# SPECIFICATION OF REQUIREMENTS

# NHS Sickle Cell and Thalassemia Screening Engagement and Outreach Service

**TABLE OF CONTENTS**

[SPECIFICATION OF REQUIREMENTS TEMPLATE 1](#_Toc448914365)

[Specification of Requirements 3](#_Toc448914366)

[1. Background to the requirements 3](#_Toc448914367)

[2. Scope of the Procurement 3](#_Toc448914368)

[3. Requirements 4](#_Toc448914369)

[5. Appendices 8](#_Toc448914371)

## Background to the requirements

* 1. The Vaccination and Screening directorate (V&S) forms part of NHS England 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.

* 1. NHS England V&S leads NHS sickle cell and thalassaemia (SCT) antenatal and newborn screening programmes. 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). There are around 270 positive cases identified and 7,500 carriers of sickle cell disease (SCD).
	2. The aim of the newborn programme is to improve child health through prompt identification of affected babies and timely transition into treatment services. The overall outcome is to achieve the lowest possible childhood death rate and to minimise childhood morbidity from sickle cell diseases and other severe haemoglobin conditions that are identified from the heel prick test. The programme aims to deliver this by:
* Offering antenatal SCT screening by 10 weeks of pregnancy.
* For those women accepting prenatal diagnosis, 50% of prenatal diagnoses to be performed before 12 weeks 6 days.
* Ensuring effective communication and engagement for at risk populations.
	1. **Antenatal screening**

Antenatal screening identifies pregnant women who are genetic carriers of SCD or thalassaemia. This enables healthcare professionals to make appropriate arrangements for care during pregnancy. It also means that genetic counselling can be offered for known carrier women and couples to determine the risk to the pregnancy.

For high-risk pregnancies (where both parents are carriers, or the biological father is unavailable) prenatal diagnosis (PND) is offered. If PND shows that the fetus has inherited SCD, or thalassaemia further counselling is offered to enable women to make decisions regarding the outcome of the pregnancy.

* 1. **Newborn screening**

Newborn screening detects babies with sickle cell disease. A health professional will offer newborn screening on day 5 (day of birth is day 0). The screening test is a simple blood sample taken from a baby’s heel. Babies who are new to the country are eligible for screening up to 1 year of age. The newborn screening procedure also identifies babies who are genetic carriers for SCD or have severe thalassaemia, these results are reported and followed up as appropriate.

* 1. The NHS SCT antenatal and newborn screening programme’s [first evaluation](http://adc.bmj.com/content/archdischild/early/2017/11/02/archdischild-2017-313213.full.pdf)

which was undertaken between 2010-2016 and showed promising outcomes and scope for improvement. Test performance and coverage appeared excellent but timeliness of care, acceptance of penicillin and adherence to treatment were challenging. Delays between screening results and enrolment in care require optimisation of fail-safe follow-ups

* 1. Public Health England acted upon recommendations from the evaluation and

commissioned a national engagement outreach programme which aimed to work jointly with people living with sickle cell and thalassaemia, their families, NHS bodies (commissioners and providers), Government, and a range of other national stakeholders to increase the uptake of antenatal and newborn sickle cell and thalassemia screening.By using outreach and engagement services the programme can address specific needs and promote inclusivity in the NHS SCT antenatal and newborn screening pathway.

* 1. The outreach and engagement service commenced in August 2018.

To date the current service has supported the improved booking targets and take up of screening offers for various cohorts.

* 1. the Programme has seen success in boosting awareness of the conditions

and screening offers as a result of the outreach and engagement service and subsequently the current supplier has started to focus on achieving more specific projects (see below).

* **Scoping and supporting the Programme in ways to reduce variation in, and ways to improve performance workstream.** For example, uptake of father testing in 2020/21 has increased since 2015/16 from 64.22% to 72.3%. The timeliness of antenatal screening is improving and is now above the acceptable level specified in the Programme standards.
* **Education and training project.** Is working closely with the SCD pathways reviews and Steering Groups regarding genetic education and training for sickle cell and thalassaemia. The current Supplier also added a chapter on the e-learning for health SCT screening module addressing health inequalities.
* **Newborn screening declines.** Numbers of parents declining the Newborn Blood Spot (NBS) screening appear to be increasing. The rate of declined screening tests for sickle cell disease in 2020/21 was 6 per 1,000 babies screened compared to 0.5 per 1,000 in 2005/06. It is not known whether this reflects a true increase in declines or improvements in reporting mechanisms. The Programme is working to collect better data and to understand who declines, if there is inequality and work needed with specific ethnic groups.
* **Reporting and receiving information on carrier results project.** Organising and coordinating conference events, producing conference reports, and supplying booklets on the raising awareness about communicating newborn genetic screening results.
* **User focus groups project.** Capturing the communication process for reporting newborn carrier status to parents and evaluating the national information for parents following universal newborn screening for sickle cell condition varies within and between regions.
* **Newborn outcome solution (NBO) and improving the pathway workstream**. Close working with the programme to ensure the implementation into clinical services of the NBO system, which supports the collection of newborn outcome data and information.
* **Health inequalities workstream.** Reviewing and developing materials and resources that represent ethnic minority groups.

## The current service continued throughout the coronavirus (COVID-19) pandemic and highlighted the known link between poorer health outcomes, ethnicity, and deprivation. Health inequalities is a key priority for the NHS England and the NHS SCT screening programme. Most workstreams include outreach and engagement covering:

* Raising awareness of sickle cell disease and thalassaemia conditions
* Engaging with communities less likely to access health information through usual NHS channels, particularly men.
* Sharing feedback from people that share the same population background or have experience of the condition and to feed into the programme updates and improvements.
* Capturing family and cultural legacy to educate and improve knowledge about sickle cell and thalassaemia in specific communities.
* Supporting NHS England to develop guidance so healthcare professionals will understand user options, how to supply better support, joined up care at the right time in the right setting.
* Focusing on outreach projects that improve the screening pathway for pregnant women and their families.
* Working with the NHS England to understand and identify the causes for why pregnant women with these conditions are tested late.
* Ensuring literature for women and families at risk which has been produced jointly by the patient organisations and the Screening Programme, resulting in information that meets the needs of families with sickle cell or thalassaemia.
* Acting as a bridge between screening services and users in the development of a referral and information solutions such as, National Haemoglobinopathy Register and Newborn outcome solution.
* Supporting the programme in developing and monitoring standards for antenatal and newborn screening.
* Sharing the lessons learned from the experiences of parents, so the screening programme can update its standards and guidelines and public and professional educational resources.
* Demonstrating working in partnership with the NHS Sickle Cell and Thalassaemia Programme and be flexible in dealing with organisational changes within the NHS.

#### The current challenges for the Programme are:

#### the definition and performance of SCT-S02 standard 2 (Antenatal sickle cell and thalassaemia screening – timeliness of test). The proportion of women having antenatal sickle cell and thalassaemia screening for whom a screening result is available by 10 weeks + 0 days gestation dropped slightly during the COVID pandemic to 51.3%. Standard 2 is a key inequalities standard focusing on timely access to screening, outreach and engagement is needed to complete this review.

#### the definition and performance of SCT-S05 standard 5a and 5b (timely offer of prenatal diagnosis (PND) to women/couples at risk of having an affected infant. These standard needs biological father testing, but performance shows a pathway issue with delayed uptake of biological father testing. Outreach and engagement have been successful in improving biological father testing.

#### issues with standard SCT-S07 the timely reporting of prenatal diagnosis (PND) to parents. Only 77.5% of women receiving results ≤ 5 working days of PND procedure. There are 31 maternity providers that do not meet acceptable threshold (SCT-S07). Outreach and engagement are needed to target areas with raising awareness and education campaigns on the impact of receiving PND results too late.

#### data quality in the SCT NBO system; data fields that need improving relate to the age of the infant with a screen positive result when: - parents receive the result.

## Scope of the Procurement

### Aims & Objectives

* 1. NHS England V&S (the Programme) are looking for a supplier that can supply an outreach and engagement service that is socially integrated, and representative of the population served by the NHS sickle cell and thalassaemia programme. Therefore, the Supplier must represent ethnic minority groups focusing on health inequalities within the community, such as language barriers, access to healthcare and screening.

