# SPECIFICATION OF REQUIREMENTS TEMPLATE

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| **Revision Date** | **Summary of Changes** | **New Version No** |
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# Specification of Requirements

## Background to the requirements.

### **Current Arrangements / Context.**

#### Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests, and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition. Further information regarding the general principles of screening can be found on GOV.UK.

#### The UK (United Kingdom) National Screening Committee (UK NSC) recommends systematic population screening in pregnancy for sickle cell and thalassaemia. The NHS Sickle Cell and Thalassaemia (SCT) screening programme, part of NHS England (NHSE), and has responsibility for implementing this policy in the NHS.

#### The V&S (Vaccination & Screening) directorate forms part of NHSE and exists to protect and improve the nation’s health and wellbeing and reduce health inequalities. This is achieved through world-leading science, knowledge and intelligence, advocacy, partnerships, and the delivery of specialist public health services.

#### NHSE V&S leads the NHS SCT (Sickle Cell and Thalassaemia) antenatal and newborn (ANNB) screening programme pathway. Each year around 650,000 antenatal screening and 14,000 pregnancies are identified as screen positive (approximately 1 in 47 women screened). Each year around 600,000 babies in England are tested (700, 000 babies in the UK (United Kingdom). Each year there are around 270 infants identified as screen positive for and 7,500 carriers of sickle cell disease (SCD).

#### NHSE and the NHS SCT ANNB screening programme (team) has responsibility for delivering this screening pathway and setting standards in England. There is a clear programme and function description with an evidence-based screening pathway/service specification that describes what should happen at each point of the pathway (see [English screening programme pathway requirements).](https://www.gov.uk/government/collections/population-screening-pathway-requirements-specifications)

#### This NHS SCT ANNB screening programme is linked, offering testing across the whole antenatal and newborn screening pathway. It is a complex programme that includes giving genetic results from the screening pathway to the public and is delivered by a range of different organisations working together. To accept the offer of screening the individual must be supported by trained and competent staff along the whole end-to-end antenatal and newborn screening pathway. The impact of a positive or carrier genetic result for sickle cell or thalassaemia provides a lifetime of genetic information for the individual and their family.

#### The aim of the NHS SCT antenatal programme is to identify people by 10 weeks of pregnancy who are genetic carriers of sickle cell or thalassaemia conditions. For pregnancies where both parents are carriers, or the biological father is unavailable, prenatal diagnosis (PND) is offered. NHS England and the NHS SCT screening programme has responsibility for delivering a screening programme that enables individuals to make informed personal informed choices. If PND shows that the fetus has inherited SCD, or thalassaemia then higher-level counselling by a trained healthcare practitioner (Genetic Counsellor) is necessary to enable women to make decisions regarding the outcome of the pregnancy.

## 1.2. Requirements for the delivery of SCT antenatal and newborn (ANNB) screening pathway.

#### 1.2.1. A trained SCT Genetic Counsellor healthcare practitioner is needed to:

#### Support individuals to understand their options.

#### Help individuals make personal informed decisions about reproduction, pregnancy, and parenting.

#### Provide genetic information for those at risk, which will enable the woman’s children and extended family members to access the genetic information needed for future genetic decision making.

#### Provide the family with a realistic view of the situation, the nature of the inherited disorder already seen in a family member, the risk of occurrence or re-occurrence, what this may mean in practical terms for all concerned, and to assist the family through what is often a difficult phase of their life.

#### 1.2.2. All NHS SCT ANNB screening providers should have the following trained staff in place:

#### Screening midwife/coordinator (and deputy) to oversee the NHS SCT screening programmes and act as a link between other members of the SCT multidisciplinary team.

#### Healthcare practitioners that are trained as SCT Genetic Counsellors to provide genetic risk assessment and counselling to pregnant women, biological fathers, parents/carers as well as extended families.

#### 1.2.3. Healthcare practitioners may include specialist nurses, antenatal and newborn screening coordinators / midwives, genetic counsellor practitioners and other relevant health and allied care professionals involved in providing the ANNB screening and specialist counselling service.

#### 1.2.4. Specialist genetic counselling workforce capacity and capability are required for an accessible, high quality screening service for the entire NHS SCT ANNB screening pathway, including any subsequent diagnostic testing, treatment, or other interventions.

