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An t-Ionad Fiosrachaidh

Briefing for the Public Petitions Committee

Petition Number: PE 1823

Main Petitioner: Sameena Javed

Subject: Full body scans to all neonates in Scotland

Calls on the Parliament to urge the Scottish Government to offer full body scans to all neonates in Scotland with the aim of detecting and hopefully treating rare and hidden conditions.

Background

The petitioner is referring to her own tragic experience of the loss of her son to a condition she believes was preventable if it had been diagnosed at birth: AVM, arteriovenous malformation, which is a 'tangle' of abnormal blood vessels connecting arteries and veins in the brain. According to a NHS Foundation Trust, they are rare, affecting less than 1% of the population. AVMs can occur anywhere in the body, but are a particular problem in the brain, and are not usually identified until someone is between 20 and 40 years of age. They can develop before birth, or later in life as a result of a head injury.

Symptoms of a bleed are often the first sign of their existence and they are diagnosed by CT scan, angiogram or MRI.

Treatment includes surgery, endovascular (repairs to blood vessels) procedures, radiosurgery (surgery using radiation) or a combination of treatments. The risks of treatment are considered to be high for AVMs that are located in deep parts of the brain or with very important functions nearby. Some AVMs cannot be treated as the risk is too high.

Current screening of neonates

Neonates are new born babies, usually under 4 weeks old. The UK National Screening Committee (UK NSC) is an expert advisory group which advises Ministers and the NHS in the four UK countries about all aspects of population screening and supports implementation of screening programmes.

NHS Inform provides information on the scanning and screening through pregnancy and at birth. The main one during pregnancy is the anomaly scan, done at around 20 weeks into the pregnancy. NHS Inform provides

information on what is examined through the scan, and what its limitations are. It provides an early warning of potential problems and allows staff to plan any treatment during the rest of the pregnancy or after birth.

At birth, a range of tests are carried out. These are done via 'blood spots' obtained through a pin prick of a baby's heel, at about five days old, and spots of the blood being gently squeezed onto a 'blood spot' card by a midwife. A thorough physical examination along with a specialised newborn hearing test are also carried out.

Information on current screening in pregnancy and of newborns in Scotland is also available through a dedicated website.

Testing during pregnancy and on newborns has to balance the potential harms from invasive or scanning procedures on many healthy babies against the benefits of carrying out such procedures to pick up rare conditions. It is an issue for most mass screening procedures. Another factor for consideration is what treatment is possible or available should a problem or condition be identified.

Added to balancing harms against benefits in population-level screening, there are other ethical considerations, particularly when treatment might not be possible. This article on the ethics, the developments and the expansion of neonatal screening considers some of the issues:

- The ethics of screening for conditions where there is no treatment (or very expensive treatment in countries where healthcare is not free).
- Retention of screening samples and their ownership.
- Consideration of genetic information – for example hereditary diseases and the impact of that on future reproductive decisions and the child's future, especially when knowledge in the field is increasing rapidly.
- Whether the information is for the benefit of individuals or society and how that information might be used or exploited.

These and other debates are considered in greater depth in a report compiled by Warwick University, *The Ethical, Social and Legal Issues with Expanding the Newborn Blood Spot Test.* Taylor-Phillips et al. August 2014. The authors were commissioned by the UK National Screening Committee and conducted a 'rapid review' into the issues, and concluded their report with a summary of considerations:

> "Decisions on expansion of the blood spot alongside advocacy of the analysis of the newborn's genome as a lifetime resource for lifestyle decisions and health care interventions appear to us to be premature. The technical flaws in this concept are powerful considerations.
>
> There are concerns such as privacy, the self-determination of the child (and the individual as a future adult), the need to decide how to handle

> the changes in interpretation of genome sequence data that are likely to occur frequently over the next decade or more, the likely deferral of most benefits from the information until well into adult life coupled with the possibility of causing harm in terms of both over and under diagnosis and identification of both false positives and false negatives…
>
> …There is advocacy and lobbying for the introduction of many screening programmes, particularly from parents of children affected by diseases detectable on the newborn blood spot test. Whilst such advocacy should be considered by policy makers, they must also consider the interests of children and parents who will be negatively affected by the introduction of screening, such as those receiving false positive results, indeterminate results or overtreatment. These people cannot advocate against screening because they are as yet unidentified.
>
> Whilst policy makers' primary considerations are often the balance of benefit and harm at the population level, clarity about how individual benefits, harms, autonomy, and interests are considered and weighted in the decision making process is an important ethical requirement.

More recently, in 2019, Genetic Alliance UK has produced a charter to extend screening.

Some scanning procedures, such as CT (Computed tomography) scans involve radiation, so carry risk. No information has been found on any recommendations on routine scanning of newborns.

Scottish Parliament Action

A petition calling for neonatal screening for a particular condition was considered by the Petitions Committee in February 2020.

Scottish Government Action

Public Health Scotland has information on changes to pregnancy and newborn screening being implemented from 28 September 2020:

> "NHS Scotland is making changes to the National Pregnancy Screening Programme for women with a booking appointment from 28 September 2020.
>
> - Introduction of screening for Edwards' syndrome and Patau's syndrome in the first trimester
> - Second Line Test: Non-Invasive Prenatal Testing (NIPT)
> - Updated Screening for twin pregnancies"

NHS National Services Division is responsible for all national screening programmes and more detail is available on the individual tests.

Anne Jepson
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22 September 2020

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Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP