



Testing babies for congenital heart defects using pulse oximetry – Frequently asked questions

Sadly, some babies are born with heart problems called *congenital heart defects* (CHD). In England, heart problems happen to around 3,500 babies a year. The UK National Screening Committee (UK NSC) runs two programmes to screen babies for heart problems so we can find as many as possible and make sure they get the correct treatment.

There is another way to look for heart problems using a machine called a pulse oximeter which measures the amount of oxygen in a baby's bloodstream. In some circumstances a reduced level of oxygen can indicate a problem with the baby's heart (or lungs). Following a 3 month consultation on the evidence for screening congenital heart defects using pulse oximetry that closed in December 2013, the UK NSC has recommended piloting the test in order to better understand the practicalities of its use within a newborn screening programme.

What can happen to babies affected by heart problems?

There are over thirty types of heart problems that can occur in a newborn baby. Some problems only require monitoring as a baby grows up. More severe heart problems may need surgery soon after a baby is born.

What screening for heart problems in babies is currently available?

The UK NSC runs two programmes which screen for heart problems both before and after birth.

- Before birth, mothers are invited for ultrasound screening at 18-20 weeks through the NHS Fetal Anomaly Screening Programme. This detects some of the babies who have heart problems. Once these problems are identified, some of the babies can be given specialist treatment before birth and some as soon as they are born.
- For babies whose heart problems are not detected before birth, the NHS Newborn and Infant Physical Examination programme provides additional assessment within 72 hours of birth and again at 6-8 weeks of age.

What is the pulse oximetry test? How is it different?

Pulse oximetry is a well-established medical technology that monitors oxygen levels in the blood. It is used as a test to help detect a variety of health problems in people of all ages. When testing babies for congenital heart defects (CHD), a small clip is placed on the baby's finger and/or the toe.

A sensor in the clip shines a red light through the baby's skin to monitor the level of oxygen in the baby's blood. If the baby is found to have low levels of oxygen in his/her blood, it can be a sign of a problem, including a heart problem. The test is simple, painless and quick.

What happens if the test finds a problem?

A low blood oxygen level may require further tests. Babies with suspected heart problems can be seen by specialist heart doctors and can receive care which can prevent death or disability in early life.

However, even a combination of screening before birth, at birth and pulse oximetry testing is still not perfect. It is still possible that some babies will leave hospital and have heart problems that cause them to become very unwell. It is also possible that some babies will be identified as having a suspected condition when they do not; this is called a false positive result.

What is the benefit of piloting the test?

The UK NSC has recommended piloting the test as this presents the best opportunity to answer a number of outstanding concerns in order to fully consider the test as part of a national screening programme:

- **Identifying babies for testing** – Not all babies would need to be tested, but it is unclear which babies would not need to be included in the screening pathway.
- **Estimating screening's impact on workload** – Pulse oximetry will identify approximately 5% of babies as having low oxygen levels soon after birth; the majority of these babies will have no underlying illness. It is not clear what impact the increased number of babies being identified would have on NHS resources and further analysis needs to be done to estimate this.
- **Diagnostic and treatment pathway** – Low oxygen levels could indicate a wide range of illnesses other than serious heart problems. It is important that clear diagnostic and treatment plans are available for all conditions that could be identified.
- **Training, monitoring and information** – The practical elements of introducing the test as part of a national programme must be determined. This includes what training is required, how the test would be monitored to ensure

it is consistently delivered to a high standard, and what information resources are needed for patients and professionals.

The details of the pilot study are yet to be confirmed, this includes which hospitals will take part and the duration of the study.