PE1823/A:
Scottish Government submission of 4 September 2020

Thank you for asking for the Scottish Government's view on the new public petition PE1823: Full body scans to all neonates in Scotland, calling on the Scottish Government to offer full body scans to all neonates in Scotland.

Scotland has a Pregnancy and Newborn Screening Programme which involves screening for a wide range of health conditions. The conditions screened for are based on the recommendations of the UK National Screening Committee and the Scottish Screening Committee, and do not currently include AVM, the condition referred to in the background to the petition. The UK National Screening Committee advises Ministers and the NHS in the four UK countries about all aspects of screening, including assessing the evidence base to make recommendations for which conditions should form part of the national screening programmes. Further details are available at: https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc

It is important to recognise all scans will carry an element of risk around false positive and false negative rates. Such an approach would have the potential to identify anomalies for which the significance is unknown and for which there may be no intervention and may very likely identify many anatomical variants.

Therefore, this response will outline what is currently offered in Scotland by way of screening both during pregnancy and as a new born, as well as providing details of improvement work the Scottish Government is leading for fetal medical conditions and procedures in terms of care pathways. It will also highlight work underway to improve data gathering on rare diseases, so as to better inform the planning of services and better understand such diseases.

National Screening Programmes

All newborn babies are offered some screening tests in their first six to eight weeks. Most babies are healthy and won't have any of the conditions the screening tests are looking for. But for those babies who do have a health problem, the benefits of screening can be enormous. Early treatment can improve their health and prevent severe disability or even death.

Tests include:

(i) newborn blood spot (heel prick) test

Scotland offers newborn bloodspot screening for a number of hereditary conditions, including congenital hypothyroidism, cystic fibrosis, medium-chain acyl-CoA dehydrogenase deficiency, phenylketonuria and sickle cell disease. On the advice of the UK NSC, screening for an additional four rare inherited metabolic diseases was introduced in Scotland on 20 March 2017. These conditions are maple syrup urine disease, homocystinuria, glutaric aciduria type 1 and isovaleric acidaemia.

The screen takes place about a week after birth with a midwife pricking the baby's heel using a special device to collect some blood onto a card.

(ii) newborn hearing screening test

All parents in Scotland are offered newborn hearing screening for their baby. Screening aims to identify moderate, severe and profound hearing impairment in newborn babies.

(iii) newborn physical examination
(not a national screening programme in Scotland)

In all UK countries, the parents of newborn babies are offered the opportunity to have their child examined shortly after birth (within the first 72 hours). In England this is a formally managed screening programme, in Scotland it is not. The examination includes a general physical check as well as an examination of the baby's eyes, heart, hips and testes in boys. The examination is repeated at 6-8 weeks of age, usually by a GP (as some conditions can develop later).

More information on newborn screening can be found on NHS Inform:
https://www.nhsinform.scot/healthy-living/screening/newborn/newborn-screening

Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS)

It is also worth noting that work on a new Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS) is well underway. The Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS) is part of a wider programme of work to improve information on individuals affected by rare diseases, and hence ultimately improve their outcome. The register will capture new information on all babies in Scotland affected by major congenital anomalies and will allow us to understand better the frequency, nature, cause and outcomes of these serious conditions.

Importantly, it will also help to inform the planning of services required by affected children and their families.

Following analysis of existing nationally available routine records, the first annual publication of estimates of the occurrence of congenital anomalies among pregnancies ending from 2020 to 2017 was published on 26 November 2019.

This first annual report highlights that around 1 in 40 babies born alive in Scotland during 2017 had a serious congenital anomaly, with the commonest group of anomalies being congenital heart defects. This report captures congenital anomalies diagnosed in babies up until their first birthday and provides Scotland with a benchmark moving forward. Work on the second report is ongoing with publication expected to take place in October 2020.

This work is being led by the NHS Information Services Division with NHS National Services Scotland and the team is working in partnership with colleagues running

similar registers elsewhere in the UK and across Europe to maximise shared learning.

The establishment of CARDRISS, was a recommendation contained within the Scottish Government's Rare Disease Scotland Progress Report which can be found online at http://www.gov.scot/Publications/2018/02/8601.

The Best Start: A Five Year Forward Plan for Maternity and Neonatal Care in Scotland

You may also wish to be aware that the Scottish Government is also aiming to improve and standardise care pathways for fetal medical conditions and procedures, as recommended within The Best Start: A Five Year Forward Plan for Maternity and Neonatal Care in Scotland.

Pregnant women are currently offered a number of screening tests for fetal medical conditions or abnormalities as part of their scheduled antenatal care. Where an abnormality is detected, further diagnostic tests are offered to identify the condition before being offered appropriate treatment.

Through The Best Start, we have convened a Fetal Medicine Expert Group comprising representatives from each Health Board in Scotland. The Group has examined current care pathways for an agreed set of common fetal conditions/procedures and proposed that a common approach to treatment was required. Although such work has currently been paused, we hope to able to remobilise The Best Start programme in the autumn.