger than 2 years, any of the following symptoms may suggest a CNS tumour, and referral (as indicated below) is required.

Immediate referral:
- new-onset seizures
- bulging fontanelle
- extensor attacks
- persistent vomiting.

Urgent referral:
- abnormal increase in head size
- arrest or regression of motor development
- altered behaviour
- abnormal eye movements
- lack of visual following
- poor feeding/failure to thrive.

Urgency contingent on other factors:
- squint.

Neuroblastoma (all ages)

Most children and young people with neuroblastoma have symptoms of metastatic disease which may be general in nature (malaise, pallor, bone pain, irritability, fever or respiratory symptoms), and may resemble those of acute leukaemia. The presence of any of the following symptoms and signs requires investigation with a full blood count:

- persistent or unexplained bone pain (and X-ray)
- pallor
- fatigue
- unexplained irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- unexplained bruising.

Other symptoms which should raise concern about neuroblastoma and prompt urgent referral include:

- proptosis
- unexplained back pain
- leg weakness
- unexplained urinary retention.

In children or young people with symptoms that could be explained by neuroblastoma, an abdominal examination (and/or urgent abdominal ultrasound) should be undertaken, and a chest X-ray and full blood count considered. If any mass is identified, an urgent referral should be made.

Infants aged younger than 1 year may have localised abdominal or thoracic masses, and in infants younger than 6 months of age, there may also be rapidly progressive intra-abdominal disease. Some babies may present with skin nodules. If any such mass is identified, an immediate referral should be made.

Wilms' tumour (all ages)

Wilms' tumour most commonly presents with a painless abdominal mass. Persistent or progressive abdominal distension should prompt abdominal examination, and if a mass is found an immediate referral be made. If the child or young person is uncooperative and abdominal examination is not possible, referral for an urgent abdominal ultrasound should be considered.

Haematuria in a child or young person, although a rarer presentation of a Wilms' tumour, merits urgent referral.

Soft tissue sarcoma (all ages)

A soft tissue sarcoma should be suspected and an urgent referral should be made for a child or young person with an unexplained mass at almost any site that has one or more of the following features. The mass is:

- deep to the fascia
- non-tender
- progressively enlarging
- associated with a regional lymph node that is enlarging
- greater than 2 cm in diameter.

A soft tissue mass in an unusual location may give rise to misleading local and persistent unexplained symptoms and signs, and the possibility of sarcoma should be considered. These symptoms and signs include:

<u>head and neck sarcomas:</u>
- proptosis
- persistent unexplained unilateral nasal obstruction with or without discharge and/or bleeding
- aural polyps/discharge

<u>genitourinary tract:</u>
- urinary retention
- scrotal swelling
- bloodstained vaginal discharge.

Bone sarcomas (osteosarcoma and Ewing's sarcoma) (all ages)

Limbs are the most common site for bone tumours, especially around the knee in the case of osteosarcoma. Persistent localised bone pain and/or swelling requires an X-ray. If a bone tumour is suspected, an urgent referral should be made.

History of an injury should not be assumed to exclude the possibility of a bone sarcoma.

Rest pain, back pain and unexplained limp may all point to a bone tumour and require discussion with a paediatrician, referral or X-ray.

Retinoblastoma (mostly children aged under 2 years)

In a child with a white pupillary reflex (leukocoria) noted by the parents, identified in photographs or found on examination, an urgent referral should be made. The primary healthcare professional should pay careful attention to the report by a parent of noticing an odd appearance in their child's eye.

A child with a new squint or change in visual acuity should be referred. If cancer is suspected, referral should be urgent, but otherwise referral should be non-urgent.

A family history of retinoblastoma should alert the primary healthcare professional to the possibility of retinoblastoma in a child who presents with visual problems. Offspring of a parent who has had retinoblastoma, or siblings of an affected child, should undergo screening soon after birth.

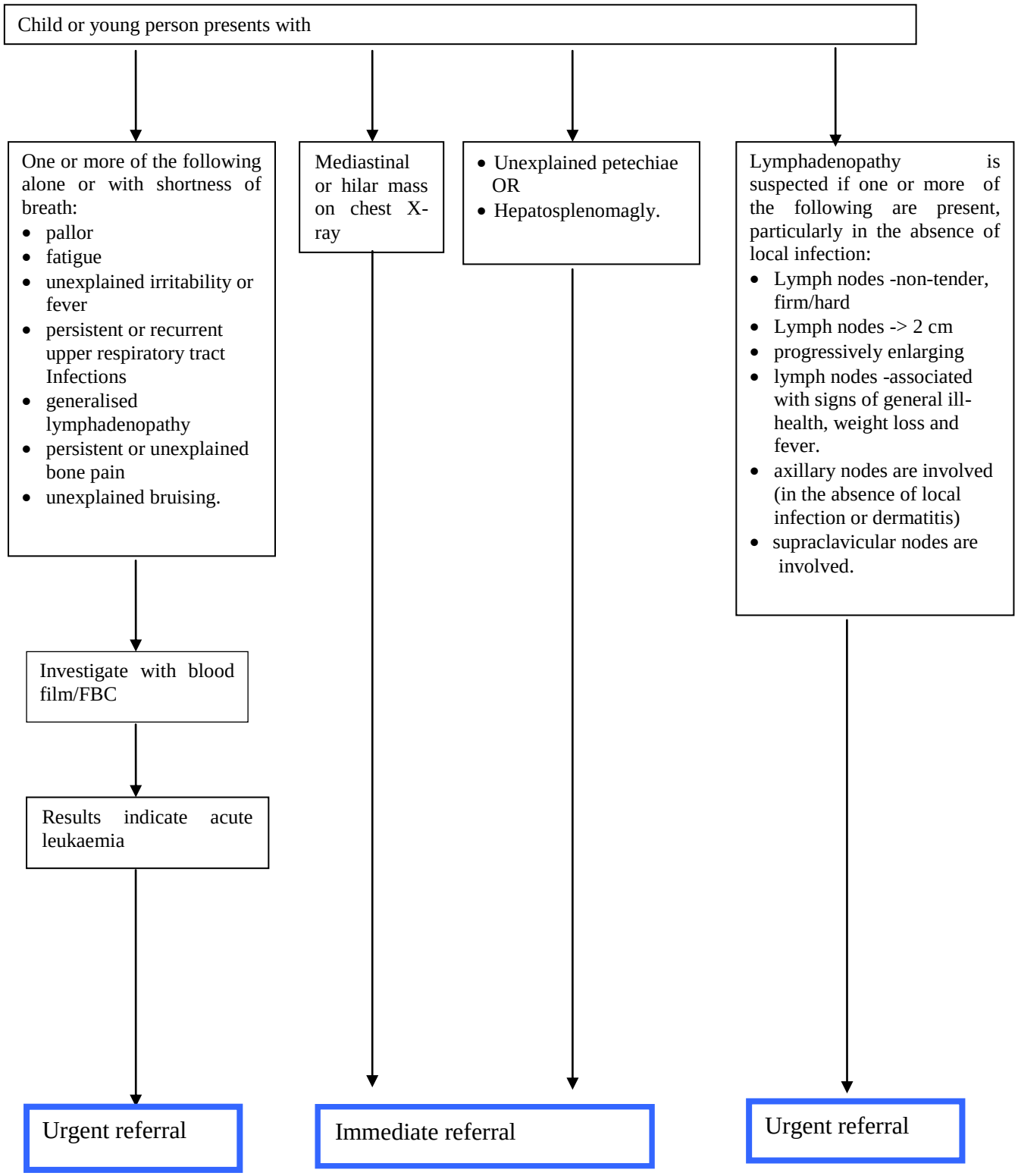
Investigations

When cancer is suspected in children and young people, imaging is often required. This may be best performed by a paediatrician, following urgent or immediate referral by the primary healthcare professional.

