



*Antenatal and Newborn
Screening Programmes*

**Evaluation of the
“Family Origin Questionnaire”**

Research Report

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Report prepared for:

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EXECUTIVE SUMMARY

BACKGROUND AND AIMS OF THE RESEARCH

The NHS Sickle Cell and Thalassaemia (SC&T) Screening Programme commissioned ETHNOS to evaluate the adequacy of the Family Origin Questionnaire (FOQ) which will be used in “Low Prevalence” areas (i.e. in areas where there are few people from black and minority ethnic (BME) backgrounds that are at high risk of SC&T) to identify parents who are in high risk groups for being a carrier for sickle cell and other haemoglobin variants.

The FOQ was piloted in seven “Low Prevalence” areas. The aim of the current research was to find out how relevant health professionals (i.e. midwives, antenatal care coordinators, consultant haematologists and biomedical scientists) in the pilot areas have used the FOQ, what problems they have encountered in seeking to implement the SC&T screening, what lessons can be learned from their experience, and what kind of training or support would be required to operate a good SC&T Screening Programme locally when screening is being rolled out nationally in 2006.

METHODOLOGY

The evaluation was based on a combination of methods:

- Interviews with 9 Antenatal Care Coordinators/SC&T Screening Midwives
- Paired interviews with 54 midwives
- Observations of 20 bookings during which midwives completed the FOQ
- Interviews with 18 biomedical scientists and consultant haematologists

The fieldwork took place between 22 November and 15 December 2005.

FINDINGS

Overall reactions to the FOQ

Across all pilot sites, the overwhelming majority of stakeholders were very positive about the FOQ. Despite initial concerns about increased workload, midwives were generally positive about the FOQ itself. They found the form clear, simple, easy to use, quick to complete and easy to integrate within the overall booking process. ANCs and SC&T Screening Coordinators were equally positive. Consultant haematologists and biomedical scientists thought the FOQ made the screening more reliable, quicker, more streamlined and less anxiety-inducing for parents than their previous screening methods.

Layout, presentation, content and administration of the FOQ

All groups of stakeholders found the layout, presentation and content of the FOQ excellent. The reported strengths of the FOQ are its overall clarity and ease of use. The use of colour-coding and the provision of open entries to write in ambiguous family origins were deemed particularly useful.

The weaknesses of the FOQ in terms of layout, presentation and content identified by stakeholders are:

- the request for the Estimated Delivery Date twice
- the absence of a category for White non-Europeans who are at low risk of SC&T
- the fact that the signature box refers to the “person” completing the form
- the lack of guidance on what to do with the third copy of the FOQ
- the lack of consistency in the nomenclature used in the FOQ

Minor amendments to the FOQ and better training can rectify these problems and improve the administration of the questionnaire.

Process of completion of FOQ

Despite general satisfaction with the FOQ, the study identified many problems with the process of completion of the FOQ by midwives.

Knowledge and understanding of Sickle Cell and Thalassaemia were low amongst midwives. This compromised their ability to seek *informed* consent from their patients. Critically, many midwives did not fully understand the purpose of the FOQ in relation to the Screening Programme. Many midwives used the “opt in” clause incorrectly, thereby generating undue increases in workloads for haematology laboratories. Some midwives were not sure either when to use the “opt out” clause and ticked that screening had been declined when it was not required based on the parents’ family origins. Many midwives were also confused over, and generally ill at ease with, the notions of “ethnic group”, “nationality” and “family origins”.

There were variations with respect to the screening of fathers. Interface with primary care for partner testing had not been thought through. Many midwives were unclear as to when fathers should be offered screening and how their blood samples should be taken and sent to laboratories.

Midwives reported that parents had highly variable knowledge and understanding of SC&T, and that access to information leaflets prior to the booking was an important factor in increasing knowledge and understanding of the conditions amongst parents. Despite uneven knowledge and understanding, midwives reported that most parents were happy to be screened and had no reservations about discussing their family origins.

Finally, there were very different practices linked to the management and dispatch of the three copies of the FOQ, leading to some loss or misplacement of forms and to some blood samples becoming detached from completed FOQs.

Organisational factors likely to impact on the success of the Programme

The research identified a number of organisational factors that could impact on the success of the Screening Programme when it is implemented nationally:

- staffing issues:
 - the need for sufficient clerical staff to handle the additional workload
 - the need to train laboratory reception staff in handling FOQ and samples
 - potential low commitment and low morale in “Low Prevalence” areas and under-resourced hospitals

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- technical issues in laboratories:
 - the need for ready access to adequate machinery
 - problems associated with the sharing of equipment across departments
 - the need for IT systems to support the Programme
 - the importance of excellent coordination and communication:
 - within the midwifery and antenatal care departments
 - within the haematology laboratories
 - between the midwifery departments, antenatal departments and haematology laboratories
 - between the sites as a whole and the central Screening Programme in London
 - between the sites as a whole and primary care providers in local areas
 - the importance of adequate materials to support the Screening Programme:
 - for parents: information leaflets about SC&T (in appropriate languages) ahead of bookings
 - for midwives: information on SC&T, flowchart on the SC&T screening process (including partner testing), guidance on FOQ completion and form management, risk charts for each ethnic group
 - for laboratory reception staff: basic information on the Screening Programme, flowchart on how to dispatch completed FOQ and blood samples
 - for biomedical scientists: screening algorithm
 - the timing of the implementation to allow sufficient time for preparation
 - the need to monitor the workings of the Programme

Training

There were wide variations between sites in terms of the training offered as part of the SC&T Screening Programme. In some sites, training had been extensive and detailed, delivered in a timely fashion in relation to the start of the programme locally, offered at various convenient times and in different venues, widely attended by relevant staff, supported by high-quality written documentation and visual aids, and subject to systematic evaluation by attendees. In other sites, training was minimal and delivered on a one-to-one, *ad hoc* basis and covered only the most basic aspects of the conditions, of the populations at risk and of the use and administration of the FOQ.

The quality of the training had a very significant impact on the attitudes of staff (especially midwives) to the Screening Programme, on their motivation to deliver good quality screening, on their knowledge and understanding of the conditions and their impact, on their confidence and morale, on the validity of the Family Origins data they gathered and processed and, generally, on the overall success of the pilot locally.

Most of the training was directed at midwives. Biomedical scientists usually received very basic training and many lacked the confidence necessary to report on more complex cases. Reception staff were given no formal training at all.

RECOMMENDATIONS

Based on the research findings, ETHNOS makes the following recommendations.

GENERAL RECOMMENDATION

- The FOQ should be used by all sites, in both High and Low Prevalence areas

FOQ: LAYOUT, PRESENTATION AND CONTENT

With respect to the design of the FOQ, ETHNOS recommends that:

- the FOQ should keep the NHS SC&T Screening Programme logo
- the current colour-coding should be maintained
- a new family origins category that includes other White non-Europeans who do not require testing (e.g. from the USA, Canada, South Africa, Zimbabwe, Australia, New Zealand) should be added to the FOQ, and that this additional category should go under the current category G
- subcategories should be systematic in identifying either countries or nationalities
- the FOQ should only request personal information about the mother that is strictly necessary for clinical purposes
- the phrase “signed by person completing the form” should be replaced by “signed by health professional completing the form”
- the FOQ form should include guidance, written on the form itself, on what to do with the *third* copy of the questionnaire - the guidance could profitably refer to each copy by reference to their colour (white, yellow and pink)

TRAINING

Midwives

With respect to the training of midwives, ETHNOS recommends that training should:

- Be mandatory
- Be tailored to reflect the institutional set up of each site
- Be offered at different times to accommodate varied working schedules
- Closely precede the implementation of the Screening Programme in each area
- Be provided by a team of stakeholders in the Screening Programme, including:
 - NHS SC&T Screening Programme Regional Coordinators
 - Midwifery
 - Antenatal and Neonatal Care
 - Obstetrics
 - Haematology
 - patients representatives
- Discuss the nature of the conditions, including:
 - mortality and morbidity rates for sickle cell and thalassaemia
 - causes and symptoms
 - risk levels in various ethnic groups
 - reality of living with the conditions
 - potential cures or treatments

- Discuss the rationale for the Screening Programme, including:
 - reasons for Screening Programme
 - links between Antenatal and Newborn Screening Programmes
 - differences between High and Low Prevalence Areas
 - advantages of screening for those in high risk groups
 - options open to parents who are carriers
- Have a “human” as well as biomedical emphasis to promote empathy
- Discuss the importance of informed consent and patient empowerment, and the role of midwives in reaching these aims
- Explain the function of the FOQ within the overall Screening Programme
- Emphasise that the routine full blood count will identify the risk of being a thalassaemia carrier for all women
- Emphasise the different risk levels for the different ethnic/national groups, and explicitly link this explanation to the use of the “Hb Variant Screening Requested by (F) and/or (G)”
- Stress the need to take booking bloods as early as possible in the pregnancy (i.e. in the first trimester)
- Describe the implications of misusing the “opt in” clause
- Focus on the practicalities of completing the questionnaire, including:
 - the fact that the midwives themselves must complete and sign the FOQ
 - the fact that the “Screening Test Declined” box only needs to be ticked by parents in “at risk” groups
 - the fact that the “yes” and “no” options in the “Screening Test Declined” box pertain to *giving a reason* only
 - the need to probe for at least two generations on each side of the family
 - what to do with people whose nationalities are not listed in the FOQ
 - what to do with patients who do not know their family origins
 - the rationale for the inclusion of the request for the EDD twice in the FOQ
 - examples of “poor practice” or common mistakes to be avoided
 - examples of complex cases (such as when ethnicity, nationality and family origins do not correspond) and how to deal with them
- Explain the differences and similarities between ethnicity, nationality and family origins:
 - stress that “family origins” cannot be inferred from ethnic group, nationality or other available evidence (e.g. name, skin colour)
 - stress that midwives should not question whether someone is “British” or not
- Focus on the practicalities of taking the blood samples, including:
 - the need to complete the Full Blood Count form for the tests required
 - the fact that fathers require testing only *after* mothers have been found to be carriers
 - the interface with primary care for the testing of fathers
 - how blood samples for couples should be matched
- Focus on the practicalities of managing the forms, including:
 - guidance on what to do with each copy of the FOQ
 - guidance on how to secure the top copy to the blood samples
- Give midwives access to further resources if they need to find more information

Laboratory reception staff

With respect to the training of laboratory reception staff, ETHNOS recommends that training should:

- Raise awareness of the Screening Programme as a whole and of the FOQ in particular

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- Explain the FOQ, with particular emphasis on:
 - the “yellow” and “white” boxes
 - the “Screening Test Declined” box
 - the “Hb Variant Screening Requested by (F) and/or (G)” box
 - Explain what to do with the samples attached to the completed FOQs

Biomedical scientists

With respect to the training of biomedical scientists, ETHNOS recommends that training should:

- Provide a general introduction to the Screening Programme
- Provide an explanation of the FOQ and of what to do with the forms
- Give detailed guidance on how to calibrate the HPLC machinery for haematology testing
- Give detailed guidance on how to use the HPLC machinery
- Give detailed guidance on how to use the screening algorithm, including:
 - clarification on the meaning of “partner” in the algorithm
 - clarification on the fact that screening needs to be carried out even where only one parent is from a high risk group (if it is not declined)
- Give detailed guidance on how to interpret test results
- Give detailed guidance on how to report test results
- Explain what to do with complex cases
- Facilitate access to consultant haematologists and senior biomedical scientists
- Ensure that mechanisms are in place to overcome the problem of staff rotation: this may include “portable” information on CD-Rom, as well as on-the-job training

General Practitioners

ETHNOS did not interview GPs as part of this research. However, findings indicate that GPs would also benefit from access to training. Training for GPs should:

- Discuss the nature of the conditions, including:
 - mortality and morbidity rates for sickle cell and thalassaemia
 - causes and symptoms
 - risk levels in various ethnic groups
 - reality of living with the conditions
 - potential cures or treatments
- Discuss the rationale for the Screening Programme, including:
 - reasons for Screening Programme
 - links between Antenatal and Newborn Screening Programmes
 - differences between High and Low Prevalence Areas
 - advantages of screening for those in high risk groups
 - options open to parents who are carriers
- Have a “human” as well as biomedical emphasis to promote empathy
- Discuss the importance of informed consent and patient empowerment, and the role of midwives in reaching these aims
- Explain the function of the FOQ within the overall Screening Programme
- Stress the need for early screening
- Stress the important role played by GPs in relation to early testing and referral, and to partner screening
- Give GPs access to further resources if they need to find more information

ORGANISATIONAL AND INFRASTRUCTURAL ISSUES

A number of organisational or infrastructural issues were found to be critical to the success of the Screening Programme. These include:

General Practitioners

- Should be informed about the SC&T Screening Programme and their role within it (see “training”)
- Should have information leaflets on SC&T (in appropriate languages) to give to mothers ahead of their booking
- Should know how to interface with midwives to screen fathers where relevant

Midwives

- Should be informed about the SC&T Screening Programme and their role within it (see “training”)
- Should have information leaflets (in appropriate languages) to give to mothers during their booking, if mothers have not received them
- Should have risk charts for SC&T in each ethnic groups
- Should have a detailed screening flowchart
- Should have pre-printed labels to affix to FOQs whenever possible
- Should have ready access to their ANCs and SC&T Screening Coordinators
- Should have ready access to spare FOQs

ANCs and SC&T Screening Coordinators

- Should monitor (in partnership with consultant haematologists) the early implementation of the FOQ
- Should offer regular update sessions to midwives, in order to clarify misunderstandings, rectify mistakes and diffuse good practice
- Should develop excellent coordination and communication with dedicated lead persons within haematology laboratories

Laboratory reception staff

- Should be informed about the SC&T Screening Programme and their role within it (see “training”)

Biomedical scientists

- Should be informed about the SC&T Screening Programme and their role within it (see “training”)
- Should know how to calibrate HPLC analysers for haematology screening
- Should be confident in using the haematology screening algorithm
- Should have ready access to consultant haematologists or senior biomedical scientists

Haematology laboratories

- Should have adequate access to HPLC analysers to support the Screening Programme

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- Should develop excellent coordination and communication with dedicated lead persons within Antenatal and Midwifery departments

All stakeholders in local areas

- All key departments on each site should have a dedicated, named contact person in charge of implementing and administering the Programme at the local level and of liaising with other dedicated people

The national SC&T Screening Programme

- Should supply standardised:
 - explanations of the Screening Programme
 - information on SC&T
 - risk charts for each ethnic group
 - guidance on FOQ completion and form management
- Should support the implementation of the Screening Programme through public health education and health promotion programmes
- Should explore the possibility of automating the screening process as far as possible, through better IT systems that link up stakeholder departments in each site
- Should provide ongoing but flexible support, through a variety of mechanisms, to balance the need for standardisation and for tailoring to local circumstances
- Should inform sites of the requirements of the Programme locally well ahead of the implementation of the Programme so that adequate planning can take place
- Should consider ring fencing budgets for the SC&T Screening Programme

NHS Trusts

- Should seek to provide midwives with pre-printed labels with the mother's personal details to affix to the FOQ
- Should consider purchasing centralised HPLC analysers to be accessed by all relevant users in the region, especially in "Low Prevalence" areas
- Should consider using IT systems that link up stakeholder departments in each site
- Should consider producing guidance on how to allocate people who have family origins that are infrequent at the national level but that are found quite regularly at the local level (e.g. through maps or alphabetical lists of countries with respective code on the FOQ)

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APPENDICES

Appendix 1: Interview schedule for Antenatal Care Coordinators and SC&T Screening Midwives

Appendix 2: Interview schedule for paired interviews with midwives

Appendix 3: Interview schedule for consultant haematologists and biomedical scientists

1.0. BACKGROUND

1.1. Background: The NHS Sickle Cell & Thalassaemia Screening Programme

The NHS Plan (2000) made a commitment to improve the provision of screening services. One screening programme focuses on Sickle Cell and Thalassaemia (SC&T). These common inherited blood conditions mainly affect people who have originated from Africa, the Caribbean, the Middle East, Asia and the Mediterranean, but they are also found in the northern European population. Given the increasing rates of people from non-northern European backgrounds in the British population, efforts must be made to reduce both morbidity and mortality from SC&T.

The NHS SC&T Screening Programme was set up to deliver two linked programmes:

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

Currently, antenatal screening policy has been implemented differently as a function of the assumed prevalence of SC&T in specific NHS Trust areas based on their local BME population.

In “High Prevalence” areas (that is, in areas where there is a large concentration of people from black and minority ethnic (BME) backgrounds), antenatal screening consists in offering screening for sickle cell, thalassaemia and other haemoglobin variants to all pregnant women and to all partners of identified carrier mothers.

In “Low Prevalence” areas (that is in areas where there is a small BME population), all pregnant women will be offered screening for thalassaemia. In addition, women who are in high risk groups for being a carrier for sickle cell and other haemoglobin variants, or whose partners are in high risk groups (as determined by a “Family Origin Questionnaire”) will be offered screening. Finally, partners of identified carrier mothers will also be offered screening for SC&T and other haemoglobin variants.

Currently, the SC&T Screening Programme is underway in all “High Prevalence” areas. It is also being piloted in seven selected “Low Prevalence” areas. These seven areas are the object of the current evaluation. They will be used to learn about any problems that could impact on the success of the SC&T Screening Programme when it is being rolled out to all “Low Prevalence” areas nationally in 2006.

2.0. AIMS AND OBJECTIVES OF THE RESEARCH

2.1. Aims of the research

As mentioned above, in “Low Prevalence” areas, a “Family Origin Questionnaire” (FOQ) is being used to determine whether pregnant women, or their partners, are at high risk for being a carrier for sickle cell and other haemoglobin variants. The FOQ seeks to determine whether there is anyone in the baby’s family (either on the father or on the mother’s side) who comes from a non-Northern European area.

The FOQ form has been the object of much consultation and scrutiny. However, the use of the form by midwives, biomedical scientists and consultant haematologists in practice has not yet been studied.

The aim of the current research is to find out how relevant health professionals have actually used the FOQ in “Low Prevalence” areas, what problems they have encountered in seeking to implement the SC&T screening, what lessons can be learned from their experience, and what kind of training or support they would require to operate a good SC&T Screening Programme locally.

2.2. Objectives of the research

Different research objectives support this overarching aim. These are to test:

- The layout and presentation of the Family Origin Questionnaire
 - is the layout clear?
 - do certain sections need improvements? which ones and why?
- The validity of the ethnic monitoring categories used
 - are the categories exhaustive?
 - are the categories mutually exclusive?
 - are the categories unambiguous?
- The ease of use of the Family Origin Questionnaire
 - is the questionnaire easy to use by midwives?
 - how long does it take to explain and administer the questionnaire?
 - what is the best way of introducing the questionnaire to patients?
 - are patients happy with the idea of completing the form?
 - do patients experience practical difficulties in completing the form?
 - are certain categories of patients (e.g. by ethnic group, by levels of fluency in English, by educational achievements) having greater difficulty than others?
- Does the questionnaire meet its intended purpose for biomedical scientists (e.g. giving sufficient, adequate and correct information)?
 - what improvements could be made to the form itself?
 - what improvements could be made to the ways in which the form is used?
- The training needs associated with the administration of the questionnaire
 - do certain staff need training?
 - what should the training consist of?
- The organisational and infrastructural issues that can impact on the success (or otherwise) of the Screening Programme

3.0. METHODOLOGY

3.1. Introduction

In this section, we describe the methodological procedures followed in the course of the evaluation.

As mentioned in the introduction of the report, the evaluation of the use of the Family Origin Questionnaire is taking place in seven pilot “Low Prevalence” sites. These are:

NHS Trusts	Hospital Units
South Derbyshire Acute Hospitals	Derby City General Hospital
King’s Lynn & Wisbech Hospitals	Queen Elizabeth Hospital King’s Lynn
South Tees Hospitals	James Cook University Hospital
Royal Shrewsbury Hospital	Royal Shrewsbury Hospital
Mid Yorkshire Hospital	Dewsbury and District General Hospital
Plymouth Hospitals	Derriford Hospital Unit
Southampton University Hospitals	Princess Anne Hospital

In each pilot site, it was planned that the evaluation would involve a combination of the following qualitative research methods:

- Individual interviews with antenatal care coordinators/SC&T screening midwives
- Paired interviews with midwives
- Observations of midwives during completion of the Family Origin Questionnaire
- Individual interviews with consultant haematologists and biomedical scientists

The rationales, procedures and samples for these methods are described in turn below. The fieldwork took place between 22 November and 15 December 2005.

3.1. Individual interviews with Antenatal Care Coordinators and SC&T Screening Midwives

In each site, ETHNOS carried an individual interview with the ANC Coordinator and, where this position existed, with the dedicated SC&T Screening Midwife. These interviews were critical because ANC Coordinators and SC&T Screening Midwives have an overview of the screening programme and are responsible for overseeing the successful implementation of key aspects of the programme at the local level. Thus, interviews explored their perception of the ease of use of the FOQ, of “teething problems”, of training and other support needs, etc. The full interview schedule is available in Appendix 1.

Establishing rapport with them was also crucial, as the planning of data collection on each site (selection of places, dates, times, identification of midwives for paired interviews and observations of bookings, etc) was done in close collaboration with ANC Coordinators and SC&T Screening Midwives. In total, nine (9) interviews were conducted with these health professionals. Interviews lasted between 30 and 60 minutes.

3.3. Paired interviews with midwives

We also carried out paired interviews with midwives to find out about their summative experience of using the FOQ. The interviews explored such issues as:

- their satisfaction with the Screening Programme
- the layout and presentation of the FOQ
- the validity of the ethnic monitoring categories used
- the ease of use of the FOQ
- the improvements that could be made to the FOQ itself
- the logistical and administrative improvements in relation to using the FOQ
- the perceived training needs of midwives

A full interview schedule is available in Appendix 2.

Paired interviews worked well with midwives. They are more flexible, easier to arrange and less time-consuming than focus groups, which is critical when dealing with busy health professionals. Paired interviews also gave midwives an opportunity to validate (or otherwise) with a colleague their own experiences of using the questionnaire.

The sample of midwives was varied in terms of seniority, but all midwives had had some experience of administering the questionnaire with a range of patients and were able to inform us about their overall experience of using the questionnaire. Paired interviews lasted between 30 and 45 minutes. In total, we conducted 26 paired interviews and 2 individual interviews (as the second midwife could not attend), thereby eliciting the views of 54 midwives.

3.4. Observations of FOQ completion during bookings

The research design made provisions for the observation of five “bookings” (the initial appointment with a pregnant woman during which the midwife completes the FOQ) in each site¹. Observing the bookings ourselves meant that we were able to pick up a number of issues with the use of the FOQ which the midwives themselves were not necessarily aware of and, therefore, could not discuss during the paired interviews. Observations enabled us to gather data on such things as:

- the ways in which midwives introduce the Screening Programme and the FOQ
- the time it takes to explain and administer the questionnaire
- the reactions of the patients
- the difficulties encountered by patients and midwives when completing the FOQ
- the number of generations midwives probed for

In total, 20 observations of bookings took place, over five pilot sites.

¹ However, in two pilot sites, it was not possible to obtain ethical approval for these observations during the short timescale of the research, and observations had to be abandoned. In other cases, bookings had to be cancelled at the last minute. The main reasons for cancellations were miscarriages, termination of pregnancy, and simply mothers missing their appointments. When possible, bookings were rescheduled, but we decided that it would not be economical to go back to a given pilot area to carry out just one observation of a booking.

3.5. Individual interviews with haematology consultants and biomedical scientists

Finally, we conducted individual interviews with haematology consultants and biomedical scientists. These interviews aimed to assess their perspective on the FOQ and the SC&T Screening Programme more generally. We wanted to find out their perceptions of the adequacy of the FOQ itself, of the algorithm they need to follow to carry out the required tests, of the technical equipment they need to take part in the Screening Programme, and of the training and other support needs they may have. A full interview schedule is available in Appendix 3.

In total, 18 interviews were conducted with haematology consultants and biomedical scientists. These lasted between 30 and 75 minutes.

3.6. Data analysis and reporting

The individual and paired interviews were tape-recorded and transcribed for analysis. The interviews were analysed thematically, to highlight key issues to relation to the themes explored in the interviews. Quotes that reflected either the trend of opinion or unusual but important opinions or experiences were then added to illustrate the main themes. After each section, we discuss the recommendations that emerge from the analysis.

4.0. OVERALL REACTIONS TO THE FOQ

4.1. Introduction

This initial chapter gives a very brief overview of the general reactions to the Family Origin Questionnaire (FOQ) amongst the different stakeholder groups: midwives, Antenatal Care Coordinators (ANCs), Sickle Cell & Thalassaemia (SC&T) Screening Coordinators, biomedical scientists and consultant haematologists. This provides a background against which to then look into the Family Origin Questionnaire section by section, which is the object of the next chapter.

4.2. Reactions of midwives

Midwives were generally extremely positive about the FOQ itself. They said that they found the form clear, simple, easy to use, quick to complete (at least for those who had the benefits of pre-printed labels to include the personal details of mothers) and easy to integrate within the overall booking process.

“This is a very straightforward form really. It isn’t one of these that need the plain English campaign at it or anything, although it does look complicated initially, when you first look at it.” (Site 2: midwives)

“M1: The form is easy to use. I don’t think there is anything else we need to add to it.

M2: You can’t have a better form than this. Once you get used to using it, it is straightforward.” (Site 3: midwives)

“Compared to everything else that we have to do and the other forms that we have to fill in, this is very easy. Nice and easy. It won’t be a trauma to start adding that to the list. It slots in quite easily with everything else.” (Site 7: midwives)

Some midwives reported that when they first heard about the SC&T Screening Programme and caught sight of the FOQ, their initial reaction was negative: “more paperwork” was the overwhelming response. Some midwives also reported feeling quite daunted at the sight of the FOQ. These views were more common amongst those who had only received very superficial training.

“Initially it looked as though it was going to be complicated and a lot of work, massively increase the workload. But in actual fact it was very simple to use. Personally I haven’t had any difficulty using the form.” (Site 2: midwives)

“Not another flipping form! More paper work! That was the general feeling around. But it’s actually gone quite smoothly. We’ve got used to it by now. We’ve just integrated it into everything else that we’ve got to tell them about during bookings.” (Site 7: midwives)

“Oh no! Not another case of death by form.” (Site 2: midwives)

Thus, midwives are generally positive in relation to the FOQ once they overcome the sheer novelty of it.

4.3. Reactions of ANCs and SC&T Screening Coordinators

Antenatal Care Coordinators (ANCs), SC&T Screening Coordinators were equally positive about the form itself and did not report very significant problems with it.

“It’s a very good form. We haven’t had problems at all with the lay out itself. The yellow and white boxes make life really easy. It’s kind of intuitive to use.” (Site 6: ANC)

“Since doing these family origin questionnaires, it has really sunk it home that you should never assume somebody’s nationality from the name. We can pick people up that we would never have done before.” (Site 3: ANC)

“The form seems to work really well. Generally been getting very good feedback. It’s easy to use, it’s very simple. The confusion generally is a training issue, because the form itself is actually very simple to use.” (Site 2: SC&T Screening Coordinator)

Thus, again, it is clear that ANCs and SC&T Screening Coordinators are very positive in relation to the FOQ. They do highlight some problems with specific aspects of the form and with the ways in which it is administered. Some of these can be addressed through simple redesign, others through training, as discussed in subsequent chapters.

4.4. Reactions of consultant haematologists and biomedical scientists

The most positive views are expressed by consultant haematologists and biomedical scientists. From their perspective, the form is not simply “easy to use”; it is positively helpful. It saves them a considerable amount of time by providing them with information on how to interpret the results of the full blood count in a more reliable way than when they merely used surnames, and by giving them immediate access to the family origins of the baby’s father, if this is required. This streamlines, speeds up, and improves the reliability of the screening process. It also saves much unnecessary anxiety to parents-to-be because they do not have to be contacted to ask for further information when, in most of the cases, results will show that they are not carriers anyway.

“It’s saved us hours and hours because without this information, you’ve got to chase up every lady whose MCH is below 25 and often that was because of iron deficiency, but you couldn’t just assume that without the ethnic data. We used to get our haemoglobin office counsellor to phone the patient and she used to get annoyed because she’s got better things to do. And from the patient’s perspective, they

were called about possible problems in pregnancy and that caused a lot of anxiety which we can now avoid. So in many ways, it's absolutely brilliant." (Site 4: Biomedical scientist)

"You've got the partner's information in front of you straight up, which is very, very good because you know right at the beginning what's high-risk and what isn't. So the FOQ is very useful for that." (Site 2: Biomedical scientist)

In fact, precisely for these reasons, one consultant suggested that the Family Origin Questionnaire should be used by all laboratories, regardless of whether they are in High or Low Prevalence areas.

"We think the FOQ is very good. We think everybody should use this questionnaire. Even high prevalence areas should use the questionnaire because it gives you information that you wouldn't otherwise have about the partner. If you're testing somebody's blood and it looks funny, you think: 'I wonder where this lady's partner comes from? It could be important.' If you haven't got that questionnaire, you don't know the answer to that question and you've got to go and find out. You've got to traipse around the hospital trying to find the maternity notes or the midwife or the GP and they don't know either where this lady's partner is from. You spend ages trying to find out this sort of information. With the questionnaire, the information is there and it saves a good 2 to 3 days fluffing about." (Site 4: consultant)

4.5. Conclusions

Across all sites, the overwhelming majority of stakeholders were extremely positive about the FOQ itself. From the perspective of midwives, ANCs and SC&T Screening Coordinators, the questionnaire was found to be easy to use and quick to complete. From the perspective of consultant haematologists and biomedical scientists, it was thought to be a major improvement on their earlier screening processes by making the screening more reliable, quicker, more streamlined and less anxiety-inducing for parents.

Despite these positive reactions, there were some problems with the midwives' understanding of the actual purpose of the form as part of the SC&T Screening Programme, with the lay out and presentation of the form, with the content of the form and with its administration. We discuss those in detail by examining each section of the FOQ one by one in chapter 5. There were also some reservations about the Screening Programme, but these were largely based on lack of resources (staff, equipment, training, etc) rather than on the Family Origin Questionnaire itself. We discuss these issues in chapter 7.

5.0. THE FOQ SECTION BY SECTION: LAY OUT, CONTENT AND ADMINISTRATION

5.1. Introduction

This chapter reports on the views of the midwives, ANCs and SC&T Screening Midwives, consultant haematologists and biomedical scientists on the FOQ itself. It considers each section of the FOQ separately. For each section, it discusses the general opinions expressed by various stakeholders, any problem inherent in the FOQ itself, the practical difficulties created by any ambiguities in the FOQ itself and the solutions devised by people to overcome difficulties with the FOQ. Each section concludes with a set of recommendations to avoid the problems currently encountered by its users.

While the FOQ essentially works and is liked by most stakeholders, the emphasis throughout the chapter is put on issues which were found to be problematic, with a view to improving the FOQ and its administration. The bulk of the chapter refers to the experiences and difficulties faced by midwives, as they are the ones who complete the FOQ.

5.1. Section 1: Logo



NHS Sickle Cell & Thalassaemia
Screening Programme

Some midwives and biomedical scientists commented on the fact that it was very useful for the NHS Sickle and Thalassaemia Screening Programme to have a readily identifiable logo on all documents pertaining to it. Given that they have to be involved in different aspects on antenatal and neonatal care, they appreciate the “branding” of the programme.

Recommendation

- Keep or include the logo on all documents related to the NHS SC&T Screening Programme.

5.2. Section 2: Box on personal details

If using a pre-printed label please attach one to each copy

Hospital Name
Hospital No
NHS No
Estimated Delivery Date
Surname
Forename
Date of Birth
Add1
Add2
Post Code

This section mainly created difficulties for **midwives**. Their overall reaction to the FOQ in part depended on whether they had access to pre-printed labels (“stickers”) to affix to the FOQ or not. Those who had stickers were generally satisfied with the form and felt that it took “no time at all” to complete; others were more likely to be frustrated with the amount of hand-writing required.

“The questionnaire is a doodle because you have room to put labels on. But sticky labels are essential. Then all you do is tick a box and file. Otherwise, it would be a right pain.”(Site 1: midwives)

“I feel it is extra paperwork, extra writing, because we haven’t got the privilege of stickers. Some have the privilege of stickers, which is wonderfully handy, but we have to write in everything, the name, address, postcode, the due date and everything.” (Site 2: midwives)

It is not clear why some sites had the benefits of stickers and others not, but it is clear that all midwives would want to have such stickers and that having them would contribute to making midwives more positive towards the FOQ.

One of the immediate consequences of not having such stickers is that many midwives leave out part of the information they are required to enter. In addition, many midwives believe that not all the information requested in the top section is in fact necessary. It is the norm, rather than the exception, for some of the information to be missing from that section.

“We don’t have stickers and we have to put everything in ourselves, so I put minimal in really. Name, EDD, hospital number and postcode.” (Site 5: midwives)

“There’s a lot of information in there that I don’t know whether it’s actually necessary. If you’ve got a name, the EDD, the first line of an address, a postcode and a hospital number, I don’t think you need anything else. Being a minimalist I fill in what I have to!” (Site 3: midwives)

Biomedical scientists are satisfied with this section. They confirm that midwives often fill in only certain sections of the personal information requested on the FOQ, but claim that this seldom impedes their work.

“Midwives don’t always enter all the personal details on the form but that’s never created any big problems for us, as far as I know.” (Site 7: Biomedical scientist)

Recommendations

- Whenever possible, NHS Trusts should ensure that midwives have access to pre-printed labels when completing the FOQ.
- Only request information which is strictly necessary: date of birth and full address are not seen as necessary by many midwives.

5.3. Section 3: Box on screening test declined

Screening test declined

Do you want to give a reason?

Yes

.....

.....

No

Many **midwives** are not entirely clear about the very logic of the SC&T Screening Programme and about the role of the FOQ in identifying the women who should be tested for SC&T. There is therefore a degree of confusion about when they should tick that the screening test has been declined.

Most midwives do tick this box for those mothers who are in the “at risk” groups but do not want to screening.

“I: What about the screening declined box, when do you tick that?”

M1: I’ve never done it. I’ve never had anyone decline.

M2: No I’ve never had anybody decline. But it’s a lot to do with the fact that it’s low prevalence here. You don’t tick it if it’s a White person. If it’s yellow and they still don’t want it, then you tick it. But I know that that’s caused a lot of confusion amongst some of our girls.” (Site 5: midwives)

“I have never had anybody in a high risk group decline.” (Site 4: midwives)

However, some **midwives** do not use this box appropriately.

“I: When would you tick that screening was declined?”

When they don’t want it.

I: If the mother is White British or in any of the white boxes and she does not want the test, do you tick this box?

Yes, of course.” (Site 7: midwives)

“M1: They were talking about the fact that some people were ticking the screening test declined box when they didn’t need to.

M2: Yes I think that was the bit that everybody was quite confused about. Everybody was doing it differently.” (Site 5: midwives)

ANCs, SC&T coordinators and **biomedical scientists** also reported that this box was sometimes used inappropriately and ticked for anyone who did not get screened, regardless of whether they are at risk or not.

“It took a few rounds of explaining before the midwives actually understood when to tick that box. Some are still in a bit of a muddle over that one.” (Site 5: ANC)

“Screening test declined’, does that mean they’ve declined the test or declined to give a reason? Because it’s not necessarily people in the yellow boxes. Midwives tick it for the white boxes as well. I reckon there’s a bit of confusion about that.” (Site 1: consultant)

Recommendations

- Training should clarify that the “Screening Test Declined” box only needs to be ticked by parents who belong to the “at risk” groups, i.e. those in yellow boxes.
- Training should clarify that the “Yes” and “No” options in the box pertain to giving a reason only.
- ANCs and SC&T Screening Coordinators should monitor the ways in which this section is being used in the early phase of the implementation of the Screening Programme to ensure that midwives are using it correctly.

5.4. Section 4: Family origins (central section: A to I)

The main part of the FOQ is the section which asks for the family origins of the baby’s mother and father. **Midwives** almost invariably claim that this section is easy and

quick to use, and that they are relatively confident about it (except for some concerns about geography and a few categories that were deemed missing or ambiguous). However, this subjective assessment conceals a number of problems. These are discussed below.

What are your family origins?

