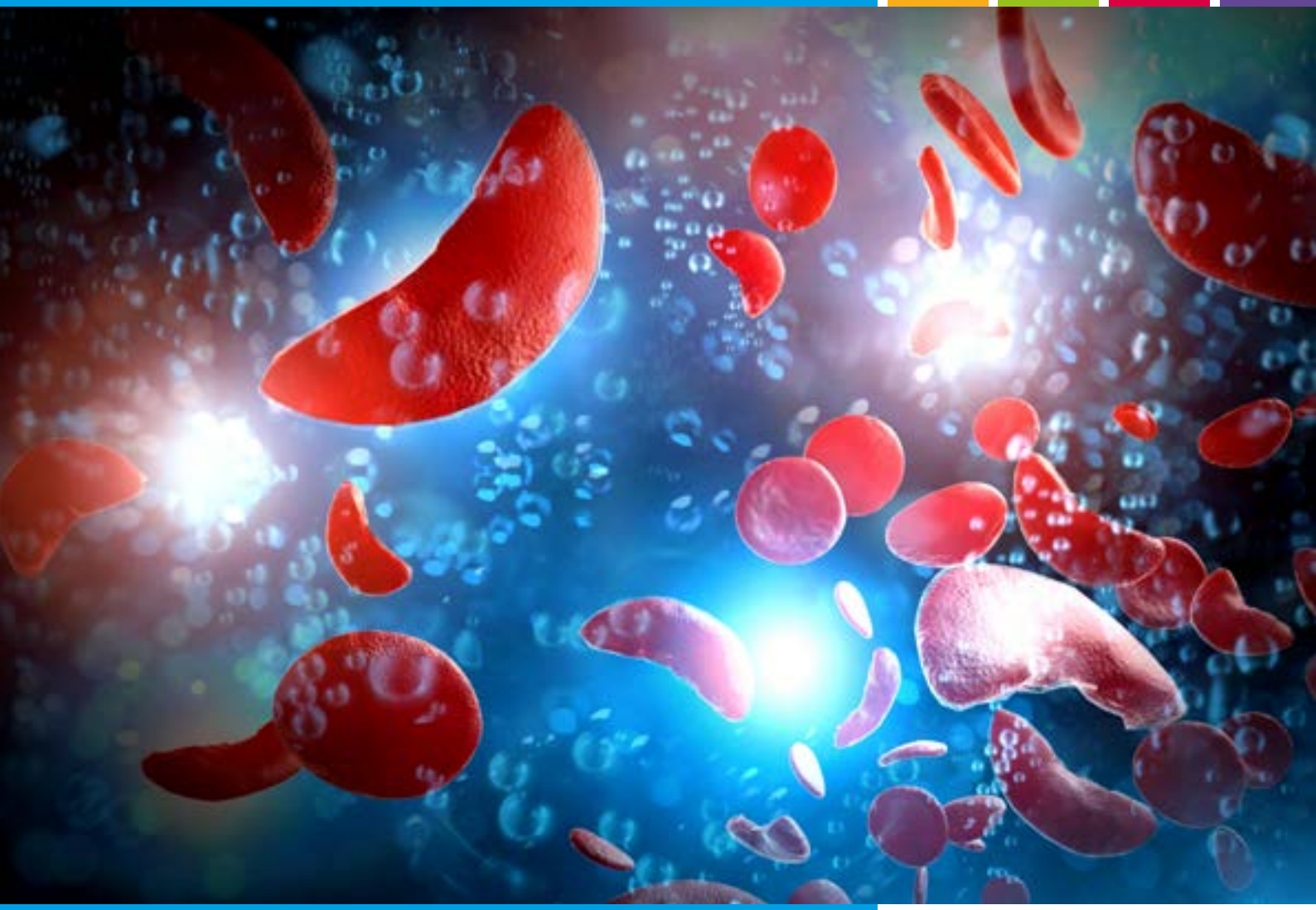
Royal College of Nursing

Caring for people with sickle cell disease and thalassaemia syndromes: a competency framework for nursing staff

CLINICAL PROFESSIONAL RESOURCE



Second edition, 2024

Acknowledgements

We listened to feedback from nurses across the country who care for patients with haemoglobinopathies in a variety of settings. This competency framework is intended to guide all health care professionals working with sickle cell and thalassaemia patients. The working group would like to thank everyone who has been involved in developing this patient-centred framework and the patients who gave their time and shared their views.

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Forewords

Royal College of Nursing (RCN)

The second edition of the Sickle Cell and Thalassaemia Competency Framework is welcomed at this pivotal time, when there is a significant spotlight and focus on the nursing workforce. The ability to provide robust, consistent, equitable and effective care to patients remains important. This updated framework is crucial for patients with sickle cell and thalassaemia disorders, as there remains a significant gap in awareness, understanding, knowledge and treatment of the conditions throughout the United Kingdom.

The competency framework describes the practical and theoretical skills that are required across the nursing workforce to ensure that quality, evidence-based care is provided. This type of care makes a real difference to reducing health inequalities and improving the health outcomes for people living with red blood cell disorders, which are termed haemoglobinopathies.

Gill Coverdale, RCN UK Head of Education

United Kingdom Thalassaemia Society and Sickle Cell Society

Thalassaemia and sickle cell syndromes are a group of complex lifelong conditions. Nursing staff who work with patients with these conditions require not only specialist knowledge but also empathy.

The lack of adequate sickle cell treatment and support was starkly highlighted in the inquiry by the All Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) into avoidable sickle cell deaths. The inquiry's report, *No One's Listening*, found failures in hospital care and identified suboptimal management of painful sickle cell episodes by the NHS as a particular concern.

This updated second edition of the competency framework reflects increasing recognition of the need to rapidly improve the experience of people living with sickle cell disease and thalassaemia syndromes, whether they are cared for in hospital or in the community.

We are delighted to see the inclusion of new chapters on managing iron chelation therapy and emphasis on early transitioning from paediatric to adult settings. Both are crucial in the management of thalassaemia.

We would like to say a big thank you to the authors and contributors for their dedication and hard work in updating this framework. It will be an invaluable asset in improving the quality of care and experience of our sickle cell and thalassaemia community.

We commend the 2024 RCN competency framework to all nurses and health care professionals supporting people living with sickle cell and thalassaemia disorders and their families.

Romaine Maharaj, Executive Director, UK Thalassaemia Society.

John James OBE, Chief Executive, Sickle Cell Society.

1. Summary

This Royal College of Nursing (RCN) competency framework for nursing staff who care for patients with sickle cell and thalassaemia syndromes has been updated to create a national framework that reflects modern-day, evidence-based care. It builds on the previous edition and defines the standards of care expected for all nurses working within the field of haemoglobinopathies. This updated version will allow for advancements in knowledge and professional development throughout a nurse's career.

This updated version will also introduce and encompass **the RCN Levels of Nursing: Enhanced, Advanced and Consultant nurse**.

2. Introduction

The RCN competency framework aims to ensure excellence in nursing practice and the upholding of equality and diversity, so that care and services are accessible to all. There is a need for greater understanding of sickle cell and thalassaemia conditions in clinical nursing practice, and for development of safe, effective and appropriate nursing care. Experts from the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS), together with members of the RCN Haematology Forum, have created competencies that can be used in clinical practice to enhance patient care. It is important to improve the quality and safety of care, in order to ensure positive patient outcomes.

Sickle cell and thalassaemia genes are inherited disorders of the haemoglobin. They mainly, but not exclusively, affect people of African, Asian, Caribbean, Mediterranean and Middle Eastern origin. An individual with a major condition has inherited a defective gene from both parents, resulting in a chronic lifelong condition where significant health issues may emerge. Long-term regular treatment is therefore required. Both sickle cell and thalassaemia conditions are associated with increased morbidity and mortality.

Individuals with sickle cell disease have a condition that consists of a chronic anaemia. The red cells elongate, causing vaso-occlusion, and patients experience bouts of severe pain, serious life-threatening infections and varying degrees of chronic complications. Analgesics (often opioids) are required to manage pain when it occurs, and prophylactic medications and disease-modifying agents are encouraged to reduce the risk of infections and improve prognosis. These will be required throughout the patient's life (2013, Serjeant GR).

Individuals with thalassaemia display a moderate to severe form of chronic anaemia, depending on the severity of the inherited thalassaemia mutation. This is a lifelong illness. Some of the other symptoms of beta thalassaemia may include one or more of the following: paleness, tiredness, low energy or muscle weakness (also called fatigue), palpitations, bone deformities (facial), an enlarged spleen and light-headedness or shortness of breath (2021, National Institute for Health and Care Excellence). More severe forms of thalassaemia are treated with regular blood transfusions, administered every two to six weeks for survival. This requires additional treatment with iron chelation therapy, which removes excess iron from the body (obtained from blood transfusions). Iron overload can result in the development of secondary conditions such as haemochromatosis and in multi-organ failure if not adequately managed.

3. Background

The first edition of this competency framework provided clear guidance on the skills and competencies required by nursing staff caring for people with sickle cell disease and thalassaemia. This second edition also incorporates the expertise of UK nurse experts, patients and their families/carers, haematologists, paediatricians, nurses, counsellors, psychologists, nursing education specialists, members of the RCN and others to ensure it is current and evidence-based.

The aims of the updated competencies are:

1. to improve nursing care for those with sickle cell disease and thalassaemia syndromes, and hence improve patients' lives
2. to provide an education and training framework for nurses wishing to pursue a career in sickle cell and thalassaemia care, so that they are encouraged to specialise and develop their careers in this area
3. to support nurses to understand the patient's journey, including their situation, perspective and feelings, and treat the patient and their family/carers with respect and dignity
4. to reduce health inequity and improve patient outcomes
5. to encourage nurses to listen to and reassure the patient about their concerns and take appropriate action
6. to encourage nurses to recognise the patient, and their family/carers, as experts in their own condition
7. to promote early recovery and minimise mortality and morbidity.

