



Peninsula and Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance

Peninsula and Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services

Children's and Young Adults' Cancer Services

Constitution

April 2019

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VERSION CONTROL

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1. Statement of Purpose

The Peninsula and Somerset, Wiltshire, Avon and Gloucestershire Cancer Network Children's and Young Adults' Cancer Site Specific Group (CCN) aims to deliver equity of access to the best available medical practice for our patient population. The essential priorities of the CCN are to provide a service that is safe, high quality, efficient and promotes positive patient experience.

To ensure that this statement of purpose is actively supported, the agreed constitution will demonstrate the following:

- The structure and function of the service is conducted, wherever possible, in accordance with the most up to date recommended best practice, as specified in the Manual of Cancer Services, Children's Cancer Measures¹
- A CCN consisting of multidisciplinary professionals from across the South West region has been established and meets on a regular basis
- Network wide systems and care pathways for providing coordinated care to individual patients are in place. This includes the process by which network groups link to individual MDTs
- A process for ensuring that the CCN clinical decision making is in accordance with the most up to date NICE Quality Standards² is in place, as are local clinical guidelines that support the standards
- There is a process by which patient and carers can evaluate and influence service improvements that supports the principle '*No decision about me without me*'³
- Internal and externally driven routine risk related clinical governance processes are in place for evaluating services across the network and identifying priorities for improvement
- The CCN has a coordinated approach via the MDTs to ensure that, wherever possible, clinical research trials are accessible to all eligible cancer patients

¹ Manual of Cancer Services, Children's Cancer Measures

² NICE guidelines

³ Improving Outcomes: A Strategy for Cancer (2011)

- Examples of best practice are sought out and brought to the CCN to inform service development
- Educational opportunities that consolidate current practice and introduce the most up to date practices are offered whenever resources allow
- Processes that can influence the funding decisions of commissioners across the network are being developed.

2. Structure and Function

2.1 CCN Principal Treatment Centre (PTC) Configuration of MDTs

The Multi-Disciplinary Teams (MDTs) within the Children’s Cancer Service consist of clinical and paediatric oncologists, surgeons, haematologists, pathologists, imaging specialists, endocrinologists, neurologists, clinical nurse specialists, and other allied health care professionals. They meet regularly to discuss and manage each patient’s care individually.

Table 1 shows the CCN agreed list of MDTs, hosted by the Primary Treatment Centre, Bristol Royal Hospital for Children.

The Peninsula and SWAG PTC hosts the only diagnostic and treatment MDTs for each disease range within the CCN. Each Peninsula and SWAG PTC MDT is reviewed separately in comparison with Quality Surveillance (Peer Review) diagnostic and treatment MDT measures.

Table 1

MDT	Date and Time	Referral Deadline	Contact Details
Diagnostic Haematology	Second Thursday 10-11	Monday afternoon	sandra.ulityan@uhbristol.nhs.uk sandra.ulityan@nhs.net paedoncmdt@uhbristol.nhs.uk
On treatment Haematology	Thursday 13:30-14:30	No deadline	Sandra.Ulityan@UHBristol.nhs.uk paedoncmdt@uhbristol.nhs.uk
Solid Tumour	Monday 12:30-13:30	Thursday afternoon but urgent referrals accepted after deadline	sandra.ulityan@uhbristol.nhs.uk sandra.ulityan@nhs.net paedoncmdt@uhbristol.nhs.uk
On treatment Oncology	Thursday 12:30-13:30	No deadline	Oncology Registrars
Neuro Oncology	Wednesday 16:00-17:00	Monday afternoon, but urgent referrals	sandra.ulityan@uhbristol.nhs.uk sandra.ulityan@nhs.net

		accepted after deadline	paedoncmdt@uhbristol.nhs.uk
Teenage and Young Adult	Wednesday 12:30-14:00	Tuesday afternoon (but accepted after deadline)	Andrea.Majai@uhbristol.nhs.uk
Aftercare (Late Effects)-	Third Wednesday 14:30-15:30	No deadline	Divya.Bassi@UH Bristol.nhs.uk

2.2 CCN Agreed Shared Care Configuration

The Peninsula and SWAG PTC is reviewed in comparison with Quality Surveillance (Peer Review) measures for delivery of children's cancer chemotherapy for the PTC and for each associated POSCU.

2.2.1 Paediatric Oncology Shared Care Unit (POSCU) Involvement

Table 2

POSCU	Level of Care	Intrathecal chemotherapy (ITC) service	Localities
Gloucestershire NHS Foundation NHS Trust	Level 3	Yes	Cheltenham, North Cotswolds, South Cotswolds, Forest of Dean, Gloucester City, Stroud and Berkeley Vale, Tewkesbury, Newent and Staunton
Taunton & Somerset NHS Foundation Trust	Level 3	Yes	Taunton, Bridgewater, Frome, Minehead, Shepton Mallet, South Petherton, Wincanton, Sherborn
Royal Devon & Exeter NHS Foundation Trust	Level 3	Yes	Exeter, Mid Devon, Woodbury, Exmouth, Budleigh and Wakley
Plymouth Hospitals NHS Trust	Level 3	Yes	From Lifton to Salcombe and Plymouth to North Bovey
Royal Cornwall Hospitals NHS Trust	Level 3	Yes	Coastal Cluster, Falmouth and Penryn, East Cornwall, Newquay, Mid Cornwall, North Cornwall, North Kerrier, Penwith, South Kerrier and Isles of Scilly, Truro
Royal United Hospitals Bath NHS Foundation Trust	Level 3	No	Bath, North Somerset, South Gloucestershire
Yeovil District Hospital NHS Foundation Trust	Level 3	No	South Somerset, North and West Dorset

2.2.2 Community Services

Definitive cancer therapy, palliative and supportive care is delivered by hospital staff under acute Trust governance by each POSCU, and partially funded by CLIC Sargent, in the associated community settings.

All the above arrangements, which constitute the configuration of the Children's Cancer Network, have been agreed by the South West Cancer Alliance Manager, Jonathan Miller.

2.3 CCN Leadership

The Chair of the CCN is Consultant Paediatric Oncologist, Dr Helen Rees.

Terms of reference are agreed in accordance with the paper *Recurrent Arrangements for Cancer Network Clinical Groups and Responsibilities for Peer Review*, as proposed by the South West Cancer Alliance Manager, Jonathan Miller (14th July 2014):

<http://www.swscn.org.uk/wp/wp-content/uploads/2014/08/Cancer-Network-Clinical-Groups-Recurrent-Arrangements-v5-Final.pdf>

2.4 CCNCG Membership

Table 3

Name	Job Title	Trust
Helen Rees	Solid tumour MDT Lead and Chair of the CCN	University Hospitals Bristol NHS Foundation Trust
Vanessa McLelland	Pharmacy Lead	University Hospitals Bristol NHS Foundation Trust
Sue Dolby	Psychology Lead	University Hospitals Bristol NHS Foundation Trust
Laura Baker	Psychologist	University Hospitals Bristol NHS Foundation Trust
Helen Morris	Lead Nurse Paediatric Oncology	University Hospitals Bristol NHS Foundation Trust
Rachel Banks	CLIC Sargent Social Worker	University Hospitals Bristol NHS Foundation Trust
John Moppett	Leukaemia MDT lead	University Hospitals Bristol NHS Foundation Trust
Rachel Cox	Neuro-MDT lead/Aftercare Lead	University Hospitals Bristol NHS Foundation Trust
Jonathan Miller	South West Cancer Alliance Manager	South West Cancer Alliance
Jagadeesh Ramachandra	Consultant Paediatrician	Royal United Hospitals Bath NHS Foundation Trust
Augusta Isaacs	Consultant Paediatrician	Gloucestershire Royal Hospital NHS Foundation Trust

Claire Harrison	CLIC Sargent Nurse Specialist	Gloucestershire Royal Hospital NHS Foundation Trust
Myooren Wimalendra	Consultant Paediatric Oncologist	Plymouth Hospitals NHS Trust
Tanya Crago	Lead Nurse Paediatric Oncology	Plymouth Hospitals NHS Trust
Katrina McDonald	Associate Specialist Paediatrics	Royal Cornwall Hospital NHS Trust
Shama Goyal	Consultant Paediatrician	Royal Cornwall Hospital NHS Trust
Karen Berriman	Clic Sargent Nurse Specialist	Royal Cornwall Hospital NHS Trust
Olivia Lines	Clic Sargent Nurse Specialist	Taunton and Somerset NHS Foundation Trust
Linda Whiteford	Consultant Paediatrician	Taunton and Somerset NHS Foundation Trust
Polly Powell	Consultant Paediatrician	Taunton and Somerset NHS Foundation Trust
Alex Stannett	Clic Sargent Nurse Specialist	Yeovil District Hospital NHS Foundation Trust
Chris Zabarowski	Consultant Paediatrician	Yeovil District Hospital NHS Foundation Trust
Camelia Vaina	Consultant Paediatrician	Yeovil District Hospital NHS Foundation Trust
Corinne Hayes	Consultant Paediatrician	Royal Devon and Exeter NHS Foundation Trust
Simon Parke	Consultant Paediatrician	Royal Devon and Exeter NHS Foundation Trust
Louise Taylor	Lead Clic Sargent Nurse Specialist	Royal Devon and Exeter NHS Foundation Trust

2.5 CCNCG Meetings

The SWAG CCN meets twice yearly. Agendas, notes and actions, and attendance records will be uploaded onto the South West Clinical Network website:

www.swscn.org.uk

Appendix 1 is an example of the agenda for the CCN meetings, which is circulated prior to each meeting to ensure that all members are aware of who is required to attend and that all subject matters requiring discussion are identified. The meeting is split for the first half of the day into a TYA and Children's business meeting. For the second half of the meeting the CTYA group come together to discuss a shared agenda.

Attendance at an individual meeting is not limited to the agreed members. Any one individual may fulfil more than one of the roles on the list, compatible with their discipline

and status. Representatives have delegated authority to make decisions on behalf of all sectors across the CCN, if necessary, when acting as a member of the CCNCG.

In the event that no user representatives are available to attend, there is an agreed mechanism for obtaining user advice.

2.6 Work Programme and Annual Report

The CCNCG produce a Work Programme and Annual Report in discussion with the South West Clinical Network (SWCN). This includes details of any planned service developments and information on how the CCNCG is addressing any inequalities of care and improvements in cancer outcomes. It specifies the personnel responsible and the timescales for implementation. The Annual Report and Work Programme are available to its constituent local authorities, statutory and voluntary health care providers, and commissioners on request.

2.7 CCN Medical Cover Arrangements

The CCNCG has, in consultation with the PTC and the POSCUs, agreed the following specialist medical cover arrangements for Paediatric Haematologist, Oncologist and BMT Consultant clinics:

Table 4

Consultant	POSCU
Adam Gassas	Our Lady's Children's Hospital, Belfast and Addenbrooke's Hospital, Cambridge
Anthony Ng	Bath and Plymouth
Helen Rees	Gloucestershire and Exeter
Rachel Cox	Taunton
Ponni Sivaprakasam	Our Lady's Children's Hospital, Belfast and Addenbrooke's Hospital, Cambridge
Rachel Dommett	Teenage and Young Adult
Stephen Lowis	Yeovil and Truro
John Moppett	Bath and Exeter
Michelle Cummins	Yeovil, Taunton and Truro

Each POSCU is a stand-alone service with medical cover independent from the PTC.

2.8 Oncology and Chemotherapy Training Programmes

The CCNCG has agreed a nurses' training programme in oncology skills and chemotherapy administration for the CCN for all nurses caring for children with cancer. All programmes are held at the UH Bristol Education Centre. The *Introduction to Children's Cancer* course for all new starters, held over 1 day 3 times a year, includes the following topics:

- Overview of childhood cancer and care
- Focus sessions on specific tumours
- Treatment and its impact
- Oncology emergencies
- Febrile neutropenia
- Best practice in central line care.

The *Cytotoxic Study Day*, held over 1 day 4 times a year, includes the following topics:

- The cell cycle
- Cytotoxic drugs
- Safe administration practice
- Intrathecal policy
- Treatment protocols and nursing care issues.

The *Regional Oncology Programme*, held twice a year over 3 days for Band 5 and 6 nurses already working in oncology, includes discussion of nursing care during the whole patient pathway and includes radiotherapy, chemotherapy, stem cell transplant, Teenage and Young Adults with Cancer, Palliative Care, Oncology Emergencies and Family Support.

The *Advanced Oncology Programme*, held once a year, covers issues relevant to more advanced practice in the oncology, haematology and BNT areas.

There are modules for continual development run by the University of the West of England.

The associated competencies related to the nurse's training are compliant with recommendations from the Royal College of Nursing.

The CCNCG, in consultation with the chemotherapy heads of service, has agreed internal training methods and assessment for medically qualified staff who may be required to administer systemic intravenous chemotherapy as part of their duties. Training for intravenous chemotherapy administration via Central venous catheters and the associated risks is provided by Consultant Pharmacist Vanessa McLelland in BRHC Oncology Day Beds. Specific training for peripheral administration is provided for medical staff by Practice Development Nurse for Paediatric Oncology, Haematology and BMT, Wendy Saegenschnitter.

2.9 Training and Qualifications for Staff for the 24-hour Telephone Advice Service

The CCNCG has agreed a policy for the minimum acceptable specialist training qualifications for nursing, medical staff and therapeutic radiographers to take part in the 24-hour telephone advice service as documented in the National Guidance *Telephone Triage Tool Kit for Children and Young People* found [here](#).

2.10 Chemotherapy Leadership

The CCN has agreed, in consultation with the Lead Cancer Clinicians of the Acute Trusts, the following named lead roles for chemotherapy, each with specified responsibilities although specific Programmed Activity (PA) time has yet to be negotiated:

- Head of service for chemotherapy for the PTC and each POSCU in the CCN from where chemotherapy is being dispensed is Consultant Paediatric Oncologist, Dr Stephen Lewis
- Lead Pharmacist for each PTC and POSCU oncology pharmacy service, is Pharmacist Vanessa McLelland.
- Sam Whiting is the pharmacist who leads for chemocare. Inpatient cover and provision of additional training are supported by two rotational pharmacists.

3. Co-ordination of Care / Patient Pathways

All new suspected cases of cancer, whether brain tumours, solid tumours or haematological malignancy, will be referred to the appropriate MDT for discussion, confirmation of diagnosis and treatment plan.

A separate MDT Operational Plan is available for treatment MDTs – Neuro-oncology, solid tumour and Haematology.

All PTC contact details for referral to haem/onc service can be found in section 3.11.2

Decision making in Paediatric Cancer Care occurs rapidly and most referrals come via emergency on call routes – see below for patient pathways. On call consultants are available 24/7 and referrals and investigation plans are made outside the MDT. The MDT is then the process by which decisions are reviewed and final diagnoses confirmed. In a number of instances – brain tumours presenting with raised intra-cranial pressure, new diagnosis of acute leukaemia – the first treatment is required to start before an MDT can convene.

3.1 MDT Referral Arrangements

The MDT discusses all patients with a new suspected diagnosis of cancer and documents the diagnostic pathway and any treatment decision. Patients may be reviewed at diagnosis or at any point during the patient's pathway where a change to the plan, or a new plan, is required.

The preferred route to discussion at the MDT is via the MDT co-ordinator. This may be through:

- The two week wait cancer referral pathway
- Outpatients
- Secondary and Tertiary hospital referral
- Inpatient referral – including referral from the Children's Epilepsy Surgical Service (South West region) for possible brain tumours
- Direct referral from general practitioners
- Referral back into tertiary care from quaternary services
- Referral from Accident and Emergency

The MDT co-ordinator receives email or telephoned referrals for any patient to be listed for discussion. A list of patients to be discussed is held on the Somerset Cancer Registry, and access is available to the members of the Children's Cancer MDTs.

The referring team (if outside UHBristol) should ensure via the MDT co-ordinator that all electronic imaging is available for review. This will involve sending via the electronic imaging portal (IEP). For informed opinions both the latest scan and any priors need to be sent. The referring team are also responsible for sending all other relevant reports eg ophthalmology reports for any tumour involving the visual pathway as follow up decisions cannot be made for visual pathway tumours without up to date ophthalmology data including visual acuity, visual fields, colour vision and disc appearance.