Please tick all boxes in ALL sections that apply to you and the baby's father

	You	Baby's father
A. AFRICAN OR AFRICAN-CARIBBEAN (BLACK)		
Caribbean Islands	<input type="checkbox"/>	<input type="checkbox"/>
Africa (Excluding North Africa)	<input type="checkbox"/>	<input type="checkbox"/>
Black British	<input type="checkbox"/>	<input type="checkbox"/>
Any other African or African Caribbean family origins (please write in...)	<input type="checkbox"/>	<input type="checkbox"/>
B. ASIAN OR ASIAN BRITISH (ASIAN)		
India or African-Indian	<input type="checkbox"/>	<input type="checkbox"/>
Pakistan	<input type="checkbox"/>	<input type="checkbox"/>
Bangladesh	<input type="checkbox"/>	<input type="checkbox"/>
C. FAR EAST ASIAN (ASIAN)		
China	<input type="checkbox"/>	<input type="checkbox"/>
Thailand	<input type="checkbox"/>	<input type="checkbox"/>
Malaysia, Vietnam, or Philippines	<input type="checkbox"/>	<input type="checkbox"/>
Any other Asian family origins (please write in...) (e.g. Caribbean Asian)	<input type="checkbox"/>	<input type="checkbox"/>
D. OTHER NON EUROPEAN (OTHER)		
North Africa, Arab, Iran etc	<input type="checkbox"/>	<input type="checkbox"/>
Any other Non European family origins (please write in...)	<input type="checkbox"/>	<input type="checkbox"/>
E. SOUTHERN EUROPE (WHITE)		
Greek or Greek Cypriot	<input type="checkbox"/>	<input type="checkbox"/>
Turkish or Turkish Cypriot	<input type="checkbox"/>	<input type="checkbox"/>
French, Italian, Maltese, Portuguese, Spanish and any other Mediterranean	<input type="checkbox"/>	<input type="checkbox"/>
F. UNITED KINGDOM (WHITE)		
English, Scottish, Welsh, N Irish	<input type="checkbox"/>	<input type="checkbox"/>
G. NORTHERN EUROPE (WHITE)		
Austrian, German, Irish, Scandinavian etc	<input type="checkbox"/>	<input type="checkbox"/>
Any other European family origins (please write in...)	<input type="checkbox"/>	<input type="checkbox"/>
*Hb Variant Screening Requested by (F) and/ or (G)	<input type="checkbox"/>	<input type="checkbox"/>
H. DON'T KNOW	<input type="checkbox"/>	<input type="checkbox"/>
I. DECLINED TO ANSWER	<input type="checkbox"/>	<input type="checkbox"/>

- **Misunderstanding of differences between ethnic group and family origins**

In most sites, the majority of stakeholders understand the differences between family origins and ethnic group. Most midwives use the FOQ correctly in that respect, probing for the origins of the baby's parents, grandparents and great-grandparents on both sides of the family.

“Family origins and ethnicity don’t always match, which makes it a bit tricky for people who don’t quite understand the difference. You’re really asking where their parents and grandparents were born. I am very clear about the difference.” (Site 4: midwives)

“I always say this is not about someone’s ethnic group. The way I introduce it to midwives is that this is about where your relatives have come from in the past. And I tend to deal with it in those terms.” (Site 1: SC&T Screening Coordinator)

However, some **midwives** are not clear about the difference, for the purposes of screening, between family origins and ethnic group. Thus, many assume that they can determine the family origins of parents simply by either looking at their physical type, reading their surname, or inferring it from their ethnic group. As a consequence, these midwives ask the mothers what is the single category which, they feel, best represents their ethnicity. Based on this (mis)understanding, and despite the fact that the FOQ form clearly states that midwives should tick “ALL boxes” that apply to the parents, some midwives would not tick more than one box for each side of the family.

“Usually, you just have to look and you know, don’t you?” (Site 2: midwives)

“If they haven’t got a weird surname, you just assume they’ve got no history.” (Site 5: midwives)

“So you could tick more than one box then, is that what you are saying? But that’s very confusing, isn’t it? So do they want us to write, say she ticked the white one, but she say’s but my great grandfather is from there, do we put beside it grandparent?

I: You don’t need to say that it can be anybody....

But isn’t that confusing then because you don’t know who are you talking about? Because it says “You” and “Baby’s father”. That’s the two boxes isn’t it? So if you say to me you’re “F” but my grandfather is “B” or whatever, I won’t know who is what.

I: I understanding exactly what you’re saying, but you are equating ethnic group and family origin. But what is meant is that the whole column is in relation to you. Is there anybody in your whole family or in the father’s entire family that comes from any of the “at risk” backgrounds?

But it doesn’t say that, you see? It says “You” and “Baby’s father”, doesn’t it? I don’t get it.” (Site 7: midwives)

“I just tend to tick just the one. There should be wording to that effect, that you are after generations and not just them personally, on that form.” (Site 3: midwives)

This confusion amongst midwives was also highlighted by **ANCs, SC&T Screening Coordinators** and **haematologists**.

“One of our major problems at the moment is that midwives have a tendency only to put one tick on a box. I keep trying, reminding them that they can put multiple ticks in.” (Site 1: SC&T Screening Coordinator)

“I think despite reasonably clear direction, people assumed that this form was only to be done where there was very obvious family origins outside the UK. In the beginning midwives went by the ethnic groups which they could observe, by people’s looks and names.” (Site 5: consultant)

- **Misunderstanding of differences between ethnic group and nationality**

A similar problem arises from the confusion between “ethnic group” and “nationality”. Many **midwives** use the words interchangeably and, in the process, can unwittingly cause very serious offence to their patients who are indeed British citizens but who are from a minority ethnic background.

Since midwives are themselves unaware of this problem, they tend to attribute the confusion to the mothers themselves and to feel rather aggrieved when the latter react negatively to their enquiries into their family origins.

“[Asians] sometimes get confused. They really do. I come across it all the time. They’ll say: “I’m British” and it’s quite clear that they’re not! So you have to explain.” (Site 7: midwives)

One **biomedical scientist** who was involved in training midwives picked up on this confusion, which she attributed to the fact that many different forms require midwives to think differently about these issues even in the course of one booking.

“The only thing midwives find a bit confusing is there are differences in antenatal and neonatal care that sometimes we look for ethnicity, sometimes we look for nationality, sometimes we look for family origins. The categories can look very similar but in fact they are used in very different ways, so that can be confusing for some of them.” (Site 4: Biomedical scientist)

ANCs and SC&T Screening Coordinators have tried to tackle these issues through both formal training and informal discussions. Some provide midwives with ready-made strategies to ask their patients about their family origins.

“In our training sessions, I try to explain to them that were not picking out Asian and Black populations. We’re trying to identify anybody who has any risk factor and that can include White races that there are definite risk factors for, including continental Europeans. It’s about how you ask the question. I give them my strategy, which is to say: “Do any of your relatives come from anywhere other than England?” And I always start with the most similar ones, like French, Italian,

Spanish, and I work up to the Asian and Black populations. I have never had a negative response from anyone I've interviewed and asked." (Site 1: SC&T Screening Coordinator)

"One midwife said to me: "They [mothers] get really irritated when you ask that question" and then I said: "Well, how do you say it?" and it was obvious what was causing the difficulty. She did not quite understand that people who looked foreign could also be British. I think the problems are more with the midwives than the women." (Site 5: ANC)

It is clear that many midwives are not at ease with the many notions - some political (nationality), some genetic (family origins), some mainly psychological and cultural (ethnic identity) - that surround ethnicity. This lack of ease can undermine the success of the Screening Programme both because some people from BME backgrounds may refuse to give their family origins, and because a "British" nationality and "White British" ethnicity can be wrongly assumed to mean that the patient is not at risk of SC&T. No less importantly, the midwives' confusion and lack of ease can create a very uncomfortable climate for their BME patients (potentially causing lower attendance rates and poorer antenatal care in these populations than in the general population).

- **Probing over generations**

The confusion over notions of ethnicity, family origins and nationality noted above in part accounts for the fact that some midwives do not probe their White and/or British patients at all for their family origins.

Notwithstanding these issues, there remain important differences in the level of probing commonly used by **midwives**. Some midwives do not probe at all. During observations, a sample of the inappropriate questions asked by midwives includes the following:

"Is there anyone in your family who is not British?" (Site 3: midwives)

"Are you all British?" (Site 7: midwives)

"Have you got any ethnics in your family at all?" (Site 1: midwives)

None of these led to any further probing. Answers were taken at face value. However, the general tendency amongst those midwives who are clear about the distinction between family origins and ethnic group, is either to probe for family origins up to grand-parents on both sides of the family or to probe "as far as people themselves know".

"Personally I only go to grandparent because I feel that person only really knows that. Unless there is a condition definitely in the family, I don't think the information goes beyond that." (Site 7: midwives)

"I'll probe them as far as they know." (Site 3: midwives)

Biomedical scientists suggest that some protocol should be given to midwives to ensure that the probing is standardised.

“There needs to be some sort of standard, as to how far back in the ancestry they go and what is relevant. I would have thought that if the patient’s parents were white European or UK, I don’t see any reason why they should go back any further than that. Maybe a convention protocol would be wise.” (Site 6: Biomedical scientist)

“There’s the obvious question of how far you go back into someone’s ancestry. We always say whatever they can remember, but that should perhaps be clarified.” (Site 4: Biomedical scientist)

- **Ethnic categories in FOQ**

The ethnic categories listed in the FOQ are generally found to be adequate. **Midwives** rarely complain that they cannot find a relevant box to tick the family origins of their patients, although most can think of one of two people whom they had difficulty locating on the FOQ.

“In the main, it works really well. It’s just one or two cases that sometimes are more difficult. But then you can always use the “Don’t Know” box, can’t you?” (Site 4: midwives)

“It’s very easy to use. Most of our ladies are in “F” anyway, and then you get to see some patterns locally for the others. There are little communities which you soon get to find out about. Like here there are lots of people from Fiji, so we just have to learn once where they should be ticked and that’s it.” (Site 1: midwives)

The only nationalities which are relatively frequent and not currently catered for in the questionnaire are *White* people who do *not* require screening and who are *not* European. **All stakeholders** consistently found it difficult to tick appropriate boxes for people who come from North America, Australia, New Zealand, South Africa, Zimbabwe, etc.

“There isn’t anything that suggests other non European, like American or Canadian or South African or Russian. Where it says other non European, it says North Africa, Arab, Iran etc. I suppose it could go into there but I don’t think these people are particularly at risk, are they?” (Site 2: midwives)

“There’s a few groups that aren’t on there like Australia, USA, New Zealand, where’s that? I mean other non-European, they said North Africa, Arab Iran, which is also yellow, but there’s nothing if you are other non-European and in a white box.” (Site 1: Biomedical scientist)

“Some parts of the world aren’t represented at all, like Russia, America, Australia, South Africa.” (Site 4: consultant)

The other categories which frequently created difficulties were Russia and Poland, both of which are in Eastern Europe. Parents with such family origins do require screening but midwives did not know what to do with them.

Despite general satisfaction with the ethnic categories on the form, **midwives** sometimes claim that they struggle to tick the right boxes because their own knowledge of geography is somewhat limited.

“M1: For those of us who are more geographically challenged, it’s not always straight forward. I don’t know what “et cetera” is!

M2: I find it slightly ambiguous to categorise who is Northern European, who is Southern European, who is Far East Asian or who is plain Asian.

M1: Where would you put Afghanistan? It probably comes under Asian because it is next to Bangladesh. But it is not on there.

M2: Would it not be along with Other Non-Europeans?

M1: We all need to go back to school and take geography as well, on top of everything else!” (Site 1: midwives)

“Sometimes it’s not clear to me, like say Poland. Is that in Northern Europe (White) or is it in Other Non European (Other)? Does it count as in Europe or not? I don’t know where Poland is. I am a midwife, not a genius!” (Site 3: midwives)

“In my mind, France is not hot, so I put it as Northern Europe!” (Site 1: midwives)

ANCs and SC&T Screening Coordinators confirm that knowledge of geography was an issue for some midwives.

“Some midwives have no clue of geography. They really don’t know where the countries are. We’ve had midwives putting Greece as an Asian country.” (Site 1: SC&T Screening Coordinator)

“It gives examples but examples are no good to us. So I think it needs a bit more identification on it and that would help enormously and I think that’s the difference between filling it in correctly and incorrectly.” (Site 2: ANC)

The fact that open-ended entries are available to write in unknown family origins usually assuages the midwives’ concerns. They are therefore confident that any mistake they make will be picked up and rectified by someone else.

“If you’re not sure, you just write where they come from and hopefully that will be sorted because there is a section where you can write where they come from. So it’s not a problem. If you tick the wrong box, people can still know where they come from, so it’s not a problem really.” (Site 3: midwives)

“There is a space at the end of each category though if they don’t fit into that yellow box. So there’s always room on the form to put people in one way or another.” (Site 2: midwives)

- **Colour-coding**

Colour-coding – that is the use of yellow boxes for those at risk and of white boxes for those not at risk – was unanimously found to be excellent and extremely helpful. That was the case across **all stakeholders**.

“I like the fact that the yellow highlights risk, it brings it out. Most of the ones I tick are in the white so it makes it jump out at you. It must make it easier for the labs as well.” (Site 3: midwives)

“The yellow alert box is absolutely marvellous, we love that, it makes the midwives ask the question, and it also sounds alarm bells immediately if they are high risk so the results get back and the sample is processed and turned round quickly.” (Site 2: ANC)

“I think the form is totally clear. It’s very useful to have the colour coding on it.” (Site 7: Biomedical scientist)

- **“Hb variant screening requested by (F) and/or (G)”**

The option of requesting Hb variant screening for those in low risk group is a key issue which needs to be addressed through training. Many **midwives** do not fully understand how to use the “opt in” clause (that is, when they should tick the yellow box below section G for those in low risk groups who nevertheless want to be screened).

“I was ticking a box that I shouldn’t have been ticking. If somebody is Caucasian White I was ticking the box to have Hb variant screening done. I initially did interpret it wrong, as were a few others.” (Site 2: midwives)

“Most of my colleagues got the impression that we were testing everybody. Now we’ve discussed it with the ANC and apparently they don’t screen everybody, they consent to it if necessary and it is only if there is a problem with the blood picture that they then screen, but that wasn’t our understanding in the beginning at all.” (Site 2: midwives)

“M1: There was one aspect of it which I didn’t quite understand initially and that was the couple of little boxes with the Hb Variant. That part of it was a little bit confusing. I couldn’t quite get my head around that.

Did you understand that part?

M2: No. I guess not. I’m not sure what you’re talking about.

M1: Well, that was not clear to me at all.” (Site 3: midwives)

“The bit on Hb variant, I think that threw a lot of people. People from the lab tried to explain it to me but I still find it quite confusing to know which box to tick, to be honest.” (Site 5: midwives)

“I never actually ticked that one. I never really paid any notice, to be perfectly honest.” (Site 7: midwives)

This confusion amongst midwives is commented on at length in discussions with **consultant haematologists and biomedical scientists**. Interviews with these stakeholders clearly demonstrate that, at least in some sites, many midwives do not understand the mechanisms of the screening process and essentially “encourage” women in low risk group to have this additional screening test taken. While the socio-economic characteristics of the respective areas in part account for these differences (with mothers from higher socio-economic areas being more likely to opt in than mothers from poorer areas), the attitudes of the midwives themselves and the ways in which they introduce the Screening Programme to mothers are by far the most important factor.

“We’ve had a lot of White Caucasian women who have not been in an “at risk” group who have ticked the “opt in” box for screening. At least a third of the samples we were running were coming from women not “at risk”, who were opting in for screening. Midwives didn’t explain why people would need screening, or why screening wasn’t particularly important. From our point of view, that was the biggest hiccup because it increased the workload so significantly and didn’t pick anybody that we wouldn’t have expected anyway.” (Site 2: consultant)

“The workload has tripled. We had a huge surge in the numbers because of people opting into the scheme who wouldn’t have been considered for haemoglobinopathy testing. That was due to the way the information was given out by midwives in the community - “you might as well have it”, kind of thing, rather than giving a proper explanation of risk levels. I did a full statistical analysis at some point and I found that over a period of a few months, I had two hundred and seven yellow boxes that were eligible for haemoglobinopathy screening, but I also had something like two hundred and twenty who had opted in when they did not need to. But I’ve spoken to the [ANC] about the “opting in” problem and she spoke to her midwives and it’s having a major impact. The numbers are reducing.” (Site 2: Biomedical scientist)

“The majority of those antenatal haemoglobinopathy screens that I do here are with [area] born and bred, White Caucasian couples who have gone along and the midwife has said to them: “Oh! There’s another blood test on offer. You’re not at risk but would you like it just the same?” They are at a very, very low risk. Now, although they are perfectly entitled to it, I think they should not be encouraged to take it up, otherwise it gets unmanageable for us.” (Site 5: Biomedical scientist)

“Some of the additional workload has been down to mothers expressing an interest in being screened where the need on the basis

of family origin is questionable in the extreme. Midwives get people to tick the “opt in” clause when they shouldn’t, arguably.” (Site 5: Consultant)

The interview data with haematology staff clearly suggest that there is a fundamental problem of comprehension of the overall role of the screening process and of the function of the FOQ is identifying the mothers who need or want to be screened. These problems go to the very core of the screening process and they have massive implications in terms of workload and resources for laboratories. This has to be addressed through training. It cannot simply be rectified through amendments to the FOQ itself.

▪ **Nomenclature**

While no interviewee picked up on the lack of consistency in the nomenclature on the FOQ, the form currently combines, with no obvious rationale for this, both country *names* (e.g. India, China) and *nationalities* (e.g. Greek, Turkish Cypriot, Austrian). It would be better to consistently use either the country names or nationalities.

Recommendations

- The FOQ should have an additional category that includes other non-Europeans who do not require testing and lists, as examples, American, Canadian, South African, Australian, etc. This additional category should probably go under the current category G. Training should explain that people with such family origins do not require screening because their ancestry is Northern European (e.g. UK, Holland, Germany).
- Subcategories should be systematic in either identifying countries or nationalities.
- NHS Trusts should produce guidance on how to allocate people who have family origins that are unusual and infrequent (at the national level) but that are found quite regularly at the local level (e.g. Russian and Polish people).
- Some mechanism should be devised to help midwives allocate people to the right box. Midwives themselves request maps. However, an alphabetical list of countries with their respective code on the FOQ may be more helpful.
- Colour-coding should be maintained.
- Training should explain in depth the very logic of the Screening Programme and the function of the FOQ within that. It should emphasise the different risk levels for the different ethnic/national groups. It should explicitly link this explanation to the use of the “Hb Variant Screening Requested by (F) and/or (G). It should describe the resources implications, from the haematology laboratory perspective, of using the “opt in” clause when this is not necessary. ANCs and SC&T Screening Coordinators should monitor how this section is being completed during the early days of implementing the Screening Programme.

Recommendations (continued)

- Midwives should be supplied with ready-made explanations of the Screening Programme and the FOQ so that greater standardisation is achieved across sites and across individuals.
- Training should stress the differences between “ethnic group”, “family origins” and “nationality”. It should make clear that “family origins” must be asked for and cannot be inferred from ethnic group, nationality or other available evidence (e.g. name, skin colour). It should stress that midwives should never question whether someone is “British” or not.
- Training should clarify that midwives should complete the FOQ themselves.
- A protocol should be developed to determine how much probing into family origins is required. Training should clarify the depth of probing required.
- Training should explore complex “cases” where a person’s ethnicity, nationality and family origins do not match and discuss how midwives should deal with such cases.
- Training should give guidance on how to deal with patients who do not know their family origins (e.g. that have been adopted).

5.5. Section 5: Estimated Delivery Date (bottom section: J)

J. ESTIMATED DELIVERY DATE
(please write in...)

One of the very few issues with the FOQ form itself which truly exercised **midwives, ANCs and SC&T Screening Coordinators** is the fact that the FOQ requires midwives to write in the mother’s Estimated Delivery Date (EDD) in section “J”, when they have already entered this information in the top section of the form, when completing the personal details.

“The one thing that springs to mind that annoys me intensely is that there is a duplication of the Estimated Delivery Date. It doesn’t sound like a big thing but when you have to write it in by hand yourself for every patient, it’s really frustrating.” (Site 4: midwives)

“The only problem with this form is it asks for the EDD twice. Why you have to put it here and then there, I don’t know. It’s a bit annoying really.” (Site 7: midwives)

“The EDD is put on twice...I know it is a little thing but it’s little things like this that wind people up.” (Site 5: SC&T Screening Coordinator)

Midwives need to be made aware of the reason for the EDD being requested twice. Section “J” has been included in the FOQ because midwives who use pre-printed labels cover up the space in which they must put in the EDD. Since this is critical information, it is requested at the bottom of the FOQ again.

Recommendation

- Explain the reason for the duplication of the request for the EDD in the FOQ during training, both to avoid frustration and to ensure midwives who use pre-printed labels do complete Section “J” of the FOQ.

5.6. Section 6: Signature box

All women need to be informed that routine analysis of blood will identify the risk of being a thalassaemia carrier.
*Options F & G can opt into haemoglobin (Hb) variant screening if requested

Signed _____ Print Name _____ Date _____
(By Person Completing the Form)

It was very broadly understood that the **midwives** themselves are meant to complete the questionnaire. However, some midwives, especially in the early days of the pilot, assumed that the patients should complete and sign the form.

“I have been doing it wrong. I’ve been getting the women to sign the form but it’s me that should sign the form, isn’t it? I only learned that last week.” (Site 1: midwives)

“Now I’m confused! Are you saying that you expect us to read that form out to them? Are you sure? But don’t they sign it or have I got that wrong as well?” (Site 7: midwives)

In some cases, **midwives** knew that they were supposed to complete and sign the FOQ themselves, but they were so uncomfortable with the idea of asking their BME patients about their ethnicity, that they opted to ask them to fill in the questionnaire and, in fewer cases, to sign it as well.

“Some lady told me: “Well, you are discriminating against me because I was not born in Pakistan. My mum wasn’t and I am British.” So now I give them the form to tick.” (Site 1: midwives)

“You can avoid having to ask the question [on family origins] by just giving them to form to complete. It’s easier that way.” (Site 7: midwives)

Another important issue is that the text in the signature box states that “all mothers need to be informed that routine analysis of blood will identify the risk of being a thalassaemia carrier.” In only two of the observations we carried out was this mentioned to the mothers. In fact, there was very little differentiation at all between sickle cell and thalassaemia. Some confirmed in interviews that they did not “go into that” with their patients.

“I must admit I don’t particularly go into that with them if I’m being honest. I must admit I haven’t ever particularly emphasised that.”
(Site 1: midwives)

“I don’t think I ever actually discussed that with my ladies. I didn’t know about that.” (Site 5: midwives)

Recommendations

- In the signature box, the phrase “signed by person completing the form” could be replaced ‘signed by health professional completing the form’.
- Training should reiterate that midwives themselves should complete and sign the FOQ.
- Training on SC&T should emphasise the differences between the conditions and relate this explanation to the fact (discussed in the signature box) that all women’s risk of being a thalassaemia carrier will be assessed through the routine full blood count.
- Training should clarify issues to do with ethnicity, family origins and nationality, with a view to empowering midwives to address these issues confidently with all their patients, regardless of their backgrounds.

5.7. Section 7: Information on management of three copies

The TOP copy of this form must be attached securely to the laboratory antenatal booking request form and sent to the laboratory with the antenatal blood samples, the second copy is to be retained in the patient’s maternity notes.

The management of the three copies (white, yellow and pink) is a source of much confusion and frustration amongst many **midwives**.

The guidance written on the FOQ itself is found to be problematic in three main ways. The first problem is that there are three copies but the guidance only refers to two (the “top” copy and the “second” copy). Midwives therefore are left to wonder what they should be doing with the third copy and whether there is any point at all in having that third copy.

“The only thing that does get on my nerves is that I can never work out which copy we’ve got to give back. It’s quite fiddly to file and I

don't know where to file the rest of it. The GP notes, the hospital notes, where? So I stick it in the hospital notes." (Site 1: midwives)

"Could I also just mention as well there are three copies of the current document and I can understand one going to file and one going to the lab, but what about the third one?" (Site 1: midwives)

"Where do the forms go? Who's supposed to have what? I'm never clear about that." (Site 5: midwives)

"I think two copies would suffice. I have to tell you that I have a little pile of pink forms in my box at the surgery now to go back into the notes. I have a pile because we've got three sheets, but we don't need that, do we?" (Site 5: midwives)

Feedback from **haematologists** and **biomedical scientists** (either given to us during the research or given directly to the midwives) indicates that problems with form management are not infrequent.

"One of my colleagues was sent a form back from the lab with a severe comment saying: "This part I believe goes into the patient's notes. We do not need this copy." They obviously got loads like that so they must get a bit bombarded with it all and a bit fed up." (Site 3: midwives)

"Sometimes we get all three copies. Sometimes we get two copies. There's no real consistency on that front." (Site 1: Biomedical scientist)

"There are still a few cases where we see all three copies through and we have then to send the copies back to Antenatal. Most of the time, they get it right, but sometimes we get the second copy, the third copy, or no copy at all." (Site 6: Biomedical scientist)

The second problem has to do with the practicalities of "attaching securely" the FOQ, the blood request form and the blood samples so that they all reach the laboratory together.

"I think there was a little bit of confusion initially. Some people put the form in with the bloods, whereas my understanding of it was that it had to be stapled. But I think some midwives thought they had to chuck it in with the samples, obviously to keep everything together. It's not clear what we're supposed to do." (Site 2: midwives)

"Have you ever tried finding a stapler? It may sound ridiculous but it's actually quite a complicated issue. Trying to attach the form to the blood form and the samples is murder. If the bloods and the forms get separated, that will compromise the standards of the screening programme." (Site 1: midwives)

Midwives adopt different strategies to ensure that the forms and the blood samples are kept together. One common strategy is to fold the FOQ and to slip it into the plastic bag with the blood samples. Many midwives argue that this is the simplest and most effective strategy to ensure that all is kept securely together. It avoids having to carry a stapler (which is awkward for midwives working in the community) and it avoids the risk of cuts from staples (“sharps”) for the laboratory reception staff who handle the forms and the samples.

“M1: I fold [the FOQ] up and put it in the bag with the bottles.
M2: I used to fold it up and put it in the bag and but then I was told you are not supposed to do that, you are supposed to staple it.
M1: Really? Why not? We’re not allowed to use staples.
M2: I know but it says “securely attach” and it has to be on the outside in case the bottles break. That’s what I was told.
M1: Oh, I always put it in the bag. Staples are a sharps risk. But anyway, my big counter-argument is I don’t have a stapler with me. It’s secure in the bag. It doesn’t get lost. Why would these bottles break anymore than the others anyway? I am going to continue to put them in until such time as somebody slaps my wrist.” (Site 5: midwives)

Another common strategy is for midwives to staple the FOQ with the blood samples and blood request form.

“We have to fold and secure the FOQ to the front of this form. If you staple that, it’s not going to go anywhere. It’s better than a paper clip.” (Site 7: midwives)

“I just staple everything together. Isn’t that what we we’ve been told to do?” (Site 2: midwives)

There were few complaints from **biomedical scientists** regarding this issue. However, this may be because we did not conduct interviews with the reception staff whose duty it is to sort the various samples out and to dispatch them to the correct laboratories.

“Occasionally we get the forms tucked into the antenatal request, which is inconvenient.” (Site 6: Biomedical scientist)

“The only thing is that the midwives sometimes put maybe ten staples to secure the FOQ to the request form, just to make sure it doesn’t fall off. But when it gets to the lab and it’s stapled or it’s folded in four or whatever, it’s a bit of a nuisance because if you times that by fifty, you know, they’re all coming in all folded up and like multiple staples in it. So the manhandling of them isn’t that easy.” (Site 2: Biomedical scientist)

The third problem, from the midwives' perspective, is that the copy that should go in the maternity notes is not in a format that can easily get integrated in these notes.

“And [the copy for the maternity notes] is loose. And it's rather bulky to put into their notes. It doesn't tuck nicely into the notes. Pain in the bum.” (Site 5: midwives)

“That extra sheet is so flimsy and the format, it's a silly thing, but it just doesn't fit in easily with the maternity notes.” (Site 1: midwives)

To overcome this problem, some midwives requested bags exclusively for the SC&T screening.

“We could do with a form with a bag attached. Then we could put the bloods in there and stick that in another bag with the form in.” (Site 1: midwives)

“I think it would be nice to have a request bag especially for that, rather than trying to pop it in the bag or trying to clip in the form. If you haven't got a stapler next to you, and not everybody can, there's a possibility of that form being misplaced.” (Site 7: midwives)

Recommendations

- The FOQ form should include guidance on what to do with the *third* copy of the questionnaire. The guidance could profitably refer to each copy by reference to their colour (white, yellow and pink).
- The guidance should be written on the FOQ itself.
- Training for midwives should include explicit guidance of what to do with each form, and how to attach the top copy securely to the blood samples. Training should also explain the *rationale* for the three copies.
- Provide guidance on how to attach securely the form to the blood sample and give justification for the preferred method.

5.8. Conclusions

Interviews with all groups of stakeholders reveal that the layout, presentation and content of the FOQ are thought to be excellent by most people across most sites. The strengths of the FOQ identified in the study are its overall clarity and ease of use. The use of colour-coding and the provision of open entries to write in ambiguous family origins are deemed particularly useful. Midwives generally agreed that the FOQ is simple to administer and that it does not add significantly to their workload.

The weaknesses of the FOQ in terms of layout, presentation and content, as perceived by research participants, are: 1) the request for the Estimated Delivery Date twice, at the top and at the bottom of the questionnaire; 2) the absence of a category for those White non-European people who are at low risk of SC&T, such as Americans, Australians and South Africans; 3) the fact that the signature box refers only to the “person” completing the form, rather than to the “health professional” completing the form; 4) the lack of guidance on what to do with the third copy of the FOQ on the form itself; and 5) the lack of consistency in the nomenclature used in the FOQ (with the questionnaire alternating between use of countries and use of nationalities). Slight amendments to the form should help rectify these problems and improve the administration of the questionnaire by midwives, reduce the workload of haematology laboratories, facilitate the handling of the forms and samples by laboratory reception staff, and help ensure that forms arrive securely attached to the samples.

Besides issues related to the lay out, presentation and content of the questionnaire itself, however, there are important issues to do with the administration of the FOQ. The most critical problem is that many midwives do not fully understand the very purpose of the FOQ in relation to the Screening Programme. As a result, many tend to offer SC&T screening to mothers whose family origins do not warrant the test. In other words, midwives do not use the “opt in” clause correctly, thereby generating undue increases in workloads for the laboratories. Another important problem is that many midwives are confused over and generally ill at ease with the notions of “ethnic group”, “nationality” and “family origins”. Issues related to the administration of the FOQ can only be addressed through detailed training. The specific training needs of the various stakeholders are discussed in a subsequent chapter.

6.0. THE FOQ: PROCESS OF COMPLETION

6.1. Introduction

This section reports on the ways in which midwives introduce the SC&T Screening Programme and complete the FOQ as part of the booking. The emphasis of this section is to highlight experiences and difficulties described by midwives, beyond those related to the completion of the FOQ itself. Findings are drawn from observations of FOQ completion during bookings and paired interviews with midwives.

6.2. Knowledge of SC&T

Few midwives have an adequate understanding of the fact that Sickle Cell and Thalassaemia are distinct conditions and grasp the implications of these differences. Some midwives have a clear understanding of the blood disorders and use their knowledge satisfactorily when they are introducing SC&T to parents. However, most midwives rush through their explanations and display limited knowledge of SC&T and a lack of understanding of the populations at high risk. The information they provide is insufficient for them to gather “informed consent” from their patients.

When asked whether they felt confident about their knowledge and understanding of SC&T, most midwives claimed that their knowledge was limited and superficial, though many felt it was sufficient for the purpose of completing the FOQ.

“Sometimes you don’t know everything but I think for the booking and the information they need to know for the screening, I don’t think it’s a problem.” (Site 2: midwives)

“I think we have an outline, but I wouldn’t say it’s a great in-depth knowledge.” (Site 3: midwives)

“One lady I screened said she had a possible alpha thalassaemia trait. She said to me: What’s that all about? And I went errr...What do I tell her? I did get stuck on that one.” (Site 1: midwives)

“I: Do you feel that you understand sickle cell and thalassaemia enough in order to be at ease with the whole process?”

M1: No.

M2: No actually. Because especially in this part of the world, we don’t really have a very broad ethnic mix. I am not seeing a lot of people who are considered to be at risk from those. And so it is, every time you encounter it, it’s a big panic.” (Site 5: midwives)

“I would be stumped if someone turned out positive.” (Site 5: midwives)

Some midwives rely on the supporting literature to guide them through their own explanations. Others simply refer to the SC&T leaflet on their patients' information pack.

“I have to get the leaflet out when I explain it to them because I'm not that familiar with it. I need to familiarise myself more.” (Site 7: midwives)

ANCs, SC&T Screening Midwives, biomedical scientists and consultant haematologists all confirm that midwives have a very limited knowledge and understanding of SC&T.

“A lot of our midwives know vaguely what sickle cell and thalassaemia are, but they don't really know anymore than the real, real basics. [...] I would strongly recommend any Trust implementing this programme to actually have their midwives properly trained in what sickle cell and thalassaemia are. I think ...people would feel more prepared.” (Site 1: SC&T Screening Coordinator)

“One of the midwives actually said ‘if you're White you don't need testing’.” (Site 6: ANC)

“Most of the people I come across have been amazed that we want to screen French people for example. Or Greek people and they go but they're European, they're fine.” (Site 1: SC&T Screening Coordinator)

“Midwives need to be trained about the conditions. I don't think they really understand haemoglobinopathies at all well enough.” (Site 7: biomedical scientist)

Recommendations

- Provide standard description of SC&T and the populations at high risk during training sessions.

6.3. Strategies to introduce SC&T screening

Midwives use very different strategies to introduce the SC&T Screening Programme to parents. The various strategies impact considerably on “opt in” rates amongst those who are not in high risk groups. Many midwives encourage their patients to be screened when there is no need for screening.

“Well first I explain a little bit about haemoglobinopathy and how it evolved as an adaptation. I explain which parts of the world it is found in and then I explain the benefits to their family of having the screening. Mostly the way I sell it is that it's an investment for their

grandchildren and their future family through having the knowledge of being able to pass on from generation to generation.” (Site 1: midwives)

“I tell them [all mothers-to-be] it's like everything in life, it's better to be safe than sorry. I don't have many declines at all.” (Site 7: midwives)

Conversely, the following strategy is very effective (if factually incorrect: the risk rate for the white British population is actually of 1 in 1,000) in restricting the numbers of women from white northern European backgrounds opting in, as it explicitly states the risk level, which are minimal in these groups.

“My little spiel is I explain the conditions and then I say that it roughly affects 1 in 10,000 white British but we know it affects more people in other countries. Then I explain what countries are at risk - basically I would say that it's the kind of thing that can be found in Asian and Mediterranean countries and sickle cell is African and Afro Caribbean - and then I also say we are taking part in a study. I ask them for their family origins and then I say, because we know it affects one in 10,000 people, I haven't got to screen you because you and your partner are both white British. Are you happy with that? And they would say: Yes.” (Site 1: midwives)

Recommendations

- Provide midwives with a ready-made introduction about the SC&T screening programme which they can then give to their patients.
- This introduction should contain the information already included in the “information for midwives” package produced by the SC&T Screening Programme. The provision of “risk charts” is particularly important to enable midwives to seek informed consent from parents-to-be.

6.4. Strategies to introduce and complete the FOQ

Midwives adopt different strategies to introduce the FOQ itself. For some midwives, introduction of the FOQ was cursory, lasting no more than a few seconds; others took some time to explain the aim of the questionnaire. There were also differences in the process of gathering information on FOQ. A minority started off with the FOQ and asked parents to answer systematically in relation to each category on the form. Other midwives asked patients if they had anyone in their family who may not be White British. The latter strategy is quicker but runs the risk of missing out people if midwives do not probe the answers given by parents who claim to be “White British”. This is particularly the case given that most people's experience with forms similar to FOQ will be in the context of asking about their ethnicity rather than family origin (see chapter 5 for a detailed discussion).

“Usually you’ve kind of broached the subject of ethnic group from the booking document. That one actually triggers the family origins question. And then I’ll say well part of why I want to know is because we offer you a range of blood tests and then sort of explain the blood tests and sickle cell and thalassaemia.” (Site 6: midwives)

“We actually ask them their ethnicity as part of their maternity notes, so I actually ask them where their grandparents are from at that point, so I’ve actually usually got the information by the time they come to filling this form in. So I don’t actually have to give them the form. I’ve already got the information out of them, to be honest. But obviously if there’s one that’s more complicated, we would do it together, but I haven’t really had anybody too complicated yet.” (Site 4: midwives)

6.5. Workload and integration in the booking process

Across all sites, the vast majority of midwives claim that it has been easy for them to integrate the Screening Programme and the FOQ within their booking process.