4. Framework structure and definitions

There are key distinctions between the levels of competence of nurses working in this field. The previous framework has been updated and the guidance will use the RCN Levels of Nursing that provide a framework for nursing beyond the level of a registered nurse to describe enhanced, advanced and consultant nursing

Nurses develop skills and understanding of patient care over time, through both a formal educational background and work experience. The levels of nursing recognise clinical knowledge and skill, rather than banding.

The framework has three sections:

1. **Level of achievement required**: Describes the level of competencies.
2. **Knowledge and understanding**: Describes the required knowledge and understanding of research and the underlying evidence base for safe and effective practice.
3. **Knows how to**: Describes how nursing staff will apply what they have learned to their practice.

These three sections are key to successful achievement of the competencies.

5. Using the competency framework

This framework should be used with the understanding that some competencies are not relevant to all clinical areas or specialist roles. The distinction between the levels are explained below.

1. Registered – new into the field

2. Enhanced

3. Advanced

4. Consultant

1. Registered nurse

Registered nurses providing care to people affected by haemoglobinopathies in a variety of settings. Nurses at this level will meet the standards of proficiency for all registered nurses.

2. Enhanced

Registered nurses working at an enhanced level are expected to be able to manage discrete activities in complex, challenging and changing situations and environments. They should also be confident to seek further guidance when they reach the boundaries of their competence.

This level is underpinned by a broad foundation of skills and capabilities across all four pillars of nursing: clinical practice, education, research and leadership. These, together with critical reflection, enable a nurse working at the enhanced level to function to a high level of autonomy within their designated area and role.

3. Advanced

Advanced level nursing describes a level which can only be delivered by registered nurses with substantial experience and expertise.

This level can be applied to the full range of registered nurse careers. The advanced level is differentiated from other levels by a registered nurses' expertise in applying highly developed theoretical and practical knowledge to complex, unfamiliar and unpredictable situations. For example, this could be through the use of critical thinking, high-level decision making and exercising professional judgement.

4. Consultant

Consultant level nursing practice describes a level which can only be delivered by registered nurses who have progressed from an advanced level within their field to reach a significantly higher level.

This level is not covered in this version of the framework.

6. Personal professional development and career enhancement

The lack of national training and courses has been acknowledged in various platforms. However, it is recommended that nurses working with sickle cell disease and thalassaemia syndromes undertake the Haemoglobinopathies: Advancing Client Centred Care Level 7 7KNIN313 course, which at the time of writing is only available at King's College, London. This course is for all levels of nurses but has a cost implication. The expert group calls on more educational institutions to develop programmes educating nurses in this important specialism.

For additional support, it is recommended that nurses become affiliated with the Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP) and the UK Forum for Haemoglobin Disorders (UKFORUM). The following organisations provide annual conferences: Annual Academy for Sickle Cell and Thalassaemia (ASCAT), UKFORUM, UKTS and STANMAP. Details can be found on their websites.

For nurses working in the accident and emergency arena, there are training resources on the NICE website, including guidance on managing an acute painful sickle cell episode in hospital (2012, National Institute for Health and Care Excellence).

Disclaimer: It is the individual nurse's responsibility to maintain within their practice:

1. knowledge and application of ethical, legal and professional issues relating to sustainable procurement in health care
2. understanding of the importance of the individual and organisational responsibilities for assuring quality, safety, and value regarding procurement of consumables, medical devices, and services
3. awareness of the digitalisation agenda: the transformation of health and care through technology may have an impact on competency development
4. understanding of the concept of sustainable health care
5. currency of knowledge regarding the genomics agenda and how this might affect delivery of health care within their speciality.

7. Guide for evidence of achievement

Evidence can be stored in a portfolio, but it may take many forms other than direct observation, such as case studies; patient/witness statements (by mentor/assessor, doctors, and other colleagues); course documentation; documented minutes of meetings with action points; evaluation of user involvement; discussion lists where sources of evidence may be obtained; formal education sessions; or signed documentation.

1. The competency framework is designed to support skills acquisition and ensure that nurses are able to apply theoretical knowledge to practice.
2. The document can be used as an assessment tool with a supervisor or colleague and doctors working alongside a nurse in the sickle cell and thalassaemia setting. This may be a doctor, specialist nurse, experienced Band 6 nurse or advanced nurse practitioner.
3. The nurse must self-assess and decide on their level: registered, enhanced or advanced.
4. Where a particular competency is not applicable to the individual's role, indicate "Not Applicable" (N/A).
5. If a nurse has completed the self-assessment column, this indicates the level of expertise they feel they have. If the nurse feels that they have met the competency, they must indicate "M". If they feel that they require further skills, they must indicate "RFS".
6. For nurses working in busy departments, there may be limited supervisors available. However, there is no expectation for nurses to produce additional evidence that they have met every competency.

It is important that nurses maintain a competency portfolio, including evidence, as discussed above. If they are part of a peer review programme, they will be asked to provide evidence of their competencies as part of a national review process. Nurses will share their assessment with their supervisor, who must be a registered nurse who is competent in the management of sickle cell and thalassaemia syndromes and recognised as an expert practitioner.

The nurse and their supervisor are expected to:

1. read this document together and agree on a SMART plan
2. review and check any evidence of courses attended and discuss what theoretical training has been undertaken
3. discuss how training will be funded
4. regularly review the nurse's self-assessment plan, discuss any areas that are identified as "requires further skills" and agree on action plans
5. indicate whether each competency is "met" or "requires further skills" in the mentor review column
6. if improvement is needed, discuss what help the nurse needs to achieve the required level, with a clear plan of how this will be achieved and a review date for further assessment
7. ensure that the relevant sections in this document are signed for the level of expertise that has been agreed on.

8. References

The evidence base for each competency has been sourced individually. All references can be found in the list on pages 137-143.

9. RCN equality impact assessment

The equality impact assessment has been completed and acknowledged with the RCN.

Competency framework for registered health care professionals

Competency 1
Provides empathy and understanding and works with the patient (and their family/ carers) as an expert in their own condition

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition.			L	Date	Sig	
Domain: Registered Nurse						
1:1:1	Asks questions and actively listens					
1:1:2	Establishes the patient's preferences and boundaries with regards to sharing personal health information, protecting their privacy and confidentiality					
1:1:3	Respects and acknowledges the patient (and their family/carers) as an expert in their own condition					
1:1:4	Empathises with, and is responsive to, the individual needs of patients with sickle cell disease and thalassaemia syndromes					

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Knowledge and understanding of:						
1:1:5	Sickle cell disease and thalassaemia syndromes, including treatment					
1:1:6	The nursing needs of patients with sickle cell disease and thalassaemia syndromes					
1:1:7	Communication skills					
1:1:8	Privacy, consent and confidentiality: NMC, local and national guidelines					
1:1:9	The patient as a person and their life outside the hospital, eg housing, employment and education					
Knows how to:						
1:1:10	Use open and closed questions					
1:1:11	Refer patients to interpreters, allied health professionals, cultural mediators and national patient groups					
1:1:12	React appropriately when being challenged or guided by patients, families or carers					
1:1:13	Assess the supportive care needs of patients and their families and refer to appropriate support services					
1:1:14	Demonstrate awareness of their own limitations by referring on to specialist staff					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition.			L	Date	Sig	
Domain: Enhanced						
1:2:1	Discusses care and treatment options. Forms partnership with the patient to reach joint and informed decisions					
1:2:2	Encourages feedback from the patient					
1:2:3	Co-develops, implements and evaluates personal care plans, treating the patient as an individual					
Knowledge and understanding of:						
1:2:4	Treatments/care options and their risks and benefits					
1:2:5	Local/national protocols, standards and guidelines					
1:2:6	Principles of the “expert patient” philosophy					
1:2:7	Acute and long-term complications related to sickle cell disease and thalassaemia syndromes					

Knows how to:						
1:2:8	Be responsive to patient feedback and address concerns appropriately					
1:2:9	Build and foster an equitable nurse-client relationship					
1:2:10	Develop care plans in conjunction with local guidelines					
1:2:11	Initiate and undertake patient and family/carer education and training					
1:2:12	Provide guidance, counselling and support in the management and promotion of health					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition.			L	Date	Sig	
Domain: Advanced Practitioner						
1:3:1	Invites the patient to share their experience as a resource for teaching nurses and others					
1:3:2	Develops patient pathways in collaboration with patients and user groups					
1:3:3	Oversees and monitors the quality of care					
1:3:4	Involves the patient in participation groups/service user groups to design, plan and obtain feedback on self-care initiatives					
1:3:5	Signposts and advises the patient on how to make a complaint					
Knowledge and understanding of:						
1:3:6	Local, regional user networks and teaching opportunities					
1:3:7	Clinical indicators					
1:3:8	Relevant NHS policies					
1:3:9	How socioeconomic status can impact patients' understanding of and engagement with their health care					

Knows how to:						
1:3:10	Create a suitable environment in which effective learning can take place					
1:3:11	Acknowledge the patient's strengths and knowledge, and empower them to address their needs					
1:3:12	Develop and implement a suitable evidence-based collaborative treatment plan					
1:3:13	Identify individual needs in relation to education or health promotion					
1:3:14	Develop and implement protocols and procedures to support identified needs					
1:3:15	Develop and implement a management plan					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 2
Works collaboratively with the patient to assess their needs, considering their age and developmental stage, and their cultural and ethnic background

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works collaboratively with the patient to assess their needs, considering their age and developmental stage, and their cultural and ethnic background.			L	Date	Sig	
Domain: Registered Nurse						
2:1:1	Explains issues that may arise during specific developmental stages					
2:1:2	Explores the patient's culture, family, lifestyle, hopes and expectations					
2:1:3	Discusses the patient's cultural/ family/ethnic background and identifies personal preferences					
2:1:4	Uses all available resources to provide information about screening/counselling, including interpreter/cultural mediator					

Knowledge and understanding of:						
2:1:5	The implications of different life stages and mental capacity on possible progression of the condition					
2:1:6	Different cultures and faiths and the potential impact of these on the patient's personal beliefs and viewpoints					
2:1:7	The range of resources to which the patient can be referred for information and support					
2:1:8	The importance of obtaining consent from the patient and maintaining confidentiality requirements					
2:1:9	Theories of developmental stages, eg Piaget, Erikson, Vygotsky					
Knows how to:						
2:1:10	Escalate concerns appropriately in relation to development or mental capacity					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works collaboratively with the patient to assess their needs, considering their age and developmental stage, and their cultural and ethnic background.			L	Date	Sig	
Domain: Enhanced						
2:2:1	Explores the impact of the patient's condition with regard to their cultural, religious and ethnic background and life choices, eg treatment options and reproductive choices					
Knowledge and understanding of:						
2:2:2	The impact of culture, religion and ethnicity on health beliefs					
2:2:3	Medical-legal implications					
2:2:4	Key policies and guidelines, ie Mental Capacity Act and Equalities Act					
2:2:5	Dealing with refusal of care by the patient or their family/carers, and escalation to a health care professional where appropriate					
Knows how to:						
2:2:6	Clearly document patient refusal of care and escalate					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works collaboratively with the patient to assess their needs, considering their age and developmental stage, and their cultural and ethnic background.			L	Date	Sig	
Domain: Advanced Practitioner						
2:3:1	Advocates for social justice, including commitment to the health of vulnerable populations and the elimination of health disparities					
2:3:2	Participates in continuous cultural competence development					
2:3:3	Respects the wishes of the patient and their family/carers in relation to treatment options and communicates effectively					
Knowledge and understanding of:						
2:3:4	The importance of culture and its incorporation at all levels					
2:3:5	Health models relating to cultural and transcultural stigma, eg Leininger, Campinha-Bacote, Helman, Purnell					
2:3:6	Promotion of diversity and culture throughout the service					
Knows how to:						
2:3:7	Access specialist support and cultural networks within regions					
2:3:8	Adapt services to meet culturally unique needs					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 3
Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions.			L	Date	Sig	
Domain: Registered Nurse						
3:1:1	Undertakes and records nursing observations, utilising tools such as Modified Early Warning Score (MEWS), Paediatric Early Warning Score (PEWS) or National Early Warning Score 2 (NEWS2)					
3:1:2	Takes appropriate action, including reporting of abnormal findings					
3:1:3	Engages in continuous professional development and maintains a suitable record of all training					
Knowledge and understanding of:						
3:1:4	The normal parameters of clinical observations and how to escalate a deteriorating patient					
3:1:5	The foundations of disorders: anatomy and pathophysiology					

Knows how to:						
3:1:6	Record nursing clinical observations and take appropriate action					
3:1:7	Refer on abnormal results and escalate appropriately					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions.			L	Date	Sig	
Domain: Enhanced						
3:2:1	Acts on findings of nursing assessments, refers to local guidelines and/or refers to appropriate specialist team					
3:2:2	Provides education to the patient and their family/carers on the condition, treatments and side-effects					
3:2:3	Monitors and advises on nutritional intake and supplements in collaboration with a dietician, to ensure optimal nutrition and growth					
3:2:4	Implements and documents an appropriate management plan					
3:2:5	Provides the patient with information on how to manage and monitor specific symptoms, eg bladder problems, alcohol and smoking advice, and triggers of priapism					
Knowledge and understanding of:						
3:2:6	The complex nature of acute and chronic sickle cell disease and thalassaemia syndromes, and management and treatment of complications (see appendix 2)					

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3:2:7	Local guidelines and national standards for sickle cell disease, such as NICE guidelines					
3:2:8	The lifestyle risk factors that may influence disease severity, eg smoking and alcohol, and environmental risk factors, eg sudden changes in temperature					
3:2:9	The types of investigation, how to interpret results, appropriate treatment options and when to refer to a specialist team					
3:2:10	The anatomy, pathophysiology and management of acute and chronic complications in sickle cell disease and thalassaemia syndromes					
Knows how to:						
3:2:11	Recognise signs and symptoms and implement appropriate actions and/or refer to specialist teams					
3:2:12	Palpate the spleen and measure spleen size, and teach family/carers how to do this					
3:2:13	For paediatric patients, assess school attainment and attendance with family/carers					
3:2:14	Administer treatment within their specialist role using patient group directions (PGDs)					
3:2:15	Identify children with additional learning needs and refer as appropriate, ensuring SENCO support where needed					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions.			L	Date	Sig	
Domain: Advanced Practitioner						
3:3:1	Undertakes an advanced physical assessment, including: 1. systematic medical history 2. advanced physical assessment 3. formulation of a working diagnosis and differential diagnoses.					
3:3:2	Initiates investigations and/or treatments and refers to specialist teams as appropriate					
3:3:3	Discusses the significance of medical investigations, test results, prognosis and treatment options with the patient and their family/ carers					
3:3:4	Demonstrates awareness of the palliative care needs of the patient and their family/carers, provides support and refers to the appropriate health professionals					

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3:3:5	Provides clinical leadership for nurses and health care professionals involved in caring for those with sickle cell disease and thalassaemia syndromes					
3:3:6	Demonstrates awareness of psychosocial aspects: adherence, anxiety, depression, needle phobia, PTSD					
Knowledge and understanding of:						
3:3:7	The complex nature of acute and chronic sickle cell disease and thalassaemia syndromes, and management and treatment of complications (see appendix 2)					
3:3:8	Accountability, including legal and ethical issues and the impact of political, social and economic influences on health care					
3:3:9	Different types of priapism, including stuttering and acute events					
Knows how to:						
3:3:10	Undertake a comprehensive physical assessment of all body systems					
3:3:11	Explain transcranial dopplers (TCDs) and their significance in treatment plans					
3:3:12	Initiate investigations according to patient symptoms					
3:3:13	Act on investigations and interpret results					

3:3:14	Formulate and document an agreed management plan, including, where appropriate, palliative care					
3:3:15	Administer treatment within their specialist role as a non-medical prescriber based on: • efficacy • safety • cost					
3:3:16	Assess competence of nurses undertaking physical assessments					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 4
Signposts the patient and their family/carers to information about their genetic condition

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Signposts the patient and their family/carers to information about their genetic condition.			L	Date	Sig	
Domain: Registered Nurse						
4:1:1	Signposts the patient to further information					
4:1:2	Directs the patient to specialist help					
4:1:3	Carries out investigations related to screening under local guidance and national standards					
Knowledge and understanding of:						
4:1:4	Resources, services and specialist staff					
4:1:5	National Screening Committee (NSC) and Department of Health policy on informed consent, confidentiality of information and ethical issues					
4:1:6	The origins of sickle cell disease and thalassaemia syndromes, and awareness of possible stigma					
4:1:7	Local guidance, national standards and referral pathways					

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Knows how to:						
4:1:8	Obtain educational information					
4:1:9	Access resources, services and staff, including from the voluntary sector					
4:1:10	Differentiate between sickle cell and thalassaemia carrier and disease states					
4:1:11	Communicate effectively					
4:1:12	Work within their level of competence					
4:1:13	Refer to specialist genetic counselling services					
4:1:14	Refer to other relevant specialists of required					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Signposts the patient and their family/carers to information about their genetic condition.			L	Date	Sig	
Domain: Enhanced						
4:2:1	Supports patients sensitively and empathetically when they receive their results and ensures that support is age-appropriate					
4:2:2	Obtains informed consent for testing					
4:2:3	Initiates antenatal and newborn screening					
4:2:4	Explains genetic inheritance and the wider family implications					
4:2:5	Identifies individuals at genetic risk, eg by taking a family history					
Knowledge and understanding of:						
4:2:6	Which blood investigations to order					
4:2:7	Genetic counselling skills					
4:2:8	How sickle cell disease and thalassaemia syndromes are inherited and the use of family history information to identify other family members who may have, be at risk of, or be a carrier for the condition					

Knows how to:						
4:2:9	Support decision-making by the patient or guardian					
4:2:10	Work within protocols, standards and guidelines, both national and local					
4:2:11	Explain genetic inheritance, the available screening tests, their implications and interpretation of the results					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Signposts the patient and their family/carers to information about their genetic condition.			L	Date	Sig	
Domain: Advanced Practitioner						
4:3:1	Interprets more complex results, eg rare or unusual haemoglobin variants					
4:3:2	Initiates further investigations, such as DNA analyses					
4:3:3	Provides education and training and works with health care professionals, including specialist and genetic counsellors (see also Competency 3)					
4:3:4	Ensures the patient and, where relevant, their family/carers, understand screening implications, the results and the available options					
Knowledge and understanding of:						
4:3:5	National standards and local guidance: actively participates in development and drafting process					

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Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 5
Develops and evaluates a self-management plan with the patient

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Develops and evaluates a self-management plan with the patient.			L	Date	Sig	
Domain: Registered Nurse						
5:1:1	Uses patient-held records or diaries where available					
5:1:2	Documents interventions and shares information with the multidisciplinary team as appropriate					
5:1:3	Provides basic information and support to patients and their families/carers					
5:1:4	Has an awareness of the groups of patients and families/carers who have more difficulty in accessing information, and knowledge of the specific resources available to assist them					
5:1:5	Develops and records a self-management plan with the patient and their family/carers, to include objectives around nutrition, hydration and activities of daily living					
Knowledge and understanding of:						
5:1:6	Age-appropriate needs for patients with sickle cell disease or thalassaemia syndromes and factors that influence these conditions					

5:1:7	Benchmarking around the activities of daily living and improvement strategies					
5:1:8	The main local and national support groups available for patients within the area of practice					
5:1:9	How to access and refer patient and their families/carers on to appropriate agencies for financial, social, spiritual and cultural advice and support					
5:1:10	How cultural and religious backgrounds influence lifestyle choices, including structural biases and racism					
5:1:11	The support strategies and interventions available to care for patients with complex needs, eg patients exhibiting denial, anger following blood transfusion treatments or deterioration					
5:1:12	The need to actively support patients and their families/carers to identify and manage their own health and social wellbeing throughout the sickle cell and thalassaemia journey					
5:1:13	Patient or user involvement initiatives in the locality					
5:1:14	Assessment of patients' basic needs, from admission to discharge					

