

Invitation to Tender to Design and Undertake a formative evaluation of the Sickle Cell and Thalassaemia Screening Programmes' service provider education and training initiative (PEGASUS) in England

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1. Introduction

The UK National Screening Committee (NSC) advises Ministers, the devolved National Assemblies and the Scottish Parliament on:

- a) the case for implementing new population screening programmes;
- b) screening technologies of proven effectiveness but which require controlled and well-managed introduction;
- c) the case for continuing, modifying or withdrawing existing population screening programmes. In particular, programmes inadequately evaluated or of doubtful effectiveness, quality, or value.

NSC decisions are based on sound evidence to inform its advice and recommendations.

The NSC has set up practical mechanisms to oversee the introduction of new programmes and their implementation in the NHS through which it monitors effectiveness and quality assurance.

The NSC is informed by reports from Advisory Groups for specific programmes on the performance of those programmes and issues that arise which would have relevance to general screening policy.

The Fetal, Maternal & Child Health subgroup (FMCH) is one of these Advisory groups. It leads on a number of antenatal and child health screening programmes.

One of these is the Sickle Cell and Thalassaemia (SC&T) Screening Programme for England (hereafter referred to as 'The SC&T Programme'). The SC&T Programme now wishes to commission an independent formative evaluation of the education and training programme (PEGASUS) to inform the future development of the SC&T education and training strategy.

Please read this tender document alongside the following key programme documents (<http://www.sct.screening.nhs.uk>):

- Policy for Newborn Screening
- Policy for Antenatal Screening
- Sickle Cell and Thalassaemia Screening Programme Standards
- Annual Reports

2. Background

2.1 NHS SCT Programme

The NHS SC&T Programme was set up in 2001 following years of lobbying by health care professionals and the voluntary sector culminating in the ministerial commitment in the NHS Plan (2000) to improve the provision of screening services.

The SC&T Programme was set up to deliver the following linked programmes:

- The newborn sickle cell screening programme; to achieve the lowest possible childhood mortality and morbidity rates from sickle cell disease by offering screening in the newborn period.
- The antenatal sickle cell & thalassaemia screening programme: to offer effective and appropriate sickle cell, thalassaemia and other haemoglobin variants to all eligible women and couples in a timely manner in pregnancy.

The SC&T Programme Centre is run by the Programme Director, Dr Allison Streetly, and is governed by the Programme Steering Group which is chaired by the Archbishop of York Most Reverend and Right Honourable Dr John Sentamu. The Steering Group has had a number of subgroups looking at specific aspects of the screening care pathway:

- Training and Education (Chair Prof. Theresa Marteau),
- Information for Users and Professionals (Chair Dr Aamra Darr),
- Laboratory (Chair Dr Josh Wright),
- Public Outreach (Chair Dr Karl Atkin)
- Quality Improvement (Dr Nonnie Crawford)

The SC&T Programme Centre is funded to deliver services throughout England, providing training for health care professionals and allied professionals involved in the screening pathway via the PEGASUS Network and specific laboratory training, and develop communication materials and programme awareness for the general public and health care professionals.

Implementation of training via the PEGASUS network began in February 2005 and runs until 2011. Awareness raising is an on going exercise; the SC&T Programme have produced a variety of documents and has run 8 regional workshops for health care professionals to aid implementation.

The SC&T Programme is also investing in the development of materials for the general public (www.sickleandthal.org.uk/publications.htm#AnteLeaf), and a

Public Outreach Project to reach some of the traditionally harder to reach communities, with the highest prevalence for these conditions.

Information technology development is a key aspect required for the linkage of the antenatal and newborn screening; the SC&T Programme is working with the UK Newborn Screening Programme Centre and Connecting for Health in the development and integration of IT systems to cover the needs of laboratories and maternity services.

The Programme recognised the need for further work to raise professional awareness and levels of expertise, especially in primary care which has to date not been engaged with the programme.

The SC&T Programme published standards for the antenatal and newborn programme in October 2006 using a Donabedian approach to define criteria to measure structure, process and outcome of the programmes. The standards now set will be reviewed on a regular basis.

