UK National Screening Committee

Screening for cardiac conditions associated with sudden cardiac death in the young

08 November 2019

Aim

1. To ask the UK National Screening Committee (UK NSC) to make a recommendation, based on the evidence presented in this document, whether or not screening for cardiac conditions associated with sudden cardiac death (SCD) in the young meets the UK NSC criteria for a systematic population screening programme.

Current recommendation

2. The UK NSC currently does not recommend systematic population screening for cardiac conditions associated with SCD in the young. The Committee based this recommendation on the evidence provided by the 2014 review carried out by Phil Wiffen and Mike Clarke.

Evidence Summary

3. The 2019 evidence summary was undertaken by the University of Warwick, in accordance with the triennial review process: https://www.gov.uk/government/publications/uk-nsc-evidence-review-process/uk-nsc-evidence-review-process

4. The 2019 evidence summary assesses the quality and volume of evidence published since 2014 on the incidence of SCD (since 2008 for UK studies), on the accuracy of screening tests and on the effectiveness of screening. The focus of this review is limited to screening of a general population of asymptomatic young individuals. Screening of symptomatic individuals and athletes is outside the scope of this review. However, where appropriate, the reviewers included evidence from studies of athletes, whilst acknowledging the limitations of using such indirect evidence.

5. The conclusion of the 2019 evidence summary is that the current recommendation, that whole population screening for cardiac conditions associated with SCD in the young should not be introduced in the UK, should be retained. This is for the following reasons:

- Sudden cardiac death is an important health problem based on its severity. However, there continues to be some uncertainty regarding the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person-years. Incidence is higher in males and increases with age within the 12-39 age range. Data on the potential impact of athletic status on incidence is inconsistent. Limited data precluded the reviewers from drawing conclusions regarding incidence of sudden cardiac arrest (SCA) or effect of race on incidence. **Severity: met; Incidence: not met; Natural history: not considered**

- Test accuracy in relation to conditions that may cause SCD was reported in 18 studies. Seven testing strategies were examined, and these included physical examination, ECG, history-taking, and combinations of these tests. In the majority of studies, there was a lack of follow-up of individuals who screened negative. In turn, this precluded the computation of key outcomes, namely sensitivity, specificity and negative predictive value (NPV). Only positive predictive value (PPV) could be reported and across the 44 PPVs calculated, only 3 exceeded 10%. The precision of the estimates for PPV was low meaning that the screening test would cause many individuals to be incorrectly told that they have a heart problem. There was also variation across studies in the criteria used to determine if an individual was screen-test positive, particularly in relation to ECG analysis. In addition, there were concerns related to the indirectness of the evidence identified and its applicability to the general population, since only data from athletic populations were identified for this question on the accuracy of screening tests. No studies were found that met the inclusion criteria and reported data on genetic testing or mobile/ electronic health devices. **Criterion 4 not met**

- No studies were found that were relevant to the question on the effectiveness of screening and met the inclusion criteria. Nonetheless, the reviewers used relevant European Society of Cardiology guidelines to determine if evidence-based strategies exist for treating asymptomatic individuals diagnosed with a condition that may cause SCD. Treatment strategies for asymptomatic individuals were identified, but the evidence quality supporting these guideline statements was often low and it was unclear how applicable these guidelines were to a general population. There remain uncertainties regarding the impact of overdiagnosis of clinically insignificant disease in the general population, and whether this might lead to overtreatment, such as the unnecessary cessation of sporting activity, anxiety and increase demand on secondary care cardiology services. **Criterion 11 and 13 not met**

- The review recommended the need for further research to address the gaps and uncertainties outlined in the document, for example in relation to the optimal testing strategy, the potential harms of screening as well as the impact of screening on individuals and families, including those with a false positive result and those with a condition where there is no recommended treatment.

Consultation

6. A three-month consultation was hosted on the UK NSC website. Direct emails were sent to 24 stakeholders. **Annex A**

7. Comments were received from the following stakeholders:

   i. Cardiomyopathy UK
   ii. Royal College of Nursing
   iii. Royal College of Physicians of Edinburgh
   iv. Royal College of Paediatrics and Child Health
   v. British Cardiovascular Society
   vi. Royal College of Physicians
   vii. Jay’s Aim
   viii. Cardiac Risk in the Young (CRY)
   ix. Two clinicians
   x. A total of 72 members of the public with personal experience of SCD

   (See **Annex B** for comments)

8. The public consultation closed on 7 September 2019. The total number of consultation responses received was 81. Of these, 6 comments were submitted via the standard comments form. The remaining 75 were submitted via email or via a separate word/PDF document.

9. Six stakeholders agreed with the conclusion of the evidence summary. These were:

   - Cardiomyopathy UK

- Royal College of Nursing
- Royal College of Physicians of Edinburgh
- Royal College of Paediatrics and Child Health
- British Cardiovascular Society
- Royal College of Physicians

The 4 Royal Colleges were joined in their assessment by 2 charities: the British Cardiovascular Society (BCS) which represents professionals who work in cardiology and patients, as well as Cardiomyopathy UK which supports people affected by cardiomyopathy. These 6 stakeholders endorsed the review's conclusion in that there is currently no new compelling evidence to support a change to the current recommendation against the introduction of a systematic population screening programme for the risk of sudden cardiac death in the young in the UK. Overall, these stakeholders supported the content of the review and its conclusion, with one stakeholder stating that it is a "balanced overview" of the available evidence.

10. Two out these six stakeholders outlined the need for ongoing research on this topic noting that it would have been very helpful if the review outlined more specific research recommendations.

    Response: The reviewers agreed with the need of additional research and on page 46 of the review document, they gave an overview of the characteristics of the studies that could help to address some of the existing gaps and uncertainties, particularly in relation to the potential short-term and long-term harms of population screening.

11. A total of 72 individuals, 2 clinicians and 2 charities (Jay's Aim and CRY) disagreed with the review's conclusions. Common themes were:

    - Sudden cardiac death is an important public health problem which leads to the loss of decades of productive life as well as having a profound impact on family, friends and local communities and which could be prevented by population screening

Response: The personal stories submitted by individuals are an important statement of the effect that SCD has on individuals, families and communities. Both the UK NSC and the review acknowledge this.

However, based on the results of this evidence summary, systematic population screening cannot be recommended for a number of reasons. In particular, no relevant studies were identified that assessed the effectiveness of screening to prevent SCD compared to no screening in the general population. In addition, there is uncertainty in relation to the accuracy of screening tests in the general population as most studies were performed in athletes. This limits the applicability of these studies to the general population. In addition, the studies did not apply a reference standard to, or follow up, screen negative test results. Finally, there remains some uncertainty as to the true incidence of SCD, particularly in the UK.

- The characterisation of the incidence of SCD as ‘low’ was considered to be incorrect. In particular, some stakeholders refer to the paper by Papadakis et al (2009), which reported an incidence of 1.8 deaths per 100,000 people per year in the UK, and they state that this equates with 12 young sudden cardiac deaths per week, more than 600 young sudden cardiac deaths per year in the UK

Response: Based on the evidence evaluated in this document, the review concluded that there remains some uncertainty as to the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person-years. Limited data precluded the reviewers from drawing conclusions regarding incidence of sudden cardiac arrest (SCA) or effect of race on incidence. The paper by Papadakis et al (2009) was considered as part of this review. This paper examines deaths across the English and Welsh population and concludes that “the incidence of cardiac death in the young in England and Wales is 1.8 per 100,000 per year, which corresponds to eight young lives per week.” This estimate is based on death certificate data. As noted in the review on page 26, use of death certificates to estimate SCD incidence is likely to lead to over-estimation. This is because the methodology considers only the cause of death as recorded on the death certificate. The precise circumstances of the death are important in determining whether an event meets the definition of SCD, in particular the time point at which symptoms were first experienced. The paper itself also acknowledges that the estimated incidence may be affected by misclassification.

During the development of the review CRY was invited to submit peer reviewed evidence on the incidence of SCD or, in its absence, to suggest a source which might provide a dataset for future research. If stakeholders have additional peer-reviewed data, these could be submitted via the UK NSC's early update process, so it might be taken into consideration and evaluated.

In addition, it is important to note that the conclusion that a systematic population screening programme should not be recommended is not solely based on the incidence. Other important factors contribute to the recommendation. These are that there is uncertainty in relation to the accuracy of screening tests in the general population, and that evidence on the effectiveness of population screening to prevent SCD compared to no screening in the general population is currently lacking.

- The fact that this policy is framed as 'screening for the risk of sudden cardiac death in the young' is considered incorrect because other screening programmes endorsed or being evaluated by the UK NSC are focused on detection of conditions. Hence, the framing of this issue should be 'screening for cardiac conditions in young adults'.

  Response: The title can be modified to read 'screening for cardiac conditions associated with sudden cardiac death in the young'. This reflects the current emphasis of the review.

- Concern that the evidence summary and the UK NSC have adopted a contradictory position whereby the ECG is an accurate test if symptoms are experienced but that the ECG is not an accurate test if symptoms are not experienced, particularly given the role of ECG in routine practice and as part of the NICE clinical guideline [CG109] "Transient loss of consciousness ('blackouts') in over 16s"

  Response: The performance of any diagnostic test, such as an ECG, will vary depending on the population and the context in which it is used, and the purpose for which it is being used (for example, to rule-out disease rather than identify disease). The review specifically examined the validity of the ECG test in asymptomatic young individuals, who would form the target population for a screening programme. The review specifically does not examine ECG use in symptomatic individuals (e.g.

breathless individuals) or individuals with specific characteristics that place them at higher risk of sudden cardiac death, such as individuals with a relative that has died of sudden cardiac death. This is explicitly stated on page 15 of the review document.

- Concern that the UK NSC is calling for randomised controlled trials (RCTs) which are unethical in this instance and “would lead to young people dying in the pursuit of ‘better’ science”

  Response: RCTs represent the gold standard in evidence-based medicine and are not unethical where there is equipoise regarding an intervention. The review did not explore the ethics of RCTs in the context of SCD. Nevertheless, other types of study such as cohort studies were eligible for inclusion in the review. However, no studies were found that met the eligibility criteria. This in turns highlights another existing gap in the evidence base, which would benefit from further research.

- Some stakeholders expressed their disagreement with the review document in relation to the point made about unnecessary cessation of sporting activity, which in turn can be detrimental to the overall health of young individuals. These consultees felt that the notion that young people will stop exercising upon discovering a heart condition which puts them at risk of SCD is generalised and anecdotal.

  Response: Concern about cessation of exercise as an outcome of screening was articulated in submissions from professional bodies. The review found that, given the low positive predictive values (PPVs) and the low precision of the PPV estimates, the tests would cause many individuals to be incorrectly informed that they have a heart problem. The review specifically pointed to the fact that uncertainties remain as to the impact of overdiagnosis of clinically insignificant disease in the general population, and whether this might lead to unnecessary cessation of sporting activities, anxiety and increase demand on secondary care cardiology services. Hence, this point mainly refers to overdiagnosis, not to the diagnosis of a condition which might cause SCD. As a result, the review outlined the need for further research on the potential harms of screening as well as the impact of screening on individuals and families, including those with a false positive result and those with a condition where there is no recommended treatment.

- Reference to Italy as one of the few countries in the world where a successful pre-participation screening programme takes place whereby young people who take part in sports are required to be screened for cardiac disorders that may put them at risk of sudden cardiac death.

  Response: The review introduction refers to the study undertaken in the Veneto area of Italy, which was published in 2006. The reviewers, as well as other commentators in the wider literature and previous UK NSC reviews, have highlighted concerns regarding the study's high risk of bias, lack of subsequent published follow-up data, and limited generalisability of study findings (see page 14 of the evidence summary for more information).

- Several responses appeared to link the conclusion of the review that systematic population screening for the risk of SCD is not recommended, to cost.

  Response: Population screening is delivered in large populations of predominantly healthy people and one of the UK NSC's aim is to maintain oversight of the evidence relating to the balance of good and harm as well as the overall cost effectiveness of existing programmes. Although cost is a factor that needs to be taken into account when implementing a new screening programme, cost-effectiveness was not considered in this review, as it was outside the scope of the document. The conclusions of this review are based on the following points, namely:

    - there is uncertainty in relation to the accuracy of screening tests in the general population because all the studies identified in this review typically relied on an assumption that individuals in whom the screening test was negative did not have the disease. Also, the tests were usually performed in athletes, which in turn limits the applicability of these studies to the general population
    - no relevant studies were identified that assessed the effectiveness of screening to prevent SCD compared to no screening in the general population
    - there remains some uncertainty as to the true incidence of SCD in the general population, particularly in the UK

12. A very small number of comments appears to question the competency and the expertise of the reviewers and those involved in the review process, as well as the credibility of the review.

    Response: The review document was developed in keeping with the UK NSC's evidence review process. It was developed by a team at Warwick University which included expertise in emergency and critical care, public health and health services research and review methodology. Independent input on the quality of the review was sought from a consultant cardiologist. Prior to public consultation the document was considered within the UK NSC's advisory structures and by the UK NSC membership. The expertise within these structures is broadly based and relevant to the review. The negative comment on the review's quality was contested by other stakeholders who agreed with the review's outcomes and reported no concerns with the methods or quality.

Recommendation

13. The Committee is asked to approve the following recommendation:

A population screening programme for cardiac conditions associated with sudden cardiac death in the young is not recommended in the UK

Criteria (only include criteria included in the review)	**Met/Not Met**
Section 1 - Criteria for appraising the viability, effectiveness and appropriateness of a screening programme	
The Condition	
1. The condition should be an important health problem as judged by its frequency and/or severity. The epidemiology, incidence, prevalence and natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease	**Severity: met; Incidence: not met; Natural history: not considered**
The Test	
4. There should be a simple, safe, precise and validated screening test.	**Not Met**
The Screening Programme	
11. There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an “informed choice” (such as Down’s syndrome or cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.	**Not Met**
13. The benefit gained by individuals from the screening programme should outweigh any harms for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications.	**Not Met**

List of organisations and individuals contacted Annex A

1. British Cardiac Patients' Association
2. British Cardiovascular Society
3. British Congenital Cardiac Association
4. British Heart Foundation
5. Cardiac Risk in The Young
6. Cardio & Vascular Coalition
7. Cardiomyopathy UK
8. Children's Heart Federation
9. Circulation Foundation
10. Faculty of Public Health
11. Graham Hunter
12. HEART UK
13. Institute of Child Health
14. Jonathon Pilkington
15. The Oliver King Foundation
16. Paul Clabburn
17. PHE adult screening programmes
18. Royal College of General Practitioners
19. Royal College of Nursing
20. Royal College of Paediatrics and Child Health
21. Royal College of Physicians
22. Royal College of Physicians and Surgeons of Glasgow
23. Royal College of Physicians of Edinburgh
24. Sudden Arrhythmic Death Syndrome UK (SADS UK)

Annex B

Screening for cardiac conditions associated with sudden cardiac death in the young

Consultation comments

1. Cardiomyopathy UK

<table>
<tr><td>Name:</td><td colspan="2">Joel Rose</td><td>Email address:</td><td>xxxx xxxx</td></tr>
<tr><td colspan="2">Organisation (if appropriate):</td><td colspan="3">Cardiomyopathy UK</td></tr>
<tr><td>Role:</td><td colspan="4">Chief Executive</td></tr>
<tr><td colspan="5">Do you consent to your name being published on the UK NSC website alongside your response?
Yes</td></tr>
</table>

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Summary p46		Cardiomyopathy UK agrees with the conclusion of the External review against programme appraisal criteria, that there is no new compelling evidence to support a change to the current recommendation against the introduction of a systematic

2. RCN response

Royal College of Nursing
The voice of nursing in the UK

Dear Sir/Madam

Re: Screening for the risk of sudden cardiac death in the young consultation

With a membership of around 435,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

The Royal College of Nursing welcomes this opportunity to respond to the screening to prevent sudden cardiac death in the young consultation. Our members have indicated that although they would like to see screening introduced they acknowledge that tests are often inconclusive, that there may be no treatment and that any abnormality may prohibit children and young people undertaking healthy exercise. In addition, it is appreciated that potentially cardiac services could receive a massive number of unnecessary referrals which may ultimately prevent the investigation and treatment of those with symptomatic cardiac issues.

I hope the above feedback from our members will be helpful to you.

Yours sincerely,

Wendy Preston

Head of Nursing Practice

3. Royal College of Physicians of Edinburgh

Name:	Dr Tom Mackay	**Email address:**	xxxx xxxx
Organisation (if appropriate):	Royal College of Physicians of Edinburgh		
Role:	Vice President		
Do you consent to your name being published on the UK NSC website alongside your response? **Yes** **~~No~~**			

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
General	General	The College supports the content of the document and its conclusions. It offers a balanced overview which reflects the pressing need for ongoing research on this topic.
Areas of uncertainties / page 11	Question 1: Evidence as to the precise incidence of sudden cardiac death in the UK	This area has so much uncertainty that College Fellows have suggested that it would have been very helpful if the review outlined more specific research recommendations, providing potential researchers with a framework of the characteristics of a project that could at least in part address the uncertainty. For example, research projects to address the issue of precise incidence of sudden cardiac death in the UK, could examine individuals by age group: 12- 18 years and 18-39 years. There is a need for consideration to be made as to what size of a cohort is needed for the study to be representative of the population of the UK, taking into account

		factors such as the multi-ethnic population and rural and urban population. It is vital that in such a project, the follow up period is long enough for the results of the study to be informative and reliable.
Areas of uncertainties / page 11	Question 2: Evidence to determine the test accuracy of screening tests for SCD in the general population	Again, College Fellows have suggested that it would have been very helpful if the review outlined more specific research recommendations, providing potential researchers with a framework of the characteristics of a project that could address the uncertainty. It is also important to specify the test/group of tests that would enable simultaneous screening for all the potential causes of sudden cardiac death. These would then need to be applied and tested as a package or programme.

4. Royal College of Paediatrics and Child Health

Email address:	xxxx xxxx
Organisation:	Royal College of Paediatrics and Child Health
Name:	Comments received on behalf of James Fraser, Eugene Strehle, Julia Thomson, Oliver Rackham and Ffion Davies

Do you consent to your name being published on the UK NSC website alongside your response?

Yes

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
General	General	The reviewer agrees with the document to not screen for sudden cardiac death.
Page 46: need for additional research	Incidence of SCD in children	This is an important program as SCD is seen as a rare cause of sudden death in teenagers. The reviewer supports the review's findings that screening for SCD is not supported by the evidence at this stage.
	Criterion 1 - Incidence of SCD	This comment also translates to Page 46: need for additional Research. In teenagers the incidence of SCD is not known. This is because historical studies have relied upon MCCD data, post mortem conclusions, and coroners verdicts - all of which are likely to underestimate the true extent of the problem.
General	General	Going forward a standardised approach needs to be adopted to investigate all that encompasses the usual history and examination, but also peri-mortem genomic tests and expert cardiac autopsy. The newly published Standardised Operational Guidance for Child Death

		Review Statutory and Operational CDR guidance, along with the Multiagency Sudden Unexpected Death in Infancy and Children guidelines SUDI guidance, provide an opportunity to do this. Additionally, the National Child Mortality Database should begin to publish reports from 2021 onwards that will be a vital resource for researchers in this area.
Page 39	998 out of every 1000 positive test results would be incorrect	It was agreed that the extremely low PPV for sudden cardiac death renders screening at best useless and at worst, dangerous for the overall cardiovascular health of children and young people as their parents would stop them doing exercise.
Page 46	Review findings do not support a change to the current recommendation against the introduction of a systematic population screening programme for sudden cardiac death in the young in the UK.	The reviewer agrees with this statement.
Criterion 4	There should be a simple, safe, precise and validated screening test NSC VERDICT: NOT MET	The last decade has seen the prominence of the use of the 12-lead ECG as a screening test across all aspects of athletic practice. This includes in prominent American sporting bodies such as the NBA and NFL even though the American Heart Association (AHA) have not recommended the routine use of the ECG as a screening tool in addition to standard medical history and physical examination. In Europe, the ESC have recommended the routine use of the ECG in the screening pathway13. The majority of conditions associated with SCD in the young can be identified on the basis of an ECG abnormality. In a meta-analysis of 47,137 athletes studied, the ECG was associated with exceptional sensitivity and specificity findings of 94% and 93% respectively. Whilst the reviewers from the national screening programme highlight some limitations of a meta-analysis design, such studies are considered to be at the top of the hierarchy of scientific evidence.

		Reference: Harmon KG, Zigman M, Drezner JA. The effectiveness of screening history, physical exam, and ECG to detect potentially lethal cardiac disorders in athletes: A systematic review/meta-analysis. J Electrocardiol [Internet]. 2015 [cited 2015 Feb 25];Available from: http://www.sciencedirect.com/science/article/pii/S0022073615000497
Criteria 11	There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an “informed choice” (e.g. Down’s syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.	There are no randomised control trials investigating the effectiveness of screening in reducing SCD. The very nature of the disease SADS, from asymptomatic low-risk individuals, through asymptomatic high-risk and then symptoms, does not make it amenable to RCT methodology. This disease requires cohort studies, comparing intervention benefit (12-lead ECG) vs non-intervention group. The most persuasive evidence supporting the theory that early identification of disease through ECG screening saves lives comes a large prospective Italian study of 42,386 competitive athletes aged 12-35 years with 26 years follow-up. Reference: Corrado D, Basso C, Pavei A, Michieli P, Schiavon M TG. Trends in Sudden Cardiovascular Death in Young Competitive Athletes. JAMA. 2006;296:1593–1601.
Criterion 13	The benefit gained by individuals from the screening programme should outweigh any harms for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications. NSC VERDICT: NOT MET	A prospective, non-randomised controlled trial of 952 high school athletes demonstrated that athletes undergoing ECG screening were likely to more likely to be satisfied with their screening, feel safe during competition, support that all athletes should receive cardiac screening and state that the ECG had a positive impact on their training. Individuals with false positive screening tests were not found to report excessive anxiety after screening. Reference: Asif IM, Johnson S, Schmieg J, Smith T, Rao AL, Harmon KG, Salerno JC, Drezner JA. The psychological impact of cardiovascular screening: the athlete's perspective. Br J

		Sports Med [Internet]. 2014;48:1162 LP-1166. Available from: http://bjsm.bmj.com/content/48/15/1162.abstract The improved diagnostic ability of the 12-lead ECG over the last decade has significantly improved the chances of a “false positive” result. Development of ECG interpretation criteria have reduced to false positive ECG rate to 1.8%-3.0%. References: Dhutia H, Malhotra A, Finocchiaro G, Merghani A, Papadakis M, Naci H, Tome M, Sharma S. Impact of the International Recommendations for Electrocardiographic Interpretation on Cardiovascular Screening in Young Athletes. J Am Coll Cardiol. 2017;70. Malhotra A, Dhutia H, Yeo T-J, Finocchiaro G, Gati S, Bulleros P, Fanton Z, Papatheodorou E, Miles C, Keteepe-Arachi T, Basu J, Parry-Williams G, Prakash K, Gray B, D'Silva A, Ensam B, Behr E, Tome M, Papadakis M, Sharma S. Accuracy of the 2017 international recommendations for clinicians who interpret adolescent athletes’ ECGs: a cohort study of 11 168 British white and black soccer players. Br J Sports Med [Internet]. 2019;bjsports-2017-098528. Available from: http://bjsm.bmj.com/content/early/2019/07/05/bjsports-2017-098528.abstract 32. Belinda G, J. AM, Christopher S, R
General	General	The reviewer agrees with the findings of this review.