#### **The broad expected outcomes of the SCT Engagement and Outreach Service are based on the NHSE aims and objectives:**

* Longer healthy life expectancy
* Excellent quality, safety, and outcomes
* Excellent access and experience
* Equity of healthy life expectancy, quality, safety, outcomes, access, and experience
* Value for taxpayers’ money

#### The SCT Engagement and outreach service will work with and support the V&S directorate on projects linked (but not limited to) the following high priority workstreams:

#### **Raising the awareness of the timeliness of antenatal screening**: Only 50% of women are screened by 10 weeks of pregnancy. Ensoulment refers to the moment the human being gains a soul. The teachings of Judaism, Christianity, and Islam affirm that what makes one a person with full moral rights is the possession of the soul, and they apply the moment of ensoulment as the cut-off point in determining legislation on abortion. The Islamic view of 134 days (19 weeks + 1 day of conception) is well described. Therefore, an early screening test by 10 weeks of pregnancy and the offer of PND by 12 weeks of pregnancy is particularly important as women/couples need to complete all the tests and have sufficient time to consider pregnancy outcomes (which may include choosing whether to continue with the pregnancy if the baby is affected with a major condition).

#### **The education and training of genetic counselling**: Supporting the development of appropriate information for women and couples to make informed choices during pregnancy and timely transition into appropriate follow up, treatment and family planning. Outreach and engagement activities are used to address misconceptions about screening tests, diagnostic tests, and the screening pathway.

#### **Raise awareness about the importance of testing for biological fathers**: Raising awareness of the need for biological father testing (currently at 72%) this testing allows for a more accurate assessment of the risk of the baby inheriting a haemoglobin condition.

#### **Emotional and psychological preparation for receiving newborn screening results:** If the baby is found to be affected by sickle cell disease or thalassemia, providing the family with an opportunity to prepare emotionally and psychologically for any potential challenges that may arise. It allows for better understanding of the conditions.

### **Constraints and Dependencies**

#### This procurement will cover all engagement and outreach activities described in this specification. The aim is to build upon the success of the work to date and to conduct projects to address service issues with views and feedback from the public and relevant health professionals. Specific initiatives and projects will be agreed jointly by the Supplier and the Programme.

#### The procurement will **not** cover any clinical activities such as: taking and reading tests, co-ordinating or managing the screening programme, producing performance and monitoring statistics for screening, identifying, and inviting eligible people, setting operational policy, carrying out interventions, setting objectives, aims and policy, or quality assurance.

#### Unless otherwise agreed by NHS England there will be 2 major, or 4 minor projects named each year by the Programme in which the supplier will lead on. The projects will be linked to the high priority workstreams as described in section 2.2.3-2.2.6

#### The decision to approve the projects will be based on the medium-term aims set by NHS England.

#### Other bespoke projects may be necessary based on the needs of NHS England and the Programme.

* + 1. As this works focuses on holistic approaches to tackling issues and joint working with people living with sickle cell and thalassaemia, NHS bodies, Government, and wider stakeholders; the supplier will have or require to recruit a governance board or equivalent which includes the following members but not limited to:
			- third sector agencies
			- academics
			- scientists
			- users of the screening pathway
			- quality assurance
			- NHSE programme representatives

This board will advise on the priorities for the projects and act as a governance and oversight steering group.

## Requirements

### Mandatory and Minimum Requirements

#### Projects

#### Unless otherwise specified the Supplier will deliver 2 large projects or 4 small projects each year based on the programme workstreams (see section 2.2.3-2.2.6 of this specification for list of high level workstreams)

#### **Project One** Within the first year of the commencement date the supplier will support the actions named in “[it's in our genes”.](https://www.sicklecellsociety.org/resource/its-in-our-genes/its-in-our-genes-2/) Sickle cell and thalassaemia are a genetic tests so only trained health professional can give genetic newborn blood spot (NBS) results. Currently there is a shortage of trained health professionals to discuss positive and carrier results.  The above report suggests that health professionals need to addressing parents’ immediate needs for information and reassurance upon notification of positive and carrier genetic results. The Supplier will review all current NBS information for health professionals, patients, and design and publish new NBS information that covers:

* using effective and empathic communication to explain what a sickle cell or thalassaemia diagnosis means for families.
* where to get support for patient care
* learning more as a healthcare professional and who should give, receive, and action results. This could mean that more health professionals would be prepared to provide carrier results.
* facilitating prompt referrals to specialists.
* how to reduce the initial parental distress associated with positive and carrier NBS results.
* how long results take to process, this is important because they tend to have relatively longer waited periods between the time of notification about other NBS results and their sickle cell and thalassaemia results.