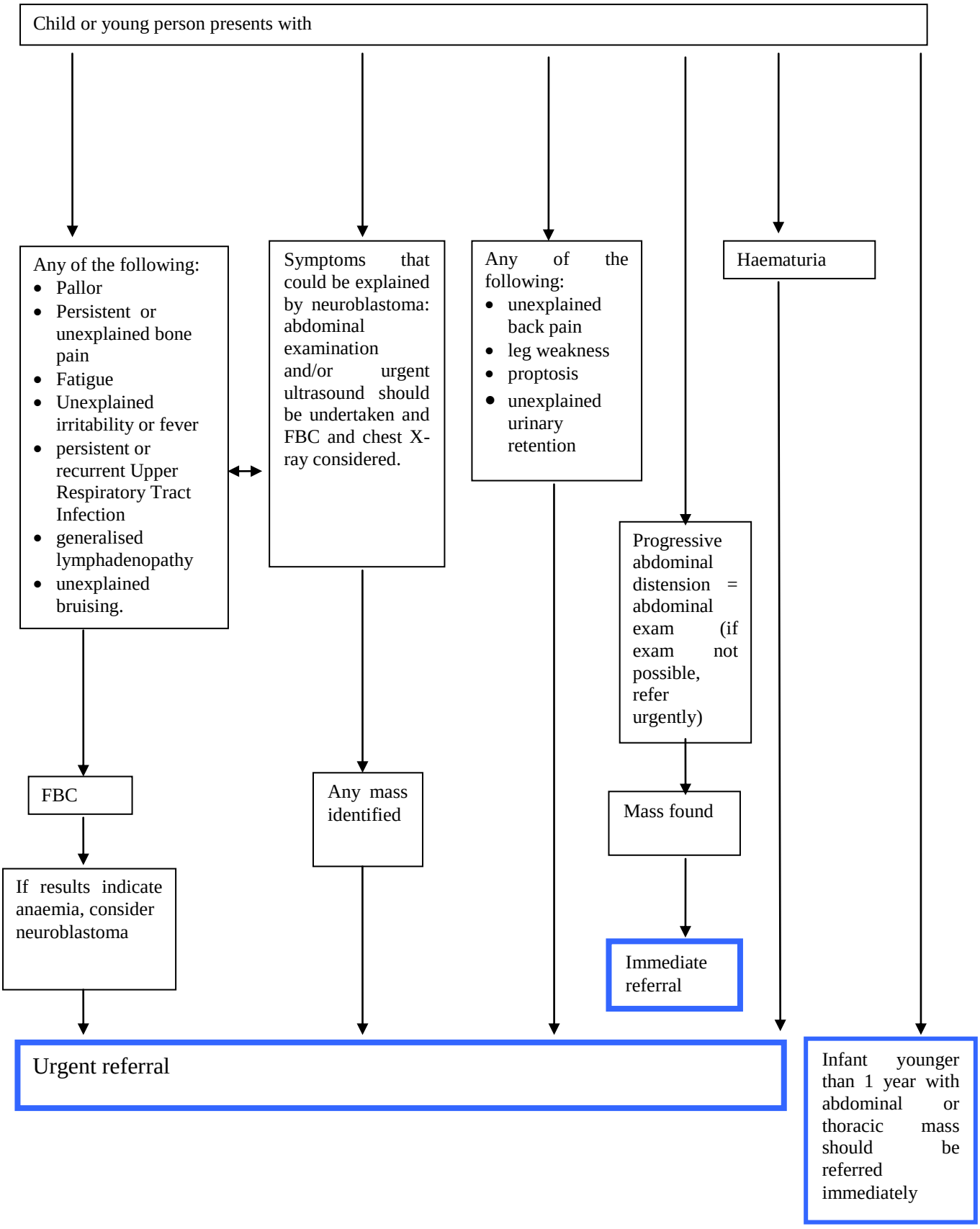
The presence of any of the following symptoms and signs requires investigation with full blood count:

- pallor
- fatigue
- irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- persistent or unexplained bone pain (and X-ray)
- unexplained bruising.

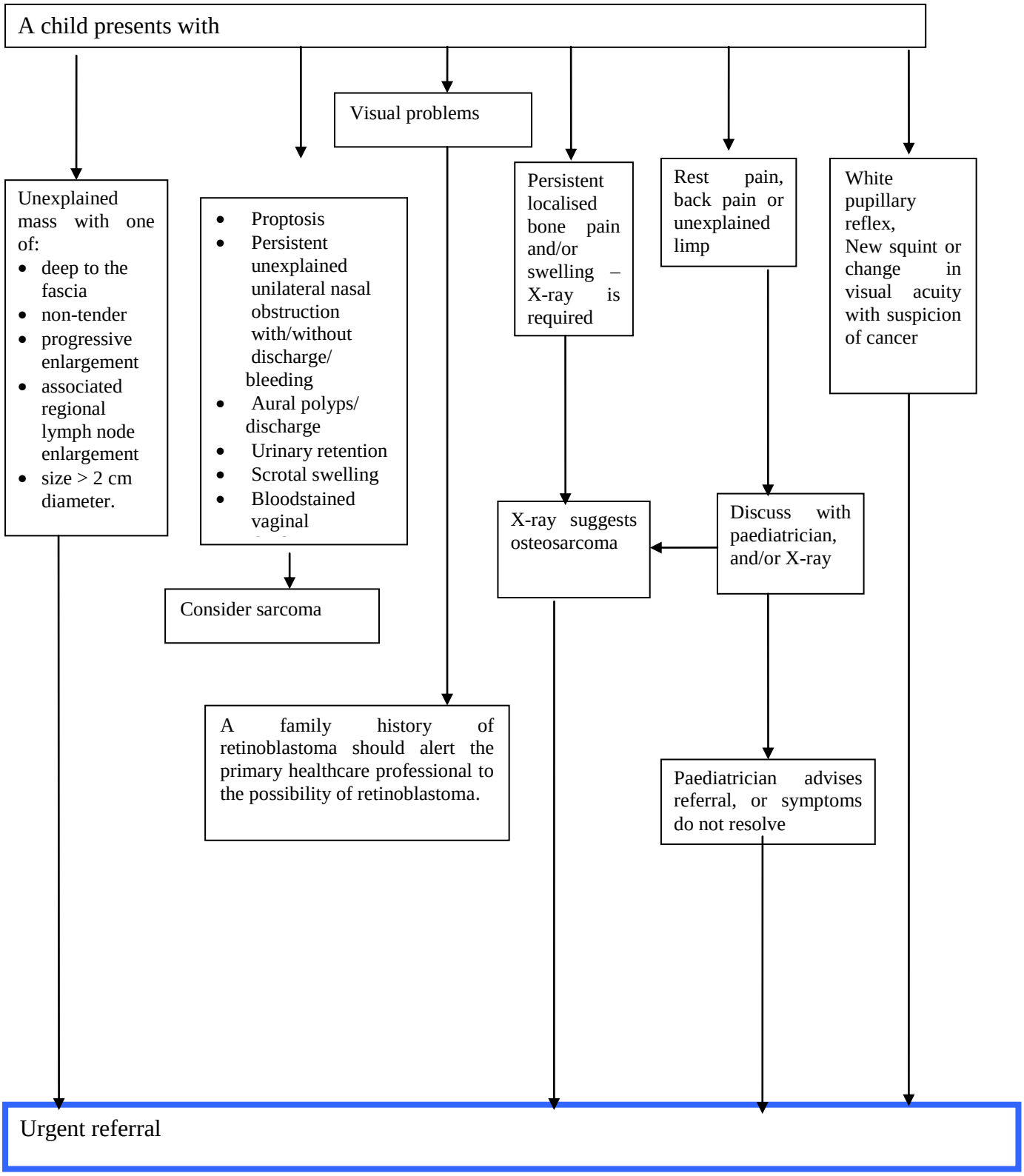
Children's cancers – leukaemia and lymphoma