5. British Cardiovascular Society

This one is urgent – closes tomorrow.

Can you respond to UKNSC as follows:

“BCS endorses the current UK NSC position on screening of the asymptomatic general population aged 12-39 for sudden cardiac death risk.“

xxxx xxxx

6. Royal College of Physicians

Dear all

The RCP is grateful for the opportunity to respond to the above.

We have liaised with the BCS and we would also like to endorse the current UK NSC position on screening of the asymptomatic general population aged 12-39 for sudden cardiac death risk.

I would be grateful if you could confirm receipt.

Best wishes

7. xxxx xxxx

Dear Sirs

Re: The UK NSC recommendation on screening to prevent Sudden Cardiac Death in 12 to 39 year olds – xxxx xxxx **-** xxxx xxxx **- Consultation Response.**

Thank you for the opportunity to comment on the NCS recommendation on screening to prevent Sudden Cardiac Death in 12-39 year olds.

As a xxxx xxxx we set up the charity xxxx xxxx - xxxx xxxx in memory of xxxx xxxx xxxx xxxx xxxx xxxx who died unexpectedly from a sudden cardiac arrest in xxxx xxxx whilst out running in xxxx xxxx. xxxx xxxx was an apparently fit and healthy xxxx xxxx who had shown no obvious previous symptoms. Unbeknown to everyone xxxx xxxx actually had an undiagnosed hereditary heart condition - ARVC. xxxx xxxx was a happy young xxxx xxxx to a xxxx xxxx xxxx xxxx and was engaged to be married to xxxx xxxx. xxxx xxxx at the beginning of what should have been a long and successful career in wealth management having been through university, gained employment at a leading firm, and recently completed xxxx xxxx professional exams . xxxx xxxx was in the prime of xxxx xxxx life. xxxx xxxx grew up in a fairly large but xxxx xxxx in the small tight knit xxxx xxxx town of xxxx xxxx and had moved to xxxx xxxx with xxxx xxxx xxxx xxxx xxxx xxxx. xxxx xxxx family and friends have been left completely devastated by xxxx xxxx premature, and (most likely) **preventable** death.

Following xxxx xxxx death xxxx xxxx have undergone cardiac screening resulting in xxxx xxxx, xxxx xxxx, and xxxx xxxx being diagnosed with Arrhythmogenic Cardiomyopathy. The xxxx xxxx have now been fitted with S-ICDs to prevent sudden cardiac death. Thankfully we are now protected but it is too late for xxxx xxxx. It is simply not right that this screening only takes place following the death of an immediate family member.

We are extremely disappointed that the NSC consultation document does not recommend population screening for sudden cardiac death in the young which we believe, and the evidence suggests, would prevent other families going through the devastation that we have experienced. We have many concerns about this recommendation as well as the basis for this conclusion. We agree with concerns raised by Cardiac Risk in the Youngs (CRY):

- It FAILS to stress that 1 in 300 people screened have a cardiac condition that can benefit from treatment or lifestyle advice.

- It FAILS to objectively evaluate the overlap between the current routine use of the ECG in the NHS / medical practice for general diagnostics and monitoring and its role in cardiac screening. For instance;
    - the contradictory position of the NSC where the ECG IS an accurate test if you experience symptoms, but the ECG IS NOT an accurate test if you DO NOT experience symptoms.
    - NICE T Loc guideline https://www.nice.org.uk/guidance/cg109/chapter/1-Guidance… where ECGs are an essential part of assessment for people who have a temporary loss of consciousness.
    - the routine use/requirement of ECGs in screening programmes
      in sport
      pharmaceutical drugs trials
      army recruits https://apply.army.mod.uk/…/soldier-recr…/soldier-assessment
      commercial pilots https://www.baatraining.com/the-aviation-medical-exam-what…/
      pre operations assessments https://www.escardio.org/…/When-to-perform-pre-operative-ECG & https://www.nice.org.uk/…/tests-before-surgery-pdf-31411086…

- it contradicts the information on the NHS choices website (e.g. WPW)

WPW is one of the most common conditions identified in the CRY screening programme, affecting more than 1 in 700 young people. The NHS states "it may only be picked up when an ECG is carried out for another reason. In these cases, further tests will be done to determine if treatment is required… with treatment, the condition can normally be completely cured…..WPW syndrome can sometimes be life-threatening and treatment can eliminate this risk" https://www.nhs.uk/conditio…/wolff-parkinson-white-syndrome/.

- It FAILS to frame the consultation correctly. The current NSC screening programmes (e.g. breast cancer) focus on identification of conditions/diseases, whereas this policy is framed as identification of the risk of sudden cardiac death. The framing of the issue should be consistent with the other NSC policies, "screening for cardiac conditions in young adults".

- The NSC is requesting for Randomised Controlled Trials to be conducted. This is UNETHICAL and would lead to young people dying in the pursuit of "better" science.

- The NSC consultation document FAILS to demonstrate the impact young sudden cardiac deaths have on our society.

A key issue in understanding the impact is understanding (and correctly interpreting) the incidence of Young Sudden Cardiac Death. The NSC document states, "There continues to be uncertainty as to the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person-years."

CRY's research has shown an incidence of 1.8 deaths per 100,000 per year in the UK. This equates with 12 young sudden cardiac deaths per week, more than 600 young sudden cardiac deaths per year in the UK. It is worrying The NSC refers to this as "low incidence". However, sudden cardiac death is one of the most common causes of death in young people, the most common cause of death in young athletes and has a massive impact on family, friends and local communities. Screening would also be likely to prevent deaths of people outside of the age group who die from the same conditions at a later stage in life.

The recommendation seems at odds with other important and successful screening programmes in the UK such as cervical cancer. It is recognised that early diagnoses of cancers can save the NHS money in treatment and that Sudden Cardiac Death does not directly result in cost to the NHS but surely screening programmes should be about saving lives rather than saving money. Society has invested in these young people for example through education and health. The benefits to society these young people provide and would continue to provide in the future are lost.

The review suggests that positive screening results may lead to anxiety and reduce the amount of sport and exercise individuals participate in. A number of these conditions can be addressed or even cured through medical procedures, and the majority can be addressed through medication and simple lifestyle changes. Although these lifestyle adjustments might involve giving up competitive sport they generally do not preclude a healthy active lifestyle. Given the choice between death and making lifestyle changes (which I have experience of) xxxx xxxx sure xxxx xxxx and the 12 other young people who die every week would have chosen the later. The number of young people taking up the opportunity of screening provided by CRY indicates that they would rather know if they have a condition and are at risk. If they are diagnosed, they can then make informed decisions based on level of risk and advice from experts whether treatment or lifestyle changes are required.

It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through simple and relatively low cost screening with an ECG. We therefore urge you to reconsider the evidence and your decision not to recommend population screening to prevent other families and communities suffering as we have.

Yours sincerely

xxxx xxxx

xxxx xxxx on behalf of the board of Trustees
xxxx xxxx - xxxx xxxx

Cc Boris Johnson MP – Prime Minister
Matt Hancock MP -Secretary of State for Health and Social Care Jonathan Ashworth MP –
Shadow Secretary of State for Health

8. Cardiac Risk in the Young (CRY)

Response from Dr Steven Cox, Chief Executive of Cardiac Risk in the Young (CRY), to the latest consultation document published by the National Screening Committee (NSC) to review the role of screening for the risk of sudden cardiac death in the young.
https://legacyscreening.phe.org.uk/suddencardiacdeath

The main conclusion of the NSC Consultation:
The NSC consultation document does NOT recommend population screening for sudden cardiac death in the young.

Summary of the CRY Response to the NSC Consultation document:
There are many problems with the external review consultation document, raising serious questions about both the process of review and its substantive content. Our main concern is particularly in relation to:

- the way in which the NSC appoints reviewers;
- the way evidence is evaluated (the criteria for sourcing and evaluation of evidence);
- the conclusions of the report (inaccurate presentation of the problem, inaccurate interpretation of evidence and erroneous conclusions as a result of these inaccuracies.

The current response will address the following key concerns:

1. Framing of the consultation
2. The type of evidence sourced
3. The way evidence is interpreted and incidence of young sudden cardiac death (YSCD) is evaluated
4. The way the screening policy is evaluated within the context of other established clinical procedures
5. The way the content is presented, in particular how the problem is initially introduced in the Plain English summary.

1. Framing of the consultation

The way the policy is framed is incorrect. This policy is framed as screening for the risk of sudden cardiac death, while other screening programmes endorsed or being evaluated by the NSC are focused on detection of conditions (or risk markers).

For example,

- Cervical cancer screening in adults
- Foetal anomaly screening in pregnant women
- Prostate cancer screening in adults
- Stomach cancer screening in adults
- Familial hypercholesterolemia screening in children
- NHS Abdominal Aortic Aneurysm Screening Programme

The difference is crucial because this consultation document repeats on a number of occasions that screening results in a significant proportion of people identified which will result in “overtreatment”. The evidence shows there are many management pathways from treatment and lifestyle advice to surgery which can reduce the risk of suffering a cardiac arrest/sudden cardiac death once a condition has been identified. Furthermore, early identification of some cardiac conditions can result in monitoring, and intervention when necessary, in order to avoid serious cardiac complications in the 4th and 5th decade of life at a point when the cardiac condition results in symptoms (e.g. breathlessness) due to cardiac damage/adaptation.

The story of England Lioness Jade Moore is an example of a young person who was screened (in 2007) and went on to have corrective surgery, after which she returned to sport at the highest level. http://www.thefa.com/news/2019/jan/10/jade-moore-hole-in-the-heart-england-100119. In 2019 she competed for England during the World Cup.

In the case of the NSC endorsed NHS abdominal aortic aneurysm (AAA) screening programme (https://www.gov.uk/topic/population-screening-programmes/abdominal-aortic-aneurysm) individuals will be identified with aortic aneurysms which will be at risk of rupturing and causing death. Cardiac screening in young people has the potential to identify an aorta which is at risk of rupturing and causing death in a similar way to a 65-year-old man within the NSC endorsed programme.

CRY recommendation: The framing of this issue should be consistent with the other NSC policies, "screening for cardiac conditions in young adults".

2. The type of evidence sourced

Another point that needs to be addressed is the NSC concern regarding the type of evidence which is informing clinical practice.

The NSC is requesting for Randomised Controlled Trials to be conducted. This is **UNETHICAL** and would lead to **young people dying in the pursuit of "better" science**.

The NSC has stated that there is an absence of protocols informing how to treat asymptomatic individuals with these conditions. This is incorrect because there are established protocols/recommendations from international scientific bodies. A prime example is an asymptomatic individual with Long QT syndrome and a QTc of 500, where something as simple as a beta blocker can reduce their risk of SCD significantly and that is why beta blockers are recommended in those individuals. The second point which contradicts the NSC position is that something as simple as lifestyle advice or monitoring has the potential to save lives. High risk patients with HCM or ARVC are routinely identified in the NHS Inherited Cardiac Condition (ICC) clinics and once they are identified they can be reviewed on a regular basis, reassessing their risk and intervening when necessary. If the argument stands that clinicians have no idea what to do with asymptomatic individuals with inherited cardiac conditions, then the entire model of ICC clinics and screening relatives and cascade genetic screening falls apart. These programmes are endorsed by the NHS, Department of Health, and Public Health England, as well as heart charities like the British Heart Foundation.

3. The way evidence is interpreted and incidence of young sudden cardiac death (YSCD) is evaluated

A key issue in understanding the impact of screening is understanding (and correctly interpreting) the incidence of Young Sudden Cardiac Death.

Whilst young sudden cardiac death has been acknowledged by the NSC as meeting their criteria for "*severity*" they have said it does not meet the criteria for "incidence". The NSC document states, *"There continues to be uncertainty as to the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person-years."*

- Qualitative characterisation of the stated incidence as "low" is inaccurate when compared to other risks of death of the young

The key research by Papadakis et al, 2009 reported an incidence of 1.8 deaths per 100,000 people per year in the UK, in line with the NSC's estimates. This equates with **12 young sudden cardiac deaths per week**, more than **600 young sudden cardiac deaths per year** in the UK. The NSC refers to this as **"low incidence"**. However, sudden cardiac death is one of the most common causes of death in young people, the most common cause of death in young athletes and has a massive **impact on family, friends and local communities and is associated with numerous decades of lost life years. The qualitative interpretation of incidence should therefore be contextualised to young people, when its incidence is high in comparison to other risks of dying of the young, such as leukaemia etc.**

- Lack of transparency about evidence used for estimation of incidence

In the light of the lack of clarity about the way incidence estimation is to be framed and characterised, and the evident misunderstanding of the problem manifest in the NSC policy document, CRY made a request (on 31st October 2018) to meet with the NSC and/or the epidemiologist appointed by Public Health England, in order to provide guidance and clarity to the policy documents. This request was rejected.

The need for greater transparency about the estimation of incidence in order to provide clarity for the process of policy making is essential, as exemplified in the recent parliamentary question, asked on 19th June 2019:

"To ask the Secretary of State for Health and Social Care, whether his Department has made an estimate of the number of 14-year-olds today that will die from a sudden cardiac death before they reach their 36th birthday." (WPQ 266733)
https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2019-06-19/266733/,

The response stated:

"The information is not available in the requested format. The chances of sudden heart attacks in apparently physically fit young people are extremely small. The overwhelming majority of heart attacks happen in elderly people."

This response demonstrates that the way in which summary of evidence (based on NSC) is subsequently interpreted by policy makers is essential for any future policy. A lack of understanding of the evidence informing the incidence and impact of young sudden cardiac death is exemplified through:

1. the use of arbitrary terms such as “extremely small” which fail to contextualise the incidence to young people. The impact of the death of a young person with 60 years of life ahead of them cannot be compared to the death of an 80-year-old. It is unacceptable to compare young sudden cardiac death (from congenital/genetic/inherited conditions) to heart attacks in elderly people.
2. the use of the term “heart attack”. The correct term is “sudden cardiac arrest”.

The inability to provide an informed answer to this simple question demonstrates an expert has not engaged in a meaningful way with the evidence, either because they do not understand the data or they have made a conscious decision to be evasive.

- Inconsistent interpretation of evidence informing incidence estimation

In this consultation document they have highlighted the importance of presenting absolute values for young sudden cardiac deaths when available. However, they applied this rule inconsistently, e.g. they failed to do this when presenting the data in a recent paper published in the New England Journal of Medicine https://www.nejm.org/doi/full/10.1056/NEJMoa1714719. In this paper it can be seen that **1 in 1,396** footballers died of cardiac conditions (8 deaths out of 11,168 footballers over a 20 year period) after being screened at the age of 16. In this study 42 of the footballers were identified with potentially life-threatening conditions and treated. 2 of these knew they had heart conditions and died after they continued to play sport. 6 of the players died having been cleared at the age of 16. The fact that they may have developed the conditions after the initial screening at 16 has led to more regular screening for elite athletes. Had there been no screening in this group the incidence of young sudden cardiac death is likely to have been significantly more than 1 in 1,396.

CRY recommendation: A request has been made by CRY to the National Screening Committee to provide the incidence figures for all the conditions where the NSC currently supports a policy of screening in the UK. The request was to provide this

- in the format which the authors of this report have used for latest review of screening to prevent SCD, i.e. number of deaths per 100,000 people per year, and
- for the non screened groups and the screened groups for each of the conditions.

Whilst the NSC have agreed to produce this information, it had not been provided by the date of this submission (6th September 2019) and therefore it is not possible to compare this incident data (in the format of deaths per year) with other conditions where the NSC has agreed the criteria for incidence has been met. CRY urge the NSC to provide this information and to allow transparent, open and accurate risk estimation and risk comparison.

4. The way the screening policy is evaluated within the context of other established clinical procedures

During the 2014 consultation CRY raised concerns that the screening policy did not reflect the current routine, accepted practices carried out within NHS, in particular this related to the way the 2014 report contradicted DoH information, NICE guidelines and the NSF chapter 8. This report has once again failed to evaluate the overlap between the current routine use of the ECG in the NHS/medical practice for general diagnostics and monitoring and its role in cardiac screening. This is of fundamental importance because the NSC continue to conclude that *"criteria 4: There should be a simple, safe, precise and validated screening test"* is not met.

CRY's specific concern is in relation to:

- The contradictory position of the NSC where the ECG IS an accurate test if you experience symptoms, but the ECG IS NOT an accurate test if you DO NOT experience symptoms.

The NSC currently recommends people with symptoms like breathlessness to go to their GP for evaluation. But it must be pointed out an initial test often used to determine if a symptom is caused by a cardiac condition is an ECG.

Similarly with young people who experience an episode of passing out, affecting >30% of the population, the ECG is the most important test and part of NICE guidelines (Note 1.1.2.2 https://www.nice.org.uk/guidance/cg109/chapter/1-Guidance

It is therefore unclear why the same test should be considered an inaccurate test when detecting cardiac conditions that do not present with symptoms. The key issue here - and it has been well established in the academic literature when comparing the screening model endorsed by the American Heart Association which is focused on symptoms - compared to the European Society of Cardiology model which also incorporates an ECG, is the evaluation of symptoms alone in the context of predicting cardiac disease is unreliable. The way in which different people experience symptoms and report symptoms is highly variable, equally the way a doctor then interprets the individual's experience of symptoms is highly variable.

The result of the subjective interpretation of symptoms by the individual and then the doctor means some symptoms may be considered arbitrary and misattributed to other causes like stress and anxiety. This was the case of Charlotte Carney https://metro.co.uk/2018/09/06/woman-undergoes-heart-transplant-after-doctors-dismiss-her-symptoms-as-stress-7915501/. After a CRY screening Charlotte was identified with a very serious condition and has now had a heart transplant.

Most young people will, at some point in time, experience some form of symptom like breathlessness, palpitations, passing out, dizziness and/or chest pain – if they report these symptoms to their GP it can be an arbitrary decision whether the GP offers them an ECG or not.

- Failure to understand the role of the ECG to detect young people with cardiac conditions in routine health checks and screening programmes

The NSC states that "the test [ECG] for SCD was safe, but is not accurate". However, it is already used routinely in screening programmes for commercial pilots, army recruits, pre-operation surgery, sport (international events/competitions), pharmaceutical drugs trials...

Aviation medical exam
https://www.baatraining.com/the-aviation-medical-exam-what-to-expect/

Every candidate must obtain Class I and Class II medical fitness certifications in order to become a commercial pilot. First class medical certificate requirements include checks of eyesight, ears, physical examination, electrocardiogram (ECG), lung function, cholesterol blood, hemoglobin blood, chest X-ray, urine, period of validity.

Army pre-selection assessment
https://apply.army.mod.uk/how-to-join/joining-process/soldier-recruitment-steps/soldier-assessment

The ECG is one of the medical tests which is part of a full assessment to check a person is healthy enough to take part, and to join the Army.

Pre-op assessment prior to surgery
https://www.escardio.org/Journals/E-Journal-of-Cardiology-Practice/Volume-7/When-to-perform-pre-operative-ECG

https://www.nice.org.uk/guidance/ng45/resources/tests-before-surgery-pdf-3141108622789

If a person is aged over 16 years and about to have planned (also called 'elective') surgery, they may be offered an ECG depending on health status. Every person having major surgery is likely to be offered an ECG.

- NSC Consultation document contradicts the information on the NHS choices website

For instance, WPW is one of the most common conditions identified in the CRY screening programme, affecting more than 1 in 700 young people.

The NHS states *"it may only be picked up when an ECG is carried out for another reason. In these cases, further tests will be done to determine if treatment is required… with treatment, the condition can normally be completely cured…..*WPW syndrome can sometimes be life-threatening………..and treatment can eliminate this risk". The latest ESC guidelines on the management of supraventricular tachycardia which were reported this week at the 2019 ESC congress suggest that a WPW ECG pattern is an indication for electrophysiological studies in high risk population such as young athletes.

https://www.nhs.uk/conditions/wolff-parkinson-white-syndrome/

Similar information can be found on other NHS pages for Long QT, Brugada, Cardiomyopathies…

The fact the ECG does not identify every young person at risk of suffering a cardiac arrest does not mean it is NOT an accurate test as the National Screening committee have stated. It is one of the most useful tests used in cardiology https://www.bhf.org.uk/informationsupport/tests/ecg. When an ECG is used as a screening tool it will identify the majority of cardiac conditions that affect young people. 1 in 300 people screened will be identified with cardiac conditions which could potentially be life threatening. Once identified these conditions can be treated and sometimes cured. These treatments and operations are routinely provided on the NHS for people once they are identified with the cardiac conditions.

5. **The way the content is presented, in particular how the problem is initially introduced in the Plain English summary,**

The plain English summary (page 5-6) is one of the most important sections and needs to be simple but accurate. Yet from the onset it is littered with inaccuracies, and the specific semantics used fail to address the seriousness of the issue of young sudden cardiac death:

- Inaccurate understanding of the problem

The Summary states incorrectly: "the way this [Screening] might work is by identifying heart conditions at an early stage before they cause *symptoms*". The screening is carried out to prevent a potential cardiac arrest which will usually occur in the absence of symptoms, not before symptoms present. This is just one of the occasions where the authors have failed to understand the issue they have been appointed to evaluate.

The final line of the plain English summary on page 6 states: "However, before researchers can do a research trial of screening, there is a need for accurate screening tests and clear guidelines to enable clinicians to treat patients that have a disease, but do not have symptoms." This statement shows disconcerting ignorance both of many routine screening programmes already implemented within the UK and abroad, as well as a lack of understanding of routine clinical practice within NHS cardiology departments.

- Lack of full appreciation of the context within which the policy is being evaluated

The opening of the second paragraph states, "Screening has been *proposed* by *some people* as a way to prevent sudden cardiac death.." The use of the phrase "*proposed* by *some people"* to connote policies endorsed by the European Society of Cardiology, governing bodies including FIFA and the International Olympic Association, the UK armed forces, aviation authorities indicates a lack of appreciation of the national and international stakeholder context within which the policy is taking place.

- The Summary document does not build on the latest evidence

This latest review builds on the evidence since 2014, without addressing the shortcomings and criticism raised in the previous NSC 2014 consultation. The Summary references the 2014 NSC report and its conclusions justified by 3 bullet points, but fails to acknowledge and incorporate the most recent evidence that has addressed and repudiated the conclusions from the NSC 2014 consultation.

The Summary document highlights the general tone of the authors throughout the document, exemplifying a subjective position they have taken to the screening debate.

CRY recommendation: The document must be submitted to the acknowledged experts in the field to amend and correct the inaccuracies within the document before it is finalised in order to ensure its veracity, objectivity and credibility.

Conclusion

The concerns raised within this response do not constitute a critical appraisal of the entire document. There are many additional issues which could be raised which further undermine the conclusions of this report. This response should be treated alongside the previous response in 2014 as the concerns raised during the 2014 consultation have not been addressed in this document.