Knows how to:						
5:1:15	Assess patients' basic needs, from admission to discharge					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Develops and evaluates a self-management plan with the patient.			L	Date	Sig	
Domain: Enhanced						
5:2:1	Works collaboratively with the patient and their family/carers to assess their level of understanding of their condition					
5:2:2	Identifies age-appropriate needs in collaboration with the patient and their family/carers, including the factors that influence their illness, and gives appropriate advice					
5:2:3	Discusses various lifestyle choices with the patient and outlines the possible implications for their immediate and long-term health care needs					
5:2:4	Identifies agreed patient goals that can be evaluated and reviewed periodically					
5:2:5	Utilises all forms of patient information to give the patient a better understanding of their diagnosis and treatment plan. This will include the use of specific resources aimed at patients from minority groups and their family/ carers					
5:2:6	Verbally summarises patient information to facilitate understanding					

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5:2:7	Assesses and provides support that is appropriate to the context and sensitive to the needs of the patient and their family/carers					
5:2:8	Develops links with support groups and provides or records information relating to these groups as required, to facilitate patient choice					
5:2:9	Utilises a range of techniques to monitor and evaluate patient or user satisfaction within the service by means of auditing					
Knowledge and understanding of:						
5:2:10	The impact of living with a chronic condition in relation to self-management and adherence					
5:2:11	Available resources and where and how to access them					
5:2:12	Local networks in the hospital and community					
5:2:13	Long-term complications and screening approaches, such as TCD					
5:2:14	The role of patient or user involvement in haemoglobinopathy services, both locally and nationally					
5:2:15	How and where to confidentially record information					
5:2:16	The barriers to continuity of care and how they can be overcome					

Knows how to:						
5:2:17	Assess for complications and create a care plan					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Develops and evaluates a self-management plan with the patient.			L	Date	Sig	
Domain: Advanced Practitioner						
5:3:1	Facilitates cross-boundary working, ensuring consistent information is provided across the patient care pathway					
5:3:2	Establishes local patient and user involvement in sickle cell and thalassaemia services					
Knowledge and understanding of:						
5:3:3	How to work collaboratively with the patient to develop and maintain a self-management plan that enables them to reach their potential and maintains their motivation and confidence					
Knows how to:						
5:3:4	Assess for complex complications, create a care and treatment plan and discharge					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 6
Works alongside the patient and their family/carers to address the psychological and social impact of their condition

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works alongside the patient and their family/ carers to address the psychological and social impact of their condition.			L	Date	Sig	
Domain: Registered Nurse						
6:1:1	Understands how having a long-term condition impacts the patient and their family/carers					
6:1:2	Communicates treatment plans clearly and recognises that hospitalisation is a major stress factor for sickle cell and thalassaemia patients and their families/carers					
6:1:3	Listens to and can empathise with the patient and their families/ carers					
6:1:4	Identifies patient coping mechanisms together with the multidisciplinary team					
6:1:5	Seeks support from colleagues in response to distressing conversations					
6:1:6	Understands how culture and religious beliefs can impact disease management and the patient's right to refuse treatment					

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Knowledge and understanding of:						
6:1:7	Verbal and non-verbal communication, including paralinguistic communication such as silence, sighs, clicking of the tongue and other non-verbal utterances					
6:1:8	How cultural expressions may be key to identifying how a patient expresses distress or pain					
6:1:9	Cultural variations of communication					
Knows how to:						
6:1:10	Listen to the patient and identify a need for further assessment					
6:1:11	Work within their own limitations of practice					
6:1:12	Explore referral pathways for external services and make appropriate contact					
6:1:13	Recognise when a professional translator is required.					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works alongside the patient and their family/ carers to address the psychological and social impact of their condition.			L	Date	Sig	
Domain: Enhanced						
6:2:1	Demonstrates good communication skills and is able to identify potential or actual psychological problems affecting the patient					
6:2:2	Communicates effectively with the patient to identify social problems that are impacting on their health and wellbeing, and signposts to appropriate support. Issues may include education, employment, housing and welfare					
6:2:3	Identifies strengths and weaknesses with individual coping mechanisms when these have been called into question; reassures the individual and makes a referral to the relevant identified psychology service					
6:2:4	Creates and evaluates care plans based on achievable goals, strengths and weaknesses, coping strategies, and family and social support					
6:2:5	Communicates in a culturally sensitive manner and understands individual health beliefs					

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6:2:6	Identifies individuals with long-term complications and explores the fear of death (if discussed) and suicidal ideation (if appropriate). Reports to a senior clinician for appropriate assessment and treatment					
6:2:7	Initiates communication during assessment and throughout the patient's journey, using both open and closed questions					
6:2:8	Provides an assessment tool and environment that is appropriate for the individual patient to ensure effective communication, eg smiley faces for children					
6:2:9	Sensitively investigates personal background and identifies family dynamics that may have an impact on health					
6:2:10	Identifies communication problems within family and/or partner relationships and takes appropriate action					
6:2:11	Advises, supports and signposts the patient and their family/carers to community sickle cell and thalassaemia services, such as the SCS and UKTS or specialist nursing teams					

Knowledge and understanding of:						
6:2:12	The criteria and thresholds for referral to the local identified psychology and psychiatric provider					
Knows how to:						
6:2:13	Complete appropriate referrals in a timely manner					
6:2:14	Liaise with other professionals to facilitate a holistic plan of care and provide the patient with the best outcomes					
6:2:15	Work within their own scope of practice and seek advice from others if in doubt					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works alongside the patient and their family/ carers to address the psychological and social impact of their condition.			L	Date	Sig	
Domain: Advanced Practitioner						
6:3:1	Identifies underlying mental health issues at an early stage: assesses anxiety and depression using PHQ-9 (recommended by NICE Clinical Guideline 91, NICE, 2023); identifies coping strategies; implements care; and refers to appropriate services					
6:3:2	Undertakes assessments of mental health and psychosocial issues, and make appropriate referrals					
6:3:3	Identifies when a patient potentially has no coping strategies and determines the impact this may have on disease management and mental health					
Knowledge and understanding of:						
6:3:4	The roles of psychologists, psychiatrists, GPs and social workers within the multidisciplinary team, and how to work collaboratively with specialists to deliver care					
6:3:5	The emotional/psychosocial impact of chronic disease manifestation					
6:3:6	Interventions, eg cognitive behavioural therapy (CBT)					

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Knows how to:						
6:3:7	Take a full comprehensive history, identify actual and potential problems, and take appropriate action in a timely manner					
6:3:8	Provide support and education to promote patient autonomy					
6:3:9	Sensitively discuss cultural issues and the impact on patient health and wellbeing					
6:3:10	Refers to the most appropriate mental health services, eg psychology service, NHS Talking Therapies , etc					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 7
Works with the patient and their family/carers to manage the pain of patients with sickle cell disease

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works with the patient and their family/carers to manage the pain of patients with sickle cell disease.			L	Date	Sig	
Domain: Registered Nurse						
7:1:1	Safely administers and monitors as-required (PRN) analgesia regimes, patient-controlled analgesia (PCA) and nurse-controlled analgesia (NCA)					
7:1:2	Takes appropriate action to ensure the safety of patients taking opiates, including awareness of under-treatment and over-treatment					
7:1:3	Observe and record pain levels in line with escalation of pain relief dosage					
7:1:4	Recognises major acute sickle cell-related complications, such as sickle cell chest syndrome seizures, and makes appropriate emergency referrals or escalates using MEWS/ NEWS2/PEWS					
7:1:5	Communicates with and advises the patient and their family/carers about pain management strategies					
7:1:6	Supervises all patients, including those preparing for discharge and deemed to be self-caring					

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7:1:7	Ensures patients are discharged safely, with appropriate follow-up and advice, eg referral to the community nursing teams					
Knowledge and understanding of:						
7:1:8	Psychosocial and environmental factors that influence pain in sickle cell disease					
7:1:9	Non-sickle cell-related pain					
7:1:10	The age-related, developmental, individual and cultural factors that influence pain					
7:1:11	Use of opiates and their side-effects					
Knows how to:						
7:1:12	Carry out safety checks while the patient is taking opiates					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works with the patient and their family/carers to manage the pain of patients with sickle cell disease.			L	Date	Sig	
Domain: Enhanced						
7:2:1	Works alongside the patient and their family/carers to identify the causes of their pain and manage their pain by taking appropriate action					
7:2:2	Differentiates between acute and chronic pain					
7:2:3	Knows when to involve the pain team or refer to the pain clinic as required					
Knowledge and understanding of:						
7:2:4	Patient group directions and when to initiate					
7:2:5	The pathophysiology and context of acute and chronic pain in sickle cell disease, including the triggers of pain					
7:2:6	Pain complications associated with sickle cell disease, eg priapism, acute chest syndrome and avascular necrosis					
7:2:7	Pain complications associated with thalassaemia, eg osteoporosis and back pain					

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Knows how to:						
7:2:8	Administer medications under a patient group direction or medical prescription, including controlled drugs					
7:2:9	Programme an NCA/PCA pump as per local guidelines and monitor use					
7:2:10	Refer to different pain management specialists and holistic services, eg aromatherapy and “expert patient” programmes					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Works with the patient and their family/carers to manage the pain of patients with sickle cell disease.			L	Date	Sig	
Domain: Advanced Practitioner						
7:3:1	Prescribes medication for the patient as a nurse practitioner or administers appropriate medication under a patient group direction					
7:3:2	Monitors care in relation to current standards and drafts and implements local guidelines					
7:3:3	Develops innovative pain services in collaboration with patients					
Knowledge and understanding of:						
7:3:4	Non-medical prescribing					
7:3:5	Increased mortality risks associated with sickle cell patients who present with frequent pain episodes					
7:3:6	Mortality risks of patients with beta thalassaemia syndromes, including non-transfusion-dependent thalassaemia (NTDT) and transfusion-dependent thalassaemia (TDT)					
7:3:7	Other treatment modalities and disease-modifying interventions that may be appropriate for the management of pain and side-effects, eg hydroxyurea, psychological therapies, and blood transfusion including apheresis					

Knows how to:						
7:3:8	Physically examine, diagnose and implement a plan of care and cease as appropriate (in collaboration with the patient)					
7:3:9	Use mediation, advocacy and conflict resolution skills in relation to opiate use and patient behaviours					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 8.0
Provides specific interventions with regards to safely undertaking phlebotomy and cannulation

