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Facilitators and barriers of introducing a screening programme for sudden cardiac death (SCD).

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Submitted to Swansea University in fulfilment of the requirements for the Degree of Masters by research.

September 2021
Ethics: EC_30-20b

Contents

Abstract

Background: This study investigated what athletes (professional, semi – professional and amateur athletes) and medical professionals knew about Sudden Cardiac Death (SCD) and the associated risk factor screening. In addition, the study explored the main perceived barriers and facilitators of implementing a nationwide screening programme.
Methods: 12 semi structured interviews were completed, 9 with athletes, between the ages of 18 – 45 years, and 3 with doctors. Interview responses aided the design of a questionnaire which further investigated athletes' knowledge, experiences, and opinions. The questionnaire was completed by 98 athletes competing at different levels of sport, again between 18 – 45 years of age. Interview and questionnaire responses were analysed using thematic inductive analysis and descriptive statistics, respectively.
Results: Interviews with athletes showed a clear consensus that there was little knowledge of SCD and SCD screening. Interview transcripts showed that athletes believed the biggest facilitator for a screening programme was peace of mind for athletes and their families, while the biggest barriers were a lack of knowledge / awareness and the potential financial costs. The mean age of the athletes who completed the questionnaire was 24.7 (± 6.3). 69% of respondents were male and most were amateur athletes (75.5%). 85% of the athlete respondents had never been screened before. Results showed that if athletes were recommended to stop participation in sport by a doctor they would adhere to this advice. Athletes believed screening was vital in all levels of sports participation and that it was equally important for males and females. Results clearly displayed that SCD risk screening would not deter athletes from sports participation and that a number of respondents, 44%, felt the choice to be screened should remain with the individual.
Doctors displayed greater knowledge during interviews, but this varied and was still limited in some cases. They agreed that SCD is a significant clinical problem and that a 12 – lead ECG was an effective screening tool, enhanced by looking at family history. Doctors' views varied on whether the incidence of SCD in the UK warranted a national screening programme. All doctors identified saving lives as a key facilitator and the main barriers revolved around the impact of screening on an athlete's mental health, as well as concerns regarding financial implications.
Conclusion: This study has obtained insight into the knowledge and perceptions of primarily athletes, along with a small sample of doctors, on the topic of SCD and SCD risk factor screening. Results identified that the main barriers currently facing the implementation of a national screening programme are, the negative impact screening can have on an individual's mental health, severe lack of knowledge about SCD and risk screening, especially within athletes, on the topic as a whole, and the financial cost and cost effectiveness of such a programme's implementation. The main facilitators identified were, that screening could be potentially lifesaving, peace of mind is provided to athletes and close family, and SCD factor screening as part of a pre – participation screening (PPS) programme would not deter people from sports participation.

Declaration

Declarations

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed..... [redacted] .....

Date.....30/09/21.....

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed... [redacted] .....

Date.....30/09/21.....

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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The University's ethical procedures have been followed and, where appropriate, that ethical approval has been granted.

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Introduction

Albeit rare, sudden cardiac death (SCD) is a harrowing and more often than not, fatal cardiac event. SCD is defined as a fatal event that is non – traumatic, non – violent and unexpected which occurs as a result of sudden cardiac arrest (SCA), occurring within 6 hours of previously witnessed normal health (Sharma et al., 1997). The exact incidence of SCD is not clear but the UK National Screening Committee (UK NSC) reports an incidence of between 1 to 2 per 100,000 person years within the general population (Couper et al., 2019). This aligns with previous study findings from 2009, in which analysis showed an average of 1.8 per 100,000 per year in England and Wales, with 27% of these fatalities attributable to cardiomyopathies (Papadakis et al., 2009). A cardiomyopathy is a disease of the heart muscle of which there are different types. One example is hypertrophic cardiomyopathy (HCM). HCM is an inherited disease which causes thickening of the myocardium of the heart, usually the left ventricle and the septum. This thickened heart muscle affects the heart's ability to pump blood around the body and can lead directly to SCD if not diagnosed (British Heart Foundation, 2021). The British Heart Foundation (BHF) estimates that approximately 1 in 500 of the UK population has the condition (British Heart Foundation, 2021). There are a number of alternate risk factors that predispose individuals to SCD, including myocarditis, coronary artery anomalies, conduction issues and arrythmias (British Heart Foundation, 2021). Current research has demonstrated that males are at greater risk of SCD than females (Corrado et al., 1998). It is also believed that the incidence of SCD is greater within the athlete population compared to non – athletes due to the increased risk associated with strenuous exercise in the presence of a dormant cardiac abnormality (Chandra et al., 2013). Furthermore, sporting activity is associated with a significantly increased risk of sudden death in competitive athletes under the age of 35 year, as in this age group sport is seen as a trigger of cardiac arrest in those who are affected by silent cardiovascular conditions (Corrado et al., 2006).

Detection of predisposing factors of SCD can be done via risk factor screening. A number of methods are available to screen individuals, but the most common method at present is the use of a 12 – lead electrocardiogram (ECG). The 12 – lead ECG provides an image of the electrical current of the heart during a heartbeat. Alternate methods used

for screening include examining family history and physical examination. However, the means of screening can differ based on recommendations within different countries, for example the European Society of Cardiology (ESC) recommends a 12 – lead ECG during the early stages of screening. In contrast, the American Heart Association (AHA) recommends a thorough medical and family history alongside a physical examination (Semsarian et al., 2015). Therefore, there is yet to be a consensus on the best method of screening athletes for the risk of SCD.

Decisions about screening methods used for specific disease detection should be led by how that method suits the planned screening programme. If a screening programme was looking to screen the general population for SCD, this approach would be recognised as 'mass screening' because of the large scale it is carried out on and the absence of a target population group (Wilson & Jungner, 1968). On the other hand, if only athletes were to be screened for SCD risk factors, this would be 'selective screening' because the focus would be on a selected higher risk group within the population (Wilson & Jungner, 1968). In the example of athlete, it may still be a large-scale screening programme but would be considered as a form of population screening on a select group (Wilson & Jungner, 1968). Although there are some questions surrounding reliability, accuracy, and ethical issues in regard to cardiac screening, it has been shown to work as an effective tool in reducing the mortality rates of SCD within populations.

The most well-known illustration of population screening is a study that was carried out in the Veneto region of Italy over a 25-year period starting in 1982, including a pre-screening period from 1979. During the screening period, 12 – lead ECGs, alongside history and physical examinations, were used for identifying HCM as part of pre-participation screening for national team athletes between 12 and 35 years old taking part in competitive sport (Pelliccia et al., 2006). Pelliccia et al. (2006) concluded that, within a large-scale population of 4,500 trained athletes, the pre-participation screening programme implemented in Italy was effective in identifying predisposing conditions to SCD, such as HCM. Athletes with cardiac disease that was deemed to demonstrate a disproportionate risk for sudden death were permanently disqualified from competition. Athletes found with myocarditis were only temporarily withdrawn from sports participation for a time period of 6 – 12 months. Athletes were then permitted to return to sport dependant on completed regression of abnormal findings that could be

identified on clinical, echocardiographic and ECG studies (Pelliccia et al., 2006). As a result, there was a clear decline in mortality rates over 26 years (1979 – 2004) following the introduction of the nationwide screening programme (Corrado et al., 2006). This was demonstrated by the annual incidence of SCD in athletes which decreased by 89% from 3.6 / 100,000 athlete years in the pre-screening period (1979-82) to 0.4 / 100,000 athlete years in the late screening period (1993 – 2004) (Corrado et al., 2008).

Although cardiac screening can be highly beneficial, and sometimes lifesaving, it does not come without issues and controversy (Landry et al., 2017). This revolves mainly around false – positives, false – negatives and the misinterpretation of results. In turn, this can lead to athletes being wrongly disqualified from participation in competitive sport. It also raises challenging ethical issues such as, does screening someone for SCD risk factors genuinely improve an individual's quality of life? Would people benefit from knowing there was something wrong with them, and as a result being disqualified from competition? But also, who has priority when screening? Athletes or the general population? A study by Maron et al. (2015) articulated that there was an ethical dilemma that arose when screening for potentially life-threatening diseases which was confined to those who engage in competitive sports while, in the process, excluding non-athletes (Maron et al., 2015). Whilst physicians may not have the power to ban an individual from sports participation, they do have the ethical, medical, and legal obligation to exhaustively inform the candidate of the risks that come with a competitive athletic lifestyle (Magavern et al., 2018). Magavern et al. (2018) did also conclude by proposing that the ultimate goal in regard to athlete disqualification would be to find an ethico–logical approach to conclude a collaborative decision-making process that allows for individualised exercise prescription, respects an individual's self-determination and at the same time offers athletes the necessary protection (Magavern et al., 2018).

Despite the importance of this issue, there are still some gaps in current knowledge on SCD screening. It is unknown what individuals, specifically athletes', views and perceptions are regarding SCD and risk factor screening. Moreover, how these perceptions may vary between different levels of athletes – professional, semi-professional and amateur, due to contributing factors such as exposure, experience and awareness of the topic. These opinions are important to understand as it is these groups

of athletes that would be affected most by a screening programme. It also remains unclear how available SCD risk factor screening is to athletes currently. It is expected that professional athletes have greater opportunity to get screened through their club's medical or pre – season protocols. Large sporting organisations, including Team GB Olympic and Paralympic athletes with the English Institute of Sport, England RFU and Premiership clubs, Welsh Rugby Union (WRU) and England Cricket and county cricket clubs are examples of organisations that have previously used C-R-Y's screening service to screen their teams (Cardiac Risk in the Young, 2021). On the other hand, this may not be the case for the majority of amateur athletes, who have little opportunity to get screened, and often have to finance and make the time for it themselves. As mentioned, there is speculation regarding cardiac screening, and there remains uncertainty around the value of relevant diagnostic testing (Drezner et al., 2013). In a 2014 American Heart Association (AHA) session, out of 1266 audience members from 86 different countries, 60% believed that ECGs should be included in screening programs (Colbert, 2014), highlighting there is still some doubt around such methods being used. Additionally, there is little evidence to demonstrate the long-term benefits of screening. Of course, if an individual's life is saved through disease detection via screening, that is a major long-term benefit, but there is no way of definitively proving that a certain individual would have suffered a SCD as a result of their condition. It is also difficult to be sure that ceasing an athlete's participation in sport would improve their life when considering the mental and physical health benefits that come as part of sports participation.

Although scientific knowledge about SCD remains limited, it is becoming apparent that SCD and risk factor screening is gaining increasing media attention and becoming more well documented within the media. There is a growing recognition for the importance of screening and a contributing factor to this may be some of the high-profile cases that occur, helping to raise awareness. For example, when Danish footballer Christian Erikson collapsed on the field as a result of cardiac arrest during Denmark's game with Finland at the Euro 2020 championships (held in 2021 due to COVID-19). The incident was breaking news on major news channels and social media outlets globally, as the final was watched on TV by 31 million viewers in the UK alone (Waterson, 2021).

SCD is an important clinical issue, because although it is rare it usually impacts young athletes who are considered to be one of, if not, the healthiest group within the population. It is vital to understand what athletes from all sporting levels think about SCD and SCD risk factor screening as they are the ones it would impact the most. By understanding what athletes know it becomes increasingly clear what areas of the topic athletes may require further education about. It also provides an insight into some of the challenges facing the implementation of a screening programme, such as factors that may deter people from getting screened and learning ways in which these factors can be overcome. As well as the above, useful information can be accessed from athletes that can influence recommendations being made when looking at the potential implementation of a national screening programme.

This study will explore what athletes from professional, semi-professional and amateur levels of sport know about SCD and the associated screening, but also what they do not know and therefore needs to be addressed. This will enable the development of campaigns to increase awareness and knowledge of SCD and screening, providing individuals with opportunities to make their own informed decision in regard to being screened and in some cases indirectly save lives. Further scope was added to this study by investigating what a handful of doctors and medical professional's views and opinions are on SCD, risk screening and the potential implementation of a national screening programme. Doing this provided a viewpoint from the opposite side of the spectrum compared to athletes. As doctors may have dealt with patients who have suffered from SCD or are found to be at risk from SCD alongside pre-existing knowledge from medical school. Efforts were to be made to explore doctors' experiences and perceptions to extract valuable information.

This study has two main aims:

1. To identify the barriers to, and facilitators of, implementing a screening programme for SCD in athletes and physically active people, in different contexts - i) amateur athletes, ii) semi – professional athletes, iii) professional athletes.

2. To explore the knowledge, experiences and opinions of athletes and medical professionals with regard to SCD and SCD risk factor screening via the implementation of a nationwide screening programme.

These aims will be addressed by accomplishing four objectives:

1. To review and summarise literature of the apparently conflicting viewpoints regarding the justification and need for SCD screening, financial viability, and ethical concerns.

2. To undertake semi-structured interviews with athletes from amateur, semi – professional and professional sporting levels to better understand their knowledge/awareness about SCD. As well as their attitudes towards screening, and their perceptions of the barriers and facilitators that might prevent or enable screening to take place.

3. To carry out interviews with medical professionals to gain a greater understanding of their thoughts, opinions and experiences about SCD and SCD screening.

4. To develop a questionnaire based on the information gained from completed interviews to obtain a wider sample of views from amateur, semi – professional and professional athletes.

Literature review

Sudden cardiac death (SCD)

What makes SCD so tragic is the lack of fundamental understanding we have of the precipitating factors that lead to the initiation of ventricular fibrillation (VF) (cardiac arrest) and thus causing SCD at a specific time (Lopshire & Zipes, 2006). Although it is not a common disease, SCD accounts for a large proportion of cardiovascular mortality (Papadakis, 2009). According to the charity Welsh Hearts, it is estimated that at least 12 deaths a week occur because of SCD in the young (Calon Hearts, 2021). SCD, especially in young athletes, is often difficult to fathom as athletes are perceived as the healthiest sector of society (Chandra et al., 2013). SCD in athletes is described as a scarce occurrence, but as participation in sports grows it is a highly relevant issue (Kochi et al., 2021). What often engages public interest in matters such as SCD is the significance of sport in numerous societies and the resultant paradox that that physical activities can have both positive and negative impacts on an individual's health (Wilhelm et al., 2011). In addition, although exercise can act as a trigger to SCD and described as deleterious beyond a certain point (Chappex et al, 2015), it is important not to forget the wide range of health benefits of physical exercise and how they can, in some cases, outweigh the increased risk for SCD (Thompson et al., 2007). Carrying on from this, a report by Tsang and Link (2021) stated how exercise is beneficial and recommended to most individuals with cardiomyopathies. Although they go on to say that the decision to continue in sports participation, for an at-risk individual, should be agreed between the individual and their physician (Tsang & Link, 2021).

Aetiology of SCD

SCD can be brought about by several conditions including arrhythmogenic right ventricular cardiomyopathy (ARVC), myocarditis, ion channelopathies (Long QT, Brugada) and hypertrophic cardiomyopathy (HCM) (C-R-Y, 2018). HCM is a genetic condition caused by the mutation of one or more genes, leading to the muscle wall of the heart thickening, (British Heart Foundation, 2021). This coincides with Dhutia and MacLachlan's (2018) work stating how SCD in young individuals is attributable to hereditary and congenital abnormalities of the heart (Dhutia & MacLachlan, 2018). In the UK definite or possible HCM was identified as the most common cause of cardiac death in athletes (Semsarian et al., 2015). A 2009 study found that cardiomyopathies

were the second most common sudden cause of cardiac death, behind only ischemic heart disease (IHD) (atherosclerosis, ischemia) accounting for 27% of cardiac deaths in this specific study cohort (Papadakis et al., 2009). Papadakis et al. (2009) specifically displayed that HCM accounted for 5% of all deaths, along with dilated cardiomyopathies and other cardiomyopathies accounting for the remaining 12% and 10% respectively.

Furthermore, a study carried out in the Lausanne region of Switzerland, reported that HCM and ILVH (idiopathic left ventricular hypertrophy) was the second most common cause of death in all cases of SCD recorded, at 15% (29 out of 188 cases), with a mean age of 39.3 years (± 8.2) (Chappex et al., 2015). A meta – analysis study from 2016 which was constructed of 34 studies and a total of 4605 subjects (≤35 years with sudden cardiac death) found that the overall pooled percentage of sudden cardiac deaths due to hypertrophic cardiomyopathy was 10.3%. Moreover 18 studies that were based in Europe identified that the pooled percentage of SCD caused by HCM was 7.1% (Ullal et al., 2016).

Gender and SCD

SCD is a disease found consistently more frequently in male athletes (Harmon et al, 2014). Data from the National Centre for Catastrophic Sports Injury Research showed that amongst high school and college athlete cohorts there was a 5-fold higher incidence of SCD in male athletes compared to females (Dhutia & MacLachlan, 2018). Dhutia and MacLachlan (2018) observed findings from the Veneto region of Italy, which evaluated over 110,000 athletes, which found that incidence rates of SCD were 2.6 per 100,000/year in male athletes and only 1.1 per 100,000/year in females (Dhutia, 2018). Moreover, Chappex et al. (2015), found that within 188 cases of SCD, of the 166 cases that occurred not during sports participation, 130 (78%) cases were in males and the remaining 36 (22%) in females, demonstrating 3.6 times increase between the 2 genders. The remaining 22 cases occurred during sport (Chappex et al., 2015). Although there are factors that this gender discrepancy in rates of SCD in sports can be potentially attributed, including lower participation rates within female athletes at the elite level and the lower prevalence of cardiac abnormalities that can lead to SCD in females (Pelliccia, 1996). In agreement with the above findings, an internet-based study carried

out by Sollazzo and colleagues concluded that the risk of SCD in athletes was greater among competitive, male athletes (Sollazzo et al., 2019).

SCD within athletic and general populations

There are question marks surrounding whether athletes or the general population are at greater risk of succumbing to SCD. Despite being a rare occurrence, SCD in athletes is usually always associated with an underlying heart condition (Tsang & Link, 2021). Due to a perceived low incidence of SCD during physical activity, the relevance of the problem of SCD in athletes is therefore debated (Schmied & Borjesson. 2014). The perceived low incidence of SCD could therefore influence people's intentions towards being screened. Further research also implied how there is a need to educate athletes, and non – athletes alike, of the cardiovascular risks during sport (Chappex et al, 2015). Despite this, examined reports did state how the incidence of SCD was greater in competitive athletes than the general population (Holst et al, 2010). Schmied and Borjesson (2014) concluded that the risk of SCD approximately doubled 2 to 3-fold in athletes compared to non – athletes (Schmied & Borjesson, 2014). Similarly, figures from Veneto, Italy have also shown a 2.8-fold increased risk of SCD among competitive athletes when compared to non – athletes (Corrado et al., 2003). Interestingly, a Marijon et al. (2011) did identify that there was a much higher prevalence of sports related SCD in the general population than previously thought, within the US. It was stated that even though the risk for potential sports related SCD remained higher in young competitive athletes rather than in 10 to 35-year-old non-competitive athletes, the absolute risk appeared to be higher in the general population (Marijon et al., 2011). When comparing predisposing conditions in athletes and non-athletes, it was reported that the prevalence of HCM was 0.2% in the general population and 0.07 to 0.08% in (Maron et al, 1995). Arrhythmogenic right ventricular cardiomyopathy (ARVC) was found to have a prevalence of 1 / 1000 in the general population (Basso et al., 2009), but as exercise exacerbates the pathophysiological changes that can lead to ARVC, there is a reported 5-fold greater risk of suffering SCD as a result of ARVC during competitive sports compared to sedentary activity (Corrado et al., 2003). Wolff Parkinson White (WPW) syndrome is an electrical cardiac abnormality, unlike HCM and ARVC which are structural abnormalities, which describes the process of ventricular pre-excitation due to anterograde conduction via an accessory atrioventricular pathway with paroxysmal

arrythmias (Hein et al., 2006). The levels of WPW syndrome a reported to be similar in both athletes and the general population at 0.1 to 0.3% (Chandra, 2013).

A study published in 2017 exploring sudden cardiac arrest (SCA) in sport did state how that within their study cohort HCM was an uncommon cause of SCA (Landry et al, 2017). The study cohort examined by Landry et al. (2017) used records obtained from the Rescu Epistry cardiac arrest database (a prospective, comprehensive registry of all persons who had out-of-hospital cardiac arrest and whose event was attended by emergency medical services (EMS) personnel) (Landry et al., 2017) allowing access to records of every cardiac arrest attended by Paramedics in the Ontario region of Canada (Landry et al., 2017). Analysis of this data, which amounted to 18.5-million-person years of observation, found that 74 cardiac arrests occurred during sporting participation (16 competitive, 58 non-competitive), with 56.2% of athlete cases being fatal (Landry et al., 2017). Landry et al. (2017) considered the total number of cardiac arrests between 2009 – 2014 in a range of competitive sports. Race events (marathons, triathlons etc) and football had the joint most cardiac arrests during this period with 4 each. Other sports that experienced events were baseball (1), basketball (2), ice hockey (2), jujitsu (2) and rugby (2). Furthermore, the age group that had the greatest incidence was 12 – 17 years with 1.167 cases per 100,000 athlete years with 4 athletes out of 342,600 experiencing SCA (Landry et al., 2017). In relation to this, Dhutia and MachLachlan (2018) reported from previous findings that in the USA basketball had the greatest incidence (Harmon et al., 2011), whereas in Europe it was football (Corrado et al., 2003). It is important to state that, within this Landry et al. (2017) study, the age group of 18 – 34 years had 9 cases but had a lower overall number of cases (0.868 per 100,000 athlete years) due to a much larger athlete years of observation at 1.036,974, also 35- 45 years had an incidence of 0.756 per 100,000 athlete years, experiencing 3 cases over 5 years. It is important to consider the fact that between the ages of 15 – 21 years people usually begin to participate in sport at a more serious level and perhaps begin to make the transition from amateur to professional or semi-professional sport. Of the 16 cases that occurred among competitive athletes, 2 deaths were due to the presence of HCM, both in young males (15 & 18 years), one of whom had previously had an ECG and echocardiogram (Echo) which showed normal results thus not warranting any follow up treatment (Landry et al., 2017). It is valuable to reinforce here that only 18.75% of

cardiac arrests experienced in competitive sports were in female athletes. Landry et al. (2017) did comment how they could attribute this low rate of HCM to potentially having a greater age range and differences in genetics between people from different geographic regions (Landry et al., 2017).

A meta –analysis from 2016, compiled from cohort studies, patient registries, and autopsy series, published between January 1990 and December 2014, examined SCD in young individuals (Ullal et al., 2016). This review identified a statistically significant difference (P=.007) between pooled percentages of SCD by HCM and structurally normal hearts at 9.2% (Ullal et al., 2016) in an age group of 14 – 35-year-olds. Moreover, further findings from Ullal et al. identified that 26.7% of cases of SCD occurred despite a structurally normal heart in athletes. Similarly, in the non-athlete cohort, 30.7% of SCDs occurred despite a structurally normal heart, whereas the amount of SCDs as a result of HCM was 7.8%. (Ullal et al., 2016). Despite this, in a similar way that Landry et al. (2017) reported that HCM was an 'uncommon' cause of death in their cohort, Ullal et al. (2016) found, across their meta- analytic subgroups that 'there was no evidence' that demonstrated HCM was a more common post-mortem finding in young subjects with SCD, than a structurally normal heart. In a more contemporary systematic review conducted in 2021, it was identified that a structurally normal heart and HCM were the most frequent causes of SCD in athletes, whereas coronary artery disease (CAD) and channelopathies were the leading causes in non-athletes (D'Ascenzi, 2021).

A systematic review performed by Dagfinn et al. (2020) focuses on prospective studies which looked into the relationship of physical activity and heart failure. Studies investigated for physical activity and SCD, from inception to March 2019. Studies with a 95% CI of SCD associated with physical activity were used. Random effects models were used to estimate summary RR's of SCD for the highest compared to lowest level of physical activity. 4080 studies were identified originally, 72 were then given detailed assessment, before a final 13 prospective studies were included in the systematic review. Of these, 8 prospective studies with 1193 SCDs among 136,298 participants were included in the meta-analysis of physical activity and SCD. 6 of the 8 prospective studies originated from Europe, while 2 were from the US. Findings from this systematic review found that participants with the greatest levels of physical activity

had almost half the risk of SCD compared to those with the lowest. There was also found to be a 42% decrease in the risk of SCD for increased vs decreased levels of cardiorespiratory fitness. Chronic heart disease was identified as one of the strongest risk factors for SCD, with studies reporting a 3-5-fold increased risk. Dagfinn et al. (2020) highlighted the importance of these results for public health, as SCD is the first manifestation of heart disease in approximately half of all cases with no warning signs in most. Dagfinn et al. (2020) suggests how prevention should be concentrated through increased levels of physical activity to decrease the burden of SCD on public health, although more research is needed to investigate which types and intensities of sport most SCDs occur. Due to the nature of this review limitations are imminent, publication bias could have factored into the results. Moreover, physical activity was self-reported across studies therefore meaning some misclassification has to be considered at this point. Finally, it was possible the factors of a healthy could have cofounded the association between physical activity and SCD. This meta-analysis is relevant to this research as it provides a further bridge between SCD and athletes participation in sport.

Environmental influence on SCD

There is further evidence to suggest that geographical / environmental factors can play a role in the incidence of SCD in the general population. A 2017 paper stated that there was a substantial association between cardiovascular mortality and the temperature of the day or preceding days (Ryti et al., 2017). A study conducted by Müller et al. (2003) explored the distribution of ventricular tachycardias (VT) and VF throughout the year, by looking at shock episodes (SE) following VT & VF in patients with an implantable cardioverter defibrillator (ICD) over an 11-year period. The study concluded that most SE occurred during January, and the least occurred during June with 93 and 39 SE respectively, this seasonal pattern was proved to be statistically significant with a peak during winter ($P = .001$) (Müller et al., 2003). It was also noted that the association between cold spells and SCD was strongest during the autumn and winter, further finding that increasing the number of cold days increased the risk of SCD by 19% per day, whereas this threat was non-existent during the spring and summer seasons (Ryti et al., 2017). Due to the fact that Müller et al.'s and Ryti et al.'s studies were carried out in Germany and Finland respectively, there is no guarantee that these findings are

representative of figures in the UK as the countries where these studies take place have different climates and extreme weather conditions.

The Screening Debate

The ongoing screening debate classifies the arguments for and against mass screening for athletes in competitive sports. Mass screening can be defined as large scale screening of whole population groups (Wilson & Jungner, 1968). There are strong arguments in literature for both sides.

Methods of screening

There is a number of methods that can be used to carry out screening, specifically for a disease such as SCD, and these include, examining family history, physical examination and blood biomarkers, but the most commonly used method is an ECG. Sometimes as a follow-up to an ECG an Echo is also required. In screening for cardiac disease, a 12 – lead ECG is used to detect and measure the electrical activity of the heart. If further treatment is required then the individual is usually sent for an Echo, which looks more closely at the structure of the heart.

This was largely enforced by a recent review carried out by the UK NSC during which they concluded that although SCD, an important health condition, research shows that tests currently used are not accurate enough in young people who are asymptomatic (Couper et al., 2019). The criteria for this specific review included looking at randomised controlled trials (RCTs), cohorts and systematic reviews comparing the effectiveness of a screening strategy to usual care (Couper et al., 2019). In this study 'usual care' was defined as no offer or receipt of screening (Couper et al., 2019). Out of 2,033 results originally identified, no studies were found that directly addressed the criteria (Couper et al., 2019). This demonstrated a significant absence of research to show that screening actually reduces the chance of SCD in the general population (Couper et al., 2019). Following their prior review, conducted in 2014, along with conclusions drawn from the latest, revised, review the UK NSC still can't recommend population screening for SCD in the young. Mainly due to the inaccuracy of current methods of screening as well as no evidence showing a reduction in mortality as a result

of screening (Couper et al., 2019). This is unlikely to change until further evidence and research is obtained to prove otherwise. These issues surrounding the methods of screening could have a negative impact on an individual's attitude towards a screening process, and potentially act as a deterring factor towards getting screened.

SCD screening

It is difficult to deny that SCD screening through the means of an ECG does not tick all the boxes for general screening criteria. Wilson & Jungner's 1968 paper titled 'Screening for Disease' (Wilson & Jungner, 1968) is still highly regarded and widely used as a key tool when evaluating the implementation of a screening programme.
In a recent systematic review that interrogated the present-day validity of Wilson and Jungner's study, the work was described as 'truncated' in aspects that looked into thoughts on screening, yet the longevity of the principles was highlighted (Dobrow et al., 2018). Furthermore, despite alluding to the principles put forward by Wilson and Jungner as ageing, Dobrow et al. (2018) did acknowledge that they were still utilised in the decision-making processes in present day screening programmes (Dobrow et al., 2018).

Wilson & Jungner (1968) set out 10 points known as the 'Principles of Early Disease Detection', which essentially highlight key criteria that a screening programme should meet and cover adequately in order to be sustainable, efficient and successful (Figure *i* & *ii*). With what is already known about current SCD screening tests, it is clear that it fails to meet some of the principles demonstrated by Wilson and Jungner (1968). Especially when looking at reliability, sensitivity and specificity where it was disclosed that specificity and negative predictive values (NPV) were good, but sensitivity and positive predictive value were extremely low (Wilson & Jungner, 1968). A report carried out in 2014 declared how screening by the means of an ECG had a high sensitivity for underlying disease in young athletes, but the level of specificity needed to be better, but the sensitivity of screening without the use of an ECG was very low (Schmied & Borjesson, 2014). Furthermore, the ECG has been described as an unproven diagnostic tool for reliable detection of Cardiovascular disease in generally healthy populations (Maron et al., 2015). This is mainly down to the alleged high rate of false positives and false negatives that surround ECG screening when compared to other

screening programmes. Yet despite this, there is no evidence that the use of an ECG in pre – participation screening (PPS) deters young people from taking part in competitive sports (Dhutia & MacLachlan, 2018).

False negatives, false positives and misinterpretation

Literature in this field of the SCD topic is fairly well documented but there is nothing definitive on whether an ECG should be used or not and if not, what would be the best other means to screen populations. Maron et al. (2015) explains how there remains controversy surrounding whether an ECG is a superior strategy when compared to history / physical examination alone for detecting the presence of potentially life-threatening cardiovascular disease, particularly when taking into account the important issues of false negative and false positive results as well as cost and resource availability. Screening techniques used currently, such as the 12-lead ECG were recently described as "sub-optimal" by Tsang and Link, (2021). Despite this, other studies have claimed that the use of an ECG has been successful for disease detection and reducing adverse cardiac events (Kochi et al., 2021). The conclusion from this Kochi et al. (2021) study was drawn from the pre- participation study carried out over a 25-year period in Italy. Kochi et al. (2021) reached this conclusion as a result of exploring findings from Corrado's (2003) study investigating pre-participation screening in Italy. It is suggested that the unknown rate of false positives and false negatives is one of the main barriers towards the implementation of a nationwide screening programme, being described as the one of the most frequently cited obstacles (Maron et al., 2015) in certain literature. This is in line with findings from Rowin et al. (2012) which state that the rate of false – negative ECG results for HCM is unknown, before further commenting on subsequent concerns regarding the tests efficacy, reliability and practicality as a result of this. Furthermore this, Rowin et al. (2012) study carried out 12 – lead ECGs on 114 asymptomatic HCM patients under the age of 35 years (Mean + 22 ± 8). Out of these 114 patients with HCM, 103 (90%) showed ≥1 pathologic ECG abnormality, while the remaining 11 (10%) had normal ECG patterns. This is a significant finding, and it is concluded that this display of a high false – negative rate of 10% which represents a crucial limitation of applying the 12 – lead ECG to large, apparent healthy athletic populations when looking to detect the presence of HCM. (Rowin et al., 2012). To provide context to demonstrate seriousness of this

conclusion, a mandatory screening programme in the US would involve around 10 – 15 million athletes annually and on the basis of an incidence of 1 in 500 of the general population, HCM could thus be missed in several hundred athletes per year (Rowin et al., 2012). Statistics such as this are important as they can be influential in an individual's intention and subsequent behaviour in terms of being screened. A prevalence of inaccuracy in the screening methods is more than likely to negatively influence their attitude towards being screened themselves.

The reason false positives and false negatives are such important issues that need to be addressed is because of the detrimental effect it can have on the patient or athlete. According to research, false negative, false positives, technical and interpretation issues, and ambiguous diagnosis can all promote anxiety, uncertainty, and legal considerations within the affected population (Maron et al., 2015). This is agreed upon throughout much of the literature analysed with Rowin et al. (2012) claiming that false positive ECG results could be potentially deleterious to athletes and would lead to unnecessary further tests, anxiety in the athlete and disqualification (from sport) without merit. (Rowin et al., 2012). This is one of the key issues that arises, the potential capacity to recommend to someone that they stop participation in sport based upon an ECG result when the reality is they are healthy individuals. This can lead to a range of consequences physically, mentally and economically for sports people competing at all levels of sport. This was referenced in the review conducted by the UK NSC which declared that uncertainties still exist around the overdiagnosis of a clinically insignificant disease, which could ultimately lead to the unnecessary cessation of sporting activity, and in turn be detrimental to the overall health of young individuals (Couper et al., 2019). Intriguingly, in the same review by the UK NSC, they set out numerous criteria that had to be met in order to implement a screening programme, one of which was as follows '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' (Couper et al., 2019) which they declared to be 'NOT MET' (Couper et al., 2019). This meant that there was essentially insufficient literature and evidence to support the accuracy of ECG screening as a method of detection for cardiovascular disease. However, in contrast to this it has been documented that false – positive findings are less common in younger and less well-trained individuals than in high performance

individuals (Löllgen et al., 2010), and further findings state that individuals with a false – positive screening test were not found to report excessive anxiety following screening (Dhutia & MacLachlan, 2018).

In efforts to tackle the issues of false negatives, false positives, and misinterpretation the Seattle Criteria was developed in 2012, hosted by the American Medical Society for Sports Medicine (AMSSM). This event was attended by the European Society of Cardiology (ESC), Sports Cardiology Subsection, and Paediatric and Congenital Electrophysiology (PACES) as well as Cardiologists and athletes from the USA and Europe. (Drezner et al., 2013). The 3 main goals of the summit as disclosed by Drezner et al. (2013) were – 1) Define ECG interpretation standards to help physicians distinguish normal ECG alterations in athletes from abnormal ECG findings that require additional evaluation for conditions associated with SCD. 2) Outline recommendations for the initial evaluation of ECG abnormalities suggestive of pathological Cardiovascular disorders. 3) Assemble this information into a comprehensive resource and online training course targeted for physicians around the world to gain expertise and competence in ECG interpretation. The end goal of the summit was to develop interpretation in such a way with close attention to balance sensitivity (disease detection) and specificity (false – positives), while maintaining a clear and usable checklist of findings to guide ECG interpretations for physicians and new learners (Drezner et al., 2013). Examining the controversial topic of the accuracy of ECG screening as a means of screening for the detection of SCD risk factors has shown that this is possibly the largest barrier that faces the implementation of a national screening programme at this moment in time. It has been well documented how concerns surrounding the undesirable rates of false negatives and false positives can be detrimental in more ways than one to athletes whom it affects. Continuous work towards developing ECG screening, and other methods such as physical examination, family history, and questionnaires, is crucial in being able to maximise the capacity for risk factor detection for SCD and reduce mortality rates.

The implications of misdiagnosis

Another barrier that faces risk factor screening for SCD is misinterpretation of ECG results by the recording physician. As with any test of this style there will always exist a

presence of subjectivity and human error, and ultimately the effectiveness of the ECG is dependent on the individual interpretation of the test (Dhutia & MacLachlan, 2018). As expressed by the UK NSC in their 2019 review, there is variability both in the criteria used to analyse the ECG and the expertise of the clinician who reviews it creating a greater opportunity for various physicians to diagnose the same condition differently based upon their expertise and judgement of the criteria (Couper et al., 2019). Dhutia and Maclachlan (2018) further expressed concerns relating to the potential for variation in ECG interpretation, especially in experienced hands (Dhutia & Maclachlan, 2018). This was demonstrated in an earlier study by Dhutia et al. (2017) that assessed inter – observer agreements in athletes. This particular study identified that cardiologists who did not routinely screen athletes were 40% more likely to categorise ECGs as abnormal compared to experienced cardiologists (Dhutia et al., 2017).

Moreover, there is unease surrounding the responsibility that lies with physicians and the impact it can have on them and their decision making in determining whether someone should be disqualified from sports participation. Essentially, there are liability issues that unavoidably impact physicians with the sole responsibility to disqualify athletes from competition and enforce that decision (Maron et al., 2015). This same dilemma is described as a 'paradoxical concern' by Pelliccia et al. (2008) who states that there is increased possibility of legal liability for the physician, by virtue of recommending disqualification from sports participation with the objective of protecting the athlete from the potential subsequent hazards of competition (Pelliccia et al., 2008). So not only can disqualification from sport have a negative impact on athletes, but also the physician who leads that decision, through feelings of guilt, anxiety and accountability. This can be identified in one particular case study described as a highly visible case regarding sanctioned college sport where a basketball player diagnosed with HCM and fitted with an implantable cardioverter defibrillator (ICD) used the Rehabilitation Act to argue that Northwestern University had violated their rights in a discriminatory fashion by disqualifying them from college basketball participation on medical grounds (Maron et al., 1998). Maron et al. (1998) disclosed that in conclusion to this case a court upheld the right of the college to exclude such an athlete on the basis of medical disability (Maron et al., 1998). Despite the outcome within this particular case, it does highlight how difficult and psychologically detrimental it can be to have to make decisions that deeply impact the livelihood of other people.

Furthermore, there appears to be a growing consensus that pre – participation examinations should include an ECG performed and interpreted by a qualified individual (Löllgen et al., 2010). Löllgen et al. (2010) pointed out that physicians with an absence of extensive experience in the area of ECG interpretation may have trouble interpreting ECGs conducted on athletes at rest. It is further highlighted that this often requires specialist cardiological knowledge relating to sports (particularly HCM, dilated & arrhythmogenic right & left ventricular cardiomyopathies), and advocates that physicians with a fundamental lack of expertise in this area can crucially miss the diagnosis of newly appreciated entities (e.g., ion channel diseases or cardiomyopathies) (Löllgen et al., 2010). Although, this said, it has been put forward that a lack of resources or physicians dedicated to performing examinations and interpreting ECG results (Maron et al., 2015) could play a role in a potential lack of experienced physicians with the ability to interpret an ECG accurately and reliability within athletes. Interestingly, in Italy it is a standard and well-defined process in the legislation, whereby the sports medicine specialist holds ultimate authority and is therefore entrusted with the responsibility as well as the enforcement of eligibility / disqualification decisions (Pelliccia et al., 2008). Moreover, it is strongly implied that the situation in Italy creates an unavoidable tendency for managing physicians to be instinctively conservative in making decisions surrounding athletic eligibility (Pelliccia et al., 2008). This point is reinforced by the fact that physicians responsible for the cardiovascular care of athletes are guided by ECG interpretation standards that improve disease detection and limit false – positive results (Drezner et al., 2013).

Despite this, there are ways that these issues are being addressed and minimalised, for example, sports physicians in Italy now undergo at least 4 years of specialised training, including in sports cardiology (Löllgen et al., 2010). As well as this, recent small studies have demonstrated significant improvements in ECG interpretation in athlete populations following online training (Dhutia & Maclachlan, 2018) clearly showing that adequate training, when implanted accurately, for physicians can curb the subjectivity in the interpretation of ECGs. This does appear to be an effective strategy as in a similar study Drezner et al. (2012) reported an overall improvement in the sensitivity of ECG interpretation from 89 to 94% and specificity from 70 to 91% before and after an online ECG interpretation tool based largely on the 2010 European Society of Cardiology

(ESC) recommendations (Drezner et al., 2012). Similarly, Dhutia and Maclachlan. (2018) told of how interpretation recommendations were devised by American and European experts in 2017, with the objective of unifying the recommendations for interpretation of athletes. It was then found that these criteria had been validated on 5000 young British athletes and resultantly that there had be a reduction in the proportion of athletes who required further investigation to 3%, rates they deemed to be acceptable in any screening programme (Dhutia & Maclachlan, 2018).

From the literature analysed surrounding the subjectivity and misinterpretation of ECG results it is vital that criteria such as ESC recommendations and the Seattle criteria are reviewed and monitored closely to ensure that they remain fit for purpose, but also provide clarity for perhaps less experienced physicians. At the same time, it is crucial that such resources remain widely accessible in order to reduce the risk of a potentially life-threatening condition being misinterpreted for a less severe condition or perhaps a training adaption in some higher performing, well trained athletes.

Condition treatment and management

A further issue surrounding SCD risk factor screening is what happens as a follow-up in terms of treatment and condition management. As disclosed by Wilson & Junger (1968), in the case of a declared disease where lies an ethical obligation to provide an accepted treatment (Wilson & Jungner, 1968), although it is later stated that this should be done only when the treatment benefits the patient and causes no further harm to them (Wilson & Jungner, 1968). At this point in time there remains a need for repetitive ECG screening during adolescence and the possibility of developing phenotypic evidence of cardiomyopathies during this time or later (Maron et al., 2015). Follow-ups and treatment are described as vitally important, and without it, case – finding must inevitably fall into disrepute (Wilson & Jungner, 1968). This can also be seen in a particular study that accessed follow-up data collected via office visits, telephone interviews or written questionnaires (Corrado et al., 1998). Corrado et al. (1998) amassed a study cohort of 621 young athletes, out of 33,735, who had been disqualified from competitive sports participation due to cardiovascular issues, following screening at the Centre for Sport Medicine in Padua. Over a follow-up period of 8.2 ± 5 years, only 4 out of the 621 patients died, on of a mild mitral-valve prolapse and the other 3 of

non-natural causes (Corrado et al., 1998). 22-patients were diagnosed with HCM and resultantly disqualified from competitive sports, of these 22 none died during the follow-up period of 8.2 years (Corrado et al., 1998). Within this cohort 2 patients with paroxysmal atrial fibrillation were treated, 1 with beta blockers and 1 with amiodarone. In both cases treatment was effective at restoring sinus rhythm. Another 1 patient with a family history of SCD was treated with amiodarone following 24 hr Holter monitoring documented the presence of non-sustained ventricular tachycardia (Corrado et al., 1998). Further studies identified how the resultant treatment of those with a genetic heart disease otherwise reflects that of non-athletes, with the potential for pharmaceutical interventions such as ß – blockers (Wilde & Ackerman, 2014) and surgical intervention via the means of an ICD which can shock the heart from potentially fatal ventricular arrythmias to normal sinus rhythm (Semsarian et al., 2015). Moreover, nearly 400 reported athletes who had an ICD have remained engaged in competitive sports, with short term follow up revealing no sports or disease related mortality and no evidence of increased damage or malfunction (Lampert et al., 2013). These results show encouraging signs in working towards effective management and "an accepted treatment for patients with recognised disease" (Wilson & Jungner, 1968), in this case SCD.

Financial strains

The cost impact of screening didn't appear to be as well documented, but when looking at designing a screening it is imperative that the cost of case findings should be economically balanced in relation to possible expenditure on medical care (Wilson & Jungner, 1968). Although echocardiography is said to be expensive and impractical for large scale use (Corrado et al., 1998) Corrado et al. (1998) did state that a 12-lead ECG would be a cost-effective method of screening. Furthermore, data retrieved from the Italian study disclosed that 33,000 athletes would need to be screened to save 1 life a year at a cost per life saved of £861,000 (Semsarian et al., 2015). This re-iterated the question of would this money be better off invested in more prevalent public health issues such as obesity in young people? In the UK the Football association (FA) reported the costs of screening per athletes. The total cost amounted to £257 per athlete for initial screening that included an ECG and Echo, with a cost breakdown of £160 for consultation, £25 for ECG, and £72 for an Echo (Malhotra et al., 2018).

Priorities

Another potential barrier to cardiac screening is the argument of who should get priority when being screened? In a study by Maron et al. (2015) it was stated that screening posed potentially troublesome ethical dilemma of confining screening for potentially lethal diseases to those who choose to engage in competitive sport, whilst subsequently excluding non-athletes. It would make sense to believe that athletes have priority in one argument because they are putting their heart under greater levels of stress and more frequently, but at the same time it must be acknowledged that the number of SCD is highest in non-athletes because that segment of the population is much larger in size (Maron et al., 2015). What can be done to aid this is raised awareness at both ends of the spectrum. For example, at a community level, increased awareness and access to automated external defibrillators (AED) along with training in cardiopulmonary resuscitation can help reduce the number of SCD (Semsarian et al., 2015). Interestingly, this can be linked to a study by Müller et al. (2006) which found that patients who received CPR from a bystander had significantly increased rates of successful resuscitation and eventually lead to release from care setting (Müller et al., 2006), showing how basic training in the likes of CPR could aid the reduction of SCD mortalities especially those that occur in a public setting. To emphasise this, the charity Welsh Hearts state that they haves screened 3, 748 hearts, placed 3,756 defibrillators in Welsh communities, and trained 62, 385 people in CPR (Welsh Hearts, 2021). Furthermore, in Japan and Austria, authorities now mandate that everyone applying for a driver's licence must complete cardiopulmonary resuscitation training to increase the prevalence of trained people in the community and thus enhance the 'chain of survival (Semsarian et al., 2015). At the other end of the spectrum, in professional sports, governing bodies are beginning to realise the importance of putting preventative measures into place, such as FIFA, who have now "implemented screening programmes for all players. (Semsarian et al., 2015). Semsarian et al. (2015) states how FIFA now recognise the emergency level of care and have developed medical emergency bags along with a series of 11 steps to help prevent SCD in footballers. These 11 steps include training for cardiopulmonary resuscitation and how to use AED's (Semsarian et al., 2015). Gaining publicity and acknowledgement from governing bodies such as FIFA provides a great opportunity to raise the profile of SCD and increase the awareness about screening for the associated risk factors.

Theory of Planned Behaviour

In line with aim 3 of this study which strives to explore and understand attitudes of individuals, specifically athletes, towards cardiac screening, it was deemed appropriate to include a behavioural model, in this case Ajzen's Theory of Planned Behaviour (Ajzen, 1991). This model was used as it explains how individuals' behaviours, in this case getting screened, can be influenced by attitudes formed from experience, knowledge and social interactions (friends, family, media etc.). Findings from this study will be interpreted using this behavioural model in order to understand influences towards getting, or not getting, screened. The Theory of Planned Behaviour was introduced by Ajzen in 1991 and aims to illustrate how an individual's attitude can influence their behaviour. Ajzen described how the model was a tool designed to explain and predict human behaviour (Tornikoska & Maalaoui, 2019). The Theory of Planned Behaviour is formed of three components – attitude, subjective norms, and perceived behaviour control – all of which influence a person's intentions and ultimately their behaviour. A 2019 study, which was an interview conducted with Icek Ajzen, defined these components as follows: Attitude – the degree to which an individual has favourable or unfavourable evaluation or approach to the behaviour in question. In the context on screening, what someone does or doesn't already know about the screening process could influence their attitude. For example, the less an individual knows about the screening process in subject, the more likely they are to have a, pre-conceived, negative attitude towards it and therefore be less likely to execute the behaviour in question, in this case, cardiac screening. Subjective norms – the perceived social pressure to perform or not to perform a behaviour. It is based on beliefs concerning whether important referent individuals or groups approve or disapprove of an individual taking steps towards executing a behaviour If, for example, a teammate, friend, or family member has had a positive experience with cardiac screening, they are then more likely to give positive feedback to the individual and influence their attitude towards the behaviour in a positive way. Perceived behavioural control – the perceived ease or difficulty of performing behaviour. It is based on control beliefs regarding the presence or absence of requisite resources and opportunities for performing the behaviour in question. Examples of how an individuals perceived behaviour control could be influenced include, convenience of the location of the screening is held, the travel, cost of screening, and length of time screening process will

take. The greater the perceived behaviour control over starting, the stronger the individual's intention to engage in the task (Tornikoska & Maalaoui, 2019).

The Theory of Planned Behaviour has previously been utilised to understand attitudes to breast cancer screening. A 2019 study based in Malaysia used the model to explore females' intentions towards screening for breast cancer (Chin & Mansori., 2019). Chin and Mansori collected data from females aged 18 and above, from public hubs such as Kuala Lumpar airport and the Sentral railway station. 600 questionnaires were distributed in every state of Malaysia using non – probability sampling. The data was collected via the snowball method through the means of social media platforms including WhatsApp, LinkedIn, and Facebook (Chin & Mansori., 2019). Of the 600, 507 (84.5%) of the questionnaires were finalised for data analysis. It was highlighted through the research that perceived beliefs and knowledge were prominent factors that influence and urge females to go for breast cancer screening (Chin & Mansori, 2019). Further studies in the field suggested that females' knowledge and awareness could be increased through the organisation of awareness campaigns at public places or sporting events. Chin & Mansori (2019) stated how health professionals and practitioners should emphasise the benefits of screening, as well as efforts towards increasing levels of knowledge towards female's breast cancer screening. Attributing this largely to the fact that people in current times prefer to understand a situation, be motivated to get screened, comfortable with the screening the screening process and as a result, will perform the behaviour willingly. In line with Ajzen's intended design for the Theory of Planned Behaviour, Chin and Mansori (2019) proposed that it can be used to accurately predict females' intentions towards breast cancer screening. This study identified highlights how Ajzens Theory of Planned Behaviour can be used as a legitimate tool to understand individuals screening attitudes. It can demonstrate how someone's attitudes, social experiences and interactions, and pre-conceived perceptions can influence their decision to get screened. Although, the focus of this study was on breast cancer screening rather than cardiac screening, although there are characteristics that can be applied to this study as there is crossover in the means of the use of the behavioural model and factors that can influence an individual's decision to get screened.

