

**Advanced Clinical Practitioner**

**Paediatric Oncology & Haematology Capability Document**

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**On behalf of the CCLG ACP Forum March 2022**

This resource has been endorsed by the Royal College of Nursing until March 2023. Endorsement only applies to the professional content of the resource.

**ACKNOWLEDGEMENTS**

For the purpose of this document service users are defined as Advanced Clinical Practitioners and other key stakeholders within the healthcare environment.

We would like to thank the members of the Children’s Cancer and Leukaemia Group (CCLG) Advanced Clinical Practitioner (ACP) Forum, the Executive Committee of the CCLG, Simon Dean, Paediatric Oncology Advanced Nurse Practitioner, Leeds General Infirmary, Dr Mark Velangi Consultant Paediatric Haematologist, Birmingham Women and Children’s Hospital NHS Foundation Trust and Dr Dan Yeomanson, Consultant Paediatric Oncologist, Sheffield Children’s NHS Foundation Trust for reviewing the draft of this capability document.

It is acknowledged that although there will be a benefit to patients and their families through an ACP completing this national capability document, the authors did not approach a Patient and Public Involvement group for comment.

**REVIEW**

The document has been embraced by the CCLG ACP forum and is already in use. Due to the nature of the document and its intention to be used as an ongoing training and continuous professional development tool (CPD), it will be reviewed annually for the first three years by obtaining service user feedback and amendments made as necessary.

This competency document will be formally reviewed every 3 years part of the CCLG ACP Forum. To provide feedback on this document or your experience in using it please email helen.woodman@nhs.net or sally.spencer3@nhs.net

**CONFLICT OF INTEREST**

There is no known conflict of interest. There was no funding support or sponsorship and no financial gain from producing the document. The document was created by and for the use of the key stakeholders, the ACP Forum.

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**ENDORSEMENT**

This resource has been endorsed by the Royal College of Nursing until March 2023. Endorsement only applies to the professional content of the resource.

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**CAPABILITY ASSESSMENT FOR PAEDIATRIC ADVANCED CLINICAL PRACTITIONERS**

**To be completed by the Advanced Clinical Practitioner**

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| --- | --- |
|  |  |
| **Name of Practitioner (please print):** |  |
|  |  |
| **Ward/Department:** |  |
|  |  |
| **Band/Job Title:** |  |
|  |  |
| **Professional Registration Number:** |  |
|  |  |
| **Signature of Self Declaration confirming achievement of pre-requisite knowledge and skills:** |
|  |  |
| **Signature:** |  | **Date:** |  |

**To be completed by the Clinical Supervisor**

|  |  |
| --- | --- |
|  |  |
| **Name of Supervisor (please print):** |  |
|  |  |
| **Department:** |  |
|  |  |
| **Job Title:** |  |
|  |  |
| **Signature confirming Practitioner has achieved pre-requisite knowledge and skills:**  |
|  |  |
| **Signature:** |  | **Date:** |  |

**Section 1 INTRODUCTION**

Cancer in children and young people is rare. It is often found in different parts of the body, looks different under the microscope and responds differently to treatment compared to ‘adult’ cancers (CCLG, 2021). Cancer and its management in this young population presents a unique set of challenges for the patient, family and healthcare providers. In order to fulfil these challenges and care for the child and family holistically, specialist roles within oncology and haematology have been developed, of which the ACP is one.

It is well recognised within the literature that it is difficult to define the role of the Advanced Clinical Practitioner (Hewison, 2009, Currie and Grundy 2011, Halliday et al, 2018). Historically, ACP roles have developed without clear boundaries or recognised remit, with individual roles being developed to support local service need and development (Paniagua, 2010 and McNab 2020). As a result of this, roles within specific specialisms such as cancer care have developed in an unregulated and confusing way (Behi, 2006). According to the International Council of Nurses, essential agreed attributes of those working in advanced practice are; to have an expert knowledge base, be able to work autonomously and to make complex decisions whilst also having expanded clinical skills (ICN, 2020). It is important, therefore, for patient safety and effectiveness of nursing practice that nationally agreed benchmarks for Advanced Practice are agreed (Behi, 2006).