## Scope of the Procurement.

### **Aims & Objectives.**

#### NHS England (NHSE) are seeking to procure a specialist academic education and practical training course Supplier to train and accredit NHS healthcare practitioners with a level 6 or level 7 competency award for Genetic Counselling on behalf of the NHSE ANNB screening programme. This will comprise of an accredited academic module on genetic counselling, and an additional 4 days of update training (Section 3.2).

#### The aim of the genetic counselling education and training is to update and provide practice guidance for those involved in providing NHS SCT genetic counselling services. This training is required for counselling those with, and at-risk of sickle cell and thalassaemia which are inherited conditions.

#### To maintain appropriate levels of trained NHS workforce, the Supplier will provide a SCT Genetic Counselling Module and 4 training update days for NHS staff across the academic year (See section 3.2).

#### This education and training will support workforce capacity and capability for the SCT screening services across England (see appendices for an example SCT Genetic Counselling Module timetable).

#### The SCT Genetics Counselling Module and the specialist training update days (see section 3 Requirements) will promote development of skills, knowledge, and competence to meet the needs of the client group (people ‘at risk’ of having a child with a haemoglobinopathy) and enable formalised assessment of individuals.

#### NHSE will as part of the contract fund 25 bursary places for approved applicants from ANNB screening pathway. The Supplier will be free to allocate up to a further 25 places on the module (See sections 2.2 & 4.5.).

### **2.2. Constraints and Dependencies.**

### 2.2.1. As the role of an SCT genetic counsellor is highly specialist, it requires additional training, a higher level and accredited academic award and/or certificate to maintain appropriate levels of trained workforce required by [service specification](http://www.england.nhs.uk/commissioning/pub-hlth-res/) (No. 18) as part of the public health functions exercised by NHSE. This means that any Supplier awarded must be accredited in delivering such services.

### 2.2.2. This service specification covers all attendees for the SCT Genetic Counselling Module, that being the 25 bursary places allocated and funded by NHSE and the up to 25 additional external organisation funded / self-funded places to be allocated by the Supplier.

#### 2.2.3. The provision and allocation of 25 bursary funded placements on the SCT Genetic Counselling Module will be decided by NHSE. The additional non bursary funded 25 places will be decided by the Supplier.

#### 2.2.4. Priority for the additional 25 external organisation funded / self-funded places on the SCT Genetic Counselling Module, the Supplier should consider:

* Any current role the learner has in the delivery of the NHS SCT ANNB screening pathway.
* Any future aspirations the learner has demonstrated through their application to work in the delivery of NHS SCT ANNB screening and onward services.

## Requirements.

### **Mandatory and Minimum Requirements.**

#### 3.1.1. The Supplier will provide a lead education facilitator that has previous or current experience, knowledge, and skills in clinical practice to teach and support learners and delegates on the specialist ANNB SCT Genetic Counselling Module and 4 training update days. Therefore, course facilitator/s would be a senior lecturer with relevant knowledge and experience of working in SCT genetic counselling and screening services and maintain continuous professional development.

#### 3.1.2. The Supplier will design, develop, and deliver bespoke academic courses for NHS healthcare practitioners involved across the entire antenatal and newborn NHS SCT screening pathway. There will be:

#### One SCT Genetic Counselling Module at academic level 6&7 (See section 3.2. SCT Genetic Counselling Module section).

#### Two haemoglobinopathies training update days: SCT screening programme update day (See section 3.5.).

#### Two haemoglobinopathies: specialist counsellor's training update (See section 3.6.).

#### 3.1.3. Each of the above requirements will be delivered per academic year.

#### 3.1.4. A Supplier working on behalf of NHSE must understand and have an ability to work effectively with diversity and difference amongst peers and learners. The Supplier should be committed to encouraging equality, diversity, and inclusion among learners, and eliminating unlawful discrimination. Suppliers will be expected to have a policy, covering equality, diversity, and inclusion, in line with the Equality Act 2010.

#### 3.1.5. Suppliers should work to a framework providing equality of opportunity, removing barriers, and ensuring full participation.

#### 3.1.6. The Supplier is expected to create a learning environment free of bullying, harassment, victimisation, and unlawful discrimination, promoting dignity and respect for all, and where individual differences and the contributions of all learners are recognised and valued.

#### 3.1.7. The Supplier will issue a paper or electronic certificate to that learner within 30 days of course completion if the learner has passed the SCT Genetics Counselling module. NHSE ANNB screening team must be informed of any learner that has failed the module, within 30 days and the Supplier must not issue a certificate to that learner.