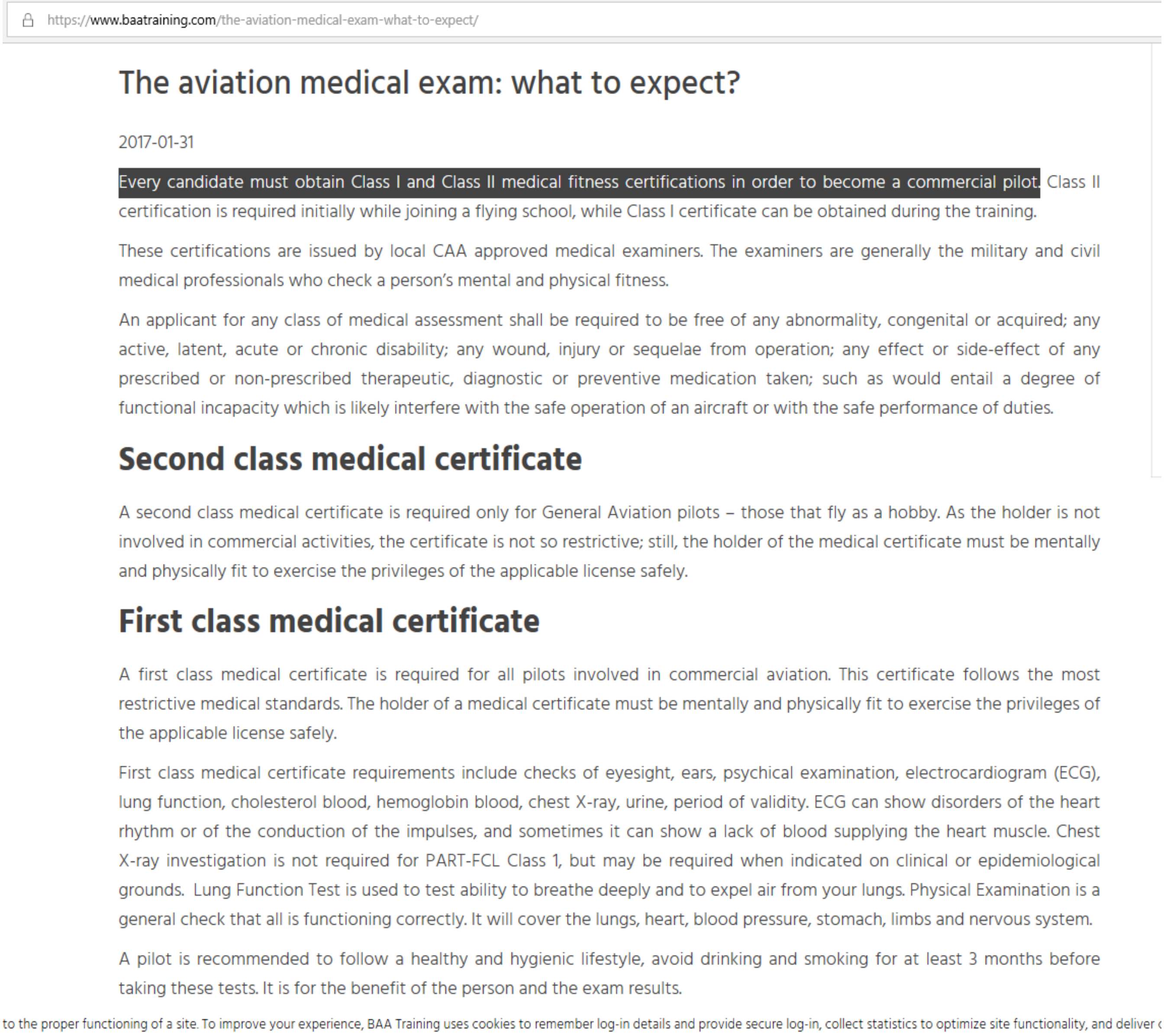
Whilst we welcome the NSC finally acknowledging that “Sudden cardiac death in the young is an important health problem”, we urge the Committee to attend to many inaccuracies, biases and inconsistencies contained within this report. It is essential that the Committee develops a transparent and open process through which the issue will be framed, evidence sourced, evaluation criteria determined, data and evidence interpreted and final conclusions made. CRY and its associated expert cardiologists call upon the NSC to engage in mutually open and constructive dialogue to ensure that the document is a credible source of information for policy makers.

The sooner the policy in the UK reflects the most up to date and strongest evidence, the sooner our country will be able to save young lives and ensure fewer families are devastated by these avoidable tragedies.

Appendix

Screen Grabs

Aviation medical exam
https://www.baatraining.com/the-aviation-medical-exam-what-to-expect/



https://www.baatraining.com/the-aviation-medical-exam-what-to-expect/

The aviation medical exam: what to expect?

2017-01-31

Every candidate must obtain Class I and Class II medical fitness certifications in order to become a commercial pilot. Class II certification is required initially while joining a flying school, while Class I certificate can be obtained during the training.

These certifications are issued by local CAA approved medical examiners. The examiners are generally the military and civil medical professionals who check a person's mental and physical fitness.

An applicant for any class of medical assessment shall be required to be free of any abnormality, congenital or acquired; any active, latent, acute or chronic disability; any wound, injury or sequelae from operation; any effect or side-effect of any prescribed or non-prescribed therapeutic, diagnostic or preventive medication taken; such as would entail a degree of functional incapacity which is likely interfere with the safe operation of an aircraft or with the safe performance of duties.

Second class medical certificate

A second class medical certificate is required only for General Aviation pilots – those that fly as a hobby. As the holder is not involved in commercial activities, the certificate is not so restrictive; still, the holder of the medical certificate must be mentally and physically fit to exercise the privileges of the applicable license safely.

First class medical certificate

A first class medical certificate is required for all pilots involved in commercial aviation. This certificate follows the most restrictive medical standards. The holder of a medical certificate must be mentally and physically fit to exercise the privileges of the applicable license safely.

First class medical certificate requirements include checks of eyesight, ears, psychical examination, electrocardiogram (ECG), lung function, cholesterol blood, hemoglobin blood, chest X-ray, urine, period of validity. ECG can show disorders of the heart rhythm or of the conduction of the impulses, and sometimes it can show a lack of blood supplying the heart muscle. Chest X-ray investigation is not required for PART-FCL Class 1, but may be required when indicated on clinical or epidemiological grounds. Lung Function Test is used to test ability to breathe deeply and to expel air from your lungs. Physical Examination is a general check that all is functioning correctly. It will cover the lungs, heart, blood pressure, stomach, limbs and nervous system.

A pilot is recommended to follow a healthy and hygienic lifestyle, avoid drinking and smoking for at least 3 months before taking these tests. It is for the benefit of the person and the exam results.

Army pre-selection assessment
https://apply.army.mod.uk/how-to-join/joining-process/soldier-recruitment-steps/soldier-assessment

oin/joining-process/soldier-recruitment-steps/soldier-assessment

Technical Selection Test - If you want to join a technical trade, you'll need to take this Maths test. The questions are similar to those in a GCSE textbook. Your Candidate Support Manager will tell you whether you need to take it or not.

Technical Corps: Royal Engineers, Royal Electrical and Mechanical Engineers, Royal Signals, Royal Logistic Corps (Ammunition Technician only).

While you're at the centre, you'll complete your pre-employment checks. paperwork. Our team will be on hand to help you with these if you need.

THE MEDICAL

On Day 1, you will be seen by a Doctor to check that you are healthy enough to take part, and to join the Army. The tests will not hurt you and don't involve taking blood or the use of needles.

You will have a full assessment, which will include looking at your past medical history, your current health and a top-to-toe medical examination along with some other tests.

Although some of your medical records have been considered already, a 'Pass' outcome is not guaranteed until the doctor has fully considered both your medical records, and a face-to-face consultation with you.

For some individuals, further information, referral or consideration by the senior army doctor in charge of recruiting is required after the pre-selection assessment to ensure that the correct decision is made about you.

THE MEDICAL TESTS:

- Urine, hearing, eyesight, colour perception and your lung capacity will all be tested.
- Measure your waist, and confirm your Body Mass Index by checking your height and weight.
- An Electrocardiogram (ECG). This involves having small pads stuck to your arms, legs and chest so that we can measure the electrical activity of your heart.

A few people will also need an Echocardiogram or an exercise spirometry.

- An echo cardiogram is a scan looking at the structure of your heart. A trained technician will use a small handheld scanner moved over your chest to do this. It only takes 30-40 minutes and doesn't hurt.
- Exercise spirometry looks at how well your lungs work before and after exercise. You will do some blowing tests then be put on an exercise bike for a short time. After that the blowing tests will be repeated. By comparing the before and after we can look at the effect that exercise has on your lungs.

PHYSICAL TESTS

You'll be asked to take part in three different tests. The standard you need to meet is different depending on which role you're hoping to join. The Assessors will be watching to see how much effort you put in. The tests have recently changed - they are not harder, and the training that you've done towards the old tests will

100% ARMY FIT APP

If you need to improve your fitness level, or keep it at a good level before starting, check out our free fitness app.

https://www.nhs.uk/conditions/wolff-parkinson-white-syndrome/

9. xxxx xxxx, Cardiology registrar and xxxx xxxx, Consultant cardiologist and electrophysiologist

Response to UK National Screening Committee Review on Screening for the Risk of Sudden Cardiac Death in the Young

Authors:

xxxx xxxx, *Cardiology registrar*

xxxx xxxx, *Consultant cardiologist and electrophysiologist*

The sudden death of a young individual is a tragic and highly emotional event. Apart from the devastation within a family unit, the sudden nature of the event and the loss of decades of potentially productive life have a lasting impact on friends, peers, and both the lay and medical communities. Deaths are usually attributable to hereditary or congenital abnormalities affecting the cardiac structure or the electrical system of the heart. Such cases galvanise discussion between physicians, health authorities and the lay community with an emphasis on improving understanding of the conditions predisposing to sudden cardiac death (SCD) and development of effective preventative strategies.

This has led to debates relating to value of cardiovascular screening to identify young individuals with cardiovascular disease that may confer an increase in risk of SCD. The UK national screening committee recently recommended against the introduction of a systematic population screening programme for SCD prevention in the young[1]. This recommendation was based on review of the evidence for and against cardiovascular screening focussing on four main criteria.

Criterion 1: The condition should be an important health problem as judged by its frequency and/or severity. The epidemiology, incidence, prevalence and natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease.
NSC VERDICT: Severity: MET. Incidence: NOT MET. Natural History: NOT CONSIDERED

Current estimates of the incidence of SCD in the young range from almost one in a million to 1:23 000 athletes per year, while some subpopulations of athletes are reported at even higher risk with an incidence of 1 in 3,000 [2,3,4]. The wide contrasts in current estimates are largely due to differing

methodology and heterogeneous population comparisons. In particular, a precise numerator (case identification -number of deaths per year) and denominator (number of participants per year) are required to accurately estimate incidence. Studies are inconsistent with respect to several factors affecting case identification including the definition of an athlete, methods of data acquisition and a lack of mandatory reporting requirements in most settings. For example, the use of media (internet/newspapers) or insurance claims are likely to significantly under-estimate the true incidence of these deaths. Furthermore, the inclusion of all cardiac events (including survivors of sudden cardiac arrest (SCA) versus only those resulting in death and the population examined can impact on the incidence estimate.
However, there is established evidence that deaths due to cardiovascular disease are the leading cause of non-accidental death (i.e. preventable causes) in the young. This is pertinent given the attention and efforts available to reduce the frequency of deaths due to suicide, cancer, homicide and alcohol and substance misuse in the young, which are reported to be less frequent than SCD[3]. In this regard, we agree with the national screening committee that even though there are uncertainties regarding the specific incidence, SCD in the young is an important public health problem for which prevention is a worthwhile exercise given the loss of several decades of potentially productive life.

The authors of this evidence summary did not review data related to the second part of the criterion, namely that the “natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease. Hence, they were unable to comment on whether this component of the criterion was met. At present, the majority of conditions implicated in young SCD are not curable and treatment is aimed at reducing the risk of SCD in those affected. Whilst it is arguable if the natural history of these conditions can truly be appreciated given their heterogeneous characteristics, there are recommendations published from international scientific authorities aimed to guide clinicians in the risk stratification of individuals identified with cardiac disease, including those in the early stage of disease by virtue of being asymptomatic. For example, validated risk stratification tools exist to predict the prognosis of individuals diagnosed with hypertrophic cardiomyopathy (HCM)[5,6]. Risk factors for SCD include: unheralded syncope, family history of SCD, severe left ventricular hypertrophy (>30mm), sustained or non-sustained ventricular tachycardia, and attenuated blood pressure response to exercise. Individuals exhibiting ≥ 1 of these 5 risk markers should be considered for prophylactic insertion of an implantable cardioverter-defibrillator (ICD)[5]. More recently, the European Society of Cardiology (ESC) has proposed and validated risk stratification criteria for patients with HCM based on clinical, imaging and electrical criteria[6]. Risk stratification for ion channel diseases implicated in SCD in young individuals may be achieved using the resting 12-lead ECG. A QT interval >500 msec or the presence of the spontaneous type 1 Brugada pattern confer a higher risk of SCD to asymptomatic individuals diagnosed with long QT syndrome and Brugada syndrome respectively[7]. Invasive electrophysiological evaluation of the asymptomatic individuals with the Wolff-Parkinson-White (WPW) ECG pattern may identify those at elevated risk for SCD[8]. We therefore conclude that asymptomatic individuals identified with several potentially life-threatening cardiovascular diseases through a screening program can be risk stratified through additional electrical or imaging assessment to potentially reduce the risk of SCD

Criterion 4: There should be a simple, safe, precise and validated screening test

NSC VERDICT: NOT MET

The overriding aim of a screening program is to reduce the frequency of SCD in the young by identifying individuals who may be at risk by virtue of harbouring conditions associated with SCD. In athletic cohorts, screening has been recommended on legal, ethical and medical grounds.
In the UK, the national service framework (NSF) chapter 8 for arrhythmia and SCD was developed and published in 2005[9]. The chapter has set national standards and put in place strategies to support the development and improvement of services within this area, including identification of young individuals at risk of SCD. The document recommends further specialist cardiovascular evaluation for young individuals with symptoms suggestive of cardiovascular disease, or a family history of inherited cardiovascular disease or premature SCD. This national strategy appears cheap and pragmatic; however, it is unlikely to identify the majority of individuals with conditions associated with SCD. In a systematic review/meta-analysis of 15 studies comparing screening strategies in 47,137 athletes, the sensitivity/specificity of history taking and physical examination was 20%/94% and 9%/97% respectively to identify cardiovascular disease associated with athletic SCD[10]. These findings are not entirely surprising as most young individuals are asymptomatic before SCD, and most diseases implicated in SCD in the young are not associated with physical signs[11]. A family history is often absent even in affected individuals, because diseases such as HCM and LQTS have low event rates; therefore, family members may not have presented with a sentinel event. In a seminal article, Maron et al. described the demographics of 134 young athletes with SCD[12]. Of 115 young athletes who died suddenly and who had had a standard pre-participation medical evaluation consisting of history taking and physical examination, only four (3%) were suspected of having heart disease, and the abnormality responsible for the death was correctly identified in only one athlete (0.9%).

We acknowledge that the current UK healthcare policy set by the NSF to identify individuals with cardiovascular disease associated with SCD is not strictly 'screening'; nevertheless, it is the foundation from which individuals in the UK are referred for specialist evaluation. Multiple studies and a large meta-analysis have consistently demonstrated that reliance on this practice is woefully inadequate in terms of sensitivity and highlights the need for an additional tool/s to improve the diagnostic yield.
The last decade has seen the prominence of the use of the 12-lead ECG as a screening test across all aspects of athletic practice. This includes in prominent American sporting bodies such as the NBA and NFL even though the American Heart Association (AHA) have not recommended the

routine use of the ECG as a screening tool in addition to standard medical history and physical examination. In Europe, the ESC have recommended the routine use of the ECG in the screening pathway[13].

We agree with reviewers that there is paucity of information relating the follow-up of screen negative individuals with most studies focussing on follow-up of individuals with abnormal ECGs However, detailed follow-up of screen-test negative individuals is challenging due to the range of tests required to exclude all conditions that may cause SCD. We are of the opinion that the ECG may be a useful screening test in addition to the NSF protocol to identify cardiovascular disease for two key reasons.

(a) The majority of conditions associated with SCD in the young can be identified on the basis of an ECG abnormality. It is now well established that the leading cause of young SCD (including non-athletes – approx. 30-50% of all deaths) is sudden arrhythmic death syndrome (SADS) [3,14,15]. In SADS, the heart is structurally normal at post-mortem and such deaths are attributable to the hereditary ion channel diseases such a long QT syndrome, Brugada syndrome and catecholaminergic polymorphic ventricular tachycardia (CPVT), as well as the congenital accessory pathway. Other than CPVT, these conditions are diagnosed by abnormal ECG patterns. In this regard, the ECG is likely to be out-perform tests such as echocardiography in the screening process. In addition, an ECG is often abnormal in 90-95% of cases of HCM and in 80% of cases of arrythmogenic cardiomyopathy[16,17].

(b) The ECG has significantly improved the sensitivity and specificity in identify conditions implicated in young SCD in asymptomatic individuals without any concerning family history. In a meta-analysis of 47,137 athletes studied, the ECG was associated with exceptional sensitivity and specificity findings of 94% and 93% respectively[10]. Whilst the reviewers from the national screening programme highlight some limitations of a meta-analysis design, such studies are considered to be at the top of the hierarchy of scientific evidence.

Criteria 11: There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an "informed choice" (eg. Down's syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.

NSC VERDICT: NOT MET

There are no randomised control trials investigating the effectiveness of screening in reducing SCD. The most persuasive evidence supporting the theory that early identification of disease through ECG screening saves lives comes a large prospective Italian study of 42,386 competitive athletes aged 12-35 years with 26 years follow-up[18]. Pre-participation screening is mandatory in Italy by law, with standard evaluation comprising of history, physical examination, and resting 12-lead ECG. The study compared the incidence of SCD in athletes in the pre-screening era (1979-1982) and late

screening eras (2003-2004). 55 cases were identified over the course of the study. The study demonstrated a reduction in the incidence of SCD from 3.6/100,000 person-years to 0.4/100,000 person-years, representing a 90% reduction in mortality.
Critics of the Italian data often cite that the reduced mortality cannot be equivocally attributed to ECG screening as the study was an observational cohort based investigation, and not a randomised controlled trial. However, it would be impossible to conduct a randomised control trial in Italy as screening of competitive athletes is mandatory by law. The Italian investigators argue the strong - cause effect of relationship of SCD, and the 90% reduction in mortality is supported a number of key findings. Firstly, the decline in SCD in athletes coincided with the implementation of ECG screening in 1982. Secondly, the reduced mortality was accompanied by an increase in the number identified, and subsequently disqualified due to cardiomyopathy. Thirdly, incidence of SCD in the unscreened age matched general population did not change significantly over the same period, remaining at 0.77-0.81 per 100,000/year.

The Italian data is strengthened by the prospective study design and case identification through systematic mandatory reporting system for juvenile sudden death with autopsies performed by specialist cardiovascular pathologists, equating to a more reliable denominator when calculating mortality rates. In Israel and the USA where screening has been found not be effective at reducing SCD, data collection was retrospective and collected predominantly from media sources and catastrophic insurance claims leading to likely underestimate the true mortality rates in these populations[19,20]. Moreover, both the Israel and USA studies estimated the true number of athletes participating in sport each year.
In the absence of randomised control trials, the reviewers assessed the performance of cardiovascular screening by addressing the evidence relating to the safety of the test, the accuracy of the test, the effect of the test outcome on patient management, and the effect of that treatment on health outcomes.

We agree with reviewers that the ECG is safe screening test by virtue of being non-invasive. The reviewers felt that none of cardiovascular screening modalities were accurate. As already highlighted, cardiovascular screening with a 12-lead ECG is associated with excellent sensitivity and specificity in identification of conditions associated with SCD. It is prudent to emphasise that no screening test is 100% accurate (i.e. correctly identify *all* individuals with disease and correctly clear *all* individuals who do not have the disease). For example, mammography is widely accepted as a periodic screening test for the detection of breast cancer, and has the support of the national screening committee. However, the screening test is associated with inaccuracies that are not insignificant. The National Cancer Institute in America has recently published a report relating to the accuracy of mammography. Approximately 10% of women are recalled for further testing after a screening examination, however, only 0.5% of tested women have cancer; thus, approximately 9.5% of tested women will have a false-positive exam[21,22]. Approximately 50% of women screened annually for 10 years in the United States will experience a false positive; of these, 7% to 17% will undergo biopsies[23,24]. Furthermore, invasive breast cancer will be present but undetected by mammography (false negative) in 6% to 46% of exams[25,26]. Whilst an in depth discussion on the merits of mammography screening for breast cancer is beyond the remit of this response, we simply highlight that not all screening tests are 100% accurate.

The reviewers examined evidence and scientific guidelines relating to outcome of disease identification on patient management. As discussed above, there are scientific guidelines available to guide clinicians on the management of asymptomatic patients with cardiomyopathy and ion channel diseases from the European Society of Cardiology (ESC)[6,7]. The reviewers are correct in highlighting that a large proportion of these guidelines are based on level of evidence B and C. However, this is in line with a recent analysis of European Society of Cardiology and American Heart Association guidelines which identified than fewer than 15% of recommendations across all cardiology guidelines are based on level A (evidence from multiple RCTs) evidence[27].

Recently, a study reporting on the outcomes of nationwide screening program involving nearly 27,000 young individuals was presented at the European Heart Rhythm Association Congress in 2018[28]. Conditions associated with young SCD were identified in 90/26,900 (0.3%) individuals, with 16 (18%) identified by abnormal symptoms or family history, 72 (80%) by ECG and 2 (2%) by a combination of the two. Interestingly, individuals diagnosed with these conditions solely on the basis of an abnormal ECG were more likely to receive disease modifying treatment (beyond lifestyle advice) at 24 month follow-up than those identified on the basis of an abnormal symptoms or family history (56% vs. 46%). These findings suggest that early identification of disease in asymptomatic individuals through screening does impact on the management of the majority of individuals even in the short term.

Criterion 13: The benefit gained by individuals from the screening programme should outweigh any harms for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications.
NSC VERDICT: NOT MET

There is no evidence that cardiac screening deters young athletes from participating in competitive sports. On the contrary, screening to promote safe exercise is likely to raise awareness of cardiac disease, promote healthier life habits and achieve the most important goal of western health care organizations: a reduction in cardiovascular disease burden. A prospective, non-randomised controlled trial of 952 high school athletes demonstrated that athletes undergoing ECG screening were likely to more likely to be satisfied with their screening, feel safe during competition, support that all athletes should receive cardiac screening and state that the ECG had a positive impact on their training[29]. Individuals with false positive screening tests were not found to report excessive anxiety after screening.

The false positive ECG rate was traditionally cited as a central argument against cardiovascular screening with ECG. The last decade has significantly enhanced our understanding of ECG changes in young individuals including in athletes. Development of ECG interpretation criteria have reduced to false positive ECG rate to 1.8%-3.0%[30,31]. These false positive rates are likely acceptable to any screening programme.

