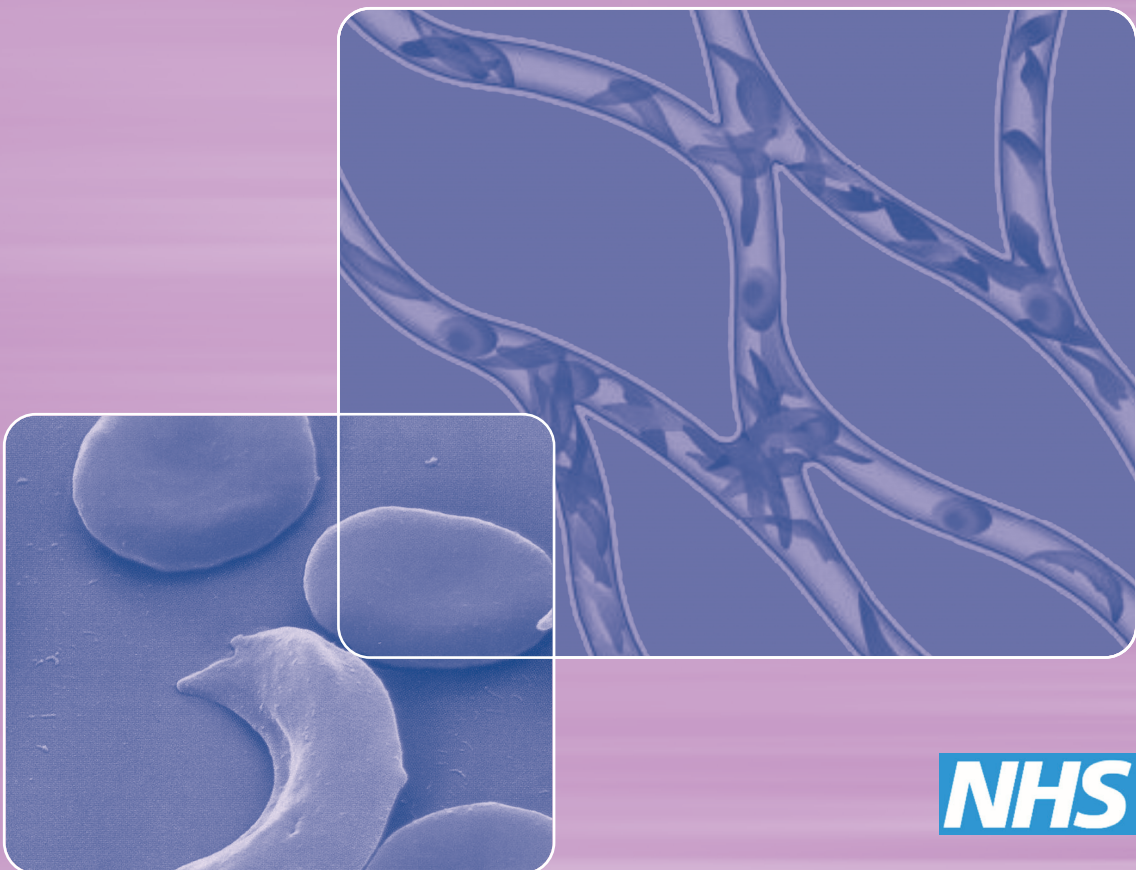


Caring for people with sickle cell disease and thalassaemia syndromes

A framework for nursing staff



Screening Programmes

Sickle Cell and Thalassaemia





Royal College
of Nursing



NHS
Screening Programmes
Sickle Cell and Thalassaemia

Acknowledgements

We hope that this competence framework will be useful for all health care professionals working with sickle cell and thalassaemia patients. The working group would like to thank everyone who has been involved in their development and, in particular, the patients for whom this framework has been developed.

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For a full list of contributors please see Appendices 1 and 2.

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RCN competences

Caring for people with sickle cell disease and thalassaemia syndromes

A framework for nursing staff

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Welcome

Dear colleagues

As patients and representatives of the two major voluntary sector groups in the field, we are delighted to have been actively involved in shaping these nursing competences.

We know from our own experience that good nursing care is crucial. It makes a huge difference to our whole experience – inside and outside hospital, and at every stage of our lives.

It is vital that nurses understand the conditions, are trained about what to do in different situations and know when, how and to whom they should refer on when necessary. We have heard too many stories about people being left in agony in Accident and Emergency, not being taken seriously when they ask for pain relief, having their wishes ignored concerning the best vein to use for a regular blood transfusion or not being monitored properly when on a ward.

For the first time, these competences mean that guidance about sickle cell and thalassaemia is in the mainstream of nurse training. Now the challenge is to make absolutely sure that the competences are actively used. They need to be incorporated into everyone's training, reviewed as part of performance management and given the serious attention that these important conditions deserve.

We thank all the people – especially patients – who have contributed to these competences and we urge you to make sure that this excellent work is put into practice.

Yours very sincerely

Anne Welsh

Chair of the Sickle Cell Society and sickle cell patient

Gabriel Theophanous

President of the UK Thalassaemia Society and thalassaemia patient

Introduction

There has been a huge amount of interest in, and support for, the development of a competence framework for nurses caring for people with sickle cell disease and thalassaemia. We have therefore been able to draw on the help and advice of many experts, including patients and carers, haematologists, paediatricians, nurses, counsellors, psychologists, nursing education specialists, members of the Royal College of Nursing (RCN) and others – all have given up many hours to attend meetings and provide comments on these competences.

The aim of these competences is to:

- improve nursing care for patients with sickle cell and thalassaemia, and hence improve the lives of their carers and families
- provide a training framework for nurses wishing to specialise in sickle cell disease and thalassaemia care so that they are encouraged to specialise and stay longer in this area.

Development of the competence framework

Sekayi Tangayi, Lead Nurse and Manager of the Newham Sickle Cell and Thalassaemia Centre, London, worked for several years in cancer nursing. She was aware of the competences required at each nursing band to provide good patient care and a structured framework for the training and development of nurses specialising in cancer. She thought a similar competence framework should be developed for sickle cell and thalassaemia.

Her initiative has been supported by the Department of Health (DH) and the NHS Sickle Cell and Thalassaemia Screening Programme, which has provided administrative support. A working group was set up, chaired by Elizabeth Anionwu (Emeritus Professor of Nursing, University of West London), and including Paul Telfer (Consultant Haematologist at the Royal London Hospital), Kim Manley (Education Facilitator, Royal College of Nursing), several eminent nurses working in both hospital and community settings, together with both sickle cell and thalassaemia patients supported by the Sickle Cell Society (SCS) and the UK Thalassaemia Society (UKTS) respectively.

An important political and professional driver was the publication in 2008 of *A Sickle Crisis? A report of the*

National Confidential Enquiry into Patient Outcome and Death, which identified examples of preventable deaths due to a lack of awareness of nurses and doctors. It recommended improved training for all health care professionals to prevent unnecessary deaths and to provide better and safer patient care. The implications for nursing education and practice were set out in an article in *Nursing and Midwifery Council News* (May 2009), entitled 'Sickle cell disease is on the increase – and nurses need to be aware' by Professor Elizabeth Anionwu, FRCN.



Working group taking the project forward



Katie Loizi Read (left) and Anne Welsh, both patient representatives, talking about their experiences.

The working group was established in November 2009 and a workshop was facilitated by the RCN in May 2010, which led to the first draft of the nursing competences. After several review meetings, the consultation draft was agreed and this was circulated to a wide group of stakeholders for comment and feedback. The consultation period lasted from August to September 2010.

Over 40 replies were received, including comments from patients, further education providers, haematologists and paediatricians, members of the Screening Programme Steering Committee, the Race Equality Foundation, together with many nurses working in all parts of the profession. Two patient review meetings were also held: one in Birmingham for thalassaemia patients and one in South London for sickle cell patients. These meetings gave patients and carers the opportunity to voice their opinions and suggestions in a very informal setting. Their input, along with comments received from the Sickle Cell Society and the UK Thalassaemia Society, has been invaluable in guiding the development of these competences.

