Regulation 28: Report to Prevent Future Deaths

Response of Cardiac Risk in the Young (CRY)

To: HM Coroner Valerie Charbit
In the matter of: Adam Ankers
Date of Report: 16 April 2026
Date of Response: 8th June 2026

Introduction

1. Cardiac Risk in the Young ("CRY") writes in response to the matters raised pursuant to Regulation 28 of the Coroners (Investigations) Regulations 2013, and, in particular, point D of the Report to Prevent Future Deaths.
2. CRY acknowledges that cardiac assessment in individuals aged between 14 and 35 years reduces the risk of sudden cardiac death ("SCD") through earlier identification of underlying cardiac disease, and that access to such assessment is not currently available to all young people, including those participating in football and other organised sport.

Response to Point D

3. It is well established that a number of cardiac conditions associated with SCD in young people will be identified through appropriate cardiac evaluation, including electrocardiogram ("ECG") based assessment, alongside clinical history and physical examination.
4. These conditions include Arrhythmogenic Right Ventricular Cardiomyopathy ("ARVC"), an inherited cardiomyopathy which may remain clinically silent but is associated with an increased risk of life-threatening arrhythmias, particularly during sustained or high-intensity exercise. Early identification allows for appropriate clinical management, including risk stratification, surveillance, and lifestyle modification such as restriction from competitive or high-intensity sport, which may materially reduce risk.
5. Notwithstanding the above, cardiac assessment is not routinely available to the general population of young people in the United Kingdom. The UK National Screening Committee ("UK NSC") does not currently recommend a population-wide screening programme for cardiac conditions associated with SCD in the young. As a result, access to screening services is largely dependent upon charitable provision, private healthcare, or limited availability through certain organisations.
6. This gives rise to a clear inconsistency in practice. Cardiac assessment is required or strongly encouraged within elite sport and certain professional settings, reflecting recognition of its preventative value. In professional football and other elite environments, structured screening pathways are embedded. However, equivalent access is not available to the significantly larger population of young people participating in grassroots and amateur sport.
7. In addition, cardiac assessment, including ECG evaluation, is already routinely undertaken within a number of established NHS clinical pathways, including

pre-operative assessment for surgery where clinically indicated. This reflects an accepted role for structured cardiac evaluation in identifying previously unrecognised risk in defined populations. CRY considers that this further demonstrates the principle that targeted, protocol-driven cardiac assessment is both feasible and already embedded within existing healthcare systems, albeit not yet consistently extended to young people in the context of risk of sudden cardiac death.

8. Criticism of cardiac screening programmes is often centred on concerns regarding the test, the ECG, particularly the potential for false positive and false negative results. However, these concerns must be considered in the context of significant advances in ECG interpretation. When ECGs are assessed by appropriately trained specialists with expertise in inherited cardiac conditions and sports cardiology, diagnostic accuracy is substantially improved, and both false positive and false negative rates can be significantly reduced. Consequently, concerns regarding ECG interpretation should not be viewed as an inherent limitation of screening itself, but rather as an issue that can be addressed through appropriate training, standards, and clinical governance.
9. Concerns regarding the management of individuals identified as being at risk of sudden cardiac death are also difficult to reconcile with routine NHS practice. Every day, patients are diagnosed with cardiac conditions through family screening, incidental investigations, symptom presentation, or clinical assessment, and are subsequently managed through established specialist services. Depending on the condition and level of risk, management may include lifestyle advice, medical therapy, implantation of cardioverter defibrillators (ICDs), pacemakers, catheter ablation, surgical intervention, or, where necessary, cardiac transplantation. The purpose of identifying individuals at risk is to provide access to these interventions and thereby reduce the likelihood of adverse outcomes. It would be inconsistent to accept the diagnosis and treatment of inherited cardiac conditions in all other clinical settings while questioning the value of identifying those same conditions through appropriately delivered screening programmes.
10. CRY's position is that all young people should have the opportunity to undergo cardiac screening, including at a minimum an ECG, from the age of 14. Current evidence demonstrates that approximately 1 in every 300 young people screened by CRY is identified with a potentially life-threatening cardiac condition. The ability to identify these individuals before the occurrence of a catastrophic event represents a significant opportunity for prevention.

11. Whilst CRY believes that all young people should have access to cardiac screening, current demand far exceeds available capacity. More than 140,000 young people are currently registered with CRY expressing a desire to be screened, and screening events frequently become fully booked shortly after being announced. This demonstrates a substantial unmet demand for cardiac screening services and highlights that many young people who actively seek screening are unable to access it within a reasonable timeframe.

12. In addition, CRY's recently published research has demonstrated that a single screening assessment will not identify all conditions associated with young sudden cardiac death. Whilst screening identifies a significant number of young

people with potentially life-threatening cardiac conditions, some diseases may only become detectable as the heart matures, whilst others may develop later through acquired or progressive pathology. These findings suggest that cardiac screening should not be viewed as a one-off intervention; and they underline the need for further research to establish the most effective intervals for repeat screening. Such evidence will be essential in informing future screening policy and maximising the number of lives that can be saved.

13. The growing recognition that repeat screening may be necessary places an additional burden on already limited screening resources. CRY currently screens approximately 35,000 young people annually, yet this capacity falls substantially short of the level required to meet existing demand, let alone provide repeat screening opportunities where clinically appropriate. It is therefore clear that current provision is insufficient to meet the needs of the population seeking access to screening.

14. A further challenge is the inconsistency of access across the United Kingdom. The majority of CRY screening events are funded by bereaved families and local communities seeking to create a positive legacy following the death of a young person. This support is extraordinary and has enabled CRY to establish one of the world's largest cardiac screening programmes, through which hundreds of thousands of young people have been screened. However, reliance on community fundraising inevitably results in geographical variation in the availability of screening services. Whilst demand for screening substantially exceeds available capacity across the UK, some communities benefit from locally funded screening events whereas others have little or no local provision. Access to screening is therefore influenced not only by clinical need but also by the availability of local charitable funding and community support. These geographical inequalities could be more effectively addressed through a coordinated national approach to cardiac screening.

Proactive and Reactive Prevention Framework

15. CRY considers that prevention of sudden cardiac death in the young necessarily involves an interplay between proactive and reactive strategies.
16. Proactive measures include structured cardiac assessment/screening, awareness of cardiac symptoms, and recognition of relevant family history of inherited cardiac conditions. These measures aim to identify individuals at risk prior to the onset of a catastrophic event.
17. In relation to paragraph 22 below, CRY notes that the existence of clinical guidance does not necessarily ensure its consistent implementation in practice. This was recognised during the 2019 review of the NICE guideline on Transient Loss of Consciousness (TLoC), where concerns were raised by nominated experts that “there are challenges to the full implementation of this guideline because TLoC is not on the top of the priority list of many clinical commissioning groups , due to competing interests from other disease conditions.”.
18. As a result, young people presenting with symptoms that may indicate an underlying cardiac condition are not always referred for appropriate

investigation, including ECG assessment, in accordance with established guidance. Furthermore, even where cardiac investigations are undertaken, interpretation may not always involve clinicians with specific expertise in inherited cardiac conditions. The variability that exists both in the implementation of guidance and in access to specialist expertise reinforces the need for clear, consistent and nationally recognised pathways for the assessment and investigation of cardiac symptoms in young people. Whilst cardiac screening does not prevent all cases of sudden cardiac death, it remains a key proactive intervention in reducing the incidence of first presentation as cardiac arrest. It therefore forms an important component of a broader prevention strategy alongside reactive measures.

19. CRY notes that the effectiveness of cardiac assessment is not solely dependent upon the act of testing, but also upon the quality and expertise of interpretation. ECG interpretation in young people requires specific specialist training due to physiological variations in the adolescent and athletic population that may otherwise mimic or obscure pathological findings. Accordingly, the value of screening programmes is closely linked to the availability of appropriately trained clinicians and governance structures for ECG review. Ensuring consistency in expert interpretation is therefore a key component of any effective screening or assessment strategy.
20. Reactive measures include high-quality education in cardiopulmonary resuscitation (“CPR”) within schools, widespread availability and training in the use of automated external defibrillators (“AEDs”), and effective emergency response systems. These interventions are critical in improving survival following cardiac arrest.

Policy Context and Symptom Evaluation

21. Through its support of families following young sudden cardiac deaths and cardiac arrests, CRY is frequently made aware of cases in which symptoms potentially indicative of an underlying cardiac condition had been reported prior to the event. These accounts suggest that opportunities for earlier investigation may not always be recognised or acted upon consistently.
22. In particular, CRY's experience of supporting affected families includes cases in which young people had presented with symptoms such as transient loss of consciousness ("TLoC"), syncope, palpitations, chest pain, breathlessness, dizziness, or a relevant family history of cardiac disease before experiencing a cardiac arrest or sudden cardiac death. Whilst CRY is not in a position to determine whether clinical management in individual cases was appropriate, these experiences highlight the importance of ensuring that healthcare professionals remain aware of relevant guidance relating to the assessment and investigation of potential cardiac symptoms in young people, including the role of ECG assessment and onward referral where indicated. CRY's experience further reinforces the importance of clear and consistent pathways that facilitate the timely recognition and investigation of symptoms potentially associated with underlying cardiac disease. Whilst symptom-based assessment remains an essential component of clinical practice, consideration should also be given to broader strategies aimed at identifying individuals who

may be at risk despite being asymptomatic, including appropriately delivered cardiac screening programmes.

Family History, Cascade Identification, and System Integration

23. In cases where an inherited cardiac condition such as ARVC is present (or other inherited cardiac diseases, including long QT syndrome, Brugada syndrome, and cardiomyopathies), there is an opportunity for cascade identification of at-risk relatives.
24. However, in practice, the effective transmission of genetic and diagnostic information to family members is not always consistently achieved within existing healthcare pathways. As a result, opportunities for early identification of at-risk individuals may be missed.
25. Where an inherited or potentially inherited cardiac condition is identified, or reasonably suspected, within a family, CRY considers that this should routinely trigger referral of first-degree blood relatives to appropriate specialist Inherited Cardiac Conditions ("ICC") services for assessment, genetic counselling, and ongoing management where indicated. Specialist multidisciplinary centres, including within the network identified by the British Inherited Cardiac Conditions Society (www.BICCS.org.uk), provide a framework for coordinated evaluation, genetic counselling, risk stratification, and cascade screening of families affected by inherited cardiac disease. Consistent referral pathways are important to ensure that opportunities for early identification and preventative management are not missed.
26. While it is not the purpose of screening to replace established clinical pathways, CRY considers that one of the incidental benefits of structured screening programmes is that they may assist in identifying individuals and families who have not otherwise been appropriately captured within existing systems of care, thereby providing an additional safeguard against system fragmentation.

Ensuring Answers, Identifying Risk and Preventing Future Deaths Through Cardiac Pathology and Information Sharing

27. CRY considers that the post-mortem investigations following sudden cardiac death in the young play a vital role in supporting bereaved families, identifying inherited cardiac conditions and enabling cascade screening of relatives.

28. Whilst the role of expert cardiac pathology in identifying inherited risk and guiding family screening is critically important, its value extends far beyond clinical decision-making. Following the sudden death of a young person, families are often left searching for answers amidst profound grief and trauma. Establishing, wherever possible, a clear explanation for the death can help families understand what has happened, reduce the burden of uncertainty, and provide an important foundation for the grieving process. Given that sudden cardiac deaths frequently occur without warning and may carry implications for surviving relatives, specialist cardiac pathology plays a vital role not only in prevention, but also in supporting bereaved families and reducing the broader

social and emotional consequences of these tragedies. For cascade screening to be effective, there must be clear and reliable mechanisms for the communication of clinically relevant findings to family members at risk. This requires clarity around responsibility for information-sharing following diagnosis or post-mortem identification of inherited disease, to ensure that opportunities for prevention in surviving relatives are not missed.

29. CRY further considers that one of the principal barriers to obtaining clinically valuable information following sudden cardiac death in the young is the absence of routine retention of suitable DNA material for future genetic analysis. Through its work supporting bereaved families, CRY is aware of numerous cases in which potentially valuable opportunities for genetic investigation have been lost because appropriate samples were not retained at the time of death. The absence of retained DNA may significantly limit both present and future opportunities to identify inherited cardiac disease within affected families, including where scientific understanding and genetic testing capabilities continue to develop over time.

30. Where retention of DNA material is dependent upon consent from the next of kin, decisions are often required at a time of profound shock and bereavement. In such circumstances, families may not be in a position to fully appreciate the potential future significance of genetic testing for surviving relatives or subsequent generations. As a result, decisions made in the immediate aftermath of a death may inadvertently preclude future investigations that could have important implications for the identification and management of inherited cardiac conditions within the wider family.

31. CRY considers that there should be a review of the existing legal and procedural framework governing post-mortem DNA retention in cases of sudden cardiac death in the young. Consideration should be given to a system whereby retention of suitable DNA material is presumed for the purpose of potential familial investigation unless and until appropriately informed first-degree blood relatives decide otherwise. Such an approach would allow families to make fully informed decisions at a later stage, outside the period of acute bereavement, and with proper understanding of the potential implications for both current and future generations.

Role of Sporting Bodies

32. Sporting governing bodies, including those responsible for football, are well placed to contribute meaningfully to prevention strategies. Organisations that mandate or support cardiac screening at elite level should also play a role in:
    (a) raising awareness of cardiac risk, family history of inherited cardiac conditions, and symptoms, among grassroots participants;
    (b) supporting education around CPR and AED use; and
    (c) facilitating access to appropriate cardiac assessment pathways where possible.

33. CRY further considers that sporting organisations occupy a unique position in communicating the importance of cardiac assessment to young participants engaged in grassroots sport. In sports where cardiac screening is already mandated or strongly encouraged at elite level, there is an important

preventative message that earlier identification of cardiac disease may help avoid catastrophic cardiac events during progression through competitive sport. Early awareness may also assist individuals in understanding potential implications for future participation in professional pathways where cardiac assessment forms part of contractual or occupational requirements. Similar considerations arise in other professions where cardiac evaluation may be required, including military service and certain aviation roles.

Conclusion

34. CRY supports the position that inconsistent access to cardiac assessment, combined with variability in implementation of symptom recognition and emergency response strategies, represents a missed opportunity to reduce avoidable deaths in young people.

35. CRY's experience, derived from supporting families affected by sudden cardiac death and cardiac arrest in the young, demonstrates the importance of a comprehensive and proportionate prevention strategy that combines both proactive and reactive measures. Such a strategy should include:
    (a) reconsideration of current cardiac screening policy through the UK NSC review process;
    (b) improved awareness and implementation of symptom-based assessment pathways, including timely access to ECG assessment and specialist referral where appropriate;
    (c) expansion of targeted and opportunistic screening initiatives, particularly for higher-risk groups and those participating in organised sport;
    (d) the recognition of CPR and AED training as an essential life skill, with consistent delivery in schools and wider communities so that everyone has the knowledge and confidence to respond effectively to a cardiac arrest, together with improved access to publicly available defibrillators;
    (e) strengthened and adequately funded systems for specialist cardiac pathology; routine retention of appropriate DNA samples; information sharing and family identification following sudden cardiac death; and ensuring that these essential services are delivered consistently and are not dependent upon charitable funding or local initiatives; and
    (f) timely cascade screening and clinical evaluation of relatives at a specialist inherited cardiac conditions clinic where an inherited cardiac condition is suspected or confirmed.

36. Whilst no single intervention will prevent every young sudden cardiac death, CRY believes that many more lives can be saved through a coordinated approach that improves the identification of those at risk, strengthens emergency response capabilities, and ensures that lessons are learned from every death, wherever possible. By combining earlier identification, effective emergency intervention, and robust family investigation following a death, there is a genuine opportunity to reduce the number of families affected by these devastating tragedies. The charity therefore welcomes the opportunity to

contribute to the issues raised in the Prevention of Future Deaths Report and would be pleased to provide any further information that may assist.

What actions are CRY taking to prevent young sudden cardiac deaths?

CRY will continue to campaign to raise awareness of young sudden cardiac death, the devastating impact it has on families, and the need for every young person to have the opportunity to have their heart tested, as well as the importance of further research into the causes and prevention of young sudden cardiac death.

The ECG is the most effective tool available for the early identification of many cardiac conditions associated with young sudden cardiac death. Once a condition is identified, appropriate advice, treatment and clinical management can be provided to significantly reduce the risk of cardiac arrest. CRY currently screens more than 35,000 young people each year and one in every 300 young people screened will be identified with a potentially life-threatening cardiac condition. Demand for screening continues to exceed CRY's current capacity to provide it. To help address this challenge, CRY is investing in machine learning and AI to make screening more cost-effective, address the shortage of specialist ECG interpreters, and help meet current and future demand. These technologies present significant opportunities for preventative healthcare, enabling expert knowledge to be applied more efficiently and consistently, increasing access to screening and helping to identify more young people with potentially life-threatening cardiac conditions at an earlier stage.

CRY is also engaging with Parliamentarians to highlight the need for funding to ensure expert cardiac pathology is available whenever required and is not dependent upon the charitable fundraising efforts of other bereaved families, and to secure specialist commissioning of inherited cardiac conditions services across the UK, providing essential support for families following a young sudden cardiac death and for those diagnosed with an inherited cardiac condition.

While not every young sudden cardiac death can be prevented, too many opportunities to identify those at risk are still being missed. CRY hopes that the findings and recommendations arising from this Prevention of Future Deaths Report will help drive the changes needed to improve prevention, diagnosis and support for affected families, and ultimately reduce the number of young people who die suddenly from undiagnosed cardiac conditions.