An important benefit of screening for cardiovascular disease that has been neglected by the National Screening Committee is the potential to identify additional asymptomatic individuals harbouring disease through family cascade screening of the index case. This is particularly relevant when considering that most inherited cardiac conditions associated with young SCD are inherited in an autosomal dominant manner meaning that family members of the index case (or pro-band) have a 50% chance of inheriting the same disease substrate[32].

Engaging patients and the public in the commissioning and provision of services is recognised as best practice and is also a statutory requirement under the Health and Social Care Act (2012). The charity Cardiac Risk in the Young (CRY) which has campaigned to raise awareness of young SCD recently published the results of a new nationwide survey launched at the start of the charity's annual "Raising Awareness Week"[33]. The survey was conducted among 2,001 UK adults aged 18 years and above and demonstrated that 82% of participants thought the Government should be doing more to help prevent sudden cardiac death in young people. Similarly, 83% of adults questioned felt that all young people should be offered cardiac testing via a free, national screening programme. Two thirds of parents of children aged 14-35 said they would actively encourage their children to be tested. It is disappointing that the National Screening Committee has failed to take into consideration the result of such surveys in their document, or conducted an independent patient and public survey prior to publishing their recommendations.

Some of the concerns highlighted by the National Screening Committee review are very important and should from an important focus for future research. One of these include that most of the evidence relating cardiovascular screening are derived from cohorts of competitive athletes undergoing pre-participation screening under banner of financial endowed sporting organisations. In the United Kingdom (UK), pre- participation screening is practiced amongst the highest echelons of sport including the Football Association, the English Institute of Sport, and Rugby Football Union. In this regard, recreational athletes, grass root athletes, exercising high school children and young non-athletes are relatively neglected. The ethics of such practice have been questioned. The conditions implicated in young SCD are predominantly genetic. As such, they do not have a unique predilection to competitive sport. There are also compelling arguments that individuals with malignant phenotypes of disease may have been selected out of competitive sport. Furthermore, deaths in this cohort are very likely to be under-reported given that these tragedies will not be afforded the same visibility as deaths in competitive athlete counterparts.

There have been commendable efforts by community and government to reduce the frequency of SCD through alternative strategies, focusing largely on secondary prevention. This essentially involves increasing awareness, training and availability for cardiopulmonary resuscitation and automated external defibrillators (AED) in public areas and in areas where exercise is undertaken. In a retrospective study of 1,710 United States high schools, it has been reported that school-based AED programs provide a high survival rate of 64% for student athletes who suffer sudden cardiac arrest (SCA) on school grounds[34]. A prospective study by the same authors reported 59 sudden cardiac arrests in 2149 high schools over a 2 year period between 2009 and 2011[35]. 39 (66%) cases occurred at an athletic facility during training or competition; 55 (93%) cases were witnessed and 54 (92%) received prompt cardiopulmonary resuscitation. A defibrillator was applied in 50 (85%) cases and a shock delivered onsite in 39 (66%). Overall, 42 of 59 (71%) SCA victims survived to hospital discharge, including 22 of 26 (85%) students and 20 of 33 (61%) adults. Of 18 student-athletes 16 (89%) and 8 of 9 (89%) adults who arrested during physical activity survived to hospital discharge. These studies equivocally support investment of resources in improving facilities for CPR and AED availability when one considers that the survival of out of hospital arrest is cited at less than 10%. In this regard, there has been universal approval to the news released that CPR/AED and first aid training are to be included as part of the school curriculum in England.

However, the circumstances of SCD in young individuals suggest that these laudable efforts may still fail to avert a significant proportion of cases. In a systematic evaluation of registry data in 469 young SCD victims in Denmark, approximately 30% were unexplained[36]. Nearly 70% of deaths occurred in the home of which a significant proportion, nearly 34%, occurred during sleep. Deaths were only witnessed in 45% of cases and only 11% occurred during moderate to high intensity exertion. Similarly, a retrospective study of national death certificate records in Ireland reported that nearly 27% of the 116 cases of SCD were unexplained and classified as SADS[37]. Overall, 45% of deaths occurred during non-exertion or sleep with only 8% occurring during exertion. More recently, a prospective study of SCD among young individuals in Australia and New Zealand reported that 40% of the 490 cases were unexplained[14]. Most cases of SCD occurred while the person was sleeping (38%) or at rest (27%), whereas SCD during exercise (11%) or after exercise (4%) was relatively uncommon. More specific to competitive athletes, data from a specialist cardiology pathology centre in the UK in 357 athletes has reported that 40% of deaths occurred outside the context of exercise including 13% in sleep[15]. These studies are consistent in demonstrating that the majority of SCDs occur at rest with a significant proportion being unwitnessed and occurring during sleep. These deaths are unlikely to be prevented by improvements in facilities for secondary prevention or AEDs in public areas or where exercise is undertaken. It is therefore plausible that early identification of those individuals with cardiovascular diseases associated with SCD through screening may potentially be useful in reducing the overall burden of young SCD.

As with any healthcare intervention, we acknowledge there may be financial implications of cardiovascular which naturally would need to be taken into consideration.
However, we must acknowledge that:

(a) Young SCD is an important public health problem with loss of decades of productive life due to cardiac conditions that can be detected during life and for which interventions are available to reduce the risk of malignant arrhythmia.
(b) There are significant limitations of the current healthcare system (as per the national service framework) for identifying individuals with disease.
(c) Secondary prevention strategies (AEDs) may fail to capture a significant proportion of SCA.
(d) Public opinion does support implementation of cardiovascular screening.

On these bases, there is sufficient evidence to justify cardiovascular screening to prevent young SCD and we would therefore encourage the National Screening Committee to reconsider their verdict.

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10. Graham Hunter (16 June response)

Dear Evidence Team

Please find attached my comments on the report.

As you can see, I feel it is highly flawed. Meanwhile at least 624 young people will die this year, as a result of NO proactive screening program.

I do hope the decision not to recommend Heart Screening can be reversed, in the interest of all.

Please note I have copied in my MP and Sports Minister, Mims Davies MP for Eastleigh, and Dr Steven Cox. CEO of CRY.

Your sincerely

Graham Hunter

<table>
<tr><td>Name:</td><td colspan="2">Mr Graham Hunter</td><td>Email address:</td><td>xxxx xxxx</td></tr>
<tr><td colspan="2">Organisation (if appropriate):</td><td colspan="3">Family of xxxx xxxx xxxx xxxx – xxxx xxxx</td></tr>
<tr><td>Role:</td><td colspan="4">xxxx xxxx</td></tr>
<tr><td colspan="5">Do you consent to your name being published on the UK NSC website alongside your response?
Yes☒ No ☐</td></tr>
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		If someone has the genetic mutations, they can be treated with drugs or have a defibrillator implanted in their chest. But how do you work out who is at risk? Genetic tests can help but not everyone with the altered genes seems to have the syndrome. Electrocardiograms or ECGs can measure the heart's electrical activity, but exactly how features on the ECG relate to risk is not fully understood. **All in the t-wave** Enter the virtual heart. By running hundreds of genetically customised hearts on a supercomputer, each for many thousands of beats, Adam Hill and his colleagues from the Victor Change Cardiac Research Institute in Sydney, Australia, have cracked some of the secrets of SADS. One sign that someone has the genetic condition that most commonly leads to SADS, known as long QT syndrome, is a distinctive bump or notched t-wave in their ECG readout. "For the past 30 years, that notched t-wave has been in the diagnostic criteria but nobody's known what's caused it," says Hill. "We show what causes it." With the wealth of virtual data created by running the simulations, they were able to establish that the more extreme the bump in the ECG is, the higher a person's risk of dying. What's more, they found the main genes thought to cause the problem can be either amplified or compensated for by complex combinations of other genes. **Better diagnosis** "We show that the degree of t-wave notching is correlated with how much risk they are at," says team member Arash Sadrieh. "So person A can have the mutation [but his ECG shows] he's absolutely normal, so you don't need to do the complex surgery to prevent sudden

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Graham Hunter (19 August response)

Dear Sir / Madam

Please find attached the response from the Family of xxxx xxxx, to your consultation.
Our xxxx xxxx died from SADS in xxxx xxxx aged xxxx xxxx. xxxx xxxx had been xxxx xxxx only xxxx xxxx.
xxxx xxxx almost certainly died from Brugada Syndrome. As both xxxx xxxx have been screened and confirmed to have Brugada.
A condition Heart Screening can detect, and positive actions put in place to protect the individual.

Please note I have copied our response to both Cardiac Risk in the Young and our MP for Eastleigh, Mims Davies.

Best wishes

Graham Hunter

For The Hunter Familiy

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If someone has the genetic mutations, they can be treated with drugs or have a defibrillator implanted in their chest. But how do you work out who is at risk? Genetic tests can help but not everyone with the altered genes seems to have the syndrome. Electrocardiograms or ECGs can measure the heart's electrical activity, but exactly how features on the ECG relate to risk is not fully understood.

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One sign that someone has the genetic condition that most commonly leads to SADS, known as long QT syndrome, is a distinctive bump or notched t-wave in their ECG readout. "For the past 30 years, that notched t-wave has been in the diagnostic criteria but nobody's known what's caused it," says Hill. "We show what causes it."

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19/08/2019 Graham Charles Hunter

11. xxxx xxxx

Dear Sir or Madam

I am writing to try and explain how a young sudden death due to a sudden cardiac arrest impacts on people's lives!

My xxxx xxxx xxxx xxxx xxxx xxxx passed away on xxxx xxxx after five days in critical care! xxxx xxxx was xxxx xxxx and had xxxx xxxx life all planned out, xxxx xxxx knew there was something wrong and knew it wasn't asthma thathe the drs had treated xxxx xxxx for most of xxxx xxxx life!!

xxxx xxxx was out jogging with xxxx xxxx xxxx xxxx when xxxx xxxx became out of breath and then collapsed, xxxx xxxx friend xxxx xxxx had to raise the alarm and then start cpr on xxxx xxxx! Emergency services attended inc the xxxx xxxx and they managed to start xxxx xxxx heart again after a number of minutes, xxxx xxxx and xxxx xxxx arrived on scene as they were defibbing xxxx xxxx! Not a very nice thing to see!! We had five days in criticall care watching xxxx xxxx die!! xxxx xxxx were in critical care with us! It was the worst time of xxxx xxxx life!! xxxx xxxx not the same person xxxx xxxx was before xxxx xxxx died that person died with xxxx xxxx, xxxx xxxx broken inside and xxxx xxxx now receiving psychotherapy and see a psychiatrist end of this month to try sort xxxx xxxx Meds out so that xxxx xxxx can function everyday!! xxxx xxxx broken inside and xxxx xxxx can't see things getting any better, during grieving xxxx xxxx have fundraiser for cardiac risk in the young with xxxx xxxx friends and the community! A young death effects the whole community not just xxxx xxxx family! We shouldn't have to do this to get our young people screened! 12 people a week DIE from these undiagnosed conditions, xxxx xxxx would still be here if xxxx xxxx had been screened!! It's such a waste of young livessels, xxxx xxxx was an amazing young xxxx xxxx who had gained 7As and 3 A* in xxxx xxxx exams! xxxx xxxx had xxxx xxxx whole life ahead of xxxx xxxx but because there is no nation screening programme xxxx xxxx condition was NOT picked!! xxxx xxxx guess if you havn't been effected by a young persons death due to these conditions you really can't imagine the deep pain that is suffered! I still get Flash backs and see xxxx xxxx lying at the edge of that field being deffibbed!! not a good thing to see! xxxx xxxx best friend xxxx xxxx said one night, xxxx xxxx watched xxxx xxxx die twice, once in the field and then in hospital 5 days later!!

xxxx xxxx wrote to my local mp and was disappointed when xxxx xxxx didn't even reply himself, I was sent a generic letter quoting old imformotion! !

We had 2 screening days at the xxxx xxxx where xxxx xxxx attended and outhe for 204 screenings they found 9 issues

xxxx xxxx guess at the end of the day it comes down to money?? A screening through the Cardiac risk in the young charity costs £50 it's £5,000 for 100 screenings xxxx xxxx sure xxxx xxxx treatment for 5 days in critical care cost more than a day of screenings!

Anyway just had to let you know how I feel on this subject, it still effects xxxx xxxx, they still contact new to chat and fundraise in xxxx xxxx memory, they and xxxx xxxx will never ever forget what happened to xxxx xxxx and how we feel so let down by the government ignoring sUchida not issue!!

Thankyou for taking time in reading my e-mail

Yours sincerely

xxxx xxxx

12. xxxx xxxx

Dear Sir/ madam,

This xxxx xxxx marks the xxxx xxxx anniversary of the loss of xxxx xxxx and xxxx xxxx to sudden cardiac death. At that time xxxx xxxx was not advised that the condition was hereditary and xxxx xxxx a 6 year battle to get xxxx xxxx screened as it was not deemed necessary due to both of them being fit and healthy young people, those happened to be the exact same words that appear at the beginning of the post mortem report into the death of xxxx xxxx. xxxx xxxx were subsequently found to have long qt syndrome and both considered a high enough risk to have implanted defibrillators. xxxx xxxx was xxxx xxxx and xxxx xxxx was xxxx xxxx when they got them. Losing xxxx xxxx was devastating to our family, bringing up xxxx xxxx alone with sudden death syndrome was to say the least stressful, but losing xxxx xxxx xxxx xxxx xxxx xxxx as well as xxxx xxxx would have destroyed xxxx xxxx, especially if xxxx xxxx had later found out that for the sake of a simple, non invasive ECG screening, it could have been prevented. xxxx xxxx cannot comprehend the reasoning behind the decision not to have a national screening programme. In xxxx xxxx years this government has changed very little to stop other families having to struggle as we have, all the while knowing that it is unnecessary for that to happen. It is unbelievable and unacceptable in this age of technology that you are happy to allow young people to die.

13. xxxx xxxx

Dear Sir/Madam,

After reading your latest consultation document https://legacyscreening.phe.org.uk/suddencardiacdeath xxxx xxxx

was deeply disappointed that the document does not recommend population screening for sudden cardiac death in the young. So many of these tragic and needless deaths could so easily be prevented.]

May xxxx xxxx also add that xxxx xxxx am confused that you state the ECG is an accurate test if you experience symptoms, but the ECG is not an accurate test is you do not experience symptoms. These two statements within your latest document are contradictory. Ministers and NHS in all four countries that you advise should not be reading contradictions or be confused by such an important document.

The document also fails to be objective in evaluating the overlap between the current routine use of the ECG in the NHS for general diagnostics and its role in Cardiac Screening. This consulting document should be objective and arm Ministers and the NHS with the full facts.

You have a paragraph below included on your website;

More about Sudden Cardiac Death

Sudden cardiac death in young people is always shocking and very sad. This is in part because it is so rare. The chances of sudden heart attacks in apparently physically fit young people are tiny. The overwhelming majority of heart attacks happen in elderly people.

The wording of this paragraph is an example of the failure of the National Screening Committee's Consultation Document to demonstrate the impact of sudden cardiac deaths on our society. xxxx xxxx understanding is that 1 in 300 people screened have a cardiac condition that could benefit from treatment or lifestyle advice.

xxxx xxxx would also add that whilst you acknowledge that these deaths are "always shocking and very sad:, and "in part because it is so rare", it would be appropriate to add that, in part, it is because they could be prevented with population screening. You also state the "chances of sudden heart attacks in apparently physically fit young people are tiny”. xxxx xxxx do not believe the hundreds of young deaths each year from undiagnosed cardiac conditions should be described as tiny. The words unacceptable, tragic and saveable would be far more appropriate.

A National Strategy for the Prevention of Young Sudden Cardiac Death is vital and each year that the government does not act, hundreds of children die due to their cardiac conditions going undiagnosed. Screening would save lives.

The document should be objective. Could these young deaths be prevented with population screening? Can we diagnose cardiac conditions in “apparently fit young people”? Do we need a National Strategy? What is the wider impact and devastation to family, friends and community that is caused by the death of a young person whose life could have been saved by screening?

The United Kingdom is failing these children and their families, friends and communities. The devastation caused by these undiagnosed deaths should be included in your Consultation Documents; the long-term family counselling, post-death family screenings, post-traumatic stress, inability of families to return to work for considerable periods due to grief. The devastation on the very fabric of our communities and wider society is not “tiny”.

xxxx xxxx am aware that at 4pm on the xxxx xxxx in xxxx xxxx , MPs are being urged to support the Cardiac Risk in the Young (CRY) Campaign and join the 142 MPs who have already signed the pledge; https://www.c-r-y.org.uk/my-pledge/ I hope that the positive results of this initiative will bring us all closer to a National Strategy for the Prevention of Young Sudden Cardiac Death.

One preventable death of a young person with an undiagnosed heart condition is an absolute disgrace. Hundreds of deaths each year due to the failure of implementing Population Screening is national disgrace. The latest consultation document is unbalanced and fails to demonstrate the impact of these deaths.

Whilst I am a xxxx xxxx of xxxx xxxx , xxxx xxxx am also a xxxx xxxx who has used fitness and physical challenges to cope with Mental Health relating to xxxx xxxx injuries. We are a nation that is becoming increasingly aware of the importance of fitness and all national sports organisations are focussing on ways to encourage young people to be more active and take up sports and continue them as they grow older. If Sports Teams and Governing Bodies are implementing screening, surely we have also have a duty to protect children and diagnose Heart Conditions in our Young People through screening. We would be saving hundreds of lives.

With regards,

xxxx xxxx

14. xxxx xxxx

Please I urge you to put into place, population screening in young people to hopefully prevent unnecessary sudden cardiac deaths.

xxxx xxxx years ago, we suddenly lost our beautiful, vibrant, healthy 19 year old xxxx xxxx to Sudden Arrhythmic Death Syndrome and population screening of the young would prevent so many families suffering the grief and horrors that we have been through.

Please, Please reconsider this and be mindful that there are at least 12 deaths each week in the UK alone of sudden deaths caused by SADS.

Many thanks.

xxxx xxxx

15. xxxx xxxx

I am writing in support of the CRY policy for national screening for possible heart defects in the young.

xxxx xxxx , xxxx xxxx , died from an undiagnosed heart condition at the age of twenty-nine in 2006.

xxxx xxxx was found in bed by xxxx xxxx flatmate. No parent is prepared to be woken at midnight by two policewomen

to be told what has happened.

If xxxx xxxx had been screened xxxx xxxx would be with us today.

I believe that some six hundred youngsters die each year from undiagnosed heart conditions.

Please introduce screening.

xxxx xxxx

16. xxxx xxxx

It always dismays me when i read that nothing is going to be done for population screening for the risk of sudden cardiac death in the young.

How many more young death's will it take before someone wakes up and understands the devastating effect this has on so many families.

I myself lost my beautiful 16 year old xxxx xxxx , who i know had xxxx xxxx had a routine screen would be here today!

Perhaps you can understand how angry, frustrated and sad i feel not only for my xxxx xxxx but the 100s of young people who's untimely death's could so easily be prevented!

Please listen and act now.

Thank you

xxxx xxxx

17. xxxx xxxx

xxxx xxxx

xxxx xxxx

xxxx xxxx

Dear xxxx xxxx

I have been advised to write to you following the publication of the report from the National Screening Committee into screening for the risk of sudden cardiac death in the young.

As a family we have suffered the loss of a young person, a pain that endures.

The charity we support, C.R.Y . (Cardiac Risk in the Young) are urging the Governmment to create a strategy where each young person can be screened to identify potential risk of a sudden heart failure.Apparently so far 142 MP's have signed this pledge and I am to urge you to add your weight to the campaign.

I attach a copy of the letter I am sending to the National Screening Evidential Team which gives some indication of the effect that our loss has had on the extended family and friends.

I know you are a very busy person but I ask that you give me three minutes of your time to read of and imagine our feelings which can be duplicated several hundred times, each year in this country.

Sincerely

xxxx xxxx

A LIFE LOST

xxxx xxxx

xxxx xxxx

On xxxx xxxx 2015 at xxxx xxxx my bedside telephone woke me from a deep sleep when xxxx xxxx rang from xxxx xxxx holiday in xxxx xxxx to tell us that xxxx xxxx, our beloved xxxx xxxx , xxxx xxxx had passed away close to where xxxx xxxx lived in xxxx xxxx .

As xxxx xxxx and xxxx xxxx negotiated an emergency flight home I established some of the circumstances of xxxx xxxx passing. Apparently xxxx xxxx and xxxx xxxx had just left a party at 11-30pm the previous night having had nothing to eat or drink. In the street xxxx xxxx had collapsed and despite the frantic efforts of xxxx xxxx friends, Police Officers, Paramedics, a Hems Doctor and later Casualty doctors and staff, xxxx xxxx was pronounced dead.

One of xxxx xxxx friends being made aware of the circumstances raced to the hospital and when in the relatives room was confronted by the Casuaalty Officer who told xxxx xxxx that xxxx xxxx was shortly to pass away as there was nothing else that could be done. This xxxx xxxx , xxxx xxxx 18 years old is reported by xxxx xxxx to have said 'I'm xxxx xxxx friend, I won't let xxxx xxxx die without a xxxx xxxx being with xxxx xxxx Such maturity in a xxxx xxxx of 18 years under these circumstances is heart rending. xxxx xxxx passed away.

The stress on the family was increased when a senior Police Officer at the scene told the Press that xxxx xxxx had taken drugs, something we knew to be wrong. Before we had chance to refute this allegation it was repeated in nearly every National newspaper and the press made leaving the house hard to tolerate as they had made their 'camp' close by. This mater was eventually settled by the Police Commissioner xxxx xxxx , a xxxx xxxx

with high standards who personally apologised to xxxx xxxx face to face and to myself subsequently. The apology was accepted and the sincerity of xxxx xxxx illustrated xxxx xxxx noble character.

xxxx xxxx was a very fit He who had completed a rigorous cycle ride in Majorca in aid of 'Dementia' charity where £4,000 had been raised. xxxx xxxx was a regular at the gym and kept xxxx xxxx active. xxxx xxxx showed no sign of the impending failure of xxxx xxxx heart which the post mortem revealed was over twice the size expected in a xxxx xxxx of xxxx xxxx age and stature.

These tragic events lead us to the charity C.R.Y. (Cardiac Risk in the Young) who tirelessly work to raise funds to arrange screening for the young at risk who, like xxxx xxxx, have never been diagnosed with any heart condition. Statistics show this is something so common in this country it occurs at least twelve times each week and each case is treated in isolation when a screening program could save many of these wasted lives.

Our family stress continues, even after xxxx xxxx years and I expect it will continue. Every day is another day close to tears and the relevant dates, the anniversary of xxxx xxxx passing, xxxx xxxx birthday and Christmas are particularly hard to bear. There is always an empty chair. On a personal not the sight of the telephone that delivered the news adds to distress conjuring memories best left aside.

xxxx xxxx xxxx xxxx recently held a birthday party for many of xxxx xxxx xxxx xxxx where xxxx xxxx spoke of xxxx xxxx friendship and duty to others. In reply xxxx xxxx was humbled and finally raised xxxx xxxx glass saying 'xxxx xxxx. There was a monetary hush followed by a repeat of the toast. Everyone of those present felt xxxx xxxx pain.

xxxx xxxx friends mark anniversaries by visiting the Crematorium where xxxx xxxx ashes lie entered in a wall. A blue and white scarf marking xxxx xxxx love of Queens Park Rangers has been left together with other items which relate to their friend. These xxxx xxxx still find it hard. They still visit xxxx xxxx and I truly believe that there is an unbeknown 'cross counselling' between them. The boys and girls in the circle of xxxx xxxx friends donated the money they were given on reaching 21 to the charity.