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely undertaking phlebotomy and cannulation.			L	Date	Sig	
Domain: Registered Nurse						
8:1:1	Identifies the patient verbally and via the name band					
8:1:2	Listens and responds to concerns and suggestions raised by the patient and their family/carers					
8:1:3	Prepares the patient using comfort and distraction strategies, eg use of topical anaesthetic cream or spray, play therapy or guided imagery (if age-appropriate)					
8:1:4	Identifies points of venous access in collaboration with the patient					
8:1:5	Agrees with the patient what to do in the event of difficulty taking bloods or performing cannulation, eg number of times to try (referring to local guidance)					
8:1:6	Selects appropriate equipment, such as blood bottles, according to the investigation required					

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Knowledge and understanding of:						
8:1:7	Patient safety and consent					
8:1:8	Local guidance and policies, eg the number of unsuccessful attempts at phlebotomy or cannulation before seeking assistance from a more experienced practitioner					
8:1:9	Potential complications during phlebotomy and cannulation, eg haematoma, phlebitis or nerve damage					
Knows how to:						
8:1:10	Record, observe and monitor cannula site for signs and symptoms of extravasation and infection, working within their scope and limitations					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely undertaking phlebotomy and cannulation.			L	Date	Sig	
Domain: Enhanced						
8:2:1	Skilfully undertakes challenging phlebotomy and cannulation					
8:2:2	Assesses the clinical need for cannulation and identifies reasons why phlebotomy or cannulation may be unsuccessful					
8:2:3	Identifies the need for using additional support, such as ultrasound (U/S), vein finders, etc					
Knowledge and understanding of:						
8:2:4	Impact of continued exposure to phlebotomy					
8:2:5	Ultrasound and cold light techniques (theoretical knowledge required)					
8:2:6	Identification of problems with phlebotomy cannulations and potential complications, eg syncope, panic attacks, anxiety					
Knows how to:						
8:2:7	Recognise, manage and deal with simple needle phobias and their impact on families/carers					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely undertaking phlebotomy and cannulation.			L	Date	Sig	
Domain: Advanced Practitioner						
8:3:1	Trains others in phlebotomy and cannulation techniques and care					
8:3:2	Assesses the clinical need for cannulation and identifies reasons why it is necessary					
8:3:3	Identifies when a patient is not suitable for cannulation and refers for central venous access or alternatives such as ports, Hickman lines, etc					
8:3:4	Advocates for the patient in terms of alternatives to peripheral intravenous access and advises on complications such as keloid scarring, etc					
Knowledge and understanding of:						
8:3:5	How to supervise, intervene and teach, working in line with current practice and relevant research					
Knows how to:						
8:3:6	Manage staffing competency issues					

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Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 8.1
Provides specific interventions with regards to safely managing central venous access devices (CVADs), including portacaths

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing central venous access devices (CVADs), including portacaths.			L	Date	Sig	
Domain: Registered Nurse						
8.1:1:1	Monitors CVAD line for possible complications, eg infection or deep vein thrombosis (DVT), and seeks advice from senior colleagues					
8.1:1:2	Assesses CVAD line for treatment using aseptic technique, according to local guidance					
8.1:1:3	Administers treatment via CVAD and ensures patient safety, according to local guidance					
Knowledge and understanding of:						
8.1:1:4	Local guidelines, policies and protocols/clinical procedures that affect practice in relation to CVADs					
8.1:1:5	The need for informed consent					
8.1:1:6	The importance of the aseptic non-touch technique (ANTT) in relation to CVAD					
Knows how to:						
8.1:1:7	Identify different types of CVAD					

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8.1:1:8	Document all interventions in appropriate nursing notes					
8.1:1:9	Identify causes of potential line blockages due to other mechanisms, not necessarily line occlusion					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing central venous access devices (CVADs), including portacaths.			L	Date	Sig	
Domain: Enhanced						
8.1:2:1	Assesses patients with poor peripheral access and discusses the need for CVADs, ie femoral lines or peripherally inserted central catheter (PICC) lines					
8.1:2:2	Orders appropriate investigations prior to insertion of the line, eg international normalised ratio (INR) blood test					
8.1:2:3	Educates the patient and their family/carers in the management of a permanent CVAD such as a portacath					
8.1:2:4	Trains others in the management of CVADs and the correct procedure when administering treatments					
8.1:2:5	Removes CVADs when clinically indicated					
Knowledge and understanding of:						
8.1:2:6	Referral pathway and processes for insertion of CVADs					
8.1:2:7	Current research and trends with regards to CVADs					

Knows how to:						
8.1:2:8	Identify any complications that may arise with CVADs, eg blocked line, and treat appropriately					
8.1:2:9	Escalate concerns as necessary with regards to all CVADs					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing central venous access devices (CVADs), including portacaths.			L	Date	Sig	
Domain: Advanced Practitioner						
8.1:3:1	Inserts femoral/PICC lines and portacaths if clinically indicated, using aseptic techniques					
8.1:3:2	Uses ultrasound and X-ray guidance for CVAD insertion					
8.1:3:3	Initiates a prescription and administers sedation if clinically indicated and maintains patient safety					
8.1:3:4	Trains others in CVAD line insertion and assesses competence					
8.1:3:5	Develops protocols and nursing guidance for CVADs within the speciality					
Knowledge and understanding of:						
8.1:3:6	Research and current developments at national level					
8.1:3:7	National guidelines, policies and protocols or clinical procedures that affect practice in relation to insertion of CVADs					

Knows how to:						
8.1:3:8	Arrange appropriate follow-up in all areas of the care pathway					
8.1:3:9	Troubleshoot and communicate effectively with other professionals and the patient's family/carers, especially if the patient is being discharged					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 8.2
Provides specific interventions with regards to safely administering transfusions and exchange blood transfusions

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering transfusions and exchange blood transfusions.			L	Date	Sig	
Domain: Registered Nurse						
8.2:1:1	Demonstrates basic understanding of transfusions					
8.2:1:2	Undertakes transfusions in accordance with local policy					
8.2:1:3	Explains procedures to the patient, including risks and benefits, and provides the patient with information					
8.2:1:4	Obtains consent for all procedures and administers transfusions safely, according to local transfusion guidelines and policies					
8.2:1:5	Shows awareness of the importance of observing the access sites before and during transfusion					
8.2:1:6	Undertakes vital observations as per local policy and procedures and acts appropriately on the results					
8.2:1:7	Acts on, reports and records complications					

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8.2:1:8	Monitors and manages fluid balance in relation to transfusion					
8.2:1:9	Maintains documentation in accordance with NMC guidance					
8.2:1:10	Shows awareness of the range of treatment options available for patients who are not transfusable, eg iron infusions or erythropoietin (EPO) injections					
Knowledge and understanding of:						
8.2:1:11	Clinical indications for transfusions					
8.2:1:12	Blood groups and the implications for safe transfusion					
8.2:1:13	The need for informed consent					
8.2:1:14	Benefits and risks associated with transfusions					
8.2:1:15	Transfusion requirements for those with sickle cell disease and thalassaemia syndromes					
8.2:1:16	Acute complications associated with blood transfusion reactions and the clinical care and investigations required in line with Serious Hazards of Transfusion (SHOT)					
Knows how to:						
8.2:1:17	Identify the risks associated with transfusions and the acute complications associated with blood transfusion reactions					
8.2:1:18	Care for peripheral access					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering transfusions and exchange blood transfusions.			L	Date	Sig	
Domain: Enhanced						
8.2:2:1	Understands local policies and guidelines that relate to automated or manual exchanges					
8.2:2:2	Knows how to prepare a patient for exchanges, eg aware of the importance of weight, height and pre-blood investigations					
8.2:2:3	Able to perform cannulation and venepuncture					
8.2:2:4	Aware of the importance of observing the access sites pre-exchange and while exchanging, eg tissuing, leaking, etc					
8.2:2:5	Undertakes the following procedures: manual exchange transfusions, automated exchange transfusions					
8.2:2:6	Enters the values for the Spectra Optia Apheresis Machine and understands the rationale behind the values entered					
8.2:2:7	Follows and understands the individual patient management plan, eg in terms of target haemoglobin S %, haematocrit (HCT) and haemoglobin level					

Knowledge and understanding of:						
8.2:2:8	The clinical indication for exchange transfusion					
8.2:2:9	Interpretation of full blood counts (FBC) for patients with sickle cell disease and thalassaemia syndromes in relation to transfusion					
8.2:2:10	The importance of following the schedule for transfusion and exchange and the need for follow-up					
8.2:2:11	Complexities and challenges associated with a transfusion and exchange programme					
8.2:2:12	How many units of blood to order for transfusion or exchanges according to the clinical picture and haematological investigations					
8.2:2:13	The benefits and risks associated with manual exchanges and automated exchanges					
8.2:2:14	Local policies and guidelines that relate to automated or manual exchanges					
8.2:2:15	The needs of cultural and religious groups with respect to blood transfusions, eg Jehovah's Witnesses, and awareness of local policies for dealing with such beliefs					
8.2:2:16	Blood transfusion guidelines					

8.2:2:17	Access requirements for exchange/ manual/transfusion , including peripheral and CVAD					
8.2:2:18	Local sedation policies, if used for CVAD, to administer blood safely and in accordance with local guidelines					
8.2:2:19	Monitoring and caring for a patient undergoing transfusion, including adverse events					
8.2:2:20	Appropriate blood investigations for transfusion programmes					
8.2:2:21	The range of treatment options for patients who are not transfusable, eg iron infusions or erythropoietin (EPO)					
8.2:2:22	The importance of observing access sites while exchanging (tissuing, leaking, etc)					
Knows how to:						
8.2:2:23	Undertake manual exchanges, automated exchanges and transfusions, including safe discharge					
8.2:2:24	Interpret the blood results required before and after transfusion and manual and automated exchanges					
8.2:2:25	Set up and prime the apheresis machine appropriately					
8.2:2:26	Carry out pre-procedure preparation without supervision					
8.2:2:27	Clean and maintain apheresis machine and equipment					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering transfusions and exchange blood transfusions.			L	Date	Sig	
Domain: Advanced Practitioner						
8.2:3:1	Provides clinical supervision for the team					
8.2:3:2	Trains, supervises and assesses the competence of others in performing automated and manual exchanges					
8.2:3:3	Able to troubleshoot the Spectra Optia Apheresis Machine					
8.2:3:4	Reviews post-transfusion blood test results and takes the appropriate action, eg fluid requirement, discharging the patient, etc					
8.2:3:5	Able to insert femoral lines					
Knowledge and understanding of:						
8.2:3:6	The Spectra Optia Apheresis Machine					
8.2:3:7	Complications requiring transfusion and exchanges within specialty					
8.2:3:8	Benefits and risks associated with transfusion and exchange transfusions					