Children's cancers – neuroblastoma and Wilm's tumour



Children's cancers – bone tumours, sarcoma and retinoblastoma



4.4 Patient Referral Pathways for Chemotherapy Complications (Measure 14-7A-116)

The CCNCG, in consultation with the Chemotherapy Head of Service of the PTC has agreed guidelines/protocols for the referral of patients with acute complications related to chemotherapy, or symptoms suggestive of those complications. The protocols include:

- Neutropenic sepsis
- Cytotoxic extravasation
- Nausea and Vomiting
- Stomatitis, diarrhoea and other mucositis
- Complications associated with venous access devices

Patients follow the unwell patient pathway by contacting the PTC via the DECT phone to the dedicated triage nurse once the symptoms or signs develop as above following discharge. Information about points of contact is contained within the 'Going Home' booklet, which all families are given after the initial diagnosis and treatment.

If the patient has shared care with a local POSCU then the triage nurse informs the Shared Care Unit and the patient is asked to attend there for further management of these symptoms.

4.5 Patient pathways for radiotherapy (Measure 14-7A-117)

The CCNCG has agreed this policy, specifying that radical courses of radiotherapy for children and/or all radiotherapy treatment needing sedation, general anaesthesia or palliative radiotherapy are only delivered at the radiotherapy department of The Christie NHS Foundation Trust under the care of the Clinical Oncologists who are members of the PTC Diagnostic and Treatment MDT.

4.6 Follow up and long term sequelae protocol (Measure 14-7A-118)

The Late Effects MDT Follow Up and Long Term Sequelae Protocol is in effect the CCN Follow Up and Long Term Sequelae Protocol **(14-7A-118)**. This has been agreed by the Lead Clinician Dr Bernadette Brennan of the PTC Late Effects MDT and PTC diagnostic and treatment MDT – solids, and Dr John Grainger PTC diagnostic and treatment MDT – Leukaemia.

The aim of the PTC Late Effects MDT is to ensure a coordinated approach to the follow up, screening and management of the late effects of childhood cancer.

The Late Effects MDT should review all patients diagnosed at the PTC, at the end of treatment, which has included radiotherapy and/or intensive chemotherapy, having received the initial follow up and care plan proforma**.** This care plan proforma is populated with the patient's diagnosis and treatment received and is produced by the consultant in charge of the treatment of the patient at the PTC. The MDT will also review any cancer patient's details at the end of treatment if there is doubt about the need for late effects follow**.**

The end of treatment summary and follow up care plan summarises:

1. The treatment that has been received

2. The role of the POSCU MDT and PTC Diagnosis and Treatment MDT in the patient's follow up and when their role ends

3. The role of the PTC Late Effects MDT and the TYA MDT in the patient's follow up, and when their role begins

4. Which team or teams should be following the patient at which stage of their journey (this may include site specific MDTs)

5. The methods of surveillance that will be used for late effects of treatment
6. What should be monitored by way of relapse detection and health related quality of life.

The end of treatment summary and follow up care plan is completed within six months of completion of potentially curative treatment.

Once patients follow up is beyond 5-6 years and hence risk of relapse is significantly reduced patients will be transferred either to the Late effects follow up clinic at RMCH or if they have received radiotherapy or greater than 16 years old and wish to do so, can be transferred to the Late Effects Clinic at the Christie Hospital where the TYA PTC sits.