The British National Paediatric Oncology and Haematology ACP group was formed in Autumn 2018 and is a recognised speciality group within the CCLG. The group is made up of ACPs from the four nations of the United Kingdom. It was quickly established within the group that roles and responsibilities were diverse and there was no standard document by which to record and assess clinical competence, capability and ongoing professional development.

This document has been produced following a review of the Framework of Competencies for Level 3 Training Special Study Module in Paediatric Oncology (Royal College of Paediatrics and Child Health, 2010) and the General Practice Advanced Nurse Practitioner Competencies (Royal College of General Practitioners, 2015). The RCN Advanced Practice Standards have also been taken into account (Royal College of Nursing, 2018).

It is widely accepted that competency documents are necessary to demonstrate knowledge and safe practice within healthcare professions. The term competence is often used to describe practice that occurs in stable and familiar environments; Capabilities however have been attributed with roles and environments that are unpredictable and are more in line with the autonomy of advanced practice roles (O’Connell et al, 2014). This document is therefore a capability framework.

**Section 2: CONTEXT OF THE CAPABILITY DOCUMENT**

This document is for trainee and qualified Advanced Clinical Practitioners who wish to work towards an expertise in primarily Paediatric Haematology and Oncology malignant conditions. However, it is recognised that these practitioners may also work with patients with non-malignant haematological conditions and so capabilities for these are included within the document. This is also a guide for clinical supervisors.

Prior to completion of this document you must have completed a recognised Advanced Practice Masters level course. The training will have included history taking, full clinical examination and independent prescribing. You will also have experience and expertise mapped against the four pillars of Advanced Practice; clinical practice, management and leadership, education and research and will be working within your scope of professional practice. These four pillars form a synergistic platform for the practitioner to develop a holistic approach to patient centred care (McNab, 2020).

The framework gives you and your supervisor guidance about the common core capabilities and the wider range of skills, knowledge and behaviours you need in order to work at advanced level within the speciality. It is important to recognise that it may take time for you to develop and consolidate the knowledge and skills to fulfil these capabilities and that your progress will be individual and dependent on your initial level; you may have a significant level of nursing experience but be a novice to Advanced Practice or the speciality. It will help you to consistently deliver high standards of evidenced based care; improve professional relationships through greater understanding of responsibilities and identify gaps in your knowledge or skills where you may require further education or development. Not all aspects will be required by all practitioners and will be dependent on your specific role. Evidence of capability should be agreed with your supervisor on an individual basis.

This document is written for use in the four countries of the United Kingdom. Users will need to ensure that local context is applied where appropriate. It may also be beneficial for employers and managers to use as a tool when developing or expanding services or workforce planning; to support funding applications for roles and service expansion giving a clear insight into the expertise and competence of the practitioner and will be a benchmark to assist professional development and practice revalidation.

Patients and their families will benefit from this national document as it will ensure consistency of the ACP role and high standards of practice throughout the United Kingdom. It will also improve the effectiveness of service provision and holistic care at the point of delivery.

**PROFESSIONAL DEVELOPMENT**

You may use this document as a framework to gain capabilities and for annual review as part of performance appraisal. This document may also be used to provide evidence during the revalidation process for nurses (NMC, 2018) or Continuing Professional Development Audits (CPD Audit) for allied health professionals registered with the Health and Care Professions Council (HCPC).

**Section 3: BACKGROUND**

**All practitioners will have knowledge and awareness of:**

* The incidence and mortality rates for common childhood cancers and/or other non-malignant haematological conditions.
* The aetiology and epidemiology of childhood cancers and/or other non-malignant haematological conditions.
* National, regional and local cancer registration policies.
* The role of clinical trials in childhood malignancy.
* The features and clinical presentations of childhood malignancy.
* The principles of cancer treatment and the rationale of systemic anti-cancer therapy (SACT) regimens and evolving therapies.
* The principles of high dose therapy and stem cell transplantation.
* The principles of radiotherapy and its role in the management of paediatric malignancies.
* The acute toxicity of cancer treatment (individual drugs and radiotherapy).
* The late effects of therapy including endocrine consequences, major organ toxicities and their causative agents.
* The other agencies able to support families of children with cancer.
* The importance of regular and effective communication between PTC (Principal Treatment Centre) and POSCU (Paediatric Oncology Shared Care Unit) or other shared care units.
* The issues around developing and sustaining effective and safe shared care of paediatric haematology/oncology patients within a regional service.
* The difficulties in discussing consent issues e.g. consent for a randomized clinical treatment trials.
* Good Clinical Practice (GCP) in line with the European Directive for all aspects of the conduct of clinical trials and have undertaken recognised GCP training.
* The importance of accurate return of toxicity data.
* The national cancer peer review process and other relevant national guidance.
* If working with patients who have non-malignant haematological conditions the practitioner will have knowledge and awareness of clinical presentation, treatment strategies and other relevant guidance.