In relating these events and their lasting effect on the family and friends we now devote some time to CRY in the hope that others will not face the pain and anguish we suffer on a daily basis.

The answer must be total screening of the young followed by treatment to prevent early death, something I am told may well be within the ability of our outstanding health service.

As a former Police Officer and xxxx xxxx a xxxx xxxx at Great Ormond Street Hospital we have confronted death on many occasions. We are ordinary people who have supported the bereaved and made ourselves available for counsel. In reality we are aware that we are, or should be the next generation to pass on. We should not be given the situation where we lose a child or grandchild when the cause of sudden death could easily be avoided.

We would strongly ask that the National Screening Committee reconsider its stance on screening of our young people. Death is final.

18. xxxx xxxx

To whom it may concern,

As the xxxx xxxx of a 17 year old child who died of Sudden Arrhythmic Death Syndrome last year, it was with great interest and even greater dismay that I read the UK NSC's review and recommendations against systematic population screening for cardiac conditions in young adults.

Before xxxx xxxx died I was only vaguely aware that young people could die from cardiac conditions and completely unaware of the very real risk sudden cardiac death represents to young people even when there are no symptoms or family history. Naturally, since xxxx xxxx died I have become more informed and have been shocked by the prevalence of young cardiac death; the lack of awareness by the population at large of the risk of such death and most especially by the fact that the overwhelming majority of sudden cardiac deaths could have been prevented.

Specifically, my criticisms of the NSC and it's recommendations are:

- The review is unbalanced and lacks objective interpretation. The NSC appears subjective and intent on avoiding recommending in favour of screening.

- The way the NSC has framed the issue is incorrect. Current NSC screening programmes (e.g. breast cancer) focus on identification of conditions and diseases and not the risk of death from the same. The NSC's policy towards this particular issue is framed as identification of the risk of sudden cardiac death. This is inconsistent with other NSC policies and should be reframed as "screening for cardiac conditions in young adults."

- The NSC is dismissive of the science which is informing everyday medical practice in the UK by reiterating the fact that there has been no Randomised Control Trial of hundreds of thousands of young people over a twenty year plus period. I understand that this is not the first time the NSC has been so dismissive and that it continues to fail to recognise that conducting Randomised Control Trials on these conditions is unethical and would lead to young people dying - and dying unnecessarily - in the pursuit of better science.

- Whatever the imperfections of an evolving science, it is already obvious that screening saves young lives; this must be accepted.

- The NSC has adopted a contradictory position whereby it regards the ECG as an accurate test if symptoms are experienced but that the ECG is not an accurate test if symptoms are not experienced. Such inconsistency is unacceptable. Research has shown that screening based on symptoms, without an ECG, is more expensive and identifies fewer people at risk.

- The NSC has failed to evaluate objectively the overlap between the current routine use of the ECG in medical practice for general diagnostics and monitoring and its role in cardiac screening.

- The review fails to emphasise that 1 in 300 people screened have a cardiac condition that can benefit from treatment or lifestyle advice.

- Instead there is too much emphasis on the potential for false positives and the possibility of unnecessary anxiety and adverse lifestyle impacts. This represents a massive assumption and is nanny statism in action. And it is contradictory: the risks posed by a diagnosed cardiac condition is surely an incentive for positive lifestyle decisions; if an individual ignores any such recommendations then that is a matter of personal choice - much like smoking is. Such choices should not be at the expense of the lives of the many more young people suffering from a cardiac condition unidentified because of the absence of screening. It seems that the NSC places higher value on the possible lifestyle of a minority who fulfil the NSC's assumptions than it does on the lives of the greater number of young people unknowingly suffering from a cardiac condition.

- The NSC fails to demonstrate the impact young sudden cardiac deaths have on our society, let alone on families. Aside from the wider social contribution a deceased young person would have made had they lived there is a significant economic consequence of each death. In my son's case alone, there is no doubt that aside from any economic and social wealth otherwise created, the loss of tax revenue to the exchequer alone runs to several million pounds over a normal lifetime; this is not exceptional.

Hundreds of young people in the UK die each year from sudden cardiac death, at least enough to fill several aircraft. If the UK were beset by even one air disaster each year one can be sure the UK government and its agencies would do all in their power to prevent such tragedies in the future. Young people's deaths are no less tragic just because they don't die in some mass disaster. To protect young people from sudden cardiac deaths the same resolve and commitment to preventing them needs to be applied; given that there is sufficient evidence that screening is effective in saving young lives there is no credible justification for not doing so.

As a progressive society and a modern economy it is unacceptable that hundreds of young people continue to die every year from cardiac conditions which could be identified through ECG based screening. There needs to be a national strategy for the prevention of young cardiac death to ensure the government acts to prevent the hundreds of deaths each year of young people from undiagnosed cardiac conditions. Policy should be informed by science and CRY's research programme, led by Professor Sanjay Sharma who, I know, is conducting world leading research and providing the evidence to better understand these conditions and save more lives.

In the interests of young people, their families, society as a whole and the economy, I urge the NSC to reconsider objectively all research and evidence concerning sudden cardiac death in young people and that it strongly advocates systematic population screening for cardiac conditions in young adults.

Yours faithfully,

XXXX XXXX

19. xxxx xxxx

Hello

I would like to say that without the screenings put on by CRY in the Isle of Man on behalf of xxxx xxxx xxxx xxxx, xxxx xxxx would not be aware of xxxx xxxx heart condition. xxxx xxxx died in xxxx xxxx sleep due to xxxx xxxx undetected heart condition and evidence shows that 12 young people every week in the UK die from undetected heart conditions.

It is unacceptable that as a government you are choosing to ignore these statistics. I wonder if it happened in your own family, would you feel the same way?

Many heart conditions do not have symptoms, they just kill. No warning.

xxxx xxxx

20. xxxx xxxx

Dear Evidence Team at National Screening

I am writing to you with regard to the recent screening review which reviews the role of screening for the risk of sudden cardiac death in the young.

I have direct personal experience of young sudden cardiac death as xxxx xxx died of an arrhythmia in xxxx xxxxsleep in xxxx xxxx 2014. xxxx xxxx was only 22 years old and had not presented with any signs of cardiac illness but I now realise xxxx xxx was one of many young people who die of hidden cardiac conditions with no prior symptoms. xxxx xxxx had just got married in xxxx xxxx and was about to graduate from University. xxxx xxxx had everything to live for. xxxx xxxx precious life has been taken all too soon and has left our family and xxxx xxxx friends in trauma and at an extreme loss. Since xxxx xxxx died at least 3,750 more young people have died of young sudden cardiac death and as each week passes still more and more continue to die this way. This is a complete tragedy and the death of young people from cardiac conditions needs to be addressed as a matter of urgency. How many more families and friends will have to face the loss of their loved ones in such a devastating way because screening for cardiac conditions is not being offered for all young people?

As a family xxxx xxx, xxxx xxx and xxxx xxxx have been screened at the specialist Arrythmia Clinic at Manchester Heart Centre to ensure none of us are risk of a cardiac condition. What a tragic shame that xxxx xxx was not offered cardiac screening, as xxxx xxxx may still be alive and with us now.

I know of a student in the xxxx xxxxI work at who attended a Cardiac Risk in the Young Heart Screening and the team on the day discovered xxxx xxx had complete heart block. xxxx xxxxwas then referred to local specialist cardiological services, had an internal defibrillator fitted and is alive and doing very well as a consequence of attending the screening. xxxx xxxx realises that before the surgery and fitting of the internal defibrillator xxxx xxxx was at risk of cardiac arrest and death at any time. However, as is the case with many young people, xxxx xxxx cardiac condition was hidden so xxxx xxxx was unaware that xxxx xxxx was at serious risk of cardiac arrest or death, until the life saving screening had taken place. The only symptoms xxxx xxxx experienced prior to the screening was dizziness. It is interesting to note that xxxx xxxx often complained xxxx xxxx was dizzy and when this was mentioned to a GP they just explained the dizziness was most likely hormonal.

The NSC continue to be dismissive of the science which is informing everyday medical practice in the UK by reiterating the fact that there has been no randomised control trial of 100,000s of young people over a 20+ year period. They fail to recognise that conducting RCTs on these conditions is

UNETHICAL and would lead to young people dying in the pursuit of “better” science. CRY’s research programme will continue to focus on answering the inevitable questions raised as medicine progress in an ethical way, but there must be an acceptance that screening will save young lives.

It is unacceptable for the NSC to adopt a contradictory position where the ECG IS an accurate test if you experience symptoms, but the ECG IS NOT an accurate test if you DO NOT experience symptoms. The research has shown that screening based on symptoms (without an ECG) is more expensive and identifies fewer people at risk.

The way the NSC has framed the issue is incorrect. The current NSC screening programmes (e.g. breast cancer) focus on identification of conditions/diseases, whereas this policy is framed as identification of the risk of sudden cardiac death. It must be reframed to be consistent with the other NSC policies, “screening for cardiac conditions in young adults”.

Policy must be informed by science and CRY’s research programme, led by Professor Sanjay Sharma, is leading the way internationally in providing the evidence to better understand these conditions and save more young lives. But it is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG.

I look forward to reply to what is an extremely urgent issue for all young people in the UK.

Yours faithfully

XXXX XXXX

21. xxxx xxxx

Dear Sir/Madam

We lost our 29 year old xxxx xxxx , to sudden cardiac death in August 2018 leaving xxxx xxxx

xxxx xxxx and six year old xxxx xxxx, xxxx xxxx, and all our lives have changed irrevocably as a result of something that could have been prevented had xxxx xxxx been screened for the underlying condition that was responsible for xxxx xxxxdeath. xxxx xxxx was a school teacher at xxxx xxxx in xxxx xxxx and a graduate of the xxxx xxx for exceptionally talented graduates who want to devote their life to teaching and nurturing the next generation. xxxx xxxx had achieved a huge amount in just four years teaching and was appreciated by parents and pupils as a genuinely caring and inspiring presence in the classroom. xxxx xxxx loved to read stories to the children and the school commissioned a beautiful reading chair in xxxx xxxx memory. As a family we are providing an annual memorial to the school in the form of £100 towards new reading books that will bear xxxx xxxx name.

xxxx xxxx was a wonderful xxxx xxxx to xxxx xxxx and xxxx xxxx gave xxxx xxxx the very best start in life. At weekends and in school holidays xxxx xxxx introduced xxxx xxxx to a wealth of activities and experience and he grew up in a loving and supportive family environment to become a confident, thoughtful and happy child. xxxx xxxx had absolutely no symptoms of any problem with xxxx xxxx heart and seemed to be in excellent health never having taken a day off work sick.

xxxx xxxx had been preparing for the Autumn 2018 term at school and was excited about taking on new responsibilities. xxxx xxxx went to bed one evening and when xxxx xxxx came to bed xxxx xxxx heart had stopped due to arrhythmia or an imbalance in the electrical charge that powers the heart beat. We have been devastated by our loss and the tragedy of a xxxx xxxx being taken without warning and not being able to live xxxx xxxx life and see xxxx xxxx child grow up. xxxx xxxx faces nearly the whole of xxxx xxxx life without the love and backing of a xxxx xxxx.

The impact of losing a xxxx xxxx on those around her has been astonishing and will sadly resonate through the years and generations in our family history and experience. xxxx xxxx could reasonably have expected to have lived a good and useful life like xxxx xxxx who is 88 and we have therefore lost nearly sixty years of xxxx xxxx companionship and contribution to society.

As a family we have all pulled together to try to accept what has happened and to mitigate the loss so that xxxx xxxx is able to grow up with as many of the advantages that xxxx xxxx ensured xxxx xxxx had and with the love and support that xxxx xxxx would have given to guide xxxx xxxx through life. We are, however, deeply troubled that the recent decisions taken by the National Screening Committee mean that xxxx xxxx wholly avoidable death goes unnoticed and will not result in a change of practice.

We now know that 12 - 15 young people who appear very fit and completely healthy suffer sudden cardiac death each week in the UK and in terms of the loss of life years and the impact on families this is tantamount to an epidemic. We believe that this is part of a pattern of imbalance in the Government's focus which neglects the health needs of young people and condemns so many of them to an early death.

We are requesting that you properly and fairly consider the impact that the sudden death of young people like xxxx xxx has on families and on society generally and agree that it warrants the commitment of appropriate screening resources and medical intervention for the 1 in 300 that are discovered to have an underlying condition that will enable them to live their lives with their loved ones and make their contribution to society.

yours sincerely

xxxx xxxx xxxx xxxx

22. xxxx xxxx

To Whom It May Concern

We need to act to do more to prevent sudden cardiac death in the young and screening is the obvious first step. The results of this tragic and all to frequent occurrence are shocking, far reaching and long term above and beyond the initial death.

xxxx xxxx (xxxx xxxx) died of a sudden undiagnosed arrhythmia age 13 in 2013. xxxx xxxx would now be 19. The impact of xxxx xxxx death was not only instantly devastating but has also had obvious long term dreadful repercussions on xxxx xxxx friends and family. In the 2 years that followed xxxx xxxx death both grandparents developed cancer; I am sure in no small part due to grief and stress. xxxx xxxxand xxxx xxxxhas come under huge strain and our future as a couple still hangs in the balance. Most significantly xxxx xxxx has developed anorexia and has largely been hospital based for the last year with the underlying cause stated as the sudden and unexpected loss of xxxx xxxx (only 20 months xxxx xxxx elder) and the subsequent trauma of living in a family in trauma.

I hope this personal example illustrates how the lack of screening can have a far-reaching emotional burden on the family and friends of the bereaved and also an ongoing financial burden on the state in terms of care for ripple effect illness and trauma.

My very best,

xxxx xxxx

23. xxxx xxxx

Dear Sirs

My xxxx xxxx xxxx xxxx xxxx xxxx died on xxxx xxxx 2012 in xxxx xxxx aged just 23 from a sudden cardiac arrest diagnosed after a post mortem as ARDC . xxxx xxxx had had few fainting episodes in the previous year and had been advised by xxxx xxx GP to drink more as xxxx xxxx was working in a very warm hospital environment .

I believe that screening may well have revealed xxxx xxxx problem or prompted further tests . Since then all the family have been screened as expected xxxx xxxx and xxxx xxxx had some at the moment minor heart problems revealed as we're both over 50 .

One of our xxxx xxxx was diagnosed aged 15 with a severe case of White Parkinson Wolf syndrome and had a successful operation. The GP only agreed to screened xxxx xxxx because of the death of xxxx xxxx . xxxx xxxx did have symptoms but did not recognise them as such as xxxx xxxx thought everyone's chest and heart felt that way !!The cardiologist said xxxx xxxx first total collapse might have killed xxxx xxxx just like xxxx xxxx first visible symptom to us was collapse and death .

We treasure the life of xxxx xxxx and view it as the one positive outcome of xxxx xxxx death. We raise money for CRY and support their cardiac screening but wish so much that national screening had been available to our xxxx xxxx

In our small community in the xxxx xxxx in the xxxx xxxx we know xxxx xxxx families who have had to go through the sudden death of a child .

Please consider national screening.

As we all know it's all about MONEY now so I suppose it's better to let these young people die as you not only save on screening but also save money on expensive heart operations too!

However the results of our xxxx xxxxdeath were economic too I have had two terms off work as a teacher as a result of xxxx xxxx death , many doctor's appointments, counselling and tranquillisers. xxxx xxxx has had similar treatment too ,although no sick pay for xxxx xxxx as xxxx xxxx xxxx xxxx. It's 7 years ago now but goodness knows So not screening and letting them die costs money too !

Please make a difference for our young people and reconsider national heart screening .

NSC UK National Screening Committee

xxxx xxxx

24. xxxx xxxx

To whom it may concern,

I am deeply concerned and appalled that the latest consultation document does not recommend population screening for sudden cardiac death in the young.

Having lost a dear school friend, xxxx xxxx in 2005 and xxxx xxxx twenty-four-year-old xxxx xxxx earlier this year, I cannot accept that these tragic deaths were inevitable. I have now suffered two traumas in fourteen years and in fourteen years one would expect progress. The NCS consultation document neither recognises the physchological impact these tragic deaths have on bereaved families, nor does it emphasise that one in three hundred people screened have a cardiac condition that would benefit from further treatment.

Twelve young people dying every week - and this number is significantly under-reported - is not a "tiny" issue and it is certianly not comparable to heart attacks in the elderly.

WIth best wishes,

xxxx xxxx

25. xxxx xxxx

Dear Sir/Madam,

I write to you in the hope that you will reconsider your position on the cardiac screening of young people.

Our xxxx xxxx died on xxxx xxxx 2015. xxxx xxxx was aged just 28, about to be married, had a great job, xxxx xxxx loved life and had everything to live for. xxxx xxxx death has torn our family apart. xxxx xxxx had such a big personality and we are utterly devastated at xxxx xxxx loss. xxxx xxxx xxxx xxxx xxxx xxxx struggles, xxxx xxxx has lost interest in life. xxxx xxxx will never be the same person. We will never be the same people. It took over a year to understand how and why xxxx xxxx died. xxxx xxxx died in xxxx xxxx sleep whilst away in xxxx xxxx. After months of tissue and toxicology testing no evidence of a cause of death was found, but the xxxx xxxx coroner concluded xxxx xxxxdeath was caused by "sudden heart death resulting from acute heart failure caused by disruption of the electrical activity of the heart (the so called arrhythmogenic death)". xxxx xxxx was sent xxxx xxxx heart tissue samples and xxxx xxxx agreed with this. xxxx xxxx death though was recorded as "Unascertained" at the inquest here in this country. We did not have this evidence at the time of the inquest. I suspect many young adult deaths are recorded as "Unascertained", not helping the true facts, and being incorrectly recorded.

I have fundraised so that we can hold screening sessions for young people in this area. On Saturday 17th August 95 young people were screened and of these 4 were referred for further investigations having had ECGs. CRYs evidence shows that 1 in 300 young people screened have some form of heart condition.Your policy needs to be based on actual evidence, and CRY have this.Take a look at the CRY website and read the stories and look at the photos of all the young people who have died needlessly.

The UK is one of the richest countries and yet in Italy Im told every young person who engages in organised sport must be screened.Why do the Italians take this seriously and we do not?

We desperately need a national strategy for the prevention of these young sudden adult deaths. As a family we need to know that other families will not suffer as we do. These young deaths can and should be prevented.

Thank you

xxxx xxxx

26. xxxx xxxx

Dear Sir/Madam

I am writing a personal statement to ask you to please reconsider your decision to not support a national screening of our young people.

This was something that I never thought that I would have to deal with. On the xxxx xxxx 1992 we celebrated the birth of our xxxx xxxx and 25 years later, on the same day we were preparing to say goodbye forever to xxxx xxxx

On the morning of xxxx xxxx 25th birthday xxxx xxxx was preparing to go to xxxx xxxx to celebrate xxxx xxxx birthday and a friends xxxx xxxx. xxxx xxxx was texting xxxx xxxx friends to say xxxx xxxx was getting ready and would meet them soon. There was nothing unusual about the day. I had woken xxxx xxxx up at 4am and I could hear xxxx xxxx walking around getting ready until I heard a small sound as if xxxx xxxx had banged xxxx xxxx foot and then silence. I instinctively knew something was wrong and I ran upstairs. I could see by xxxx xxxx face that xxxx xxxx had gone. There was no response from xxxx xxxx The emergency services were quick to arrive and worked on xxxx xxxx for about an hour to get heart started. xxxx xxxx was taken to critical care where we were told that xxxx xxxx had suffered serious brain damage and the next few day were crucial as they put xxxx xxxx in a coma. xxxx xxxx condition deteriorated and xxxx xxxx life support was turned off on the 1st of xxxx xxxx. We donated xxxx xxxx organs. Then we were given a cup of tea and sent on our way with no support to deal with it.

There are no words to explain the devastation this has had on our family, xxxx xxxx friends, xxxx xxxx work colleagues etc. xxxx xxxx was fit and healthy and was the last person I thought that this would happen to. Exactly one week from wrapping xxxx xxxx birthday presents , I was choosing xxxx xxxx coffin. If you can try to imagine what it was like,multiply it by a thousand and you might have a small fraction of what its really like. We waited 15 months for xxxx xxxx inquest ,which said xxxx xxxx died of a cardiac arrest, cause unknown. The pathologist said that unfortunately if there was a problem with xxxx xxxx heart, it could only be detected while xxxx xxxx was alive.

Since then xxxx xxxx, xxxx xxxxand xxxx xxxx have all been screened and so far nothing unusual has been found. We are still waiting for the results of a genetic test.This has all had a devastating effect on our family. xxxx xxxx friends are all moving on buying their first homes ,getting engaged, married, having children. All things that xxxx xxxx will never have the chance to do. We'll never know what sort of xxxx xxxx xxxx xxxxxxxx xxxx would have been or where xxxx xxxx career would have taken xxxx xxx has really struggled with the loss of xxxx xxxx xxxx xxxx. Next month xxxx xxxx turns xxxx xxxx and is distraught that xxxx xxxx will be older than xxxx xxxx or even worse that the same could happen. xxxx xxxx has Parkinson's which has been made worse by all the stress and I struggle to get out of bed every day to face another meaningless, traumatic existence. xxxx xxxx and xxxx xxx are having counselling to help to deal with it.

If there had been a national screening programme , I wouldn't be writing this. If xxxx xxxx had a defect in xxxx xxxx heart, it would have been picked up. We're encouraged to have breast screening, smear tests, bowel cancer tests to allow early intervention of disease but our young aren't been offered a simple screening that could save their lives. This HAS to change. These are the people of our future and we're failing them. Please reconsider and put forward a national screening programme for them. It's the worst thing in world to lose a child but not to know why you've lost them is so difficult to comprehend.

This is just my story. Please look on the memorial fund pages on CRY and you will see how many heartbreaking stories there are. Some families have lost two children, some children have lost mothers or fathers. Please put to an end this senseless loss of our young.

Thank you

xxxx xxxx

27. xxxx xxxx

As a 29 year old xxxx xxxx I have a sibling, a father, and aunt and two cousins who has been diagnosed with LQTS. This discovery was a complete fluke discovery and I have found the fact that I have gone the majority of my life not knowing about xxxx xxxx mentally distressing - more so than the actual discovery itself. I think the rationale that people may stop exercising altogether upon discovering a heart condition is rather generalised and anecdotal. We have all taken steps to improve our diets and ensure we get plenty of exercise to keep our hearts and bodies strong and healthy. I am even cycling to Paris from London to raise money for CRY UK and the screening work they do in communities. They have supported me throughout the process and helped me come to terms with the fact I have been at risk my whole life - as a healthy xxxx xxxx my first ever surgery was my ICD being fitted. There would have been no opportunity to pick up my condition through usual means and I have been completely asymptomatic yet as an adult xxxx xxxx with LQTS my risks are highest at this time. I have worked for St John Ambulance and have seen the crippling impact sudden cardiac deaths cause to families and with the current lack of public access defibrillators and trained first aiders in communities, we need to be identifying issues before they become potential fatalities.

xxxx xxxx

28. xxxx xxxx

To whom it may concern.

