



Public Health
England



Listening to Parents

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Background

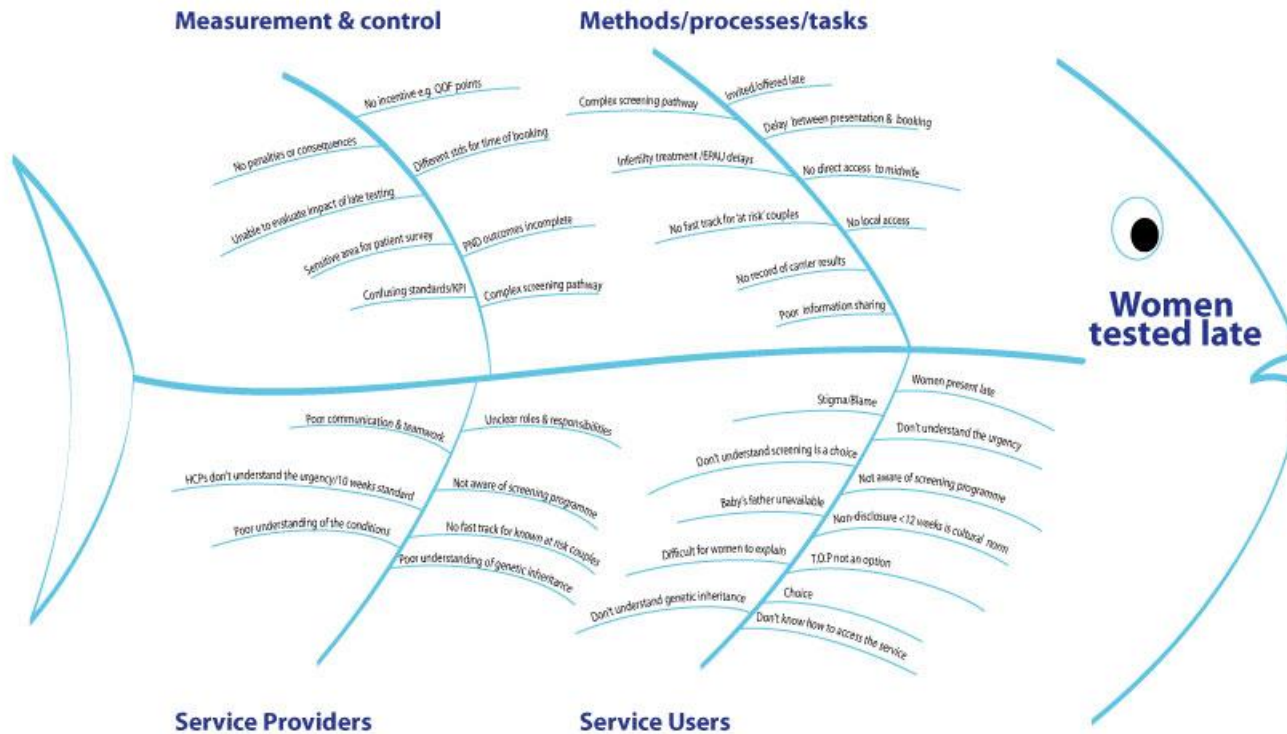
The NHS Sickle Cell and Thalassaemia Screening Programme screens pregnant women to find out if they're at risk of having a baby with sickle cell disease or thalassaemia major.

Pregnant women and couples at risk of having a baby with one of these conditions can face some very difficult decisions. These include whether to have prenatal diagnosis and if the baby is affected to decide whether to continue or to end the pregnancy.

Early access to screening and the early offer of prenatal diagnosis is important in giving women and couples time to consider their options.

In 2016, national data revealed that many trusts were failing to meet the standards for early offer of screening and prenatal diagnosis.

The problem



Why women are tested late?

In collaboration with the Sickle Cell (SCS) and UK Thalassaemia Societies (UKTS) we examined maternal and service delivery factors that impact early access

This involved face to face interviews and clinical and service delivery audits

Criteria for inclusion in the interviews and clinical audit:

- recent experience of NHS SCT screening programme
- either an 'at risk couple' or 'carrier woman' where baby's biological father's was unavailable
- either accepted or declined PND

Iyamide Thomas (SCS) and Elaine Miller (UKTS) did the interviews using a survey questionnaire designed by a multi-disciplinary group

Included 13 women and timeliness data at significant points in the screening pathway were collected on 16 pregnancies

Parent's needs (1)

As parents we fully understand that we are at risk of having a child with thalassaemia with every pregnancy. In accordance with our religious beliefs and personal ethics we do not believe in antenatal screening or in termination of pregnancy unless the mother's life is at risk. We need the healthcare professionals to:

- be respectful of our beliefs
- treat an informed decision to decline screening and PND with sensitivity and respect
- tell us about the positive outcomes for children being treated for thalassaemia in this country
- put us in touch with patient organisations so that we can:
 - i. find someone in our community to help explain genetic inheritance to our families
 - ii. meet young people/ adults living successfully with thalassaemia

Parent's needs (2)

As a couple at risk of having a child with thalassaemia who believe in “ensoulment” at 120 days’ gestation and have made the decision that we do not wish to bring another child with thalassaemia into the world, our needs are:

- self-referral to counselling and PND
- for healthcare professionals to be aware that timing of PND is crucial to informed choice
- for healthcare professionals to be aware of the Muslim belief of ‘ensoulment’, women who hold this belief may opt for PND and TOP of an affected child but only if this happened before the 120 days gestation

Parent's needs (3)

As a couple unaware of the risk of having a child with thalassaemia, our needs are:

- healthcare professionals who understands the condition, can explain genetic inheritance, take the screening tests and refer promptly
- all screening tests and if required counselling and offer of PND and PND tests to be performed as soon as possible

Parent's needs (4)

As a couple who understand the risk of having a baby with sickle cell disease who have declined PND we need healthcare professionals to:

- tell us about the positive outcomes for children being treated for sickle cell disease in this country
- put us in touch with patient organisations so that we can: i. find someone in our community to help explain genetic inheritance to our families
- meet young people/ adults living successfully with sickle cell disease
- tell us how and when our baby's heel prick result will be communicated
- advise on pre-implantation genetic diagnosis
- advise on direct access to counselling and PND in future pregnancies. Even though I did not accept it in my first pregnancy, I might reconsider and accept next time around

Parent's needs (5)

As a couple who understand the chance of having a baby with sickle cell disease who have decided we cannot bring up a child with the disease, we need healthcare professionals who:

- understand our situation and the screening and diagnostic pathway
- can advise on pre-implantation genetic diagnosis
- who are accessible; we need direct access to counselling and PND
- have knowledge of sickle cell disease and genetic inheritance

Re-designed the screening pathway

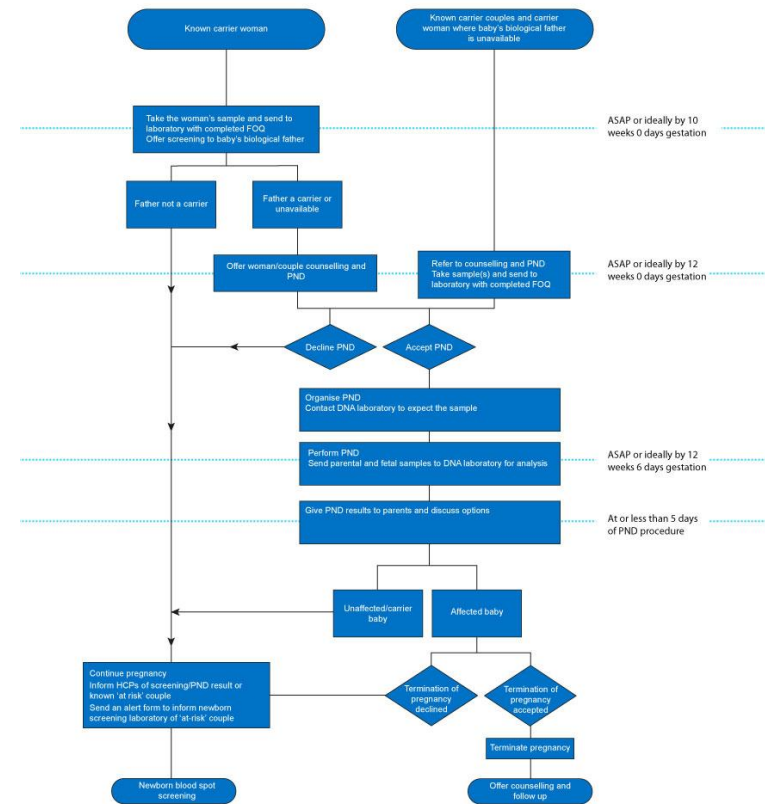
Couples or women at risk are defined as:

both biological parents being carriers of a significant haemoglobin variant

the woman is a carrier of a significant haemoglobin gene variant and the screening status of the biological father is unknown

- all maternity units should provide a publically available and advertised direct dial number or email address for the use of women, GPs and midwives.
- testing at first appointment
- Streamlined access to specialist counselling

NHS Sickle Cell & Thalassaemia Screening Programme
counselling and referral to prenatal diagnosis (PND)
for known carrier couples and women where father's result is unavailable



Parents leaflets

More information on choice

Less 'medical'

Less 'wordy'



Education resources

Sickle cell and thalassaemia screening e-learning module a

comprehensive 9 module elearning is available at <http://www.e-lfh.org.uk/latest-news/?#15183>

Genetic Risk Assessment and Counselling Module 4 days

https://www1.kcl.ac.uk/teares/nmvc/external/prospectus/course_info.php?code=118

Haemoglobinopathies: an overview 1 day course

<https://cpdscreening.phe.org.uk/sct-externaltraining>

Specialist counselling update 1 day course

https://www1.kcl.ac.uk/teares/nmvc/external/prospectus/study_info.php?code=KSCTS_