**Section 4: HOW TO USE THE CAPABILITY FRAMEWORK**

* The document provides a breadth of skills and knowledge that are within the remit of an ACP working in the speciality of Paediatric Oncology and Haematology. There are some generic capabilities and some very role specific, which it is acknowledged will not be appropriate or relevant for everyone. However this document aims to be as inclusive as possible within the speciality.
* It is recommended that at the start of using this document you identify with your clinical supervisor the priority capabilities that are related to your specific role requirements to ensure these can be completed in an agreed time frame. As your experience and confidence increases you may identify other areas of practice which you can include within your personal scope and remit.
* The framework is designed to be an ongoing professional development tool that is held electronically and updated at frequent intervals.
* During the preceptorship or trainee ACP period this will be more frequent and you should negotiate an action plan with your clinical supervisor, setting allocated time for reviews and feedback.
* You will be required to work with your clinical supervisor or another agreed clinical mentor in order to gain many of the clinical capabilities.
* You will need to review the taxonomy of achievement levels and agree with your clinical supervisor the following:
	+ The initial level; for example some skills and knowledge you will be inexperienced but an advanced beginner (Level 1) others you may be Level 2 or 3.
	+ The final level to be achieved on a capability – this will be role specific and individualised. This must be discussed and agreed at the first review.
	+ How you demonstrate completion of the capability – some may be by direct observation, case discussion, reflection, supervisor or colleague feedback.
* Each time you have a review the current level of practice column should be updated to show progression, acquisition of skills and knowledge and demonstration of safe clinical practice.
* With the agreement of your clinical supervisor your capabilities may be signed by another suitably qualified health professional; however the overall completion of capabilities must be signed by your named clinical supervisor.
* The document should be used as a foundation portfolio for continuous professional development enabling self-assessment and regular review of capability level; ensuring practitioners continue to work within their recognised scope of practice whilst identifying opportunities for learning and development.

Benners (1984) Stages of Skill Acquisition have formed the basis of the taxonomy of achievement for this document (See page 14 for more details on the Taxonomy of Achievement). Benners (1984) stages of development were:

Stage 1 – Novice

Stage 2 – Advanced beginner

Stage 3 – Competent

Stage 4 – Proficient

Stage 5 – Expert

Benners (1984) taxonomy was considered, but ‘Stage 1 – Novice’ does not reflect the baseline skills and knowledge of a trainee or established ACP. Therefore it was agreed that the first stage would be Advanced beginner as per the taxonomy of achievement used by the General Practice Advanced Nurse Practitioner Competencies (Royal College of General Practitioners, 2015).

This document acknowledges that to be an ACP you must have some advanced general clinical skills and theoretical knowledge. It is likely that you will achieve different levels of capability within the framework of the document, depending on the specific requirements of your role. It is agreed within the CCLG ACP Forum that advanced practice is classified at Grade 3 (Capable and proficient) or Grade 4 (Expert).

Please remember that you do not have to achieve all the capabilities – you must identify the relevant sections with your clinical supervisor in accordance with your role, scope of practice and local service requirements.

**Who can be your Clinical Supervisor?**

* Your clinical supervisor must be identified and agreed at the start of your preceptorship/training and ongoing use of the document.
* Your clinical supervisor must be either an Advanced Clinical Practitioner who is advanced and competent in the speciality or a medical practitioner; either Speciality Registrar at ST7/8 or Consultant. Clinical mentors must also be recognised at this level.
* Your clinical supervisor must be able to commit time to you, your training and reviews.