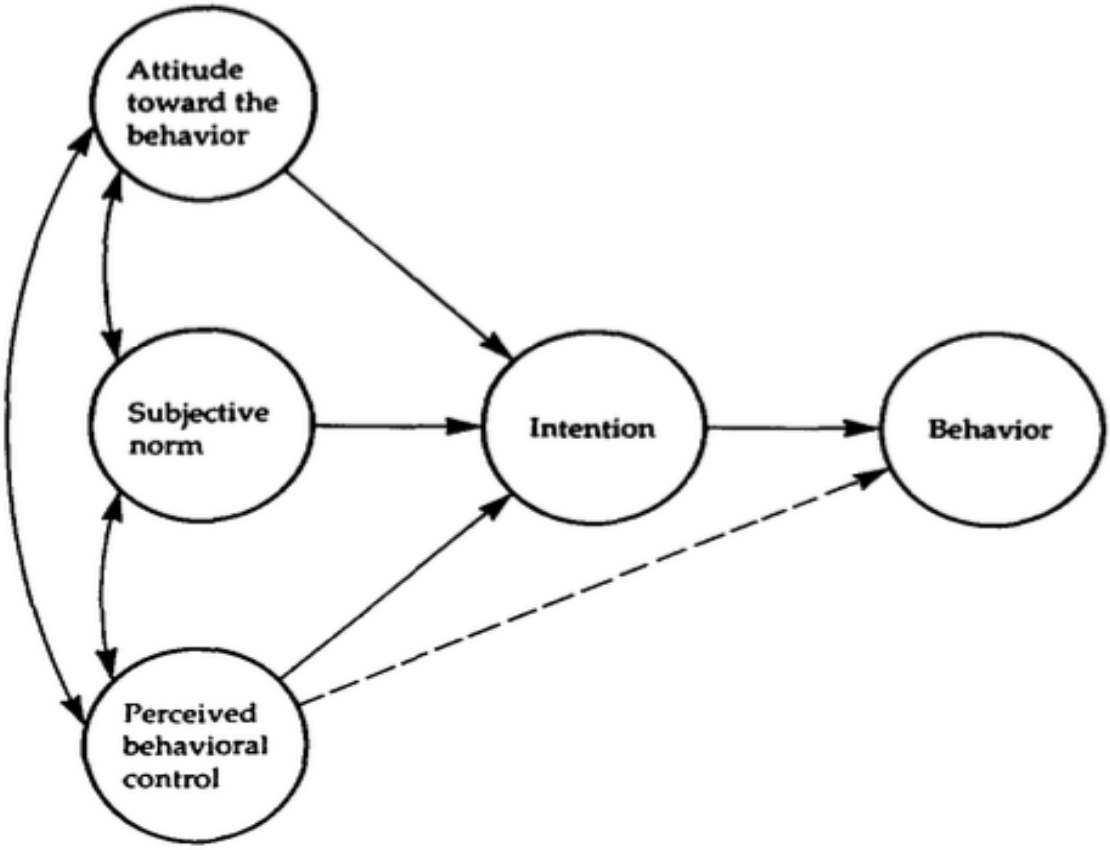

Fig 1. Ajzen's Theory of Planned Behaviour model (1991)

Conclusions

From studying the literature, it becomes clear that the biggest obstacles facing cardiac screening are the potential inaccuracies with the screening method (ECG) in terms of false-positives, false-negatives and misinterpretation of ECG results. Despite the UK NSC committee now accepting that SCD is an important health problem (Couper et al., 2019), which has changed since the previous review in 2014, they still see no viable way to warrant the implementation of a screening programme which is not only rare, but also problematic at times. Literature on the rates of false-positive and false-negative test results in ECG'S is well documented. It is a common theme throughout papers on SCD and the associated risk factor screening as it is probably the biggest barrier facing the implementation of a national screening programme for SCD currently in the UK. It is difficult to refute that, at this moment in time, based on analysis of well-regarded papers on the topic, the rate of false-positives and false-negatives are still too high

within ECG screening to be able to promote its use within large populations, such as those outside of competitive sports. Furthermore, the published literature highlights issues with interpretation by the physicians taking the ECG are currently still too great of an occurrence. Although, with the creation of interpretation of criteria being set out and put into place, this issue can be limited. The main factor as to why these are such big issue is because of the devastating impact that they can have on the subsequent individual, athlete or not. Especially in terms of inducing, sometimes needless stress, and anxiety to the patient, which will undoubtedly cause mental harm to the patient but also creates greater financial costs for health services who have to provide care to deal with these issues.

Gaps in the literature in this field mainly revolve around follow up treatment, focus on athlete's knowledge, more specifically when looking at different levels of sporting participation, and exploring the evolvement of screening methods currently used.

There appears to be a lack of literature surrounding treatment and management strategies for people diagnosed with potential risk factors of SCD. This, said there are some comments about various pharmaceutical developments, but very little remains documented in terms of follow-up treatment. Also, when exploring the well cited study carried out in the Veneto region of Italy it was clear that the introduction of a pre – participation screening programme implemented over a 25-year period lead to a significant decrease in rates of SCD cases. But these results have failed to be repeated on the same scale since, leading to questioning of the reliability of the testing and whether such programmes are feasible to implement. There also appears to be a gap in the literature on what athletes' knowledge, perceptions and experiences are in regards to SCD and SCD risk factor screening. Especially when looking at different levels of sports participation (amateur, semi-professional and professional).

Key considerations the literature identified included, the continuation of development of ECG interpretation tools, such as ESC recommendations and Seattle Criteria, to ensure that all administrative physicians are at the same level of understanding, in order to minimise subjectivity.

After studying the published literature, and identifying the gaps within this field, the main aims of this research are to: 1. identify the barriers to, and facilitators of, implementing a screening programme for SCD in athletes and physically active people, in different contexts - i) amateur athletes, ii) semi – professional athletes, iii) professional athletes, and 2: explore the knowledge, attitudes, experiences and opinions of athletes and medical professionals with regard to SCD and SCD risk factor screening via the implementation of a nationwide screening programme. Ajzens 1991 Theory of Planned Behaviour will also be integrated into the research alongside this study as it will potentially provide insight into predicting individual's behaviour towards cardiac screening. In order to do this research will consist of two studies. Study 1 will consist of carrying out a number of semi-structured interviews with athletes from different levels of sporting participation and with doctors/medical professionals. This is to gain an insight into what they know about, their attitudes towards, and what their perceived barriers and facilitators are in regard to, screening for SCD risk factors. The data collected from study 1 will be used to underpin study 2. The second study involves developing and administering a questionnaire exploring screening for SCD and what athletes' attitudes are towards such a programme, their knowledge of SCD and their thoughts about the impacts of being screened for SCD. The questionnaire will be designed using key themes that were identified within the responses given during interviews with athletes and doctors in study 1. The purpose of this second study is to develop a tool that will enable researchers to gain insight from a larger population and provide quantitative data that can be easily compared across studies.

Study 1 – Athlete interviews

Introduction

In order to answer the key question in this qualitative cohort study, primary data collection was completed through the means of specifically designed, semi-structured, one – to – one qualitative interviews with athletes and doctors. Gathering data from these interviews aided the understanding of the knowledge and perceptions of athletes and doctors on SCD, the relevant risk factor screening, and the potential for the implementation of a national screening programme. For this study an athlete was defined around an ESC definition as an individual of younger or adult age who is engaged in regular exercise training and sometimes competition (McKinney et al., 2019; Pelliccia, 2005). Either at an amateur, semi-professional or professional level of participation. In the context of this study the different classification of athletes was as follows: Professional – individuals who complete the greatest volume of exercise per week through training and competition, with the receipt of financial premium for participation. (e.g. – national & regional athletes, Olympians etc.) (McKinney et al., 2019; Pelliccia, 2005). Semi – professional athletes – individuals that complete moderate levels of exercise volume per week through training and competition, usually competing in official competitions and leagues (McKinney et al., 2019; Pelliccia, 2005). Amateur – an individual who partakes in a low volume of training and competition per week. Participation level is usually based around personal fitness, recreational competitions, and open events (McKinney et al., 2019; Pelliccia, 2005).

Methods

Participants

Of the athletes contacted to take part, 9 completed interviews. The make-up of those who completed an interview with the research team was: 4 amateur, 3 semi-professional and 2 professional athletes. 2 of the 8 (25%) athletes that took part in the interviews were female, the remaining 6 (75%) were male. Across the study cohort there was a variety of 7 different sporting disciplines – Badminton, Squash, Golf, Netball, Rugby and one participant competing in Surfing and Triathlon to a high level. As part of the interview's participants were not required to provide their age but were identified as being between 18 – 45 years of age by the research team to satisfy the data collection

inclusion criteria. Moving through the study it was decided by the research team that it would be beneficial to include and carry out interviews with doctors and medical professionals to provide further scope to the study and gain views from the opposite perspective to athletes. Doctors were contacted, agreed and consented to take part in the study in the same capacity as the athletes. Again, they were reassured that all data would remain anonymous.

The inclusion criteria that were used were: **1)** Participant must be part of a professional, semi – professional or amateur sports club. **2)** Participants must be between the ages of 18 -45 years old (athletes only). **3)** A medical professional with a general medical background or specialising in cardiac health (doctors only).

In tandem with this, the exclusion criteria for the data collection were devised, **1)** Individuals who are not members of a sports team or organisation or are not medical professionals. **2)** Athletes under the under of 18 years old, as the confidence in screening outcomes is lower in younger people. **3)** Athletes who are over the age of 45, due to the fact that older individuals are increasingly likely to be at risk of lifestyle-related cardiac illness, rather than hereditary. **4)** Individuals who have been directly impacted by SCD in such a way that could prompt distress and anxiety within the participant when talking about the topic.

Methodological Decisions

Study 1 of the research focussed on gaining an understanding as to what athletes and medical professionals knew about SCD, the associated risk factor screening, and what may influence their decision to get screened. It was decided upon by the research team that interviews would be the most effective method of extracting this initial data from athletes. This decision was reached to carry out semi-structured interviews, via Zoom as the benefits of adopting video interviews for data collection allow for greater accessibility to participants and increase leeway for time and length of interviews. The participant was likely to feel more comfortable being interviewed in a space they are more familiar with, whilst still feeling a particular connection with the interviewer (Gray et al., 2020). This connection can encourage an open conversation with the interviewer. Negative impacts of carrying out interviews, stem from the fact it's not face to face, including external distractions, a reluctancy to speak over video, and technical difficulties (Gray et al., 2020), and varied level of engagement from participants

(DeJonckheere & Vaughn., 2019). Moreover, from examining the relevant literature in the field it became clear there was a gap, little to no studies had been carried out that had spoken directly to athletes about what they knew about cardiac screening and the potential risks, as well as the facilitators and barriers towards getting screened. This decision was thoroughly considered by the research team as identified trends from the interviews tend to reflect trends throughout the reviews of relevant literature (Artino Jr et al., 2014). The format of interviews aided the research team in determining how the interviewed participants, athletes, perceive and understand the subject (Artino Jr et al., 2014). of SCD and cardiac screening. Through the methodological approaches used in this research, the interviews were justified as they provided a solid platform to form the basis of the second component of the research, the questionnaires. As documented by Artino Jr et al. (2014), interviews can provide a practical method of providing "input to inform the design" of a questionnaire. The questionnaire which formed the second study in the research was developed utilising the themes that were identified from the interviews carried out in the previous section. The questionnaire design and structure would allow the research team to dig deeper into understanding what a greater number of athletes knew and understood about SCD, and also their perceptions and attitudes towards cardiac screening. Using a questionnaire as well as an interview had its benefits. Unlike an interview, the researcher is not speaking directly to the participant which reduced unavoidable bias through using specialist terms and potentially having an influence on their response (Artino Jr et al., 2014, Dalati & Marx Gomez., 2018). Moreover, participants can maintain a higher degree of anonymity (Dalati & Marx Gomez., 2018). In terms of practicality, a questionnaire is a low-cost method of data collection and often has a quicker turnaround with regards to results than other methods of data collection (Dalati & Marx Gomez., 2018). A questionnaire is an effective tool of data collection as it allowed the research to reach out to a wider birth of athletes from all sporting levels, and crucially, do this in a relatively short period of time. As with any means of data collection there are barriers to using a questionnaire, in this case participants could misunderstand the questions being asked and then provide an inaccurate response, also participants may sometimes accidentally or unintentionally miss out a question which can result in missing data (Dalati & Marx Gomez., 2018). Documenting the methodological decisions made in this research aid the understanding of why data collection methods were used, and why they were predicted to be the most

beneficial.

Methodological approach

The methodological approaches that were mainly used, and best suited to the research were pragmatism and mixed – methods approaches. The pragmatic stance allowed the studies to take a natural course and develop the most effective means of data collection. At the same time this encouraged an element of innovation when exploring for resolutions to the key questions being asked. A methodological approach utilising pragmatism is beneficial as it can aid in establishing various types of data, but also provide a substantial platform for the addition of factors into the study. In this research, for example, data from interviews being used to form the basis of a questionnaire. As with all methodological frameworks, there are limitations to pragmatism. These include the difficulties that can arise when arranging data collection, but then also within study cohorts. Sometimes it can also become challenging to interpret data with variation between data types. Despite these limitations to a pragmatic approach, it was utilised in this study due to the innovative and productive characteristics that it promotes, and it naturally provided a progressive pathway from the initial qualitative study, to the second quantitative study. The application of a mixed methods approach permitted elements of both studies that construct this research to strive to answers to the research question. One of the most prominent advantages of using the above approach is that it permits qualitative and quantitative studies to be brought together to reach the research goal. As a result, it provided greater confidence in subsequent results and solidified conclusive arguments. Conversely, this can be a complex and time-consuming approach to pull off. Within this research a mixed methods approach will allow for the collaboration of qualitative interviews and quantitative questionnaires to reach a strong outcome.

Interview design

Semi-structured interviews were used as the primary source of data collection for this research as it would allow the investigators to home in on the area of research that the study is primarily focused on (Naz et al., 2022). In this instance providing the researcher with the ability fixate on extracting information from participants that will address the fundamental aims of the research exploring SCD and cardiac screening. At the same

time the interviewee will retain the ability to portray their own "personality and perspective" (Barrett & Twycross, 2018) on the topic by ensuring the resilience of the interview structure. Moreover, this strategy of interviewing presented the opportunity for the researcher to ask further questions in efforts to examine and extract relevant information from the interviewee (Naz et al., 2022; Rabionet, 2011). If conducted in a thorough and accurate manor, these interviews present an unambiguous means of extracting desired data (Barrett & Twycross, 2018) from athletes and Doctors. On the contrary carrying out interviews of such a format can be time consuming, through the means of transcribing interview, and the analysis of transcripts (Barrett & Twycross, 2018). As well as the potential subject to bias through the means of "leading questions" and "non – verbal signals" (Barrett & Twycross, 2018) which in some way could instigate a certain response from participants. The questions asked throughout the semi – structured interviews which constructed the qualitative component of this research were designed using 2 approaches. Firstly, some questions originated from the background knowledge of the researcher and the research team. This approach was done by asking questions in the regions that the researchers felt needed exploring, but also questions that were going to provide information rich responses and encourage open conversation. Secondly, questions were informed by findings of the previously orchestrated literature review, allowing for further exploration into areas not so well documented in this field. This contributed to the novelty of this study. Both approaches in the design of the questionnaire fed into the main aims and goals of the research.

An original interview topic guide was designed to address the fundamental questions of this study. The interview guide for athletes was completed over 3 drafts. The initial draft focused on what questions could be asked to target specific areas, in this case the participants (athletes) knowledge and perceptions of SCD and SCD risk factor screening. This initial draft was revised by the research team, and as a result the second draft consisted largely of restructuring questions into sub-sections to aid the flow of conversation when completing interviews. The final draft included an introduction to the study and provided context for the interview, as well as including a small number of questions that had been produced by the research team (Figure *iii* & *iv* in appendix*)*. The final draft was then approved by all members of the research team. 2 pilot interviews were carried out with individuals close to the researcher, to ensure the open-ended questions encouraged flowing conversation as intended. Following the

completion handful of interviews, the interview guide was reviewed to ensure validity and minor amendments were made before the remainder of interviews were completed. The design of the interview guide used for doctors followed a similar process to that of athletes. Only 2 drafts were required for doctors' interviews. Again, the original draft focused on asking questions that would provide sought after information on doctor's knowledge, opinions, and experience of SCD and a risk factor screening programme. While the second draft examined the structure of the interview so that the questions were asked in a logical order and were clear for the participant to follow. Minor amendments were made, and the final draft was agreed by the research team (Figure *v* in appendix).

Ethical approval:

Following the completion of the final draft, the athletes interview guide was then formulated into a semi-structured interview format. The interview design was then sent to the Swansea University Ethics Committee for approval prior to beginning data collection. This process was then repeated for the interview guide used in doctors' interviews later on in the study. Data collection was only initiated, in both groups, after the ethics applications had been approved.

Recruitment:

The main method of sampling for the qualitative element of this research is convenience sampling. Convenience sampling is a method of "non-probability or non-random sampling" where the targeted cohort meet practical criteria, for example, they are easily accessible (Etikan et al., 2016). The main facilitators of using such a strategy are that it is affordable, straightforward, and time-effective, on the other hand it can sometimes increase the risk of potential bias (Etikan et al., 2016). Convenience sampling is a common strategy used throughout qualitative research, and best complimented this study, due to the unique position of the lead researcher amongst athletes and physically active populations. Snowball sampling was a technique also used as part of convenience sampling. This consisted of initial participants recommending potential participants who they felt would be willing to contribute to the research (Parker et al., 2019). One of the advantages of snowball sampling is that it is likely to increase the number of participants who take part in the study. Potential participants were contacted in a professional capacity via phone or email, either directly in person or through their sports

club. Doctors were also contacted via phone and email, but primarily through Gatekeepers - individuals in administrative positions who can provide access to a particular group or individuals (Roulston, 2018). This aided the professionalism of the study and solidified the anonymity of these individuals, although it can increase the time taken to collect data.

On initial contact, the potential participant was provided with an introduction to the study, to see if they were willing to take part, and a brief explanation of what they would be required to do if they chose to take part in the study. If they then chose to partake in the study, they were sent an official invitation, along with an in-depth information sheet about the research study. Interviews were arranged at a date and time that best suited the participant. The interviews were originally set to be carried out in a face – to face format at Swansea University or a location where the participant would feel comfortable, but this became impossible due to the outbreak of the COVID -19 pandemic which led to subsequent lockdowns. Therefore, this meant that interviews had to be carried out virtually using the video communications platform Zoom, usually with the participant completing it from their own home. Participants provided written informed consent prior to the interview. At the start of each interview, participants were read a brief introduction, reiterating the purpose of the study, that all data/responses would remain anonymous, and to confirm they were comfortable to proceed with the interview. Finally, before the interview started, participants were informed that the interviews were to be recorded and saved anonymously, which was agreed before beginning the interview.

Conducting interviews:

The interview itself consisted of 14 questions for athletes and lasted usually around 35 minutes. The semi-structured format employed open-ended question in order to encourage a flowing, relaxed discussion which allowed the participant to express their knowledge, views and experiences freely. Upon completion of half of the interviews with athletes, the interview structure being utilised was reviewed and some minor amendments were made to ensure the validity remained and the questions being asked were fit for purpose. Following interview recordings being saved, the interviews were then transcribed. Despite this being a lengthy process, it was a vital step in order to

analyse the interviews and extract valuable data. The interview structure for doctors consisted of 22 questions and was designed using the same format used for athlete interviews. Some of the questions were constructed from responses already given in completed athlete interviews. These interviews were, again, semi-structured and encouraged open conversation. All participants, both athletes and doctors, were reassured that the data they provided would remain anonymous.

Analysing data:

The analysis strategy used while looking at all interview responses was thematic inductive analysis. The analysis strategy used while looking at interview responses was inductive thematic analysis. Thematic analysis is defined by Braun and Clarke (2006) as an analytical technique for "identifying, analysing and reporting themes within data" (Braun & Clarke, 2006) and furthermore, described as powerful, robust and versatile (Kiger & Varpio, 2020) method for analysis. The process of thematic analysis is completed using codes and the "construction" of themes (Braun & Clarke, 2006; Kiger & Varpio, 2020) where the researchers judgement plays a vital role in the identification of themes (Braun & Clarke, 2006). In Kiger & Varpio's 2020 work, a theme is defined as a "patterned response or meaning" (Braun & Clarke, 2006; Kiger & Varpio, 2020) which is usually driven by the data collected, specifically for the means of the research (Braun & Clarke, 2006). The specific type of thematic analysis used throughout the qualitative component of this research was inductive thematic analysis as presented by Braun & Clarke (2006). An inductive approach allowed for clear links to the data (Braun & Clarke, 2006) and presented a more inclusive and broader means of analysis directly from the data collected (Braun & Clarke, 2006; Kiger & Varpio, 2020). Braun & Clarke, 2006 declare a range of advantages to using thematic analysis throughout qualitative research, including its flexibility, ability to summarise key features of large data sets, ability to produce analysis suited to informing policy development, potentially in this research a national screening programme, and offering insights into unanticipated findings (Braun & Clarke, 2006). Thematic analysis allows for the coverage of a vast topics throughout all interviews, before being able to categorise these into 7 themes to incorporate all of the data from within the interviews in this research. By using thematic analysis, it was possible to identify a large number of key topics throughout all interviews analysed before being able to categorise these into 7 broader themes to incorporate all of the data from within the interviews. These 7 themes that were derived

from common and reoccurring topics from interview were: Awareness & Knowledge, Facilitators, Barriers, Views & Opinions, Incentives, Experience and Emotional impacts. The grouping of the data into these categories aided the design of the questionnaire. From doctor's interviews there were 5 themes derived from the analysis which were Knowledge & Experience, Views, Awareness, Facilitators and Barriers. Participants interviewed were given unique ID tags to ensure their anonymity, these were only known to the lead researcher. For athletes this ID tag was derived from the level of sport they competed at e.g., amateur = AM, and what number participant they were from that particular group e.g., the first person interviewed for each group would be = 01, meaning that the first amateur athlete to be interviewed would be AM01, then the second AM02 etc. SP and PRO were used for semi-professional and professional athletes, respectively. For doctors the ID tag was 'Doct' with the number of the order they were interviewed e.g., Doct-02 was the second doctor interviewed.

Reflexivity & Trustworthiness

Reflexivity is a fundamental component of qualitative research. Reflexivity is the area within a study that the researcher makes clear any potential crossovers in the context of relationships between participants, in this case interviewees and the researcher. (Dodgson., 2019). Thorough reflexivity requires the researchers to focus on self-knowledge, sensitivity, any role they may play in the formulation of knowledge, and monitoring potential bias and beliefs (Berger., 2015; Dodgson., 2019). Acknowledging intertwining relationships between participants and interviewer can increase "credibility of findings and deepens understanding of the work" (Berger., 2015; Dodgson., 2019). In the qualitative component of this research specialist terms are regulated and only used when necessary, to not overwhelm participants and encourage conversation between researcher and participants. This, in turn, capped any potential self-bias from the researcher through terminology and language, used in questions. Athletes and doctors pre-disposing feelings informed by any experiences of SCD and relevant screening, could influence interview responses. A handful of questions contained statistics regarding SCD and cardiac screening, that could be interpreted differently by each participant, leading to altered patterns in responses given. There are factors of reflexivity that lie outside of the researcher's control. One example of this could include any high-profile cases of SCD covered in social media or news outlets and seen by participants. As a result, this could have changed any opinions and feelings towards

SCD, therefore altering responses that would have been given prior to said event.

Trustworthiness is an equally important component of qualitative research. Trust between reader and research is "imperative" (Stahl & King., 2020). Trustworthiness of qualitative research is largely formed of criteria set out by Lincoln & Gruba in 1985. Although dated, this criterion is still used throughout literature at present. The four main criteria consist of: 1. Credibility – the confidence placed in truth of findings. 2. Transferability – the degree to which the results can be transferred to other settings. 3. Dependability – the stability of findings overtime. 4. Confirmability – the degree to which findings can be confirmed by other researchers. (Korstjens & Moser., 2018; Lincoln & Gruba., 1985). Trustworthiness was ensured throughout this study, through statement of aims, description of recruitment and data collection processes. Moreover, through explanation of rigorous analysis methods used throughout the qualitative component of this research aiming to maximise trustworthiness of findings. Ensuring the reflexivity and trustworthiness of the qualitative component of the research are vital in enhancing and reinforcing the arguments and findings.

Results

Athlete interviews

Knowledge and Awareness

Participants tended to have heard of SCD risk factor screening and knew that it existed, but they did not necessarily know what it was. One participant stated, "I am aware of what it is, and I know roughly how it works but not sort of the details of it" (AM01). This trend was seen commonly throughout, especially in amateur athletes. Athletes at higher levels of competition became increasingly familiar with it, largely because they had been screened in the past or it was more prevalent in their sport. Despite this, a number of those who had been screened still had a degree of uncertainty as to why they had been screened, with one semi-professional athlete stating, "Yeah I am aware of what cardiac screening is, I have been screened a couple of times myself, but besides from that I don't really know why they are doing it or what the reasoning is behind it" (SP03). Further to this a professional athlete disclosed they were aware of what cardiac screening is "only because [they had] had it done to [them]" (PRO02). In contrast a

semi-pro triathlete who says they believe they are aware of what cardiac screening is and they "know how it looks at your heart functions" (SP02) but a semi – professional golfer had "never actually heard of [cardiac screening] before" (SP01). Only one was able to provide a scientifically correct answer by providing a reasonable definition of SCD. Three athletes spoke about their experiences with a case of SCD, two of the three said they had no experiences of a case of SCD. The remaining athlete said how they knew someone who had been fatally affected by SCD – "I actually personally know someone who has died of SCD. He was just playing football casually" (AM02).

Awareness of SCD in the athletes interviewed largely came from high profile cases, either seen live, on the news or other media outlets with one athlete stating they had "only heard of cases on the news" (AM03) and another responded, "No not really, the vast of my knowledge of [SCD] would be from Fabrice Muamba…" (AM04) (Fabrice Muamba is a former professional footballer who suffered a cardiac arrest during a competitive football game). Different sporting disciplines lead to different levels of awareness of SCD, with participant SP02 saying "Yeah, I have definitely become aware of [SCD]" since taking up competitive triathlon, compared to previously just competing in surfing and, "yeah, definitely yeah" (SP02) in regard to whether they are now more aware of cardiac screening since taking up triathlon. In a similar fashion to answers given in regard to knowledge about cardiac screening, a handful of participants commented that they had heard of SCD but were not able to say what it was: "Not in detail, I've heard of it but I wouldn't know exactly the scientific [processes] that goes on in the body" (PRO02) and "Yeah, I have heard of it" (SP03). The overarching finding is that levels of knowledge and awareness of cardiac screening and SCD are relatively low within the athlete cohort interviewed.