8.2:3:9	The importance of ensuring that apheresis machines are checked and only used within service dates					
8.2:3:10	Preparation of patients for exchanges, eg weight, height and blood investigations					
Knows how to:						
8.2:3:11	Train/educate others in undertaking manual or automated exchanges, including assessing competence					
8.2:3:12	Ensure apheresis equipment is maintained and serviced according to local guidance					
8.2:3:13	Competently and confidently report faults and service requirements					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 8.3
Provides specific interventions with regards to safe fluid management and hydration

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safe fluid management and hydration.			L	Date	Sig	
Domain: Registered Nurse						
8.3:1:1	Recognises the importance of fluid management and hydration					
8.3:1:2	Observes and records fluid input and output accurately and identifies signs of dehydration and fluid retention					
8.3:1:3	Reports on abnormal outcomes					
8.3:1:4	Helps patients to hydrate using appropriate drinking aids or manages artificial hydration routes					
8.3:1:5	Reviews a fluid management plan for each patient					
Knowledge and understanding of:						
8.3:1:6	The pathophysiology of sickle cell disease and thalassaemia syndromes					
8.3:1:7	Vulnerability to dehydration because of sickle cell disease					
8.3:1:8	The consequences of dehydration for patients with sickle cell disease, ie trigger for vaso-occlusion and reduced viscosity					
8.3:1:9	Complications due to fluid overload					

8.3:1:10	Individual oral fluid intake targets for sickle cell disease patients (according to age, weight and existing morbidity)					
8.3:1:11	Local guidance regarding oral or nasogastric fluid and intravenous fluids					
Knows how to:						
8.3:1:12	Take action to ensure that hydration status is not compromised if there are problems with swallowing					
8.3:1:13	Pass a nasogastric tube					
8.3:1:14	Administer fluids via an infusion device or appropriate equipment in accordance with local and national guidance					
Bespoke competencies						
Competency statement:	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
Domain:			L	Date	Sig	
Action plan to achieve required competency level.						

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Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safe fluid management and hydration.			L	Date	Sig	
Domain: Enhanced						
8.3:2:1	Demonstrates an understanding of normal distribution of fluid between extracellular and intracellular spaces					
8.3:2:2	Recognises the complications associated with acute kidney injury (AKI)					
Knowledge and understanding of:						
8.3:2:3	Colloids and crystalloids					
8.3:2:4	Peripheral, dependent, generalised and pulmonary oedema					
8.3:2:5	AKI: what it is and how it affects patients					
8.3:2:6	The risk factors associated with AKI					
8.3:2:7	Renal complications in patients with sickle cell disease and thalassaemia syndromes					
Knows how to:						
8.3:2:8	Assess for signs of pulmonary and peripheral oedema, understand the significance of findings and determine appropriate treatment options					
8.3:2:9	Administer fluid challenges and measure their effectiveness					

8.3:2:10	Educate practitioners and families/ carers to identify their roles and responsibilities in recognising patients' hydration					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safe fluid management and hydration.			L	Date	Sig	
Domain: Advanced Practitioner						
8.3:3:1	Ensures clear guidance and documentation on fluid management and hydration is available to all staff					
Knowledge and understanding of:						
8.3:3:2	How to work with nurse managers, medical staff and hospital IV fluids lead					
8.3:3:3	How to take responsibility for training, clinical governance, audit and review of hydration and IV fluid prescribing and patient outcomes					
8.3:3:4	How to provide clinical supervision of the different members of the team					
Knows how to:						
8.3:3:5	Ensure that existing learning materials for patients and families/ carers are used to increase knowledge of how to manage conditions as part of clinical governance					

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Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 8.4
Provides specific interventions with regards to safely administering pharmacological treatments and side-effects

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering pharmacological treatments and side-effects.			L	Date	Sig	
Domain: Registered Nurse						
8.4:1:1	Assesses pain and uses age-appropriate, patient-led pain assessment tools					
8.4:1:2	Provides information and education to patients about their treatment (such as opiate analgesics) and any side-effects					
8.4:1:3	Ensures the patient is always aware of safety parameters, eg maximum tolerated dose					
8.4:1:4	Documents all procedures and observations					
8.4:1:5	Observes pain and monitors the patient, including respiration, pulse, blood pressure and oxygen saturation (on-air and off-air)					
8.4:1:6	Responds appropriately to the MEWS/NEWS2/PEWS scores by escalating where appropriate					

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Knowledge and understanding of:						
8.4:1:7	Opiates and other analgesics and all related medicines such as adjuvants and treatment for pruritis					
8.4:1:8	NICE recommendations for the treatment of mild-to-moderate pain (NICE, 2021)					
8.4:1:9	The difference between acute and chronic pain					
8.4:1:10	Understanding of the mechanism of the function of analgesics					
8.4:1:11	Complications and their treatment					
8.4:1:12	The importance of having contact procedures in place for the patient and their family/carers if they require advice and support following treatment					
8.4:1:13	Local policies and guidelines for the care and management of patients receiving opiate analgesics and related complications					
Knows how to:						
8.4:1:14	Assess patients on strong opioid treatment or associated complication management, and determine when to refer to an experienced practitioner					
8.4:1:15	Initiate a care/treatment plan for patients receiving opiates or complication management					

8.4:1:16	Provide training, education and information to patients and their family/carers on an associated medicines regimen and side-effect management					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering pharmacological treatments and side-effects.			L	Date	Sig	
Domain: Enhanced						
8.4:2:1	Identifies individuals with long-term complications such as strokes, priapism, fear of death, compliance issues, hydroxyurea fertility issues, growth and chronic pain, and carries out an assessment					
8.4:2:2	Creates a care plan and liaises with other analgesic teams such as the pain management team, palliative care team, multidisciplinary teams, etc					
8.4:2:3	Demonstrates a comprehensive knowledge of the common and rare side-effects of medications used to treat sickle cell disease and thalassaemia syndromes					
8.4:2:4	Is familiar with local policies and guidelines within their own practice					
8.4:2:5	Provides training and education to others					
8.4:2:6	Provides patients and their family/ carers with support to promote their physical and psychological wellbeing, referring on to other members of the multidisciplinary team where appropriate					

Knowledge and understanding of:						
8.4:2:7	Professional and legal issues associated with medicines					
8.4:2:8	The implications of medicinal abuse and their own accountability and responsibility					
8.4:2:9	National guidelines and policies that impact on local services					
8.4:2:10	Opiates, hydroxyurea, chelation therapies and related complications, including fast-track processes					
Knows how to:						
8.4:2:11	Provide and supervise care related to their specialty area, using their technical skills. This may include: • clinically examining patients • siting CVADs • undertaking invasive procedures • initiating treatment to manage complications associated with opiates, hydroxyurea, chelation and other related treatments					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely administering pharmacological treatments and side-effects.			L	Date	Sig	
Domain: Advanced Practitioner						
8.4:3:1	Instigates and contributes to changes to the management of treatments which reflect the current evidence-based practice					
8.4:3:2	Responds to innovations in treatment and care associated with a specialty area					
8.4:3:3	Shows the requisite technical skills to manage a caseload of patients requiring specialist interventions					
8.4:3:4	Trains, educates, supervises and mentors senior registered practitioners and other members of the multiprofessional team to acquire an expert level of knowledge and technical skill					
8.4:3:5	Engages with commissioners and NHS England to inform and develop local services					
8.4:3:6	Advises on resource issues associated with the nursing contribution to ensuring safe practice					
8.4:3:7	Participates in clinical trials and research initiatives					

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8.4:3:8	Monitors, audits and evaluates adherence to policy, procedures, guidelines and standards of practice, and initiates training where appropriate to improve delivery of care to patients and their family/carers					
Knowledge and understanding of:						
8.4:3:9	Treatment regimens, including those currently in development, such as Hydroxycarbamide, Voxelor, Casgevy (Exagamglogene autotemcel), CRISPR–Cas9 gene, Stem cell transplantation (expert knowledge)					
8.4:3:10	Associated common and rare side-effects of therapy used within their specialty (expert knowledge)					
Knows how to:						
8.4:3:11	Develop and agree local Standard Operation Procedures and guidelines for the use of new treatment pathways to develop					
8.4:3:12	Provide expert knowledge to assist nursing leadership with the development of evidence-based guidelines and protocols					
8.4:3:13	Independently manage patient complications					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 8.5
Provides specific interventions with regards to safely managing hydroxycarbamide therapy

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing hydroxycarbamide therapy.			L	Date	Sig	
Domain: Registered Nurse						
8.5:1:1	Understands hydroxycarbamide therapy and its indication for use					
8.5:1:2	Identifies patients who have been initiated for hydroxycarbamide therapy and need assessment by appropriate practitioner					
8.5:1:3	Recognises and reports on non-adherence to appropriate professional standards					
8.5:1:4	Administers hydroxycarbamide where appropriate, according to local policy and guidelines					
8.5:1:5	Provides appropriate advice in relation to drug cytotoxicity, eg pregnancy and conception					
Knowledge and understanding of:						
8.5:1:6	Side-effects					
8.5:1:7	The referral process: who to refer to for advice and management					
8.5:1:8	The potential complications resulting from a lack of disease-modifying interventions					