Following the consultation period, the working group met to review comments and agree revisions. This process was greatly helped by advice from Kim Manley (RCN), together

with a small group of dedicated revisers including Neill Westerdale (Advanced Nurse Practitioner, Haemoglobinopathies, Guy's & St Thomas' NHS Foundation Trust). The final draft was agreed and submitted to the RCN Accreditation Board meeting in November 2010. The accreditation panel made some very useful suggestions and the competence framework was formally accredited.

The working group is now focusing attention on working with higher education institutes to incorporate these competences within relevant nurse training courses; this will lead to the provision of better nursing care for patients.

Future editions of the competence framework

Accreditation by the RCN is given for three years and therefore this competence framework will need to be formally reviewed and updated in 2013. We also appreciate that this document does not include specific competences on counselling sickle cell and thalassaemia patients in respect to their genetic conditions. This is because it has been recognised that genetic counselling is part of a wider review by the Department of Health and is becoming a profession in its own right. It is therefore hoped that the counselling aspects will be the subject of other competences and other training programmes.

We welcome comments and input from stakeholders: haemscreening@kcl.ac.uk

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Programme Director NHS Sickle Cell and Thalassaemia Screening Programme

The ten competences

1. Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition.
2. Assesses, in collaboration with the patient, their needs, taking into account the impact on their age and developmental stage, and their cultural and ethnic background.
3. Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists, for relevant chronic health care conditions.
4. Signposts and supports patients (and families/carers) in their understanding of their genetic condition.
5. Develops and evaluates a self-management plan with the patient.
6. Works alongside and with the patient (and families/carers) to address the psychological and social impact of their condition.
7. Works with the patient (and family/carers) to manage their pain (patients with sickle cell disease).
8. Provides specific interventions safely with regards to:
 - 8.1. undertaking phlebotomy and cannulations
 - 8.2. managing Central Venous Access Devices (CVAD), including portacaths
 - 8.3. transfusions and exchange blood transfusions
 - 8.4. fluid management/hydration
 - 8.5. pharmacological treatment and side-effects
 - 8.6. iron overload management including chelation therapy.
9. Uses early warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action.
10. Actively improves and promotes services across the care pathway.

Competence 1:

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition	Core 1 Core 6 HWB1 HWB3 HWB4	a. Asks questions and actively listens b. Establishes the patient's preferences and boundaries for sharing personal health information, i.e. protecting their privacy and confidentiality c. Respects and acknowledges a patient or family member/carer as an expert in their own condition d. Empathises with, and is responsive to, the needs of patients with sickle cell disease and thalassaemia syndromes	Knowledge and understanding of: <ul style="list-style-type: none"> treatment/care options and their risks/benefits the patient as a person and their life outside of the hospital, e.g. housing, employment and education communication skills privacy, consent and confidentiality the nursing needs of patients with sickle cell disease and thalassaemia syndromes Knows how to: <ul style="list-style-type: none"> use open and closed questions refer patients to interpreters and cultural mediators react appropriately when being challenged or guided by patients or families/carers seek support from specialist staff 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Aware of role limitations 	<ul style="list-style-type: none"> Patient Safety First campaign, www.patientsafetyfirst.nhs.uk Patient-centred policy documents Data Protection Act National occupational standards for health and social care HSC31 and HSC35 Standards and guidelines on sickle cell disease and thalassaemia syndromes via NHS Sickle Cell and Thalassaemia Screening Programme, http://sct.screening.nhs.uk/ Nursing and Midwifery Council (NMC) Nursing Code of Conduct, www.nmc-uk.org Royal College of Nursing (RCN) <i>Principles of nursing practice</i> (2010), www.rcn.org.uk
5	Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition	Core 1 Core 6 HWB1 HWB3 HWB4 HWB5 HWB6	a. Discusses care/treatment options and offers choices to reach joint and informed decision making b. Encourages feedback from the patient	Knowledge and understanding of: <ul style="list-style-type: none"> local protocols, standards and guidelines sickle cell disease and thalassaemia syndromes, including treatment principles of the Expert Patient philosophy Knows how to: <ul style="list-style-type: none"> be responsive to patient feedback and address concerns appropriately 	<ul style="list-style-type: none"> Works in partnership Supportive Empowering Provides choices Gives and receives feedback Willing to reflect on and learn from own practice 	<ul style="list-style-type: none"> Department of Health (DH) guidance on the Expert Patient, www.dh.gov.uk
6	Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition	Core 1 Core 6 HWB1 HWB3 HWB4 HWB5 HWB6	a. Co-develops, implements and evaluates personal care plans, treating the patient as an individual ALSO SEE COMPETENCE 5	Knowledge and understanding of: <ul style="list-style-type: none"> acute and long-term complications related to sickle cell disease and thalassaemia syndromes Knows how to: <ul style="list-style-type: none"> build and foster an equitable nurse-client relationship develop care plans in conjunction with local guidelines 	<ul style="list-style-type: none"> Models best practice Has a clear understanding of local and national vision and how to contribute Actively promotes sickle cell and thalassaemia nursing care and better health for patients 	

Competence 1: (continued)

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition	Core 1 Core 6 HWB1 HWB3 HWB4 HWB5 HWB6	a. Invites the patient to share their experience as a resource for teaching nurses and others b. Develops patient pathways in collaboration with patients and user groups c. Oversees and monitors the quality of care	Knowledge and understanding of: <ul style="list-style-type: none"> local user networks and teaching opportunities clinical indicators relevant NHS policies 	<ul style="list-style-type: none"> Provides strong leadership 	

Competence 2:

Assesses, in collaboration with the patient, their needs, taking into account the impact of their age and developmental stage, and their cultural and ethnic background

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Assesses, in collaboration with the patient, their needs, taking into account their age and developmental stage, and their cultural and ethnic background	Core 1 HWB2 HWB5 HWB6 HWB7 Core 6	a. Explains issues that may arise during specific developmental stages b. Explores the patient's current lifestyle, hopes and expectations c. Discusses the patient's cultural/family/ethnic background and identifies personal preferences d. Uses all available resources to provide information, including interpreter/cultural mediator	Knowledge and understanding of: <ul style="list-style-type: none"> the implications of different life stages, capacity and possible progression of the condition different cultures and faiths and the potential impact of these upon the patient's personal beliefs and viewpoints the range of resources for information and support where the patient could be referred obtaining consent from the patient confidentiality requirements theories of developmental stages, e.g. Piagets' Stages of Development 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Accountable Aware of role limitations 	<ul style="list-style-type: none"> Race Equality Foundation Briefing Paper 17 on sickle cell disease and thalassaemia (February 2010) by K Atkin and EN Anionwu, www.better-health.org.uk/briefing-paper.asp?id=17 Mental Capacity Act (2005) NMC Nursing Code of Conduct Piagets' Stages of Development Equality impact assessments
6	Assesses, in collaboration with the patient, their needs, taking into account their age and developmental stage, and their cultural and ethnic background	Core 1 HWB2 HWB5 HWB6 HWB7 Core 6	a. Explores the impact of the patient's condition with regard to their cultural and ethnic background and life choices, e.g. treatment options and reproductive choices	Knowledge and understanding of: <ul style="list-style-type: none"> culture, religion and ethnicity on health beliefs medical-legal implications Knows how to: <ul style="list-style-type: none"> deal with refusal of care by patient, family or carers, and refer to a health care professional where appropriate 	<ul style="list-style-type: none"> Builds relationship with peers Shares ideas Facilitates involvement of stakeholders 	

Competence 3:

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Undertakes nursing observations, records accurately and reports all changes	Core 1 Core 6 HWB1 HWB3 HWB4 HWB6	a. Undertakes and records nursing observations b. Takes appropriate action including reporting abnormal findings	Knowledge and understanding of: <ul style="list-style-type: none"> the normal parameters of nursing observations for sickle cell disease and thalassaemia syndromes Knows how to: <ul style="list-style-type: none"> record nursing observations and take appropriate action/referral for abnormal results 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Pays attention to detail Aware of role limitations 	<ul style="list-style-type: none"> Standards and guidelines on sickle cell disease and thalassaemia syndromes via NHS Sickle Cell and Thalassaemia Screening Programme, http://sct.screening.nhs.uk/ British National Formulary (BNF), www.bnf.org Standards for clinical practice and training (joint statements) from: <ul style="list-style-type: none"> Royal College of Anaesthetists Royal College of Physicians The Intensive Care Society The Resuscitation Council Local protocols and guidelines NMC Standards of proficiency for nurse and midwife prescribers (2006) www.nmc-uk.org
5	Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Undertakes and records nursing assessments b. Acts on findings of nursing assessments, refers to local guidelines and/or refers to appropriate specialist team c. Provides education to patient and family/carers on condition, treatments and side-effects FOR PAIN, REFER TO COMPETENCE 7 FOR IRON OVERLOAD, REFER TO COMPETENCE 8.6	Knowledge and understanding of: <ul style="list-style-type: none"> the anatomy, pathophysiology and management in relation to acute and chronic complications in sickle cell disease and thalassaemia syndromes the lifestyle risk factors that may influence disease severity, e.g. smoking and alcohol environmental risk factors, e.g. sudden changes in temperature the types of investigation, how to interpret results, appropriate treatment options and local guidelines when to refer to specialist team Knows how to: <ul style="list-style-type: none"> undertake a comprehensive physical assessment of adults and children recognise signs and implement appropriate actions and/or referral to specialist teams palpate the spleen, measure spleen size and teach family/carers assess school attainment and attendance with family/carers 		

Competence 3: (continued)

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	<p>a. Undertakes a comprehensive physical assessment</p> <p>b. Discusses with patients and family/carer the significance of medical investigations, test results, prognosis and treatment options</p> <p>c. Monitors and advises on nutritional intake and supplements in collaboration with dietician to provide optimal nutrition and growth</p> <p>d. Implements and documents an appropriate management plan</p> <p>FOR PAIN, REFER TO COMPETENCE 7</p> <p>FOR IRON OVERLOAD, REFER TO COMPETENCE 8.6</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> Specific acute and chronic complications that can arise in sickle cell disease or thalassaemia syndromes, including: <ul style="list-style-type: none"> Acute Chest Syndrome (ACS) and that it is a principal cause of mortality in adults with sickle cell disease infection splenic sequestration and acute complications, including hypovolemia and shock pulmonary complications, chronic heart and lung diseases stroke in adults and children with sickle cell disease different types of priapism including stuttering and acute events renal complications caused by sickle cell disease leg ulcers ophthalmic complications in sickle cell disease biliary complications including gallstones avascular necrosis in sickle cell disease and osteoporosis in thalassaemia syndromes local guidelines and national standards for sickle cell disease and thalassaemia syndromes <p>Knows how to:</p> <ul style="list-style-type: none"> undertake a detailed, comprehensive physical assessment in adults and children in accordance with local guidelines and national standards for sickle cell disease and thalassaemia syndromes recognise signs and implement appropriate actions for complications of sickle cell disease and thalassaemia syndromes, e.g. stroke/ophthalmic complications or acute infection undertake and interpret Arterial Blood Gases (ABG) monitor growth during childhood development and optimal nutritional status for child and adult 		

Competence 3: (continued)

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	Undertakes comprehensive physical assessment and follows up with appropriate action, including referral to medical specialists for relevant chronic health care conditions	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	<p>a. Undertakes a medical history, completes a detailed physical and nursing examination, formulates a diagnosis, initiates investigations and/or treatments and refers to specialist teams as appropriate</p> <p>b. Provides the patient with information on how to manage and monitor specific symptoms, e.g. bladder, alcohol and smoking advice for patients experiencing priapism</p> <p>c. Demonstrates awareness of the end of life care needs of the patient and their family, provides support and refers to the appropriate health professionals</p> <p>d. Provides clinical leadership for nurses and health care professionals involved with care of those with sickle cell disease and thalassaemia syndromes</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the complex nature of acute and chronic sickle cell disease and thalassaemia syndromes, and management and treatment of complications, including: <ul style="list-style-type: none"> Acute Chest Syndrome (ACS) infection stroke splenic complications acute anaemia priapism renal complications painful swelling of hands and feet cardiac and pulmonary complications endocrine dysfunction eye complications leg ulcers liver complications biliary complications, i.e. cholecystitis pain (REFER TO COMPETENCE 7) iron overload (REFER TO COMPETENCE 8.6) bone complications End of life care <p>Knows how to:</p> <ul style="list-style-type: none"> undertake a detailed physical and nursing assessment undertake Transcranial Doppler (TCD) scanning, interpret results and explain its significance initiate investigations appropriately act on investigations and interpret results formulate an appropriate management plan, including, where appropriate, end of life care administer treatment within their specialist role as a non-medical prescriber assess competency of nurses undertaking physical assessments 		<ul style="list-style-type: none"> Standards and guidelines for TCD scanning of children with sickle cell disease, (March 2009), http://sct.screening.nhs.uk/ NHS Core competencies for end of life care, (July 2009) www.library.nhs.uk Liverpool Care Pathway for the Dying patient, (December 2009) www.liv.ac.uk/mcpcil/liverpool-care-pathway Preferred Priorities of Care, www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforare Gold Standards Framework for people nearing the end of life, www.goldstandardsframework.nhs.uk/ DH <i>Making a Difference</i> (2008), www.dh.gov.uk RCN advanced nurse practitioner: An RCN guide to the advanced nurse role competences and programme accreditation, (May 2010), www.rcn.org.uk

Competence 4:

Signposts and supports patients (and families/carers) in their understanding of their genetic condition

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Signposts patients (and families/carers) to information about genetic condition	HWB1 HWB2 HWB3 HWB5 HWB6 Core 1 Core 3	a. Signposts the patient to further information	Knowledge and understanding of: <ul style="list-style-type: none"> resources, services and specialist staff Knows how to: <ul style="list-style-type: none"> obtain educational information or direct patients/families/carers to available resources, services and staff, including the voluntary sector work within their level of competence 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> NHS Sickle Cell and Thalassaemia Screening Programme, http://sct.screening.nhs.uk Sickle Cell Society, www.sicklecellsociety.org UK Thalassaemia Society, www.ukts.org Mental Capacity Act (2005), www.legislation.gov.uk
5	Signposts and supports patients (and families/carers) in their understanding of their genetic condition	HWB1 HWB2 HWB3 HWB5 HWB6 Core 1 Core 3	a. Identifies individuals at genetic risk, e.g. through taking family history b. Directs the patient to specialist help c. Carries out investigations related to screening under local guidance	Knowledge and understanding of: <ul style="list-style-type: none"> National Screening Committee (NSC) and Department of Health policy on informed choice, consent, confidentiality of information and ethical issues the origins of sickle cell disease and thalassaemia syndromes, and awareness of possible stigma local guidance and referral pathways Knows how to: <ul style="list-style-type: none"> differentiate between carrier and disease states communicate effectively refer to specialist services 	<ul style="list-style-type: none"> Empathetic 	<ul style="list-style-type: none"> <i>Fit for Practice in the Genetics /Genomics Era: a revised competence-based framework for nurse education.</i> NHS National Genetics Education and Development Centre, www.geneticseducation.nhs.uk Science and Technology Committee Second Report, Genomic Medicine, (June 2009), www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/10702.htm Guidelines on informed consent and mental capacity http://www.patient.co.uk/doctor/Consent-To-Treatment-%28Mental-Capacity-and-Mental-Health-Legislation%29.htm NMC guidelines on confidentiality, www.nmc.org.uk

Competence 4: (continued)

Signposts and supports patients (and families/carers) in their understanding of their genetic condition