In tandem with this there appeared to be a (lack of) education provided around the topic; participant SP03 spoke of their experience of being screened with their sports team, saying "the thing that was lacking, like you just said, was there was no education about why we were doing it or anything like that, it was kind of turn up, stick the pads on, lie there for a couple of minutes, sign the forms, then that was us done" (SP03). Moreover, a further semi – professional athlete spoke about how they only become aware of SCD and screening when they took up a different sport – "It wasn't until I started doing

[Triathlon] and seeing all the cases and actually like become aware of it" (SP02) showing how there is a discrepancy in levels of education between different types of sport.

Facilitators of a potential screening programme

Participant AM02 stated how they believed the "positives outweigh the negatives" in terms of screening. The vast majority of participants commented on how they thought piece of mind was an influential benefit of choosing to be screened and potentially lead to reduced levels of anxiety while partaking in their sport – "for someone like myself who's lucky not to have had any problems, at the moment, having that peace of mind, knowing I can go into a game and not worry about my body" (SP03) and also "yeah, like peace of mind that I can go in and work hard" (PRO01). Further to peace of mind on an individual level, athletes also discussed that an advantage of screening would be providing peace of mind to their families, either through the fact that their family can now have less of a concern (as conditions can be hereditary) and they are less likely to experience the sudden loss of a close family member – "I think my parents would definitely have supported [their decision to get screened], just knowing it would be peace of mind for me and them as well I suppose. People also identified a key facilitator towards cardiac risk screening is the prolonging, and ultimately saving, lives of individuals who, if they had not been screened, would have no idea they had a condition potentially predisposing them to SCD. One participant said, "Well obviously for one, its potentially lifesaving, that's probably the massive one" (AM04). A less common, but equally important, response given by three interviewees identified the important opportunity for condition management that was presented by problem identification and the potential to receive treatment if available for certain conditions, as implied by the following two statements – "knowing that you've got that issue now you can continue in a different way, learn to manage it …" (AM02) and "Yeah, so that's the benefit of it, you're managing something" (AM03). Interviewees also spoke of how the identification of other potential cardiac issues when being screened was a benefit of screening in their view.

Barriers to cardiac screening

During interviews participants appeared to be able to identify more barriers to screening

than facilitators. The main barrier towards people's decision to get screened or not seemed to be a severe lack of awareness and education around the topic of SCD. One participant spoke of how oblivious they had been to cardiac screening, saying "I didn't even know you could get screened to be honest" (SP01). This general lack of awareness combined with a lack of an opportunity to get screened, presented a barrier particularly in lower levels of sports competition.

Financial barriers

Some participants alluded to the financial implications of screening, such as the cost to clubs, especially amateur sports clubs and lower league sports teams, personal costs, if an individual decides to get screened themselves, and also the cost on health services such as the NHS. This financial strain is greater in less well – funded sports, as referred to by one participant that "in netball we are not very funded, and we don't have as many opportunities as other sports" (AM03). Some of the athletes interviewed alluded to the financial implications stopping sport could have on an athlete, especially semi – professional and professional athletes who would lose a, if not their main, source of income, as athletes "playing right at the top level, [sport] could be their way of making a living and then being told they can't do this" (AM02) could have serious financial repercussions.

Well-being barriers

Athletes also identified how a potentially positive screening result could impact an individual in different ways, psychologically – "not being able to carry on playing your sport the way you like to play your sport may seriously, I guess, disrupt your mental health" (AM02) and also, "…if that's your job and something that you have done all your life and it could all of a sudden be taken away from you, I think the problems you would have psychologically would be pretty big" (PRO01). These perceived psychological impacts of screening have the potential to develop into serious health issues, with one participant saying, "knowing the fact you've got an issue that's not healthy, that's going to cause anxiety issues" (AM03). Furthermore, athletes spoke of the issues that ceasing participation in sport could have on an individual's physical health, with one participant pointing out that stopping "exercise completely and [people] then may have more issues arise from that because they then become obese and that can lead to diabetes" (AM03). Health issues such as these would place further strain

on services such as the NHS. Finally, one athlete spoke interestingly how having a positive screening result could negatively affect goals they had in their sporting career – "say if you did go and you had a bad result, from my point of view that means [I] don't get to go to the World Cup or anything" (PRO02).

Practical barriers

Some other barriers that athletes raised less frequently but still held significance included the difficulty of screening large populations of people – athletes or the general population, how there was little or no advertisement for screening and how they had never been encouraged to get checked/screened by their coaches – "it's not something you see advertised or there's never been a health campaign that says make sure you get screened" (SP03) and "I've never seen it being advertised at a local club or events saying its going on and I haven't been encouraged to go by any coach" (AM01).

Perceptual barriers

An important potential barrier that was raised by one interviewee focused on the accuracy and the integrity of the screening methods used, in this case usually an ECG, stating "I'm pretty sure there's a high false – positive rate within [screening via ECG]." (AM01) before going on to talk about how a false – positive result could affect a person and their career. Two athletes alluded to a sense of naivety when it comes to SCD risk and how this had influenced their decision to get screened. Because they have always taken part in sport, they assume they are healthy and nothing of the sort will happen to them which is not always the case – "it's never been anything that's crossed my mind, because I have always thought that personally I am pretty healthy" (AM02). Similar to this, the argument was raised with regard to people not getting screened because they don't want to know if they have something wrong with them with one participant explaining how some teammates felt at a screening event they attended – " the fact that most of us are going to be fine I think some people thought 'why do they need to test me, I knew I was fine before' you know what I mean" (SP03).

Views / Opinions on cardiac screening

Four of the athletes interviewed felt that screening was of greater value to higher levels of sporting performance. One athlete said how they felt that screening was more useful

for “those that are doing [sport] for a living” (AM01) and they attributed this to a “greater risk” (AM01) in more professional athletes. Another amateur athlete agreed with this point saying - “I think definitely at professional and semi – professional, where there is a bit more money should start to make it more mandatory” (AM02). The majority of athletes interviewed had believed that athletes should have priority to cardiac screening as they usually put their body, and thus heart, through greater physical demands, as stated by one of the interviewees: “I would probably say athletes because they do put their heart under more stress.” (PRO02).

Despite this, participant SP03 did also mention how “the general public in a way probably should almost have priority because if you think there is probably a higher chance of someone in the general public maybe having heart problems.” (SP03). With participant SP02 voicing the same opinion. In line with this another interviewee made the point that no one should necessarily have priority but did say that “athletes should be, at least, presented with the opportunity to be screened” (AM03).

An interesting point was made by a participant who suggested that the priority to get screened should be placed on populations / sports that have been identified as at greater risk and experience higher incidence of SCD – “weigh up the risks of screening to see which populations or sports are most at risk and prioritise them” (AM04). In line with this, two athletes believed cardiac screening to be of greater importance in endurance sports – “I would definitely say sports that are endurance based, so those such as football, rugby and then marathons that sort of thing. I’d say they’re the ones that should probably be more targeted as opposed to something like badminton that’s short and intense where you get breaks in-between to recover.” (AM01). In contrast, two athletes then believed that screening would be most beneficial in sports that are of a shorter duration but a high intensity rather than longer endurance sports – “I’d definitely say it’s more important in the high intensity sports” (AM02). Another athlete thought screening was equally important throughout all sports, saying “it is equally important throughout because all sport requires some type of fitness or some type of endurance.” (PRO01), athlete PRO02 stated how they felt screening would only be required in the sports “that really puts the under stress or like really tests the heart to pump blood around the body” (PRO02).

Moreover, two of the athletes interviewed believed that sometimes clubs should take the responsibility to screen their athletes, especially professional athletes who are likely contracted to that club, "clubs have a responsibility to screen players, and it would have a positive impact on the players" (PRO01). Although SCD fatalities are relatively rare compared to other diseases, two athletes still believed that any deaths as a result of SCD were too many – "I think obviously everyone matters, like one or two deaths is still too many" (SP03). Finally, an interesting point was made by two participants, which is related to athletes, especially professional, being seen as assets to their club and that "big sports" (AM03), professional sports teams screen athletes to cover themselves – saying that "they're covering their arses" (PRO02) in case anything bad does happen.

Influences on screening decisions

Athletes most commonly identified that an increased knowledge about SCD and screening would encourage them to get screened – "probably the main thing, the knowledge" (AM01) and "I would [get screened] if I knew more about it" (SP01). They discussed wanting to be made aware of any risks or implications. One participant said, "I think before you do the [screening] you have to have to know the implications if like the test comes back with an issue" (AM03) and "Yeah definitely, the awareness, like I'm sure people don't know the risks and benefits if they get screened. I wouldn't know where I could do it, how much it would cost, or if it would cost the NHS, I think a lot of it is awareness." (AM04). Three of the athletes interviewed stated how having a family history of a cardiac condition could and, on occasion, act as an incentive for individuals to be screened. Participant AM01 explained that if they "knew [cardiac condition] ran throughout the family or maybe if there had been something in my life personally that could make it more likely that I would definitely make me more inclined to get tested…" (AM01).

Five of the nine athletes interviewed also spoke of ways in which awareness and the level of knowledge about screening could be increased, via the internet, to encourage people to get screened. These suggested incentives included a strong social media presence, emails from NGBs which offered explanations about dates and location, an easy to use website – "a website for Wales, like here's the information and you can book here if you want to get screened" (SP01), another participant suggested creating "small YouTube videos" (SP02) which could provide information about SCD and

screening – "just couple of minutes just saying about cardiac screening and [what] we are screening for…" (SP02). Two participants, who had been screened before, discussed the value of receiving a physical leaflet or information sheet to be handed out at a screening event to provide details on the procedures and reasons for screening. However, one of these participants said how, when they had attended a screening event with their sports team, saying about the event – "I think the only thing that was lacking, like you just said was there was no education about why we are doing [screening] or anything like that" (SP02) before then going on to say how "all the players would have needed, even like a little leaflet or handout, because I think it makes it a bit more real then and the team would buy into it a bit more" (SP02).

Two athletes discussed making screening convenient to individuals by holding it at local venues, sports clubs, or facilities – "being local would help, definitely" (PRO01). Some participants raised that due to the high number of young individuals at universities across the UK, universities should offer screening for their sports teams and that they should "put out information about it and just things like that" (SP02). One of the two professional athletes said how they thought doing cardiac screening as part of baseline testing, at the beginning of each season, would act as an incentive for professional players to be regularly screened. Interestingly, one of the athletes believed that providing information on the support that would come after screening would positively influence an individual's decision to get screened – "I think maybe there should be some further support after that from a healthcare professional, like maybe if they give advice and like especially if it is a top athlete…" (AM03).

Experience of cardiac screening

Six of the nine athletes had not been screened for SCD risk factors. The remaining three that had previously been screened had all taken part as a mandatory requirement with their sports teams. Two of whom were professional athletes and 1 was a semi – professional athlete. All of these athletes had been screened more than once either at academy, regional or national level teams. One athlete in particular spoke about their screening experience, explaining that it was seen as a routine check, "it was mandatory to all the players. We saw it as an ordinary sort of health check-up" (PRO01). Whereas another talked about how they have been screened mainly for the national team or major

sporting events, saying how screening had only been done for "big events like World Cups or when you travel away" (PRO02).

Emotional impacts of cardiac screening

All of the athletes interviewed said they would stop participation in their sport if they were advised to by a doctor following SCD risk factor screening – "I would definitely, personally I would just stop, I just wouldn't want to put the rest of my life at risk …" (AM02), "I'd be able to realise that and know that stopping playing would be for my benefit and that on its own" (SP03), and "trust the doctor. I'd always take the doctor's advice and see what [they] recommend to do" (PRO02). Nevertheless, most of the athletes highlighted how hard it would be for them to completely cease participation in sport, and they would seek ways to try and complete some degree of physical activity. For instance, "if it was the doctor's recommendation to stop, I would probably take the decision to stop even though it would have a massive impact, and would look at other means of getting my activity in." (AM01), and "just wanting to know more about it, like how bad it is and what I can do … it does come down to understanding how much I could do … would I be able to find something else to occupy my time because that's all I kind of do, so if you take that away from me, I'm a bit like what do I do with myself." (SP02).

A couple of athletes discussed what their anticipated initial feelings would be if they were screened and found to have a condition predisposing them to SCD, including relief and worry – "the first emotion would be like so relieved that you're aware of it, so at least then you can work out how you are going to move forward…" (AM04) and "I would be scared, but then I would probably ask questions like what I could and couldn't do in terms of physical activity." (SP01). One athlete discussed how "initially there would be that worry" of being diagnosed with a condition potentially predisposing to SCD, but also "that kind of relief that nothing's happened up to now." (SP03). Three of the nine athletes said how being forced to stop sport would leave them "gutted" (SP02), "heart – broken" (PRO01) and "devastated" (PRO02), with two of these athletes attributing this to the fact they had participated and competed in their sports all their lives. One athlete questioned the purpose of carrying on in sport if they were found to

be at risk of SCD, saying – "if I'm not going to give 100% then what is the point." (SP02).

Some athletes were less likely to stop playing sport after a positive result, commenting, "I have been playing for 15 years and nothing has happened, I'll be fine." (SP03) but went on to comment that they would be very likely to stop sport if told to do so by a doctor, and family and friends would also play a role in this decision. Another felt that doctors should not be able to tell athletes outright that they have to stop sport, but instead they should "strongly advise and just give you the consequences of [potential outcomes]" (AM03), ultimately leaving the decision with the athlete of what to do. Two participants said how if they were found to be at risk of SCD, they would be keen to learn more about their condition, and immediately research ways that they could manage their specific condition. In contrast, another athlete felt they "wouldn't really want to know anymore unless I had a problem, because I wouldn't want to worry about it and all that or overthink anything" (PRO02).

Doctors' interviews

There were 5 key themes identified from these interviews, which were: Knowledge, Experience, Views, Facilitators and Barriers. The following sections identify and depict data that was extracted from the interviews.

Knowledge & Experience

Levels of knowledge regarding SCD, and the implementation of a national screening programme varied between the doctors who were interviewed. Participant Doct – 1 had a reasonable degree of knowledge around SCD, from their medical degree, but noted that SCD was not covered in as much detail as other cardiac conditions, such as ischemic heart disease, due to the fact SCD is not as common. However, they felt that parts of SCD education had stuck with them as, "it feels a little more kind of applicable to you than the things that typically affects us when we are much older." (Doct – 1). Furthermore, they felt that the level of education medical students receive on SCD was adequate in terms of the "context of the sheer amount of information that [medical students] have to take on board" (Doct – 1). This participant did explain how they were

taught to look into family history when a young patient comes in with a cardiac condition but did later say how they "didn't know enough about [SCD]" (Doct – 1) when asked about the potential implementation of a national screening programme. The following participant, Doct – 2, had the greatest degree of knowledge on SCD and the relevant screening, as they worked within an environment that was heavily linked with SCD. To illustrate this, they discussed how the, "majority of sudden deaths are SADS (Sudden Adult/Arrhythmic Death Syndrome)." (Doct – 2) and how this can make it harder to find a cause as there could be some "hidden pathologies" (Doct – 2) for example Wolff- Parkinson White Syndrome Participant and demonstrated their knowledge of rarer conditions such as aortic dissections which can be a "cause [of] sudden death in athletes" (Doct – 2). Participant Doct 3 had the most limited knowledge of the topic and did state how they "don't ever remember having any formal training on it" and suggesting that "training would certainly be beneficial" (Doct – 3).

Each doctor had a different level of experience with SCD. Doct – 1 had a moderate level of experience as they had a role within cardiology previously. They had never attended a screening evet but had experienced a case of SCD, indirectly, whilst working in a GP practice – "there was a student that collapsed. I don't know which marathon it was and died during finishing a half marathon in South Wales" (Doct – 1). Doct – 2 had the most experience and exposure to SCD out of the 3 doctors interviewed. Having worked for C-R-Y (Cardiac Risk in the Young) for a number of years and attending various screening events. Doct – 2 spoke of the negative impact that diagnosis can have on athletes, and also talks of finding "conditions that predispose [individuals] to SCD or we are seeing families that have lost a loved one to sudden death" (Doct – 2). Lastly, Doct – 3 had the least experience directly with SCD and did state how they had never picked up a case themselves while working they were aware of people it has affected. This participant further went on to say that the only "cases [they'd] ever come across weren't [within] sports people." (Doct – 3).

Views

Firstly, all 3 doctors believed that SCD was a significant clinical problem and believed that the risk factors should be screened for more proactively, with one participant saying – "Yes, it is a significant clinical problem." (Doct -2). However, interviewees felt this

was a complex issue, adding, it's, "difficult to answer in a yes or no fashion because from my point of view, having been witness to it, there's so many unknowns" (Doct – 2), a view shared by Doct – 1 who stated that there would have to be, "a balance of picking up [positive] cases vs. the number of people that might get either a diagnosis of uncertain significance that could cause anxiety or just the general kind of cost in the context of the NHS to screen a large population …" (Doct -1).

Cardiac screening comparisons

When asked about how SCD risk factors compare with other cardiac conditions seen in people between 18 – 45, the doctors each gave different responses. Doct – 1 said how SCD is somewhat dwarfed by much more significant diseases such as Ischemic Heart Disease (IHD), as this outnumbers SCD in the number of people affected in the same age bracket. They further explained how they felt that there isn't quite the "same crossover" (Doct – 1) in the population being screened for SCD when compared to screening for other illnesses or disease. Views on how SCD compared with other cardiac conditions varied. Doct-1 felt there were much more significant diseases such as IHD to warrant screening for SCD. Doct-3 similarly felt that screening for SCD was less important than for other conditions but because of the difficulty involved as people usually "don't have many symptoms". In contrast, Doct-2 felt that SCD screening would be more justifiable, especially in sports people, than other cardiac conditions, as exercise can act as a trigger to an event such as cardiac arrest, stating, "in the inherited heart conditions or the conditions that predispose to sudden death, exercise is an influencer" (Doct – 2).

Methods of cardiac screening

All doctors agreed that the use of an ECG was an effective method of screening for SCD risk factors. Doct – 2 expressed how they felt an ECG was "the best method of [screening] currently" (Doct – 2) for symptoms that could predispose an individual to SCD, specifically within athletes. The three participants were in agreement that the observation of family history would enhance risk factor screening, when used alongside an ECG, a "strong family history is particularly relevant" (Doct – 1). Furthermore, Doct – 1 suggested how screening methods that record over a prolonged period of time, such as Holter monitors, could be useful as they are "slightly more likely to pick up [issues/abnormalities]" (Doct – 1). Doct – 2 voiced how the inclusion of physical

examination as a means of screening is currently not needed as it "isn't particularly additive or [doesn't] increase diagnosis" (Doct – 2) when looking for potentially lethal conditions.

Incidence of SCD

Doctors' views on whether the incidence of SCD in Wales and UK was significant enough to require a national screening programme all varied. Only one of the doctors said that they thought a screening programme "would be worthwhile" (Doct – 3), whilst Doct -2 felt that "It's not because the incidence isn't great enough it's because the incidence isn't actually relevant to the justification for it" (Doct – 2). Doct – 1 agreed with this view, stating that justification had to prove it was cost – effective and would need to balance "picking up those few cases vs. the potential harms of screening a large population who for the most part will be perfectly healthy." (Doct – 1). They went on to say that a screening programme is, "perfectly possible as we do big screening programmes in the NHS for lots of things" (Doct – 1).

Who should get screened?

Participant Doct – 1 assessed the number of individuals that would have to be covered in a screening programme and the challenge this may pose, "you've got such a massive population" (Doct -1) that would have to be screened, referring to amateur and university athletes. Participants recommended screening athletes across all levels of sport. They identified that this could only be done if it was financially viable to do so, "if there was the money available" (Doct – 3). Doct – 2 believed that screening should be based on the physical output of the sport, stating how, "[screening] depends on the level of exertion" (Doct – 2). There was discussion throughout interviews on whether screening should also be implemented for those outside of sport, non-athletes, concluding that in order to do so the, "balance of spending a huge amount on screening for not a very high pick up" (Doct -1) would have to be evaluated.

The participants were asked their views on whether they would encourage their own family to get screened, Doct – 1 was against this, as their "inclination would be that I wouldn't personally and that's someone who does, you know, a degree of sports" (Doct – 1). Doct 2 and 3 shared the same views as each other, that they would only encourage their family members to get screened if they took part in sport – "not unless they were

doing some type of like extreme sports" (Doct – 2), with Doct – 3 adding how they had, in the past, had a conversation about getting screened with their son.

Awareness of SCD risk factor screening

Participants Doct 2 and 3, believed that people in Wales were aware of SCD especially because of the high-profile cases that are seen within the media although Doct – 3 did question whether "people [are] aware [SCD] can happen outside of sport." (Doct – 3). All participants agreed that social media would be the best way to raise awareness of SCD.

Facilitators of screening

Key facilitators of decisions to participate in screening were the fact that the screening method is non – invasive (unlike some other diseases such as bowel cancer, and the potential of losing a loved one to SCD: "witness of the loss of a loved one, things like that" (Doct – 2), further saying how "perceived risk" and "misunderstanding the purpose and consequences of having screening" (Doct – 2) can facilitate screening in a similar way. Finally, Doct – 3 alluded to the point that "cheaper and readily available" (Doct – 3) methods of screening, particularly an ECG, would be a facilitator of the potential implementation of a national screening programme.

Benefits of screening

In a similar way that the athletes were asked, the doctors interviewed were also asked what they thought the facilitators of implementing a national screening programme would be. All of the doctors identified that saving lives would be a key benefit of screening, with participants saying, "I think it would be worthwhile because you'd save lives" (Doct – 3) when talking in regards to implementing a screening programme, and "in terms of benefits from saving however many lives through screening" (Doct – 1). The remaining facilitators identified by the interviewed doctors were relatively subjective. Doct – 1 talked how, from a financial point of view that people who have been identified to be at risk via screening will now be able to contribute to society, whereas this would not have been possible if they had suffered from a fatal SCD event, stating how individuals "subsequent impact on society obviously by being still with us is probably quite significant" (Doct – 1).

Barriers to screening

Psychological barriers of screening

The main barrier identified by the doctors interviewed appeared to be the potential impact on an individual's mental health. Doct – 1 highlighted the problems that might result from, "the risk of harm of over diagnosis or prompting anxiety in the population you're screening … also the emotional and mental health costs of screening, causing anxiety and that side of things … misdiagnosis, overdiagnosis, false – positives, all that kind of stuff has an impact on people." (Doct – 1). Doct -2 discussed their experience and how they have witnessed the mental toll an undesirable screening result can take on someone which could potentially lead to putting others off being screened, "the struggles they go through psychologically, the battle that we have to go through to get them to reduce their exercise because they're addicted" (Doct – 2). Doct – 3 offered an alternative point of view stating how actually increasing awareness of SCD and SCD screening may in fact "cause a lot of anxiety" (Doct – 3) in people who would have previously been unaware of the implications and therefore not worried about it. A crucial barrier identified by one participant is that just because you have been able to detect someone at risk through screening there is no guarantee that it will have a positive impact on their future with the psychological issues that come into play through ceased participation in sport. This participant said, "you could destroy someone's livelihood and it may not be necessarily changing / improving their life in anyway, or preventing sudden death, so just by diagnosing a condition you can't translate that to 'this has had a positive effect on their life'" (Doct – 2).

Financial barriers to cardiac screening

All the interviewees touched on some form of financial barriers to cardiac screening, with two commenting that it would have to be proven as a cost-effective strategy of disease detection before anything could be fully implemented. Some other financial barriers towards screening included the difficulty of justifying costs on a large scale, "doing an echocardiogram on everyone, the cost benefit is not justifiable" (Doct – 2). Also, as many of the risk factors associated with SCD are hereditary there will also be a cost of future screening for close family of anyone identified to be at risk, which could place strain on services such as the NHS.

Further barriers to cardiac screening

Some other potential barriers raised in interviews included the lack of capacity to reach lower-level sports – "I'd be a bit cautious thinking how feasible it would be to sort of bring it out to more amateur running clubs and I would struggle to see a project like that reaching that kind of lower level as it were." (Doct – 1) and the fact that people might just not want to get screened. Finally, but nonetheless important, one doctor raised how the implementation of a screening programme for SCD does not meet the screening criteria set out by the UK NSC, making it more unjustifiable – "it doesn't meet the screening criteria, so we can't justify the clinical benefit or cost – benefit" (Doct – 3).

Discussion of Study 1

The overall level of knowledge and awareness of screening for SCD risk factors is low, with the exception of a small number of athletes. This could mainly be attributed to little or no education on the topic; even those who had performed at the highest level of sporting performance and had been screened before admitted their knowledge was scarce. The majority of athletes' knowledge and awareness came from either high-profile cases seen in the media or personal experience of someone they know being affected by SCD. There is a gap in evidence surrounding athletes' level of knowledge on SCD and what education they should be receiving. The findings from this study highlight the need for research into improving athletes' levels of education within the field.