8.5:1:9	Where to obtain and find age-appropriate information and support groups, local policies and national guidelines					
Knows how to:						
8.5:1:10	Refer appropriately					
8.5:1:11	Provide patient-centred care, displaying empathy and good communication skills					
8.5:1:12	Be open to receiving feedback from patients and colleagues					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing hydroxycarbamide therapy.			L	Date	Sig	
Domain: Enhanced						
8.5:2:1	Monitors blood levels, including FBC, on a regular basis					
8.5:2:2	Discusses medication and potential myths/stigma with the patient and their family/carers					
8.5:2:3	Explains to the patient and their family/carers the weight-based dosage, side-effects, and off-label use					
8.5:2:4	Assesses patient and their family/ carers for their knowledge and understanding of treatment with hydroxycarbamide and its benefits and rationale for use					
8.5:2:5	Monitors patient adherence to hydroxycarbamide					
8.5:2:6	Communicates effectively and in an age-appropriate manner					
Knowledge and understanding of:						
8.5:2:7	Normal FBC levels and the factors that influence them					
8.5:2:8	Risks associated with hydroxycarbamide, pregnancy, conception and related side-effects including neutropenia, thrombocytopenia, etc					

8.5:2:9	The importance of initiating appropriate investigations					
Knows how to:						
8.5:2:10	Educate patients on their blood test results and explain findings					
8.5:2:11	Assess the factors that impact on adherence and develop strategies to promote patient engagement					
8.5:2:12	Recognise and support appropriate psychosocial referrals in relation to treatment adherence, transition, etc					
8.5:2:13	Explain a range of techniques for promoting patient engagement and independence					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing hydroxycarbamide therapy.			L	Date	Sig	
Domain: Advanced Practitioner						
8.5:3:1	Monitors bloods, including FBC, urea and electrolytes, and liver function test levels, and is able to explain drug efficacy by results					
8.5:3:2	Undertakes appropriate referrals and arranges appropriate follow-up					
8.5:3:3	Discusses treatment variations and escalates/reduces treatment regimen where appropriate					
8.5:3:4	Discusses the option of sperm banking with male patients					
8.5:3:5	Discusses the risks of transfer via breastfeeding and the use of contraception while receiving treatment					
8.5:3:6	Discusses the risks of bone marrow suppression					
Knowledge and understanding of:						
8.5:3:7	Alternative disease-modifying interventions, current research, and previous trials and studies					
8.5:3:8	Side-effects and appropriate management					

Knows how to:						
8.5:3:9	Interpret complex results and investigations and take appropriate action					
8.5:3:10	Refer to consultant haematologist for appropriate advice and support					
8.5:3:11	Determine when to discontinue treatment temporarily and when to restart					
8.5:3:12	Communicate effectively with the wider multidisciplinary team, including GPs and counselling services					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 8.6
Provides specific interventions with regards to safely managing iron overload, including chelation therapy

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing iron overload, including chelation therapy.			L	Date	Sig	
Domain: Registered Nurse						
8.6:1:1	Understands chelation therapy and its indication for use					
8.6:1:2	Recognises and reports non-adherence to the appropriate professional(s)					
8.6:1:3	Administers chelation where appropriate, according to local policy and guidelines					
8.6:1:4	Provides appropriate dietary advice in relation to iron overload, eg nutritional shakes and supplements					
Knowledge and understanding of:						
8.6:1:5	Role limitations					
8.6:1:6	Specific treatments that are likely to contribute to iron overload for patients with sickle cell disease or thalassaemia syndromes, eg regular blood transfusions					
8.6:1:7	Knowledge of the referral process and who to refer to for advice and management on further complications					

8.6:1:8	Potential complications resulting from iron overload, eg heart, liver, etc					
8.6:1:9	Where to obtain age-appropriate information and support groups. Local policies and National guidelines					
Knows how to:						
8.6:1:10	Refer appropriately					
8.6:1:11	Provide patient-centred care, displaying empathy and good communication skills					
8.6:1:12	Be open to receiving feedback from patients and colleagues					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing iron overload, including chelation therapy.			L	Date	Sig	
Domain: Enhanced						
8.6:2:1	Monitors ferritin levels					
8.6:2:2	Assesses the patient's/carer's technique when setting up self-infusers and syringe drivers					
8.6:2:3	Explains to patients and their family/carers the different drugs available, routes and side-effects					
8.6:2:4	Assesses the patient's/carer's knowledge and understanding of chelation drugs and the rationale for use					
8.6:2:5	Monitors patient adherence to chelators					
8.6:2:6	Communicates effectively and in an age-appropriate manner					
Knowledge and understanding of:						
8.6:2:7	Normal ferritin levels and the factors that influence them					
8.6:2:8	The risks associated with chelation and pregnancy and related side-effects					
8.6:2:9	The importance of initiating appropriate investigations					

Knows how to:						
8.6:2:10	Advise patients embarking on chelation regimens in relation to appropriate contraception					
8.6:2:11	Educate patients on their blood results and explain findings					
8.6:2:12	Assess the factors that impact on adherence and develop strategies to promote patient engagement					
8.6:2:13	Recognise and support appropriate psychosocial referrals in relation to treatment adherence, transition, etc					
8.6:2:14	Explain a range of chelation techniques and ways of monitoring iron overload					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Provides specific interventions with regards to safely managing iron overload, including chelation therapy.			L	Date	Sig	
Domain: Advanced Practitioner						
8.6:3:1	Monitors ferritin levels and other indicators of iron overload, eg T2* and R2*					
8.6:3:2	Undertakes appropriate referrals and arranges appropriate follow-up					
8.6:3:3	Discusses chelation options and changes treatment regimen where appropriate					
Knowledge and understanding of:						
8.6:3:4	Interpretation of results					
8.6:3:5	Iron overload and associated complications, eg endocrine issues					
8.6:3:6	Side-effects and appropriate management					
Knows how to:						
8.6:3:7	Interpret complex results and investigations and take appropriate action					
8.6:3:8	Refer to appropriate specialists, eg endocrinology, cardiology, etc					
8.6:3:9	Encourage a treatment regimen that supports patient adherence					

8.6:3:10	Start and stop chelation in line with local and national guidelines					
8.6:3:11	Determine when to discontinue treatment temporarily and when to restart					
8.6:3:12	Communicate effectively with the wider multidisciplinary team, including GPs					
8.6:3:13	Monitor the side-effects/toxicity of iron chelators					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency 9
Uses early-warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Uses early-warning tools/ approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action.			L	Date	Sig	
Domain: Registered Nurse						
9:1:1	Uses a range of early-warning tools to detect changes in vital signs and other indicators of deterioration					
9:1:2	Assesses the patient for any identified complications					
9:1:3	Documents, monitors and acts on findings, and discusses findings with senior teams					
9:1:4	Educates the non-registrant nursing team on the significance and importance of taking regular clinical observations and escalating concerns					
Knowledge and understanding of:						
9:1:5	The importance of interpreting vital signs in relation to acute sickle cell disease or thalassaemia complications					
9:1:6	Signs and symptoms of deterioration, and early-warning tools for complications					

Knows how to:						
9:1:7	Action any changes in the patient that might lead to deterioration in their condition					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Uses early-warning tools/ approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action.			L	Date	Sig	
Domain: Enhanced						
9:2:1	Investigates the causes of early signs of deterioration and takes appropriate action					
9:2:2	Assesses and identifies patient problems, documents all findings and liaises with the medical teams					
Knowledge and understanding of:						
9:2:3	The pathophysiological changes that can occur suddenly or gradually in patients with sickle cell disease or thalassaemia syndromes, resulting in rapid deterioration or death					
Knows how to:						
9:2:4	Assess and identify significant signs and symptoms of complications related to sickle cell disease or thalassaemia					
9:2:5	Undertake, record and act on nursing observations					

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Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Uses early-warning tools/ approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action.			L	Date	Sig	
Domain: Advanced Practitioner						
9:3:1	Provides and evaluates clinical supervision for the team					
9:3:2	Undertakes a comprehensive history and initiates treatment according to local guidelines or protocols, documents this appropriately in the nursing and medical notes, and reports to specialist teams or medics					
9:3:3	Educates junior nursing and medical teams on sudden or gradual changes in the patient's condition					
9:3:4	Educates all members of the team on major complications associated with the conditions and signs and symptoms to look out for					
Knowledge and understanding of:						
9:3:5	The pathophysiology and context of sudden onset of deterioration precipitated by the disease					

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Knows how to:						
9:3:6	Order and undertake appropriate investigations and interpret the results, identify acute complications and make an appropriate plan of care, and refer to specialist teams					
9:3:7	Develop and draft local guidelines or protocols, to help in the scope of practice when initiating treatment					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 10
Actively improves and promotes services across the care pathway

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Actively improves and promotes services across the care pathway.			L	Date	Sig	
Domain: Registered Nurse						
10:1:1	Invites patients and support groups to talk about their experiences					
10:1:2	Attends workshops and conferences					
10:1:3	Has a developing ability to manage emotional issues relating to stages in the patient's journey					
10:1:4	Recognises own limitations in managing the situation, referring on to appropriate health professional(s)					
10:1:5	Communicates with other health professionals and support agencies					
10:1:6	Recognises individual personal conflicts, referring these on to a senior member of staff					
10:1:7	Understands the importance of documentation and records information, including sensitive and confidential details, appropriately.					
10:1:8	Able to lead a team on a short-term basis to achieve a clearly defined goal					

Knowledge and understanding of:						
10:1:9	Sickle cell disease and thalassaemia syndromes					
10:1:10	The need to actively support the patient and their family/carers to identify and manage their own health and social wellbeing throughout their journey with sickle cell disease and thalassaemia syndromes					
10:1:11	Patient or user involvement initiatives in the locality					
Knows how to:						
10:1:12	Seek help and support when engaging others to promote services					
10:1:13	Display leadership skills that have an impact on the team, patient, outcomes and organisations					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Actively improves and promotes services across the care pathway.			L	Date	Sig	
Domain: Enhanced						
10:2:1	Embeds competencies within their local trust's courses/qualifications					
10:2:2	Engages with primary care (including with community and practice nurses) to promote awareness of sickle cell disease and thalassaemia syndromes					
10:2:3	Engages with local education providers where appropriate (for example, by establishing relationships with school nurses)					
10:2:4	Encourages patients to talk to their GP about their condition					
10:2:5	Uses their specialist knowledge and skills regarding disclosure of sensitive information					
10:2:6	Acts as a communication resource for other members of the multidisciplinary team					
10:2:7	Acts as a role model, educating and mentoring junior staff					
10:2:8	Demonstrates ability to communicate information to patients and their families/carers					
10:2:9	Demonstrates skills in assessing the patient's/carer's level of understanding					
10:2:10	Leads a team to define and achieve goals					

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10:2:11	Manages change through effective leadership					
Knowledge and understanding of:						
10:2:12	The prevalence rate in the local population					
10:2:13	Local resources					
10:2:14	Support group websites, in order to guide and advise patients					
10:2:15	The role of patient or user involvement in sickle cell and thalassaemia services, both locally and nationally					
Knows how to:						
10:2:16	Engage others to promote the services					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

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Action plan to achieve required competency level.