Each patient list will be finalised and circulated by the MDT coordinator in a timeframe specified within the operational policy of each specific MDT. The MDT list is usually sent out approximately two days prior to each meeting in order to allow appropriate circulation to members of the MDT. A paper copy is available in the MDT room. It is the responsibility of the MDT co-ordinator to ensure that medical notes, imaging reports, histology slides and blood results are available for the meeting.

Any MDT meeting which needs to be cancelled must be identified to the MDT co-ordinator to ensure all members of the MDT are aware of the cancellation.

An annual MDT operation policy review meeting will discuss any operational issues. If an operational policy issue arises in the interim, it shall be dealt with during the normal weekly MDT meetings and agreed outcomes recorded in the MDT minutes.

The MDT will hold annual meetings to agree areas of training and research in the MDT and discuss short term and long term outcome data.

The core MDT member responsible for imaging will report regularly on the imaging of children with cancer by various modalities recommended in local guidelines.

The histopathology (paediatric and neuropathology) members shall take part in histopathology EQA which includes paediatric malignancy.

The MDT provides a forum for training juniors and informing medical students in the process and function of the MDT. It also ensures that protocols, guidelines and standards in operating procedures are developed and updated for all aspects of management, diagnosis and treatment of patients with paediatric cancer.

The MDT provides all patients, families and cares with a point of contact (key worker) within the MDT for any queries relating to an individual's management. Patients or carers wishing to access MDT members may do so through the patient's key worker. Patients needing referral to the specialist MDT must follow the agreed pathways. The key worker is allocated within the integrated care meeting.

3.2 Case discussion and Treatment decisions at MDT

The MDTs will discuss the following patients:

- All newly diagnosed patients with malignancy.
- All patients with recurrent, refractory or progressive disease requiring additional treatment.
- Any complex case requiring decisions, such as patients developing unusually severe toxicity, or requiring consideration of additional therapies not initially planned.

Treatment decisions will be discussed with relevant clinicians immediately after the MDT. Treatment decisions are recorded electronically on the Somerset Cancer Register at the MDT meeting. Each treatment decision is fully agreed by everyone present at the meeting.

Outcome information from the MDT meeting is emailed to each referring hospital's MDT co-ordinator and CNSs once the minutes have been confirmed, this is usually within 48 hours of the MDT. Outcome information may be communicated by telephone if actions need to be implemented urgently.

When a final treatment decision cannot be made, appropriate alternatives are outlined by the MDT. The responsible clinician then shares treatment alternatives with the patients and parents or carers and a final treatment decision will be reached.

If treatment decisions change from those suggested by the MDT, they will be reported back at the next available MDT

Follow-up communication for patients and GP's may vary. These may include:

- Outpatient clinic or next available clinic appointment
- Local hospital outpatient appointment
- Telephone conversation with the patient by the CNS or Consultant
- Secure email or letter to GP

3.3 Treatment Decisions between MDT meetings

The policy to manage patient referrals requiring a treatment planning decision before the next scheduled MDT meeting is described here. Where a patient requires urgent advice for treatment prior to the next MDT meeting the following procedure is undertaken:

- Telephone contact will be made with the relevant referring consultant.
- A formal written letter of referral to follow-up this telephone discussion as a record.
- The case will be discussed at the next available MDT meeting

3.4 Referral to another MDT

If a patient requires referral to another MDT within the trust, it is the responsibility of the patient's consultant to facilitate that discussion. This is appropriate where, for example, the child may have an adult-type malignancy such as adenocarcinoma of the bowel, and expertise from the colorectal MDT is required.

3.5 How to refer a new oncology patient

3.5.1 Patients referred from outside Bristol Royal Hospital for Children.

Any patient identified as having a possible tumour or malignancy should be discussed with the ATTENDING Consultant (haematology or Oncology) during daytime hours (Mon-Frid 9am-5pm). For out of hours discussion, contact ON-CALL Paediatric haem/Onc consultant

via Switchboard. See below for specific recommendations when referring a new brain tumour.

Neuro-oncology referrals

- Any patient with radiologically demonstrated intracranial or intraspinal tumour will be referred directly to the on-call paediatric neurosurgical team; the rota is held by the Switchboard. All tumour referrals should be made via the ON CALL neurosurgical registrar. Where possible, CT or MR images will be available to the neurosurgical team at the time of referral.
- Any referral made firstly to the paediatric oncology service will prompt immediate involvement of the on call neurosurgical team, and an initial plan of investigation leading to biopsy or resection of the tumour will be made, together with the neuroradiologist. This is typically by telephone or face to face communication. The on call oncology consultant can also be contacted directly via the switchboard if the Registrar is not available. ONLY the on-call consultant should be contacted with any new referral. Routine queries can be addressed to the consultants via their secretaries, whose numbers are available via Switchboard.
- The neurosurgical team will agree immediate management with the referring doctor, and decide when the patient should be transferred. This will normally be without delay.
- Patients who present as an emergency, and undergo resection without discussion will be discussed between the neurosurgeon, paediatric oncologist, radiologist and pathologist, generally within 24 hours.
- There is a presumption that a complete surgical resection of a tumour is to be preferred, except where initial urgent control of intracranial pressure is required.
- For Neuro-oncology cases, patients presenting without emergency symptoms (risk of raised intra-cranial pressure, cord compression) may be discussed first at the MDT before admission but most patients will require emergency admission.
- Following a pathological diagnosis, if a further decision is required before the next MDT, this will be by discussion with the involved surgeon, paediatric and clinical oncologist, radiologist and pathologist. All patients' imaging and pathological tissue will be reviewed at the next planned MDT.

Solid Tumour referrals

- Any new referrals requiring discussion should be referred during daytime hours to attending consultant unless more urgent eg mediastinal mass. Once a case is accepted and if they require urgent transfer, it will be the discretion of the referring centre how best to transfer the patient, although advice from the oncology team should be considered.
- In the event of a symptomatic mediastinal mass please discuss urgently with oncology consultant and discuss with Watch Retrieval service regarding safe transfer to BCH. These patients can be fragile with cardiac compromise that may only become evident on ECHO. Cross sectional imaging with CT scan may be required to assess airway status if patient is able to lie flat, prone may be preferable. Critical information will be presence of SVC obstruction, presence of a pleural effusion and in particular presence of a pericardial effusion on imaging. These factors may influence the decision regarding type and timing of transfer as well as the need for critical care bed.
- For a mass in the head and neck region, especially if impacting on the upper airway, urgent transfer will be required and biopsy should be undertaken at the tertiary centre.
- Any request to discuss imaging/case oncology team in a non-urgent manner should be made to the daytime attending consultant who will request written referral to be sent to the MDT coordinator via email (see PTC minimum dataset referral proformas) and appropriate imaging transferred via IEP if appropriate. Discussion will not take place unless information is complete.
- Referral of a Liver tumour, Retinoblastoma or a primary Bone tumour should be made directly to the quaternary centres as directed by the CCN guidelines for referral outside the service of the CCN's catchment area (see 3.5.5). Any referral should be copied in to the linked consultant for that POSCU or to the attending consultant. This last step is essential to ensure we are aware of a potentially new cancer diagnosis within our MDT that will need to be tracked by our MDT.

Malignant Haematology

- Any new malignant haematology referral should be made during daytime hours to the attending haematology consultant unless a more urgent discussion is required. The out of hours on-call service is supported by paediatric oncology consultants only

and they can be contacted through switchboard. Transfer of new referrals will generally be arranged during working hours unless there is a clinical urgency requiring expertise from within the Children's hospital.

3.5.2 Patients referred from Bristol Royal Hospital for Children.

- Any patient identified as having a possible tumour or malignancy should be discussed with the attending Oncology Consultant of the week or the Oncology/haematology registrar.
- Any patient with radiologically demonstrated intracranial or intraspinal tumour will be referred directly to the Paediatric Neurosurgical team. The attending paediatric oncology consultant should also be contacted directly by telephone, or failing this, the Oncology SpR will be contacted by hospital bleep. The neurosurgical team will agree further management with the referring doctor.
- Any patient with suspected haematological malignancy should be referred directly to the attending haematology consultant or haematology registrar.
- If someone wishes to discuss imaging with the oncology team in a non-urgent manner, please contact the Oncology registrar or Oncology attending consultant to arrange to attend the MDT/Xray meeting to present the case for discussion. Formal referral and details of imaging/pathology will then be requested and sent to the MDT coordinator.
- Out of hour referrals for any (non neuro-oncology) malignancies should be made directly via switchboard to the on-call consultant for haematology/oncology.

Integrated Care MDT

In addition to the specific treatment MDTs, the entire department meets weekly on Wednesday morning between 9.00am and 10.00am for the integrated care meeting. At this meeting, a key worker will be assigned and specific areas of concern within the holistic needs assessment identified. All new patients are reviewed at this meeting, and selected patients (such as those at relapse and those entering palliative care) may be discussed on more than one occasion.

Specific consideration of patients entering or receiving palliative care will be made. The meetings will be recorded, and decisions entered into the Somerset Cancer Register.

3.6 Neuro-Oncology MDT - additional information

Patients referred from the Children's Epilepsy Surgical Service

This is a supra-regional service centrally commissioned and provided from the Bristol Royal Hospital for Children. Currently the service receives referrals for children with epilepsy, for consideration for surgery from the SW oncology shared care network but also South and West Wales, Southampton area including Channel Islands and Oxford. Currently 10% patients ultimately receive a diagnosis that would require ongoing follow up or management by a neuro-oncology MDT. Referral to neuro-oncology MDT is made by the epilepsy MDT co-ordinator to ensure:

- All patients with suspected tumour diagnosis have opportunity to meet neuro-oncology CNS
- that all histology is reviewed for patients having epilepsy surgery
- Cancer diagnoses are recorded in Somerset Cancer register
- Inter-provider transfer is made where another neuro-oncology MDT will be providing treatment or FU

Care of Paediatric Neuro-Oncology patients as inpatients

Children with CNS tumours at acute presentation will be cared for in the Bristol Royal Hospital for Children admitted under the neurosurgical, or occasionally paediatric neurology service.

Immediate treatment at night and at week-ends will be under the care of the consultant paediatric neurosurgeon on call. All paediatric patients with CNS tumours will also be referred to the Paediatric Oncology team at the time of admission. The CNS will meet all patients during their first admission.

Care of patients with Pituitary tumours, tumours needing frame guided biopsy and complex skull base tumours

Children with these tumours may require the joint care of both a paediatric and adult neurosurgeon with the specific subspecialty expertise (e.g. pituitary surgery). These children are to be admitted under the care of a consultant paediatric neurosurgeon, who will oversee care and, where appropriate share care with the appropriate adult neurosurgeon, with both consultant's sharing responsibility for any surgical intervention undertaken. The

Paediatric Neuro-oncology MDT should have oversight of the management of these cases, with support of the skull base or pituitary MDT at NBT.

Care of patients with endocrinopathy

Patients presenting with tumours involving pituitary and hypothalamus should also be referred to endocrinology by referring team. The admitting neurosurgical team should confirm that this has been done.

Interval surgery on these patients should also involve endocrine team being alerted to the date of surgical admission in advance. All other planned and emergency admissions should trigger a referral to endocrine team about the admission.

Contact information

Attending service team: Monday- Friday 9am-5pm

On-call Consultant: Monday-Thursday 5pm-9am, Friday-Monday 5pm-9am

- Attending Oncology Consultant contact via Switchboard
- Attending Haematology Consultant contact via Switchboard
- Out of hours Haem/Onc consultant via Switchboard

3.7 Clinical Guidelines

The CCNCG has produced a directory of Clinical Guidelines for the following:

- Leukaemia
- Lymphoma and reticulo-endothelial malignancy
- CNS tumours
- Sympathetic nervous system tumours
- Retinoblastoma
- Renal tumours
- Hepatic tumours
- Malignant bone and soft tissue sarcomas
- Other malignancies.

The guidelines are available on the SWCN website [here](#).

3.8 Chemotherapy Guidelines

Common guidelines and protocols are available throughout the CNN via [The Hub](#).

The CCNCG has produced the document *Prescribing, Handling and Administration of Cytotoxic Drugs For Stem Cell Transplant and Paediatric Haematology and Oncology Patients* (revision date 2019), Author: Wendy Saegenschnitter, contains guidelines on the following issues:

- Cytotoxic administration techniques
- The recognition and treatment of cytotoxic extravasation
- The recognition and treatment of allergic reactions including anaphylaxis.

The CCNCG has produced the document *Guidelines for the Use of Ports Totally Implanted Venous Access Devices* (revision date June 2018), Author: Wendy Saegenschnitter, contains guidelines on the following:

- The care of venous access devices used in the hospitals, including the treatment of line complications.

National guidance on the use of blood products is available in each PTC and POSCU.

3.9 Agreed Chemotherapy Regimens

The CCNCG, in consultation with the PTC and POSCUs, use nationally ratified chemotherapy regimens that contain the following regimen-specific information:

- Cancer type
- Name of regimen, therapeutic intent(s), palliative/adjuvant/neo-adjuvant/radical (2), as applicable
- Cytotoxic drugs
- Doses (per m² or Kg as applicable)
- Routes of administration
- Number of cycles or whether this is indeterminate
- Length of cycle and schedule of administrations within a cycle
- Mandatory tests prior to a course and individual cycle
- Mandatory supportive drugs with each cycle
- Mandatory cytotoxic dose modifications and their indications.

The CCNCG have an agreed written standard operational policy (written in consultation with the PTC chemotherapy group) for off-protocol prescribing which requires sign off by two

PTC medical consultants and a pharmacist. All off protocol prescribing is governed by the PTC.

The CCNCG annually review the records from the CCN's chemotherapy services of the use of off protocol regimens as documented in Appendix 1, template agenda.

Terms of Reference for the Chemotherapy Governance Group:



Terms of Reference
Chemo Governance G

3.10 Guidelines for Psychosocial Assessment

The CCNCG, in consultation with the MDTs, has an agreed CCN-wide process for psychosocial assessment of patients and carers, which involves a structured discussion, (see Appendix II) of all new, relapsed, recurrent, palliative and complex situation patients at a Wednesday morning MDT, to identify needs requiring action.

The CCNCG, in consultation with the MDTs, has agreed CCN-wide guidelines for psychosocial assessment of patients and carers, which includes the following:

- Information needs
- Practical support issues
- Social and cultural circumstances
- Education related issues
- Employment related issues
- Psychological, emotional and spiritual issues.

The patient, their family and other relevant carers will be included in the assessment, which will be considered on at least the following points in the care pathway:

- Diagnosis
- During definitive treatment
- During post-treatment follow up
- At transition to adult cancer care
- At relapse
- During palliative care (for family and carers) at bereavement.

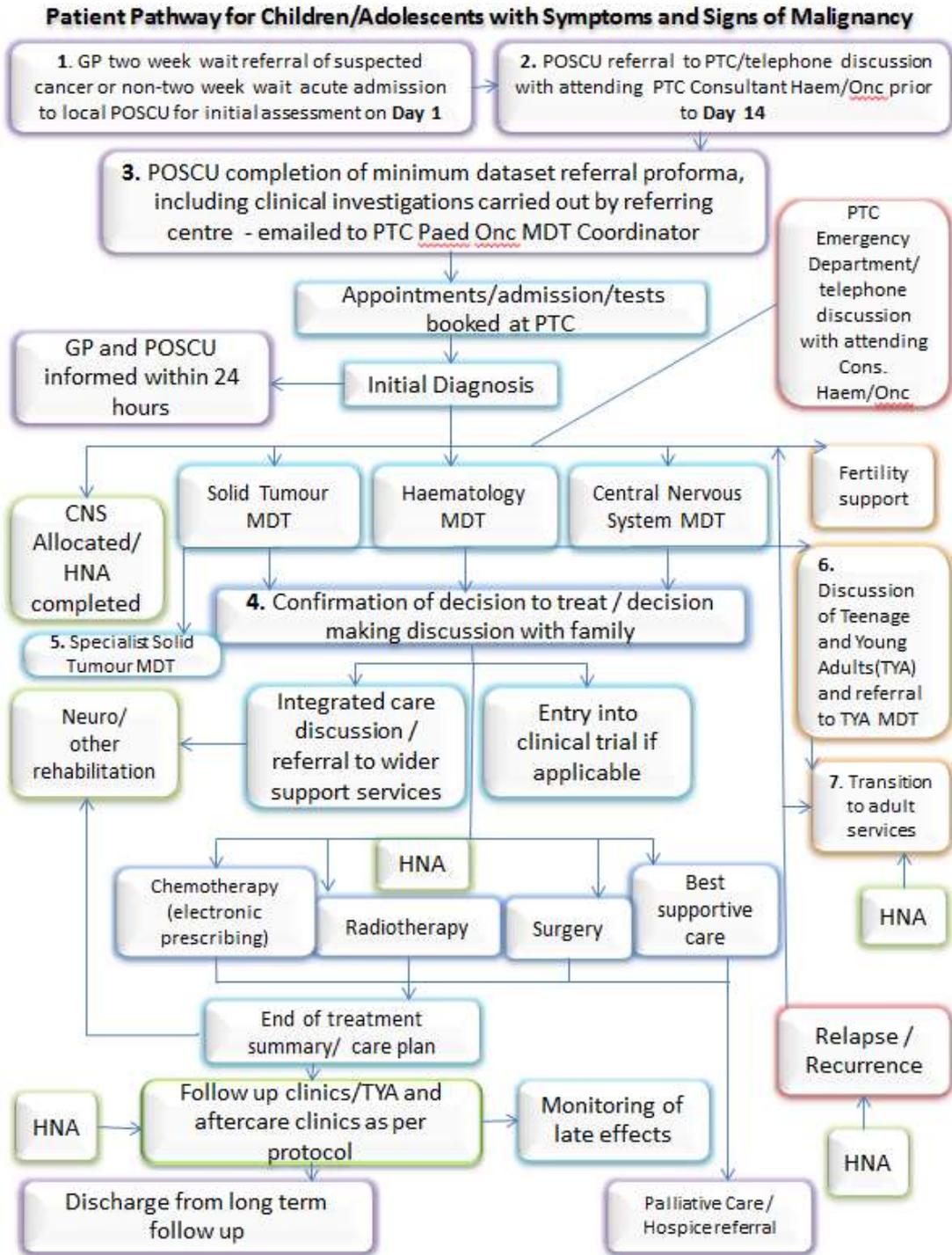
The assessment is currently being developed into an electronic holistic needs assessment.



Assessments for TYA patients are available to complete independently at any point in the patient's pathway, on the [IAM](#) website developed by the PCT. This includes the option to book a face to face appointment with the psychosocial assessment team when required.

The resources available for psychosocial services are in the process of being reviewed. The current service, which consists of 1 Consultant Psychologist, 1 Band 8a Clinical Nurse Specialist (CNS) and 1 Band 7 CNS, can provide support to patients across the Bristol, North Somerset and South Gloucestershire (BNSSG) region. There is a shortage of Children and Adult Mental Health Services (CAMHS) social workers; further resources are required to ensure that there is supported transition to psychosocial services across the wider region and to provide Level 2 psychological training to staff in regional centres.

3.11 Patient Pathways



3.11.1 Note 1: South West Childhood Cancer Referral Proforma

The majority of referrals are received as acute admissions. Referrals of suspected cancer from General Practitioners should be made using the South West Childhood Cancer Referral Proforma:



SW Childhood
Cancer Referral Proforma

3.11.2 Note 2: PTC contact details

Trust Switch Board: 0117 9230000

Bleep numbers:

Oncology Registrar, 09:00-17:00, Monday to Friday: 2950

Haematology Registrar, 09:00-17:00, Monday to Friday: 3496

Bone Marrow Transplant (BMT) Registrar, 09:00-17:00, Monday to Friday: 2240

Oncology, Haematology and BMT Out of Hours: 2406

Medical Speciality Team 2 Registrar for Oncology, Haematology and BMT, 22:00-08:30:
6734

3.11.3 Note 3: PTC minimum dataset referral proformas

PTC minimum dataset referral proforma for Solid Tumour MDT

Paediatric Solid Tumour MDT – Monday 12.30 (weekly)

To refer patient to MDT proforma below must be completed and returned to MDT coordinator by 12pm on Thursday. For late additions, please discuss with MDT coordinator directly.

Patient details: Name / D.O.B/ NHS number Consultant Shared care centre	Diagnosis, Stage and treatment plan to date.	Reason for Referral to MDT (please indicate) <ul style="list-style-type: none"> • New patient • End of treatment • On treatment assessment (details) • Relapse • Progression • Other 	Imaging to be reviewed	Pathology Yes/no

INCOMPLETE INFORMATION WILL RESULT IN PATIENT BEING DEFERRED TO NEXT MEETING

MDT Coordinator: Sandra Ulityan

Email: paedoncmdt@uhbristol.nhs.uk

Phone: 0117 3428108

Haematology & Oncology
 Bristol Royal Hospital for Children
 Upper Maudlin Street
 Bristol
 BS2 8BJ
 Oncology Day Beds
 Level 6

PTC minimum dataset referral proforma for Neuro-Oncology MDT

Paediatric Neuro-oncology MDT – Wednesday 4pm (weekly)

To refer patient to MDT proforma below must be completed and returned to MDT coordinator by midday on Monday. For late additions, please discuss with MDT coordinator directly.

Patient details: Name / D.O.B/ NHS number Consultant Shared care centre	Diagnosis, Stage and treatment plan to date. If new patient – indicate	Reason for Referral to MDT (please indicate) <ul style="list-style-type: none"> • New patient • End of treatment • On treatment assessment (details) • Relapse • Progression • Other 	*Imaging to be reviewed	**Pathology Yes/no

Please note:

***Radiology** – place and dates of scans essential for radiologist. Please indicate question being asked e.g. dimensions required, tumour response etc

****Pathology** – place and date of biopsy/surgical resection required. If pathology requested from elsewhere please ensure MDT coordinator aware to chase.

INCOMPLETE INFORMATION WILL RESULT IN PATIENT BEING DEFERRED TO NEXT MEETING

MDT Coordinator: Sandra Ulityan

Email: paedoncmdt@uhbristol.nhs.uk

Phone: 0117 3428108

Haematology & Oncology
 Bristol Royal Hospital for Children
 Upper Maudlin Street
 Bristol
 BS2 8BJ
 Oncology Day Beds
 Level 6

PTC minimum dataset proforma for Leukaemia MDT

New Patient proforma for Leukaemia MDT

1. Name & DOB
 2. Consultant
 3. Diagnosis
 4. Date of diagnosis
 5. Trial Y/N?
 6. Name of treatment cycle #1
-
- a. UKALL2011 Reg A standard dex
 - b. UKALL2011 Reg A short dex
 - c. UKALL2011 Reg B standard dex
 - d. UKALL2011 Reg B short dex
 - e. R3 Induction
 - f. ADE
 - g. MyeChild 1
 - h. MyeChild 2
 - i. MyeChild 3
 - j. MyeChild 4
 - k. Other

**Table 1
Play Performance Scale for children**

100	fully active, normal
90	minor restrictions in physically strenuous activity
80	active, but tires more quickly
70	both greater restriction of, and less time spent in, active play
60	up and around but minimal active play, keeps busy with quieter activities
50	gets dressed, but lies around much of the day; no active play; able to participate in quiet play and activities
40	mostly in bed; participates in quiet activities
30	in bed; needs assistance even for quiet play
20	often sleeping; play entirely limited to very passive activities
10	no play; does not get out of bed
0	unresponsive

7. Start date
8. Height and Weight
9. What is their Lansky play scale?

3.11.4 Note 4: Communication of results

The Solid, Haematology and Neuro-oncology MDTs will determine and communicate the results of the initial diagnosis and assessment of stage/extent/severity of the disease, and results of all on treatment and follow up surveillance conducted in the PTC, plus confirmation of relapse/recurrence and its extent/severity, where considered relevant.

The POSCUs will communicate the results of on treatment and follow up surveillance results that have been delegated to the POSCU by the PTC, in accordance with the clinical guideline protocols.

3.11.5 Note 5: Indications for referral outside the service of the CCN's catchment area

- Hepatoblastoma: Surgery is undertaken in Birmingham Children's Hospital NHS Foundation Trust
- Primary malignant bone tumours: Surgery is undertaken in Royal Orthopaedic Hospital, Birmingham
- Retinoblastoma: Referrals are sent to the Retinoblastoma Service in Birmingham Children's Hospital NHS Foundation Trust.