#### **Project Two**: to improve performance of standard 5a and 5b which is the offer of Prenatal Diagnosis by 12 weeks. The Supplier will be part of the major standards review and consultation and they will help raise awareness of the new information related to standard 5. The review will cover:

* providing direct access to counselling and PND for known at risk couples and known carrier women
* offer testing to the baby’s biological father
* identify women and couples at risk of having a baby with sickle cell disease or thalassaemia major in their current pregnancy
* counsel women and couples and refer for PND
* Follow up after PND
	+ 1. Project Three: To be confirmed
		2. Project Four: To be confirmed
		3. Projects three and four execution and agreement will take place subject to volumes of work in volved and time taken to complete projects 1 and 2
	1. **Project Reporting and Management**
		1. The supplier will on an annual basis liaise with the Programme to produce an end of year report. The report will detail each project and outlining the issues addressed, the approach taken, number and range of participants, results, and recommendations.
		2. The supplier will set up, facilitate, and attend an annual mandatory review meeting with the Programme. This meeting will take place 9 months from the commencement date. Projects for the year ahead will be to be confirmed at the annual mandatory review meeting.
		3. Every 3 months (in the last week of every quarter), the Supplier will set up, facilitate, and hold a review meeting with the programme.
		4. The supplier will submit to the Programme and to the outreach and engagement oversite and governance board, the current and proposed project workplan for the following year which will set out:

#### projects to be delivered in the coming year.

#### timeframes for delivery.

#### performance measures.

#### fixed cost for the year.

* + 1. The supplier will recruit a cross-section of the public in geographic areas for projects or board meetings. For projects, recruit members of the public based on data provided by the Programme, standards, as per section 1.1.3 above, are not being met and in populations at increased risk of sickle cell and thalassaemia. The number and type of participants will vary according to the needs of each project but are expected to involve approximately 2 to 5 people for each project, from the following groups:

#### women of childbearing age and men – reflecting local demographics

#### women and men who have been through SCT screening in the target area.

#### eligible population not offered SCT screening and those that decline.

#### known carrier women and couples.

#### parents of affected children.

#### healthcare professionals from the target areas.

#### academic with a special interest.

* + 1. Every 5 months from the commencement date set up, facilitate, and hold a biannual oversight governance board that includes a range of stakeholders including but not limited to:

#### parents of affected children; and / or

#### healthcare professionals from the target areas.

#### academic with a special interest.

#### Quality Improvement/Assurance.

#### The board should have a Chair, core membership as agreed by the terms of reference, agenda, action log and minutes.

#### The Supplier will:

## be responsible undertaking outreach and engagement outlined in this service specification.

#### have an auditable IT (Information Technology) system and process in place to collect data on key indicators such as raising awareness events, workshops, and user feedback from the public and relevant health professionals.

#### be flexible in leading outreach and engagement events in local, regional, and national locations.

#### work within the community and the population served by the SCT screening programme, the Supplier will understand diverse cultures, traditions, and religions to ensure a suitable antenatal and newborn screening pathway.

#### work collaboratively, fostering community outreach and engagement and be in regular dialogue with families and communities affected by haemoglobinopathies.

* + 1. have knowledge and understanding of the purpose of the screening programmes to build trust, be an advocate for and represent the target population. This built trust is particularly important where there is public uncertainty about the SCT screening pathway or anxiety about testing and receiving screening results.
		2. have earlier experience of working with the women and families to weigh up the benefits, and harms of health screening programmes. This experience is used to help public expectations about screening that do not always match with what screening programmes can deliver.
		3. Liaise with the Programme to develop creative approaches to maximise the Programme’s outreach to families living with sickle cell and thalassaemia and communities with increased chance of inheriting sickle cell and thalassaemia.
		4. Use bespoke outreach and engagement activities to understand the unique challenges, aspirations and concerns of families and communities with increased risk of inheriting sickle cell and thalassaemia.
		5. Seek input from families and communities with increased risk on the SCT screening pathway in decision-making processes, ensuring that their voices are heard and respected.
		6. Supply platforms such as events, workshops, and cultural celebrations that advocate for the needs of the target populations.
		7. Support the development of culturally sensitive screening programme materials and resources. These include patient leaflets, educational materials, awareness campaign materials and guidance documents. The material and resources will show an understanding of diverse cultures, traditions, and religions to ensure fair treatment for all.
		8. Have in place set up networks that includes academics, scientists, users of the screening pathway, quality assurance representatives and public health and other professionals involved in the hemoglobinopathy health care services.

###  **Timescales & Implementation**

* + 1. For timescales on reporting see section 3.1. 1 – 3.1.8. Section 3.1.1 outlines key timescales or dates required to support the overall programme.
		2. There will be an initial 2 month mobilisation and handover period in which the supplier will, within 2 weeks of the commencement date, meet with the programme to cover the overall goal, and to design and agree the workplan for the term of the first year of contract.  Other ad hoc meetings at the request of the Supplier or the Programme will be facilitated in the first 3 months of the commencement date.
		3. As a local, regional, and national service, the Supplier will work in various locations across England to deliver awareness campaigns, outreach and engagement events, and board meetings. This may be on occasions virtual, hybrid or face to face.

#### Locations chosen will be the best choice for the project and for the people involved. The Supplier should tailor the location to better support individuals, to meet the project needs and to make best use of public resources. This might include face to face venues, virtual facilities, or a hybrid of both.

#### Travel to multiple locations may be needed on a regular basis (monthly) to attend board meetings, meetings with the Programme and events and workshops. Some meetings maybe virtual or hybrid

### **Roles and Responsibilities**

### The Programme (NHS England) has responsibility for implementing and delivery of the NHS SCT antenatal and newborn screening pathway and setting standards in England

* + 1. NHSE Programme manager and the supplier chief executive are the senior representatives of this service
		2. The supplier will be responsible for
		3. As part of mobilisation, within 2 weeks of the commencement attending an initial goal setting meeting
		4. Subject to mutual agreement with the Programme, attending other ad hoc planning meetings or advisory board meetings
		5. Attending the screening programme advisory group which meets every 6 months
		6. Delivering a biannual oversight governance board that includes a range of stakeholders including but not limited to academics, scientists, users of the screening pathway, quality assurance representatives, public health specialist and other professionals involved in the hemoglobinopathy health care services. The board should have a Chair, core membership as agreed by the terms of reference, agenda, action log and minutes
		7. Setting up and holding an annual project proposal/ planning meeting with the V&S and/or the Programme.
		8. liaising with the Programme to produce an annual report for each project outlining the issue addressed, the approach taken, number and range of participants, results, and recommendations
		9. Collecting data and feeding back to the Programme at the quarterly performance review meetings on key indicators such as events, workshops, and user feedback
		10. Providing and maintaining a project workplan that shows high-level activities for each year that will meet the requirements of Section 3.1.1.1- 3.1.8 of this specification.  The proposed project workplan will clearly set out the projects to be delivered, timeframes for delivery and proposed performance targets.  The project workplan will be reviewed and updated at the performance review meeting and a copy of the project workplan will also be kept by the Programme
		11. The Programme will be responsible for:
		12. As part of mobilisation, within 2 weeks of the commencement date, setting up, and holding an initial kick off review meeting
		13. Facilitate planning meetings required by the Supplier within the first 3 months of the commencement date.
		14. Reviewing performance of the Suppliers workplan at each quarterly review performance meeting. The Programme will keep a copy of the Suppliers project workplan.
		15. Attending an annual mandatory review meeting with the Supplier
		16. Confirming project themes for subsequent years
		17. Attending the engagement governance and oversite board and sharing responsibility for agreeing core membership, terms of reference, agenda, and minutes.

### **Management Information & Governance**

* + 1. Data collected by the Supplier, will be used in the annual report to refine, and improve strategies for year 2 and year 3 projects
		2. At 10 months from the commencement date, the Supplier will produce an end of year (annual) written report and send via email to the outreach and engagement governance board for review and comments. The end of year report will set out the purpose of each project undertaken, results, recommendations and workplan for the following year. The report will also cover an update on budgets costs/finances.
		3. A final printable version of the report will be given to the Programme board and the outreach and engagement governance and oversight board at the end of each project year. A web version should be available on the Suppliers website.
		4. The Supplier will comply with the Accessible information standards: [NHS England » Accessible Information Standard](https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/)
		5. The Supplier will comply with UK Standards for public involvement: [UK Standards for Public Involvement](https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf)
		6. The Supplier will have robust measure and policies ij place relating to:
		7. Information Governance
		8. Data Protection
		9. Confidentiality

### **Performance and Measurement**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| ***KPI Ref. Number*** | ***Services that KPI relates to*** | ***Description of KPI*** | ***Measurement*** | ***KPI Tolerances (Percentage tolerance)*** | ***No. Primary Service Failure Points per failure*** |
| 01 | Two large projects or 4 small projects delivered each year.Project size to be defined collectively via the programme and supplier  | Unless otherwise specified by the Programme, there will be 2 large projects **or** 4 small projects each year. | Quarterly performance review meetings.Annual mandatory review meeting. Annual report. Project outcomes/ objectives achieved delivered  | Unless otherwise specified by the Programme the tolerance is not used.  | 100% |
| 02 | Annual/end of year report.  | Before the end of the contract year a report is submitted to the Programme.  | An end of year report submitted to the programme which details each project outlining the issues addressed, the approach taken, number and range of participants, results, and recommendations. | Not used | 100% |
| 03 | Annual mandatory review meeting  | Nine months from the commencement date, the Supplier will set up, facilitate, and attend an annual mandatory review meeting. | projects identified and confirmed for the year ahead.annual mandatory review meeting set up, facilitated, and attend by the Supplier.  | Not used  | 100% |
| 04 | Four performance review meetings. | Every 3 months, (in the last week of every quarter), the Supplier will set up, facilitate, and hold a performance review meeting.   | 1. four performance review meetings per year held by the Supplier with the Programme.
2. workplan showing evidence of meetings and progress of each project.
 | Not used | 100% |
| 05 |  | Project workplan submitted to the Programme. | 1. at 9 months, a copy of the current project workplan as well as a new workplan is submitted to the Programme.
2. the new workplan sets out projects to be delivered in the following year submitted to the Programme.
 | Not used | 100% |
| 06 | Support the sickle cell society and UKTS JOINT recommendations named in “[it's in our genes”.](https://www.sicklecellsociety.org/resource/its-in-our-genes/its-in-our-genes-2/)  | Set up and deliver support to the Programme by appraising the results to parents’ protocol for health professionals.  | 1. protocol reviewed and evaluated by the Supplier.
2. supplier comments given to the Programme.
3. improvements to the protocol are made based on user representative feedback.
 | Not used | 100% |
| 07 | Recruit a cross-section of the public for projects.  | Based on data provided by the Programme, The Supplier will provide user representatives for projects. standards expected to  | For projects set out in the workplan, recruit approximately 2 to 5 representatives from the following groups: 1. women of childbearing age and men – reflecting local demographics.
2. women and men who have been through SCT screening in the target area.
3. eligible population not offered SCT screening and those that decline.
4. known carrier women and couples.
5. parents of affected children; and / or
6. healthcare.
7. professionals from the target areas.
8. academics with a special interest.
 | Not used | 100% |
| 08 | Oversight and governance board. | Every 5 months from the commencement date, the Supplier will facilitate and hold a biannual oversight governance board that includes a range of stakeholders. involved in the haemoglobinopathy health care services. | 1. two oversight governance boards held each year.
2. chair appointed.
3. terms of reference in place with an agreed core membership.

(Membership includes, but not limited to third sector agencies, academics, scientists, users of the screening pathway, and quality assurance)1. agenda, action log and minutes in place for each meeting.
 | Not used | 100% |

### **Contract Term**

* + 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 12 months (36 months in total) subject to performance review, budgetary approval and business planning.