“It’s not a big burden because the information that is needed at the time of booking doesn’t take that much time. It’s not as though we have to spend an awful lot of time on it.” (Site 3: midwives)

“I haven’t found myself that it’s been a huge problem. No big impact on workload or anything.” (Site 4: midwives)

“It’s really not that cumbersome because you’ve just explained HIV and the Triple Test and STDs and it’s just part of that whole package.” (Site 5: midwives)

“I would say that the form adds not more than 10 minutes to a booking – we already have information on blood tests to be taken anyway so it’s not that much more additional.” (Site 6: midwives)

6.6. Reactions of patients to SC&T screening and FOQ

Overall, patients do not display any concerns about SC&T screening.

“Patients never ask any questions. They just nod and say yes.” (Site 3: midwives)

“Half the women I see don’t perceive themselves to be at risk so they don’t want the screening.” (Site 7: midwives)

“They tend to be very open really, especially if you’ve explained to them why you want to know. That’s the important thing, isn’t it, how you explain it to them.” (Site 1: midwives)

Some midwives are concerned to the general acquiescence of parents may stem from their lack of understanding of SC&T and of the screening process, rather than being based on genuine “informed consent”.

“It’s consent, but it’s not informed consent. A little bit more knowledge would not go amiss. People just go, alright, ok, but they don’t know what they are saying ok to, because you can only give them minimal information.” (Site 5: midwives)

“The problem is do they really understand what we are telling them?. I don’t think they understand what we are asking them about. It’s not really informed consent we are getting most of the time.” (Site 3: midwives)

According to midwives, people’s reactions to SC&T screening depend on their level of understanding of SC&T and the screening programme, which varies depending on a number of factors, including social class, education, awareness of SC&T in the community, and previous access to information leaflets on SC&T.

“Some people have heard of sickle cell and they do connect it with being more common in certain ethnic backgrounds. Other people will have never heard of either of them [SC&T].” (Site 7: midwives)

“You get entirely clueless people and you also get people from the other end that want to know everything. They are usually well informed themselves and want to know more.” (Site 2: midwives)

“Some have read their leaflets and they know about the conditions even before we speak to them, but some have not read them or understood them, even if they have been given the leaflets.” (Site 5: midwives)

There is much variation across sites with respect to whether parents receive information leaflets prior to their booking. In some cases, midwives can safely assume that mothers have received written information on SC&T prior to meeting with them. In other cases, the booking process itself is the first time mothers are given information leaflets and told about SC&T by their midwives.

“There’s a huge difference between those that have received the booklets and those that haven’t. You still have to explain, but they know what you are referring to, at least.” (Site 6: midwives)

“I find how well prepared they are beforehand can make a booking very easy or very long. If you’re giving them all this information at a booking, if they haven’t read anything at all before, the bookings can take a good hour and a quarter.” (Site 7: midwives)

Some midwives also deplore the fact that they only have access to information leaflets in English. Although they work in Low Prevalence areas, there are often pockets of High Prevalence in the midst of these areas, where many parents need to be able to read the information in languages other than English (or to take it home to their family for translation and discussion) before they can actually discuss with them.

“Unfortunately the information we use about SC&T is all in English and obviously the high-risk groups tend to be in those that don’t speak English. It really needs translation in other languages. It’s crazy because you can’t really get informed consent.” (Site 4: midwives)

- **Patients’ views on discussing their ethnicity, nationality and family origins**

According to midwives, most patients do not have concerns about disclosing their family origins, especially since more sensitive issues have already been covered during a booking.

“I’ve never had a problem with discussing their family origins with them.” (Site 5: midwives)

“The clients are quite happy to answer these. The ladies I’ve had have been quite forthcoming with their history.” (Site 2: midwives)

However, as we found for some midwives, some parents do not understand the difference between their nationality and their family origins. In such instances, midwives have difficulties asking parents about their family origins, especially when they have people from ethnic minority backgrounds who are British but do not differentiate their nationality and their genetic ancestry.

“I have so many [ethnic minority patients] that get upset because I have had so many ladies tick “British”. They view themselves as British but then I say it’s just origins. But many are so westernised they say: “Sorry, I am not from Pakistan.” It’s very hard.” (Site 2: midwives)

“They don’t always understand the difference between ethnicity and nationality, so you have to explain that to them sometimes.” (Site 5: midwives)

Recommendations

- There is a need for public health education and health promotion to support the implementation of the Screening Programme.
- Structures should be put in place so that most pregnant women have access to information leaflets on SC&T before meeting their midwives. However, midwives should not rely on the fact that patients have read the leaflets. Their description of the SC&T should be as detailed regardless of whether the mothers have read the leaflets or not.
- The SC&T leaflet needs to be made accessible in a variety of different languages to midwives. Where already available, this needs to be advertised more widely to midwives.
- Midwives need to receive training on how to make it clear to patients that they are concerned with genetic ancestry, not with ethnicity or nationality. Midwives need to acknowledge with the patients that they are British citizens and that this is never in question, while probing for their family origins.

6.7. Screening of baby's father

Across all sites, there were variations in the understanding of the pathway concerning the screening of fathers. Most midwives did not have copies of the algorithm and some were unclear about when fathers should be offered screening.

“The only thing that would be useful to know is who do you screen? And I know that you screen the dad but before I always used to screen the mum. You should be told step by step what to do. Maybe a card with a summary on it would be very useful?” (Site 1: midwives)

Across all sites, some midwives were unclear about a number of issues in relation to screening of the baby's father. In some sites, there was an assumption that if the mother of the baby or the father of the baby were from any “high risk” group according to the FOQ, then the father's blood had to be taken and tested immediately, regardless of the blood test results of the partner.

“I have had two blokes that I haven't bothered testing them because they weren't there so I thought we'll see what comes up on the woman's test and if there's anything funny there we can get the father tested. But normally, the father would be tested if he or the mother is in a yellow box.” (Site 1: midwives)

“M1: It's usually when the partners need screening that I think you find more resistance. Isn't it really? They don't want to get their blood taken and if they do want it done, they want you to do it and obviously we can't because we're not covered to test, which is silly really.”

M2: Actually I think that's when we probably fall down because I don't think half of them then get themselves screened when they should, because after we've gone from the booking, there's no push till we next see the lady, and if you booked them at 12 weeks, then its within our guidelines that we won't see them again until 22 weeks." (Site 1: midwives)

Apart from the confusion over *when* fathers need to be screened, midwives are also unclear in some instances about the practicalities of getting the fathers' bloods (whose role it is, where this should be done, etc).

"We may have a scenario where the mum is based at one GP surgery but the partner is somewhere else. So how do you organise that blood test?" (Site 3: midwives)

"If as midwives we need to be providing some form of healthcare to the fathers, I think that we need to address that because it isn't in our remit...I think it is a little bit outrageous just to assume that we are happy to do it." (Site 6: midwives)

"It's a bit of an issue if the husband has to have blood taken. Although midwives are not supposed to take men's blood because we are not licensed to do so, I can do the honours if you like!" (Site 1: midwives)

Some midwives also reported that they did not know how to ensure that the blood sample they took off a baby's father would be matched with the blood sample taken off the same baby's mother.

"Whether we are told or not, I don't know, but I write on the blood form, if I've done a screening with a partner, I would write partner of the mum's name, the mum's hospital number and why we are doing the screening. But I would imagine that some people don't do that. The haematologists must be getting blood forms and not know why, who it's connected with, and what they're supposed to do with them". (Site 1: midwives)

"The thing I didn't know is what to do if we got a lady who was picked up as a carrier and the partner's blood needed to be taken. It is difficult to marry the two results." (Site 2: midwives)

There are unresolved issues with respect to the screening of fathers. Relations with primary care providers need to be clarified.

Recommendations

- Clarify to midwives the process for offering screening to fathers.
- It may be good to produce an algorithm for midwives based on the one that was published in the journal of the Royal College of Midwives and printed on the reverse of the FOQ.
- Ensure training covers the taking of father's bloods. Provide guidance about the pathway to be followed when fathers' blood samples are needed.
- Ensure that the interface with primary care for taking the bloods of fathers has been worked out.
- Establish a clear mechanism to match the parents' blood tests.

6.8. Access to spare Family Origin Questionnaires

Finally, a number of midwives working in the community struggled with getting hold of spare copies of the FOQ when their patients' files did not already contain a questionnaire.

"The problem I have in the community is where do you have to collect the forms from if you are caught offhand? It can be irritating if you haven't got additional ones." (Site 6: midwives)

"I've been stuck without spare ones. Luckily they were not too complicated so I could just fill the forms in afterwards. But that could be a problem." (Site 3: midwives)

6.9. Conclusions

This chapter reported on a number of key issues which affect the validity of the information collated by midwives and which could impact on the smooth running of the Screening Programme. These include: the limited knowledge and understanding midwives have of Sickle Cell and Thalassaemia; the different strategies midwives use to introduce the Screening Programme and the Family Origin Questionnaire; the sporadic availability of information leaflets to expectant parents (especially in minority ethnic languages) prior to meeting with the midwives for their booking; the attitudes of parents-to-be towards the Screening Programme, the FOQ and the disclosure of their family origins to midwives; the misunderstandings and difficulties faced by midwives in relation to the screening of fathers; and the problem of obtaining spare copies of the FOQ for midwives working in the community. Recommendations have been made in relation to all these issues.

7.0. ORGANISATIONAL FACTORS LIKELY TO IMPACT ON THE IMPLEMENTATION OF THE SCREENING PROGRAMME

7.1. Introduction

The remit of the study was to focus on the layout, presentation, content and use of the Family Origin Questionnaire. However, in the course of the research, it became clear that a range of organisational and logistical factors are also critical to the success of the SC&T Screening Programme. Thus, this section reports on the organisational and logistical factors in the various pilots areas which, according to those in charge of implementing the Screening Programme (in antenatal departments and haematology laboratories), are likely to have a significant impact on the success or otherwise of the Programme.²

7.2. Staffing issues

7.2.1. Laboratory reception staff

Laboratory reception staff³ are responsible for sorting out the completed FOQs, together with the antenatal blood request forms and the blood samples that are sent to laboratories for analysis. Laboratory reception staff need to identify the samples that pertain to antenatal care and that require haematology testing in order to dispatch the samples to the right laboratories and biomedical scientists. They are an essential, but overlooked, link in the chain of staff who are involved in the Screening Programme. Mistakes from them could result in many samples not being screened.

“The people who just de-bag and label up, they don’t have degrees or any medical background at all. They just basically take samples out, match them up with the forms, make sure all the details are correct and label them up for processing, mark them up for whatever test they require. That is where we are having the most problems, getting those people to understand the questionnaire.” (Site 7: biomedical scientist)

“Reception staff don’t always grasp what they are supposed to do with the samples.” (Site 2: biomedical scientist)

“We had quite a few issues with our reception staff at the beginning because they didn’t know anything about the Programme and couldn’t quite work out what to do with the samples based on the forms, you know with the “declines” and “the opt ins”.” (Site 3: biomedical scientist)

² The evaluation of the pilots is exclusively *procedural*. It does not discuss the actual effectiveness or the outcomes of the Screening Programme. Any such discussion would require the possibility of matching data from both the antenatal and newborn Screening Programmes to determine whether some babies are born with the condition who were not detected during pregnancy.

² The study did not include interviews directly with laboratory reception staff. Their experiences are therefore only reported through the perspective of consultant haematologists and biomedical scientists.

Reception staff therefore need to be aware that the Screening Programme is being implemented and to become familiar with the FOQ. A very simple flowchart or step-by-step description of what to do with the forms and the blood samples should be developed for them.

Recommendation

- Laboratory reception staff should receive basic training so that they are aware of the Screening Programme as a whole and of the FOQ in particular, and that they know what to do with the samples attached to the completed FOQ.

7.2.2. Clerical staff

Haematology laboratories in all pilot sites commented on the shortage of clerical staff to manage the administrative burden generated by the Programme. The requirements are mainly for staff with relatively low qualifications who can handle the routine full blood count (rather than for highly qualified bio-medical scientists who can follow through the entire screening algorithm, operate the machinery, interpret the results and report on them), who can input results into the IT system, and who can chase missing information.

“It’s time-consuming. We have a shortage of support staff and overqualified staff have to go through all of these forms. We’re getting a hundred a week and we struggle with processing it all. We need another clerical member of staff.” (Site 7: Biomedical scientist)

“There’s been quite a lot of administrative burden within the Department. We need clerical support to deal with the increased clerical burden and to free up our more qualified BMS staff.” (Site 5: consultant)

“They are time consuming to go through, cos we’re looking at each one individually and we’re looking at the MCH and the patient’s ethnic origin. If the MCH is less than twenty-seven, we add on a haemoglobinopathy screen and a ferritin to look into it. Then, having added on those screens, we then need to find those samples to do those with, which is also time-consuming. We also need to fish out the original request form to look at and, again, that is also time-consuming. So the admin side of this has snowed us under.” (Site 5: biomedical scientist)

Most sites recognise that the need for greater administrative support is linked to some extent to the fact that some midwives are misusing the “opt in” clause and requesting far too many tests for women in low risk groups, as well as to the monitoring processes required by the pilot itself. However, they still believe that shortage of clerical staff will remain a problem when these issues are ironed out.

Recommendations

- Training for midwives should explain in detail when and why to use the “opt in” clause to reduce the workload associated with mothers in low risk groups opting to be screened when the clinical need for the test is minimal. This would help cut down on the clerical work generated by the Programme.
- The Screening Programme should explore the possibility of automating the screening process as far as possible, through better IT systems.

7.2.3. Staff motivation and commitment

As a general rule, the staff involved in SC&T antenatal screening were positive about the Programme. As discussed earlier, most midwives were happy to provide pregnant women with greater information and greater choice, and most haematologists felt that the FOQ provided them with more reliable data through which to interpret results of the full blood count and that the questionnaire generally “made their life easier” by cutting down the amount of time spent on “chasing partners” to obtain information of their family origins.

However, in some sites, there was also a sense that the programme was not a high priority at the local level and that clinical needs may not justify the additional workload generated. This was felt both by midwives and by biomedical scientists and consultant haematologists. Some **midwives** argued that the SC&T Screening Programme was taking up valuable time during their booking, which they would rather allocate to “more important” issues.

“The booking takes an hour. It is not a quick procedure and if you want to give the information properly you need to try to cut down time from other areas. It really is a squeeze to fit this into the hour.” (Site 3: midwives)

“I’d rather take time to discuss diet, smoking, exercise and stuff that’s important for everybody really.” (Site 2: midwives)

Some **haematologists** and **biomedical scientists** were not convinced of the relevance or importance of screening for SC&T in their Low Prevalence area either.

“I don’t think we ever had a positive trait from this population. So you wonder whether it’s really worth screening all those people and being snowed under as we are.” (Site 7: biomedical scientist)

“From the funders’ perspective, “Low Prevalence” means that this issue is of extremely low relevance. In the past 12 years, we’ve had no births with any form of significant disease. So it’s not even a question of finding the needle in the haystack. Arguably there are no

needles there. If you were a commissioner, it would be difficult to justify prioritizing this Programme.” (Site 5: consultant)

The lack of perceived relevance of the Programme in Low Prevalence areas – especially when it is coupled with already long booking appointments for midwives, and with staff shortage and insufficient access to equipment in laboratories - leads to lower commitment, lower motivation and lower staff morale.

“It’s not always easy to motivate the midwives about this because they already have so much stuff to cover during their booking.” (Site 6: ANC)

“You cannot really push people to do something that they are actually not interested in and don’t see any point to. They just get to a point where they do get fed up. That’s what the situation here is.” (Site 7: biomedical scientist)

It seems reasonable to assume that the Low Prevalence areas which are included in the sample may, as a whole, be more positive about the Screening Programme than other areas, since they volunteered to take part in the pilot. The Screening Programme may have to address low commitment and low morale in many areas, especially where the prevalence is indeed very low and where staff and technical resources are very limited.

Recommendation

- Issues of low commitment and staff motivation are likely to be relatively frequent in “Low Prevalence” areas. This could jeopardise the successful implementation of the Screening Programme nationally and will have to be addressed.
- The low priority accorded to the Programme may make it necessary to ring fence budgets so that funding does not get diverted to other issues deemed more important.

7.3. Technical issues

7.3.1. Adequacy of laboratory equipment

It is clear from the study that without adequate equipment (i.e. HPLC analysers) to carry out the screening tests, laboratories will not be able to handle the workload generated by the Programme.

“The main problem is having an instrument that can cope with the workload.” (Site 7: Biomedical scientist)

“Places where the numbers of these tests are very low and the machinery is ancient or unsatisfactory and there is a queue of other people wanting to use the machinery won’t have the facilities for this.” (Site 4: consultant)

“We had a few months of using the old technology, which completely snowed us under.” (Site 5: biomedical scientist)

“There are some four other hospitals within the region that are not doing HPLC at the minute. They’re using gel. They could never cope with a programme like that.” (Site 2: consultant)

7.3.2. Shared laboratory equipment

In only two of the seven pilot sites did biomedical scientists have regular and sufficient access to HPLC analysers to carry out their work for the Screening Programme. Those who had sufficient access to HPLCs to meet their needs were generally satisfied with the Screening Programme as a whole.

“We do have two [analysers] so we can use one for A1C and one for haemoglobin and thalassaemia screening. So we don’t have an issue of sharing equipment. We’ve got good laboratory facilities here, with good equipment and staff that are keen and involved.” (Site 4: consultant)

In all other sites, access to laboratory equipment was limited because HPLC analysers were shared with other departments. Sharing equipment is riddled with problems. It means that particular time slots are allocated to each department (with haematology usually being allocated only one or two days a week), thereby increasing the turnaround time for reporting the results of the tests to pregnant women and forcing existing staff to work extended hours and over the weekends as a matter of routine. Much time is also wasted resetting the equipment so that it meets the requirements of haematology screening.