Details of Solid Tumour MDT Referral Pathways can be found [here](#).

The tertiary referral form for the Royal Orthopaedic Hospital Bone Tumour Service can be found [here](#).

3.11.6 Note 6: Teenage and Young Adult services

The CCNCG has agreed with the Chair of the relevant Teenage and Young Adult cancer network co-ordinating group (TYACNCG), TYA patient pathways for initial management, follow up on completion of first line treatment and cases involving NHS specialised services. The pathways include the relevant contact points for the services, hospitals and MDTs and can be found [here](#).

3.11.7 Note 7: Indications for referral to a site specialised MDT dealing with adults

- All diagnoses of skin cancer
- Skull base tumours
- Thyroid cancer (Head and Neck MDT)
- Any 'adult' cancer (e.g. colorectal carcinoma)
- Patients reaching the age of transition to adult services.

3.12 Patient Referral Pathways for Chemotherapy Complications

The CCNCG, in consultation with the chemotherapy heads of service, has agreed guidelines/protocols for the CCN for referral of patients with acute complications related to chemotherapy and/or symptoms suggestive of those complications. These fulfil the following criteria:

The symptoms and signs suggestive of, and indications for referral with the following:

- Neutropenic sepsis
- Cytotoxic extravasation
- Venous-occlusive disease
- Nausea and vomiting
- Mucositis
- Complications associated with venous access devices.

Pathway for medical review of Haem/Onc patients in the Emergency Department:



Pathway for
HaemOnc patients to

3.12.1 Local POSCU contact points for advice or acceptance of patients with symptoms or signs of complications:

Gloucestershire Royal Hospital Paediatric Oncology Service:



Gloucestershire_Paed_Onc_Service.pdf

Taunton and Somerset Hospital Paediatric Oncology Service:

Hospital Switch Board: 01823 333444

Oak Ward: 01823 342016

Out of hours, ask for the on call Consultant or Registrar via switch

Royal Devon and Exeter Hospital Paediatric Oncology Service:

Hospital Switch Board: 01392 411611
Bramble Day Case Ward: 01392 406078
Bramble Yellow (out of hours): 01392 402678/79

Plymouth Hospital Paediatric Oncology Service:

Hospital Switch Board: 01752 202082
Further contact details: <https://www.plymouthhospitals.nhs.uk/dccs>

Royal Cornwall Hospital Paediatric Oncology Service:



RCH_Paediatric_Oncology_Service.pdf

Royal United Hospital Bath Paediatric Oncology Service:



RUH_Bath_Paediatric_Oncology_Service.p

Yeovil District Hospital Paediatric Oncology Service:



Yeovil_Paediatric_Oncology_Service.pdf

The contact points will be distributed to the following:

- Primary care practices and polyclinics
- A&E departments
- Consultant paediatricians
- Acute paediatric wards
- NHS direct services
- NHS walk-in centres
- Out of hours primary care service providers.

3.13 Patient Pathways for Radiotherapy

The CCNCG has agreed a policy specifying that:

Radical courses of radiotherapy for children and/or all radiotherapy treatment needing sedation or general anaesthesia is only delivered in the Bristol Haematology Oncology Centre (BHOC) Radiotherapy Department for the CCN.

The radiotherapy is only delivered under the care of Consultant Clinical Oncologists Alison Cameron and TBC (vacant post), who are core members of the PTC diagnostic and treatment MDT.

Palliative courses of radiotherapy for children not needing sedation or general anaesthesia can be delivered in any radiotherapy department in the CCN under the care of any clinical oncologist, provided the proposed course is discussed with a core consultant member of the PTC diagnostic and treatment MDT prior to the treatment.

Patients requiring radical treatment with proton therapy are referred to relevant treatment centres, as directed by the PTC MDT, and in accordance with national referral processes.

3.14 Follow Up and Long Term Sequelae Protocol

The CCNCG, in consultation with the POSCU, MDTs and the PTC diagnosis and treatment MDT(s), PTC late effects MDT(s) and the TYA MDT, has produced a single follow up and long term sequelae protocol which fulfils the following:

- The requirement of an end of treatment summary (specifying who will be responsible for its production) and follow up care plan, for each patient completing potentially curative treatment which states:
 - The treatment that has been received
 - The role of the POSCU MDT and PTC diagnosis and treatment MDT in the patient's follow up and when their role ends
 - The role of the PTC late effects MDT and the TYA MDT in the patient's follow up, and when their role begins
 - Which team or teams should be following the patient at which stage of their journey (this may include adult site specific MDTs)
 - Which methods of surveillance are used for late effects of treatment
 - 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.

The CCNCG follow up and long term sequelae protocol will be distributed to the Chairs of the adult cancer network groups in the catchment area from which the CCN takes referrals, with accompanying instructions which require the ongoing distribution of the protocol to the lead clinicians of all their associated site specific adult MDTs.

3.14.1 Paediatric Oncology Aftercare Policy



Operational Policy -
Paeds Aftercare - 20:

4. Patient and Public Involvement

4.1 Patient Experience

A Children's Friends and Family patient experience survey is routinely distributed.

A Teenage and Young Adult patient experience survey, developed by the Psychology Service, is distributed on an annual basis.

An Aftercare patient experience survey is distributed on an annual basis.

Results are analysed to inform the priorities and actions for the Annual Improvement Programme.

5. Clinical Governance

5.1 Clinical Outcomes / Indicators and Audits

In the course of their regular meetings, the CCNCG annually review the progress (or discuss the completed results, as relevant) of their associated MDTs' outcome indicators and audits, and the data examined across all its associated MDTs.

The TYA service organises a continual audit of the service provision offered across the South West.



6. Clinical Research

6.1 Discussion of Clinical Trials

The CCNCG discuss the MDT's report on clinical trials at every meeting, and annually with each of its associated MDTs, to agree a collaborative Annual Improvement Programme.

7. Appendices

7.1 Appendix 1



Peninsula and Somerset, Wiltshire, Avon and Gloucestershire Cancer Services
Meeting of Children's Cancer Network Group

Statement of Purpose: To deliver equity of access to the best medical practice for our patient population

Template Agenda

Network group membership to attend:

Chair; Lead Clinician of the PTC; Lead Nurse of the PTC; POSCU representative; Chief Executive representative from the CCN Trust; Area Team representative relevant to the CCN; Specialist Commissioner representative; User representative 1; User representative 2; Administrative support.

Date: xxx

Time: xxx

Venue: xxx

TIME	AGENDA ITEM	LEAD
09:30-10:00	Coffee and registration	
10:00-13:00	SWCTYA network meeting – children's meeting	Helen Rees
	1. Apologies, Minutes, introductions and matters arising	Helen Rees
	2. News items in brief from each SCC	All SCC leads
	3. Review of Action Log	Helen Rees
	4. Quality surveillance	Helen Rees
	5. Network quality standards <ul style="list-style-type: none"> • Psychology • Palliation • Aftercare • Transition 	All
	6. Nursing	Helen Morris

	7. Pharmacy /chemotherapy/chemocare	Vanessa Mcllelland
	8. Incidents & risk	Helen Rees
	9. Quality/Audit	Helen Rees
	10. Clinical pathways/clinical guidelines	Helen Rees
	11. User and patient experience	Helen Morris
	12. AOB - suggested	All to discuss
13:00-13.30	LUNCH	
13.30-15.30	JOINT CTYA MEETING 1. TYA service spec, age criteria and PTC – RD 2. NCEPOD Report - HR	ALL
15.30	CLOSE OF MEETING	

Dates of next meetings

- **Regional Meeting 7.3.19 – train disruption!!**
- **Network meeting: 17.9.19**

Attendance

√ - present

x-absent/apologies

NAME	SIGNATURE	CENTRE/ROLE
Dr Helen Rees		Bristol - Network Clinical Lead, MDT lead & Research Lead.
Dr John Moppett		Bristol - MDT lead
Dr Rachel Cox		Bristol - MDT lead
Jon Miller		NHS England
Vanessa Mcllelland		Bristol - Network Pharmacy lead
Sue Dolby		Bristol Psychology
Laura Baker		Bristol Psychology
Josie Steel		Bristol Psychology
Helen Morris		Bristol – Network Lead nurse
Dr Polly Bates		Bath

Dr Jagadeesh Ramachandran		Bath
Alison Richardson		Bath
Sarah Fay		Bath
Dr Thomas Kus		Gloucester
Dr Augusta Isaacs		Gloucester
Kelly Prosser (CNS)		Gloucester
Claire Harrison (CNS)		Gloucester
Dr Myooren Wimalendra		Plymouth
Dr Claire Turner		Plymouth
Tanya Crago (CNS)		Plymouth
Dr Katrina McDonald		Truro
Dr Shama Goyal		Truro
Karen Berriman (CNS)		Truro
Janey Smejkal (CNS)		Truro
Andre Clinchant (CNS)		Taunton
Olivia Lines (CNS)		Taunton
Dr Linda Whiteford		Taunton
Dr Polly Powell		Taunton
Alex Stannett (CNS)		Yeovil
Dr Chris Zabarowski		Yeovil
Dr Camelia Vaina		Yeovil

Dr Corinne Hayes		Exeter
Dr Simon Parke		Exeter
Janine Roberts		Exeter
Louise Taylor (CNS)		Exeter
Andrew Cooper		CLIC Sargent
Rachel Banks		CLIC Sargent

7.2 Appendix II

Clinical Guideline

PSYCHOSOCIAL ASSESSMENT OF HAEMATOLOGY/ONCOLOGY/BMT PATIENTS AT INTEGRATED CARE MEETING

SETTING	Bristol Royal Hospital for Children - Haematology/Oncology/BMT service
FOR STAFF	Nursing and medical staff
PATIENTS	Paediatric Haematology/Oncology/BMT patients and carers

GUIDANCE

Background

All patients/carers entering the Haematology/Oncology/BMT service require a psychosocial assessment. This should be undertaken by team around the patient and be multidisciplinary and then presented at the weekly integrated team meeting. Further assessments will be undertaken at certain time points in the patient journey, for example during treatment, during follow-up, at relapse, and for family/carers at bereavement

Attendees at Integrated care

- Consultants

- Junior Doctors
- Clinical Nurse specialists
- Ward nurse/ODB representatives
- Social worker
- Teacher
- Play specialists
- Dieticians
- Physiotherapists
- Hospice staff
- Palliative care consultant
- MDT coordinator
- Psychologists
- Other relevant staff as required

Patients to be presented at Integrated care

- New Patient
- Palliative Update
- Significant change in needs

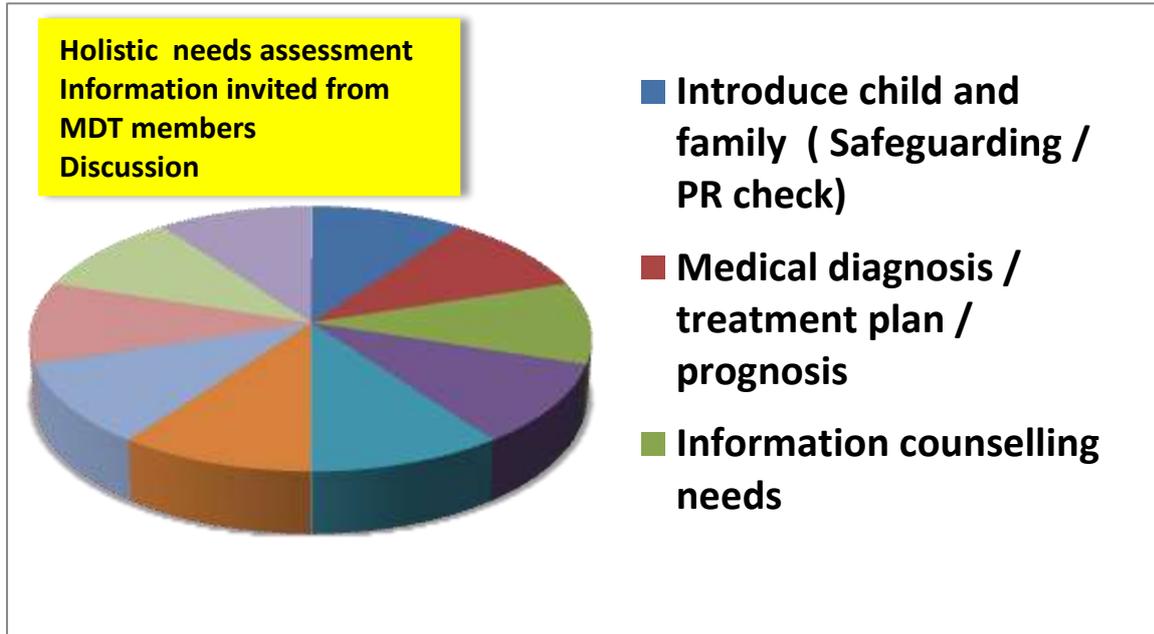
Reasons for presentation

- For information only
- For reflection / discussion
- For liaison/planning

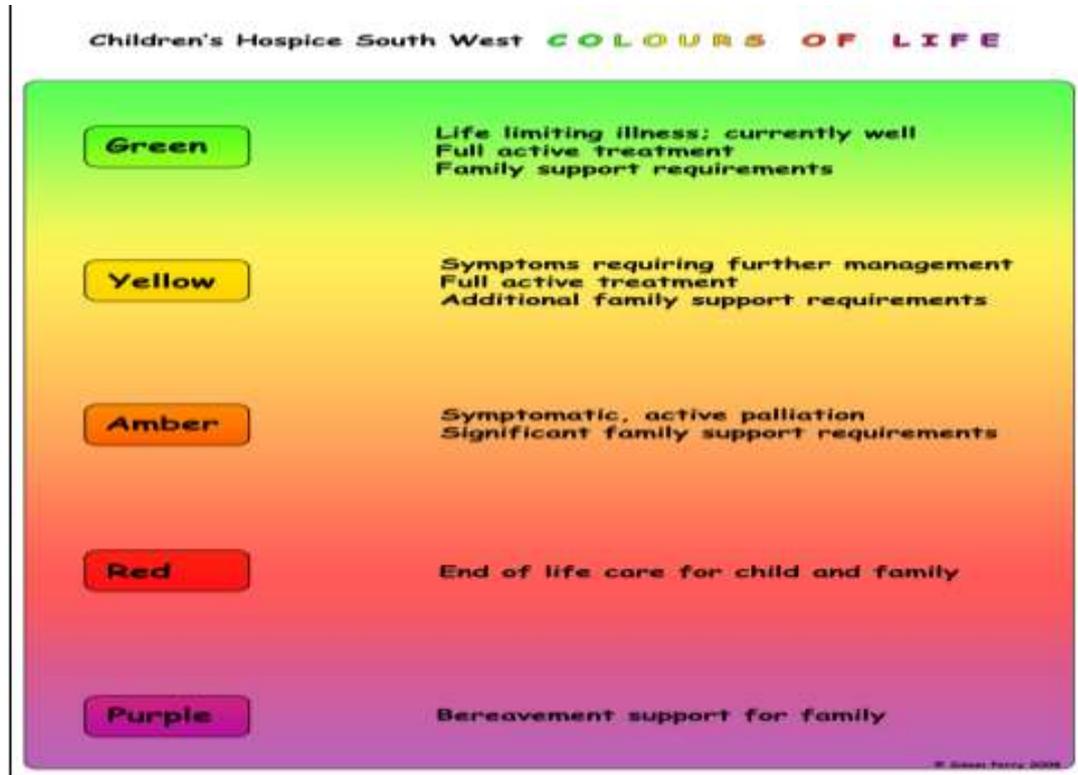
Data to be presented

- DOB:
- Location:
- NHS number:
- Shared care team:
- Diagnosis/Prognosis:
- Treatment plan & location:
- Consultant:
- CNS (s):
- Clic SW:

Discussion during meeting



All patients should be assessed against Colours of Life and any actions agreed are then documented, along with the finalised named team around the patient at PTC and Shared Care. The action documentation is then shared to relevant staff.