When exploring athletes' perceived facilitators of a potential screening programme, the main areas identified were peace of mind, reduction in mortality due to SCD, and disease detection of other potential cardiac conditions. Evidence does suggest that screening for risk factors and SCD via the means of a diagnostic testing performed on a nationwide scale can lead to a reduction in the mortality of athletes at risk of SCD (Corrado et al., 2013; Corrado et al., 2006). These factors, although few, are important as they can help to forge a positive attitude towards screening. For example, if an individual's attitude is that their life could be saved, and their mind put at rest as a result of getting screened, then they are more likely to participate in screening.

Athletes were able to talk about the barriers towards a potential screening programme in more depth than the facilitators. As already mentioned, one key barrier was the lack of knowledge and awareness on the topic. There were financial barriers raised, which included who would take responsibility for the cost of a nationwide screening programme: the individual, or health providers such as the NHS, and, if this would be plausible. Important health barriers were raised also, suggesting that if screening leads to an individual's withdrawal from sport this could impact not only their physical, but also, mental health. Correlating with findings from the previous literature review that a clinically positive screening result could have a detrimental impact on the athlete (Pelliccia et al., 2008). However, all individuals interviewed discussed that if they were recommended to cease sports participation by a doctor, they would do so, but this would be very difficult.

Practical and perceptual barriers were also identified, which included a lack of opportunity to get screened and the fact that some people would rather not know if there was something wrong with them, respectively.

The facilitators discussed could influence a person's attitude in a positive way and the identified barriers had an adverse effect on their attitude. Nevertheless, the interviewed athletes' views and opinions on screening did vary, a small cohort of athletes did feel that screening was of a greater importance to those competing at a higher level of sporting performance. Conversely, it was identified that perhaps the priority of screening lies within the general public as there is a greater proportion taking part in physical activity, than there is at a professional level. A small number of participants highlighted that they felt the responsibility of athletes getting screened rested with their sports club.

The main influencer to getting screened was an increased awareness and knowledge on the screening progress and education on SCD risk factors, including holding events locally to encourage some of the athletes to get screened. Only a small proportion of the athletes interviewed had been screened and were therefore able to talk about their previous screening experiences. The athletes who had been screened highlighted that it was treated like a routine test that was done with their teams with little information provided about the reasons for screening.

When delving into the potential emotional impacts of screening, most athletes said that they would cease participation in sport, or physical activity if they were advised to do so by a medical professional or doctor, following screening. Despite this almost all of these athletes spoke of how difficult it would be to halt physical activity full stop. They also talked about how they would be more comfortable if they were made aware of what they could and couldn't do in regard to physical activity. Positively, a handful of athletes touched on the relief they would feel following screening either from now being aware of a risk factor, potentially pre-disposing to SCD, or the peace of mind that would arise from the fact they can be more confident they are at a lower risk of SCD. Athletes interviewed also spoke about condition management, but also a minority said how they felt they would be inclined to carry on with sports participation, if they were found to be at risk, due to the fact they had never experienced any symptoms, or indications of risk prior to being screened.

Doctors' levels of knowledge varied between each participant. This was expected to a certain degree as each participant had received training longer ago than others and they each specialised in different disciplines. This was also reciprocated when looking at their experiences, all of which differed due to different levels of exposure within a cardiology setting.

Medical participants views did all align in regard to SCD being a significant clinical issue, believing that more should be done in order for earlier detection of potential risk factors. Although they did identify issues with the potential efficiency of setting up a large-scale screening programme. The interviewed medical professionals agreed that the use of an ECG was an effective tool for disease detection, and also that this method would be enhanced by the addition of family history examination. Views did vary on the incidence and whether a screening programme would be a worthwhile implementation, with concerns also raised about how such a programme would accommodate such a large cohort of individuals. This was reinforced when looking at who should get priority to be screened, some saying that amateur sports clubs / athletes due to the enormous amounts of people that partake in physical activity at this level, and others implying that who should get screened should be determined by the physical demands of the sport being undertaken. The majority of doctors interviewed did believe

that people within the UK were aware of SCD mainly due to high profile cases that were showed throughout the media. A point was raised questioning to what extent the public were aware that SCD can occur outside of a sports setting.

Doctors described that the main facilitators of a screening programme would be the non – invasive screening techniques that are used and the relatively lost cost means of screening currently used. Saving lives was again identified as a key benefit of screening for SCD risk factors, the same way it was in athlete interviews. Conversely, the barriers identified by doctors largely revolved around the potential psychological impacts. Highlighting how stress and anxiety could be exacerbated by the risk of mis diagnosis and false readings. One of the participants questioned whether an individual's quality of life is in anyway being enhanced by risk factor identification through screening if it results in the said individual having to be withdrawn from physical activity. As there is no guarantee that their life has been saved / prolonged, and their sports participation may have formed a large part of their life. Further identified barriers included the obvious financial issues that would be associated with the implementation of a cardiac screening programme, with the cost only set to rise if further diagnostic tests are needed, such as an Echo. As well as the financial burden, doctors also raised questions about the potential difficulties of such a screening programme reach lower-level sports, and how currently a screening programme for SCD risk factors does not meet criteria set out by the UK NSC.

The interviews carried out in this study were able to provide a valuable insight into what athletes from all sporting levels, as well as doctors, currently know about SCD and the associated screening, as well as feelings towards getting screened. This study has made way for the identification of the main perceived facilitators and barriers towards screening from athletes themselves. Furthermore, it has allowed the exposure of individuals feelings towards potential cessation in sport, how awareness of the SCD needs to be raised, and importantly beginning to understand individuals' attitudes and behaviours towards getting screened. Moreover, how these attitudes can be influenced and potentially predicted. In order to explore these findings further a questionnaire was developed using the results from the prior interviews to form the second study in this research. By carrying out a definitive questionnaire, it will allow the research to reach a wider cohort of athletes across all levels of sporting performance and disciplines. This

will provide greater weight to reinforce the findings already disclosed from the prior study in order to achieve the research aims set out. As well as this, the constructed questionnaire will allow the research project to delve further into understanding athletes' knowledge and perceptions towards SCD and cardiac screening, why these attitudes have formulated, and perceived facilitators and barriers of getting screened. These will be vital factors when considering the effectiveness of a potential national screening programme.

Study 2 – Athlete Questionnaire

Introduction

The second study as part of this research was concocted of an explicit questionnaire, that was developed and designed using the main themes that were identified when completing and analysing previous interviews. The online questionnaire enabled the study to be accessible to a much larger population which meant that a greater volume of information could be accessed on specifically athletes' knowledge and awareness of SCD and risk factor screening. By developing the questionnaire using responses from interviews specific areas where there was perhaps less knowledge and understanding, more so within athletes, could be targeted, as well as important points that had been flagged during interviews with doctors.

Methods

Question development:

The key themes identified in the analysis of the interviews were used to develop a questionnaire to assess athletes' knowledge and views surrounding SCD and risk factor screening (Figure *vi* in appendix). The majority of questions required a Yes or No answer, but the questionnaire also included questions that required multiple selection answers, ranking of answers and sometimes a brief explanation was required. The design of the questionnaire was completed using the online survey platform JISC (Joint Information Systems Committee). JISC was chosen because it was simple, yet effective and professional to use, it also complied with Swansea University GDPR (General Data Protection Regulation) guidelines. During the design of the questionnaire 2 drafts were fashioned before the final version was agreed upon. The more experienced members within the research team expertly scrutinised and ensured the face validity of the questionnaire as they were highly proficient in this field. This helped maximise the reliability and optimise the opportunity for desired responses when the questionnaire was sent out online. This was important as unlike with the interviews; the questionnaire structure could not be majorly amended after some responses.

Final Questionnaire:

The final questionnaire took no longer than 10 minutes to complete and included 31 short answer questions divided into 7 different sections (Figure *vii* in appendix). These sections were as follows:

• **Introduction** – Give participants a brief description of the study and the purpose of the questionnaire. Consent was given by participants ticking a box that allowed them to continue to the remainder of the questionnaire.

• **About you** – Gathers essential background information about the participant, including age and what sport they partook in. No information was given here that could lead to the formal identification of the participant.

• **Knowledge of SCD** – Gain insight into participant's knowledge about sudden cardiac death and the associated risk screening.

• **Experience of SCD** – Explore participants experiences (if any) with SCD and what factors may therefore contribute towards the decision to get or not to get screened for SCD risk.

• **Attitude towards screening** – Delve into athletes current attitudes towards screening, potential risk of SCD, medical advice, importance of SCD risk screening in sport.

• **Pre – participation screening (PPS)** – In this section we directed the questions in such a way that would allow us to gage how it would be perceived if SCD risk factor screening was included in PPS for sports.

• **SCD screening and education** - Focus on the potential implementation of a national screening programme which would see the screening of large populations across the country. Also, if people would be interested in and what would be the most effective way for people to learn more about SCD.

Ethics:

Prior to the questionnaire being sent out to participants, it was sent to the Swansea University Ethics Committee to seek approval. Once approval had been sought, we were able begin distributing the questionnaire.

Recruitment:

To send out the questionnaire JISC created a unique link (URL) which would lead participants directly to the online questionnaire which meant it could be simply completed and returned. The questionnaire was promoted through social media, via

email, word – of – mouth and sports teams / organisations group chats. The questionnaire was directly aimed at participants who were between the ages of 18 – 45 years old, and partaking in any discipline of sport, competing at any level from amateur, semi – professional to professional. The questionnaire was available for participants to complete for a duration of 10 days, encouraging as many responses as possible within that time frame. There was no specific time, date or location for the questionnaire to be completed, as long as it was done within the 10 days it was open. It is therefore expected that participants completed the questionnaire at home via smartphone device or computer.

Data analysis:

All responses were anonymous and recorded on JISC once the participant had completed and submitted the questionnaire. Responses to the questionnaire were analysed using descriptive statistic techniques to compare responses between participants. Data was interpreted both on JISC and Microsoft Excel, where responses could be displayed clearly in tables and charts.

Athlete Questionnaire Results

106 responses from a combination of professional, semi – professional and amateur athletes were received. 8 had to be excluded due to the fact they exceeded the study ages of 45 years, resulting in 98 responses.

Respondent characteristics

The average age of the athletes who completed the questionnaire was 24.7 years old (range = 18-45, SD = ± 6.3 years). Of the 98 participants who completed the questionnaire 4 (4.1%) were professional athletes, 20 (20.4%) were semi – professional, and 74 (75.5%) were amateur athletes. The majority of the athletes trained and competed in sport or physical activity 2 to 3 times a week (24, 24.5%), and only 13 (13.3%) competed or trained over 5 times a week. The athletes competed in 14 individual different sports, with the remaining participants declaring they participated in multiple sports. The most popular sport in the study cohort was Rugby with 39 (39.8%) athletes, with some of the less common sports including Hockey and Cricket with 1 participant each (Figure *viii* in appendix). 93 (94.9%) of the 98 participants were from

the UK: UK (12), Wales (58), and England (23). 6 additional countries with 1 participant each were also identified, including USA, Wales/Bahrain, South Africa, Portugal/UK, and New Zealand (Figure *ix* in appendix). 67 (69.1%) of the athletes being male and 30 (30.9%) were female. Respondents mostly identified as White and White – British with 40 (41.2%) and 37 (38.1%) athletes, respectively. Other ethnicities reported were: British – Asian (1%), Black – White Caribbean (1%), British (6.2%), Caucasian (2.1%), Mixed British/Middle Eastern (1%), Black-White mixed (1%), White British/Irish (1%), Welsh (2.1%), White – European (2.1%), and White-Welsh (1%). (Figure *x* in appendix). 78 (80.4%) athletes reported no family history of cardiac conditions but 19 (19.6%) reported a family history, some of which included heart attacks, arrythmias and cardiac arrests.

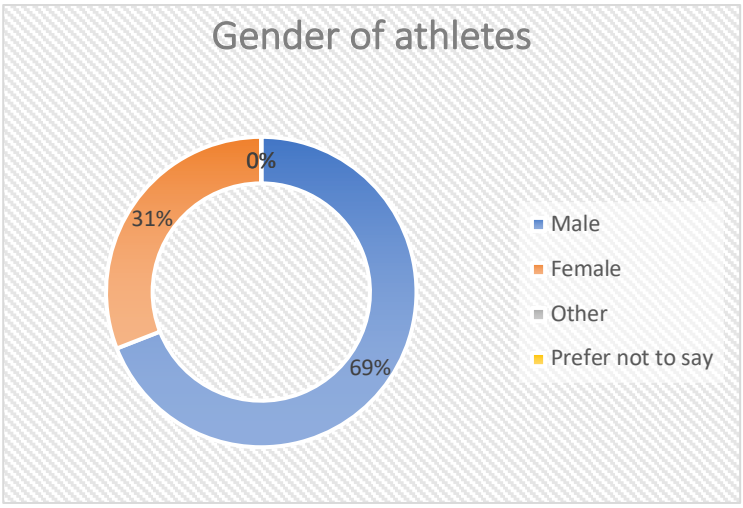

Fig 1 – The ratio of genders that completed the questionnaire.

Knowledge of SCD

The majority of respondents has heard of SCD previously (79, 80.6%) and 19 (19.4%) had not. Despite this, only 60 (61.2%) of the athletes said they were aware of what SCD is and the remainder said no. 47 (48%) of the respondents had previously heard of SCD risk screening, whilst 51 (52%) had not. 88 (96.7%) athletes had heard of the British Heart Foundation (BHF), and 21 had heard of Welsh Hearts whereas only 14 (15.4%) athletes had heard of C-R-Y (Cardiac Risk in the Young).

Experience of SCD

57 (59.4%) participants had heard of a case of SCD and the remaining 39 (40.6%) had not previously heard of a case before. Most were aware of cases in famous athletes (36), followed by family and amateur athletes with 6 and 5 responses, respectively. 15 (15.5%) respondents had been screened before, and 82 (84.5%) had never previously been screened for SCD risk factors. Only 1 (1%) participant had turned down the opportunity to be screened. 'Cost / funding' was most likely to be a barrier to respondents getting screening, and athletes 'Preferring not to know if there was an issue' was least likely to prevent them from getting screened. The fact that screening could be potentially 'Life – saving' was most likely to encourage the participants to get screened and 'Peace of mind' was the least likely to influence their decision to get screened.

Attitudes towards screening

76 (77.6%) respondents reported they would stop sports participation if they were recommended to by a doctor following a positive screening result, answering yes and the remaining 22 (22.4%) saying that they wouldn't stop. The most common reasons noted that would influence the athlete's decision included the severity of the condition (16), that the doctor is the expert (9) and the positive impact exercise had on their mental health (7). Participants felt screening was most important in 'All levels of sport' and least important in just 'Amateur' levels of sporting activity. 77 athletes ranked that screening was most important across 'All types of sport' and 30 ranked it as least important in 'Team sports'. 85 (87.6%) respondents believed that there was 'No difference' in whether cardiac screening was more important in males or females, whereas 12 (12.4%) believed it to be of greater importance to males compared to females. The majority (36, 38.3%) of respondents felt cardiac screening was most important in the 21 -30 age range and least important in 31 – 45 years olds and people under 12 years old with 13 (13.8%) and 0 responses, respectively.

Is screening more important at different levels of sport…	1 = Most important	2	3	4 = Least important
Professional		2		
Semi - professional			3	
Amateur				4
All levels of sport	1			

Fig 2 - How athletes ranked which level of sport screening was most important within.

Pre – participation screening (PPS)

90 (91.8%) respondents said pre-participation screening would not deter them from taking up sport, whereas 8 (8.2%) said it would act as a deterrent for them. When asked why it would deter them, 55 identified the main reason as 'Potential career implications' (17 said 'Other' with 3 identifying 'Inconvenience', and the remaining 14 saying 'It wouldn't' deter them). When participants were asked what may mitigate or change their concerns, the most common answers were that the screening was carried out by professionals (18), there was better education provided on the topic (15), and the screening was organised by the sports club or teams (13). Finally, participants believed that the sporting level that required pre-participation screening the most was professionals, followed by semi – professionals then amateur athletes.

SCD screening and education

Most respondents felt it should be the individual's decision if they get screened (43, 44.3%), and 36 (37.1%) felt there should be a mandatory programme for all those who take part in competitive sport, whilst only 1 (1%) felt that there was not a need for a mandatory screening programme in the UK. 70 (71.4%) athletes believed that their sport's national governing body (NGBs) should provide the opportunity for screening to their athletes, while 48 (49%) and 44 (44.9%) believed that it should be up to 'Health boards' and 'Sports clubs', respectively. Five (5.1%) athletes believed it should be up to the individual to organise getting screened. When asked what the best method to educate people about SCD and the associated risk factor screening would be, the joint most effective methods identified were organised talks and social media, were selected, whereas hand handouts / leaflets were seen as the least effective way to educate people.

91 (93.8%) participants were interested in learning more about SCD and the associated risk factor screening and only 6 (6.2%) were not.

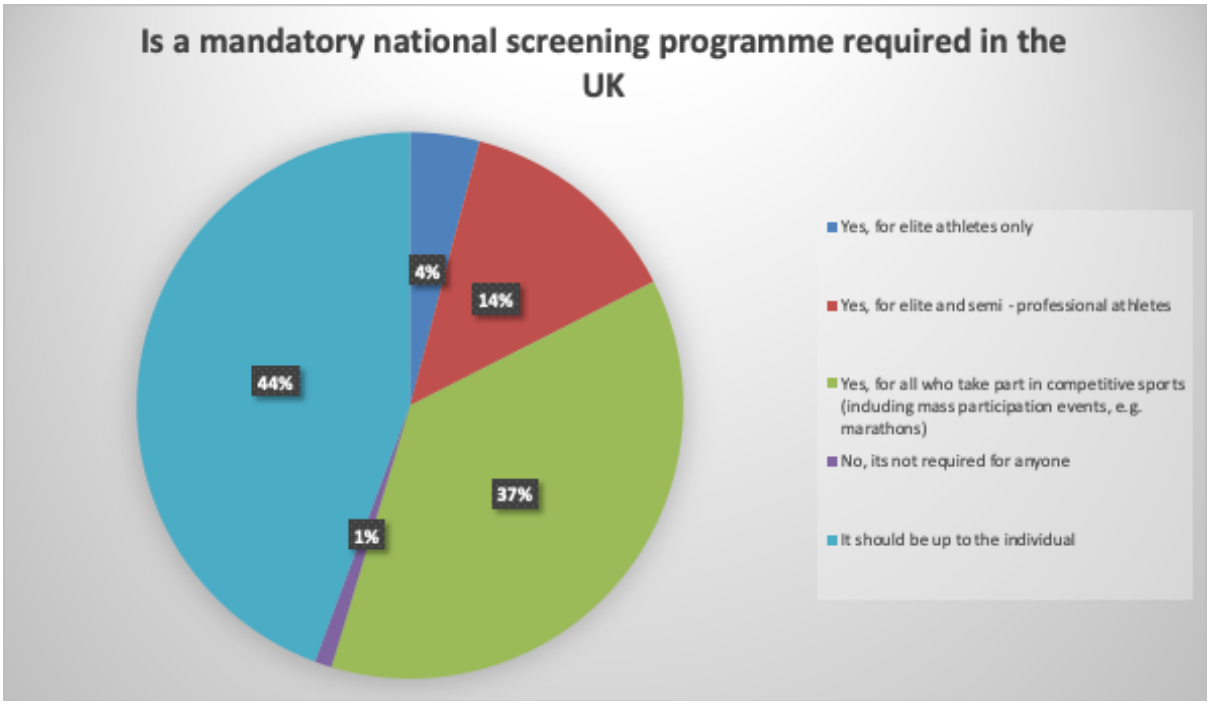

Fig 3 – Athletes' views on whether a mandatory nationwide screening programme is required in the UK.

Discussion of Study 2

Data retrieved from the questionnaire showed that the majority of athletes that took part had previously heard of SCD in some capacity, but out of these athletes not all of them could say what it actually was. This potentially points towards a lack of education surrounding the topic and could also inform an individual's attitude towards getting screened, if they don't know what SCD actually is then would they be motivated to get screened for potential risk factors. To reinforce this point further, even fewer athletes said they had ever heard of risk factor screening, and some not at all, and it must be considered the impact this will have on their thoughts towards getting screened. Here it becomes clearer how these results can be integrated into a behavioural model, such as the Theory of Planned Behaviour, and used to possibly predict and understand individuals' attitudes leading up to the execution of a behaviour, in this case cardiac screening.

Most participants said they had heard of a case of SCD in the past it became clear that most of these cases were high profile cases that had occurred and been covered by the media. Although it may not seem it at first glance this can be an influential pull factor towards people getting screened as it makes them more aware of the potential risks associated with SCD, and subsequently encourage people to learn more about SCD and associated screening. The more people know and understand, usually, will have a positive impact on their thinking towards getting screened, thus increasing the likelihood of doing so. Less than a quarter of the athletes who responded had been screened before, demonstrating the lack of coverage of current screening programmes. The most influential factor in an individual's decision to get screened was the fact that it could be potentially lifesaving, which would, again, be a strong pull factor towards getting screened. Conversely, the financial barriers, cost, and funding, were identified as the main reasons why an individual would not get screened. The financial barriers here slot efficiently within the perceived control section of the Theory of Planned behaviour, if a person believes that the cost of screening is too great, and outweighs the potential of any risk identification, then they are increasingly unlikely to get screened.

As seen in the interviews carried out prior, the lion's share of the study cohort who completed the questionnaire demonstrated that they would cease participation in sporting activity if recommended to do so by a doctor. Although, a small proportion did say that they would continue participation in sports, accepting the potential risks. Athletes believed that cardiac risk factor screening was of greatest importance across all levels of sports rather than just one, and that it was least important in just amateur athletes. However, there are important considerations to be made at this finding. No athlete's life is more important than another's, no matter what level of sport they compete at. However, when considering the potential impact on a professional athlete having to cease participation in sport, in essence their career, the financial toll this could have on their livelihood is likely to be devastating. When compared to amateur athletes it is unlikely that the financial burden of stopping sports participation would be as detrimental. When looking at the emotional and health implications of cessation in sports there is little way of telling, without further research, which sporting cohort would be impacted greatest. Cardiac screening was also thought to be just as important throughout all sports rather than just team or individual sports. The majority of athletes believed that there was no difference as to whether screening was more important in

males or females, but a small minority felt that screening was more important in males. Interestingly, SCD is found to be more frequent in male athletes rather than female athletes (Corrado et al., 1998), although this could be down to a larger number of males competing in sport compared to females rather than anything solely cardiac related. Athletes believed that screening would be most beneficial for athletes in the 21-30 years old age range. This is most likely down to the fact that most athletes in this age bracket are competing at their highest level of sports. This is also the most common age for professional and semi – professional athletes to be competing, although vast amounts of amateur athletes take part in regular sport outside of this age range.

Almost, all the respondents said that preparticipation screening would not act as a deterrent for taking up, participating in sport. This could be an influential factor when considering the implementation of a national screening programme as people are still going to take up sport should they be required to be screened. This was able to show that, if athletes did, have any concerns, these could be mitigated by screening carried out professionally, clearer education provided, and screening organised by sports team or club.

When inquiring about athletes' thoughts on screening, the findings exhibited how respondents felt that it should remain the athlete's decision as to whether they get screened. An important influencer towards an individual getting screened is that they are in control of the situation and can make decisions about when and where to get screened. Some athletes did believe that screening should be mandatory for all those who participate in competitive sport. With only a minority believing that it was an individual's responsibility to arrange to be screened, almost all the athletes felt that the responsibility sat with either sporting NGB's or health boards and individual sports clubs. This study was able to highlight the most effective method of raising awareness and increasing education of SCD and the associated risk factor screening, which was identified as organised talks and social media. Finally, almost all of the athletes who responded to the questionnaire would be interested in learning more about SCD and the risk factor screening in the future.

Discussion of Research

Aims and key findings

The two aims of this study were to identify the barriers to, and facilitators of, implementing a screening programme for SCD in athletes at different levels of competition i.e., i) amateur athletes, ii) semi – professional athletes, iii) professional athletes, and to explore the knowledge, experiences and opinions of medical professionals and athletes with regard to SCD and SCD risk factor screening via the implementation of a nationwide screening programme. The main barriers towards the implementation of a national screening programme were a substantial lack of knowledge and training on the topic of SCD and SCD risk factor screening, which was evident in both athletes and doctors, but more so in athletes. Secondly, the negative implications that screening could have on an individual's mental health in a variety of different ways was also a perceived barrier. This could result from being withdrawn from sport due to a screening result or receiving an inaccurate screening result (false-negative or false – positive). Finally, a significant barrier was the cost both on an individual and organisational level, of introducing a screening programme, as cited by athletes and doctors. Conversely, the main facilitators that were identified in this study included the peace of mind that would be provided to both the athlete and their family in the event of a clear screening result and the lives that would be saved as a result of screening, irrespective of the absolute number. Lastly, athletes' perspectives clearly demonstrated that cardiac risk factor screening would not deter people from taking up sport.

Awareness levels of SCD and the associated screening

The evident lack of awareness within the athlete cohort of this study, within both interviews and questionnaire responses, was largely attributable to little education and awareness provided on the risks of SCD provided by sports clubs and sporting governing bodies. It could be argued that these organisations have a duty of care to their athletes to inform them about the risks of SCD and make them aware of relevant screening. This precedent has been established in rugby union where players are consistently made aware of the symptoms and impacts of concussions and any implications this can have. In the case of athletes, this diminished level of awareness of SCD means there is an increasingly unlikely chance of them attending screening or

investigating screening simply due to the fact they only know so little about it. These results agreed with findings previously published regarding screening for cervical cancer which suggested that low levels of information on the programme were associated with women not participating in screening, further speculating how an increase in educational information may encourage women's participation in screening (Fylan, 1998).