**TAXONOMY OF ACHIEVEMENT**

|  |  |  |
| --- | --- | --- |
| **Grade** | **Classification** | **Description of behaviour by Advanced Clinical Practitioner** |
| **1** | **Inexperienced but advanced beginner** | * Able to practice under close supervision
* Has reasonable theoretical knowledge and clinical skills
* Has prior knowledge of the situation and has observed relevant practice
* Respects the patient and family
 |
| **2** | **Borderline capable** | * Able to practice with minimal supervision
* Sound underpinning knowledge and clinical skills
* Integrates theory into practice and identifies priorities
* Communicates satisfactorily with other professionals
* Manages own workload with minimal supervision
* Patient and family centred approach
 |
| **3** | **Capable and proficient** | * Capable to practice autonomously
* Very good theoretical knowledge and clinical skills
* Demonstrates  a systematic application of knowledge and critical awareness
* Demonstrates high level of decision making
* Works effectively within the multidisciplinary team
* Liaises and communicates effectively within the multidisciplinary team and with other specialities/agencies
* Advanced communication skills; including the ability to have difficult or complex conversations with the patients and family
 |
| **4** | **Expert** | * Acts autonomously, disseminates knowledge and can supervise learners within the multidisciplinary team
* Excellent in-depth theoretical knowledge and clinical skills
* Shows intuitive understanding of critical situations and can troubleshoot problems that may arise
* Initiates innovative practice and continuously reviews the service and development
* Patient and family are at the centre of care and service development
 |