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Actively improves and promotes services across the care pathway.			L	Date	Sig	
Domain: Advanced Practitioner						
10:3:1	Provides quality accounts, including reports on mortality and morbidity within sickle cell disease and thalassaemia populations in areas where prevalence is high					
10:3:2	Uses their expert skills and knowledge to provide nursing leadership that informs the development of supportive care policy and strategy within the multidisciplinary team					
10:3:3	Provides clinical supervision and acts as an expert resource for support and training of others					
10:3:4	Demonstrates effective communication skills that address the complex needs of patients and their families/carers					
10:3:5	Acts as a professional leader within the specialty and organisation, and across the wider health care setting					
10:3:6	Develops the strategic direction for their specialty and service					

10:3:7	Effectively communicates the strategic direction for the specialty and service area to secure support and commitment across the health economy					
10:3:8	Contributes to strategy and policy development, at a local, strategic health authority and national level					
10:3:9	Facilitates the development of leadership skills amongst junior colleagues					
10:3:10	Initiates and implements innovations in care through effective delegation and collaboration					
10:3:11	Communicates effectively and involves all appropriate personnel in the decision-making process					
Knowledge and understanding of:						
10:3:12	Leadership roles and the range of leadership skills that can be utilised					
Knows how to:						
10:3:13	Liaise within the network at a senior level and provide strategic leadership and direction for policy development					

Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

Competency 11
Transition – early planning and preparation. Ideally this competency should be undertaken by a specially appointed transition nurse

Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Transition – early planning and preparation. Ideally this competency should be undertaken by a specially appointed transition nurse.			L	Date	Sig	
Domain: Registered Nurse						
11:1:1	Provides basic health promotion/ education and information around the concept of transition					
11:1:2	Uses a validated assessment tool (ie a standard generic tool such as Ready Steady Go) in addition to the local transition passport/pathway to assess and collect baseline information about the young person					
11:1:3	Assesses the overall readiness of the young person to transition to adult services by discussing this with the young person					
11:1:4	Signposts any gaps in readiness to necessary personnel					
Knowledge and understanding of:						
11:1:5	Requirements for transition and the age to commence the process in line with local policy and guidance					
11:1:6	Reasons for transition and the importance of preparing the young person ahead of time					

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11:1:7	Ready Steady Go questionnaires and how to use the information provided to support the young person					
Knows how to:						
11:1:8	Analyse information from patient questionnaires and surveys to inform the patient journey					
11:1:9	Advise and signpost the young person to appropriate services for guidance and support					
11:1:10	Engage in open communication with the young person about any worries and concerns they may have regarding transition					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	
Action plan to achieve required competency level.						

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Competency statement:	Level of achievement required	Self-assessment	Level achieved (assessed)			Evidence of achievement
Transition – early planning and preparation. Ideally this competency should be undertaken by a specially appointed transition nurse.			L	Date	Sig	
Domain: Enhanced						
11:2:1	Building on the Registered Nurse criteria, engages in a meaningful in-depth discussion with the young person and their family/ carers to identify their needs for a successful transition					
11:2:2	Builds on the questionnaire and addresses any concerns/issues jointly with the young person, formulates a transition care plan and acts as a link to other health and social care professionals					
11:2:3	Has knowledge of issues facing young people in transition and communicates using different mediums; able to provide appropriate information and advice as required					
Knowledge and understanding of:						
11:2:4	Issues affecting transition and readiness of the patient					
11:2:5	Parental concerns around transition and hesitation around child moving to adult services, influenced by family dynamics					
11:2:6	Adult services and the patient's pathway					

Knows how to:						
11:2:7	Assess the patient's development and awareness of their own condition					
11:2:8	Initiate conversations about transition with the young person and their family/carers, exploring any concerns and fears					
11:2:9	Review the patient's assessments and use the information to support the transition pathway					
Bespoke competencies						
Competency statement: **Domain:**	**Level of achievement required**	**Self-assessment**	**Level achieved (assessed)**			**Evidence of achievement**
			L	Date	Sig	

Action plan to achieve required competency level.

Contextual factors

The transition process should provide the young person with the skills they need to function effectively on arrival in the adult service and a jointly produced care plan that meets their needs. The young person and their family/carers must be given opportunities to meet the adult providers prior to transfer, in order to address any concerns they may have and discuss their care plan. The plan can then be shared with adult services at the point of transfer. It should include information about the young person's health condition, education and social care needs, their preferences regarding parent and carer involvement, emergency pain management plans, and their strengths, achievements and future aspirations.

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The many patients and nurses who contributed.

Appendix 1: Further reading and guidance

These competencies align with the national sickle cell and thalassaemia standards for patients in the United Kingdom, which were produced to support local guidance and practice.

Sickle Cell Society (2018) **Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK**

UK Thalassaemia Society (2023) **Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK** in the UK 4th edition

Nursing knowledge and competence is essential to deliver safe and effective care to patients. You should be aware of, and regularly familiarise yourself with, any updates to practice. Below are some links to relevant information that may inform your future practice and development.

NHS Patient Safety Strategy: **www.england.nhs.uk/patient-safety/the-nhs-patient-safety-strategy/**

Further learning resources

Below are some eLearning platforms where further training can be accessed to support learning and development against the competency framework.

OSCAR Sandwell: **www.oscarsandwell.org.uk/** (accessed 7 February 2024)

OSCAR Birmingham: **https://oscarbirmingham.org.uk/** (accessed 7 February 2024)

Sickle Cell and Thalassaemia Screening e-learning module: **https://portal.e-lfh.org.uk/Component/Details/449905**

Genomics Education Programme
Adult nursing – Beta-thalassaemia:
www.genomicseducation.hee.nhs.uk/nursing-educators-toolkit/adult-nursing-beta-thalassaemia/

NHS Blood and Transfusion Service **www.nhsbt.nhs.uk/what-we-do/diagnostic-and-therapeutic-services/therapeutic-apheresis/** (accessed 16 September 2024)

It is important that nurses take responsibility for discussing their training needs with their supervisors as part of their annual professional development. Appraisals and supervision are key opportunities to plan and provide a record of ongoing proficiency. This can also provide evidence for nursing revalidation.

Further resources

Sickle Cell Society: **www.sicklecellsociety.org/** (accessed 7 February 2024).

UK National Screening Committee: **www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc** (accessed 7 February 2024).

UK Thalassaemia Society: **www.ukts.org/** (accessed 7 February 2024).

UK Forum on Haemoglobin Disorders: **www.haemoglobin.org.uk** (accessed 7 February 2024).

Appendix 2: List of complications

Acute
1. Acute chest syndrome (ACS)
2. Infection
3. Stroke
4. Splenic complications
5. Acute anaemia
6. Priapism
7. Renal complications
8. Painful swelling of hands and feet
9. Gastrointestinal complications
10. Biliary complications, ie cholecystitis
11. Pain (refer to competency 7)
12. Aplastic crisis
13. Sepsis
14. Cardiac and pulmonary complications
15. Meningitis
16. Hyperhaemolysis and transfusion reactions
17. Aplastic crisis/Parvovirus B19 and Fat Embolism Syndrome

Chronic
1. Pulmonary hypertension
2. Endocrine dysfunction
3. Eye complications
4. Leg ulcers
5. Liver complications
6. Iron overload (refer to competency 8.6)
7. Bone complications
8. End-of-life care
9. Extramedullary haematopoiesis
10. Exocrine pancreatic insufficiency
11. Rheumatological complications
12. Neuropathy
13. Bone complications
14. Avascular necrosis
15. Priapism
16. Urological conditions

Appendix 3: List of abbreviations

ACS	acute chest syndrome
AKI	acute kidney injury
ANTT	aseptic non-touch technique
ASCAT	Annual Academy for Sickle Cell and Thalassaemia Conference
CBT	cognitive behavioural therapy
CV	central venous
CVAD	central venous access device
DNA	deoxyribonucleic acid
DVT	deep vein thrombosis
eg	for example
EPO	erythropoietin
etc	et cetera
FBC	full blood count
GP	general practitioner
HCT	haematocrit
ie	that is
IV	intravenous
M	met
MDT	multidisciplinary team
N/A	not applicable
NCA	nurse-controlled analgesia
NEWS2	National Early Warning Score
NHS	National Health Service
NMC	Nursing and Midwifery Council
NSC	National Screening Committee
NTDT	non-transfusion-dependent thalassaemia
PCA	patient-controlled analgesia
PEWS	Paediatric Early Warning Score
PGD	patient group direction
PICC	peripherally inserted central catheter
PHQ9	Patient Health Questionnaire
PRN	pro re nata (as needed)
PTSD	post-traumatic stress disorder

RCN	Royal College of Nursing
RFS	requires further skills
SENCO	Special Educational Needs Coordinator
SMART	Specific, Measurable, Achievable, Relevant, Time-Bound
STANMAP	Sickle Cell and Thalassaemia Association of Nurses, Midwives and Allied Professionals
TCD	transcranial doppler
TDT	transfusion-dependent thalassaemia
U/S	ultrasound
UK	United Kingdom
UKFORUM	United Kingdom Forum on Haemoglobin Disorders
UKTS	United Kingdom Thalassaemia Society
WHO	World Health Organization

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

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