From the perspective of the doctors that were interviewed as part of this study, there also appeared to be limited levels of knowledge on SCD, although one doctor did admit that they felt the training received in medical school on this element of cardiovascular disease was justified in comparison to the incidence of SCD. Results from this investigation agreed with findings from Badir et al. (2014) which identified that within Turkish nursing students, the overall level of knowledge was high but there were gaps in certain areas. It is understood that doctors will have differing levels of knowledge on specific areas depending on their speciality of medical practice, and those involved with cardiology will understand and know more about the disease. Nonetheless, it is vitally important that general doctors and physicians receive adequate volumes of training on diseases such as SCD in order to maximise early disease detection, in support of findings from Papadakis et al. (2009). When interviews were carried out with doctors, they all believed SCD to be a serious clinical issue, something that was also agreed by the UK NSC in their review (Couper et al., 2019). Furthermore, we identified that on the topic of the best means of screening, the doctors interviewed as part of our study though that the use of a 12 – lead ECG, was an effective tool for the detection of SCD risk factors (usually alongside family history), but conversely a study by Maron et al. (2015), questioned the controversial use of an ECG compared to family history and physical examination assessments, specifically referring to false negatives and false positives as a cause for concern alongside cost and reliability (Maron et al., 2015). This discrepancy in findings is likely due to the fact that this research by Maron et al. (2015) had a greater focus on the eligibility and disqualification of competitive athletes as a result of screening rather than identifying the facilitators and barriers of a screening programme.

To be critical of the responses given by athletes in this section, it could be argued is there any requirement to have a greater knowledge and awareness of screening for SCD at this point in time if it is not currently supported by the UK NSC. On the other hand, the lack of awareness and/or training within doctors could stem from SCD not being considered a serious clinical issue and therefore not as much time needs to be focussed into teaching it.

Screening as a deterrent

In this study 91.8% of athletes said that pre – participation screening (PPS) would not deter them from sports participation, we then explored the reasons behind why people might be deterred from sports participation, with 62.2% of athletes attributing this decision to potential future career implications (Figure *xi* in appendix). This was an important finding because, although the study cohort was relatively small, it demonstrated that if a pre – participation screening programme for the risk factors of SCD was introduced, mandatory or not, the majority of athletes studied would be willing to go through the process to compete in sport replicating the results found in this study on a larger scale. This finding was in agreement with conclusions drawn by Sharma et al. (2013), who deemed that PPS was no deterrent to participation in competitive sports. Furthermore, we also asked athletes what could be done to mitigate any concerns they may have about current SCD risk factor screening and could therefore act as a deterrent. The majority of athletes who responded to this question said their concerns would be mitigated if the screening was carried out by a professional body (31%) and if they had better education on the topic of SCD (25.9%) (Figure *xii* in appendix). Despite the points made by athletes surrounding screening not being a deterrent for sports participation, it would be hard to definitively say exactly if it would or wouldn't be a deterrent until it is executed on a widespread, perhaps nationwide scale.

Lifesaving

A key facilitator of screening for predisposing factors of SCD identified from data collected during the study, is the fact that it can be potentially lifesaving, which is a relatively self-explanatory facilitator in itself. Findings in the study demonstrated how athletes felt that screening being 'potentially lifesaving' was an influential facilitator to

getting screened. Corrado et al. (2012) further considered pre – participation screening for SCD to be a life – saving strategy for disease detection (Corrado et al., 2012). Maron (2005) also conceded screening via ECG is feasible and potentially lifesaving (Maron 2005). The fact that screening can be potentially lifesaving means that there are a number of lives will be saved as a result of disease detection via screening, especially in young athletes where exercise if often a trigger to cardiac events. Despite there being no solid means of proving that an individual's life has been saved, looking at the mortality rates of predisposing conditions will more often than not, suggest that this is likely the case and in instances justify the decision for disqualification from sporting activity to minimise the risk of fatality. Although any number of lives saved as a result of screening is a considerable amount, it must be balanced alongside the potential, resultant, health issues that could arise from cessation in sporting activity.

Psychological impacts

A main barrier identified throughout the study was the impact of screening on an individual's mental health. As previously discussed, a person's mental health could be impacted detrimentally through a number of different ways associated with screening, but study participants felt this was most likely to occur as a result of being disqualified from sports participation, concurring with Magavern et al. (2017). Removing an athlete from an environment which they have presumably been in for most of their life, where they have built up social relationships and developed their own athletic identity, is likely to result in deterioration of their mental health, in line with findings of I. M. Asif al. (2014). Conversely, Collins et al. (2011) concluded that there was no evidence that undergoing screening has an adverse emotional impact, within 4 weeks of being screened (Collins et al., 2011). It is vital to realise that psychological impacts should not solely be seen as an excuse against screening (I. Asif et al., 2014) especially considering how taking part in sport, even at a recreational level can positively impact mental well – being (Steptoe & Butler, 1996).

Financial implications

A further barrier identified was that of the financial costs involved with screening which can be viewed from different perspectives. First, the cost – effectiveness of the screening programme and the cost to the individual getting screening or organisation

providing the screening. Previous research has shown that if a screening programme is cost – effective it will begin to be implemented, as was seen when the UK NSC set up two pilot programmes for colorectal cancer screening due to the fact that it was deemed to be a cost-effective strategy of disease detection (Atkin, 1999). A nationwide cardiac screening programme would have to be cost – effective to make it justifiable in the UK. This means that the costs of the diagnostic tests, consultations and any follow-up tests would have to be outweighed by the costs of identifying risk factors of cardiac disease. Dhutia et al. (2016) stated how ECG screening is expensive when considering the number of young athletes that would require screening and the low incidence rate within that population (Dhutia et al., 2016). Sharma et al. (2013) pointed out how performing in a cost-effective manner was one of the main goals of any screening programme (Sharma et al., 2013). This research showed that the cost of screening would be most likely to influence a person's decision not to be screened, demonstrating that if the cost was too high, they would not get screened. This, therefore, emphasises that if screening is to become more widespread and have a greater uptake throughout the nation it must be affordable. If there was no nationwide programme individuals and sport teams would be forced to finance screening themselves, some of whom may struggle, especially when considering consultation fees, follow – up treatment, and future screening that is required in some cases. This has also been stated in previous literature that has looked into the costs of a screening programme for SCD, specifically in this case a study by Sharma et al. (2013) which it was identified that people already pay significant costs for participation in sports and a little bit extra for the cost of screening would not make it that much more expensive. In contradiction to this argument presented by Sharma et al. (2013), it could be argued that if people are already paying considerable financial costs to take part in sports, they might not be willing to pay extra for something that is not guaranteed to be effective. Whereas, if the methods used for disease detection were proven as more effective and greater evidence was gathered to show that the screening was a solid lifesaving tool would people still be opposed to paying for the service?

If a national screening programme was introduced in the UK the financial strain would be borne by the NHS, when looking at costs of resources and staff needed to perform the relevant tests. In the case that a screening programme was introduced and made mandatory then people would be required to be screened. On the other hand, this could also be seen as a facilitator of a large-scale screening programme which would be state

sponsored or run through the NHS, because if there was a reduced cost to individuals, athletes, and sports clubs they would be encouraged to use it. This said, it is important to realise the financial implications that withdrawing athletes from sport can have as well, more so semi-professional and professional athletes whose motives for sports participation are usually increasingly financially influenced. As identified in earlier interviews with athletes for some athletes participating in sport is their livelihood and provides them with a source of income. Taking this away suddenly would lead to serious financial difficulties faced by having no or a limited source of income as a result.

Theory of planned behaviour

In line with the aims of this research, findings can be clearly integrated into Ajzens 1991 Theory of planned behaviour, in order to understand influences towards getting or not getting screened. Doing this specifically using data from the research conducted surrounding SCD and the associated risk factor screening can confidently be used to try and predict individuals' intentions towards a behaviour.

Intention: The intention in this instance is to get screened for any potential risks of SCD.

Attitude: The individual's attitude is determined by their pre – existing feelings towards risk factor screening for SCD. An individual's attitude here will likely be influencing their evaluation of the behaviour, in this case getting screened. A poor level of knowledge and education within athlete populations on the topic of SCD and screening has become evident throughout this research. Findings have clearly depicted how, even if athletes had heard of SCD before, they didn't know what it was, with even less knowing that screening for the risk factors of SCD existed. Utilising the principles at play in Ajzens theory, this is likely to aid the construction of a negative attitude towards cardiac screening within an individual. As a result, this negatively formulated attitude towards screening is increasingly likely to deter the individual from getting screened. Conversely, this can work in the opposite way as well. Throughout the research it was consistent that the main benefit of cardiac screening identified by athletes was the fact that it could be potentially lifesaving. If an individual believes that

screening for cardiac risk factors could save their life this is going to, naturally, promote positive association towards screening, leading to the individual being more likely to get screened in line with Ajzens theory. In addition, an individual may weigh up the possible outcomes of the screening here, for example, potentially having forfeit sports participation as a result of risk factor identification, sports which may form a large part of their identity and livelihood. Although it was identified that almost all athletes would stop sports if they were advised too, it wouldn't come without psychological health, physical health, and in some cases, financial implications. Across the studies, increased awareness was the main influencer in the decision to get screened.

Subjective norms: Based on what people around the individual, and who they interact with, think about the behaviour. People's experiences with the behaviour will influence what they say about it to the next person. In relation to this research, the majority of the athlete cohort across both studies had not been screened before. Furthermore, the athletes who had been screened said that despite getting screened there had been no real information provided as to why they were there or what it was for, leaving them with a negative experience of the process. As a result of these adverse experiences when they interact with people about getting screened in a negative way and influence their attitude towards SCD screening in a negative way. Of the athletes who had heard of cases of SCD, the vast amount of these were high profile cases that had been shown throughout the media. As discussed earlier in the paper, this can have a constructive influence on raising awareness of screening for the risk factor of SCD, and how it could be a potentially lifesaving act thus leading to positive affinity towards the intention of getting screened. A positive result could pass on this negative feeling towards the behaviour in society. Conversely, Asif et al. (2014) described how athletes that had received a positive screening result would still recommend screening to other athletes, within the cohort they examined.

Perceived behavioural control: This is where factors such as resources and opportunity can influence an individual's decision towards a behaviour. Therefore, suggesting that a lack of opportunity to get cardiac screened would mean an individual is less likely to execute the behaviour, this was replicated in this study when athletes described how a lack of opportunity either within their sport or sports club to get screened had been a factor in their behavioural outcome. Athletes across both studies spoke about where the

responsibility to get screened lie. Some believed it was up to the individual whereas others believed it rested with the sports NGB's, health boards, or sports clubs themselves. If the responsibility to get screened is with the individual this leaves them in control of their decisions and as a result become more comfortable with the process having a positive influence on their attitude. Moreover, if screening was provided by the aforementioned authorities and sports clubs, this potentially increases practicality for an individual to get screened and an effective use of the resources at disposal. An individual is more likely to attend a screening event if it is held at a location close to them e.g., sports club they are affiliated to or local leisure centre. The cost of screening would have to be seen as a worthwhile expenditure, as athletes identified this as one of the main barriers towards getting screened, if the screening is perceived as expensive for what it actually provides then people are less likely to execute the behaviour. This could be combatting by screening being part or fully funded by sports clubs or NGB's as an incentive for athletes and individuals to get screened.

Novel findings of this study

The novelty of this study's findings revolved around the fact that athletes' perceptions were obtained on SCD and risk factor screening for SCD, this type of study has rarely been explored. Although 80.6% of athletes interviewed declared that they knew SCD existed, only 61.2% said they actually knew what SCD was, although their understanding could not be verified in this study. In this study we learned that the majority of athletes interviewed had never been screened before (85%). Applying the implications of my study on a greater scale would imply that the majority of competitive athletes have not been screened before. It was identified in this study that the fact that screening could be potentially lifesaving was most likely to encourage athletes to get screened, while the cost of screening was most likely to influence their decision not to get screened. This study has allowed us to understand how athletes would feel about having to withdraw from sport following a doctor's recommendation, with results showing how 77.6% said they would stop. Moreover, data collected during this study demonstrated that the majority of athletes and doctors felt that screening should not be made mandatory and there is currently little justification for a national screening programme. It was clear from the data collected that athlete's feel the best means to educate people on the topic of SCD is through organised talks and social

media. Despite the incidence of SCD being greater in males than females (Dhutia & Maclachlan, 2018), most of the athletes in this study believed that screening was not more important in one gender over the other. Similarly, whilst athletes felt that screening was most important for professional athletes, they felt it was equally important across different sports.

Whilst there is a large body of literature regarding the causes and incidence of SCD there remains little understanding on what athletes' current perceptions are towards SCD and the associated risk factor screening. This study offers a unique insight into what athletes' knowledge, experience, opinions, and perceptions of SCD and SCD risk factor screening, as well as that of doctors. This can help to identify areas that need to be targeted and addressed if a successful and effective screening programme was to be put in place or determine if one is needed.

Practical implications

There are a number of practical implications of these findings. First, if there was a screening programme put in place there would have to be psychological support offered to those who get screened, especially those who have an unfavourable screening result as the potential to be withdrawn from sport and the knowledge of suffering from a cardiac condition preventing participation could have a detrimental impact on a person's mental health. Second, justifying the cost of screening, at either an individual level or an organisational level, is challenging. Third, athletes from all levels need to be provided with a greater degree of knowledge or education on the topic of SCD prior to screening, to make sure the risks of SCD and rationale for screening are fully understood. This research showed that athletes believed the best means to educated people on SCD would be through social media and in person talks. Finally, if a screening programme were to be implemented in the UK it should be made accessible to athletes at all levels of sports, not just professional or semi – professional athletes.

Future research

Based on the findings from this study a number of future avenues can be identified. First, more research is needed that focuses on doctors' and physicians', perceptions and feelings towards SCD and an SCD screening programme. Further research which

explores the potential cost – effectiveness of a large-scale screening programme would provide a worthwhile insight into what might need to be done to make sure it is a viable investment. Finally, more research and understanding is needed of how athletes' mental health could be impacted in any way as a result of screening, including ways to limit these detrimental impacts.

Limitations

As with all studies there are limitations of this research. First, only a small sample of doctors interviewed, even for a qualitative study. This was mainly due to drop out which was not unexpected given the pressures the medical profession faced at the time of research, occurring during a global pandemic. The final limitation was to do with the data collection itself and the unavoidable presence of potential bias due to language used throughout interviews. This aimed to be combatted by focusing on the reflexivity and trustworthiness of the study.

Conclusion

In summary, this study has gained insight into athletes' and doctors' views and thoughts towards SCD and SCD risk factor screening as well as identifying the main barriers to, and facilitators of, a nationwide screening programme. The main barriers that are facing the implementation of a screening programme currently include a lack of knowledge on the topic in athletes. This stems from little awareness or education provided to athletes, in some cases even at screening events, on the risks of SCD and the role of SCD risk factor screening. Barriers were also the detrimental impacts that screening, repeated screening and screening results could have on an individual's mental health; these impacts are likely to be more extreme if the individual is disqualified or withdrawn from participation in sports. Finally, it was identified that the financial costs of a large scales screening programme would act as a barrier towards its implementation, regardless of whether the individual or organisations were responsible for the costs.

The main facilitators of a national screening programme include the fact that screening could be potentially lifesaving to some individuals, in the case where a lethal risk factor was identified and therefore the risk of SCD was decreased. Screening athletes would provide peace of mind to not only athletes but also their family, as many risk factors are hereditary, meaning relatives can be screened, further reducing the potential risk of SCD. The final influential facilitator we identified was that overall, screening for SCD risk factors would not act as a deterrent for people participating in sport, which is important when considering the health benefits that physical activity provides both physically and mentally. From these findings we can recommend that the aforementioned barriers be primarily targeted if and when looking to implement a successful, large scale screening programme. The development of such a programme should strive to ensure the benefits outweigh the negatives.

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Appendix

Screening result	True disease classification of apparently well population	
	Diseased persons	Persons without disease
Positive	With disease and with positive test (true positives)	Without disease but with positive test (false positives)
Negative	With disease but with negative test (false negatives)	Without disease and with negative test (true negatives)
Total	Total unknown cases of disease	Total persons without disease

$$\text{Sensitivity}^a = \frac{\text{Diseased persons with positive test}}{\text{All persons in population with disease}}$$

$$\text{Specificity}^a = \frac{\text{Non-diseased persons with negative test}}{\text{All persons in population without disease}}$$

[a] These values are often expressed as percentages.
[b] Adapted, by permission, from Remein & Wilkerson.[15]

Figure i - The efficiency of a screening test (Wilson & Jungner, 1968). Example not specific to cardiac screening but same prinicples can be applied.

Total population	Anaemic patients	Screening level							
		10 g haemo-globin/100 ml blood				12 g haemo-globin/100 ml blood			
		Positive		Negative		Positive		Negative	
100	20	True	False	True	False	True	False	True	False
		15	2	78	5	19	10	70	1
Sensitivity		$\frac{15}{20}\times 100=75\%$				$\frac{19}{20}\times 100=95\%$			
Specificity		$\frac{78}{80}\times 100=98\%$				$\frac{70}{80}\times 100=88\%$			

Figure ii - Effect of sensitivity and specificity of varying screening level of haemoglobin in detecting anaemia (Wilson & Jungner, 1968). Example not specific to cardiac screening but same principles can be applied.

Interview structure for athletes: First draft

Interview structure
(Athletes)

Athlete name/ID:

Name of interviewer:

1. Are you aware of what cardiac screening is?

2. What are your current views about cardiac screening for athletes and general public?
   - *Do you believe it's a good or bad thing?*
   - *Should it be mandatory in anyway?*

3. What would encourage a person such as yourself to be screened, whether you have or have not been screened in the past?
   - *If it was held at your club / organisation?*
   - *Cost?*
   - *Had greater knowledge about the topic?*
   - *Do you know any people who have been screened for a cardiac condition?*

4. The reason we try to screen is to detect symptoms, that if undetected and/or untreated, could ultimately lead to sudden cardiac death (SCD). Have you heard of or are you aware of SCD and what it is?
   - *Can relate to any personal experience.*
   - *Do they know anyone it has affected?*

5. Have you previously been cardiac screened before?
   Yes (Go to 5.1)
   No (Go to 5.2)
   5.1 – Why did you get screened? *Location, Private healthcare etc.*
   5.2 – Why have you decided not to be screened? *Time, unaware, money etc.*

6. In your opinion, what would you consider the main benefits of screening and being able to identify symptoms of SCD?
   - *Save life*
   - *Peace of mind*

7. In contrast what are the main negatives, in your opinion, towards cardiac screening?
   - *Consider: Physical, psychological and ethical issues that could arise here?*

8. If say you were screened and it turned out you had a condition such as hypertrophic cardiomyopathy (HCM), which has little to no symptoms and only detectable via screening, you otherwise wouldn't have known about, how would you feel?
   - *Scared / worried*

- Not bothered and carry on with what you have been doing
- Relieved that the issue has been identified and can now be managed accordingly

9. How would you feel if you were told by a doctor that you could no longer take part in sport anymore, with immediate effect?
   - Would you take the advice on board and listen? Does someone have the right to tell you to stop?
   - Would you want to know?
   - Seek continued advice on management.

10. Do you ever think that there could be a condition that could lead to SCD within your family?
    - Does your family have any history of cardiac problems?
    - When do you think about this (sport, work, everyday life) and who do you think about it affecting the most?
    -Do you worry about it?

11. What age do you believe is most beneficial to be screened? And Why?
    - Young or old?

12. Do you think cardiac screening is more important in some sports than others?
    - Which sports?
    - Why?

Figure iii – This shows the original interview structure that was designed for use when interviewing athletes, before any alterations were made.

Interview structure for athletes: Final draft

Interview structure
(Athletes)

Athlete name/ID:

Name of interviewer:

Title of study: Barriers and facilitators to introducing a screening programme for sudden cardiac death in various sporting populations.

Aim: To scope the barriers to, and facilitators of, implementing a screening programme for SCD in athletes / physically active people.

Introduction of topic:
As part of my study for my postgraduate degree I am looking to identify what people, more specifically athletes, know about sudden cardiac death and also about screening for such a condition. One of the main purposes of this study is to gain knowledge and information about cardiac health screening throughout the country, looking at athletes in amateur, semi-professional and professional environments. From carrying out these interviews I will aim to develop a questionnaire to then be able to distribute to a wider population of athletes. From this we aim to gain an insight into the facilitators and barriers of cardiac screening in Wales and the UK but also how these factors vary between different sporting levels. The reason you have been asked to take part in this study is because you are within the required age bracket and also you are an athlete who competes in sport at either an amateur, semi pro or professional level.
We greatly appreciate your time for this interview and would like to remind you that all interviews will be anonymous and also that you are free to withdraw from this process at any point should you wish.

1. Are you aware of what cardiac screening is?

2. The UK government, via the UKNSC and the European society of cardiology do not currently support screening the general public for SCD, but do support its use for athletes, what are your current views about cardiac screening for athletes and general public?
   - *Do you believe it's a good or bad thing?*
   - *Should it be mandatory?*

3. What would encourage a person such as yourself to be screened, whether you have or have not been screened in the past?
   - *If it was held at your club / organisation?*
   - *If it was offered at no or little Cost?*
   - *Had greater knowledge about the topic?*
   - *Do you know any people who have been screened for a cardiac condition?*

4. The reason we try to screen is to detect symptoms, that if undetected and/or untreated, could ultimately lead to sudden cardiac death (SCD). Have you heard of or are you

aware of SCD and what it is?
- *Can relate to any personal experience.*
- *Do they know anyone it has affected?*

5. The UK NSC, in a recent review of cardiac screening, stated that the incidence of SCD was between 1 and 2 per 100,000-person years. It should be stated that the exact incidence in the general population of the UK is uncertain. Do you believe this incidence is significant enough to need a screening programme or do you think the incidence needs to be higher in order to set up a nationwide screening programme? For a comparison around 1 in 20 people will develop bowel cancer in their lifetime in the UK, with up to 16,000 people dying annually.

6. Have you previously been cardiac screened before?
   Yes (Go to 5.1)
   No (Go to 5.2)
   6.1 – Why did you get screened? *Location, Private healthcare etc. Who encouraged you to be screened?*
   6.2 – Why have you decided not to be screened? *Time, unaware, money etc.*

7. In your opinion, what would you consider the main benefits of screening and being able to identify symptoms of SCD?
   - *Save life*
   - *Peace of mind*

8. In contrast what are the main negatives, in your opinion, towards cardiac screening?
   - *Consider: Physical, psychological and ethical issues that could arise here?*

9. If say you were screened and it turned out you had a condition such as hypertrophic cardiomyopathy (HCM), which has little to no symptoms and only detectable via screening, you otherwise wouldn't have known about, how would you feel?
   - *Scared / worried*
   - *Not bothered and carry on with what you have been doing*
   - *Relieved that the issue has been identified and can now be managed accordingly*

10. How would you feel if you were told by a doctor that you could no longer take part in sport anymore, with immediate effect?
    - *Would you take the advice on board and listen? Does someone have the right to tell you to stop?*
    - *Would you want to know?*
    - *Seek continued advice on management.*

11. Do you ever think that there could be a condition that could lead to SCD within your family?
   - *Does your family have any history of cardiac problems?*
   - *When do you think about this (sport, work, everyday life) and who do you think about it affecting the most?*
   -*Do you worry about it?*

12. What age do you believe is most beneficial to be screened? Do you think your views on screening have changed from when you were this age to now?
    12.1 – Do you believe that your parents would have agreed to you being screened or

not?
- *What would you do if it was your own child?*

13. Do you think cardiac screening is more important in some sports than others?
    - *Which sports?*
    - *Why?*

14. Would you be more inclined to learn more about SCD and screening after this interview or potentially even consider getting screened?
    14.1 – What do you feel would be the best means to inform people like yourself, would you rather someone coming to talk to you about it or maybe just a website?

Figure iv – This is the final interview structure used for interviews with athletes with amendments following expert scrutiny from the research team. Changes made included the addition of questions, formatting of questions and the addition of an introductory paragraph to be read to participants prior to interviews.

Interview structure for doctors and medical professionals: Final draft

Interview Structure
(Medical Professionals)

Name/ID:

Name of interviewer:

Title of study: A research study exploring the facilitators and barriers of introducing a screening programme for sudden cardiac death, looking at different sporting populations.

Aim: To scope the barriers to, and facilitators of, implementing a screening programme for SCD in athletes and physically active people as well as sports staff and medical professionals.

Introduction to topic:
As part of my study for my postgraduate degree I am looking to identify what people, more specifically athletes and medical professionals, know about sudden cardiac death and also about screening for this condition. One of the main purposes of this study is to gain knowledge and information about cardiac health screening throughout the country, looking at athletes in amateur, semi-professional and professional environments. From carrying out these interviews I will aim to develop a questionnaire to then be able to distribute to a wider population of athletes. From this we aim to gain an insight into the facilitators and barriers of cardiac screening in Wales and the UK and how these factors vary between different sporting levels.
We greatly appreciate your time for this interview and would like to remind you that all interviews will be anonymous and also that you are free to withdraw from this process at any point should you wish.
Interview:

1. Do you believe SCD is a significant clinical problem, and do you think that we need to be screening for the associated risk factors more proactively?

