NHS

Screening Programmes

Sickle Cell and Thalassaemia

Newborn Outcomes Information Governance and Clinical Board Group

Terms of reference

Aim:

To assure users and healthcare professionals that data on newborn outcomes is held, obtained, recorded, used and shared in a respectful, secure and confidential manner in compliance with legislation, and to provide assurance that the newborn outcomes work addresses appropriate clinical issues.

Objectives:

In compliance with legislation to:

- review data collection, storage and use in the newborn outcomes work
- comment on recommendations from the Health Research Agency Confidential Advisory Group
- provide advice on engagement with users and professionals
- report back on the outcomes and recommendations of this work to the NHS Sickle Cell and Thalassaemia Steering group
- report to the NHS Sickle Cell and Thalassaemia Steering group any complaints or concerns regarding culturally insensitive practice or broader inequalities
- provide feedback from the Newborn Outcome Information Governance and Clinical Board to and to share best practice with other groups collecting data on outcomes of screening programmes
- To advise on clinical issues arising from the newborn outcomes work such as the timely entry of babies to care
- To advise on links between local and specialist centres within clinical networks
- To advise on timely referrals between newborn screening laboratories and clinical networks
- To link with National Haemoglobinopathy Register
- To develop links Haemoglobinopathy forum
- To achieve the above in a timely and cost effective manner.

Membership:

Membership should represent the views of users and healthcare professionals

Professor Elizabeth Anionwu - Chairperson	Professor Emeritus of Nursing, University of West London
Baba Inusa	Consultant Paediatrician, Lead Sickle Cell and Thalassaemia, Evelina London
Cathy Coppinger	Programme Manager, SCT Screening Programme
David Rees	Consultant Advisor to the SCT Screening Programme
Dianne Plews	Consultant Haematologist
Dr Allison Streetly	Deputy Director Healthcare Public Health, Programme Improvement and Delivery, Health and Wellbeing
Dr Elizabeth Dormandy	National QA Manager, Newborn bloodspot, Infectious diseases and SCT screening Programmes UK National Screening Committee/NHS Screening Programmes
Dr Shirley Henderson	Consultant Clinical Scientist/Scientific Lead National Haemoglobinopathy Reference Laboratory Molecular Haematology
Elaine Miller	Co-ordinator UKTS
Hartley Hanley	Chairman, Manchester Sickle Cell Association and user representative
Jem Rashbash	Chief Knowledge, Public Health England
John James	CEO, Sickle Cell Society
Lisa Farrar	Laboratory Lead, Haematology Department, Leeds
Maria Pelidis	Consultant Paediatric Haematologist
Nkechi Anyanwu	Clinical Nurse Manager, Haemoglobinopathy, SE London SCTC
Moira Dick	Clinical Director Children's Community Services/Consultant Paediatrician

Nellie Adjaye	Consultant Community Paediatrician (retired) Medical advisor to the Sickle Cell Society
Olu Wilkey	Consultant Paediatrician
Professor Karl Atkin	Deputy Head of Research, University of York
Radoslav Latinovic	Data and Information Lead UK National Screening Committee/NHS Screening Programmes
Rupa Sisodia	Newborn Outcomes Screening Coordinator
Swapna Uddin	User representative, UKTS
Papers only	
Dr Frances Flinter	Chairman Pan London Caldicott Guardian Group
Yinka Williams	Information Governance Manager, Guy's and St Thomas' Trust

Meetings Administrator: Rupa Sisodia, Newborn Outcomes Screening Coordinator

Other individuals will be invited to meetings depending on the agenda

Members have agreed, where possible, to ask alternates (with similar background and experience) to attend meetings should they be unable to attend in person.

Members have also agreed that, should they have to resign from the Board, they will use best efforts to secure a replacement member who has a similar background and experience so that the Board does not lose the benefit of that member's expertise.

Membership to be reviewed every three years. Note that two patient representatives have recently resigned and are due to be replaced.

Chair:

Elizabeth Anionwu has been appointed Chairperson of the Board.

If Elizabeth Anionwu is unavailable, those present can elect one of their member's to act as Chairperson for that particular meeting.