#### 3.1.8. The Supplier will secure additional colleagues working in or linked to the SCT screening pathways to enhance the learner’s experience, for example, guest speakers, subject matter experts and the NHSE ANNB screening team.

#### 3.1.9. The Supplier will suggest, find, and help to book guest speakers from clinical and non-clinical backgrounds for planned sessions. Speakers must be suggested and sourced by the Supplier at no cost to NHS England. Where speakers are unable to be booked, it will be the responsibility of the education facilitator to deliver these sessions.

#### 3.1.10. All relevant course design and materials are to be provided to the ANNB programme team for the SCT Genetics Counselling Module and all training update days at least 3 months prior to each. The design and materials for all the education and training will meet the requirements set out in section 3.2.

#### 3.1.11. As part of their internal governance structure, the Supplier must have a process in place to manage learner matters such as extension times, non-attendance, and course failure.

### **3.2. SCT Genetic Counselling Module.**

#### 3.2.1. The SCT Genetic Counselling award or certificate must be ratified by a higher education organisation. The qualification is one bespoke, high-quality professional practice module at academic standard of either level 6 or level 7. The supplier must have the ability to deliver the course at level 6 &7, however it is the choice of the learner at which level they wish to choose.

#### 3.2.2. The Module must have SCT screening, genetic counselling, and risk assessment focused content. The Module will align with NHS health care practitioners practice who are providing antenatal and newborn SCT genetic counselling.

#### 3.2.3. There will be a strong focus on current issues and an emphasis on the practical application of knowledge, skills, and expertise. The overall outcome should be that healthcare practitioners are trained and competent to counsel and/or support individuals and their families with a high-risk pregnancy for sickle cell or thalassemia conditions.

### **3.3. Genetic Counselling Module Overview.**

#### 3.3.1. The module will cover the 8 core competences and associated learning outcomes and practice indicators described in the resource: Sickle cell and thalassaemia counselling knowledge and skills resource. [https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-counselling-knowledge-and-skills.](https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-counselling-knowledge-and-skills)

#### 3.3.2. The overarching themes are:

#### Haemoglobin conditions.

#### Practical applications of genetics in health care.

#### Genetic testing and giving genetic results.

#### Prevention of genetic disorders; and

#### Prenatal diagnosis and genetic counselling.

#### 3.3.3. The module will also cover the current key legislation, local, national, and international drivers and how these apply to the management within the NHS SCT screening programme.

### **3.4. Genetic Counselling Module Structure.**

#### 3.4.1. The Supplier is expected to deliver the core competencies of the various training (either face to face or virtual) as they see fit. Due to the nature of the Genetic Counselling for inherited conditions,the Genetic Counselling Module willrequire the need for some practical learning and Suppliers are expected to deliver some elements of the core competencies of this training course face to face for more intense learning. The face-to-face days will not exceed the maximum of 4 days.

#### 3.4.2. The location of the face-to-face taught competencies is to be mutually agreed between the NHS England ANNB screening team and the Supplier on or before each academic year.

#### 3.4.3. Throughout the whole SCT Genetic Counselling Module, the Supplier will provide ongoing education and training support to the learner.

#### 3.4.4. The Supplier must:

* Have module documentation, handouts, links to key documents and supplementary articles of interest available online.
* Provide the relevant course design and materials to learners, meeting the required outcomes set out in requirements section.
* Have a suitable advertising and registration system via a website or equivalent where learners can apply for the learning module.
* Have (or source) a suitable venue for a maximum of 50 learner places.
* Support and encourage learners who wish to publish their final assignment or alternative publication because of attending the course.

### **3.5. Haemoglobinopathies training update days: general SCT screening training update days.**

#### 3.5.1. The Supplier will design and deliver two individual haemoglobinopathies training update days: SCT screening programme training update days per academic year. All training must reflect the minimum requirements for healthcare practitioners working with families affected by, or at risk of, sickle cell or thalassaemia. Healthcare practitioners may include (but is not limited to) midwives, health visitors, screening coordinators, sickle cell and thalassaemia nurse counsellors, and SCT genetic counsellors. The focus of education and training should be on how healthcare practitioners should support families or individuals to deal with genetic risk or genetic test result. The content of these days will be discussed and planned with the support of NHSE ANNB screening team members, to ensure that all relevant issues to the national screening programme are included.

#### 3.5.2. The Supplier will provide a 1-day face to face course in central London and 1-day face to face course in the north of England. For each training date to take place there must be a minimum of 15 delegates booked and the course should facilitate up to a maximum of 35 places. If the number of applicants exceeds 35 places or does not meet the minimum of 15, the Supplier is required to discuss NHSE ANNB team.

#### 3.5.3. The Supplier will a have a website signposting delegates to how and when to apply for the training update days. NHSE will advertise the training update days through their website, regional Quality Assurance Teams (QA) and internal bulletins.

### **3.6. Haemoglobinopathies training update days: specialist counsellor's training update day.**

#### 3.6.1. The Supplier will design and deliver two individual haemoglobinopathies training update days: specialist counsellor training update days per academic year. The training update days are for healthcare practitioners who have previously undertaken the Professional Education for Genetic Assessment and Screening (PEGASUS) course, a higher-level (level 6 & level 7) genetic risk assessment and counselling module or an alternative sickle cell and thalassaemia related module.

#### 3.6.2. The training update day will provide a benchmark of professional competence. This will be aimed at healthcare practitioners who want to improve the quality in counselling people 'at risk' of having a child with sickle cell disease or thalassaemia. The content of these days will be discussed and planned with the support of NHSE SCT ANNB team members, to ensure that all relevant issues to the national screening programme are included.

#### 3.6.3. The Supplier will provide a 1-day face to face course in central London and a 1-day face to face course in the north of England. For each training date to take place there must be a minimum of 15 delegates booked and the course should facilitate up to a maximum of 35 places. If the number of applicants exceeds 35 places or does not meet the minimum of 15, the Supplier is required to discuss NHSE ANNB team. The Supplier will a have a website signposting delegates to how and when to apply for the training update days. NHSE will advertise the training update days through their website, regional Quality Assurance Teams (QA) and internal bulletins.

### **3.7. Haemoglobinopathies training update days (general SCT screening training update and specialist counsellor's training update).**

#### 3.7.1. The Supplier must:

* Have (or source) a suitable venue in agreement with NHS England (NHSE).
* Provide lunch for delegates/learners, the lunch must accommodate dietary requirements including but not limited to faith-based requirements.
* Run all training update days either in October or November each year.
* Have a system in place to advertise all training update days and use of a registration system where healthcare practitioners can apply.
* Provide each delegate/learner with a certificate of attendance.
* Provide the relevant course design and materials to delegates/learners, meeting the required outcomes set out in requirements section.

#### 3.7.2. NHS England (NHSE) will publish the agreed training update dates using regional quality assurance team communications and bulletins.

### **3.8. All SCT screening haemoglobinopathies training update courses and the SCT Genetic Counselling Module.**

#### 3.8.1. The Supplier is expected to design and update a project work plan outlining the intended timescales and work required to deliver again the service specification, including but not limited to preparation, delivery and review and feedback of training.

#### 3.8.2. The Supplier is expected to cover their own costs for travel and accommodation to external venues from within the contract budget. Costs of travel and hotel should be capped in line with the NHSE Business Travel and Expenses Policy. Please see Appendix 4.6

#### 3.8.3. The Supplier is expected to:

* Further the delegates/learner’s leadership skills by demonstrating personal qualities such as self-awareness, managing self and others, reflective practice, influencing skills and overcoming demanding or complex situations.
* Enhance knowledge, understanding, and skills in relation to the antenatal and newborn SCT screening pathway.
* Enable healthcare practitioners to make appropriate arrangements for further follow-up care or genetic counselling needed throughout the whole screening pathway.

#### 3.8.4. The outcome of the of the training update days and SCT Genetic Counselling Module will be to equip healthcare practitioners with the following knowledge and skills:

* Knowledge of the genetic disease
* Ability to provide and impart up to date information.
* Capacity to listen and be empathetic.
* Understanding of the impact of lifetime genetic information for the pregnant woman and her family.
* Knowledge of mechanisms available to support individuals, families, and communities.
* Ability to take account of socio-cultural diversity and respond according to client’s need.

## Roles and Responsibilities

### **4.1. NHSE will:**

* Have a named screening team lead as a point of contact for the Supplier.
* As part of mobilisation, within 2 weeks of the commencement date, set up, and holding an initial kick off review meeting.
* Facilitate planning meetings required by the Supplier within the first 1 month of the academic year or the commencement date. The meeting will cover the content of the SCT Genetic Counselling Module and training update days will be discussed and planned with the support of NHSE ANNB screening team members, to ensure that all relevant issues to the national screening programme are included.
* Review performance of the Suppliers against the service specification at the annual performance review meeting.
* Keep a copy of the Suppliers project workplan.
* Attend an end of year annual mandatory review meeting, set up and facilitated by the Supplier.
* Co-develop a delegate/learner feedback survey with the Supplier.
* Confirm with the Supplier, the education and training themes for the subsequent year training update days and SCT Genetic Counselling Module.