2. How does SCD risk factors compare with other cardiac conditions that you see in people aged between 18 – 45? *Incidence? Severity?*

3. How does the need for risk screening for SCD compare to screening for other conditions? *Highly important? Not as important?*

4. How do you rank the following risk factors of SCD in order of importance: conduction issues, myocardial pathologies, cardiomyopathies or perhaps something else? Or what would you consider the main risk factor of SCD?

5. The most common method used to carry out screening for SCD risk factors is an ECG. Do you think this is the most effective method or would you perhaps choose a different one?
   - Personal history
   - Physical examination
   - ECG
   - Holter monitoring
   - Blood biomarker

- CT angiography
  5.1 – Would you rank any of these as more important / effective than others?

6. Do you believe it is possible to implement a national screening programme in Wales? *Do you think it would be a beneficial and worthwhile project? Cost effective?*

7. Do you believe the incidence of SCD in Wales, or the UK, is significant enough to require a national screening programme?

8. Using data collected from earlier interviews with athletes from different sporting levels, 62.5% had never been screened at all and the remaining 37.5% had only been screened due to it being a mandatory requirement in a professional sporting set up. Do you think more should be done to make screening available to lower levels of sports? Perhaps considering gyms and universities?

9. Is enough being done across the country to prevent and reduce the amount of fatalities as a result of SCD?
   - *Government*
   - *National health boards*
   - *Sports clubs / governing bodies*

10. Are you aware of any SCD risk screening services in the UK? Have you heard of Welsh Hearts or CRY? Are you aware of the service they provide?

11. Have you previously attended a cardiac screening event?

12. Have you ever experienced a case of SCD or encountered a condition that could lead to SCD? If so, what was your and the patient's reaction, what impact did it have on their life? Also, what did they require following a diagnosis - psychological and mental health support?

13. The UK NSC do not currently support cardiac screening for the general public but do support its use in athletes, do you agree with this? *If so / If not … Why?*

14. Do you think a national screening programme should focus on athletes (Pro, SP) / people who are physically active, or should it include everyone aged 18 – 45 who is taking part in sport / exercise / PA? What are the reasons for this?

15. If it was up to you, would you implement a nationwide cardiac screening programme? If so or if not, why?

16. Would you yourself get screened and would you encourage family, such as children, to get screened? Why and what may influence this decision? If not, why?

17. In your opinion, what are the main barriers towards screening in the UK? And what views do you hold on NHS funded screening compared to private screening?
   - *Cost, availability, lack of awareness and knowledge, impact on physical and mental health.*
   - *Why?*

18. In your opinion, what are the main facilitators towards screening in the UK?
   - *Awareness in media, club & NGB endorsements, celebrity endorsement, public health schemes, peace of mind.*
   - *Why do you hold these views?*

19. Do you think that health professionals need better training regarding SCD and the associated risks?
    18.1 – What do you think would be the best means of providing this?

20. Do you think enough is being done to make people aware of the risks of SCD in Wales? Do you think there could be negative impacts to raising awareness about screening, such as ethical issues and stress levels?

21. What do you think would be the best means to reach out to people to raise awareness of screening? *Internet, PH campaign, endorsements?*

22. Do you believe COVID -19 and subsequent lockdowns have had an impact on incidence of SCD, the risk factors and potentially management strategies for those considered to be at high risk? *(In regard to mental and physical health)*

Figure v – The final draft of the interview structure used in interviews with doctors and medical professionals. This again included an introduction and questions formatted into different sections of knowledge and experience to help the conversation flow throughout the interview.

Questionnaire questions	How it was extracted from interview data
Have you heard of sudden cardiac death? & Do you know what sudden cardiac death is?	Participants had mixed responses to this. The minority had heard of it and knew what it was. Some had heard of it but didn't know what it was and had only heard about it through cases in the media and news, the remainder didn't know what it was and hadn't heard of it. Some responses in the interviews included: "Is it just when your heart stops? Is that what it is?", "it's a condition where someone appears to be healthy, and 5 or 6 hours before they are appearing healthy and then they undertake some exercise and then they've got heart failure", "Yeah I guess so, but I think just from reading it when there's marathons and it happens then, I think if that hadn't happened then I wouldn't be as clued up on it".
Have you previously heard of cardiac screening?	The vast majority of people were aware that cardiac screening existed, and they had heard of it but were not too sure as to what its purpose was. The only ones who really knew about it were those that had been screened before. Responses included: "Umm, probably not in depth", "No, I've never actually heard of it before", "Yeah I am aware of what cardiac screening is, I have been screened a couple of times myself, but besides from that I don't really know why they are doing it or what the reasoning behind it is" & "Yes, well only because I've had it done to me, if someone had asked me before I had had it done, well even after I had it the first time, probably wouldn't have had it for a few years and someone had said we are going cardiac screening I would still have been like 'What's that?'"

Have you ever heard of a case of SCD?	During interviews the majority of cases of SCD that people had heard of were the high-profile cases e.g., Fabrice Muamba and other cases seen in the news, only a couple of people were able to talk about people they knew that had been affected or a friend of a friend etc. It is interesting to explore if many people have ever heard of a case of SCD perhaps at their local sports club or gym or perhaps they can relate to some personal experience. Responses from interviews include: "I've heard about Fabrice Muamba because that was widespread and spread throughout the media ... I haven't really had any personal experience.", "I had a friend who went up with 10 or so mates seemingly fine, he had been at work that day and had no obvious symptoms and was just playing 5 - a - side football and then just the next thing he was on the floor ... and unfortunately he lost his life.", "we did a triathlon race in November, like a BUCS [British Universities & Colleges Sport] one, and there's always a normal race before it and one of the guys in that had a heart attack on course and he didn't know he had a condition" & "I know obviously of ex - athletes like Fabrice Muamba who had the heart, and then there's the cricketer James Taylor, I think he got stopped from playing because of cardiac screening, apart from that, that would be my only experience".
Have you ever been screened for SCD before?	From the interviews carried out the majority of participants had not been screened for SCD but did take part in sport regularly competing at an amateur or semi - professional level. The participants interviewed that had been screened were all competing at a professional bar 1 who had recently dropped from professional to semi - professional. This question will explore if this is replicated throughout the wider population and to also get an idea of how many people have been screened.

What would be the main reason for you to choose not to be screened?	In interviews there were a number of reasons which arose that may lead people to not be screened. It would be insightful to see if there are anymore that could be identified that haven't already been covered in the responses given in the interviews, but also try and determine if there is one main factor as to why people choose not to get screened e.g., Cost that can be sourced from a larger sample size through the questionnaire. Interview responses: "...the awareness, how much the cost, I think always I have probably had the wrong attitude that because I have been into sport, I am probably quite fit and healthy and it's not something that's crossed my mind", "lack of availability. From what I've seen I have never seen it being advertised at a local club or events saying its going on and haven't been encouraged to go by any coach or anything so yeah lack of awareness I guess" & "...as a surfer, I never really thought about it, it wasn't until I started doing Tri and seeing all the cases and actually like became aware of it ... I've just not really known enough about it...".
What would be the main reason for you to choose to be screened?	People who had been interviewed who had been screened had only had it done because their professional sports club required them to. It is also important to understand what influences and what is the main driver for people to get screened at say a lower level of sporting competition where it is not necessarily a requirement, but also what can be done to encourage people to get screened even if they're not competing at a professional level. Some responses from interviews: "Yeah, so I think the first one I did was at academy level, I think one was with the national team at under 18s or under 20s, that sort of age grade and then I think the most recent one was about 18 months ago.", "Yes, (it was through club) well basically it's all just been for Wales, so basically for the employer".
Have you heard of any of the following organisations?	This question is being asked to participants about BHF, C-R-Y and Welsh Hearts because these are the main services that offer information about cardiac screening. People can use them to find out if they can be screened, organise / book to be screened as well as finding out valuable information about conditions that can predispose to SCD. Throughout interviews people have said that they didn't know enough about the topic to raising their awareness of these organisations may help

	them learn and also raise the profile of the organisations.
If a doctor recommended to you that you stopped your participation in sport with immediate effect, would you follow their advice?	This is an interesting question because some people have completely different approaches, most say that they would adhere to doctor's advice and stop sport aligning with there's more to life than sport, others say that they don't think they would physically be able to stop playing sport altogether so they would just have to limit how much they do a week for example, some say that nothing has affected them or thy haven't had any problems previously so why should they stop now and all reasons have some valid arguments. There is no guarantee that because someone has been identified as 'at risk' that stopping sport will improve their life because nothing might ever come of the issue identified. Interview responses included: "if I was strongly advised then I think I would give up my sport if it was to keep my life", "I'd go from playing 3 - 4 times a week to maybe playing socially once or twice a month, just because the risk would be so much lower if it's at a lower intensity and less frequent" & "I don't think there's a day where I'm not doing something active so I think that would be extremely hard".
What would influence your decision towards whether you take their advice or not?	Being asked in order to try and gain a better understanding as to why people have the opinion that they do and where this has derived from, whether its family, coaches or maybe even the sport they play. For example, if somebody plays golf and they have been identified as at risk they may think 'My heart rate rarely gets that high so I'm not really at risk'.

Do you have a family history of any cardiac conditions?	Participants interviewed did have a history of cardiac issues within their family but had never really thought about how this could potentially affect them, whether they could have inherited a condition and therefore potentially be at risk. Hopefully asking this will be a good indicator of how many people have a family history of any cardiac conditions if they are aware of it and whether they have been screened or never really thought about it that much. Some examples from interviews include "Its more forward in the mind now, but before it would've definitely been back of the mind just because I think I'm under the impression that I am fit and healthy" & "my grandfather died of a heart attack, I'm not sure whether there has been more people before that does kind of worry me a little bit".
Who do you believe should be putting on and organising screening events?	This question aims to find out who people believe should be providing the opportunity for people to get screened and provide the access to it. Whether it should lie with the health board / public health, your sports team, governing bodies or potentially family. Interview examples include "your sport's governing body kind of gave you information, kind of even said 'right, we're running a screening day here in south Wales, so everyone who surfs in South Wales come and get screened' and like providing that information" & "I definitely think it would be beneficial for clubs and organisations to start giving presentations and making more people aware about the risks of death and stuff".
Would you be interested in learning more about SCD and the associated risk factor screening? & What would be the best means to educate people further on the topic of SCD?	This is to gage if people are interested in learning more or whether they are perhaps not that concerned about SCD. Furthermore, also seeing if they are interested in learning more what would be the best means of doing this would be. Some options could include someone giving a talk, handouts, emails, webpage, social media and videos. This could vary on a number of things such as a person's age, what sport they do, perhaps even where they live. Examples from interviews that inspired these questions included: "if it was just like a website for Wales like here's the information and you can book here if you want to get screened", "like a leaflet or a handout, because I think it makes it a bit more real then and the team would buy into it a bit more" & "probably a website would be the one which would get the best traction ... a little website or a leaflet or even like

	small YouTube videos ... just a couple of minutes just saying about cardiac screening ...".
Do you think a mandatory nationwide screening programme is required in the UK?	Mixed responses from interviews with doctors have influenced the decision to ask this question to a wider group of athletes, with some believing that it would not be justifiable due to costs and the rarity of the condition.
Do you believe screening is more important in some sporting levels than others? & Do you believe cardiac screening is more important in different types of sports?	These questions will provide a useful insight into how people think and their attitudes towards screening based on what level of sport they play. For example, someone who competes in sport at an amateur or recreational level may not feel they need to be screened as they only do it once or twice a week, whereas on the other hand a professional sports person may feel thy should have priority for screening because it is their job, they do it every day and if anything were to happen then it would ruin their livelihood. The second question here was asked in the interviews in a similar if not the same manor in order to see if people believed that some sports should have greater priority / access to screening perhaps if the heart was put under greater amounts of stress during some sports compared to others. Some examples of interview responses were: "it's so much more intense within a quick space of time, so like a 100m sprint or something , whereas in netball its stop start and your heart rate isn't as high...", "I think it's like equally important throughout the whole of the population because I don't think your sport necessarily ... it's not going to think 'oh you're doing an easy sport you're not going to have that condition'" & "I would say it is

	equally important throughout because all sport requires some type of fitness or some type of endurance and that can have some sort of impact on your body...".
Would pre – participation screening deter you from joining or taking up a sport? & Why would PPS potentially deter you from taking up a particular sport?	This question is mainly influenced by published literature on SCD and SCD risk factor screening. In a paper Dhutia et al (2018) & Sharma et al (2013) it stated that there is no sign that the use of an ECG in PPS would deter someone from taking up a sport. This question was asked to see if the same results would be replicated in a cohort of athletes from amateur, semi – professional, and professional level of sports participation.
Which sporting levels do you believe require PPS?	Again, this question was asked in a similar, if not the same style and allows us to see which sporting levels people perceive require PPS over others.

Figure vi – This table demonstrates how the questions asked in the questionnaire were developed using responses given and themes identified from previous interviews and research.

Original athlete questionnaire structure
Questionnaire

Level of sport: Professional / Semi – professional / Amateur
Sport:
Occupation (if necessary):
Age:

Questions:
1. Have you heard or aware of sudden cardiac death?
- Yes
- No
2. Do you know what sudden cardiac death is?
- Yes
- No
3. Have you previously heard of cardiac screening?
- Yes
- No
4. Have you ever heard of case or any experience with SCD?
- Yes
- No
- Brief description (famous person, family, friends etc) …
5. Have you ever been screened before?
- Yes
- No
If yes: Why? Part of job, sports club, referred or personal choice.
If no: Why? Time, cost, lack of awareness.
6.What do you believe to be the biggest barrier facing cardiac screening?
- Cost / funding
- Time
- Lack of awareness
- Inaccuracies
- Other … (please disclose)
7. What do you believe is the biggest facilitator towards cardiac screening?
- Life – saving
- Peace of mind
- Knowing there's an issue
- Other … (please disclose)
8. Have you heard of any of the following organisations?
- C-R-Y
- Welsh Hearts
- British Heart Foundation
- None of the above
9. If a doctor recommends you stopped your participation in sport with immediate effect, would you follow their advice?
- Yes
- No
10. Do you have a family history of any cardiac conditions?
- Yes
- No

-Brief description …

11. What age do you think would be most beneficial to get screened?
- ≥ 18
- 18 – 25
- 26 – 35
- 36 – 45
- ≤ 45

12. Who do you believe should be putting on and organising screening events?
- Sports clubs
- National governing bodies
- Local authorities
- Health boards
- None, it should be up to individual to organise if they want it.

13. Would you be interested in learning more about SCD and the associated risk factor screening?
- Yes
- No

14. Do you think a nationwide screening programme is required in the UK?
- Yes
- No

15. Do you believe screening is more important in some sports than others?
- Yes
- No
- Brief description …

16. Would pre – participation screening deter you from joining or taking up a sport?
- Yes
- No

Figure vii – Original design for athlete questionnaire, prior to expert scrutiny and recommended amendments suggested and implemented by the research team.

Final athlete questionnaire structure:

This questionnaire is part of my ongoing master's study at Swansea University exploring athletes' knowledge, perceptions and experiences about sudden cardiac death (SCD) and associated risk factor screening. Having completed a number of interviews with athletes I hope that this questionnaire will allow me to reach a wider audience to obtain the views of a larger group of athletes from professional, semi – professional and amateur levels of sports competition.

This questionnaire should take approximately 15 minutes to complete. Please work through the questions on the questionnaire below. The majority of questions are a simple yes or no but some of them also require some additional information. For these questions, please complete your answer in the text box attached to the question.

Participants are reminded that this questionnaire is completely voluntary. In the unlikely event that you feel distressed or uncomfortable whilst completing the questionnaire you may withdraw from the process. If this continues, please contact the researcher on the email below. All questionnaires and responses are, and will remain, anonymous.

Thank you for taking the time to complete this questionnaire, it is greatly appreciated and will be a massive help to me in completing my Master's degree.

Thanks again,
Ed Couzens
[redacted]

By completing questionnaire, you are giving consent to take part in the study and for your responses to be used anonymously in reports of the data that will be used further on in the study.

Questionnaire

About you:

Level of sport: Professional, Semi – Professional or Amateur
How many times a week do you train/compete per week: 1-2, 2-3, 3-4, 4-5, more…
Sport:
Age:
Country:
Gender:
Ethnicity:
Do you have a family history of any cardiac conditions?
- Yes
- No
- If yes, the please provide brief details.

Knowledge of SCD:

In this section we are interested in finding out what you currently know about sudden cardiac death and associated risk screening.

1. Have you heard of sudden cardiac death (SCD)?
   - Yes
   - No

2. Do you know what SCD is?
   - Yes
   - No

3. Have you previously heard of SCD risk screening?
   - Yes
   - No

4. Have you heard of any of the following organisations?
   - C-R-Y
   - Welsh Hearts
   - British Heart Foundation
   - Other

Experience of SCD:

In this section we are interested in finding out your experiences (if any) with SCD and what factors may contribute towards your decision to get or not to get screened for SCD risk, if you haven't already.

5. Have you ever heard of a case of SCD?
   - Yes
   - No
   - If yes, then was this a famous person, friend, or family member?

6. Have you ever been screened for SCD risk before?
   - Yes
   - No

7. Have you ever been offered the opportunity to be screened for SCD risk in the past and refused it?
   - Yes
   - No

8. What would be the main reasons for you to choose not to be screened for SCD risk? (Please rank from most likely to influence your decision to least likely)
   - Cost / funding
   - Inconvenience
   - Lack of understanding about SCD and associated risk screening
   - It may affect my future sporting career
   - I would prefer not to know if I had health problems
   - Potential inaccuracies in results
   - Other ... please describe briefly

9. What would be the main reason for you to choose to be screened? (Please rank from most likely to influence your decision to least likely)

- Life – saving
- To provide peace of mind
- I would want to know if there's an issue
- Other … please describe briefly

Attitude towards screening:

Here we are exploring your current attitudes towards screening, what you would do if you were screened and you were identified as being at risk for SCD, and how important you think SCD risk screening is throughout sport.

10. If a doctor recommended to you that you stopped your participation in sport with immediate effect following SCD screening, would you follow their advice?
    - Yes
    - No

11. What would influence your decision towards whether you would take their advice or not?
    - …

12. Do you believe screening is more important at some sporting levels than others? (Please rank in order of importance)
    - Professional
    - Semi – professional
    - Amateur
    - All levels of sport
    - None of the above

13. Do you believe cardiac screening is more important in different types of sports? (Please rank from most to least important)
    - Team games (rugby, football, hockey etc.)
    - Endurance sports (marathons, triathlons etc.)
    - High-intensity sports (100, 200 & 400m etc.)
    - Equally important throughout all types of sport
    - None of the above

14. Do you think that the importance of cardiac screening differs according to gender? Do you believe it's more important in…
    - Males
    - Females
    - No difference

15. Do you believe cardiac screening is more important in different age groups?
    - younger than 12 years of age
    - 12 – 20 years of age
    - 21 – 30 years of age

- 31 – 45 years of age
- over 45 years of age

Pre – participation screening (PPS):

Pre – participation screening (PPS) is the process of screening individuals or groups of people prior to them joining or competing in competitive sports, e.g., a footballer having an ECG during a medical examination when signing for a new team.

16. If screening for SCD was a mandatory part of PPS for sports, would it deter you from taking up a particular sport?
    - Yes
    -No

17. Why would SCD risk screening potentially deter you from taking up a particular sport?
    - Potential career implications
    - Prefer not to know
    - Other…please disclose

18. If yes, what would mitigate or change these concerns? Would any of the following convince you to undertake screening?
    - Screening carried out by professional body or organisation
    - Better education on the topic of SCD
    - Privacy
    - Screening organised by sports club or sport's governing body
    - More accurate method of testing
    - Other …

19. Which sporting levels do you believe require SCD risk screening? (Please rank from most to least important)
    - Professionals (medical assessments)
    - Semi – professional
    - Amateur
    - None of the above

SCD screening & education:

In this final section of the questionnaire, we focus on the potential implementation of a national screening programme which would see the screening of large populations across the country. Generally, screening programmes could be mandatory or voluntary and can be made available to everyone or specific populations.

20. Do you think a mandatory nationwide screening programme is required in the UK?
    - Yes, for elite athletes only
    - Yes, for semi – pro and professional athletes
    - Yes, for all who take part in competitive sports (including mass participation events, e.g. marathons)
    - No, it's not required for anyone
    - It should be up to the individual

21. Who do you believe should be putting on and organising screening events and educating people about SCD? (Please select all that apply)
    - Sports clubs
    - National sports governing bodies
    - Local authorities
    - Health boards
    - None, should be up to the individual to organise it for themselves.

22. What, do you think, would be the best means to educate people further on the topic of SCD? (Please rank from most to least effective)
    - Website
    - In – person
    - Organised talk
    - Social media account
    - Online videos
    - Handouts

23. Would you be interested in learning more about SCD and the associated risk factor screening?
    - Yes
    - No

Figure viii – This is the final questionnaire structure that was input into JISC and sent out online for athletes to complete. The questionnaire includes new questions, formatted different sections with an explanation to participants why the questions are being asked. As well as an introductory paragraph to participants which ensures their consent is given before advancing through the questionnaire.

Types of sports	Number of athletes
Water polo	5
Rugby	39
Football	7
Badminton	1
Horse riding	2
Rowing	2
Netball	8
Gym / Weightlifitng	5
Hockey	1
Circus performance	1
Triathlon	4
Running	7
Cricket	1
Bouldering	1
Multiple sports:	
Rugby, cricket, cycling, running	1
Golf, surfing, football, tennis	1
Rugby, weightlifting	1
Rugby, cycling, running	1
Running, tennis	1
Football, weightlifting	1
Running, swimming	1
Cycling, running, football, tennis	1
Swimming, weightlifitng	1
Running, weightlifting	1
Swimming, running, cycling	1
Gym, running	1
Football, cricket	1
Surfing, triathlon	1

Figure ix – The breakdown of sports or physical activity that the athletes who completed the questionnaire took part in. including those who listed multiple sports.

Country	Number of athletes
UK	93
Wales / Bahrain	1
South Africa	1
New Zealand	1
USA	1
Portugal / UK	1

Figure x – The nationalities represented by the respondents to the questionnaire.

Ethnicity	Number of athletes	Percentage (%)
British	6	6.2
Caucasian	2	2.1

White - British	37	38.1
Mixed British / Middle eastern	1	1.0
Black - White mixed	1	1.0
White	40	41.2
White - British / Irish	1	1.0
Welsh	2	2.1
White European	2	2.1
British - Asian	1	1.0
White - Welsh	3	3.1
Black - white Caribbean	1	1.0

Figure xi – Ethnic backgrounds of the participants who completed the questionnaire.

Why would it potentially be a deterrent from sport …	**Number of athletes**	**Percentage (%)**
Potential career implications	56	62.2
Would prefer not to know	17	18.9
Other	17	18.9

Figure xii –Factors why people might see SCD as a deterrent from sports participation.

What would change or mitigate these concerns …	**Number of athletes**	**Percentage (%)**
Screening carried out by professional body or organisation	18	31
Better education on the topic of SCD	15	25.9
Privacy	3	5.2
Screening organised by sports club or sport's governing body	13	22.4
More accurate method of testing	3	5.2
Other	6	10.3

Figure xiii – Factors that may mitigate respondents concerns about current SCD risk factor screening.

Swansea University
Prifysgol Abertawe

Figure xiv – Ethics application approval.

APPLICATION FOR ETHICAL COMMITTEE APPROVAL OF A RESEARCH PROJECT

In accordance with A-STEM and College of Engineering Safety Policy, all research undertaken by staff or students linked with A-STEM must be approved by the A-STEM Ethical Committee.

RESEARCH MAY ONLY COMMENCE ONCE ETHICAL APPROVAL HAS BEEN OBTAINED

The researcher(s) should complete the form in consultation with the project supervisor. After completing and signing the form students should ask their supervisor to sign it. The form should be submitted electronically to Coeresearchethics@swansea.ac.uk.

Applicants will be informed of the Committee's decision via email to the project leader/supervisor.

1. TITLE OF PROJECT

Barriers and facilitators to introducing a screening programme for sudden cardiac death in various sporting populations.

2. DATE OF PROJECT COMMENCEMENT AND PROPOSED DURATION OF THE STUDY

Start: 14/1/20
Duration: 2 years

3. NAMES AND STATUS OF RESEARCH TEAM

904892 Edward Couzens (MSc by research student)
Prof Michael Lewis (Supervisor)
Dr Dareyoush Rassi (Supervisor)
Dr Joanne Hudson (Supervisor)

4. RATIONALE AND REFERENCES

Sudden Cardiac Death (SCD) describes a fatal event that is non-traumatic, non-violent, unexpected and that results from sudden cardiac arrest within 6 hours of previously-witnessed normal health (Sharma et al., 1997). Many conditions, if undetected and therefore untreated, can lead to SCD in young people (e.g. hypertrophic cardiomyopathy, myocarditis, coronary artery anomalies and arrhythmias). These conditions can be symptomless and so might only be diagnosed following a catastrophic event (a cardiac arrest) in individuals succumbing to SCD. However, many of these conditions could be detected and treated if appropriate cardiac assessment ('cardiac screening') was

offered to young people. For example, hypertrophic cardiomyopathy (HCM, an inherited muscle disorder) appears to be the leading cause of SCD in young people and athletes (O'Mahoney et al., 2013; Van Brabandt et al., 2016), and this can be diagnosed from simple ECG and echocardiography tests. In their review and appraisal of the potential value of SCD screening, the UK National Screening Committee (UKNSC) observed that the overall (multi-national) incidence of SCD is 1-3 cases per 100,000 young people (those aged 1–39 years), whilst the UK incidence was 1.8 per 100 000 young people (aged 1-34 years) (UKNSC, 2019). This equates to 419 deaths annually (or around 8 deaths per week) in the UK (Papadikis et al., 2009). The charity Cardiac Risk in the Young (CRY), which supports research into SCD in young people, suggest a slightly higher incidence - stating that around twelve apparently healthy people under the age of 35 die from an undiagnosed heart condition each week in the UK (CRY, 2018). Although these figures show that SCD is relatively uncommon, it remains an issue that could (and perhaps should) be addressed by national screening programmes.