“I have been pushing for another analyzer for months and months now because I cannot manage this amount of work in one day. Before you start making all these wonderful screening programmes up, you’ve got to make sure that everything is in place in the pathology section. At the moment, we share our instrument with biochemistry and I get it one day a week on a Friday. The turnaround time for processing the antenatal work is three days, so obviously we are not meeting that deadline because we only process the samples on a Friday.” (Site 7: biomedical scientist)

“Sharing equipment proves hopeless. Specifically, the equipment needs recalibrating to be set up to do your haemoglobinopathy work and that ties in with a completely unacceptable turnaround time. So you might think that we’ve got the hardware there, we can share the use of that, but it will rapidly become clear, as it did here, that sharing

technologies with others is riddled with problems and that labs need their own HPLC.” (Site 5: consultant)

“We are hoping to have our own dedicated instrument because at the moment we borrow it once a week from Biochemistry and it’s not brilliant sharing it because of the turnaround times expected within the pilot scheme cannot be met. There is an expectation of a three-day turnaround time, when the best we can do is once a week.” (Site 2: Biomedical scientist)

“We’re having to leave the HPLC running over night but if there’s a problem with it during the night, nobody’s going to spot it and then the samples are going to be too old to give the information you need because then you’re looking at maybe not being able to get somebody onto the machine for another week. So that’s a very big problem for us.” (Site 7: Biomedical scientist)

The very process of resetting the HPLC analyser is complicated, time-consuming and requires an experienced member of staff to do it.

“It takes us about an hour and a half each time to get the machine ready for our specifications because we share it with biochemistry and they have their own set up. It’s complicated and it takes an experienced person just flushing through the machine and making sure that calibres are working and controls are working and the temperatures are set okay... After that, it’s quite easy, but it’s a temperamental machine and there’s not that many people in the lab who know who to operate it.” (Site 7: Biomedical scientist)

Recommendation

- The successful implementation of the Screening Programme will require sufficient access to HPLC analysers. The NHS SC&T Screening Programme will need to give consideration to laboratory equipment.
- Trusts in Low Prevalence areas may consider purchasing centralised HPLCs to be accessed by all relevant users in the region.

7.3.3. IT systems

Across the seven pilot sites, there were enormous discrepancies in the level and quality of IT support for the Screening Programme. One site was fully computerised and had a system which linked together the Antenatal Department and the Haematology Department.

“The key for us has been the Hicks system [IT]. I think that’s what’s made this a huge success for us. Because the midwives simply cannot

get access to any of their ladies' files unless that have completed their questionnaire and entered it into the Hicks system. So you have 100% completion rate because of that. So that's made a huge difference on the antenatal side, but it's also linked with haematology. We all share the same system. It's bloody marvellous!" (Site 1: SC&T Screening Coordinator)

"It's been quite easy around here, possible because we've got a very good computer system whereby Pathology and Midwifery are linked up. You can just look up the results almost immediately. Everything is accessible straightaway, in the same format, by everybody. Without good IT support, this would be a pain." (Site 1: biomedical scientist)

At the other extreme, one site had virtually no IT system at all to support the Programme.

"I mean we haven't even got a PC! We just got this PC here just recently. I think it arrived at the end of last week. The whole computer side of things is in a mess and that creates its own problems. Without a PC, without the right programmes on it, and without a clerk, the programme can't run successfully." (Site 7: biomedical scientist)

"We have no IT support full stop in this place. We run such an outdated system. We're always stuck manually sorting things out with the consultants." (Site 7: biomedical scientist)

The most common situation, however, was for the various Departments to have unrelated or incompatible systems.

"The other problem is that the Antenatal data system doesn't talk to the laboratory system. You can't pull data across." (Site 2: consultant)

"Maternity uses one IT system, we use another, and neither of them seems to be the master system, so we can overwrite each other's data... We would need to capture patient information into a central computer that then feeds into both the Antenatal Clinic's system and my system." (Site 5: biomedical scientist)

"The IT support side is a major pain really. Everything else works fine, but the database is a fairly big problem because our antenatal hospital computer is not linked at all to our laboratory system. You can't get them to talk to each other, so you've got to manually input all the data." (Site 4: biomedical scientist)

"Getting everything to be paper free, to be electronically done, that I think is quite a priority because we are generating a lot of paper reports with the FOQ." (Site 5: consultant)

Having good IT systems saves time and reduces the scope for human error. It could significantly contribute to reducing the turnaround time. If implemented in the same fashion as in SITE 1, it could ensure that completion rate for the FOQ are near 100% in all sites.

Recommendation

- The Screening Programme will need to consider the need for IT resources to support the Programme. In one pilot site, a successful IT system was implemented. This could be used as good practice and replicated in other areas.

7.4. Coordination and communication

When asked about the main lessons that they had learned from the pilot and the recommendations they would wish to make to other sites, **nearly all interviewees** mentioned the importance of having excellent communication and coordination between the key stakeholders involved in the Screening Programme.

7.4.1. Coordination within Antenatal Clinics

It is critical to have one dedicated person associated with the SC&T Screening Programme to coordinate all aspects of the Programme at the local level. Midwives need to know who to turn to ask any question they may have in the implementation of the Programme. Having a dedicated person also facilitates both internal (within midwifery) and external (with specialist genetic counsellors, haematology laboratories, GPS and the national Screening Programme) communication.

“[The ANC] is absolutely marvellous. We know we can all turn to her when there’s something we’re not entirely clear about.” (Site 7: midwives)

“[The ANC] handles all the positives and the more complicated cases. That takes a lot of the pressure off us.” (Site 2: midwives)

“I’ve been in pretty close contact all the key people involved in this to tie up loose ends. Midwifery have been pretty good. If I had to half raise my hand to say anything about problems with the FOQ in midwifery, they are down on them like a ton of bricks. They really are very good, very pro-active as well. I’ve got one central person I can contact, but I’ve got a list of all the midwives and their mobile numbers, so can always chase them up myself if there’s anything urgent or whatever.” (Site 4: biomedical scientist)

7.4.2. Coordination within haematology laboratories

For much the same reasons, a similarly coordinated approach needs to be developed within haematology laboratories.

“With [X] being the Coordinator and our link person, if I’ve got anything I need following-up or clarifying, then I just get in touch with [X]. It’s the same on the haematology side. I see the Consultant Haematologist and we sort things out.” (Site 2: biomedical scientist)

“You need good, solid communication between Consultants and yourselves, so you’re not left high and dry with the situation.” (Site 4: biomedical scientist)

7.4.3. Communication between key stakeholders

Good internal coordination facilitates good communication between stakeholders, as named, dedicated people act as points of contact for other departments.

“The main lesson is that all those involved in this need to know who to turn to to get the information that they need.” (Site 5: ANC)

“The fact that we can speak to the consultant directly. He’s more than happy to speak to midwives and he’s very midwife friendly, he’s got a good strong link with the midwifery services.” (Site 4: ANC)

“They have a lead technician who is very good at keeping an eye on things. He lets me know when there are problems. They are very, very good.” (Site 1: SC&T Screening Coordinator)

“If they find a form that they are not happy with, or there is something missing they will contact me, straight away...we both know we are at the other end of the phone.” (Site 2: ANC)

“The most important thing is having one or two dedicated staff that sort of at my end are fairly persistent at sorting things out. So when you find a problem, you actually chase it back to its source and find out why it had happened and rectify it as soon as you can.” (Site 4: biomedical scientist)

“You need a named person to be able to contact in Antenatal. You need a lead Clinician or Haematologist to make the decisions and give advice.” (Site 2: biomedical scientist)

“What has worked well has worked well mainly because midwifery and the lab have worked very closely together. That’s probably the critical thing that you need. The Antenatal Clinic know who to contact, the lab know who to contact. Everybody is very aware of what the purpose is and how to identify high-risk couples and if they have any issues, they know who to get hold of.” (Site 2: consultant)

7.4.4. Central support from the Screening Programme

Coordination also needs to be established between each site and the NHS SC&T Screening Programme nationally. The Programme provided much valuable guidance

to the sites by a variety of means, including websites, information leaflets, Regional Coordinators and group meetings in London. These were deemed extremely helpful and it is hoped that this level and range of support will continue throughout the life of the Screening Programme, but especially in the first year of the national roll out to “Low Prevalence” areas.

“I would presume there will still be a committee of people ready to help out centrally, because that is critical really.” (Site 5: ANC)

“All of the information the laboratory required to run the pilot scheme, we could download from the Programme’s website - what was expected of the laboratory, the criteria we have to meet, accreditation, standard operating procedures, what type of equipment you were expected to be running the pilot with, etc. That was very helpful and should be given to all new sites now.” (Site 2: biomedical scientist)

Some interviewees were adamant that local hospitals would need central support from the Programme, but that this should take the form of advice, information, guidance, rather than a very prescriptive approach. They felt that guidance was required to support local areas and to standardise working practices across sites as much as possible, but that each hospital would have to make decisions based on their own circumstances.

“Each area will have to work out how they are going to do it themselves and just listen to how we’ve done it, listen to some of the problems that we came across so they don’t fall into the same pitfalls. Every region’s got a different set of midwives, a different set up of labs, a different kind of population and everything. Some of the very, very, very low prevalence areas might actually refer their screening to another site or clump two or three sites together to get it done in a timely fashion, but again that’s got to be decided on an individual basis. So I think the Programme can’t be too prescriptive, but they need to provide the guidance, advice and support that various areas say they need. That could be going out there and doing any training that we feel the need, or just sitting on the end of the phone or an e-mail for people to phone up and say: ‘This is happening, what do you suggest?’ But at the end of the day, the details need to be worked out at the local level.” (Site 4: biomedical scientist)

“The support will have to vary from place to place. You’d have to look at it on an individual basis. There needs to be a degree of freedom for the hospitals to decide what is best for them, according to their particular set up.” (Site 5: consultant)

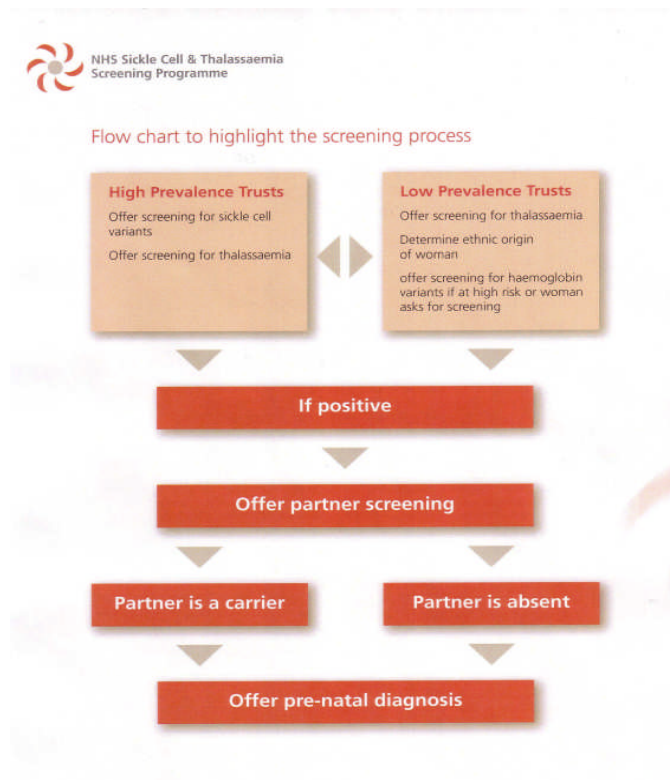
Recommendations

- All antenatal clinics and haematology laboratories sites should have a dedicated, named contact person in charge of implementing and administering the Screening Programme at the local level.
- Communication across stakeholders in each site needs to be facilitated.
- Central support from the NHS SC&T Screening Programme must be ongoing but flexible, to balance the need for standardisation and the need to tailor support to local circumstances.

7.5. Algorithms

The implementation of the SC&T Screening Programme is relatively complex. To ensure that due processes are followed by all stakeholders across all areas, it is critical that detailed algorithms are developed for, distributed to, and used by each group of stakeholders.

7.5.1. For midwives



The Screening Programme produced an algorithm to support midwives as they complete the FOQ, as part of an information package for midwives. However, only a very small proportion of the midwives interviewed had actually seen this information

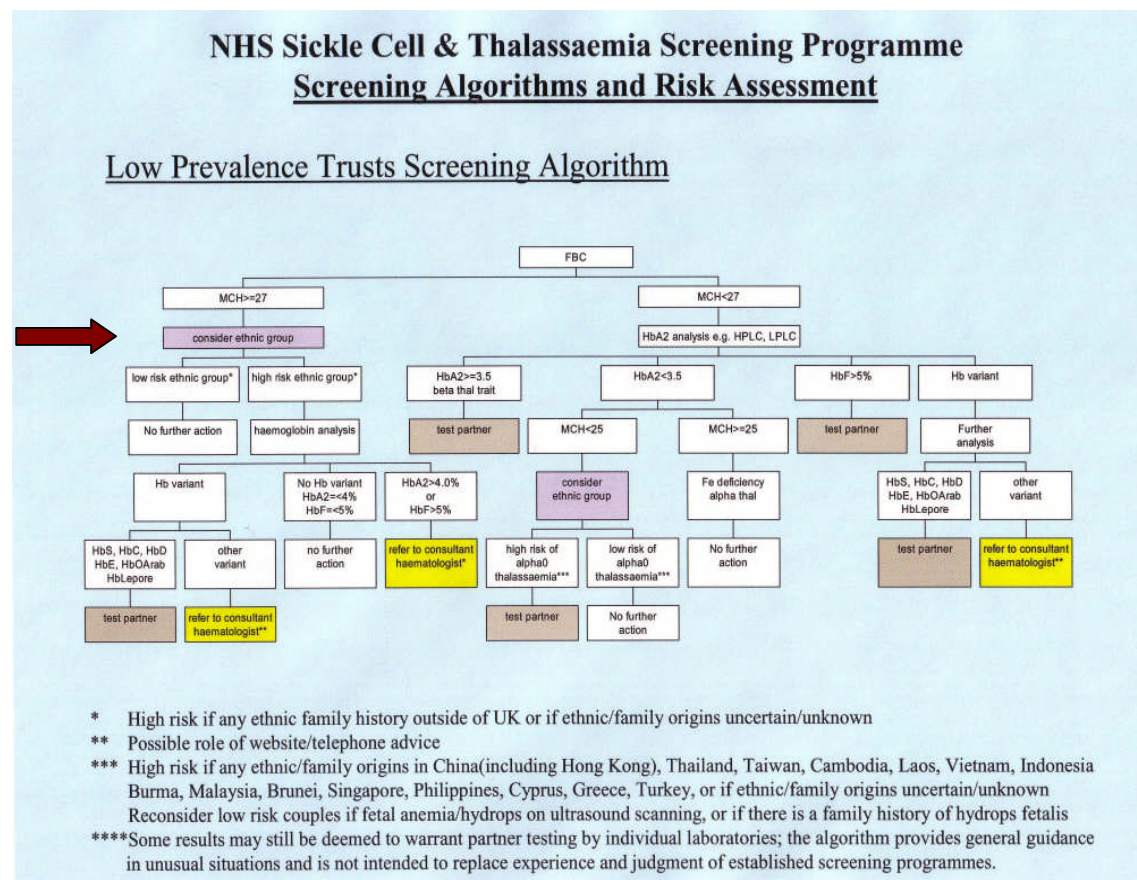
package and the algorithm within. Those who had seen it found it very useful, but also believed that the algorithm could be more detailed. For instance, some midwives wanted the algorithm to indicate that they should show the person the chart of risk levels in each group. Most midwives wanted the algorithm to contain “bullet points” on the specific dimensions of the Programme and of SC&T that they should discuss with the parents. Some also felt that the word “partner” may be confusing when the partner was not the baby’s father.

7.5.2. For laboratory reception staff

As mentioned earlier, there is a case for developing a very basic flowchart, for laboratory reception staff to ensure that they know what to do with the blood samples and the completed FOQ, and where to dispatch these.

7.5.3. For biomedical scientists

The Screening Programme developed an algorithm for biomedical scientists to clarify and standardise the screening process, and to allow less qualified staff to handle confidently at least parts of the screening process, while leaving the more difficult and rarer decisions to more experienced biomedical scientists and consultants.



By all accounts, this algorithm works extremely well. It was slightly amended by one site and then adopted by many sites.

“The algorithm just works a treat. It really streamlines it and makes it very easy.” (Site 4: biomedical scientist)

“The algorithm works fine. It’s mapped out quite clearly on the algorithm what course to take, and I have full access to our lead Consultant Haematologist where there is any sort of queries involved. I haven’t found any problems at all with it. Fairly straightforward.” (Site 2: biomedical scientist)

“We have basically adopted the algorithm that other sites are using and that has an end point to it where it says, “test partner”, or “no further action needed”, or “refer to consultant”. There are ten different end points which are numbered, which is the kind of conclusion of the algorithm that the lab staff have followed. So then it’s easy, all that we do on the computer is type in those codes, those numbers, and then it expands and we can retrieve the whole process.” (Site 1: biomedical scientist)

However, one point in the algorithm (where the dark brown arrow has been inserted) may require clarification. Currently, the algorithm simply states “consider ethnic group” without specifying whether this pertains to the ethnic group of one parent or both parents. Different laboratories have evolved different protocols over this issue.

“We are screening low risk women with high risk partners [...] The beauty of the FOQ is now you’ve got the partner’s family origins, and that way we can be a little bit more selective. So a UK woman that we wouldn’t normally have been screening, we are now going to screen because her partner is Caribbean and that just puts down the odds of having one that slips through the net, because you do get the occasional HP variants in Caucasians.” (Site 4: biomedical scientist)

“But we don’t screen if one parent is not in the high risk group because you need both, don’t you, in order to have an affected birth.” (Site 7: biomedical scientist)

Recommendations

- Diffuse algorithm amongst midwives to ensure all have access to it. Clarify the meaning of “partner” in the algorithm. Provide more detailed guidance in accompanying notes.
- Produce a brief flow chart for laboratory reception staff to ensure that samples are not lost and that they are processed in a correct and timely fashion.

Recommendations (*continued*)

- Diffuse widely the haematology screening algorithm. Clarify that screening should be carried out (if not declined) even where only one parent is from a high risk group.

7.6. Timing of implementation

Many across the various groups of stakeholders commented on the fact that the timing of the implementation of the Screening Programme in their pilot area had been problematic, leaving them with little time to prepare adequately ahead of “going live”.

M1: The other thing that’s caused a lot of debate around the table amongst midwives was the timing of the whole thing.

M2: Yes. The timing of it was wonderful. That was a joke. It was planned but it appeared over night.

M1: One minute it was just being thought about and the next minute we had to start doing it.

M2: “Oh, by the way, we are starting it tomorrow!” I heard that there was suddenly some pressure to get it off the ground.