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Signposts and supports patients (and families/carers) in their understanding of their genetic condition	HWB1 HWB2 HWB3 HWB5 HWB6 Core 1 Core 3	a. Supports patients sensitively and empathetically when they receive their results, which may include giving bad news, taking into account whether the patient is an adult or a child b. Obtains informed consent for testing c. Initiates initial screening, i.e. antenatal and newborn screening d. Explains genetic inheritance and the wider family implications	Knowledge and understanding of: <ul style="list-style-type: none"> • which blood investigations to order • counselling skills • how sickle cell disease and thalassaemia syndromes are inherited and the use of family history information to identify other family members who may have, or be at risk of, or be a carrier for the condition Knows how to: <ul style="list-style-type: none"> • support decision making • work within protocols, standards and guidelines 		
7	Signposts and supports patients (and families/carers) in their understanding of their genetic condition	HWB1 HWB2 HWB3 HWB5 HWB6 Core 1 Core 3	a. Interprets more complex results ¹ e.g. unusual haemoglobin variants b. Ensures patient (and family/carers where relevant) understands screening implications and results, and discusses options available c. Initiates further investigation ¹ d. Works with health care professionals, including specialist and genetic counsellors (ALSO SEE COMPETENCE 3) e. Ensures timely referral to clinical care where appropriate, and follow up, e.g. newborns diagnosed with sickle cell disease	In-depth knowledge and understanding of: <ul style="list-style-type: none"> • genetic inheritance, screening tests available, their implication and results • national standards and local guidelines Knows how to: <ul style="list-style-type: none"> • refer to specialist genetic counselling services 		

1. It is proposed to make genetic counselling for sickle cell disease and thalassaemia syndromes a specialism with specific training and accreditation requirements.

Competence 5:

Develops and evaluates a self-management plan with the patient

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Develops and evaluates a self-management plan with the patient	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Uses patient-held record/diaries where available b. Documents interventions and shares information with the multidisciplinary team, as appropriate c. Demonstrates skills in mediation, conflict resolution and advocacy d. Develops and records a self-management plan with the patient/family/carers, to include objectives around nutrition, hydration, maintenance of environmental temperature and activities of daily living, including relaxation techniques, e.g. massage	Knowledge and understanding of: <ul style="list-style-type: none"> the impact of living with a chronic condition in relation to self-management and adherence age-appropriate needs for sickle cell disease and thalassaemia patients, and factors that influence the illness available resources and where and how to access them how cultural, ethnic and religious backgrounds influence lifestyle choices Knows how to: <ul style="list-style-type: none"> work collaboratively with the patient develop and maintain a self-management plan that achieves the potential of the individual and maintains their motivation and confidence develop goals collaboratively that are SMART (Specific, Measurable, Achievable, Realistic and Time-specific) benchmark around the activities of daily living and improvement strategies confidentially record and report information, the electronic record and databases, and data that can support quality improvement through sharing and peer-review 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> National Service Framework DH, <i>Our Health, Our Care, Our Say</i>, www.dh.gov.uk Expert patient reports Department of Health/NHS Long-term conditions, www.dh.gov.uk Data Protection Act (1998) NMC record keeping guidance, www.nmc-uk.org NHS Constitution www.nhs.uk Nursing practice principles, www.rcn.org.uk National Service Framework for Long Term Conditions (2005), www.dh.gov.uk

Competence 5: *(continued)*

Develops and evaluates a self-management plan with the patient

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Develops and evaluates a self-management plan with the patient	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Collaboratively works with the patient and/or carers to assess their level of understanding of their condition b. Identifies age-appropriate needs in collaboration with the patient and/or family/carers, including the factors that influence their illness, and gives appropriate advice c. Discusses various lifestyle choices with the patient and possible implications for their immediate and long-term health d. Identifies agreed patient goals that can be evaluated and reviewed periodically e. Agrees appropriate screening and investigations as part of the patient's self-management plan	Knowledge and understanding of: <ul style="list-style-type: none"> the barriers to continuity of care and how they can be overcome local networks in the hospital and the community, and knowledge of how to build good relationships long-term complications and screening approaches, such as Transcranial Doppler (TCD) 		
7	Develops and evaluates a self-management plan with the patient	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Enables continuity of care for those patients with complex health needs to implement their self-management plan, for example in the community	Knowledge and understanding of: <ul style="list-style-type: none"> the principles of care in respect to complex health needs long-term and chronic disease delivery care pathway, including end of life care Knows how to: <ul style="list-style-type: none"> plan and deliver care build and strengthen community and hospital relationships to create seamless services innovate and improve services to enhance health-related quality of life 		

Competence 6:

Works alongside and with the patient (and families/carers) to address the psychological and social impact of their condition

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Provides simple psychological and social interventions and seeks support appropriately	KSF Core1 HWB2 HWB4 HWB5 HWB6	a. Provides support and encouragement by familiarising the patient with the ward environment (e.g. toilet location, meal times, visiting times) b. Communicates treatment plans clearly and recognises that hospitalisation is a major stress factor for sickle cell disease and thalassaemia patients c. Is able to listen and empathise with the patient, documents information and discusses with all involved in the care, and takes appropriate action d. Seeks support from colleagues in response to distressing conversations	Knowledge and understanding of: <ul style="list-style-type: none"> • verbal and non-verbal communication including paralinguistics such as silence, sighs, clicking of the tongue and other non-verbal utterances 	<ul style="list-style-type: none"> • Patient-centred and compassionate • Listens • Understanding • Non-judgemental • Welcoming • Open to receiving feedback • Confidential • Takes responsibility for own actions • Works in partnership with others • Aware of role limitations 	<ul style="list-style-type: none"> • National Institute for Health and Clinical Excellence (NICE) guidance NSG 91 (2009) www.nice.org.uk/CG91 • DH, <i>Long Term Conditions – Improving Access to Psychological Therapies</i>, (March 2008), www.dh.gov.uk • Mental Capacity Act 2005, www.legislation.gov.uk
5	Works alongside the patient (and families/carers) to address the psychological and social impact of their condition	KSF Core1 HWB2 HWB4 HWB5 HWB6	a. Assesses patient and identifies potential or actual psychological problems b. Assesses patient and identifies social problems that require support c. Identifies strengths and weakness, and an individual's coping strategies when this has been called into question; reassures the individual and makes an appropriate referral to the sickle cell/thalassaemia psychology team or local psychology/psychiatry service d. Identifies social issues, including education, employment, housing and welfare, and makes appropriate referral to social workers or non-health agencies e. Creates and evaluates a care plan based on achievable goals, strengths and weaknesses, coping strategies, family and social support. ALSO SEE COMPETENCE 5 f. Provides support and identifies psychological and social needs in relation to pain management and the impact of the condition in general g. Identifies individuals with long-term complications and concerns such as strokes, priapism, chronic pain, growth and pubertal delay; compliance issues, treatment-related fertility issues (e.g. hydroxyurea and bone marrow transplantation), fear of death and suicidal ideation h. Identifies verbal and non-verbal signs of distress, supports the patient, discusses with the medical teams and refers to the sickle cell/thalassaemia psychology team or local psychology service i. Initiates communication during assessment and during the patient's journey using open/closed questions and provides an environment for effective communication j. Demonstrates the ability to investigate personal background and identify family dynamics that might have an impact on health k. Identifies communication problems within family relationships and/or partner relationships and takes appropriate action l. Advises, supports and signposts patient and family/carers to community sickle cell disease and thalassaemia services available, such as the sickle cell and thalassaemia societies and the nursing teams m. Makes referrals where appropriate	Knowledge and understanding of: <ul style="list-style-type: none"> • the criteria and thresholds for referral to sickle cell/thalassaemia psychology team or local psychology service • the criteria and thresholds for referral to psychiatry services • cultural expressions/ways of expressing distress and pain • cultural variations in ways of communication • different communication strategies • psychological support services or other resources available such as bilingual health advocates 		<ul style="list-style-type: none"> • <i>The psychological care of medical patients: A practical guide</i> (2003). Report of a joint working party of the Royal College of Physicians and the Royal College of Psychiatrists, www.rcpsych.ac.uk • Anie KA and Green J (2002) <i>Psychological therapies for sickle cell disease and pain</i>. Cochrane Database Systematic Review, 2, CD001916

Competence 6: *(continued)*

Works alongside and with the patient (and families/carers) to address the psychological and social impact of their condition

