Eluned Morgan AS/MS Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services



Llywodraeth Cymru Welsh Government

Eich cyf/Your ref P-06-1351 Ein cyf/Our ref EM/01912/23

Jack Sargeant MS Chair - Petitions Committee Senedd Cymru Cardiff Bay Cardiff CF99 1SN

7 August 2023

Dear Jack,

Thank you for your letter of 11 July 2023 on behalf of the Petitions Committee regarding availability of heart-screening for all 11-35-year-olds who play sport.

This issue has been raised by the Petitions Committee previously and the advice remains extant. Population screening programmes generally can save lives through early risk identification but can also do harm by identifying risk factors that would never otherwise develop into a serious condition or complication. Screening programmes may have false negative results, so do not guarantee protection. Additionally, receiving a low-risk result does not prevent the person from developing the condition at a later date. Population screening programmes should only be offered where there is robust, high-quality evidence that screening will do more good than harm.

The UK National Screening Committee (UK NSC) advises Ministers in the four UK countries about all aspects of population screening. It brings academic rigour and authority to what is an extremely complex area and is a world leader in its field. Unselected whole-population screening to prevent sudden cardiac death (SCD) in 12 to 39-year-olds has been considered by the UK NSC and is not recommended. This recommendation has not changed.

The UK NSC concluded the harms of whole-population screening for SCD currently outweigh the benefits. There are uncertainties about the overall benefits of identifying people with risk factors, current tests are not reliable enough (many people would be missed and provided with false reassurance, and many would be given false positive results) and there is currently no agreed treatment for someone who has been identified at

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risk. If a person is incorrectly identified as being at risk, they may become anxious about their physical activity and stop exercising regularly or be excluded from participating in sports, which could have a negative effect on their overall health. It could also potentially affect their ability to get life insurance. The evidence has been comprehensively reviewed and below is a link to the UK NSC review and recommendation: <u>https://view-health-screening-recommendations.service.gov.uk/sudden-cardiac-death/</u>.

Given that the UK NSC does not recommend whole-population screening for SCD for 12 to 39-year-olds due to the inaccuracy of current testing, the Welsh Government cannot introduce screening for all those in this age group. The UK NSC keeps all its policy positions under regular review and as a Government we will consider our position if these were subject to change.

I fully support the need to address the preventable causes of SCD; however, there is a balance to strike in the provision of health information to the public to ensure proportionality and accessibility in the messages being provided, without creating unnecessary anxiety. At a population level, it is beneficial for young people not to be discouraged from cardiovascular exercise – the benefits of which are well established.

Although whole-population screening is not beneficial, families of individuals with SCD should be offered individual clinical assessments to assess their risk. This is 'cascade' case-finding in a higher-risk population rather than whole-population asymptomatic screening. Additionally, young people who have symptoms or concerns, particularly if they are very physically active, should speak to their GP who will be able to advise them as appropriate.

Welsh Government has worked in partnership with the Wales Cardiac Network, Welsh Ambulance Services NHS Trust and the third sector to develop the Out of Hospital Cardiac Arrest Plan published in June 2017. The aim is to increase survival from out of hospital cardiac arrest through optimising the "chain of survival".

We established the Save a Life Cymru partnership in January 2019 to bring together all the different pieces of the jigsaw in relation to encouraging public participation in taking action when faced with an out of hospital cardiac arrest.

I hope this information is helpful.

Yours sincerely,

M. E. Maga

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