I am backing the call for a need to screening as xxxx xxxx collapsed in 2013 of a cardiac arrest. xxxx xxxx had to be defibrilated several times and it took over an hour to bring xxxx xxxx back to us. As a family, we went through hell at the time trying to find the cause. xxxx xxxx suffered arrhythmia and this made xxxx xxxx go into a cardiac arrest.

From this we could not find a cause and our family have been screened because of this travelling between xxxx xxxx and xxxx xxxx in London regularly.

Through screening, we have found out that xxxx xxxx has Brugada Syndrome and has a another less worrying issue with xxxx xxxx heart along with xxxx xxxx. I have four children and my youngest xxxx xxxx has a floppy mitral valve and recently been diagnosed with CPVT.

We would never have known any of their conditions if we weren't screened after our xxxx xxxx cardiac arrest. I campaigned at the time with our local Councillor xxxx xxxx who took our letter to the houses of Parliament and I have campaigned with our council locally to get defibrillators installed in my community. They have now installed 3 with a fourth pending.

Therefore in my opinion screening is vital as sudden deaths can be avoided if made aware of unknown heart conditions.

Please keep me informed of any progress.

xxxx xxxx

29. xxxx xxxx

To whom it may concern, we must start screening young athletes, those who participate in sports and energetic activities.

We lost our 18 yr old 6ft 3" young xxxx xxxx at 18 to an undiagnosed heart condition ARVC while xxxx xxxx was at footie training. xxxx xxxx was always at the gym, training, playing football xxxx xxxx worked on the beach with a team of donkeys, whom xxxx xxxx was responsible for.

When we lost xxxx xxxx our world took a different course.

xxxx xxxx

Please add out name to the shocking list of youngsters that are our future that we have lost needlessly, with a simple test this could have been picked up, and prevented.

Yours xxxx xxxx

30. xxxx xxxx

I strongly believe that all young people should have cardiac screening. My own xxxx xxxx was 15 when xxxx xxxx was diagnosed with a serious heart condition. This was found by pure chance when xxxx xxxx was admitted to hospital for suspected appendicitis & xxxx xxxx blood pressure was checked prior to operation. xxxx xxxx was at the time very sporty & did not appear to have any symptoms of a heart condition at least to medically untrained parents. We were told by his Consultant that had this not been discovered it would only have been a matter of time before xxxx xxxx had a stroke or something worse. xxxx xxxx also recommended that my other children be screened. My GP advised me that although they sympathised with us, unfortunately this was not available on the NHS. I luckily found out about CRY & got my other children screened, thankfully they were ok. I was also advised that my other xxxx xxxx condition could have been discovered earlier with routine screening. Apparently xxxx xxxx had the condition since birth. The emotions & feelings of guilt for this not being discovered earlier we felt were terrible, but we are one of the lucky ones as xxxx xxxx xxxx xxxx now receiving excellent care from the NHS.

The xxxx xxxx of one of my closest friends attended a CRY screening funded by my employers & at 28, a teacher & about to become a xxxx xxxx for the first time, was discovered to have a heart condition. A letter of referral for further tests was sent to xxxx xxxx GP. When xxxx xxxx spoke to the GP, xxxx xxxx asked xxxx xxxx why on earth xxxx xxxx had had this screening done & it told xxxx xxxx nothing other than xxxx xxxx might have a heart condition , did not examine xxxx xxxx in anyway & was very very reluctant to refer xxxx xxxx for further investigation . My friends xxxx xxxx xxxx xxxx who is a nurse said that the letter quite clearly stated the necessity for a cardiac referral. Apparently after much pleading the GP did agree to refer xxxx xxxx, xxxx xxxx is now waiting on an appointment.

On our screening day out of 89 that were screened 4 were recommended to be referred for further investigation.

I appreciate the strains that the NHS is under, but my xxxx xxxx condition came to light, with a test as simple as taking xxxx xxxx blood pressure. I know that all heart conditions are not the same & very complex, but a simple screening such as blood pressure & or ECG, carried out routinely could help to save more young lives, also more awareness given to GP's when young people present with these suspected conditions, as in my friends xxxx xxxx case with the attitude of xxxx xxxx GP could quite still be walking around with a heart condition & no further investigation or treatment until something far more serious happened. xxxx xxxx paternal grandparents also died very young with heart conditions a fact that xxxx xxxx also had to explain to xxxx xxxx GP to justify why xxxx xxxx had attended a heart screening, even though it WAS NOT funded by the NHS.!!!!

A xxxx xxxx who played for my xxxx xxxx football team sadly died recently with an undiagnosed heart condition, a local xxxx xxxx who attended a screening was found to have a serious heart condition, xxxx xxxx & my friends xxxx xxxx & the 3 other people that attended the screening my employers funded & that’s just the young people that I am aware of.

Please take this matter seriously & put some procedures in place if you can, as other countries do, to protect our young people.

Thank you for your time

31. xxxx xxxx

Good morning,

I am emailing in support of the CRY campaign to get young children and adults screened and tested.

I have recently just over a month ago lost xxxx xxxx at the age of 20. xxxx xxxx died of ‘sudden adult death syndrome’ the cause is unknown. xxxx xxxx was a fit, healthy young xxxx xxxx with so much to live for and xxxx xxxx and I had our futures set out and planned together. There was no warning, no signs or symptoms xxxx xxxx heart just stopped and xxxx xxxx fought in hospital for 4 days never returning conscious. This is an extremely difficult time for me and the family as we just wish we could have helped and something could have been found to prevent xxxx xxxx death. We as a family are heartbroken and will never understand why it happened to xxxx xxxx

As a family we feel it is vital for young adults and children to be screened in order to detect a defect in the heart, this could have potentially saved our loved one if xxxx xxxx was screened. xxxx xxxx was a premature baby and xxxx xxxx was never screened throughout xxxx xxxx life which I feel is Terrible.

Our lives are completely town apart and feel strongly about young adults being screened. No one should have to go through the heartbreak many of us are going through.

Thanks,

xxxx xxxx

32. xxxx xxxx

Dear Sir/Madam,

Last August, I lost my xxxx xxxx, xxxx xxxx, to sudden cardiac death. This took place a week before my wedding and xxxx xxxx left behind xxxx xxxx partner xxxx xxxx and xxxx xxxx xxxx xxxx. Since xxxx xxxx death we have been attempting to come to terms with the tragedy of losing a young loved one so suddenly.

I am writing to ask that you consider introducing a screening program for young people. A comprehensive screening programme for young people would have identified the underlying condition and xxxx xxxx could have accessed treatment. xxxx xxxx would very likely still be alive today.

xxxx xxxx was a school teacher at xxxx xxxx in xxxx xxxx and a graduate of the xxxx xxxx for exceptionally talented graduates who want to devote their life to teaching and nurturing the next generation. xxxx xxxx had achieved a huge amount in just four years teaching and was appreciated by parents and pupils as a genuinely caring and inspiring presence in the classroom. xxxx xxxx loved to read stories to the children and the school commissioned a beautiful reading chair in xxxx xxxx memory. As a family we are providing an annual memorial to the school in the form of £100 towards new reading books that will bear xxxx xxxx name.

xxxx xxxx was a wonderful xxxx xxxx to xxxx xxxx and xxxx xxxx gave xxxx xxxx the very best start in life. At weekends and in school holidays xxxx xxxx introduced xxxx xxxx to a wealth of activities and experience and xxxx xxxx grew up in a loving and supportive family environment to become a confident, thoughtful and happy child. xxxx xxxx had absolutely no symptoms of any problem with xxxx xxxx heart and seemed to be in excellent health never having taken a day off work sick.

xxxx xxxx had been preparing for the Autumn 2018 term at school and was excited about taking on new responsibilities. xxxx xxxx went to bed one evening and when xxxx xxxx came to bed xxxx xxxx heart had stopped due to arrhythmia or an imbalance in the electrical charge that powers the heart beat. We have been devastated by our loss and the tragedy of a young xxxx xxxx being taken without warning and not being able to live xxxx xxxx life and see her xxxx xxxx grow up. xxxx xxxx faces nearly the whole of xxxx xxxx life without the love and backing of a devoted and resourceful xxxx xxxx.

The impact of losing a young xxxx xxxx on those around xxxx xxxx has been astonishing and will sadly resonate through the years and generations in our family history and experience. xxxx xxxx could reasonably have expected to have lived a good and useful life like her xxxx xxxx who is 88 and we have therefore lost nearly sixty years of xxxx xxxx companionship and contribution to society.

As a family we have all pulled together to try to accept what has happened and to mitigate the loss so that xxxx xxxx is able to grow up with as many of the advantages that xxxx xxxx xxxx xxxx ensured xxxx xxxx had and with the love and support that xxxx xxxx would have given to guide xxxx xxxx through life. We are, however, deeply troubled that the recent decisions taken by the National Screening Committee mean that xxxx xxxx wholly avoidable death goes unnoticed and will not result in a change of practice.

We now know that 12 - 15 young people who appear very fit and completely healthy suffer sudden cardiac death each week in the UK and in terms of the loss of life years and the impact on families this is tantamount to an epidemic. We believe that this is part of a pattern of imbalance in the Government's focus which neglects the health needs of young people and condemns so many of them to an early death.

We are requesting that you properly and fairly consider the impact that the sudden death of young people like xxxx xxxx has on families and on society generally and agree that it warrants the commitment of appropriate screening resources and medical intervention for the 1 in 300 that are discovered to have an underlying condition that will enable them to live their lives with their loved ones and make their contribution to society.

yours faithfully,

xxxx xxxx

33. xxxx xxxx

Hello,

I want you to consider the effects that young cardiac death have on those that are left behind.

Knowing firsthand on how the death of a seemingly fit and healthy young person can effect parents, siblings and wider family I say that it shouldn't happen on our watch!

The death of a young person is not only so sad for the wasted life but those who are left behind.

Please consider screening

each and every young person for heart problems and not only save a young life but those who love them most.

xxxx xxxx

Godmother to my cousins child who died unnecessarily at the age of 17.

34. xxxx xxxx

Dear Sirs

We have been made aware of the National Screening Committee's consultation document on the role of screening for the risk of sudden cardiac death in the young. We note that, once again, the NSC are not recommending systematic screening for the age group 12 - 39. We have looked at the reasoning which has guided the decision and would comment as follows.

You state that there is "uncertainty over the test" and that there has been "very little research into the reliability of the tests". Presumably, by "tests", you are referring to the standard electrocardiogram and echocardiogram tests, amongst others, that are routinely used by the NHS in cases of suspected heart attacks and other conditions (palpitations, irregular heartbeat etc) in order to diagnose and monitor such conditions. Surely, if these tests are reliable enough to be used "after the event" then they ought to be considered as useful tools to be used in preventing sudden and unexpected cardiac death.

You also argue that those identified as having a high risk of SCD may become anxious about their physical activity and stop regularly exercising, "which can be detrimental to their overall health". From this, do we understand you to mean that it is best that people are not made aware of a condition and are therefore allowed to die suddenly and unexpectedly. There is nothing more detrimental to health than sudden death!! As with all screening programmes people have the choice to participate or not. If one decides to participate then there is an acceptance that, however unlikely, there is a chance that that a condition could be identified. Understandably, anxiety will follow but at least there is a chance of receiving appropriate treatment.

"Sudden cardiac death in young people is always shocking and very sad" you state. It is far, far more than that we can assure you, but we accept that, without having experienced such loss, you will struggle to find the appropriate words. Apparently you feel this is in part because it is so rare and that the chances of sudden heart attacks in apparently fit and healthy young people are tiny. Terms such as "rare" and "tiny" can be misleading. It depends on what they are being compared with and you seem to be comparing with the "overwhelming" instances of heart attacks that occur in the elderly. This is hardly a fair comparison given that the hearts of the elderly have been subjected to a greater degree of "wear and tear" and often poor lifestyle choices. We do not happen to consider that hundreds of cases of Young Sudden Cardiac Deaths per year deserve to be treated as insignificant. Thousands of people, parents, grandparents, siblings, children in some cases and dear friends have had their lives impacted in a devastating manner following the loss of a young person.

What does it say about a Government and its agents that, even when fully aware of the conditions that can lead to the unacceptable number of deaths of young people, even when it has the means to do something to significantly reduce that number, it stands by and does nothing?

Yours faithfully

xxxx xxxx

xxxx xxxx Representatives - Cardiac Risk in the Young

35. xxxx xxxx

Sir,

I wish to register my lack of confidence in the NSC consultation process and it's recommendations on screening to prevent sudden cardiac death in 12-39 year old people.

In the recommendations published below the report fails to recognise that 1 in 300 people screened exhibit a cardiac condition that can be managed by medication or lifestyle advice - without which there can be a risk of SCD.

There is a clear lack of distinction between routine NHS cardiac screening and the more in-depth screening offered by the C-R-Y service - routine screening does not investigate in sufficient detail to reveal all possible cardiac anomalies.

The focus of C-R-Y screening is exactly that - to screen individuals and identify anomalies that, undiscovered by conventional ECG methods may lead to SCD.

The work of C-R-Y in addition to being a diagnostic and preventative assessment is also an ongoing research programme amassing vital and useful data and evidence for the continued use of cardiac screening in the young.

One life saved as the result of a screening justifies the existence of such a scheme. There is evidence available to prove that this has happened on numerous occasions as a result of C-R-Y screening.

I would ask you to consider the wide implications of failing to diagnose a fatal Cardiac issue which could be picked up by these investigations should it's validity be questioned.

Yours Sincerely

xxxx xxxx

36. xxxx xxxx

Hi

Please reconsider the potential withdrawal of the cardiac screening in the young.
This is an important service that needs to continue, it saves young lives and without it many more lives could be lost.

Many thanks

xxxx xxxx

37. xxxx xxxx

I am a xxxx xxxx of xxxx xxxx good level athletes. I have had xxxx xxxx of them checked through the CRY programme as soon as they were of age to do so.

It is so reassuring to have this check when they are so active and the stories of sudden deaths caused by undiagnosed heart conditions seem to have become more frequent.

A friends xxxx xxxx secured a scholarship in xxxx xxxx to do basketball and on xxxx xxxx medical check they found an enlarged right ventricle.

Had heart screening been given to all children xxxx xxxx would have been able to deal with this issue before it was found when xxxx xxxx is 20.

I full support heart screening as a mandatory test perhaps when the children receive their BCG at 15?

xxxx xxxx

38. Marion Hayman xxxx xxxx

To the National Screening Council,

I would just like to respond to your recent document “The UK NSC recommendation on screening to prevent Sudden Cardiac Death in 12 to 39 year olds (currently in consultation), on a personal level.

As a bereaved parent of a young adult- xxxx xxxx, I would like to highlight the impact that such an unnecessary loss has on a family.

We lost xxxx xxxx, at the age of 27, just when xxxx xxxx was about to embark on the next stage of xxxx xxxx life, having recently become engaged and intending to marry the following year.

The impact on family members is devastating. As a xxxx xxxx, wrapped up in my own grief, I found it very hard to identify with the grief of other family members. Obviously I tried to make the effort. Whatever effort I made, it was not always enough on its own. Losing xxxx xxxx, could not help but put strain on my marriage, xxxx xxxx also lost in xxxx xxxx grief, trying to find a way through. I could not completely console xxxx xxxx, aged 87, at the time of xxxx xxxx, and xxxx xxxx death most likely contributed to her xxxx xxxx hastened journey along the dementia route. My xxxx xxxx, who was a xxxx xxxx xxxx xxxx, with a xxxx xxxx of xxxx xxxx, found that when everything should have been wonderful in xxxx xxxx life, without any warning, xxxx xxxx was suddenly a bereaved xxxx xxxx -where did that come from? xxxx xxxx found xxxx xxxx way of coping was, and is, that everything had/has to be perfect in the home, the children dressed immaculately and behaving impeccably, which in turn has put a strain on xxxx xxxx marriage. xxxx xxxx xxxx xxxx xxxx xxxx whom I have remained in contact with, is desperately trying to achieve xxxx xxxx goals in xxxx xxxx profession, but emotionally has not met anyone that measures up to xxxx xxxx. xxxx xxxx whole future ripped from xxxx xxxx in a few minutes. Other family members, aunts, uncles, cousins also feel the enormous loss of losing a family member so young. xxxx xxxx friends still cannot believe that xxxx xxxx is no longer with them and hurt more than they let on.

In those early days, months and years, it is hard to face a new day, hard to work out what is important in life, and if indeed there is any point to it anyway. Emotions are hard to cope with and yet one is feeling so many of them, all at the same time. To try and avoid these feelings one can also feel very numb. One can start to lose confidence and cannot cope with anything negative or problematic. It takes so much to try and find a purpose again, some motivation, some reason to keep going.

The loss of a child is devastating and yet somehow so many families affected by this have managed to find strength. In selfless acts of constant fundraising CRY families have raised money for screening, research and bereavement support, in a determined effort that this should not happen to anyone’ s son, daughter, partner, sibling again. We are all trying to spare others from going through this constant heartache- the pain never goes away.

Since losing xxxx xxxx and being supported by CRY in so many ways, I have been involved with raising funds, to hold screenings in the local community. I have been trying to raise awareness of cardiac arrests in the young and the importance of screening. I am trying to prevent what happened to us happening to another family in our area. If xxxx xxxx had been screened, xxxx xxxx would probably still be with us today. Surely an ECG or an Echocardiogram is a small price to pay for a young life. These youngsters have so much to offer, so much energy and enthusiasm to contribute to the world in which they should be living, so many experiences to enjoy, so much love and enjoyment to give, so many smiles to leave lasting impressions. Should they be denied any of this?

I don’t want sympathy. I don’t feel sorry for myself. I feel sorry for the life xxxx xxxx has been deprived of, which could possibly have been avoided. I have recently been to the weddings of two xxxx xxxx. xxxx xxxx loved those cousins and would want them to be happy but xxxx xxxx was not there- xxxx xxxx was mentioned in the ‘absent friends’ sections. xxxx xxxx was 27 years old !!!!

xxxx xxxx has been deprived of getting married, having children, being a xxxx xxxx, getting on with the life xxxx xxxx so enjoyed, fulfilling xxxx xxxx potential in so many ways. xxxx xxxx wanted to be there to support xxxx xxxx, be the ever-loving xxxx xxxx and family member that xxxx xxxx was. xxxx xxxx worked hard and played hard- to xxxx xxxx life was for living!!

I urge you to take into account the personal and devastating effect that these deaths have upon individual families, friends and indeed communities. Surely a heart screening is a small price to pay for a young life.

Yours sincerely,

xxxx xxxx

39. xxxx xxxx

TO WHOM IT MAY CONCERN

I am a supporter of Cardiac Risk in the Young and I am amazed that you will not undertake a National Screening Programme as I believe that prevention is better than cure and in the long run is less costly both in lives saved and financially.

I was unfortunate to lose my only child xxxx xxxx on xxxx xxxx, 2002 to an undetected Heart Defect. xxxx xxxx actually visited our G.P. six months prior to xxxx xxxx death with what I now know to be classic symptoms of Heart problems but was told to rest xxxx xxxx back etc. He xxxx xxxx was 21 years and 11 months old and not a day passes that I don't think of xxxx xxxx and what might have been. Unless you have lost a child, you will never know the anguish every parent experiences, especially on birthdays and anniversaries. As my xxxx xxxx 17th anniversary approaches I dread the day and try to occupy myself as much as possible, but living alone, without family or friends who think you get over ''these things'' as though it was a boil to be lanced, is not something I would wish upon anyone.

I implore you to reconsider your opinions, for the sake of all the families who have already lost their precious loved ones, and for those in the future who may unfortunately find themselves in our positions.

Yours sincerely,
xxxx xxxx

40. xxxx xxxx

Hi,

I wanted to tell you about my experience with CRY. My xxxx xxxx 11, xxxx xxxx 17 and xxxx xxxx 13 all passed away due to cardiac matters. CRY have screened my heart thoroughly and this has been a huge impact to my life. It has reduce/removed my stress and worries of any possible hereditary issues. Allowed me to get back to living as much of a normal life as possible following the loss of my loved ones. I think I would have not got though the past few years without cry's continuous support. The relief of knowing I am ok to live a normal life including continue my love of football.

I feel every young person deserves the opportunity for a potential longer life and also a less worried life.

Thanks,
xxxx xxxx

Thank you for getting back to me.

Please please please please please help CRY continue to make a difference. The world needs more happy and healthy young people that want to live their lives. My xxxx xxxx and xxxx xxxx did and I'd have been willing to give them mine so they could continue their potential in life. Would you allow someone the same?

Thanks,
xxxx xxxx

41. xxxx xxxx

With urgent reference to your consultations on the above.
It horrifies me that your results do not take on the main project of preventing loss of young lives.
80%have no symptoms and their lives are lost in a nanosecond.
Is this what you are about now? Ignoring the valid statistics shown by CRY?
A simple screening test for all children in schools is the need.
The tests by the CRY Screening Units prove the results can safe lives.
Surely that is what you are about?

On a personal note Families are devastated as with any death. But to suffer one that could possibly have been prevented .... beggars belief. What if it were your child .... a so called healthy child with all their life in front of them ... and then bang no more!!!! Horrendous!

You have it in your power ... do something about it.

A bereaved mum.

42. xxxx xxxx

Hi,

My name is xxxx xxxx, I am xxxx xxxx and at age 23 I was found by chance via my gp's curiosity to have dilated cardiomyopathy. My left ejection fraction was at 22% despite me feeling good and being a fit and healthy person who did not take drugs or smoke.

If I had not had an ecg and then an echocardiogram I would not be here today. Since my diagnosis I have been a lot more aware of people around me who have suffered a similar cardiac problem, but have not been so lucky as they were never found with it untill it was too late.

A simple ecg can make all the difference. I had palpitations and that was my only symptom that my heart was swollen up and about to fail on me.

Please recomend screening so that people do not have to suffer this tragedy. It is not an obvious issue to people however is deadly. As a xxxx xxxx to xxxx xxxx children, and still at a loss as to how my dilated cardiomyopathy was triggered I will need to have them checked in the future. My xxxx xxxx have a chance, others unfortunately do not.

Yours sincerely

xxxx xxxx

43. xxxx xxxx

To whom it may concern

On xxxx xxxx 2018, my 23 year old xxxx xxxx xxxx xxxx suffered a sudden death cardiac arrest. xxxx xxxx was down for 20 minutes and had five teams of emergency services working on xxxx xxxx. They managed to get xxxx xxxx back but xxxx xxxx has suffered significant hypoxic brain damage leaving xxxx xxxx in a very very low minimally conscious state.
In the 10 months xxxx xxxx spent in hospital they discovered xxxx xxxx has long QT syndrome which caused the cardiac arrest. xxxx xxxx hadn't shown any symptoms.
With screening, this could of been prevented. Because xxxx xxxx xxxx xxxx had already had open heart surgery at 3 years old, xxxx xxxx would of benefited from some form of screening.
But now xxxx xxxx has had xxxx xxxx life taken away from xxxx xxxx. In 2017 xxxx xxxx got a law and criminology degree and was going back to do xxxx xxxx masters this year, thats all gone.
xxxx xxxx will never be a xxxx xxxx.
xxxx xxxx will never have a xxxx xxxx.
xxxx xxxx will never be able to be without 24 hour care.
The affect on xxxx xxxx has been life changing, and life changing for xxxx xxxx family too.
My heart breaks everytime I look xxxx xxxx xxxx xxxx.
Please consider screening in the young and stop these young people dying or being left with life changing conditions.