#### 4.1.1. NHSE will offer, provide, and allocate of 25 bursary funded places for eligible healthcare practitioners for each academic year. The Supplier can appoint a further 25 places that are to be self-funded or funded by an external organisation. The number of students should not exceed 50.

#### 4.1.2. To obtain a bursary place on the SCT Genetic Counselling Module, eligible healthcare professionals must apply to both the Supplier and the NHS SCT screening programme and be accepted for the course by both organisations.

#### 4.1.3. NHSE will supply the names of the SCT Genetic Counselling Module learners with bursary places 2 weeks prior to the module being open for applications. The Supplier must inform NHSE if any learner with an allocated bursary has not applied to attend the module with the Supplier 30 days prior to the closing date for applications.

#### 4.1.4. NHSE does not pay for lunch for learners on the SCT Genetic Counselling Module. It is the responsibility of the learners to provide this.

### **4.2.** **The Supplier will:**

#### As part of mobilisation, within 2 weeks of the commencement attending an initial goal setting meeting.

#### Within the first 1 month of the academic year or the commencement date, attend a planning meeting with the NHSE ANNB screening team. The meeting will cover the content of the SCT Genetic Counselling Course and training update days will be discussed and planned with the support of NHSE SCT ANNB team members, to ensure that all relevant issues to the national screening programme are included.

#### Attend and contribute to end of year annual review meeting with the NHSE ANNB screening team.

#### Subject to mutual agreement with the NHSE ANNB screening team, attend other ad hoc planning meetings or advisory board meetings.

#### 4.2.1. Within 1 week of the SCT Genetic Counselling Module and each training update day, the Supplier will inform the NHSE ANNB screening team by email who attended these courses, and if any cancellations were received.

#### 4.2.2. The Supplier will work with the NHSE ANNB screening team to update the course materials as and when required.

#### 4.2.3. The Supplier should make available all necessary resources required by learners online from 6 weeks prior to the SCT Genetic Counselling Module start date to include: an online reading list and any lecture notes then available, samples of past essays and links to any academic support which may be available, links to the screening programme, programme e-Learning and other educational resources.

#### 4.2.4. Any additional materials used in teaching on the SCT Genetics Counselling Module and training updates days are to be made available to learners online for download or circulated via email as appropriate following all courses as required. Learners should be free to make use of materials following the course, providing they acknowledge the source of the material.

#### 4.2.5. Any equipment required for the delivery of the SCT Genetics Counselling Module and training update days is to be provided by the Supplier. This could be, but not limited to:

* Projectors.
* Laptops for used by the trainer.
* Presentation equipment.

### **4.3. Timescales and Implementation.**

#### 4.3.1. To familiarise suppliers with programme content, up to 3 months will be allocated for mobilisation and on-boarding for the SCT Genetic Counselling module and training update days (before contract start date on the 1st of September 2024).

#### 4.3.2. The Supplier will develop a mobilisation work plan with dates for deliverables. They will agree the final design and content of the SCT Genetic Counselling Module and training update days, materials, and equipment with NHSE ANNB screening team.

#### 4.3.3. The mobilisation work plan will include but not limited to:

* + - Academic Module design.
    - Communication and collaboration with the ANNB SCT programme/team.
    - Resources including appropriately trained course facilitators.
    - Training update days content and structure.
    - IT (Information Technology) interfaces.

### **Location.**

#### 5.1.1. The Supplier must provide suitable venue(s) to hold the courses; such venues must meet the physical needs of all delegates/learners and must accord with prevailing legislation including but not limited to Health and Safety and Accessibility. Delegates/ learners will need to fund and provide their own travel and accommodation.

#### 5.1.2. Learners will be travelling from all parts of England, therefore multiple locations for the SCT Genetics Counselling Module should be avoided.

#### 5.1.3. For the training update days, locations should be in central London and in the north of England.

### **6. Bursary.**

#### 6.1.1. NHS England (NHSE) will request expressions of interests (EOIs) from the relevant healthcare practitioners who need a bursary place for the SCT Genetic Counselling Module. NHSE will request the EOIs 3 months prior to the Supplier advertising how and when to a apply for a learner place.