### **Budget**

### The annual budget is £130,000.00. (£390,000.00 in total for the lifetime of the contract including extension period)

* + 1. Payment will be each quarter in arrears, with the successful progress of the projects. Payment will be on standard NHS terms of 30 days.
	1. **Exit Plan**
		1. The Contract will terminate following the initial contract period or after any extension period as notified
		2. An exit plan should be developed by the supplier and agreed 6 months before the end of the contract to ensure sustainability of the projects.

### **Sustainable Development Requirements**

* + 1. The Supplier, through the delivery of the contract, will ensure the supply chain remains resilient. The approach to resilient supply must be from the source of your product/service, including outside of the UK
		2. The Supplier will report half-yearly (or as appropriate) on the activities they are undertaking to ensure that supply or the provision of the service will continue uninterrupted.
		3. The Supplier, through the delivery of the contract, will plan to reduce the road miles required for the provision and running of the service in scope.
		4. Where possible virtual facilities or a hybrid event will be facilitated

## Appendices

### SCT screening is one of 11 [NHS national population screening programmes](https://www.gov.uk/guidance/nhs-population-screening-explained) available in England.

* + 1. The [UK National Screening Committee](https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc) (UK NSC) makes [recommendations](https://legacyscreening.phe.org.uk/sicklecellthalassaemia) to ministers in the 4 UK countries on all aspects of population screening. It ensures that screening provides more benefit than harm, at a reasonable cost to the NHS. Recommendations are based on [internationally recognised criteria](https://www.gov.uk/government/publications/evidence-review-criteria-national-screening-programmes) and a rigorous process. There are separate UK NSC recommendations on:

### [SCT screening in pregnancy](https://legacyscreening.phe.org.uk/sicklecellthalassaemia)

### [SCD screening in new-borns](https://legacyscreening.phe.org.uk/sicklecelldisease)

* + 1. [Sickle cell and thalassaemia screening: community outreach good practice](https://www.gov.uk/guidance/sickle-cell-and-thalassaemia-community-health-outreach-good-practice-guidance)

#### [Sickle cell and thalassaemia screening: examples of outreach resources](https://www.gov.uk/government/publications/community-outreach-examples-of-outreach-resources)

#### [Sickle cell and thalassaemia screening: overview of community outreach](https://www.gov.uk/government/case-studies/sickle-cell-and-thalassaemia-screening-overview-of-community-outreach)

#### [Sickle cell and thalassaemia screening: community outreach research](https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-screening-community-outreach-research)

#### [SCT screening: handbook for antenatal laboratories](https://www.gov.uk/government/publications/sct-screening-handbook-for-antenatal-laboratories)

#### [SCT screening: handbook for newborn laboratories](https://www.gov.uk/government/publications/sct-screening-handbook-for-newborn-laboratories)

* + 1. [Sickle cell and thalassaemia: screening handbook](https://www.gov.uk/government/publications/handbook-for-sickle-cell-and-thalassaemia-screening)

#### [Sickle cell and thalassaemia screening programme: standards](https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-screening-programme-standards)

#### [Newborn blood spot screening: sampling guidelines](https://www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines)

#### [Sickle cell and thalassaemia screening: care pathway](https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-screening-care-pathway)

#### [Sickle cell and thalassaemia screening: commission and provide](https://www.gov.uk/government/collections/sickle-cell-and-thalassaemia-screening-commission-and-provide)

#### [Commission care services: sickle cell and thalassaemia](https://www.gov.uk/government/publications/commission-care-services-sickle-cell-and-thalassaemia)

#### [NHS population screening: role and functions of quality assurance](https://www.gov.uk/guidance/nhs-population-screening-quality-assurance)

#### [NHS trusts: area prevalence for sickle cell and thalassaemia](https://www.gov.uk/government/publications/nhs-trusts-area-prevalence-for-sickle-cell-and-thalassaemia)

#### [Sickle cell and thalassaemia screening: newborn outcomes solution](https://www.gov.uk/government/publications/sickle-cell-and-thalassaemia-screening-newborn-outcomes-system)