Yours faithfully

xxxx xxxx

44. xxxx xxxx

Please accept this email as confirmation I would like provisions to be improved to identify cardiac conditions in the young. With 1 in 300 having a condition this is a pertinent and broad reaching issue.

Thank you

45. xxxx xxxx

In response to the consultation on the above, I am fully in support of screening for the prevention of sudden cardiac death.

xxxx xxxx

46. xxxx xxxx

Our 17 year old xxxx xxxx died 22 years ago. xxxx xxxx was fit, healthy and extremely active. xxxx xxxx had just completed xxxx xxxx A levels and was looking forward to university with xxxx xxxx life ahead of xxxx xxxx.
xxxx xxxx collapsed and died in xxxx xxxx bedroom while getting ready for tennis- xxxx xxxx 26 year old xxxx xxxx found xxxx xxxx dnd tried xxxx xxxx best to revive xxxx xxxx with cpr while also calling the ambulance.
All to no avail- xxxx xxxx life snuffed out just like that. xxxx xxxx life gone and our family changed forever.
xxxx xxxx friends also devastated struggled to come to terms with this- how could such a thing happen to someone so fit and healthy.
To then some time later (and only through contact with Cardiac Risk in The Young) find out an ECG test correctly and expertly reviewed would have been very likely to have highlighted his problem and led to the prevention of this tragedy served only to add to our distress.
Now 22 years on it seems nothing has changed. Every week young people die of hidden heart conditions and families are devastated and changed forever.
Think of all these wonderful young people who will now play no part in society, who will make no contribution because a national committee is able to make the decision that they are not worth it.
I am disappointed and disgusted that a group of people can ignore all the evidence and come to this decision.
I refer you for example to all the evidence from the CRY screenings of which I know you should be aware.
I urge you to consider this matter again and to take into account the sheer numbers involved and the impact on families and society.
Yours,

xxxx xxxx

47. xxxx xxxx

Hi

I support the need for this screening. I also appreciate there is a balance between cost and benefit. However the article I read said 1 in 300 people have a heart condition so I would have thought the benefit (life) outweighs the cost.

xxxx xxxx

48. xxxx xxxx

Dear Sir/Madam

I lost my cousin to an undiagosed heart condition at 27 years old, 3 weeks before xxxx xxxx was due to become a xxxx xxxx for the first time. xxxx xxxx simply dropped dead at work. If heart screening had been offered by the NHS and awareness was raised there is a good chance xxxx xxxx condition might have spotted and my cousin saved and it would definitely save lives of other young people. The shock of suddenly losing a seemingly healthy young xxxx xxxx has had a profound effect on the entire family. My cousin's xxxx xxxx endured the birth of xxxx xxxx whilst still in shock and grieving for xxxx xxxx and xxxx xxxx has grown up never knowing xxxx xxxx.
I believe all young people should have the opportunity to have their hearts tested and lives saved.

Yours faithfully

xxxx xxxx

49. xxxx xxxx

To whom it may concern

Re: External review against programme appraisal criteria for the UK National Screening Committee

Four years ago on the xxxx xxxx 2015 our 22y old xxxx xxxx xxxx xxxx had a fatal cardiac arrest out of the blue whilst returning home to prepare for xxxx xxxx new life in xxxx xxxx, before going into xxxx xxxx a life xxxx xxxx did not get to enjoy. Ironically, xxxx xxxx was awaiting xxxx xxxx xxxx xxxx entrance medical during which an ECG would have picked up xxxx xxxx covert heart condition. xxxx xxxx may not have made it into the xxxx xxxx, but xxxx xxxx would still be alive today, as we now know that a properly performed and interpreted ECG would have identified the underlying problem and allowed preventative intervention.

Our family has been left bereft by xxxx xxxx death. We would not be alone as parents to say that our s xxxx xxxx on was a kind, generous, intelligent, gentle and very funny young xxxx xxxx who brought joy to those who knew xxxx xxxx. At xxxx xxxx funeral and over the last 4 years it has become increasingly apparent that it is not only us, xxxx xxxx family, who have suffered the loss but the staff, friends and parents who knew xxxx xxxx at his schools, college and university; those who played rugby with xxxx xxxx, rowed with hi xxxx xxxx m, and worked with xxxx xxxx; those who would have benefitted from all xxxx xxxx amazing qualities.

Our xxxx xxxx xxxx xxxx died that night; but literally hundreds of others also lost a part of themselves and will never be the same again. Whilst we cannot bring back xxxx xxxx, we are determined to prevent further loss and heartache for other families and are doing this by raising awareness and funds for free cardiac screening for young people under the auspices of Cardiac Risk in the Young (CRY).

We do this, not only as bereaved parents, but also as recently retired (due to our xxxx xxxx death) Associate Professor in Clinical Diabetes and Professor of Molecular Medicine. In our professional work we have been involved in developing and implementing screening programmes for other conditions for which early detection allows earlier treatment and prevention of morbidity and mortality such as Type 2 diabetes and gestational diabetes. In the research setting, we have also been involved in the prediction and prevention of type 1 diabetes and for complications such as diabetic nephropathy. In all of these examples, we are very well aware that screening would be appropriate when we are dealing with a serious condition, with a screening tool which is both sensitive and specific and an intervention whose positive effects in preventing morbidity and/or mortality massively outweigh any adverse effects.

As such, we have read with interest the current external review of literature from 2014. CRY's own data reveal there to be at least 12 deaths per week under the age of 35y from a number of cardiac conditions. As with our xxxx xxxx, 80% of those suffering such a young sudden cardiac death do so without any prior symptoms. Therefore, knowing there to be a simple, cheap, acceptable screening test with high sensitivity and specificity to prevent such deaths, it is personally very important to us, as we approach Thomas' peers to encourage them to have their hearts screened, that CRY's screening protocol is made available, free of charge.

The report commissioned by the National Screening Committee (NCS) was to assess: 'Screening for ***the risk*** of sudden cardiac death in the young' (in a general, asymptomatic population) addressing 3 questions.

1. *What is the reported incidence of sudden cardiac death (SCD) in young individuals aged 12 to 39 years old in the UK?*
2. *In young individuals aged 12 to 39 years old, what is the accuracy of: history-taking; physical examination; 12-lead electrocardiogram (ECG); mobile health devices such as mobile phones, tablets, smart watches and other wearables; and genetic testing as screening tools, alone or in combination, to identify risk of sudden cardiac death?*
3. *What is the effectiveness of screening to prevent sudden cardiac death (SCD) in young individuals aged 12 – 39 years old compared to no screening?*

Clearly, since 2014 there have not been specific studies to help answer the actual questions that are important to parents and scientists such as ourselves, which may be why the report does not support universal screening in the general population as yet. A review addressing 'Screening for cardiac conditions in young adults' would be a more appropriate and helpful topic.

There is a suggestion that further studies need to be completed including a randomised controlled trial (RCT). In our opinion, an RCT testing either the efficacy of screening with an ECG vs no screening, or intervention vs no cardiac intervention in prevention young cardiac death is now not possible given the number of screenings already carried out by CRY.

Whilst there are undoubtedly still questions to be answered, it is of interest that NHS England have just proposed the use of high-street ECG screening for cardiac conditions in the over 40's https://www.england.nhs.uk/2019/09/high-street-heart-checks-on-the-nhs/. The ECG remains the investigation of choice in these individuals to pick up Atrial Fibrillation and other signs of ischaemic heart disease, as it is for young people with cardiac-like symptoms which might be harbingers of Sudden Arrythmogenic Death Syndrome (SADS).

In summary, as for other conditions, a lower level of evidence might be all that is possible to inform best practice for the screening of conditions resulting in SADS.

We have some positive suggestions:

1. We fully support that funding be made available for a universal cardiac screening programme in the young. As for the new NHS England enterprise, this should be piloted using the information and protocol developed by the CRY team and utilises a 3 stage screening strategy (for all - family and personal history & ECG; cardiac echo for those with abnormalities) which would inform the development of a National screening programme. The pilot should include different demographics areas (inner city, rural, different ethnicities) including such questions as in 2&3 below.

2. With CRY's huge existing clinical research in the general population does positively pick up 1 in 100 individuals with a cardiac abnormality, 1 in 300 of which are urgent and life- threatening. If it has not already been published, a retrospective examination of those who were screened negative >10 years ago, linking research and routinely collected NHS data, would add to the knowledge about false negatives. I am aware that these data do exist in elite athletes.

3. With respect to the concerns about the degree of anxiety suffered by those being screened, particularly those who have an abnormal result as with many other screening programmes, these data are often very scarce. It would appear that for most who just receive the screening ECG the anxiety is short lived. However, it may now be possible to investigate this prospectively in more detail by adding specific qualitative questionnaires addressing the degree and severity of anxiety during different phases of the screening – being invited to screening; having an ECG; having further investigations; before and after an action plan if a serious abnormality is shown.

One young sudden cardiac death has a ripple effect that affects hundreds of people. It is impossible to put a price on that, though as scientists we must. That these deaths could be picked up and prevented by a suitable screening tool has to be an over-riding aim not only of affected families, but also those in Public Health. We urge you to consider supporting such a programme in the UK whilst gathering more important information to improve its outcomes and cost- effectiveness.

Yours

XXXX XXXX
XXXX XXXX

UK National Screening Committee

50. Paul Clabburn

Name:	Paul Clabburn	**Email address:**	xxxx xxxx
Organisation (if appropriate):			
Role:	**Parent of teenager who died from SCD.**		

Do you consent to your name being published on the UK NSC website alongside your response?

Yes

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
P5	It does not consider the role of screening in special groups such as athletes …	There is no definition of ‘athlete’. There is no definition of ‘general population.” It is therefore impossible to decide whether the omission of special groups like athletes is justified.
P8	“The review authors also found no relevant studies that evaluated the effect of screening by comparing outcomes in screened and non-screened individuals.”	To do such a study would surely be unethical and thus should not be considered by the authors. It implies a control group with one set of people being screened and another not. The consequences for the latter might be fatal. Screened individuals are not, of course, guaranteed survival but they are at least given a chance. Not to extend that chance is wrong.
P10	“Uncertainties remain as to the impact of overdiagnosis …”	Cart before horse. You can do something with a live young person. You can’t do much with a dead one.
P10	“This review has key limitations. Firstly, in line with UK NSC standard practice …”	A review that admits to “key limitations’ before it starts hardly inspires confidence, neither is one that adopts a “standard” approach to a subject the report itself goes on to make non-

		standard ie the focus is on the identification of risk, not the identification of conditions.
P10		
P94	“Reference 79. Cardiac risk in …”	CRY are currently screening more than 20,000 young adults a year. There appears to be no examination of the evidence of the extent of the issue that this large cohort provides. There is no evaluation of CRY’s claim of the numbers who die each week, a figure supported by the British Heart Foundation’s August 2019 Fact Sheet. “In the UK it is estimated that at least 12 young people (aged under 35) die every week from an undiagnosed heart condition.” Why not? This goes to the core of the issue. The best available evidence from a large scale testing programme suggests 1 in 300 people screened have a heart condition which can benefit from intervention. Yet that’s been ignored.

51. xxxx xxxx

I think it's very important for children to be screened for potential sudden cardiac death, It could save a lot of lives and sadness to many families. The argument that it might stop children excising is erroneous we all know children exercise less today than 20 or 30 years ago already, if a child knew they may develop a heart condition they maybe more likely to do health heath exercises. They would also be informed about activities that maybe problematic eg instead of taking up boxing, running or rugby they might opt for swimming or yoga. Anything that informs people about their bodies and the best way to look after themselves tailored to their needs must be a good thing

xxxx xxxx

52. xxxx xxxx

As an avid fundraiser for CRY I would like to add my name to the list of people wanting heart screening for young people.

I live in xxxx xxxx and I know four families within a 30 mile radius that have lost children in their 20's due to undiagnosed heart conditions. The family names I speak of are xxxx xxxx, xxxx xxxx, xxxx xxxx and xxxx xxxx. All appeared healthy. All were sporty but un unbeknown to anyone. They were ticking time bombs awaiting their fate and the devastation of their families. I believe had they been aware, things would've been so different. Treatment could have prevented their deaths and awareness would've instigated treatment.

Please, I beg you, consider heart screening of our young to prevent future losses.

We service our car on an annual basis. Why not a test on our most vital organ?

I know the cost involved. I raised money for a screening session in my home town which had 100% turnout and I along with others remain dedicated to raising funds for future screening. However, people will only donate so much to each charity as there are so many worthy causes out there.

Please support CRY and please reconsider testing to prevent any other deaths. 12 a week is just horrendous. Have a heart and save someones heart I beg you.

xxxx xxxx

53. xxxx xxxx

Good Morning

I read with great dismay that screening is due to discontinue.

We have two xxxx xxxx who are cyclists who both race Cyclocross, Road and Track at a National Level. As a result there is a lot of training in their own time. They also Swim, play Rugby/Football and do Cross Country for their School and County.

As a parent of sporty kids we have the normal concerns that every parent has. However, we also worry that they may never wake up one morning due to a pre-existing undiagnosed heart condition. We also worry that they may suffer a head or brain injury as a result of racing or rugby.

One of our consoling thoughts was that when our xxxx xxxx reached the age of 14 we could get them tested. We have been to our local GP as a result of a young rider called xxxx xxxx dying unexpectedly a few years ago but the GP said our xxxx xxxx were too young to be tested.

PLEASE ENSURE THAT THIS SERVICE CONTINUES THOUSANDS OF SPORTY KIDS AND THEIR PARENTS NEED THIS SERVICE TO CONTINUE AS IT WOULD GIVE PEACE OF MIND TO MANY PARENTS. HOWEVER, AND MORE IMPORTANTLY IT WOULD HELP TO FIND CHILDREN/TEENAGERS WHO DO HAVE A PRE-EXISTING UNDIAGNOSED HEART CONDITION.

We have seen the impact of child deaths as a result of heart issues and for the sake of some money this service must continue.

Kind regards

xxxx xxxx

54. Fiona Gore

Dear Sir/Madam

Writing this letter and trying to put into words to tell you about my beautiful xxxx xxxx is something that I would never have imagined in a million years, how is this even possible I ask myself.

My xxxx xxxx was a Loving, Caring, beautiful soul, who brought so much fun, laughter and happiness into everyone's lives, a University Student just about to graduate with a predicted 2-1 BSc Honours Degree. xxxx xxxx passion in life was Music, a guitarist in a band with xxxx xxxx 4 best friends.

My xxxx xxxx suddenly collapsed and died on xxxx xxxx 2018 from a Cardiac Arrest, due to a undiagnosed heart condition, age 20, thirteen days before xxxx xxxx 21st Birthday.
The devastation, shock and disbelief that my xxxx xxxx life was so cruelly taken away from him is something that i will never accept or never recover from, my purpose and meaning in life has been destroyed. xxxx xxxx had so many plans, hopes and dreams for xxxx xxxx amazing life ahead of xxxx xxxx.

I have been told on numerous occasions from Pathologists, Surgeons and GP's that xxxx xxxx undiagnosed Heart Condition would never have been picked up as there was no sign's, symptoms and being of a young age is another factor that I've been told so many times. It's so devastating to even comprehend that my beautiful xxxx xxxx is now a statistic of those 12 a week young sudden cardiac deaths, due to a undiagnosed heart condition.

There is no "moving on," or "getting over it.

There is no bow, no fix, no solution to my heartache.

There is no glue for my broken heart, no exilir for my pain, no going back in time.

For as long as I breathe, I will grieve and ache and love xxxx xxxx with all my heart and soul.

There will never come a time when I don't think about who xxxx xxxx would be, what xxxx xxxx would look like, and how xxxx xxxx would be woven perfectly into the tapestry of my family.

There is and will always be a missing space in our lives, our families, a forever-hole-in-our-hearts.

I want to highlight the importance of (CRY)Cardiac risk in the young life saving campaign to reduce the number of young sudden cardiac deaths by providing heart screening to all young people, in the hope that another child can be saved and to emphasise my agreement with the feedback provided by CRY.

In that, the report FAILS to stress that 1 in 300 people screened have a cardiac condition that can benefit from treatment or lifestyle advice.

- FAILS to objectively evaluate the overlap between the current routine use of the ECG in the NHS / medical practice for general diagnostics and monitoring and its role in cardiac screening. For instance;

The contradictory position of the NSC where the ECG IS an accurate test if you experience symptoms, but the ECG IS NOT an accurate test if you DO NOT experience symptoms.

§ NICE T Loc guideline https://www.nice.org.uk/guidance/cg109/chapter/1-Guidance… where ECGs are an essential part of assessment for people who have a temporary loss of consciousness.

The routine use/requirement of ECGs in screening programmes

§ in sport

§ pharmaceutical drugs trials

§ army recruits https://apply.army.mod.uk/…/soldier-recr…/soldier-assessment

§ commercial pilots https://www.baatraining.com/the-aviation-medical-exam-what…/

§ pre operations assessments https://www.escardio.org/…/When-to-perform-pre-operative-ECG & https://www.nice.org.uk/…/tests-before-surgery-pdf-31411086…

It contradicts the information on the NHS choices website (e.g. WPW)

§ WPW is one of the most common conditions identified in the CRY screening programme, affecting more than 1 in 700 young people.

§ The NHS states "it may only be picked up when an ECG is carried out for another reason. In these cases, further tests will be done to determine if treatment is required… with treatment, the condition can normally be completely cured…..WPW syndrome can sometimes be life-threatening……….and treatment can eliminate this risk"

§ https://www.nhs.uk/conditio…/wolff-parkinson-white-syndrome/

- It FAILS to frame the consultation correctly. The current NSC screening programmes (e.g. breast cancer) focus on identification of conditions/diseases, whereas this policy is framed as identification of the risk of sudden cardiac death. The framing of the issue should be consistent with the other NSC policies, “screening for cardiac conditions in young adults”.
- The NSC is requesting for Randomised Controlled Trials to be conducted. This is UNETHICAL and would lead to young people dying in the pursuit of “better” science.

We request that you reconsider your initial recommendations. It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG.

We consent to our names being published on the UK NSC website alongside our response.

Yours Sincerely

Fiona Gore

55. xxxx xxxx

Hello,

I am writing to you in regards to the consultation for sudden cardiac death, to share my experience and offer it as evidence for heart screenings to be made available to young people.

In December 2014 my xxxx xxxx was admitted to accident and emergency with intense abdominal pain. The ER doctor was concerned with the placement of the pain and chose to check xxxx xxxx ECG, and in doing so revealed Brugada Syndrome, a very rare genetic heart condition that causes sudden cardiac death. My xxxx xxxx was only 29 at the time, and until that point we had no idea of the danger that xxxx xxxx had been in every single day. People with Brudaga are susceptible to sudden changes in temperature, which means even something as simple as a fever can be extremely dangerous. We were extremely lucky to become aware of xxxx xxxx condition before it became fatal.

Unfortunately we have been unable to find out whether any of xxxx xxxx family members have inherited the same condition. My xxxx xxxx dad died when xxxx xxxx was 10 years old, and xxxx xxxx paternal grandparents have passed away. While xxxx xxxx mother has been tested the current restrictions mean that xxxx xxxx aunt and cousins are unable to request a heart screening. Until they start to show symptoms, which with a sudden cardiac condition is often too late, we won't know if they also have Brugada Syndrome. Situations like this are just one of the many reasons why the current policies regarding heart screenings need to be revisited and corrected.

Kind Regards,

xxxx xxxx

56. xxxx xxxx

Please listen to CRY (Cardiac Risk in the Young). My friend's xxxx xxxx died unexpectedly of a heart attack - xxxx xxxx was under 40 and had no idea there was a problem until xxxx xxxx had the fatal heart attack. This has been terrible for xxxx xxxx and also for xxxx xxxx family. I imagine that it was also a horrible ordeal for the members of the public who tried hard to save xxxx xxxx life until help arrived.

57. xxxx xxxx

Hello

I just wanted to add my opinion - I believe that ALL young people should be given the opportunity to be screened for cardiac problems. I have have witnessed at close hand the devastating effects of undiagnosed cardiac defects in the young, and the frustration which comes from knowing that, for at least some individuals, such problems might be avoided altogether or at least made less likely if simple screening tests were available across the board.

Yours faithfully

xxxx xxxx

58. xxxx xxxx

It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG. It is a simple and effective test and all young people should have the opportunity to have their hearts tested.

I have now experienced the deaths of 3 young people I knew well for the want of having easy access to this test and having watched their families go through this has been heart breaking.

I would urge you strongly to listen to the evidence from CRY and please help prevent these unecessary deaths.

xxxx xxxx

59. xxxx xxxx

It is a no brainer that cardiac screenings should be made available to the young.

This is my story-

xxxx xxxx

xxxx xxxx
I don’t know what more you need to make such an obvious right decision! I’ve got xxxx xxxx young children that could have similar episode to me, how do you think this makes me feel!!?

60. xxxx xxxx

Dear Sirs

I am writhing to you as a close friend of a club runner who died of sudden Cardiac Arrest during a xxxx xxxx Race. xxxx xxxx had an underlying heart condition but because xxxx xxxx had never been screened xxxx xxxx was totally unaware of it, if xxxx xxxx had been xxxx xxxx may well still be alive today. I am also a leader in a local young persons running club and in this capacity I would very much support cardiac screening for all young athletes as the health and safety of all young adults should always be paramount. I urge the NHS to consider offering this life saving screening.
Regards

xxxx xxxx

61. xxxx xxxx

Hi

It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG.

I therefore urge you to consider that all young people have the right to have the hearts tested should they /their parents wish to.

Kind regards

xxxx xxxx

62. xxxx xxxx

Hi

63. I am responding along with many others to campaign for national screening for young people aged 12 -39. We can evidence that over 600 young people die needlessly every year! Testing could have saved their precious lives. This could have been the case for our xxxx xxxxwho sadly died from ARVT at just 27.

Please bring in national screening it is vital!

Many thanks in consideration

xxxx xxxx

Devastated Dad

64. xxxx xxxx

It is with a broken heart that I urge you to make screening for all young people available.

On xxxx xxxx this year, my xxxx xxxx year old son went to work and never came home.

xxxx xxxx passed away from Arrhythmogenic Cardiomyopathy. We didn't know xxxx xxxx had a rare heart condition, we had no time to say goodbye to one of the kindest, hard working, loyal person you could ever meet.

The devastation, heart ache and grief caused to myself and the rest of the family by xxxx xxx sudden passing I cannot put into words.

If screening was available, this tragedy may have been avoided.