#### 6.1.2. The bursary funded applicants must meet the criteria specified by the NHSE ANNB screening team and the Supplier should accept the bursary funded applicant on to the course. NHSE will provide details of learners with a bursary funded decision 30 days prior to the Supplier opening their application portal/website.

#### 6.1.3. If the Supplier has any concerns regarding an applicant who has been awarded a bursary funded place, this should be discussed as a matter of urgency with NHSE ANNB screening team.

### **7. Management Information and Governance.**

#### 7.1.1. The Supplier will attend an annual contract review meeting (either virtually or face to face) with the NHSE ANNB screening team. This may include SCT clinical or programme scientific advisors. This meeting is expected to take place 10 months from the commencement date of the academic year.

#### 7.1.2. The Supplier will verbally report the on the outcome of each education and training session undertaken within the current academic year and discuss a workplan for plan for the following year. The verbal report will also cover an update on numbers of delegates/learners for each education and training session, budgets costs/finances and recommendations for around course content for the following year.

#### 7.1.3. The Supplier will have robust measure and policies in place relating to:

* Information Governance
* Data Protection
* Confidentiality

## 8. Performance and Measurement.

### **8.1. Feedback and outcomes.**

#### 8.1.1. Within 30 days after each course, the Supplier must provide the NHS ANNB screening team with an initial summary report outlining the outcomes of the course assessments; such a report must include but not be limited to:

#### Title, date, and location of course

#### Names of learners/delegates

#### Result of assessment (for the SCT Genetic Counselling course)

#### 8.1.2. The Supplier must provide NHSE with a final report 3 months prior to the end of the academic year; such a report must include but not limited to:

#### Title, date, and location of course.

#### Names of learners.

#### Result of assessment.

#### Survey results.

#### Finance summary report.

#### 8.1.3. The Supplier must manage individual feedback and evaluation process, ensuring that learners/delegates provide individual feedback on the SCT Genetic Counselling Module / training update day in the form of an evaluation survey, the content of which is to be agreed with the NHS ANNB screening team. All survey results must be shared with NHSE 3 months prior to the completion of each academic year and be included in an end of year final report.

#### 8.1.4. All assessed learners who attended the SCT Genetic Counselling Module must be given individual feedback by the education facilitator/course assessor after they have completed their assessment. This is to be done within 30 days after receiving results or course completion.

#### 8.1.5 Key Performance Indicators

|  |  |  |  |
| --- | --- | --- | --- |
| ***KPI (Key Performance Indicator) Ref. Number*** | ***Description of KPI*** | ***Measurement*** | ***KPI Tolerances*** |
| 1 | Delegate/Learner surveys that includes feedback on each of the 5 courses. | % of people responding in each survey | 90% |
| 2 | Learner feedback survey that includes: In general, how well did the SCT Genetic Counselling Module prepare you for your present or future role? | % of people responding with positive feedback on the module | 70% |
| 3 | One assessed genetic risk assessment and counselling module provided and delivered per year. | % of learners who have completed the course and gain the award/ qualification at level 6 or 7. | 95% |
| 4 | Two haemoglobinopathies SCT screening programme updates provided and delivered per year. | % of delegates that booked the haemoglobinopathies SCT screening programme training update days that then attended. | 90% |
| 5 | Two haemoglobinopathies specialist counsellors’ updates | % of delegates that booked the haemoglobinopathies specialist counsellors’ training updates that then attended. | 90% |
| 6 | Within 30 days after SCT Genetic Counselling Module, an initial summary report outlining the outcomes of the course assessments. | Report submitted to the NHS ANNB screening programmes/team by 30 days providing:   1. the title, date, and location of course. 2. names of attendees. 3. result of assessment. | 100% |
| 7 | Within 3 months prior to the end of the academic year; provide NHSE with a final report. | Report submitted to the NHS ANNB screening programmes/team within 3 months prior to the end of the academic year providing: title, date, and location of course.names of learners/delegatesresult of assessmentSurvey results.Finance summary report. | 100% |

### **9. Contract Term**

#### 9.1.1 The contract term will run for 24 months; however, the contract will have an option to extend up to a further period or periods of an additional 24 months (48 months in total) subject to performance review, budgetary approval, and business planning.