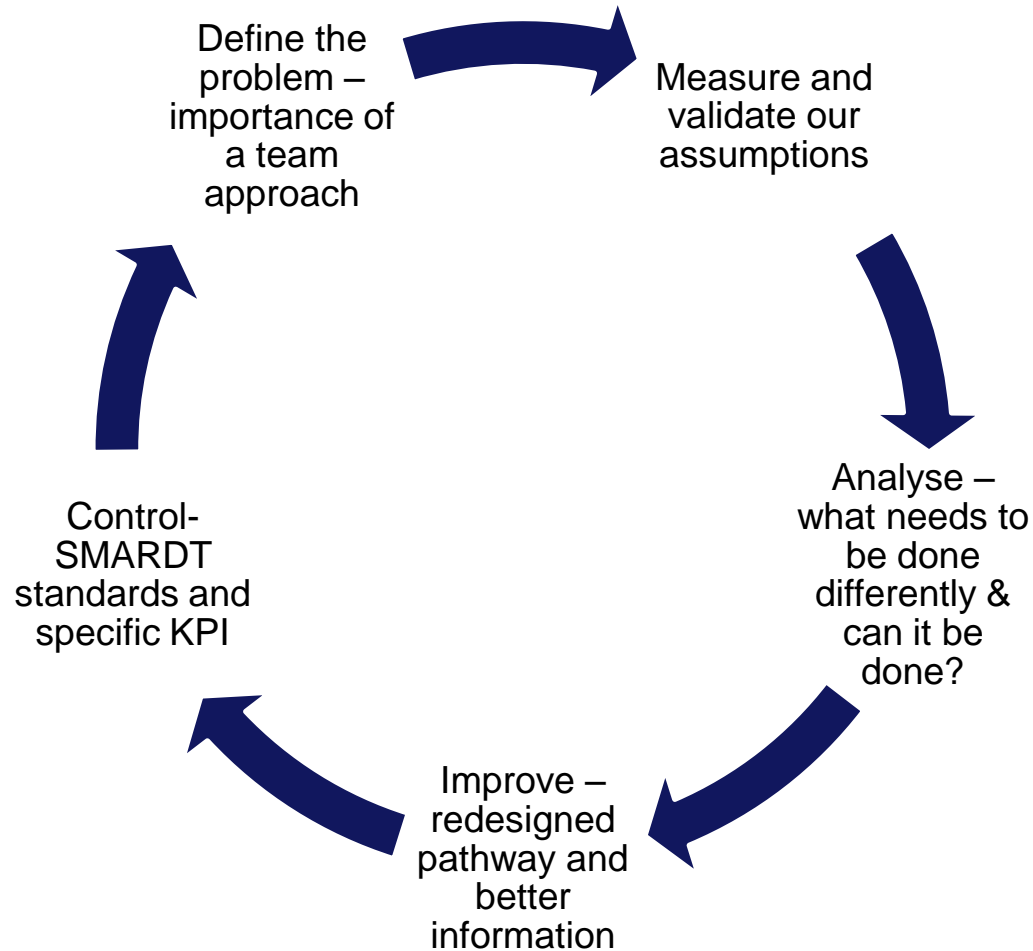
Take the test to raise awareness in schools is available at

<http://www.engagingscience.eu/en/2014/07/03/take-the-test/> and
<http://www.engagingscience.eu/en/2014/09/12/making-decisions/>

New KPI

Timely offer of prenatal diagnosis (PND) to women at risk of having an affected infant													
Data source: Maternity													
5a.) Carrier women where baby's biological fathers' status is unknown (at risk women)											Comments		
<u>Number of at risk women (denominator)</u>													
<u>Number of at risk women offered PND by 12 weeks and 0 days (numerator)</u>													
Data quality check: Is the numerator less than or equal to the denominator?											Yes		
5b.) At risk couples (1 in 4 chance of affected fetus based on both biological parents)											Comments		
<u>Number of at risk couples (denominator)</u>													
<u>Number of at risk couples offered PND by 12 weeks and 0 days (numerator)</u>													
Data quality check: Is the numerator less than or equal to the denominator?											Yes		

Improving the antenatal pathway



New publications

Updated PND guidelines

<https://phescreening.blog.gov.uk/2017/10/04/weve-updated-sickle-cell-and-thalassaemia-screening-guidelines-for-counselling-and-referral-for-prenatal-diagnosis/>

SCT Screening Programme Standards

Programme standards <https://www.gov.uk/government/publications/standards-for-sickle-cell-and-thalassaemia-screening>

Checks and audits to improve quality and reduce risk

<https://www.gov.uk/government/publications/sct-checks-and-audits-to-improve-quality-and-reduce-risks>

Parent stories

<https://phescreening.blog.gov.uk/2017/09/01/parents-stories-personal-experiences-of-sickle-cell-and-thalassaemia-screening/>

At risk leaflets

<https://phescreening.blog.gov.uk/2017/08/22/revamped-sickle-cell-and-thalassaemia-at-risk-leaflets-published/>