M1: Which is why I think there was such a muddle to start with, because people were being asked to introduce something that they really didn’t have sufficient information on.” (Site 5: midwives)

“You need to let everyone know well ahead of time when things will go live so that all the different aspects of it are working well. We were so late here that there was no way I could organise a kind of centralised training session for my midwives so I had to speak to each one of them individually whenever I could catch them.”(Site 1: SC&T Screening Coordinator)

“The main issue I would say to any site is to start early. Formulate a team together and get things going as early as possible.” (Site 3: ANC)

“The whole thing was so rushed through without any preparation, any support, any resources, we couldn’t prepare for it properly either.” (Site 7: biomedical scientist)

Recommendation

- All areas should be informed well ahead of the implementation of the Screening Programme of all the requirements of the Programme locally so that adequate preparations can be made.

7.7. Monitoring

Finally, to ensure the success of the Screening Programme, it is critical that every effort in the early month of the implementation to monitor and address any “teething problems” that could compromise the quality of the Programme. ANCs, SC&T Screening Coordinators and haematologists should keep track of emerging problems and develop mechanisms to overcome them.

“I double-checked every single questionnaire to make sure that things made sense, basically, like not having the Screening Declined ticked for people in low risk groups, and getting the midwives to staple the forms without putting them inside the plastic bags, or... You can’t pick everything up but you can get rid of a lot of problems even within the first few weeks.” (Site 5: ANC)

“I think the most important thing is having one or two dedicated staff at my end that are fairly persistent at sorting things out. When you find a problem, you actually chase it back to its source and find out why it has happened and rectify it as soon as you can. [...] We kept a note as well on midwives who weren’t filling forms in properly. We logged a name on a little sheet and if we got a repeat offender, we phoned them and said we’ve noticed this problem or I write on a little form what the “crime” was that they committed and how they’re supposed to fill it in, and then that goes back with the report, and that’s been extremely effective.” (Site 4: biomedical scientist)

Recommendation

- Ensure that dedicated staff are properly resourced to monitor the early implementation of the Screening Programme, as “teething problems” are inevitable but can usually be rectified easily.

7.8. Conclusions

This chapter has highlighted a number of organisational factors that are likely to impact on the success of the Screening Programme when it is implemented in Low Prevalence areas nationally. In particular, it singled out the role of staffing issues (the need for sufficient clerical staff to handle the additional workload, the involvement of laboratory reception staff in handling and dispatching the samples and FOQ, and potential issues due to low commitment and low morale amongst staff in Low Prevalence areas and in under-resourced hospitals); of technical issues in laboratories (the need for ready access to adequate machinery, the problems associated with the sharing of equipment across departments, and the need for IT systems to support the Programme); of coordination and communication (both within and across the departments involved in the Screening Programme, and between sites as a whole and the central Screening Programme in London); the importance of clear algorithms and flowcharts for all key staff (midwives, laboratory reception staff and biomedical scientists) to standardise working practices; the timing of the

implementation to allow for sufficient preparations to be made in each site; and finally, the need for monitoring the workings of the Programme, especially in the early days of the implementation, to rectify initial problems. Recommendations were made in relation to each of these factors.

8.0. TRAINING

8.1. Introduction

There were wide variations between sites in terms of the training offered as part of the SC&T Screening Programme. In some sites, training had been extensive and detailed, delivered in a timely fashion in relation to the start of the programme locally, offered at various convenient times and in different venues, widely attended by relevant staff, supported by high-quality written documentation and visual aids, and subject to systematic evaluation by attendees. In other sites, training was minimal and delivered on a one-to-one, *ad hoc* basis and covered only the most basic aspects of the conditions, of the populations at risk and of the use and administration of the FOQ.

The study showed that the quality of the training had a very significant impact on the attitudes of staff to the Screening Programme, on their motivation to deliver good quality screening, on their knowledge and understanding of the conditions and its impact, on their confidence and morale, on the validity of the Family Origins data they gathered and processed and, generally, on the overall success of the pilot locally.

The study also showed that most of the training had been directed at midwives, with biomedical scientists usually having received a basic introduction to the screening algorithm and being expected to “get on with it”. Reception staff had received no formal training at all in any of the sites.

Based on this evidence, this final chapter discusses training issues in relation to the key groups involved in the Screening Programme: midwives, laboratory reception staff and biomedical scientists.

8.2. Training for midwives

8.2.1. Aims of the training amongst midwives

All groups of stakeholders believe that key to the success of the SC&T Screening Programme is to have a team of midwives who are well trained to implement the Programme.

“If you can get the midwives on your side then you will succeed in whatever it is you’re trying to do. But if for any reason they don’t see the point or they can’t understand what it is you want to do, then you might as well go and do something else because you’ll struggle! So you’ve got to make sure that you bring them along to training and that you make the training interesting, relevant and varied.” (Site 4: consultant)

“The real training is needed for midwives. They are at the front end, the ones who are doing most of the work. If you don’t get them doing it right, the rest falls apart.” (Site 3: biomedical scientist)

“We spent a lot of hours training midwives, a hell of a lot of time. But it definitely paid off. It’s paid back tenfold.” (Site 4: biomedical scientist)

“The key to our success was the training we set up. Not only did we tell all the midwives what they’d got to do, we told them how they’d got to do it, and we told them why they’d got to do it. And that’s not just a ten minute explanation of tick these boxes. We showed them the form, we told them the best way to do it, we told them one or two things not to do. We got them committed to the whole Programme. I stood up there and enthused over it and said how much time it would save and how harmless it would be, and please, please do it, and they did.”(Site 4: biomedical scientist)

Recommendation

- The aims of the training should be to ensure that midwives are sufficiently knowledgeable about the conditions to enable parents to make informed choice, are motivated to take part in the Programme, understand the function of the FOQ in identifying parents who are at high risk, are able to administer the FOQ properly, and know where to find more information, if necessary.

8.2.2. Content of training

▪ Knowledge of SC&T

Midwives need to have a basic knowledge and understanding of sickle cell disorders and thalassaemia. They need to have enough knowledge to feel confident in discussing the Screening Programme and in answering basic questions from parents. They must be able to impart correct knowledge to parents, so that they, in turn, can make informed decisions about being screened or not.

However, it is crucial that this information is not too complex or technical. In their everyday duty, midwives cover strictly the basics when they introduce screening to patients and the questions they are asked are equally simple. In the rare cases when more technical and detailed information is sought, midwives need to know who can provide this information and have sufficient knowledge to understand what it means for mothers.

“There is no point in blinding people with science. Even though I’ve had a lot of training, it is not what I specialise in. So far I’ve been able to answer the questions that people have asked me and I know where I can go to take more in-depth answers for them.” (Site 3: ANC)

“I went to a training session and I just switched off completely after a while because it was all the minute details of molecular stuff and that wasn’t what I needed in my work, I felt.” (Site 1: midwives)

“We had a two hour session but it was all about conditions...it wasn’t about the actual issues that we really needed training on.” (Site 5: midwives)

Recommendation

- Training should give midwives a ready-made, concise description of the conditions: mortality and morbidity rates, causes, symptoms, “potential cures”, risk levels in various ethnic groups, reality of living with the conditions, reasons for screening, advantages of screening for those in high risk groups, etc. It is important to “humanise” the training so that midwives can relate and empathise.

▪ **Understanding of the NHS SC&T Screening Programme**

Midwives need to understand the new antenatal and newborn screening policies. They need to understand the rationale for the Screening Programme and the aims it seeks to achieve. This is particularly important as many midwives do not understand the relevance of the programme in relation to the populations they are screening and therefore may lack commitment to the Programme.

“A lot of midwives don’t really understand why we are doing it all. I think a lot of them think that this is just something that has come from on high that is not really giving anybody anything and there not really seeing this as actually giving women additional choice.” (Site 1: SC&T Screening Coordinator)

Recommendation

- Training should give midwives a ready-made, short description of the Screening Programme. The content could be based on the information provided in the “Information for midwives” document.

▪ **Understanding of the Family Origin Questionnaire**

Before midwives are introduced to the Family Origin Questionnaire, they need to understand the notions of “High Prevalence” and “Low Prevalence” areas. They also need to know how common Sickle Cell and Thalassaemia are in England. It must be stressed that people whose family origins are Northern European are at very low risk and that “opting in” for screening is not justified on clinical grounds alone, although this possibility is opened to parents.

“The workload has tripled. You’ve got people opting into the scheme, who wouldn’t have been considered for Haemoglobinopathy testing. That was due to the way the information was actually given out by the

Midwives in the community. [...] I've spoken to the [ANC] about the opting in problem and she spoke to her midwives about it and it's having a major impact. The numbers are reducing. There's less opting into the scheme now." (Site 2: biomedical scientist)

"I think in Low Prevalence areas, the additional workload would be manageable if the midwives were better educated as to what really constitutes a worthwhile investigation. Currently, we are getting too many tests because we're investigating inappropriate cases given the actual ethnic origin. So you could cut back on the seeming expansion in numbers, but you would have to have fairly global midwife education to achieve that." (Site 5: consultant)

Recommendation

- Training should explain the function of the FOQ in relation to the Screening Programme. Understanding the basic logic of the questionnaire – to identify people in high and low risk groups and to give them the choice of opting in or out of the screening programme – is the crux of the matter.

▪ Guidance on the administration of the FOQ

Midwives should then be taken through the FOQ section by section and given guidance on how to complete the form and where to send the various copies. As a general rule, this kind of information should be either preceded or followed by a clear rationale so that midwives know what they are doing, why they are doing it, and how they should be doing it.

"What we should have done is have a programme whereby midwives were introduced to the questionnaire, how to fill it out and were given scenarios for slightly more complex people." (Site 1: SC&T Screening Coordinator)

"Community midwives are people who want to know 'what am I going to say' 'what am I going to do'." (Site 5: ANC)

"I think you should tell them 'this is the family origin questionnaire, this is the reason and this is how you do it, let's go through it, stage by stage.'" (Site 2: ANC)

"We just got a basic introduction package for the midwives, just an overview of SC&T themselves, not the Family Origin Questionnaire. I don't think it was the most helpful training we could have had." (Site 2: midwives)

Recommendations

- Training should focus on the practicalities of completing the questionnaire and managing the forms and the blood samples. It should stress:
 - That midwives themselves should complete the FOQ
 - How to use the “Screening Test Declined”
 - The differences and similarities between ethnic group/ethnicity, nationality and family origins
 - The need to probe for two generations on each side of the family
 - What to do with people they cannot allocate to the nationalities listed in the FOQ
 - That “family origins” cannot be inferred from ethnic group, nationality or other available evidence (e.g. name, skin colour)
 - What to do with each copy of the FOQ
 - How to attach securely the FOQ and the blood samples
- Training could also provide examples of “poor practice” or common mistakes to be avoided, as well as examples of complex cases and how to deal with them.

▪ Guidance on how and when to test fathers

As discussed in chapter 6, many midwives are uncertain as to when and how they should take blood samples from the baby’s father. Some take the samples of all fathers who tick a yellow box. There are practical difficulties linked to convincing the fathers to book an appointment to have their blood taken, but also difficulties linked to the fact that midwives are not entitled to take blood off fathers themselves. Midwives have not been given advice on how to ensure that the blood samples of parents can be matched by laboratories.

Recommendations

- Training should cover when fathers require testing and emphasise that this is only *after* mothers have been found to be carriers.
- Training should provide practical guidance on how to ensure that blood samples for couples are matched.

8.2.3. Access to training

There were wide variations across sites in terms of the proportion of the midwives who had received formal training about the SC&T Screening Programme. In some sites, a significant number had missed out on training, either because training was provided at inconvenient times for them, because of sickness or because they were on annual leave.

“I was off sick for quite a while so it was quite a shock when I came back and found that we had to ask all these questions. It was something new and I had missed everything, all the training so that was a really bad period for me. [...] I had not offered it before and when I came back it was: “Right! You have to do these bookings and you have to ask them about all this now”. I was suddenly asked to inform somebody about a test that I didn’t know anything about.” (Site 7: midwives)

“M1: Did you have your training?

M2: No, it got cancelled. I don’t really know what I’m doing!” (Site 5: midwives)

All midwives recognised the value of good training and wanted to have access to more information to increase their competence and confidence with the Screening Programme and the FOQ. They wanted the training to be mandatory.

Recommendations

- Training should be mandatory.
- Training should be tailored to reflect the institutional set up of each site (sometimes offering large-scale, hospital-based training, sometimes offering smaller-scale, community-based training).
- Training should be offered at different times to accommodate the diverse working schedules of midwives.

8.2.4. Format and timing of training sessions

It is important to ensure that training sessions expose midwives to the perspectives of all key stakeholders in the Screening Programme. Short and varied sessions can be provided by Screening Programme representatives, Heads of Midwifery, Antenatal Coordinators, SC&T Screening Coordinators, Consultant Obstetricians, Consultant Haematologists, etc.

“It’s important to make the training interesting and to have a number of different approaches to the training. You need the medical approach, the midwife approach, the Department of Health approach, the haematology approach. You need to know why you are doing this, what you are doing, and how to do it.” (Site 4: consultant)

“Ad hoc” training based exclusively on the narrow needs of midwives and of FOQ completion without an understanding of the whole screening programme and process is insufficient. One SC&T Screening Coordinator had to resort to such minimal training and realised that it was woefully inadequate. Our own interviews and observations with midwives in this area confirm the negative impact – for quality of care as well as morale – of inadequate training. Many midwives in this area did not

understand the purpose of the Screening Programme and were not motivated to take part.

“Anytime I saw midwives I basically grabbed them and said you need to know about this and it was awful. It was an awful five weeks. I don’t think that’s generally how you’re meant to implement a project. But it’s how I had to do it in order to get around everybody in the short space of time we had.” (Site 1: SC&T Screening Coordinator)

The main barrier to the provision of good quality training is the fact that midwives are often based in the community, have different working practices and schedules, and that it is difficult to bring them together to attend formal sessions. Some overcame these problems by warning midwives well ahead of time and by providing lunch during the training sessions. Others resorted to providing a greater number of smaller scale sessions.

The timing of the training sessions also matters. In some pilot areas, midwives had received their training too long ahead of the Programme going live and had forgotten much of its content. In others, midwives started using the FOQ and only subsequently received any training. Ideally, training should be given just ahead of implementation, when perceived relevance is likely to be higher.

Recommendations

- Ideally, training should expose midwives to the perspectives of all key stakeholders in the Screening Programme: the National Screening Programme, Midwifery, Antenatal and Neonatal Care, Obstetrics, Haematology, etc.
- Training should closely precede the implementation of the Screening Programme in each area.

8.2.5. Ongoing monitoring and retraining

Some ANCs and SC&T Screening Coordinators suggested that one-off training sessions may not suffice and that, at least in the early phase of implementation, regular small sessions should be held to discuss common mistakes and to develop good practice. This would also enable the training providers to train those midwives who would have missed out on earlier sessions.

“In the early days, you need to audit the system regularly, to see where the problems are and take those problems back out and go through them again definitely. You need to have organised feedback sessions for your midwives. You just have to go out and retrain and educate and go into it time and time again. Unfortunately we have rotation on midwives and some of the midwives that weren’t on community when I went out to educate them all, have now gone out there. So really, you just need to do

it all the time and regularly send something out, to reiterate what they need to do.” (Site 2: ANC)

Recommendation

- ANCs and SC&T Screening Coordinators, supported by consultant haematologists and biomedical scientists, will need to monitor the success of midwives with using the FOQ and offer regular update sessions to clarify misunderstandings, rectify mistakes and diffuse good practice.

8.3. Training for reception staff

As mentioned in the previous chapter, laboratory reception staff will need to undergo basic training. In nearly all sites, there were unforeseen difficulties arising in this group, with reception staff being completely unfamiliar with the new Screening Programme. They did not know what the samples and the FOQs were about, and they had no idea to which laboratories they should send them.

“You need to have a worked out system for how you’re going to deal with the actual FOQs coming through your laboratory and how you’ll sort and handle the forms and the samples.” (Site 2: biomedical scientist)

“There were a few hiccups initially because the people on the reception desk weren’t familiar with the forms and what to do with them.” (Site 4: consultant)

“The people who just de-bag and label up, they don’t have degrees or any medical background at all. They just take samples out, match them up with the forms, make sure all the details are correct and mark them up for whatever test they require. That is where we are having the most problems, getting those people to understand the questionnaire.” (Site 7: biomedical scientist)

“All of the samples come into one big reception area, and it’s just like a madhouse because now there was an extra form which was this family origin questionnaire. And it would get stapled to the micro form, it would get sent to the transfusion centre. So they needed some training as well to explain to them what to do with this new form and the samples.” (Site 4: biomedical scientist)

Apparently, the Screening Programme had not put in place mechanisms to support them and mistakes were a regular occurrence.

Recommendation

- Training is required by reception staff on how to read the FOQ and understand the logic of the yellow and white boxed, and the “opt in” and “opt out” clauses.

8.4. Training for biomedical scientists

8.4.1. Content of training

The focus of the training for biomedical scientists is very different from that for midwives. Although they too require a general introduction to the Screening Programme and to the Family Origin Questionnaire as part of the Programme, biomedical scientists mainly need to be able to use the HPLC machinery to process the blood samples competently. They also need to understand and use the screening algorithm, and to interpret and report competently and confidently the results of the screening tests they are doing. Until staff are at ease with these different dimensions of their work, the burden remains on the shoulders of too few staff and the risk of errors is too high.

“Staff will need fairly comprehensive HPLC training.” (Site 5: consultant)

“If I am not here and [X] is not here either and the machine’s not working properly, then they’re not able to process the samples. It is just chaos. But that’s because I’ve only got two people who are fully trained. I really need everyone trained in the lab to use the equipment and rotate round there, so anyone can take over from anyone else.” (Site 7: biomedical scientist)

“More people need to know how to use the analyser.” (Site 1: biomedical scientist)

It is also critical that biomedical scientists be trained to understand the screening algorithm, to understand the results of the tests, to interpret any abnormal peaks, to know when and how to request partner testing or to turn to consultants when there is a real need for it.