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	Works alongside the patient (and families/carers) to address the psychological and social impact of their condition	KSF Core1 Core 3 HWB2 HWB4 HWB5 HWB6	<p>a. Assesses anxiety and depression using PhQ9 (recommended by NSG 91, NICE), and coping strategies; implements care and carries out an evaluation based on the problems identified</p> <p>b. Demonstrates the ability to undertake assessments that includes mental health; identifies mental health issues and psycho-social issues and makes appropriate referral(s)</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the roles of psychologists and social workers within the multidisciplinary team, and how to work with specialists to deliver care the emotional/psycho-social impact of chronic disease manifestation interventions, e.g. cognitive behavioural therapy (CBT) <p>Knows how to:</p> <ul style="list-style-type: none"> take a full comprehensive history, identify actual and potential problems and take appropriate action undertake mental health and depression/anxiety assessments 		

Competence 7:

Works with the patient (and family/carers) to manage their pain (patients with sickle cell disease)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Works alongside the patient (and families/carers) to manage their pain (patients with sickle cell disease)	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. With the patient, identifies and undertakes assessment of pain b. Communicates effectively with the patient in relation to their pain c. Assesses and documents pain using age-appropriate tools d. Safely and appropriately monitors a patient with acute pain and undertakes appropriate action	Knowledge and understanding of: <ul style="list-style-type: none"> the principles of assessment and control of pain acute and chronic sickle cell pain opiates and side-effects the importance of vital signs in relation to acute sickle complications, opiates and sedation common stereotypical and racist responses, and strategies to address them Knows how to: <ul style="list-style-type: none"> document vital signs and report abnormal readings undertake an assessment using an age-related pain assessment tool 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> National Confidential Enquiry into Patient Outcome and Death (NCEPOD) <i>A sickle crisis?</i> (2008), www.ncepod.org.uk Standards and guidelines on sickle cell disease and thalassaemia syndromes via NHS Sickle Cell and Thalassaemia Screening Programme, http://sct.screening.nhs.uk/ BNF, www.BNF.org
5	Works alongside the patient (and families/carers) to manage their pain (patients with sickle cell disease)	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Safely administers and monitors as required (PRN) analgesia regimes, patient-controlled analgesia and nurse-controlled analgesia b. Takes appropriate action for patients on opiates to ensure patient safety, including under-treatment or over-treatment c. Recognises major acute sickle cell related complications and makes appropriate emergency referrals d. Communicates and advises patient and their family/carers about pain management strategies e. Supervises all patients, including those preparing for discharge and deemed to be self-caring f. Ensures patients are discharged safely with appropriate follow-up and advice, e.g. referral to the community nursing teams g. Differentiates between acute and chronic pain	Knowledge and understanding of: <ul style="list-style-type: none"> pathophysiology and context of acute and chronic pain in sickle cell disease, including the triggers of pain pain complications associated with sickle cell disease, e.g. priapism, acute chest syndrome, avascular necrosis psycho-social and environmental factors that influence pain in sickle cell disease non-sickle cell related pain the age, developmental, individual and cultural factors that influence pain the increased mortality risks associated with sickle cell patients presenting with frequent pain episodes other treatment modalities that may be appropriate, e.g. hydroxyurea cognitive behavioural therapy (CBT) for the management of pain Knows how to: <ul style="list-style-type: none"> ensure patient safety whilst on opiates refer to different pain management specialists, holistic services (e.g. aromatherapy) and Expert Patient programmes 		<ul style="list-style-type: none"> Relevant courses for non-medical prescribing WHO step ladder for pain relief Local guidelines in relation to pain and sickle cell disease NICE guidance on the management of sickle cell pain (future publication) NMC Record Keeping Guidance for Nurses and Midwives (2010) Piagets' stages of development

Competence 7: (continued)

Works with the patient (and family/carers) to manage their pain (patients with sickle cell disease)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Works alongside the patient (and families/carers) to manage their pain (patients with sickle cell disease)	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Works in a multidisciplinary manner (e.g. in collaboration with pain management teams, GP and psychologists) to ensure effective and safe pain management	Knowledge and understanding of: <ul style="list-style-type: none"> patient group directives Knows how to: <ul style="list-style-type: none"> administer medications under a patient group directive use mediation, advocacy and conflict resolution skills programme an NCA/PCA pump 		
7	Works alongside the patient (and families/carers) to manage their pain (patients with sickle cell disease)	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Prescribes or administers appropriate medication under a patient group direction (PGD) b. Monitors care in relation to current standards and guidelines c. In collaboration with patients, innovates and develops pain services	Knowledge and understanding of: <ul style="list-style-type: none"> non-medical prescribing Knows how to: <ul style="list-style-type: none"> (in collaboration with the patient) physically examine, implement a plan of care and administer treatment appropriately 		

Competence 8:

Provides specific interventions safely with regards to:

8.1 – undertaking phlebotomy and cannulations

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Provides specific interventions safely with regards to: <i>undertaking phlebotomy and cannulations</i>	HWB7 Core 3	a. Undertakes blood investigations safely and identifies the patient verbally and via patient identification bracelet b. Selects appropriate blood bottles according to investigation c. Selects an appropriate cannula butterfly or needle d. Chooses dressing for cannulation e. Listens and responds to the patient and their carers/family concerns or suggestions f. Re-sites cannula if clinically indicated, e.g. infection or tissue damage g. In collaboration with patient identifies points of venous access h. Selects vein informed by a range of factors, e.g. with regards to pain and asepsis i. Agrees with the patient what to do if difficulty taking bloods or with cannulation, e.g. number of times to try j. Listens to the patient/family/carers and is sensitive to family/carer concerns (particularly when the patient is a child) and acknowledges the adult as an expert patient	Knowledge and understanding of: <ul style="list-style-type: none"> patient safety and consent local guidance and policies the position of veins/arteries and relevant nerve location different types of cannulation/butterflies or needle sizes needle stick guidance 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> NMC: Scope of Professional Practice, www.nmc-uk.org Skills for Health Module, www.skillsforhealth.org.uk Sickle Cell Standards of Care, www.sicklecellsociety.org RCN IV Standards 2010, www.rcn.org.uk Healthcare Associated Infections guidance www.nice.org.uk/guidance/CG2 Local protocols and guidelines in relation to the management of blood spillages RCN (2010) Competences: an education and training competence framework for capillary blood sampling and venepuncture in children and young people. www.rcn.org.uk
5	Provides specific interventions safely with regards to: <i>undertaking phlebotomy and cannulations</i>	HWB7 Core 3	a. Assesses the clinical need for cannulation b. Prepares patient using comforting and distracting strategies, e.g. use of topical anaesthetic cream or spray, distraction and comfort c. Records, observes and monitors cannula site	Knowledge and understanding of: <ul style="list-style-type: none"> the impact of continued access to veins distraction techniques the increased risk of keloid/scarring/ infection/ psychological distress possible complications aids to dilate venous access the rationale for cannulation, e.g. fluid replacement/dehydration/ transfusion when to request assistance or referral to IV team or medical team Knows how to: <ul style="list-style-type: none"> recognise, manage and deal with simple needle phobias, and its impact on families and carers refer to specialist help when relevant monitor cannulation site for signs of tissue damage and infection 		

Competence 8: *(continued)*

Provides specific interventions safely with regards to:

8.1 – undertaking phlebotomy and cannulations

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Provides specific interventions safely with regards to: <i>undertaking phlebotomy and cannulations</i>	HWB7 Core 2 Core 3 G1	a. Trains others in cannulation/phlebotomy techniques and care b. Undertakes cannulation/phlebotomy using ultrasound techniques or cold light c. Trains others in ultrasound and cold light techniques	Knowledge and understanding of: <ul style="list-style-type: none"> theoretical knowledge required to undertake ultrasound and cold light techniques 		<ul style="list-style-type: none"> NICE (2002) Guidance on the use of ultrasound locating devices for placing central venous catheters. TA49. http://guidance.nice.org.uk/TA49 Local guidance on cold light techniques

Competence 8:

Provides specific interventions safely with regards to:

8.2 – managing Central Venous Access Devices (CVAD)², including portacaths

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Provides specific interventions safely with regards to: <i>Central Venous Access Devices (CVAD)² including portacaths</i>	HWB7 Core 3	a. Assesses those patients with no peripheral access for CVAD, i.e. femoral lines or peripherally inserted central catheter (PICC) lines b. Orders appropriate investigations prior to insertion, e.g. INR blood test c. Monitors CVAD line for possible complications, e.g. infection, or deep vein thrombosis (DVT) and takes appropriate investigations and referrals d. Removes CVAD when clinically indicated e. Assesses CVAD for treatment utilising aseptic techniques according to local guidance f. Administers treatment via CVAD according to local guidance and ensures patient safety g. Educates the patient and family in the management of a permanent CVAD such as portacaths	Knowledge and understanding of: <ul style="list-style-type: none"> the clinical indications and risks associated with CVAD the need for informed consent the venous and arterial system in relation to CVAD local policies regarding documentation and monitoring of CVAD the appropriate equipment to access CVAD for treatment how to flush and care for CVAD pre- and post-treatment and to undertake blood investigations via a CVAD the importance of asepsis in relation to CVAD 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> RCN IV Standards (2010), www.rcn.org.uk
7	Provides specific interventions safely with regards to: <i>Central Venous Access Devices (CVAD)² including portacaths</i>	HWB7 Core 2 Core 3 G1	a. Inserts femoral/PICC lines, portacaths or CVAD if clinically indicated using aseptic techniques b. Uses ultrasound and X-ray guidance for CVAD insertion c. Prescribes and administers sedation if clinically indicated and maintains patient safety d. Trains others in CVAD line insertion and assesses competence e. Develops protocols and nursing guidance for CVAD within the specialty	Knows how to: <ul style="list-style-type: none"> insert femoral/PICC lines and portacaths use ultrasound and X-ray guidance for CVAD insertion 		<ul style="list-style-type: none"> DH (2002) Guidance on AHPs ordering tests and X-rays, and nurses administering medicines intravenously. www.dh.gov.uk

² CVAD applies to those nurses with relevant training in respect of the Nursing & Midwifery Council: *Scope of Professional Practice*.

Competence 8:

Provides specific interventions safely with regards to:

8.3 – transfusions and exchange blood transfusions

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Provides specific interventions safely with regards to: <i>transfusions and exchange blood transfusions</i>	Core 1 HWB7 Core 3 Core 6	a. Undertakes transfusions b. Explains procedures to patient, including risks and benefits, and provides patient information c. Obtains consent for all procedures d. Undertakes vital observations and take action as necessary e. Monitors and manages fluid balance in relation to transfusion f. Documents procedures, ensuring compliance with guidelines including local transfusion policies g. Acts on, reports and records complications h. Administers transfusions safely according to local guidance	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the clinical indications for transfusion/exchange transfusions blood groups and the implications for transfusion the need for informed consent the benefits and risks associated with manual exchanges, automated exchanges and transfusions the transfusion requirements for those with sickle cell disease and thalassaemia syndromes the different acute complications associated with blood transfusion reactions and the clinical care and investigations required the needs of cultural and religious groups with respect to blood transfusions, e.g. Jehovah's Witnesses, and awareness of local policies for dealing with such beliefs blood transfusion guidelines the access requirements for exchange/manual/transfusion, including peripheral and CVAD local sedation policies if used for CVAD the importance of maintaining transfusions and exchanges schedules and the need for follow up the complexities and challenges associated with a transfusion and exchange programme how many units of blood to order for transfusion or exchanges according to the clinical picture and haematological investigations <p>Knows how to:</p> <ul style="list-style-type: none"> administer blood safely and in accordance with local guidelines monitor and care for a patient undergoing transfusion including adverse events order appropriate bloods investigations for transfusion programs interpret full blood counts for patients with sickle cell disease and thalassaemia syndromes in relation to transfusion 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> NICE Guidelines Skills for Health Modules Mental Capacity Act (2005), www.legislation.gov.uk DH, Better blood transfusion toolkit, www.transfusionguidelines.org.uk/index.aspx?Publication=BBT RCN (2006) <i>Right blood, right patient, right time. RCN guidance for improving transfusion practice</i>, publication code 002 306 www.rcn.org.uk

Competence 8: (continued)

Provides specific interventions safely with regards to:

8.3 – transfusions and exchange blood transfusions

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Provides specific interventions safely with regards to: <i>transfusions and exchange blood transfusions</i>	HWB7 Core 2 Core 3	a. Undertakes the following procedures: <ul style="list-style-type: none"> • manual exchange transfusions • automated exchange transfusions b. Follows individual patient management plan in terms of target haemoglobin S % and haemoglobin level	Knowledge and understanding of: <ul style="list-style-type: none"> • the range of treatment options for those patients who are not transfusable, e.g. iron infusions or erythropoietin (EPO) • local policies and guidelines that relate to automated/manual /exchanges • how to prepare a patient for exchanges, e.g. weight, height and blood investigations • the importance of observations of access sites whilst exchanging (tissuing etc) Knows how to: <ul style="list-style-type: none"> • undertake manual exchange, automated exchanges and transfusions, including safe discharge • care for peripheral access • interpret blood counts and results required for transfusion, manual and automated exchanges (pre and post) • interpret full blood counts for patients with sickle cell disease and thalassaemia syndromes in relation to automated exchange or manual exchange transfusion load and programme the apheresis machine and blood warmer • clean and maintain apheresis machine and equipment 		<ul style="list-style-type: none"> • <i>Guidelines for the Blood Transfusion Service in the UK</i>. 7th edition. Section 6.6. http://transfusionguidelines.org/Index.aspx?Publication=RB&Section=25&pageid=564
7	Provides specific interventions safely with regards to: <i>transfusions and exchange blood transfusions</i>	HWB7 Core 2 Core 3 G1	a. Trains and assesses competence of others in automated and manual exchanges	In-depth knowledge and understanding of: <ul style="list-style-type: none"> • apheresis • complications requiring transfusion and exchanges within specialty • the benefits and risks associated with transfusion and exchange transfusions Knows how to: <ul style="list-style-type: none"> • train/educate others in undertaking manual/automated exchanges including assessing competence • ensure apheresis equipment is maintained and serviced according to local guidance 		

Competence 8:

Provides specific interventions safely with regards to:

8.4 – fluid management/hydration

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Provides specific interventions safely with regards to: <i>fluid management /hydration</i>	Core 1 HWB7 Core 3	a. Undertakes continuous observation b. Tracks fluid balance c. Observes and records input and output d. Reports on abnormal outcomes e. Helps patients to hydrate f. Recognises importance of fluid management/hydration g. Documents all observations and actions accurately	Knowledge and understanding of: <ul style="list-style-type: none"> the vulnerability to dehydration because of sickle cell disease the consequences of dehydration for patients with sickle cell disease, i.e. trigger for vaso occlusion complications due to fluid overload the pathophysiology of sickle cell disease renal complications in patients with sickle cell disease and thalassaemia syndromes oral fluid intake targets for SCD patients (three litres) Knows how to: <ul style="list-style-type: none"> maintain fluid balance charts and calculate input and output fluid balance 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Attention to detail Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> National Patient Safety Agency (NPSA) guidance on hydration, www.npsa.nhs.uk RCN guidance on food and hydration, www.rcn.org.uk NCEPOD <i>A sickle crisis?</i>, (2008), www.ncepod.org.uk
5	Provides specific interventions safely with regards to: <i>fluid management /hydration</i>	HWB7 Core 2 Core 3	a. Acts on abnormal outcomes b. Assesses whether the patient is able to hydrate themselves or not (considers patient for intravenous or nasogastric fluids) c. Monitors and acts on observations d. Maintains vigilance when patients are self-caring (looking after themselves)	Knowledge and understanding of: <ul style="list-style-type: none"> local guidance regarding oral /nasogastric fluid and intravenous fluids Knows how to: <ul style="list-style-type: none"> administer fluids via nasogastric route administer fluids via pump or appropriate equipment 		

Competence 8:

Provides specific interventions safely with regards to:

8.5 – pharmacological treatment and side-effects

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Provides specific interventions safely with regards to: <i>pharmacological treatment and side-effects</i>	Core 1 HWB7 Core 3	FOR PAIN-RELATED DRUGS AND SIDE-EFFECTS SEE COMPETENCE 7 FOR CHELATION DRUGS SEE COMPETENCE 8.6 a. Communicates with patient b. Ensures patient is safe at all times by observing, monitoring and recording all identified side-effects and taking appropriate actions	Knowledge and understanding of: <ul style="list-style-type: none"> • medications commonly used in acute and chronic management of sickle cell disease and thalassaemia syndromes • how medications work • side-effects and what to do 	<ul style="list-style-type: none"> • Patient-centred and compassionate • Listens • Understanding • Non-judgemental • Welcoming • Open to receiving feedback • Confidential • Attention to detail • Takes responsibility for own actions • Works in partnership with others • Aware of role limitations 	<ul style="list-style-type: none"> • <i>NMC record keeping guidance for nurses and midwives</i> (2010), www.nmc-uk.org • Standards and guidelines on sickle cell disease and thalassaemia via NHS Sickle Cell and Thalassaemia Screening Programme: http://sct.screening.nhs.uk • NMC guidelines on the administration of medicines (2008), www.nmc-uk.org • NMC Code of Professional Conduct (2004), www.nmc-uk.org • Local guidelines and protocols

Competence 8:

Provides specific interventions safely with regards to:

8.6 – iron overload management including chelation therapy

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
5	Provides specific interventions safely with regards to: <i>iron overload management including chelation therapy</i>	Core 1 HWB7 Core 3	a. Recognises and reports on non-adherence b. Administers chelation according to local policy/guidelines c. Provides appropriate dietary advice in relation to iron overload	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> specific treatments that are likely to contribute to iron overload for sickle cell disease and thalassaemia patients, e.g. blood transfusion the range of referral options and the process for referral the complications resulting from iron overload and side-effects of chelation drugs appropriate dietary advice in relation to iron overload the pathophysiology of iron overload methods of monitoring iron overload normal ferritin levels and the factors that influence them the range of chelation techniques and how to provide them the available age-appropriate information sources and support groups the factors that impact on adherence and non-adherence, and strategies that promote adherence local policies and national guidelines how nutrition and dietary supplements influence iron overload the risks associated with chelation and pregnancy <p>Knows how to:</p> <ul style="list-style-type: none"> assess and recognise psycho-social impact of chelation and related therapies, referral procedures and treatment strategies advise patients embarking on chelation regimes in relation to contraception 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Aware of role limitations 	<ul style="list-style-type: none"> Standards and guidelines on sickle cell disease and thalassaemia via NHS Sickle Cell and Thalassaemia Screening Programme, http://sct.screening.nhs.uk UK Thalassaemia Society Standards, www.ukts.org NCEPOD (2008) <i>A sickle crisis?</i>, www.ncepod.org.uk Pharmaceutical websites, e.g. 'The iron files' (Novartis pharmaceutical company), www.theironfiles.co.uk Patient information, e.g. supplied by the UK Thalassaemia Society

Competence 8: (continued)

Provides specific interventions safely with regards to:

8.6 – iron overload management including chelation therapy

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Provides specific interventions safely with regards to: <i>iron overload management including chelation therapy</i>	HWB7 Core 2 Core 3	a. Monitors ferritin levels and other indicators of iron overload (e.g. MRI and T2* and R2) and undertakes appropriate referrals and follow-up b. Assesses a patient's technique in relation to chelation therapy c. Introduces and explains to parents the drugs, techniques and side-effects d. Assesses the parent/family/carer and patient's knowledge and understanding, and provides information that is age-appropriate e. Communicates with the family/carer and patient in a way that is appropriate to the patient's age in respect to chelation management f. Initiates appropriate investigations and interprets results g. Recognises, supports and makes appropriate psycho-social referral in relation to chelation treatment, e.g. during transition to self-management	Knowledge and understanding of: <ul style="list-style-type: none"> in depth knowledge of iron overload complications, investigations and treatment Knows how to: <ul style="list-style-type: none"> interpret complex results and investigations refer to relevant specialist advise patient considering pregnancy (contraception) and the importance of ceasing chelation prior to conception 		
7	Provides specific interventions safely with regards to: <i>iron overload management including chelation therapy</i>	HWB7 Core 3 G1	a. Recognises clinical complications relating to iron overload and makes appropriate referral	Knows how to: <ul style="list-style-type: none"> caseload-manage a group of patients on transfusion and chelation regimes 		

Competence 9:

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1-4	Uses early warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action	HWB2 HWB3 Core 3	a. Undertakes clinical observations and reports all findings to qualified nursing staff b. Assesses patients' wellbeing c. Makes a note of verbal complaints or any physical changes in condition d. Reports to qualified nursing staff and documents e. Uses the Pandemic Medical Early Warning Score (PMEWS) to monitor early signs of deterioration	Knowledge and understanding of: <ul style="list-style-type: none"> the significance of performing clinical observations on sickle cell patients even if they might look well early warning tools (basic knowledge) Knows how to: <ul style="list-style-type: none"> report any changes in the patient that might lead to deterioration in their condition 	<ul style="list-style-type: none"> Patient-centred and compassionate Listens Understanding Non-judgemental Welcoming Open to receiving feedback Confidential Takes responsibility for own actions Works in partnership with others Aware of role limitations 	<ul style="list-style-type: none"> Pandemic medical early warning score Glasgow Coma Scale NMC News. (May 2009). "Sickle cell disease is on the increase – and nurses need to be aware," Elizabeth Anionwu, www.nmc-uk.org
5	Uses early warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Uses a range of early warning tools to ascertain changes in vital signs and other indicators of deterioration from the following complications: <ul style="list-style-type: none"> Acute Chest Syndrome (ACS) stroke acute anaemia splenic complications infection acute eye complications acute renal biliary complications, e.g. cholecystitis priapism cardiac complications acute liver complications acute endocrine dysfunction b. Assesses the patient for the above complications c. Documents, monitors and acts on findings, and makes appropriate referral d. Educates unqualified nursing team on the significance and importance of taking regular clinical observations	Knowledge and understanding of: <ul style="list-style-type: none"> the importance of interpreting vital signs in relation to acute sickle cell disease or thalassaemia complications signs and symptoms of deterioration, and early warning tools for complications, including: <ul style="list-style-type: none"> Acute Chest Syndrome (ACS) stroke acute anaemia splenic complications infection acute eye complications acute renal complications biliary complications, e.g. cholecystitis priapism cardiac complications acute liver complications acute endocrine dysfunction 		<ul style="list-style-type: none"> Local guidelines and protocols Standards and guidelines on sickle cell disease and thalassaemia syndromes via NHS Sickle Cell and Thalassaemia Screening Programme: http://sct.screening.nhs.uk/ The Resuscitation Council, www.resus.org.uk NPSA (2007) <i>Safer care for the acutely ill patient: learning from serious incidents</i>, www.npsa.nhs.uk NHS Equality and Diversity Council's 'Equality Delivery System' (forthcoming) NMC Nursing Code of Conduct, www.nmc-uk.org

Competence 9: (continued)

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Uses early warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3	a. Investigates the cause of early signs of deterioration and takes appropriate action b. Documents all findings and liaises with the medical teams	Knowledge and understanding of: <ul style="list-style-type: none"> the varying sickle cell and thalassaemia related pathophysiological changes that can occur suddenly or gradually, resulting in rapid deterioration or death Knows how to: <ul style="list-style-type: none"> order and undertake appropriate investigations and interpret results; identify acute complications and make appropriate plan of care and referral to specialist team undertake, record and act on nursing observations 		<ul style="list-style-type: none"> NCEPOD report <i>A sickle crisis?</i> (2008), www.ncepod.org.uk British National Formulary (BNF), www.BNF.org Standards for clinical practice and training (joint statements) from: <ul style="list-style-type: none"> Royal College of Anaesthetists Royal College of Physicians The Intensive Care Society
7	Uses early warning tools/approaches (for example, red alert) to identify the patient's changing and deteriorating condition, and takes appropriate action	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3 G1	a. Undertakes a full comprehensive history and initiates treatment according to local guidance or protocol, documents in the nursing and medical notes, and reports to specialist team or medics b. Educates junior nursing and medical teams on the sudden or gradual changes in patient condition c. Educates all members of the team on the major complications of the conditions and signs and symptoms	Knowledge and understanding of: <ul style="list-style-type: none"> the pathophysiology and the context of sudden onset of deterioration precipitated by the disease Knows how to: <ul style="list-style-type: none"> assess and identify significant signs and symptoms, including the following: <ul style="list-style-type: none"> Acute Chest Syndrome (ACS) stroke acute anaemia splenic complications infection acute renal complications biliary complications, e.g. cholecystitis priapism heart failure acute liver complications acute endocrine dysfunction work within the local guidelines or protocol, and the scope of practice when initiating treatment 		<ul style="list-style-type: none"> NMC scope of practice (1996/2000), www.nmc-uk.org