**Section 5: CAPABILITY FRAMEWORK ASSESSMENT**

| **Performance Criteria** | **Capabilities** | **Initial Level****Signature and Date of ACP and Clinical Supervisor** | **Final Level to be Achieved****Agreed by ACP and Clinical Supervisor****Signature and Date** | **Current Level** **(If progressive practice)****Signature and Date of ACP and Clinical Supervisor** | **Comments/Evidence** | **Final Level Achieved** **Signature and Date of ACP and Clinical Supervisor** |
| --- | --- | --- | --- | --- | --- | --- |
| **EXAMPLE** | **The practitioner should be able to lead and make autonomous clinical decisions where appropriate in:*** The management of febrile neutropenia including management after failure of first line antibiotic therapy
 | **2*****HW 02/01/21******SS 02/01/21*** | **4*****HW 02/01/21******SS 02/01/21*** | **3*****HW 02/02/21******SS 02/02/21*** | Summary of evidence of learning and achievement would be documented here with examples/comments. Wider evidence could be held electronically. | **4*****HW 05/03/21******SS 05/03/21*** |
| **Generic Clinical Decision making & Skills** | **The practitioner should be able to lead and make autonomous clinical decisions where appropriate in:*** The management of febrile neutropenia including management after failure of first line antibiotic therapy
 |  |  |  |  |  |
| * The investigation and management of bacterial, fungal and viral infections in the immuno-compromised child
 |  |  |  |  |  |
| * Formulating a symptom control plan for pain management recognising the different patterns of pain and their different therapeutic interventions including non-pharmaceutical approaches
 |  |  |  |  |  |
| * The management of symptoms such as breathlessness, bowel obstruction, urinary retention
 |  |  |  |  |  |
| * The management of neurological deterioration in the haematology/oncology patient
 |  |  |  |  |  |
| * The overall management of central venous access catheters including trouble shooting and emergency situations
 |  |  |  |  |  |
| **The practitioner should:*** Demonstrate a proactive multi-disciplinary approach to nutritional assessment in children receiving treatment for cancer
 |  |  |  |  |  |
| * Demonstrate the ability to do a holistic assessment and escalate to other healthcare professionals appropriately (e.g. other speciality, dietician, physiotherapy etc)
 |  |  |  |  |  |
| * Initiate innovative practice
 |  |  |  |  |  |
| **If taking consent the practitioner must:*** Undertake GCP training and updates
 |  |  |  |  |  |
| **Patients receiving Systemic Anti-Cancer Therapy****(SACT)** | * Demonstrates an excellent knowledge of how to interpret and enact treatment protocols, including:
* supportive care required
* dose adjustments and omissions
* disease and toxicity reassessment time points and imaging/tests required e.g. MRI, CT, GFR, ECHO, BMA.
* the interactions that can occur between different treatment modalities
 |  |  |  |  |  |
| * Be able to appropriately carry out a pre-chemotherapy assessment including:
* fitness for treatment,
* exploring previous experiences of treatment
* interpretation of vital signs
* toxicities and side-effects
 |  |  |  |  |  |
| * Understand and assess specific treatment side effects e.g. peripheral neuropathy, constipation, mobility
 |  |  |  |  |  |
| * Pre-empt SACT related issues and develop management plans
 |  |  |  |  |  |
| * Demonstrate an excellent knowledge to recognise the correct level of emetogenicity for specific chemotherapy and prescribe appropriately
 |  |  |  |  |  |
| * Be able to prescribe, handle and administer chemotherapy safely using an electronic prescribing package where available
 |  |  |  |  |  |
| * Be able to recognise and manage SACT related emergencies including:
* acute chemotherapy drug reactions
* extravasation of chemotherapy agents both peripherally and centrally
 |  |  |  |  |  |
| **Radiotherapy**  | **Demonstrates:*** A sound understanding of radiotherapy; the different treatment modalities e.g. Photons v Protons; its role in the management of malignant conditions; the potential acute and long term side effects
 |  |  |  |  |  |
| * An understanding of the referral pathway for different treatments
 |  |  |  |  |  |
| * Collaborative working relationships with the radiotherapy team
 |  |  |  |  |  |
| * The ability to manage/assess a patient admitted with radiotherapy side effects
 |  |  |  |  |  |
| * Understanding of relevance of full blood count in relation to radiotherapy and actions required
 |  |  |  |  |  |
| * Ability to perform a skin assessment and the very specific management required and have knowledge of when to escalate to radiotherapy clinical team
 |  |  |  |  |  |
|  | * Understanding of potential SACT and radiotherapy interactions/radio-sensitisers and timings of regimens
 |  |  |  |  |  |
| **Radiological investigations** | * Have an understanding of specific radiological investigations and when appropriate to use
 |  |  |  |  |  |
| * Be able to make clear and concise patient management plans based on findings of radiological imaging
 |  |  |  |  |  |
| * Complete the online training, e-IRMER, if requesting investigations and update every 3 years as per IRMER guidelines
 |  |  |  |  |  |
| **Patients having general anaesthesia for procedures**  | * Show an awareness of the booking process for theatre/procedure lists
 |  |  |  |  |  |
| * Have an awareness of the consent process and is able to participate at the level agreed locally (including GCP training)
 |  |  |  |  |  |
| * Independently assess a child/YP’s fitness for procedures under general anaesthesia including:
* clinical examination of the child/YP including exploring previous experiences with general anaesthetic
* recognition of blood results and any actions required for all haematology/oncology procedures
* communication of any potential post op complications to the child/YP and family
 |  |  |  |  |  |
| **Haematopoietic Stem Cell Transplant****(HSCT)** | * Demonstrate an understanding and can educate colleagues regarding allogeneic and autologous stem cell transplant and their role in overall treatment for all diagnoses
 |  |  |  |  |  |
| * Be able to pre-assess children/YP starting conditioning pre HSCT including chemotherapy and Total Body Irradiation (TBI) including:
* clinical examination and recognition of fitness for HSCT
* prescription of supportive care including anti-
* emetics, infection prophylaxis and any other medications
 |  |  |  |  |  |
| * Demonstrate sound under pinning knowledge of toxicities and expected side-effects of the conditioning agents and required supportive care for the child/YP
 |  |  |  |  |  |
| * Recognise the complications of HSCT including:
* graft-vs-host disease (GvHD)
* veno-occlusive disease
* graft failure
 |  |  |  |  |  |
| * Have an awareness of the role of TBI in HSCT, including its short and long term side effects
 |  |  |  |  |  |
| * Understand of the principles of immunosuppression and the types of immunosuppressive agents used in HSCT
 |  |  |  |  |  |
| * Understand of the consequences of myelosuppression and immunosuppression post-HSCT, including the need for infection prophylaxis
 |  |  |  |  |  |
| * Have an awareness of the late effects of HSCT in children, including growth, fertility and second malignancy
 |  |  |  |  |  |
| * Be able to review a patient post HSCT and assess toxicity such as mucositis, GvHD, interpret findings and develop a management plan
 |  |  |  |  |  |
| * Have a sound understanding of how to assess graft function through Chimerism assessment, FBC differentials, immunosuppression drugs
 |  |  |  |  |  |
| * Be able to interpret Virology PCR results, discuss initiating treatment and know if more tests and/or further evaluation is required
 |  |  |  |  |  |
| * Understand the surveillance of immunosuppression drug level monitoring (Ciclosporin, Tacrolimus etc), and has the ability to interpret and act on these level
 |  |  |  |  |  |
| * Have an understanding of the prophylactic measures required for patients post HSCT
 |  |  |  |  |  |
| **Long Term Follow Up** | **Demonstrates:*** Knowledge and understanding of the late effects complications associated with cancer and non-malignant conditions that require SACT/radiation/ haematopoietic stem cell transplant
 |  |  |  |  |  |
| * A comprehensive understanding of treatment sequelae appropriate to own specialty area for example, endocrine, skeletal, developmental effects
 |  |  |  |  |  |
| * A clear understanding of the potential physical, psychological and social current and long-term consequences of cancer and its treatment on children and young adults
 |  |  |  |  |  |
| * Knowledge of the wider physical, psychological and social factors that can affect children and young adults treated with cancer
 |  |  |  |  |  |
| * The ability to complete End of Treatment Summaries and the importance of individualised care plans
 |  |  |  |  |  |
| * Specialist knowledge to recognise deviations in expected childhood and adolescent development
 |  |  |  |  |  |
| * Ability to recognise signs and symptoms of health problems associated with late effects care requiring urgent review by senior colleagues
 |  |  |  |  |  |
| * Expertise to prescribe, initiate, interpret and monitor diagnostic tests and investigations utilised within late effects care according to the child or young person’s clinical need
 |  |  |  |  |  |
| * Expert knowledge to independently assess, evaluate, select and implement appropriate late effects care plans according to patients’ clinical needs
 |  |  |  |  |  |
| * Ability to assess the impact of cancer diagnosis and treatment on lifestyle and future education and employment needs
 |  |  |  |  |  |
| * Understanding of the impact of diagnosis and treatment, particularly radiotherapy to the brain, on a child’s ability to learn
 |  |  |  |  |  |
| * An awareness of the need for specialized assessments (such as neuropsychology) that may influence the process of formal statutory assessment
 |  |  |  |  |  |
| * Ability to organise educational programmes to enable young people to improve their knowledge, confidence and skills to take more responsibility for self- management and self-care and make healthy lifestyle choices
 |  |  |  |  |  |
| * Ability to organise a long-term follow up programme and develop strategies for surveillance of survivors using national guidelines
 |  |  |  |  |  |
| * Ability to provide suitable information about transition from paediatric to adult care
 |  |  |  |  |  |
| * Ability to review self-management skills of young people to support adult care after transition
 |  |  |  |  |  |
| * Expertise to ensure smooth transition from paediatric care/hospital to adult care/hospital
 |  |  |  |  |  |
| **Haemoglobinopathy** | **Demonstrates:*** An understanding of the molecular basis of abnormal haemoglobins and thalassaemia syndromes
 |  |  |  |  |  |
| * An understanding of the epidemiology, presentation and natural history of sickle cell and thalassaemia syndromes
 |  |  |  |  |  |
| * Ability to describe the techniques for the diagnosis of haemoglobin disorders including an awareness of national screening programmes
 |  |  |  |  |  |
| * Ability to describe the diagnosis and management of specific major acute complications, including the acute chest syndrome, painful crisis, stroke