“We picked things up as we went along but we could have done with some training. With like recognising peaks and things, I am fine with the most common ones, like the Ss and Cs, Es and Ds, the more straightforward things, but if you get to the really unusual variances of haemoglobin, then I would have to refer it to [a more senior person].” (Site 7: biomedical scientist)

“The difficulties arise when there is an abnormal. Most of the time, they’re able to follow through the algorithm, but many will lack the confidence to report the results. In our lab, there’s only three other

BMS staff who are confident enough to report and to do the tests from start to finish.” (Site 5: biomedical scientist)

“If they get different peaks, lab technicians will say: “What’s this?” They won’t know what it is. They won’t be able to report it if I’m not here. So that’s a problem. They lack the knowledge to report. They have to turn to me all the time.” (Site 7: biomedical scientist)

“We needed some training just going through the form and the flow chart. Cos what’s happened is that we all did it our own way or we kept repeating our questions. We’re never entirely sure what we are doing. It’s not been too bad but a bit of training would definitely have helped.” (Site 6: biomedical scientist)

“The tests just tended to get left to the people who knew what they were doing, whereas anyone really should have been able to check them off. It’s only a matter of checking if they come within the normal range, if they need the ferritin done, but it got left to just a few people. So I think some training would have been required to spread the burden otherwise people can just lack the confidence and leave the work for others to do.” (Site 7: biomedical scientist)

Recommendations

- The content of training for biomedical scientists should include:
 - A general introduction to the Screening Programme (as for midwives)
 - An explanation of the FOQ and of what to do with the forms
 - Guidance on how to calibrate the HPLC machinery for haematology testing
 - Guidance on how to use the HPLC machinery
 - Guidance on how to use the screening algorithm
 - Guidance on how to interpret test results
 - Guidance on how to report test results
 - What to do with complex cases
 - Contact details of key stakeholders

8.4.2. Access to training

As for midwives, it may be difficult to ensure that all relevant biomedical scientists have access to training, both because the shortage of staff makes it very difficult to free up anyone for training, and because most laboratories seem to operate on a “rotation” system whereby staff work for a short period of time in one department and then move on to another department before coming back to their initial laboratory. In some cases, a few months may have elapsed before staff come back. Any training they would have received is likely to have been forgotten.

“It’s a catch 22 situation: we don’t have enough qualified staff in place to be able to train other staff, because we cannot leave the laboratory.” (Site 7: biomedical scientist)

“All the BMSs rotate through on a two-weekly basis and I explain it to them at the time. But when they then come back a few months later – it could be four, five, six months since they did that – they’re feeling a bit rusty and possibly what we’re doing has actually changed. So there are very real training issues and those are because we’ve not had enough staff to enable me to take people away on training. There’s just been a lack of training opportunity because of the shortness of staff because every time I take a person away on training, that means something else doesn’t get done.” (Site 5: biomedical scientist)

“We got partial rotation. Some staff rotate across the three sections on a monthly basis, and other staff are fixed. It does make training a bit more difficult than if people were just in one section all the time.” (Site 1: biomedical scientist)

“The only training issue that there may be is the fact that the wider haematology staff that haven’t rotated through this department aren’t desperately aware of why we are doing it.” (Site 4: biomedical scientist)

Recommendation

- There is no immediate solution to the problem of staff rotation. Training will have to be tailored to reflect the institutional set ups of the various laboratories. However, it may be worth having “portable” information in the form of CD-roms that can be used more flexibly by staff, in conjunction with on the job training.

8.5. Conclusions

The success of the Screening Programme will largely depend on the quality of the training made available to the various stakeholders in the Programme. This chapter has provided a range of recommendations regarding the content, the format and the timing of the training required by each stakeholder group.

APPENDIX 1: INTERVIEW SCHEDULE FOR ANCs AND SC&T SCREENING COORDINATORS

NHS SICKLE CELL & THALASSAEMIA SCREENING PROGRAMME THE “FAMILY ORIGIN QUESTIONNAIRE”

INTERVIEW SCHEDULE FOR ANTENATAL CARE CO-ORDINATORS

The NHS Sickle Cell and Thalassaemia Programme is in the process of rolling out a Screening Programme for Sickle Cell & Thalassaemia throughout England.

Currently the Screening Programme is being piloted in seven areas, one of which is your NHS hospital. Before the Screening Programme is used nationally, we need to find out more about your experiences of having used the Family Origin Questionnaire, so that lessons can be learned and mistakes can be avoided.

It is important to find out from you about all the difficulties you have encountered in implementing the Screening Programme and in using the Family Origin Questionnaire, as well as all the things that went smoothly so that good practice can be shared. We need to draw on your experience to ensure that the Screening Programme is implemented in the best possible way at the national level.

The overall research also involves paired interviews with community and hospital based midwives, observation with midwives as they administer the Family Origin Questionnaire to their patients, and interviews with biomedical scientists and consultant haematologists to find out their views on the Family Origin Questionnaire.

We expect that this interview should last no longer than 45 minutes. Your views will be kept strictly confidential.

1.0. Institutional set up

- Can you tell us about the ways in which the antenatal care team is set up here?
- How many midwives are in your team?
- What is your role in the NHS SC&T Screening Programme?

2.0. The Screening Programme: Early implementation

- When did you start implementing the Screening Programme?
- How did you explain it to midwives? (e.g. newsletter, seminar, training programme, one-to-one sessions, etc). Did any strategy work better than others?
- Are all midwives (i.e. community based or hospital based) equally well-informed in your view?

3.0. Use of the Family Origin Questionnaire

- Do you think midwives understand the role and importance of the Family Origin Questionnaire?
- Are midwives using the FOQ with all their patients?
- Do they explain what SC&T is about to all patients?
- Do they explain the role of the FOQ to all patients?
- Have midwives reported any problems to you about the layout, presentation and content of the Family Origin Questionnaire?
 - Probe for:
 - Difficulties in understanding the layout and presentation of the form?
 - Difficulties in coding patients' responses in existing categories?
 - Probe for variation in terms of:
 - Ethnic backgrounds
 - Degree of fluency in English
 - Educational level / understanding of biology and genetics
- Have midwives reported any problems to you about their *use* of the FOQ?
 - Probe for:
 - Difficulties in introducing the Questionnaire?
 - Difficulties in finding the time to complete the Questionnaire?
 - Lack of information and guidance about how many generations to probe for?
 - Lack of guidance about what to do when they are in doubt?
 - Lack of training on how to answer questions on SC&T?
 - Unease in asking people about their family origins?
 - Concerns about how to feed the results back to patients?
- What is the current completion rate of the FOQ?
- What do you think could help improve the completion rate of the FOQ?
- What could help ensure that the form generates valid information?
- Do you think biomedical scientists understand the FOQ?
- Have they reported any problems to you about the FOQ *itself*?
 - Probe for:
 - Difficulties in understanding the layout and presentation of the form?
 - Difficulties in knowing what to do with the data and the test results?
- Have biomedical scientists reported any problems to you about their *use* of the FOQ?
 - Probe for:
 - Logistics related to the questionnaire?
 - Lack of time to analyse the tests?
 - Data entry
 - Poor understanding of the “Low Prevalence” antenatal screening algorithm
- From the perspective of consultant haematologists, biomedical scientists and midwives, what could help enhance the success of the SC&T Screening Programme?
- Is there any direct communication between haematologists and midwives? If not, would that be helpful?

4.0. Training and support needs

- Do you think midwives could benefit from some training in relation to the Screening Programme and/or the FOQ?
- If so, what kind of training should be offered?
- What would be the best way of providing this training?

-
- Are there any other ways in which midwives could be supported to help implement the SC&T Screening Programme?
 - Are there any other ways in which you think haematology consultant haematologists or biomedical scientists could be supported to help implement the SC&T Screening Programme?

5.0. Relations with other stakeholders

- Can you tell me more about who are the other key stakeholders in the process of driving through the Screening Programme and the FOQ?
Probe for:
 - Role of GPs
 - Other?
- How can all these people best be coordinated to maximise the success of the Screening Programme?

6.0. Evaluation: Lessons learned and mistakes to avoid

Thinking about your experience of implementing the Family Origin Questionnaire in this pilot area, and with the benefits of hindsight:

- What do you think was handled the most successfully in this pilot area?
- What would have helped you, in your function, with the process of implementing the Family Origin Questionnaire for SC&T Screening?
- Is there anything else that could have been done to support you with the implementation of the Screening Programme?
- What lessons, if any, should be passed on to other sites?
- What mistakes, if any, should be avoided elsewhere?

7.0. Close and thanks

- Is there anything else which we have not covered that you would want to add?
- Many thanks for taking time to share your experiences and views with us.

APPENDIX 2: INTERVIEW SCHEDULE FOR PAIRED INTERVIEWS WITH MIDWIVES

NHS SICKLE CELL & THALASSAEMIA SCREENING PROGRAMME

THE “FAMILY ORIGIN QUESTIONNAIRE”

SCHEDULE FOR PAIRED INTERVIEWS WITH MIDWIVES

The NHS Sickle Cell and Thalassaemia Programme is in the process of rolling out a Screening Programme for Sickle Cell & Thalassaemia throughout England.

Currently the Screening Programme is being piloted in seven areas, one of which is your NHS Trust. Before the Screening Programme is used nationally, we need to find out more about your experiences of having used the Family Origin Questionnaire, so that lessons can be learned and mistakes can be avoided.

It is important to find out your views of the questionnaire, how easy or difficult it is for you to introduce it to their patients, what difficulties you encounter, whether you feel confident probing people on their family origin, what support you would require, and any other relevant issues which would help to ensure that the Screening Programme is implemented in the best possible way at the national level.

The overall research also involves interviewing antenatal care coordinators in the seven pilot sites, observing midwives as they administer the Family Origin Questionnaire to their patients, and interviewing consultant haematologists and biomedical scientists to find out their views on the Family Origin Questionnaire.

We expect that this joint interview should last no longer than 45 minutes. Your views will be kept strictly confidential.

1.0. Warm up

- How long have you worked as midwives for?
- Have you always worked in this area?
- Do you work?
- In the community?
- In a hospital?
- In a GP or health centre?
- How many pregnant women do you see on an average week?

2.0. Understanding of the Screening Programme and the FOQ

- Do you feel you understand the SC&T Screening Programme and what it is trying to achieve?
- Do you feel you understand the FOQ and how to use it?
- Are there any aspects of the FOQ that are not clear to you?
- Do you find the layout and presentation clear enough?
- Do patients experience any difficulties in answering the FOQ?
- Are you always clear about which box to tick when people tell you about their family origin?
- Have you come across anyone who did not fit into any of the categories?
- What do you do when in doubt about how to code a response?
- How many generations back do you probe for?
- What questions do patients most frequently ask you?
- Do you feel equipped to deal with their questions?

3.0. Experience of using the Family Origin Questionnaire

- How long have you been using the Family Questionnaire for?
- Do you use it with all your patients?
- If not, which patients do you use it with?
- What makes you use the questionnaire with some people and not others?
- Probe for:
 - Logistics and lack of time
 - Unease with the questionnaire
 - Perception that some patients will not be at risk
 - Other
- At which point do you introduce the Family Origin Questionnaire?
- Probe for:
 - First visit? Other visit?
 - At which point in the visit?
- How do you normally introduce the Family Origin Questionnaire?
- Do you explain what SC&T is about to all patients?
- Do you explain the role of the FOQ to all patients?
- How long does that introduction or explanation take you?
- Probe for variation in terms of:
 - Ethnic backgrounds
 - Degree of fluency in English
 - Educational level / understanding of biology and genetics
- How do patients usually react?
- Do you feel that patients understand what the Screening Programme is about and why you are asking them about their family origin?
 - Are they happy or unhappy about being asked for their family origin?
- Probe for variation in terms of:
 - Ethnic backgrounds
 - Degree of fluency in English
 - Educational level / understanding of biology and genetics
- What do you do when patients are reluctant to complete the FOQ?
- Probe for:
 - Do you try to convince them to take part?
 - Do you think you should respect their choice and not press them any further?
 - At what point, or on what basis, do you make the decision not to press further some to complete the FOQ?

-
- What do you do when dealing with patients who have very little knowledge and understanding of genetics? How do you go about seeking informed consent?
 - How long does it take you to complete the Family Origin Questionnaire?
 - Probe for:
 - Is that manageable?
 - Is it too burdensome?
 - If it is too time-consuming, could anything help speed up the process?

4.0. Training and support needs

- Have you received any training in completing the FOQ?
- If yes:
 - What kind of training was it?
 - Who gave it to you?
 - Was it helpful?
 - How could it be improved?
- Do you think yourselves, or midwives in general, could benefit from some training in relation to the Screening Programme and/or the Family Origin Questionnaire?
- If yes:
 - What kind of training would you like to get?
 - What would be the best way of providing this training to you?
- Are there any other ways in which you think midwives could be better supported to help implement the SC&T Screening Programme?

5.0. Lessons learned and mistakes to avoid

- Thinking about your experience of using the FOQ, do you believe that:
 - Improvements could be made to the form itself? If so, which ones?
 - Improvements could be made to the ways in which the form is used? If so, which ones?
- What would have helped you, as midwives, with the process of using the FOQ?
- What lessons should be passed on to other sites?
- What mistakes could be avoided?

6.0. Close and thanks

- Is there anything else which we have not covered that you would want to add?
- Many thanks for taking time to share your experiences and views with us.

APPENDIX 3: INTERVIEW SCHEDULE FOR HAEMATOLOGY STAFF

NHS SICKLE CELL & THALASSAEMIA SCREENING PROGRAMME THE “FAMILY ORIGIN QUESTIONNAIRE” INTERVIEW SCHEDULE FOR HAEMATOLOGISTS

The NHS Sickle Cell and Thalassaemia Programme is in the process of rolling out a Screening Programme for Sickle Cell & Thalassaemia throughout England.

Currently the Screening Programme is being piloted in seven areas, one of which is your NHS hospital. Before the Screening Programme is used nationally, we need to find out more about your experiences of having used the Family Origin Questionnaire, so that lessons can be learned and mistakes can be avoided.

It is important to find out your views of the questionnaire, how easy or difficult it is to use, what are the logistical issues around using the questionnaire, what difference the questionnaire makes to your work, and any other relevant issues which would help to ensure that the Screening Programme is implemented in the best possible way at the national level.

The overall research also involves interviewing antenatal care coordinators and midwives in the seven pilot sites, and observing midwives as they administer the Family Origin Questionnaire to their patients.

We expect that this interview should last no longer than 45 minutes. Your views will be kept strictly confidential.

1.0. Understanding of the Screening Programme and the FOQ

- Do you feel you understand the SC&T Screening Programme and what it is trying to achieve?
- Do you feel you understand the FOQ and how to use it?
- Do you find the FOQ clear and easy to use?
- Does the FOQ give you the information you need to decide what to do with the blood sample?
- Do you feel confident that you would be able to identify everyone at risk of SC&T?

2.0. Experience of using the Family Origin Questionnaire

- How long have you been using the Family Origin Questionnaire for?

Layout and content

- What do you think about the layout and presentation of the FOQ?
 - Are the layout and presentation clear?
 - Are the categories unambiguous?
 - Are the categories exhaustive?
 - Should more categories be added? Which ones?
 - Should some categories be deleted? Which ones?
 - Is there any relevant information missing from the current layout?

Logistics

- What about the logistics surrounding the use of the FOQ?
- How does the physical handling of the completed questionnaires and the blood samples take place?
- Is there anything that could be improved about that?
- Are there risks in the ways in which the physical handling of the forms and samples logistics is currently organised? (questionnaires being lost, samples being lost, important information missing, etc)
- Do you have the resources (in time, money, qualified staff) to deal with the samples from the SC&T Screening Programme?
- How long does it take to sort out the samples/completed FOQ?
- Do you share equipment used to analyse samples?
 - Does sharing equipment cause any specific difficulties?
- How long does it take to test each sample for SC&T?
 - Is that manageable?
 - Is it too burdensome?
 - If it is too time-consuming, could anything help speed up the process?
- What do you do with the positive samples?
- Who do you inform about any positives?
 - Is the process satisfactory?
- Would speaking to the midwives directly help?
- Have you encountered any other logistical difficulties which we have not discussed so far?

3.0. Training and support needs

- Do you think yourself, or biomedical scientists in general, could benefit from some training in relation any aspects of the Screening Programme and/or the Family Origin Questionnaire?
 - If so, what kind of training would you like to get?
 - What would be the best way of providing this training to you?
- Are there any other ways in which you think biomedical scientists could be supported to help implement the SC&T Screening Programme?

4.0. Lessons learned and mistakes to avoid

Thinking back about your experience of using the FOQ:

- What would have helped you, as haematologists, with using the FOQ?
- What lessons should be passed on to other sites?
- What mistakes could be avoided?

5.0. Close and thanks

- Is there anything else which we have not covered that you would want to add?
- Many thanks for taking time to share your experiences and views with us.

APPENDIX 4: OBSERVATION SCHEDULE: FOQ COMPLETION

1. Hospital Unit:

<input type="checkbox"/>	Southampton General Hospital
<input type="checkbox"/>	Shrewsbury Hospital
<input type="checkbox"/>	Derriford Hospital Plymouth
<input type="checkbox"/>	Derby Hospital
<input type="checkbox"/>	James Cook/Friarage Hospital, South Tees
<input type="checkbox"/>	Dewsbury and District and Pinderfields Hospitals, Mid Yorkshire
<input type="checkbox"/>	Queen Elizabeth, King's Lynn and Wisbech

2. Observer: _____

3. Date of observation: _____

4. Midwife:

<input type="checkbox"/>	Hospital
<input type="checkbox"/>	GP or health clinic
<input type="checkbox"/>	Home visit
<input type="checkbox"/>	Other

5. Expectant mother:

<input type="checkbox"/>	From visible minority ethnic group
<input type="checkbox"/>	Not from visible minority ethnic group

1. EXPLANATION OF THE NHS SC&T SCREENING PROGRAMME

Note whether the explanation is factually correct, sufficiently exhaustive, displays knowledge and understanding of SC&T, is sensitively done, respects questions and concerns from woman, etc.

Strengths
Weaknesses
Other

2. EXPLANATION OF THE FAMILY ORIGIN QUESTIONNAIRE

Note whether the explanation is factually correct, sufficiently exhaustive, displays knowledge and understanding of SC&T, is sensitively done, respects questions and concerns from woman, etc.

Strengths
Weaknesses
Other

3. PROCESS OF QUESTIONNAIRE COMPLETION

Is the woman informed that routine blood analysis will identify the risk of being a thalassaemia carrier?

Yes

No

If screening test is declined

Reason given:

No reason given:

Management by midwife:

Strengths
Weaknesses
Other

If screening test is accepted:

Strengths
Weaknesses
Other

▪ **Categories which cause difficulties:**

- a) _____
- b) _____
- c) _____

▪ **Number of generations probed for on each family side**

Sufficient

Insufficient

▪ **Time taken to complete the questionnaire**

Less than 1 minute

1 to 5 minutes

5 to 10 minutes

More than 10
minutes

4. TRAINING AND SUPPORT NEEDS IDENTIFIED

--

5. ANY OTHER ISSUE

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