Frequency of Meetings: Frequency of meetings will be decided by the Chairperson depending on the need to review work undertaken or issues arising. Any member of the Board can also request in writing, outlining reasons to hold a meeting at any time.

A quorum is five members.

If necessary, meetings can be held by telephone or by video conference, if members are unable to meet physically.

All meetings must be recorded by the meetings administrator or, in her absence, by any member elected to record the minutes. Minutes must be made available to all members

within four weeks of the meeting and must be presented at the next meeting so that members have the opportunity to raise and agree amendments to the minutes.

Members can agree to set up “task forces” with clear terms of reference to deal with particular items or issues and these task forces will report back to the Board within a specified time period.

Current Reporting Structure:

The Information Governance and Clinical Board reports to the NHS Sickle Cell and Thalassaemia Screening Programme Steering Group and other relevant governance groups within PHE.

Individual members of the Information Governance and Clinical Board will report back to their host organisation.

Payment: Unless agreed otherwise, no fees will be paid to members of the Board for work undertaken in connection with this project.

Patient Representatives will be reimbursed for all reasonable travel expenses incurred in connection with attending meetings, subject to producing all relevant receipts and complying with expense claim procedures as set down by King’s College London which hosts the Newborn Outcome Project for NHS Sickle Cell & Thalassaemia Screening Programme.

Support for users who attend meetings:

Users can provide a unique perspective on the work of the screening programme and provide valuable insight into how we can improve the programme. While user input at screening programme meetings is valuable for the screening programme, it is acknowledged that taking part in meetings can sometimes be daunting for users - professional members of the group use jargon and technical terms, are on top of the issues being discussed, know one another well and often outnumber users. It is therefore important that the programme supports users appropriately. The aim of this support is to ensure that users feel able to contribute to meetings and know their contribution to the meeting is highly valued.

The following methods may be used to provide support to users (this is a guide and not exhaustive):

- Develop a clear rationale on why users are involved in the group – users are usually asked to comment on how suggestions and proposals feel from the user perspective, rather than to provide technical advice.

- Give a clear idea of what is required in terms of frequency and length of meetings.

- Give clarity on exactly what is required from the user at specific meetings. It is suggested that there is a face to face meeting with users at least a week before the meeting to explain, in lay terms, what matter will be discussed at the meetings and what the programme sees as the particular key points for discussion, so that the user has the opportunity to reflect on the issues. Meeting papers should be discussed at this pre meeting.

- Ensure clarity on payment. It is important to be clear with users what expenses or other payments are available before the meetings, to ensure that robust and timely methods of payment are in place. Any rules in this regard e.g. no first class travel claims and the need for supporting receipts, should be clearly communicated.

- Give clear timescales on future meetings and check if the user is happy to continue working with the programme.

- Consider supporting the user with an advocate.

- Review how the user found the meeting after each meeting.

- Thank the user for their input to the meeting and the time it took. Explore if anything further can be done by the programme to support the user's involvement in the meeting.

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Project Owners	SCT Screening Programme
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Revision History:

Revision Date	Version	Summary of Changes
05/12/13	V0.2	Amendments and updates made to objectives section: users, health professionals and administrator
22/04/14	V0.3	Amended onto headed paper; inclusion of amendments for version control
06/01/15	V0.4	Amended onto headed paper with updated logo for version control

Approvals:

This document requires the following approvals:

Name	Signature	Date of Issue	Version
Professor E. Anionwu			
Radoslav Latinovic			
Cathy Coppinger			

Distribution:

This document has been distributed to:

Name	Version	Date

1.5 Related documents

Ref.	Document ID/Title	Version
	Annex One: Terms of Reference for Newborn Outcomes Information Governance Board Updated January 2013 And *Annex Two:* Terms of Reference for Newborn Outcomes Clinical Group Version 1.1 9th September 2013 *In Outcome Evaluation:* Newborn SCT Screening Programme using named patient data without consent as supported by NIGB - information and proposals for post-transition (filename sctspEvaluationProjectOverview_v05doc)	