 |  |  |  |  |  |
| * Knowledge to explain the appropriate use of transfusion in sickle cell and thalassemia syndromes
 |  |  |  |  |  |
| * Ability to describe the complications, assessment and treatment of transfusion related iron overload
 |  |  |  |  |  |
| * Ability to describe the long term complications of haemoglobin disorders (including orthopaedic, ophthalmic, renal, pulmonary, endocrine and fertility issues) and their management, in particular need for comprehensive multidisciplinary care
 |  |  |  |  |  |
| * Understanding of the need to use disease modifying agents in haemoglobin disorders
 |  |  |  |  |  |
| * Understanding of the interacting abnormalities and competence in genetic counselling
 |  |  |  |  |  |
| * Ability to counsel patients appropriately on the benefits and risks of screening
 |  |  |  |  |  |
| * Appropriate use of transfusions and management of iron overload
 |  |  |  |  |  |
| * Ability to use and interpret appropriate screening methods for chronic organ damage
 |  |  |  |  |  |
| * Ability to lead and implement individual home treatment training
 |  |  |  |  |  |
| * Ability to evaluate training programmes
 |  |  |  |  |  |
| **Haemophilia** | **Demonstrates:*** Knowledge and skills to recognise signs and symptoms of bleeding
 |  |  |  |  |  |
| * A detailed knowledge of pathophysiology to explain presenting symptoms
 |  |  |  |  |  |
| * Knowledge and skills to assess physiological functioning and develop intervention plan
 |  |  |  |  |  |
| * Knowledge and skills to determine differential diagnoses, using examination and investigations
 |  |  |  |  |  |
| * Skills to perform venepuncture in non-problematic, complex and challenging situations
 |  |  |  |  |  |
| * Ability to administer coagulation factors
 |  |  |  |  |  |
| * Ability to formulate a care plan in liaison with other members of the HMDT
 |  |  |  |  |  |
| * Ability to co-ordinate more complex clinical interventions
 |  |  |  |  |  |
| * Ability to prescribe replacement therapy
 |  |  |  |  |  |
| * Ability to take a family history of a bleeding disorder and draw a family tree
 |  |  |  |  |  |
| * Ability to identify patterns of inheritance and using a family history identify patients with or at risk of a bleeding disorder and refer as appropriate
 |  |  |  |  |  |
| * Ability to recognise the impact that genetic information may have on individuals and families
 |  |  |  |  |  |
| * Ability to explain modes of inheritance to patients and families
 |  |  |  |  |  |
| * Ability to apply detailed genetic knowledge to inform treatment in complex situations
 |  |  |  |  |  |
| * Ability to order genetic tests and communicate results to patients and families
 |  |  |  |  |  |
| * Ability to advise children/young people and their families about managing coagulation factors including storage, administration, transportation and disposal
 |  |  |  |  |  |
| * Knowledge and skills to enable children and young people and families to monitor treatment planning and response
 |  |  |  |  |  |
| * Knowledge to identify the risk factors to health of menorrhagia for girls/women with bleeding disorders including symptoms and management initiating further referrals if required
 |  |  |  |  |  |
| * Ability to provide education and information to aid girls/women to make informed choices regarding treatment and management of menorrhagia
 |  |  |  |  |  |
| * Knowledge of the risk factors and ante-natal care pathways for carriers of haemophilia and women with bleeding disorders
 |  |  |  |  |  |
|  | * Ability to carry out the specific management plans required for pre-operative haemophiliac patients including:
* admission clerking
* relevant laboratory investigations
* factor replacement ordering and prescription
* liaison with wider MDT involved
 |  |  |  |  |  |
| **Transfusion and non-medical authorisation of blood products**  | **Has the required knowledge and training in blood product administration to:*** Recognise the indications for transfusion and treat appropriately
* Consent the child/YP for transfusion if required
* Prescribe the necessary blood products including special requirements such as irradiated blood products
* Diagnose and treat any transfusion reactions both mild and severe
* Counsel families appropriately regarding the requirement for short and long term irradiated blood products
 |  |  |  |  |  |
| * Knowledge about the hazards of blood transfusion including transfusion-transmitted infection and transfusion reactions
 |  |  |  |  |  |
| **Specific Additional Skills** | Demonstrates the technical skills to carry out a bone marrow aspiration and trephine biopsy * Be able to prescribe and administer intrathecal drugs safely according to local and national policies
 |  |  |  |  |  |
| **Additional individual Trust Specific Competencies** | * **Please add as required depending on individual roles and responsibilities**
 |  |  |  |  |  |

**Section 6: GLOSSARY OF TERMS**

ACP – Advanced Clinical Practice/Practitioner

BMA – Bone Marrow Aspirate

CCLG – Children’s Cancer and Leukaemia Group

CT – Computerised Tomography

ECHO – Echocardiogram

FBC – Full blood count

GCP – Good Clinical Practice

GFR – Glomerular Filtration Rate

GvHD – Graft versus Host Disease

HMDT - Haemophilia Multidisciplinary Team

HSCT – Haematopoietic Stem Cell Transplant

IRMER – Ionising Radiation (Medical Exposure) Regulations

MDT - Multidisciplinary Team

MRI – Magnetic Resonance Imaging

PCR – Polymerase Chain Reaction

SACT - Systemic anti-cancer therapy

TBI – Total Body Irradiation

YP – Young person

**Section 7: REFERENCES**

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