I will never get over the loss of xxxx xxxx but if I can prevent another xxxx xxxx going through what I am then I will do everything in my power to do so.

My tears never stop, my life has changed. I will never get to see xxxx xxxx marry or hold xxxx xxxx children in my arms. I can only talk to xxxx xxxx in my head.

Please make screening available for all young people. Unless you have lost a child you cannot understand the grief all mothers, fathers,step parents, brothers, sisters, grandparents, aunties, uncles, cousins, nieces and nephews are going through. It affects us all.

Regards xxxx xxxx

65. xxxx xxxx

Having a close friends family go through the awful pain of loosing a child at xxxx xxx due to sudden heart failure I would strongly welcome this screening programme to support our young people and try to avoid future occurrences.

66. xxxx xxxx

I believe this is an excellent idea. I work in the Cardiology Department at a xxxx xxxx and I come across young patients with cardiac conditions, however unfortunately as we know sometimes others aren’t so lucky.

We have screening for other conditions so why not for cardiac conditions, many of which people may live with but have so symptoms and go undetected. How many more young people have to die before action is taken?

I am also shocked that I have only just heard of this fantastic idea today, on the deadline.

Yours faithfully,

xxxx xxxx

67. xxxx xxxx

I would fully support any screening for possible heart problems in young people.

My xxxx xxxx had an OOHCA, aged xxxx xxxx, at work on June xxxx xxxx. Due to a rapid response from xxxx xxxx colleagues, a passing ambulance crew and a defibrillator in the shop next door, xxxx xxxx survived.

It took 4 shocks, 6 days in ICU and 2 weeks on Cardiology unit - ending with an S-ICD fitted.

There was no warning, no earlier symptoms or previous health issues. xxxx xxxx

has recently been tested, as a precaution, but not had results yet.

We cannot let so many young people die, unnecessarily, if a screening programme could be implemented.

Please don't let funding issues be their cause of death!!

A very shocked, relieved and thankful mother -

xxxx xxxx

68. Murray Nee (Mr)

Dear Sir/Madam,

We are aware that the deadline for responses to the consultation is September 7th. We have spent the last two months trying to find the strength to do this. As the bereaved parents of our wonderful xxxx xxxx xxxx xxxx we believe strongly that we need to provide feedback with regards to the serious flaws within your document.

The strongest point we need to make is that of the total failure to demonstrate the devastating, life changing impact of young sudden cardiac death within families, friends, the local community and wider society.

Our xxxx xxxx, xxxx xxxx, collapsed and died on xxxx xxxx way to work on xxxx xxxx xxxx xxxx was a bright, compassionate, caring, thoughtful, loving young xxxx xxxx with a strong moral compass, a great sense of humour and a desire to make a difference. xxxx xxxx was and is so loved by us, xxxx xxxx xxxx xxxx aunties, uncles, cousins, friends and work colleagues. The loss of xxxx xxxx beautiful light with all our lives will be lifelong.

It is so difficult to articulate the pain we carry and the grief we now live with every day in this terrible new world we now inhabit. We are fortunate to have very close family and friends who continue to support us. I know this is not true for all bereaved families. I have had bereavement counselling from CRUSE which was excellent with regards to the validation of the huge loss of xxxx xxxx. There is often a false assumption that the purpose of bereavement counselling is 'to make you better'. Could you please advise all members of the committee that there is no 'better' for bereaved families? I had to take early retirement after working as a xxxx xxxx and xxxx xxxx in xxxx xxxx for forty years, my xxxx xxxx struggles with xxxx xxxx work every day, we do not sleep very well, we cry, we grieve, we see xxxx xxxx pain and feel helpless. To quote xxxx xxxx , writer, speaker and bereaved mother:

'The moment our child died is now, yesterday, tomorrow, forever. It is the past, the present, the future. It was not just one finite horrific moment in time that happened last whenever. It is not just the moment, the hour, the second, the millisecond our life became permanently divided into before and after...... Our child dies all over again every morning when we wake up. And again every moment they are (yet again) missing. And again every moment in between. And again every breath we take. Our child dies every moment they are not here with us - for the rest of our lives.'

Since xxxx xxxx died we have become involved in raising awareness of sudden cardiac death in the young and in fundraising to support the fantastic work of the charity Cardiac Risk in the Young (CRY). CRY's research has shown an incidence of young sudden cardiac deaths of 1.8 per 100,000 per year in the UK.

(NB - The NSC document incorrectly states, 'There continues to be uncertainty as to the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person - years. The NSC also refers to this as 'low incidence' which it is not.)

1.8 deaths per 100,000 equates with at least 12 deaths per week and more than 600 young sudden cardiac deaths per year in the UK. When we consider the terrible impact xxxx xxxx death has had on so many people in our lives it is incomprehensible to even begin to think about hundreds of thousands of parents, siblings, cousins, aunts, uncles, friends and colleagues affected every year in the UK by young sudden cardiac death. So much worse than this is the fact that more than 600 beautiful young lives are cut short every year when they have their whole lives ahead of them and when so many could be saved if a national screening programme was implemented.

If the statistics published by the NSC were accurate it is likely that a higher national profile would be given to the shocking number of SCDs in the UK. We noted earlier this year that by May 19th 2019, 100 fatal stabbings had been reported in the UK. By comparison we calculated the likely number of young people who had died due to sudden cardiac death by May 19th 2019 to be at least 228. To reinforce our earlier point this is not 'low incidence'.

Writing this email and attempting to describe the impact of our xxxx xxxx death is extremely difficult and emotional which is why it has taken us so long to write it. I am sure, for this reason, many families also affected by this tragedy will be unable to share their experience. I am a member of a xxxx xxxx group for bereaved xxxx xxxx whose son or daughter died due to sudden cardiac death so I read the pain and suffering of others on a daily basis. It is so important that you try and have some understanding of the impact. If it would help, we would be happy to meet with committee members.

While we have tried to provide you with a glimpse of the horror of life for bereaved families and a brief description of our xxxx xxxx

who would have done so much good in this world we also want to emphasis our agreement with the feedback provided by CRY in that the report ;

- FAILS to stress that 1 in 300 people screened have a cardiac condition that can benefit from treatment or lifestyle advice.

- FAILS to objectively evaluate the overlap between the current routine use of the ECG in the NHS / medical practice for general diagnostics and monitoring and its role in cardiac screening. For instance;

The contradictory position of the NSC where the ECG IS an accurate test if you experience symptoms, but the ECG IS NOT an accurate test if you DO NOT experience symptoms.

- NICE T Loc guideline https://www.nice.org.uk/guidance/cg109/chapter/1-Guidance… where ECGs are an essential part of assessment for people who have a temporary loss of consciousness.

The routine use/requirement of ECGs in screening programmes

- in sport
- pharmaceutical drugs trials
- army recruits https://apply.army.mod.uk/…/soldier-recr…/soldier-assessment
- commercial pilots https://www.baatraining.com/the-aviation-medical-exam-what…/
- pre operations assessments https://www.escardio.org/…/When-to-perform-pre-operative-ECG & https://www.nice.org.uk/…/tests-before-surgery-pdf-31411086…

It contradicts the information on the NHS choices website (e.g. WPW)

- WPW is one of the most common conditions identified in the CRY screening programme, affecting more than 1 in 700 young people.
- The NHS states “it may only be picked up when an ECG is carried out for another reason. In these cases, further tests will be done to determine if treatment is required… with treatment, the condition can normally be completely cured…..WPW syndrome can sometimes be life-threatening……….and treatment can eliminate this risk”
- https://www.nhs.uk/conditio…/wolff-parkinson-white-syndrome/

- It FAILS to frame the consultation correctly. The current NSC screening programmes (e.g. breast cancer) focus on identification of conditions/diseases, whereas this policy is framed as identification of the risk of sudden cardiac death. The framing of the issue should be consistent with the other NSC policies, “screening for cardiac conditions in young adults”.

- The NSC is requesting for Randomised Controlled Trials to be conducted. This is UNETHICAL and would lead to young people dying in the pursuit of “better” science.

We request that you reconsider your initial recommendations. It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG.

We consent to our names being published on the UK NSC website alongside our response.

Yours faithfully,

Cath Nee (Mrs) RGN, RSCN, BSc (Hons), MA

Murray Nee (Mr)

69. xxxx xxxx

We must screen for Cardiac death in the young. xxxx xxxx was refused in spite of symptoms.

70. xxxx xxxx

I support the campaign by Cardiac Risk in the Young for all young people to have the opportunity to have their hearts tested.

Regards

xxxx xxxx

71. xxxx

We lost a friend just before xxxx xxxx birthday due to an undetected cardiac problem, it was heartbreaking and even more so to know that xxxx xxxx

death was one of many that could have been prevented. My children will be screened due to the work CRY is doing but this should be available to everyone not just those that have found out about the work of this charity.

xxxx xxxx

72. xxxx xxxx

Screening for our youngsters is imperative i lost my xxxx xxxx old xxxx xxxx something which would not have happened if xxxx xxxx had been screened. Through our loss all family members have been checked with several including myself having a genetic heart condition. We cannot allow lives to be lost in this manner. I urge you to consider this.

Yours hopefully

xxxx xxxx

73. xxxx xxxx

I write to say I wholly support the call for screening of ALL young people for heart disease. Having witnessed the pain and sorrow of a young mother dying needlessly I will try everything to ensure it doesn't happen again.

xxxx xxxx

74. Gordon Murch

Name:	Gordon Murch	**Email address:**	xxxx xxxx
Organisation (if appropriate):	n/a		
Role:	n/a		

Do you consent to your name being published on the UK NSC website alongside your response?

[✓ Yes] **No**

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Extract from the invitation to respond to the consultation, taken from the PHE website: https://legacyscreening.phe.org.uk/suddencardiacdeath	"The chances of sudden heart attacks in apparently physically fit young people are tiny".	I write as a parent who has lost a xxxx xxxxas a result of YSCD. I find the use of the term 'tiny' deeply unsatisfactory. When I lost my xxxx xxxx12 years ago, a senior cardiologist told me 'it was rarer than being struck by a bolt of lightning on a sunny day'. I am not a health professional but, since my xxxx xxxx died, I have spoken to 'many' families similarly affected. Therefore, to describe the incidence of YSCD as 'tiny' is, in my experience, misleading and deeply unhelpful.

Page 6	“research shows that current tests are not accurate enough to use in young people without symptoms”	ECGs, widely used within occupational health checks, may detect conditions, even in the absence of symptoms. As a teacher, I know from personal experience of screening events within schools that serious conditions have been detected.
Page 6	“there was no research showing that screening reduces the chance of a sudden cardiac death in the general population”	I find it astonishing that the wealth of experience built up by Cardiac Risk in the Young in almost 25 years of screening young people in the 14-35 age range seems not to be taken more seriously.
Page 6	“Further research is necessary to understand whether screening is effective.”	Given the number of young people lost to YSCD each year (conservatively 600+) when their ‘asymptomatic’ conditions may have been identified and treated by existing tests and pathways, this response seems inadequate to say the least.
Page 6	“there is a need for accurate screening tests”	See comment 2 above. It seems odd that the ECG is recognised as an acceptable standard in other contexts, but not the identification of conditions that may result in YSCD.
Page 6	“clear guidelines to enable clinicians to treat patients that have a disease, but do not have symptoms”.	Surely these treatment pathways already exist, ie when patients are identified as being at risk (even if unsymptomatic) following genetic screening as a result of YSCD in their family.
Final personal comment		At the moment, my understanding (and experience) is that familial genetic tests are usually only carried out following an incidence of YSCD. While I recognise the importance of these tests, surely everything

		possible should be done in order to help prevent the deaths of so many young people in the first place. I find it unacceptable that their loss seems to be accepted as largely unpreventable.

75. xxxx xxxx

Hello. I'm emailing in response to your consultation on screening for cardiac risk. As a xxxx xxxx who has a child (5) who was discovered to have life threateneing heart condition age 6 weeks, requiring emergency surgery and ongoing heart treatment, and also xxxx xxxxwho was extremely fit and keen cyclist dying suddenly overnight, i know the absolute heartbreak of genetic heart conditions. Especially in the absence of ANY risk factors, screening for both xxxx xxxx and my xxxx xxxx would have been beneficial, maybe even saving my xxxx xxxx life. xxxx xxxx was a world leading psychologist and the people who he helped will miss xxxx xxxx work. xxxx xxxx family, my children miss xxxx xxxxeveryday. We all do all we can to be healthy and fit. Screening is the only additional thing which may protect.

Regards

xxxx xxxx

76. xxxx xxxx

Dear Sir/Madam

I am writing in response to the decision of the National Screening Committee not to recommend population screening for sudden cardiac death in the young. Cardiac Risk in the Young (CRY) have prepared a detailed response to this decision with particular reference to their screening programmes, the number of people with a heart condition they say can be detected and the impact it has on wider society. This is not my area of expertise and I do not wish to comment on their reply. Rather, I would like to add my personal perspective to this matter.

My xxxx xxxx died suddenly on xxxx xxxx at the xxxx xxxx . We had been together for just xxxx xxxxand married for less than xxxx xxxx. Two months after xxxx xxxxdeath, xxxx xxxx was diagnosed with arrhythmogenic right ventricular cardiomyopathy, (ARVC), a genetically inherited condition that affects the proteins that ‘glue’ the cells of the heart muscle together. The effects that xxxx xxxxdeath have had on myself, and xxxx xxxxwider family, as you can imagine, have been dramatic and severe.

Now I appreciate that compared to the big killers such as cancer and diabetes, conditions such as xxxx xxx are rare. But there is something profoundly tragic about heart conditions such as these, which affect the young and strike without warning. At xxxx xxxxis actually the oldest undiagnosed victim of ARVC that I have yet found. Most people, if not diagnosed and treated, die in their 20s and early 30s. If xxxx xxxx had been screened and diagnosed say 15 years ago, xxxx xxxx could well still be here today. But 15 years ago, xxxx xxxx heart function would have been a lot better and there would have been no reason to suspect anything was wrong. That is the tragic irony of these conditions – there are normally no symptoms and no warning signs. Therefore, it seems to me, detection via a screening programme would appear to be the only way to prevent more people going through what I have had to. ARVC has no cure, at least not at the moment, but there are treatments available that enable it and other similar conditions to be managed. If I could have had, say, another 10 years with xxxx xxxx , that is something I would have gladly taken.

I appreciate that people get ill and die. It’s something we all have to deal with. But if it is possible to prevent people from dying so suddenly, and at such young ages, surely this is something we should be doing.

Yours sincerely

xxxx xxxx

77. xxxx xxxx

Hi

I have ARVC as does my xxxx xxx . My 2 xxxx xxxx are being checked for it.

This has had a huge inpact on our lives.

Please recommend cardiac screening for all. It is one of the was to make a massive difference.

Thank you. If you need more info please let me know.

Kind regards,

xxxx xxxx

78. xxxx xxxx

Further to my previous email, sent slightly prematurely to make the deadline of 7/9/19:

My apologies for the lateness of the submission and the lack of compatibility with the pro-forma provided online. I had only become aware of the consultation in the last 24 hours, and family care duties prevented me from having the time to answer specific points in the review, as is required by the pro-forma. Instead I have given a general response to the summary conclusions. I hope that my submission may still be considered.
xxxx xxxx

Comments on the conclusions of the review

1. Regarding the accuracy of tests

   Tests described by the review as being insufficiently accurate for recommendation in screening are the same tests that were offered to me by the NHS (via Addenbrookes hospital) when ascertaining my risk of SCD after the death of a relative. The consultant at Addenbrookes was clearly in agreement with the advice I received from Cardiac Risk in the Young (CRY) as to the suitability of those tests. How are tests considered accurate enough for use by the NHS not also accurate enough to be used for screening?

2. The conclusion of the review suggests that being diagnosed with a condition and the limitations of possible treatments in some cases MIGHT result in anxiety in some individuals which would offset any benefits in identifying individuals at risk.

- "Someone who is identified as having a high risk of SCD may become anxious about physical activity and stop regularly exercising which can be detrimental to their overall health"

  The underlying argument here seems to be about taking choice away from young people in case they become anxious. Screening programmes are not mandatory. In the same way that some people may not want to participate in cancer screening programmes, but should be given all available information on which to base a decision that feels right for them, why not give young people information about possible outcomes, possible treatments (even if these are limited to lifestyle recommendations) and allow them to decide for themselves whether they are happy to proceed? My experience of SCD shows that many people in the wider community affected by a young death DO choose to have screening via CRY's screening service having considered the available evidence. I believe that this review's conclusion results in denying the general population the opportunity to make decisions for themselves simply because they are unaware of the possibility of being screened.
- Possible treatments or lack thereof

There may be no treatments as such for some of the conditions identified through screening, but there are lifestyle recommendations that may prove to be lifesaving. Simple precautions such as adequately rehydrating following diarrhoea and vomiting, actively managing fevers and avoiding hot environments such as saunas, avoiding certain common drugs (antidepressants, local anaesthetics) – these could all be the difference between life and a tragic death. I, and many others like me, chose to have the screening knowing that lifestyle advice such as this may be the only way to reduce my risk of any condition identified. Others may choose differently, but it should be about having the choice.
The review suggests that any benefits of screening could be outweighed by anxiety caused by being diagnosed with conditions that may or may not have reduced treatment options. I would argue the opposite. The absence of screening availability in order to protect people from becoming anxious or worried about a lack of cure cannot possibly be justified in view of the huge potential benefits of identifying those at risk, and in light of the fact that being screened would not be mandatory. Young people should be able to make choices for themselves.

3. Screening may not not just prevent deaths but could help those identified with lower risk conditions to live healthier lives.

4. Potential false positive results.

   Individuals identified as being at risk will surely be referred for further investigation, which is likely to pick up any such results. This is not a waste of resources – many people have symptoms investigated on NHS where results are happily negative.

5. Underestimating the effect on surrounding community

   I understand that screening must take into consideration cost/benefit analysis. I believe that the review grossly underestimates the impact of a loss of a young person to SCD on the surrounding family, friends and wider community, and therefore this is not weighted sufficiently in its considerations.

   A SCD bereavement is a uniquely traumatic event due to the lack of warning and inability to do anything to fight it. It is confusing and disorientating and incredibly traumatic for those who are present when it occurs. It leads to a profound sense of insecurity about the lives of your loved ones. My experience of such an event nearly 5 years ago led to widespread mental health difficulties within the victim's community, ranging from depression, anxiety, post traumatic stress disorder, and complications with postnatal depression/anxiety. There have been several individuals who have needed to take sabbaticals from school or work. There have been at least two people I have been aware of with an increased suicide risk directly related to their experience of SCD.

79. xxxx xxxx

Dear UK National Screening Committee

My xxxx xxxx died at xxxx xxxx in xxxx xxxx and my life partner xxxx xxxx died at xxxx xxxx in xxxx xxxx- both from sudden cardiac death. Had they been screened they might still be alive today. Had they been screened I might not be still struggling daily with the shock and the grief of their sudden deaths, I might not be struggling with mental health problems, I might still be in full time employment, I might not struggle for income, I might not have suicidal thoughts.

I beg you to please carefully read and consider the evidence laid out in the report by Dr Steven Cox (from Cardiac Risk in the Young (CRY)). Hundreds of young people's lives are being cut short in an instant and you have the power to change that death toll.

I also wish to highlight that it is not just the lives that are taken by sudden cardiac death that need to be considered, but the inexorable butterfly effect on the partner, family, friends and community left behind with their world destroyed in an instant. The sudden and unexpected nature of the deaths creates untold anxiety in loved ones as they grapple to make sense of the unthinkable. There is no opportunity to say goodbye, to discuss wishes or wills, organ donation or funeral plans. Overnight I literally went from planning our wedding to planning xxxx xxxx funeral. The person that means most to you in the entire world is ripped from you in an instant. The police and ultimately the coroner confirm your worst nightmares and then you are left to fend for yourself. There is no NHS-approved/recognised pathway of support. There are no peers or friends made along the journey as you might in a hospice or on a cancer treatment journey. There is nothing. If you are tenacious enough you will fight for counselling, and even then depending on your postcode or your income you could be waiting 6-18 months+. You will then be allowed treatment for the same period of time as for mild low mood or work stress and given more than 10 hours of appointments, then your time is up. You can of course request to be re-referred and wait another 6+ months and have to go right back to square one with someone completely different. I could go on, but to summarise - it's truly a lottery as to how psychologically destroyed you will end up.

If there had been a National Screening Programme for xxxx xxxx and xxxx xxxx to have got tested they might have had options, they might have had a chance of life. Myself, the families and friends might be the happy, life-loving souls we once were, instead of the shadows of our former selves struggling to get through each day, each week, not wishing to think about enduring another year in the pain that will forever haunt us.

Please, imagine for an unthinkable moment what it might be like to watch your wife/husband/partner/son/daughter/brother/sister die suddenly and unexpectedly without any warning whatsoever in front of your very eyes. Would you than appreciate a National Screening Programme?

Thank you for reading and please do the right thing.

Yours sincerely

XXXX XXXX

(PS: Please don't publish my name or email)

80. xxxx xxxx

Dear Sir

In regard to the importance of screening young people and actual experience.

Several years ago we lost a friend at the age of xxxx xxxx from sudden death syndrome, xxxx xxxx was a good Cyclocross racer and this tragedy made us aware of C-R-Y and its screening programme.

I run a team of 18 riders under 23 years old, we encouraged all the riders in the team that they should be tested. All the riders were checked and two were found to have anomaly’s, one actually required an urgent operation and the second requires an annual check up.

We now insist that all our riders are checked before they join the team and generally encourage all riders to be checked, we believe that the checking of young people should be a fundamental check for all, we know it saves lives.

Yours faithfully

xxxx xxxx

xxxx xxxx

81. xxxx xxxx

It is unacceptable that hundreds of young people continue to die suddenly every year from cardiac conditions which could be identified through screening with an ECG.

xxxx xxxx dies in xxxx xxxx at the tender age xxxx xxxx - this could have potentially been avoided if screenings had been in place - please don’t let families suffer as it ruins lives and we all deserve the best things to live life to the fullest!

Thank you!

xxxx xxxx

82. xxxx xxxx

My xxxx xxxx xxxx xxxx xxxx xxxx died on xxxx xxxx at the age of xxxx xxxx xxxx xxxx had fainted a couple of times before and been taken by xxxx xxxx to the Doctors, in xxxx xxxx who said this was normal adolescence hormone problems and lots of teenage xxxx xxxx fainted.

Had xxxx xxxx been screened, they would have been able to detect a heart malfunction.

On xxxx xxxx death certificate it says "A Massive Heart Attack on a Healthy Heart"

The devastation this has caused in our family is indescribable. We are all grieving and suffering from shock.

xxxx xxxx was the xxxx xxxx of five and we are working with councillors to have the other children and other family members screened, but it like walking up a hill made of treacle... progress is really slow.

have recently raised xxxx xxxx by having a tattoo...(which is something I never thought I would do in my life...as I hate them...!) for the charity CRY and as a family we will carry on raising money for them, so that others may be saved this tragedy.

We believe, in times of catastrophic tragedy, to think of others will help us get through this together...we will never be able to get over our loss, but by working for this cause we may be able to get through the depth of despair that we are all in.

Please lodge my vote for screening. xxxx xxxx