Competence 10:

Actively improves and promotes services across the care pathway

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	Actively improves and promotes services across the care pathway	Core 1 HWB3 HWB5 HWB6 HWB7 Core 3 Core 4 Core 5 G1	<p>a. Writes and updates protocols for care pathway</p> <p>b. Undertakes regular service reviews/audits and takes appropriate action to improve service</p> <p>c. Organises feedback from patients, their families/carers and makes appropriate changes to ensure services meet patients' needs</p> <p>d. Provides staff training and assessment for nurses working with patients with sickle cell disease and thalassaemia syndromes, e.g. training of A&E staff to recognise acute symptoms and understand the need for pain relief</p> <p>e. Keeps up to date with medical/nursing research so that new developments are adopted</p> <p>f. Ensures that the whole care pathway is seamless for patients by engaging with own institution (e.g. A&E) and other service providers, including:</p> <ul style="list-style-type: none"> • other specialist services (e.g. cardiac, psychology) • primary care (including community and practice nurses) • education, including school nurses and university staff • social services, housing and benefits advisers • voluntary sector and local support networks <p>g. Coordinates transition so that children can move confidently and seamlessly from paediatric to adult services</p> <p>h. Undertakes research and publishes</p> <p>i. Undertakes teaching in relevant post-registration courses</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> • clinical governance • appraisal and staff development (KSF) • assessing competency • clinical supervision and mentoring • ethics • barriers to continuity and the strategies to overcome these barriers <p>Knows how to:</p> <ul style="list-style-type: none"> • submit protocols for approval according to local guidance • conduct research according to local ethics and governance guidance • undertake audit and undertake quality reviews • enable all grades of staff with their learning and development 	<ul style="list-style-type: none"> • Patient-centred and compassionate • Listens • Understanding • Non-judgemental • Welcoming • Open to receiving feedback • Confidential • Takes responsibility for own actions • Works in partnership with others • Aware of role limitations 	<ul style="list-style-type: none"> • RCN (2010) <i>Measuring for quality in health and social care: an RCN position statement</i>. Publication code 003 535, www.rcn.org.uk • RCN (2010) <i>Principles of nursing practice and example measures</i>, cards, posters and summary report, www.rcn.org.uk

Competence 10: (continued)**Actively improves and promotes services across the care pathway**

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
8	Actively promotes and improves services across the care pathway	Core 1 HWB1 HWB3 HWB5 HWB6 HWB7 Core 3 Core 4 Core 5 G1 G2 G6 G7 Ik3	<p>a. Contributes to quality accounts: where prevalent, these should report on mortality and morbidity within sickle cell disease and thalassaemia populations</p> <p>b. Engages with other parts of the organisation concerning the whole care pathway so that care is seamless for patients</p> <p>c. Ensures smooth transfer and documentation of patients entering into and leaving local services</p> <p>d. Ensures relevant clinical data are confidentially collected, audited and evaluated to support and improve patient care across organisational boundaries</p> <p>e. Delivers workshops/ conferences</p> <p>f. Develops nurse-led clinics and services that address the health needs of patients with sickle cell disease and thalassaemia syndromes</p> <p>g. Continuously identifies gaps in service, develops innovative solutions and monitors outcomes</p> <p>h. Leads, manages and appraises staff</p> <p>i. Ensures good clinical governance</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> local networks community services the services offered by the voluntary sector the services offered by the statutory sector (including local schools, local housing departments and local social services departments) best practice standards and policies developments and innovations the consequences of poor practice best indicators leadership 'champion' skills change/development skills the skills needed to build good relationships with professional colleagues in other departments and services the prevalence rate in local populations information systems for sharing information across boundaries evaluation, professional standards and measurement and their relationship <p>Knows how to:</p> <ul style="list-style-type: none"> utilise patient information systems maintain patient records in compliance with standards at local level and across the NHS quality improvement and practice development strategies evaluate care develop a culture of effectiveness in the workplace 		<ul style="list-style-type: none"> National Standards for clinical care for adults/children with thalassaemia in the UK National Standards for clinical care for adults/children with sickle cell disease in the UK Pegasus training, www.pegasus.nhs.co.uk UK Forum on Haemoglobin Disorders, www.haemoglobin.org.uk Sickle Cell Society, www.sicklecellsociety.org UK Thalassaemia Society, www.ukts.org OSCAR Electronic information systems and national data warehouse Information governance NMC Nursing Code of Conduct, www.nmc-uk.org

Appendix 1:

Major contributors to the development of the competences

Organisations consulted:

- **Department of Health Clinical Services Development Group** – nurse and consultant haematologists were involved in Working Group; participated in the May workshop; and reviewed comments received through the consultation exercise.
- **NHS Sickle Cell & Thalassaemia Screening Programme** – guidance and support offered by Programme Director who is also a public health consultant specialising in sickle cell and thalassaemia. Programme also provided project management, editorial and administrative support.

Comments from the following organisations and their members were received during the consultative process:

- **UK Forum on Haemoglobin Disorders** – main multidisciplinary professional body. Chair and several members contributed comments in the consultation exercise
- **Sickle Cell Society**, including several individual patients
- **UK Thalassaemia Society**, including several individual patients
- **Sickle Cell and Thalassaemia Association of Counsellors (STAC)**
- **Forum for Acute Sickle cell and Thalassaemia nurses (FAST-N)**
- **Deputy Chief Nursing Officer for England** – aware of, and supportive of, project; contributed comments to the consultation
- **Minority and Ethnic Health JISC** email-based network – This list of over 600 members is aimed at professionals working in the academic, NHS and local government sectors who continually strive to improve the health of minority ethnic communities in the UK via a multi-disciplinary approach.

Names and designation of RCN staff members who have been involved in this work:

- **Christine Mckenzie**, Clinical Leadership Facilitator, RCN
- **Rose Gallagher**, Nurse Advisor Infection Prevention and Control, RCN and Principal Staff Lead for the RCN Haematology and Intravenous Therapy Forum
- **Dr Kim Manley**, RCN Lead Quality and Standards and Learning and Development Manager

Names and designation of people (non-RCN staff) involved in preparation of competences:

- **Elizabeth Anionwu** – Chair of the Working Group, Emeritus Professor of Nursing, University of West London (formerly Thames Valley University) and Fellow of the RCN
- **Sekayi Tangayi** – Lead Nurse and Manager of the Newham Sickle Cell and Thalassaemia Centre, London
- **Neill Westerdale** – Advanced Nurse Practitioner, Haemoglobinopathies, Guy's & St Thomas' NHS Foundation Trust
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- **Roma Haigh** – Administrator, NHS Sickle Cell and Thalassaemia Screening Programme
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- Patient representatives from the Sickle Cell Society and UK Thalassaemia Society, including and with particular thanks to **Anne Welsh** and **Katie Loizi Read**.

Appendix 2:

Full list of contributors to the development of the competences

We would like to thank all those who have contributed to the development of these competences through attending meetings, participating in the workshop, responding to our consultation process, and commenting on the many drafts that were circulated before reaching the final product. We would particularly like to thank all the many sickle cell and thalassaemia patient representatives who very generously gave their time and whose input has helped reflect patient needs in nursing care:

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