PE2067/I: Improve data on young people affected by conditions causing Sudden Cardiac Death

UK National Screening Committee written submission, 9 May 2024

Thank you for your letter addressed to Professor Sir Mike Richards in respect of the petition PE2067. I am responding on his behalf as the head of the UK National Screening Committee (UK NSC) secretariat.

The UK NSC reviewed population screening for Sudden Cardiac Death (SCD) in 2019 and concluded that there was not enough evidence to recommend screening because there is:

- not a sufficiently predictive test for risk of SCD
- insufficient understanding of the genetic risk for SCD
- no agreed treatment for those detected through screening

The UK NSC's article alert and horizon scanning function and its open discussions with stakeholders have not indicated there is significant new work on whole population screening that would suggest a different outcome to that of the 2019 review. However, the UK NSC plans to review the evidence relating to population screening for SCD within the next three years, in line with their current work plan.

The committee will wish to note that since the review in 2019, the committee's terms of reference have been expanded to include consideration of targeted (groups of people identified as being at elevated/above average risk of a specific condition), and stratified screening programmes.

The UK NSC has not been asked to consider targeted or stratified screening for SCD, but it can be alerted to any new published peer reviewed evidence which may suggest the case for a new screening programme.

Proposals to change or review a topic early can be submitted via the UK NSC's annual call which will open in July 2024. More information can be found at UK NSC annual call: submitting a screening proposal.

There are currently 11 national screening programmes (in England), covering 36 health conditions.

The NHS newborn blood spot (NBS) screening programme enables early identification, referral and treatment of babies with 9 rare but serious conditions. These are sickle cell disease (SCD), cystic fibrosis (CF), congenital hypothyroidism (CHT), phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (HCU). Ministers in England have also agreed this year to add tyrosinemia (HT1) to the conditions tested for at this stage.

More directly related to the issue of SCD, is the physical exam offered to babies at birth and again at 6-8 weeks. This tests for (among other things) congenital heart

disease. This test was introduced in 2014, meaning children under 9 years of age should have been tested for this condition.

There are also adult screening programmes for bowel, breast and cervical cancers, abdominal aortic aneurysms (AAAs) and for diabetic retinopathy.

The UK NSC does not make decisions regarding which conditions to screen for based on how rare a condition is or is not. Rather, it assesses evidence against a set of internationally recognised criteria covering the condition, the test, the treatment options, and the effectiveness and acceptability of the screening programme.

More information on the UK NSC and NHS England's screening programmes can be found https://www.gov.uk/government/organisations/uk-national-screening-committee and https://www.gov.uk/government/publications/population-screening-applying-all-our-health/population-screening-applying-all-our-health.

We hope this information provides you with what you were looking for.

Yours sincerely,

Professor Anne Mackie
Head of the UK NSC Secretariat