2.2 The Education & Training programme (PEGASUS)

The PEGASUS Project was commissioned in 2004 by the NHS Sickle Cell and Thalassaemia Screening Programme to develop education and training for health professionals involved in antenatal and newborn screening.

The Programme Steering Group wish to use a formative evaluation of the PEGASUS Programme (i) to help inform and direct the SCT Programme's education and training strategy over the next five years, including advice on the practical steps to be taken to address especially gaps in education and education issues and (ii) to help share good practice and learning with other NHS services facing similar issues in implementation.

The University of Nottingham Division of Primary Care led a collaboration of four NHS and academic institutions in the development and implementation of PEGASUS resources:

Collaborating centres

- University of Nottingham Division of Primary Care
- National Genetics Education and Development Centre in Birmingham
- Camden and Islington Sickle Cell and Thalassaemia Counselling Centre (Islington Primary Care Trust)
- Centre for Health Informatics and Multiprofessional Education (CHIME) at University College London

Project aims

To contribute to education and training in basic genetics for health professionals involved in antenatal and newborn screening; this includes opportunity for interactive learning and is supported by tailored resources online.

PEGASUS assists health professionals to:

- Develop their skills and practice in basic genetic assessment and screening
- Contribute effectively to new genetic screening programmes, such as Sickle Cell and Thalassaemia and Cystic Fibrosis
- Enhance how they respond to ethnic diversity
- Identify training and professional development needs
- Promote informed choice for patients

The PEGASUS learning environment

PEGASUS can be viewed as a complex educational intervention. The programme is developed around a framework in which there are three distinct groups of healthcare workers who need skills and knowledge about haemoglobinopathies; Front Line Practitioners (e.g. Midwives, General Practitioners), Specialist Practitioners (usually counsellors) and 'Public Health'.

Within this framework the programme has developed:

- Specific learning materials
- Mixed modes of delivery (e.g. web based learning materials, face to face workshops)
- Cascade model of implementation via 'train the trainers' workshops.

The programme has obtained extensive student feedback on the learning materials and workshops that have been run to date.

3. Generic Evaluation Principles

The Steering Group have agreed a set of principles that they would wish to see underpin any approach to evaluation. These are:

- **Being integrated:** an integrated antenatal and newborn screening programme requires an integrated approach to evaluation. The SC&T Programme is also moving to develop a seamless integrated approach between screening and treatment and care services for diagnosed babies.
- **Promoting equality and recognising diversity:** the evaluation should reflect the importance of this Programme to wider engagement of communities and the NHS in equality and diversity issues.
- **Focussing on parents and babies:** evaluation should be sensitive to the existence of the other antenatal and newborn screening programmes and the importance of seeing the whole screening process as an integrated package of care from the mother and father's perspective.
- **Being formative:** evaluation should inform the improved delivery of improved sickle cell and thalassaemia screening and treatment services.
- **Recognising context:** assessment of progress of the SC&T Programme should be set within the context of NHS reorganisation changes in recent years and recommendations should be forward looking within the wider health system reform agenda eg National Social Marketing Strategy, Payment by Results, increasing independent sector provision.
- **Having wider impact:** evaluation should inform the NHS's future role in the commissioning and delivery of health services generally, through promoting and disseminating good practice and transfer of knowledge, especially across other national programmes.
- **Demonstrating efficiency:** the practical methods used for evaluation should ensure that information gathering (eg surveys, focus groups, interviews etc) is efficient and informs all aspects of programme evaluation. Where possible, evaluation should use existing sources of programme internal evaluation activity eg Pegasus, training needs analysis reports, EQUANS study, etc.
- **Capacity building:** evaluation should not just be seen as a one off exercise. Ideally it will build future capacity within the SC&T Programme to support on-going evaluation as the Programme evolves over time.
- **Being methodologically broad:** evaluation should use an appropriate mix of qualitative and quantitative methodologies that are sensitive to the current phase of implementation, look at implementation across both primary and secondary care services, and encompass the views of the wide group of stakeholders involved in the SC&T Programme
- **Taking a holistic approach:** evaluation should ensure that important generic processes within the SC&T Programme are appropriately assessed especially communication, partnership development and training and education issues.

4. Requirements

4.1 Selecting evaluation questions

You are invited to tender for this work to design and undertake a formative evaluation of the SC & T Programme's Education and training initiative (PEGASUS) in England that will help us to understand the factors that influence the uptake and impact of the different programme elements. The original PEGASUS programme aims and objectives provide a framework for the specific questions we wish to be addressed in this evaluation:

<http://www.pegasus.nhs.uk/about.php>.

We are seeking an evaluation that helps to understand the factors affecting implementation and uptake of the cascade model used in the PEGASUS Programme and of the individual Programme components.

The SC&T and the PEGASUS programme have been and are subject to numerous evaluation activities. Of significance is the recent interim evaluation of programme implementation across England. The report of this evaluation will be made available to the successful applicant. In addition to this, audit and training needs analyses carried out by the National Screening programme will also provide information to inform understanding of the uptake of the PEGASUS programme. The Steering committee has in conjunction with stakeholders spent considerable time considering how to maximize the value added of this evaluation.

To this end we have used the evaluation framework proposed by Cervero in order to identify a focus for this work (see box 1 below) . The focus on the questions below was informed by the resources available for this piece of work and the issues in the framework which do not appear to be well covered by existing evaluative information sources. Furthermore we already know there has been differential uptake of the various education and training programmes in different areas of the country but at present we have only a limited understanding of why this is.

Box 1: Framework for the evaluation of continuing professional education¹

- Programme design and implementation
- Learner participation
- Learner satisfaction
- Learner knowledge, skills and attitudes
- Application of learning after the programme

¹ Cervero R. M. *Effective continuing education for professionals*, (San Francisco, Jossey-Bass, 1988)

- Impact of application of learning (second order effects – e.g. improvements in the health of patients)

4.2 Broad evaluation questions

The broad evaluation questions proposed are:

- What are the organisational structural and socio-cultural factors that have helped or hindered the successful implementation of the cascade model of training used to implement the PEGASUS programme
- What are the organisational structural and socio-cultural factors that have helped or hindered the successful implementation of the discrete elements of the PEGASUS programme

A third more specific question has been added that will provide information to help design future evaluation and monitoring efforts

- Where the cascade model is perceived to have been successfully implemented how is it perceived to have affected SCT screening practices?

4.3 Evaluation methods

The evaluation will take a broad methodological approach that is feasible within the resources and time available employing an appropriate mix of quantitative and qualitative methods. Taking account of the PEGASUS Internal Evaluation Document that will be available to the successful applicant(s).

i) Data sources

We anticipate that data to inform the evaluation will come from two sources

a) Relevant data from existing evaluative activity

There are already in place a range of evaluative initiatives relevant to addressing the broad evaluation questions. These vary in the type of data collected and their purposes. The SC&T will indicate these sources and facilitate collaboration between the respective evaluators. The tender should propose methods for integrating the information from these different sources to answer the evaluation questions

b) New data

Given the evaluation questions it is suggested that the evaluation will need to use a contrasting case study approach comparing different geographical areas with 'apparently different' levels of uptake of PEGASUS activity. These areas will need to be identified and agreed with the SC&T programme. Multiple sources of data from a range of relevant stakeholders (to be defined) in those areas should be collected on for example:

- The organisational, structural and cultural relationships in relevant services in those areas
- The way in which PEGASUS has been used/ implemented in those areas
- Perceptions about PEGASUS materials in those areas
- The relationships between these three sets of factors in each area.

The tender should detail how collecting this kind of data would be approached

ii) Analytical frameworks

The SC&T programme has anticipated the use that will be made of the results of this evaluation and suggests that analysis and interpretation of data from the evaluation could be usefully informed by reference to work on the design of learning environments and from workbased learning. However the analysis should not be limited to these approaches and the tender should specify how analysis will be undertaken including the use of these and other frameworks.

We would expect the successful evaluation team to be able to deliver a formal full evaluation report, executive and lay summary to the timetable detailed below. This would be delivered in appropriate electronic formats. The SC&T Programme will be responsible for printing and distribution costs of the report. Access and ownership of evaluation research data will be agreed before award of the final tender. The successful bidders will be responsible for ensuring relevant research ethics and governance issues are addressed at the outset.

5. Key Tasks

To meet our requirements, we expect the contractor to:

- a) design an evaluation methodology that is feasible and deliverable within the resources available and timescales identified below;
- b) meet with the Evaluation Monitoring Task Group to finalise the evaluation methodology and agree outputs required;
- c) address relevant research ethics and governance issues
- d) pilot & amend any evaluation tools that are needed to ensure maximum response and validity;
- e) undertake the evaluation;

- f) Collaborate and coordinate their evaluation activities with other concurrent evaluation activities within the SC&T programme and the National Screening programme
- g) produce drafts of the agreed evaluation outputs;
- h) consult with the Evaluation Monitoring Task Group on the drafts;
- i) present evaluation findings and draft recommendations to a number of key Programme Steering Group stakeholders
- j) produce final electronic versions of the full evaluation report as well as appropriate executive and lay summaries;
- k) co-ordinate a one-day workshop (hosted by the SC&T Programme) for key stakeholders (approx 100 people) on conclusion of the evaluation including a write up of the workshop.

6. Timetable

The timetable outlined below is indicative and within reason can be amended to suit the preferred bidder at the beginning of the contract

Key Task	Deadline
Design an evaluation methodology that is feasible and deliverable within the resources available and timescales identified	March 2009
Meet with the Evaluation Monitoring Task Group to finalise the evaluation methodology and agree outputs required	April 2009
Address relevant research ethics and governance issues	May 2009
Pilot & amend any evaluation tools that are needed to ensure maximum response and validity	June 2009
Undertake the evaluation	July to September 2009
Produce drafts of the agreed evaluation outputs	October 2009
Consult with the Evaluation Monitoring Task Group on the drafts; present evaluation findings and draft recommendations to a number of key Programme Steering Group stakeholders	November 2009
Produce final electronic versions of the full evaluation report as well as appropriate executive and lay summaries	December 2009
Co-ordinate a one-day workshop (hosted by the SC&T Programme) for key stakeholders (approx 100 people) on conclusion of the evaluation including a write up of the workshop	January 2010

7. Evaluation of Submitted Proposals

Applications will be assessed against the following criteria. The most important of these are indicated in bold

- **The extent to which the proposals meet the evaluation principles, requirements and key tasks**
- **Value for money**
- **The extent to which the proposals demonstrate an understanding of and experience of working in the following areas**
 - **Health care workforce education and training**
 - **community engagement principles and practice**
 - **national screening programmes**
 - **sickle cell and thalassaemia screening and care**
- **Appropriateness of methodologies proposed**
- **A track record of having met and exceeded customers' expectations on similar projects**
- a clear and succinct proposal, written in plain English
- whether appropriate professional and ethical research governance standards will be met
- proposed team composition and anticipated timescales

8. Funding

The Sickle Cell and Thalassaemia Screening Programme has a maximum budget of £75,000 (inclusive of VAT) to support this evaluation and associated costs.

Bids up to this amount are welcomed. As stated above value for money is a key criterion to be used when evaluating the submitted proposals.

Bids should set out how resources will be deployed in managing and carrying out the proposed work plan. A short Curriculum Vitae is requested for each of the research staff who will work on the project; this should include details of similar projects that they have worked on in the past.

You must also make clear any intention to use subcontractors; these should be named and details of their input, expertise, quality standards and costs should be included in your proposal.

We encourage you to discuss your proposal and any queries you may have regarding this important evaluation project with Dr Mark Newman, Education Consultant, 020 7612 6575 or Dr Allison Streetly, Programme Director. Please contact the Programme Centre office 020 7848 6634.

9. Conflict of Interest

We would also encourage any interested parties who may see a conflict of interest in bidding for this project to please contact the Programme Centre office to discuss any concerns which may affect their ability to apply for this tender.

10. Proposal Instructions

The proposal should be a maximum of 20 A4 pages and contain as a minimum:

- Introduction
- Background including aims and objectives
- Proposed Methodologies
- Demonstrable experience of delivery projects to time
- Curriculum Vitae of all applicants
- Proposed Costs (including staff costs, travel, and consumables)

Please email haemscreening@kcl.ac.uk and Nelly.Jackson@kcl.ac.uk by **1pm on Friday, 20th February, 2009**