## 10. Appendices

### 10.1.1. Current competencies https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-counselling-knowledge-and-skills/sct-counselling-knowledge-and-skills-guide:

### BLOG <https://phescreening.blog.gov.uk/2021/03/17/return-of-the-sickle-cell-and-thalassaemia-screening-and-kings-college-specialist-counsellor-update-days/>

### BLOG <https://phescreening.blog.gov.uk/2021/03/08/sct-genetic-risk-assessment-counselling-module/>

### BLOG <https://phescreening.blog.gov.uk/2020/11/20/register-sickle-cell-thalassaemia-resources-launch/>

### Current course: <https://www.kcl.ac.uk/short-courses/genetic-risk-assessment-counselling-level-6-6knin640-term-3>

### Example Timetable: GENETIC RISK ASSESSMENT & COUNSELLING

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  |  |  |  |  |  |
| **Teaching mode** | **Date** | **Type of Session** | **Title** | **Time** | **Lecturer** | **Room** |
| University based study |  | **Introduction** | Welcome & Introduction  Course overview including assessment strategy and learning resources; Competences - frameworks Introduction – | **0930-1015** |  |  |
| **Lecture** | Abnormal haemoglobins  The aetiology, epidemiology, and natural history of and their genetic basis. | **1045-1300** |  |  |
| **Lecture** | Abnormal haemoglobins (CONTINUED)  The aetiology, epidemiology, and natural history of and their genetic basis | **1345-1445** |  |  |
| **Workshop** | Principles of genetic counselling  Differences between screening and diagnosis.  Taking and recording a genetic family history  Recording and interpreting a family pedigree  Cultural and genetic implication of kinship and consanguinity  Cascade screening  Introduction to methods of communicating genetic information  Principles of non-directive counselling  Assessing and providing correct information on genetic risk Providing non-directive pre-conception or early pregnancy advice to at-risk carrier couples | **1500-1700** |  |  |
|  |  |  |  |  |  |  |
| University based study |  | **Seminar** | Laboratory organisation and investigations  Identification tests available to detect carrier including the distribution of values in the target population  Policy on further laboratory investigations of haematological and molecular testing | **0900-1030** |  |  |
| **Seminar** | Understanding the importance of first trimester screening and diagnosis  Use of and interpretation of laboratory blood tests for carrier testing (including implications for childbearing woman and her unborn child)  Referral guidelines for expert counselling/prenatal diagnosis | **1100-1230** |  |  |
| **Seminar** | Guidance on e-learning –and formative assessment strategy | **1330-1400** |  |  |
| **Workshop** | Counselling in practice  - counselling session practice exercise | **1400-1700** |  |  |
| **Optional** | Course leader time | **1700** |  |  |
|  |  |  |  |  |  |  |
| **E-learning** |  |  | **PLEASE SEE KEATS SITE FOR FORMATIVE ASSESSMENT GUIDELINES** |  |  |  |
|  |  |  |  |  |  |  |
|  |  |  | Screening in the NHS  Overview of NHS Sickle Cell & Thalassaemia Antenatal & Neonatal Screening Programme | **0930-1100** |  |  |
| **Seminar** | Research presentations  Ethical, cultural, and social issues in the understanding of genetic risk | **1115-1315** |  |  |
| **Workshop** | Research presentations (Continued)  Ethical, cultural, and social issues in the understanding of genetic risk    Group exercises (Role play) Part 1  Choosing strategies for effective communication Dealing with the potential consequences of ineffective  communication (including breakdown in communication, displays of stress, anger, and aggression | **1400-1500**      **1515 - 1700** |  |  |
| University based study |  | **Workshop** | Group exercises (Role play) Part 2  Choosing strategies for effective communication Dealing with the potential consequences of ineffective  communication (including breakdown in communication, displays of stress, anger, and aggression | **0900-1030** |  |  |
|  | Group Tutorial  Summative Assessment strategy | **1100-1140** |  |  |
| **Seminar** | Establishing and operating fail-safe quality management systems  (Group work and feedback from guided study) Audit, data requirements and recording, Critical incidence analysis, Patient satisfaction surveys  Collating and reporting data for different stakeholders | **1145-1300** |  |  |
| **Seminar** | The role of the specialist practitioner  Professional Regulation  Career progression - Mentoring and Coaching | **1330-1500** |  |  |
|  |  | **Seminar** | Course Evaluation/Close | **1500-1600** | ALL |  |

### NHSE Business Travel and Expenses Policy