7.3 Appendix III

PAEDIATRIC HAEMATOLOGY, ONCOLOGY AND BMT DEPARTMENT

STANDARD OPERATING PROCEDURE

TITLE: LONG TERM FOLLOW UP / LATE EFFECTS SURVEILLANCE

Code: 6.17	PHO/SOP/LTFULESV02	Issue No:	04	No. of Pages:	11	Copy No:	
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Replaces: PHO/SOP/LTFULESV02 Issue 03
 Revision details: New appendices 1 & 3

1. INDICATIONS FOR PRACTICE

1.1 As survival from cancer in childhood / adolescence has improved, there is an increasing need to assess quality of survival, continue to support these individuals and to make provision for review and management of actual or potential medical and psychosocial problems in the increasing population of survivors. This provision must meet the needs of survivors both during adolescence and in adult life. It must provide a holistic approach reviewing medical, social, psychological, emotional, and financial / employment needs.

2. AUTHORISED PERSONNEL/TRAINING REQUIRED

- 2.1 Experienced medical personnel, late effects nurse specialists, psychologist, social worker, dietician and general practice support.
- 2.2 Close links with cardiology, endocrinology, gynaecology, fertility services, respiratory and renal services.

3. PROCEDURE

3.1 DEFINITIONS

There is no consistent definition of the terms 'survivor', 'late effects' or 'long term follow up'. For the purposes of this document these are defined as follows:

- Survivor: All patients who are at least 5 years from first diagnosis and 3 years since completion of last therapy for their primary or any subsequent cancer.
- Late Effects: The actual or potential impact of cancer diagnosis and its treatment on subsequent health, educational or psychosocial well being.
- Long Term Follow Up: Continuing contact between health services and survivors (defined above) in relation to screening for, or management of, Late Effects (defined above). This includes contacts with hospital and primary care services or remote (postal / telephone follow up).

ISSUED BY:	NAME	DATE
PROGRAMME QUALITY MANAGEMENT ADMINISTRATOR	Sandrine Jones	13 th Nov 2017

Effective Date:	13 th Nov 2017	Review Date:	13 th Nov 2019	Obsolete Date:	13 th Feb 2020
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7.4 Appendix IV

PAEDIATRIC HAEMATOLOGY / ONCOLOGY END OF TREATMENT SUMMARY

Bristol Consultant:

Shared Care Centre:

Date of Diagnosis:

Diagnosis:

Primary treatment / Relapse:

Cancer Risk and Pre-existing Conditions:

Treatment details:

Protocol Name / Individualised: On Trial:	Trial FU until: Modified: Why:
End of Treatment Date:	
Chemotherapy: (see reverse for drug details)	
Radiotherapy:	Dates:
Special techniques:	Dose / fractions:
Sites:	
<small>Attach plan or copy of letter detailing organs at risk</small>	
Surgery: (state if not performed in Bristol)	Dates:

End of treatment summary sheet, Issue 02

7.5 Appendix V

UBHT PAEDIATRIC ONCOLOGY LONG TERM FOLLOW UP SUMMARY SHEET

PATIENT DETAILS				
Surname:		Forename:		
BRHC no:		DoB:		
Diagnosis:		Date of diagnosis:		
Shared Care Clinic:		Date first seen in LTFU clinic:		
Relapse:	1.	Date:		
	2.	Date:		
Second Malignancy:		Date:		
Pre existing Risk Factors:				
TREATMENT SUMMARY				
Chemotherapy				
Protocol 1		From	To	
Protocol 2		From	To	
Protocol 3		From	To	
Radiotherapy				
Site 1	Dose	From	To	
Site 2	Dose	From	To	
Site 3	Dose	From	To	
Surgery				
1.		Date		
2.		Date		
3.		Date		
LONG TERM FOLLOW UP ISSUES				
		Date active	/	Date Inactive
1.				
2.				
3.				
4.				
5.				
6.				

7.6 Appendix VI

SWAftercare Service MDT Clinical Review																											
Date	Age	Label1																									
Level of Care:																											
Key worker:																											
Treatment Summary	Y N																										
Care Plan	Y N <input type="checkbox"/>																										
		<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 15%;">BMI</th> <th style="width: 30%;">Height (cm)</th> <th style="width: 30%;">Weight (kg)</th> <th style="width: 25%;"></th> </tr> </thead> <tbody> <tr> <td style="background-color: #e0e0e0;"></td> <td style="background-color: #d2b48c;"></td> <td style="background-color: #add8e6;"></td> <td></td> </tr> <tr> <td style="background-color: #add8e6;">BP</td> <td style="background-color: #add8e6;"></td> <td style="background-color: #add8e6;">Repeat BP if Needed:</td> <td style="background-color: #f08080;"></td> </tr> </tbody> </table>	BMI	Height (cm)	Weight (kg)						BP		Repeat BP if Needed:														
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Other Professionals involved in care:																											
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CURRENT CONCERNS (including new diagnoses since last clinic visit):																											

7.7 Appendix VII

PAEDIATRIC HAEMATOLOGY, ONCOLOGY AND BMT DEPARTMENT
STANDARD OPERATING PROCEDURE

TITLE: END OF TREATMENT PROCEDURES

Code:6.18	PHO/SOP/EOTPV03	Issue No:	03	No. of Pages:	03	Copy No:	
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Replaces: PHO/SOP/EOTPV03, Issue 02 Revision details: No changes required. SOP re-issued

1. INDICATIONS FOR PRACTICE

- 1.1 To plan the long term-follow up of a child treated for cancer.
- 1.2 To ensure that the 'End of Treatment Summary' sheet has a record of all necessary information required to produce an individualised plan for long term follow up.

2. AUTHORISED PERSONNEL/TRAINING REQUIRED

- 2.1 The Lead Clinicians and registrars and or shared care consultants will be responsible for completing the end of treatment summary on patient discharge form ward or Oncology Day Beds (ODB) when a patient completes their treatment.

3. PROCEDURE

3.1 END OF TREATMENT SHEET

The summary sheet is located on the UHBristol intranet in the SWAftercare site. Shared Care Units (POSCUs) can obtain a copy from Divya Bassi, Aftercare Care Co-ordinator, via SWAftercare@UHBristol.nhs.uk.

The End of Treatment sheet should be completed for all patients completing treatment within our service with a more detailed letter attached if required for complex patients. A further 'End of Treatment' sheet should be completed for an episode of relapse. This should be filed in a plastic envelope in the front of the notes and for UHBristol patients put onto CDS. A copy should be emailed to the SWAftercare care Co-ordinator.

3.2 COMPLETING THE END OF TREATMENT SHEET

This must be completed within three months from the end of treatment. This date should be documented by the treating MDT – solid, neurooncology, haematology or BMT.

The sheet must be completed with the patient's:

- Forename, surname, hospital number and birth date.
- Diagnosis and date, including site, stage and histology/pre-existing risk factors and pertinent secondary diagnoses e.g. Downs syndrome and NF1.

ISSUED BY:	NAME	DATE
PROGRAMME QUALITY MANAGEMENT ADMINISTRATOR	Sandrine Jones	7 th November 2017

Effective date:	7 th November 2017	Review date:	7 th November 2019	Obsolete Date:	7 th February 2020
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7.8 Appendix VIII

List of Abbreviations

CCLG	Children's Cancer and Leukaemia Group
CCN	Children's Cancer Network
CCNCG	Children's Cancer Network Co-ordinating Group
CE	Chief Executive
D and T MDT	Diagnostic and Treatment Multidisciplinary Team
DCC	Direct clinical care
ENB	English Nursing Board (now disbanded)
EQA	External quality assurance
HDU	High dependency unit
ITC	Intrathecal chemotherapy
ITU	Intensive care unit
MDT	Multidisciplinary team
NSCG	National Specialist Commissioning Group
ODP	Operating department practitioner
PA	Programmed activity
PCT	Primary care trust
POSCU	Paediatric oncology shared care unit
PTC	Principal treatment centre
PTCCG	Principal Treatment Centre Chemotherapy Group
RCN	Royal College of Nursing
RN	Registered nurse
RSCN	Registered sick children's nurse



Peninsula and Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance

SCG Specialist commissioning group

SLA Service level agreement

ST3 Specialist trainee (Level 3) TYA Teenage and young adults

TYACN Teenage and Young Adults Cancer Network

TYACU Teenage and Young Adults Cancer Unit

WTE Whole time equivalent

-END-