However, the UKNSC have recently re-issued (following review and re-evaluation) their statement that systematic population screening for SCD is not recommended in the UK (UKNSC, 2019). In support of this recommendation UKNSC cited current uncertainties about the value of relevant diagnostic tests, about the conditions that can cause SCD, and about the benefit of identifying those at risk when weighed against potential harm (e.g. an individual who is identified as having a high risk of SCD might become anxious about their physical activity and stop exercising, which could be detrimental to their overall health); they also noted that there is no agreed treatment or care pathway for supporting those who have been identified as being at risk of SCD. CRY provided a detailed response to the UKNSC statement, refuting these claims (see UKNSC, 2019). Research into the causes of SCD and the benefits of SCD screening in young people is indeed somewhat limited and equivocal. Some studies have concluded that screening for SCD conditions in young people is extremely useful, and the opinion of some experts is that it allows many lives to be saved each year. Others consider it wrong to screen for SCD, as it can cause needless worry and might unduly influence future health and prosperity.

Despite this, there is now a growing call to have a national screening programme in the UK, with petitions being set up by organisations and charities such as CRY and Welsh Hearts. Moreover, SCD is becoming increasingly documented - high-profile cases reported on the news and in social media (with deaths often occurring during or following sports participation) have helped to raise awareness amongst the general public of this silent condition. This possible association of SCD with sport and exercise has also provoked the question "Should a mandatory screening programme be established for every young person engaged in competitive sport in the UK?". The aim of such a programme would be to save, or at least prolong, the lives of those who do not realise they are at risk of SCD. Such a screening programme would likely be similar to that of the pre-participation screening process employed in Italy since 1982. This programme required all Italian citizens who were participating in organised and competitive sport to undergo "preventive general medical and cardiovascular evaluation using a 12-lead ECG, personal and family history, and physical examination". Peliccia et al. (2006) studied 4,450 participants of the programme, all of whom were competing in Italian international sports teams (from 38 different sports and disciplines). The study concluded that Italy had low numbers of HCM cases (and, by implication, SCD) in sport due to the national pre-participation screening programme, which was effective in identifying HCM (Pelliccia, 2006).

Important aspects of the ongoing SCD screening 'debate' that have thus far seemingly been ignored are the views (and understanding) of athletes and sports management personnel regarding SCD

screening. We suggest that we urgently need to solicit the opinions of these individuals about the utility and desirability of SCD screening, thereby better informing this debate.

References

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Pelliccia AD, Di Paolo FM, Corrado D, Buccolieri C, Quattrini FM, Pisicchio C, et al. (2006). Evidence for efficacy of the Italian national pre-participation screening programme for identification of hypertrophic cardiomyopathy in competitive athletes. European Heart Journal, 2196 - 2200.

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UK National Screening Committee (2019). The UKNSC recommendation on screening to prevent sudden cardiac death in 12 to 39 year olds. Dec 2019. http://legacy.screening.nhs.uk/suddencardiacdeath

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5. OBJECTIVES

The main driver for this study was the recognition that we need to better understand what athletes and sports management personnel understand about SCD, thus informing the screening 'debate'. The **primary research question** for the study is therefore "What are the opinions of athletes and sports management personnel about the utility and desirability of SCD screening?". We will also ask participants (athletes) to let us know if they subsequently decide to undertake SCD screening (within one year of our initial contact with them); at that point we will ask them if they will consent to a further discussion about the reasons they decided to do so, and for their comments about the screening process. Thus, our **secondary research question** is "Which factors ('values') prompt athletes (or their managers) to undertake SCD screening?" **(Note that the decision to undergo screening lies entirely with the participant; the research team will not encourage them to undergo screening in any way.)**

Aims:

1. To scope the barriers to, and facilitators of, implementing a screening programme for SCD in athletes and physically active people, in the context of different scenarios e.g. i) an amateur running club, ii) a professional sports club and iii) a commercial gym/sports club.
2. To explore the knowledge, experiences and personal opinions of medical professionals with regard to SCD and SCD risk factors screening.

3. To explore medical professionals' personal opinions about implementing a nationwide screening programme for SCD risk factors.

Objectives:

1. To review and summarise the apparently conflicting viewpoints regarding the justification and need for SCD screening, and of its viability on a local/national and private/publicly funded scale.
2. To undertake semi-structured interviews with individuals or groups of participants (athletes and sports management personnel) and to use inductive analysis to better understand this population's knowledge/awareness about SCD, their attitudes towards screening, and their perceptions of the barriers and facilitators that might prevent or enable screening to take place.
3. To re-interview those participants who have attended a screening event in order to hear about the reasons for their decision to do so and their perceptions of the screening experience.
4. To carry out interviews with a number of doctors and medical professionals to gain a greater understanding of their personal thoughts, opinions and experiences about SCD and SCD screening.
5. Invite a larger group of individuals to complete a bespoke questionnaire that explores the themes identified in the previous interviews.

6.1 STUDY DESIGN

This will be a qualitative cohort study, consisting of 2 parts. Part 1 will be carrying out structured one-to-one interviews with participants. Part 2 will consist of accessing a much larger athlete population using a specific questionnaire designed using the main themes that were identified when completing and analysing previous interviews.

6.2 STUDY DESIGN

Part 1 – Interview design:

Participants will be individual athletes, members of a sports/athletics team, or part of the management or coaching staff for an athlete or sports/athletics team. Approximately 10 amateur and professional teams and sports/athletic organisations will be approached and invited to participate. Representatives of the management/coaching staff from each will be interviewed. We estimate that 10-15 athletes from a variety of sporting disciplines will consent to be interviewed either individually (e.g. for non-team event athletes) or in small groups (e.g. for team athletes). It is anticipated that some participants might subsequently decide to attend an organised SCD screening event, the purpose of which will either be: i) for athletes to have a personal SCD risk assessment, or ii) for management/coaching staff to observe what the screening event involves. Participants who have decided to attend a screening event will be asked to let us know about this (after they have attended the screening); at that point we will ask them if they will consent to attend a further interview so that we can hear about their experience and views of the screening process. **(Note that participant**

attendance at a screening event is not a part of this study; this is a decision for the participant, and there would likely be a cost associated with this that would need to be met by the participants themselves. We will tell participants about the Welsh Hearts charity and the C-R-Y organisation, both of whom provide SCD screening for sports teams, athletes and members of the public.)

Participants will also include medical professionals (doctors and allied health professionals). The reason for this is to give an insight into knowledge and personal opinion about SCD and SCD risk factor screening from the opposite side of the spectrum (compared to athletes). We will aim to recruit and interview at least 5 medical professionals, all of whom will have a general medical background (e.g. GPs, Paramedics, nurses) or be specialists in cardiac health and so would reasonably be expected to have some insight into SCD and its associated risk factors.

Part 2 – Interview design
Following completion and the subsequent analysis of the interviews, the main themes will be used to develop a tailored questionnaire to explore and evaluate these findings. By using a questionnaire that will be distributed and accessed online, we aim to reach out to a significantly larger group of participants. The questionnaire will be sent out online for a 10-day time period. We aim to gain over 100 responses in order to obtain a greater insight into participants views and opinions on SCD and the associated risk factor screening.

Potential participants will be required to satisfy the following inclusion and exclusion criteria, which will be assessed prior to taking consent for participation:

Inclusion criteria: Individuals must be

- Part of a professional or semi-professional sports team/association, or part of the associated management set-up OR a member of an amateur sports club or gym.
- Between the ages of 18 and 45 years old (athletes only).
- A medical professional with a general medical background or specialising in cardiac health.

Exclusion criteria:

- Individuals who are not members of a sports team or organisation, or who are not medical professionals.
- Athletes under the age of 18 years (confidence in screening outcomes is lower with younger people as they have a developing cardiac system).
- Athletes over the age of 45 years (older people are more likely to be at risk of lifestyle-related cardiac illness).
- Individuals who have been directly impacted by SCD (e.g. by the death of a friend or family member that was attributed to SCD).

Participant requirements/commitments:

- Participants will be asked to attend an interview that will last no longer than 45 minutes. Interviews will be conducted either online (using an audio/video communication platform), at Swansea University or (in the case of teams) at the team's training/playing location.

Vulnerable populations: None (see exclusion criteria).

6.3 PARTICIPANT RECRUITMENT

Part 1 – Interviews:
Participants will be approached by the student (EC) via email, telephone, hand-outs or in person, to arrange an initial discussion/presentation about the aim and purpose of the study:

i) In the cases of 'team participants' and all professional/semi-professional athletes: The management/coaching staff will be asked to consent to themselves being interviewed as part of the study and also to provide permission for their athletes to be interviewed. Team members will then be approached individually via the manager/coach and the student (EC) to ask if they would be happy to participate in individual or group interviews. The manager/coach/student will be discrete when speaking to individuals about this, and they will not ask the group publicly about participation (this will allow the individual to freely provide consent if they wish).

ii) In the case of 'individual participants' (amateur): The athlete will be approached by the student (EC) to ask if they would be happy to participate in individual or group interviews.

iii) Medical professionals will be approached individually by the student (EC) by telephone and email, and a brief introduction to the study will be provided to see if they are initially interested in taking part in the study; those who are interested will then be sent more detailed information about the study and given time to consider this before being contacted again to arrange an interview.

All potential participants will be asked to confirm that they have not been directly affected by SCD before being allowed to participate in the study.
Part 2 – Questionnaire:
People will be invited to complete the questionnaire online through social media and sports organisations / teams group chats, via a URL link that will be provided. People who wish to complete the questionnaire will click on the link and it will take them to the online survey platform JISC to complete the questionnaire.

Once the questionnaire has been accessed on JISC participants will see text at the beginning of the questionnaire which explains the purpose of the study and what the participant requirements are.

The questionnaire will be advertised on social media, via email, word of mouth and sports teams / organisations group chats.

The questionnaire is directed at participants who partake or compete in any discipline or level of sport from recreational through to professional athletes.

6.4 DATA COLLECTION METHODS

Preliminary Procedures:

- Gather knowledge and research in study field.
- Identify and contact potential sporting individuals and/or organisations that could be legitimate participants for the study.
- Construct and prepare semi-structured interviews ('topic guide').
- Send information sheet to potential participants to gauge interest, allowing them up to 1 week to respond.

Experimental Protocol:

- Contact and engage with participants and carry out interviews (individually or in groups, as deemed appropriate after discussion with participants).
- After carrying out interviews across a range of participant types/levels, qualitative analysis methods (inductive and thematic analysis) will be used to identify common themes and trends from the interview answers/discussions.
- A questionnaire will be developed based on the identified themes, with a view to using this as a tool to obtain data from a wider range of participants later in the study.
- Later in the study, those participants who have attended a screening event will be invited to attend a second interview, using a similar interview topic guide but with additional comparative (pre/post screening comparison) and exploratory questions. Following thematic and inductive content analysis there might be a shift in the common themes identified compared to the first interview data. The questionnaire might be updated to reflect any new themes identified.

Interview structure:

- The interviews will be semi-structured, consisting of open-ended questions (encouraging participants to give extended, more detailed answers about screening rather than just one word or short answers).
- Interviews will last upto 45 minutes each.
- All interviews will be audio or video recorded and later transcribed.
- The location of the interviews will vary for each participant (as discussed in Section 7).
- Any names mentioned in the interview by the participant, whether their own or another person's, will be redacted to maintain absolute anonymity.
- A number of pilot interviews will be conducted prior to the main study. This is to make sure we are able to access and obtain the information we want from the participants using the questions that have been asked, and to encourage the participant to give an extended answer.

Questionnaire structure:

- The questionnaire consists of 23 questions derived from responses given from earlier interviews.
- Questions consisted of multiple-choice answers, some that required multiple answers or ranking, and some requiring small amounts of text.
- The main themes that are covered in the questionnaire are the individual's knowledge and experience of SCD and screening, their attitudes towards screening, pre-participation screening, national screening programme implementation and education.
- The questionnaire (see Appendix 1) was deployed using the JISC online survey platform, which complies with Swansea University GDPR guidelines. It also allows the questionnaire to be sent out to participants via a link (URL) to participants meaning it can be simply completed and returned.
- Responses will then be accessed and extracted for further analysis using JISC.

6.5 DATA ANALYSIS TECHNIQUES

- A Dictaphone will be used to audio record all face-to-face interviews, and online interviews will be audio/video recorded using the online communication software (Zoom) Upon reviewing these interviews (at a later date), participant responses will be transcribed to a Word document and key themes/responses will be identified. All comments will be anonymised.
- Thematic analysis will be used to identify, analyse and interpret common themes in the data collected.
- Inductive content analysis will similarly be used to develop theories from answers and identify themes from the interview recordings and transcripts. After interviews have been transcribed, they will be read carefully and key themes will be grouped and filtered to identify the major themes and most prominent reasons behind the different facilitators of, and barriers to, health screening.

- The data collected from the questionnaires will be analysed using descriptive statistic statistics techniques in order to compare responses between respondents.

6.6 STORAGE AND DISPOSAL OF DATA AND SAMPLES

- The student will be responsible for collecting, collating and storing all data. Interview recordings and questionnaire responses will all be anonymised.
- Anonymised interview recordings and transcript data and questionnaire responses will be stored on password-protected computers and an external USB device belonging to either Swansea University or the student.
- The data will be accessible only by the research team (student and supervisor).
- The data will be retained for a period of five years and the supervisor (Prof Lewis) will be responsible for disposal of the data at the end of this period.

6.7 HOW DO YOU PROPOSE TO ENSURE PARTICIPANT CONFIDENTIALITY AND ANONYMITY?

All data generated from this study will be treated in the strictest confidence and participant anonymity will be maintained throughout. Participants who complete the questionnaire will not be required to identify themselves. All participant data will be anonymized with regard to any future publications relating to this study and data will be accessible only by the research team. Data will be anonymized by a third party assigning a number to each participant (of which they will keep a record) and then data will be referred to by that identifying (ID) number only. Participants will not be identifiable in any subsequent publication from the ID numbers. The original list aligning the ID codes and participant details will be stored in password-protected Swansea University computers, which will not be accessible to the research members until after the study.

6.8 PLEASE PROVIDE DETAILS OF ANY DIETARY SUPPLEMENTATION (DELETE IF NOT APPLICABLE)

Not applicable

7. LOCATION OF THE PREMISES WHERE THE RESEARCH WILL BE CONDUCTED.

- Interviews will be conducted either at Swansea University or (in the case of teams) at the team's training/playing location or sports centre. The location of interviews will depend on the preference of each participant, but in all cases it will be at a location that is accessible, private and quiet (without distractions) and where both interviewer and participant feel comfortable and safe.
- Owing to the ongoing COVID pandemic, interviews might be carried out via audio or video call (using the Zoom online communication platform) rather than with face-to-face interviews.
- The questionnaire will be completed online using the survey platform JISC. A URL will be sent to participants which will then take them online to JISC to complete the questionnaire.
- Due to the questionnaire being online it is probable that participants will complete the questionnaire within their own home.

8. POTENTIAL PARTICIPANT RISKS AND DISCOMFORTS

- During interviews the safety of both participant and interviewer will be a primary consideration. The research team will speak to participants throughout the study protocol to check if they are experiencing any issues and ensuring they are comfortable at all times. Participants might experience psychological discomfort and might become upset, although we expect the risk of this to be low (especially as anyone with a close personal experience of SCD will not be allowed to take part in the study). In the case of any such events, the interview will immediately be stopped for a short period, after which the participant will be asked if they would like to continue. If they say that they would then the interview will continue with caution. However, if the answer is no, they will be given the chance to talk and they will be offered a contact number or email address by the researchers. (We recommend that they refer to 'CRY – Cardiac Risk in the Young', the UK organisation for SCD, via https://www.c-r-y.org.uk).
- Participants completing the online questionnaire will be reminded that it is voluntary and they do not have to complete it if they do not wish to. Although unlikely, if a respondent begins to feel distressed and uncomfortable during the questionnaire, they may stop completing it and withdraw from the process. If this persists, similar to above, the participant will be offered to talk to the researchers via phone or email.
- Participants will be told that they are free to withdraw from the study at any point if they wish.

9.1 HOW WILL INFORMED CONSENT BE SOUGHT?

Informed consent will be sought following the initial meeting (to introduce the study) with individual athletes or the team manager/coach. Potential participants (those who express an initial interest in participating) will be provided with a copy of the participant information sheet and given up to one week to read this. If after reading the information sheet they are willing to take part in the study, then they will be asked to sign a consent form prior to taking part in the first interview.

For the second part of the study consent will be sought by completing the questionnaire, it will be clearly stated at the beginning of the questionnaire that by accomplishing the questionnaire consent has been given. Therefore, those who complete and submit the online questionnaire will be giving consent to use the anonymous data they have provided.

9.2 INFORMATION SHEETS AND CONSENT/ASSENT FORMS

- Have you included a participant information sheet for the participants of the study? Yes
- Have you included a parental/guardian information sheet for the parents/guardians of the study? No
- Have you included a participant consent (or assent) form for the participants in the study? Yes
- Have you included a parental/guardian consent form for the participants of the study? No

10. IF YOUR PROPOSED RESEARCH IS WITH VULNERABLE POPULATIONS (E.G. CHILDREN, PEOPLE WITH A DISABILITY), HAS AN UP-TO-DATE DISCLOSURE AND BARRING SERVICE (DBS) CEHCK (PREVIOUSLY CRB) IF UK, OR EQUIVALENT NON-UK, CLEARANCE BEEN REQUESTED AND/OR OBTAINED FOR ALL RESEARCHERS? EVIDENCE OF THIS WILL BE REQUIRED.

Not applicable.

11. HUMAN TISSUE SAMPLES

Does your research involve the collection or storage of human tissue samples? If yes, give details of sample collection, anonymisation, storage (including location) and disposal.

Please note that college ethics committee approval is not currently sufficient to comply with legislation for the storage of HTA relevant material. If the sample you intent to collect is listed as a relevant material (https://www.hta.gov.uk/policies/list-materials-considered-be-'relevant-material'-under-human-tissue-act-2004), seek NHS approval.

Not applicable.

12. COVID-19 DECLARATION

- Confirm that you have considered the latest (date of submission) UK government COVID-19 guidance and restrictions.
- State how you are accounting for the UK government COVID-19 guidance and restrictions in your proposed application, specifically relating the participant – researcher interaction and equipment hygiene.

Latest UK government advice: https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public
UK and Wales Government guidelines and restrictions have been considered when designing this study. Local safe operating procedures, including the use of appropriate PPE, will be followed.

13. APPLICATION DECLARATION

Please read the following declarations carefully and provide details below of any ways in which your project deviates from these. Having done this, each student listed in section 2 is required to sign where indicated.

- ***I have ensured that there will be no active deception of participants or the ethics committee.***
- ***I have ensured that no data will be personally identifiable.***
- ***I have ensured that no participant should suffer any undue physical or psychological discomfort (unless specified and justified in methodology).***
- ***I certify that there will be no administration of potentially harmful drugs, medicines or foodstuffs (unless specified and justified in methodology).***
- ***I certify that the participants will not experience any potentially unpleasant stimulation or deprivation (unless specified and justified in methodology)***
- ***I have attached a local Risk Assessment Form***
- ***If a student applicant, I certify that any ethical considerations raised by this proposal have been discussed in detail with my supervisor***
- ***I certify that the above statements are true***

Lead applicant signature (on behalf of all co-applic [redacted]
Date: 30/11/2020

Where submitted electronically the committee will accept the lead supervisor/researcher's email of the application as confirmation that both they and other researchers on the project have discussed and are happy to adhere to the above.

14. IF STUDENT APPLICATION, SUPERVISORS APPROVAL (if appliable)

Swansea University
Prifysgol Abertawe

Supervisor's [redacted] **signature:** **Date: 30/11/20**

[redacted]

PARTICIPANT INFORMATION SHEET
(Version 1.1, Date: 07/1/2020)

Project Title:

Barriers and facilitators to introducing a screening programme for sudden cardiac death in various sporting populations.

Contact Details:

Ed Couzens
[redacted]

1. Invitation Paragraph

I would like to invite you to take part in my postgraduate research study. My name is Ed and I am a postgraduate masters student at Swansea University. Before you decide if you would like to take part, it is important to understand why the research is being done and what it will involve for you. Please take your time to read the following information carefully and discuss it with someone else if you wish. If there is anything you do not understand or about which you would like more information, please do not hesitate to ask us.

2. What is the purpose of the study?

Sudden Cardiac Death (SCD) is the term used to describe the unexpected death of a person who (shortly before) was apparently healthy, and whose cause of death is attributed to sudden cardiac arrest (i.e. their heart ceasing to beat properly). Around twelve fit and healthy young people (aged under 35 years) are thought to die from SCD each week in the UK. SCD in young people has become more well known in recent years, with high-profile cases reported on the news and in social media (often occurring during or following sports participation). Such reports have provoked the question “should a mandatory screening programme be established for every young person engaged in competitive sport in the UK?”. The aim of such a programme would be to save, or at least prolong, the lives of those who do not realise they are at risk of SCD. However, not everyone thinks that screening for SCD is a good idea, because it has an associated cost and it might lead to anxiety in some people. Important aspects of the ongoing SCD screening ‘debate’ that have not been considered so far are the views (and understanding) of athletes and sports management personnel regarding SCD screening. We urgently need to ask their opinions about whether they think SCD screening is a good thing in their particular sport and to see if there is support for a mandatory SCD screening programme. This is the purpose of the present study. We want to speak to athletes across a range of sporting levels (e.g. professional, semi-

professional and amateur teams, local sports club and gyms) as well as doctors and allied medical professionals. We will interview individuals about their understanding of SCD and their opinions about SCD screening. By doing so, we aim to get an insight into the opinions of people such as yourself on this topic, and to see whether views differ between different sporting levels, and to also gain insight into doctors and medical professionals knowledge and personal opinions on the topic. Later, we will develop a questionnaire designed around the answers from these interviews; we plan to send these questionnaires to a large number of athletes to get the views of as many people as possible about SCD screening. We hope that this information will be useful in showing whether or not there is a desire amongst the sporting community to establish a mandatory SCD screening programme in the UK.

3. Why have I been chosen?

You have been chosen to take part in this study because, according to the information you have provided, we believe you to be either a) a healthy person in the age range 18-45 years, of generally good health, and someone who engages in regular physical activity and sports participation, b) part of a sports team's management structure, or c) You are a medical professional with a general medical background or specialising in cardiac health. Please note that the participation in this study is completely voluntary and you can withdraw from this study at any point if you wish to do so. If you would like to take part, we will give you a consent form to read and sign to show that you agree to take part in the study.

4. What will happen to me if I take part?

Once you have agreed to take part in the study and completed the consent form, we will arrange an interview date and time which is convenient for you. We will aim to complete the interviews via Zoom, this provides privacy and also ensures that interviews will be carried out at a safe social distance, therefore not breaching COVID-19 restrictions. The interview will be audio recorded and will last for no longer than 45 minutes. Your interview will later be transcribed (typed out to allow easier analysis) along with those of the other participants, to allow us to identify any common themes mentioned by people taking part in the study.

N.B. Athletes:
After learning more about SCD you (or your manager/coach) might decide that you should undergo SCD screening. **This will be entirely your decision (or that of your coach/manager) and you should be aware that there is likely to be a cost associated with this.** We can provide you with more information about screening providers if you would like us to do so. **Our research study is not about the screening itself - it is about your knowledge and views about SCD and SCD screening – and we would like you to take part in the research irrespective of whether you are likely to undertake SCD**

screening. We will ask you to let us know if you do subsequently attend a screening event. In that case, when you let us know we will ask you if you are willing to attend a further interview so that we can hear about the reasons for your decision and your opinions on the screening experience.

Participant information for those who complete the questionnaire will be provided on the questionnaire.

5. What are the possible disadvantages of taking part?

The risks associated with this study are minimal. We recognize that talking about screening and personal experiences could potentially lead to the onset of mild anxiety and stress, but you will be free to end the interview if this occurs, and the interviewer will also be vigilant for any signs of distress during the interview.

6. What are the possible benefits of taking part?

Should you choose to take part in the research study you will be aiding us by giving us insight into attitudes towards cardiac screening among athletes/management from different sporting levels, or about the knowledge, experiences and personal opinions of medical professionals with regard to SCD and SCD risk factors screening. You will also provide us with invaluable data to work towards hopefully implementing a nationwide screening program at some point in the future.

7. Will my taking part in the study be kept confidential?

All of the information that is collected about you during the study will be kept strictly confidential. You will be given a unique number as a code so that you cannot be identified from any of the study's data or results. Data will only be accessible to the research student and the supervisor. Password protected computers will be used for storage of the data and will only be accessible to the researchers of the study. We aim to publish our findings in a thesis at the end of the study. Please read the text below for more information on the Data Protection and Confidentiality regulations that are applicable to your participation in this research:

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team.

All electronic data will be stored on a password-protected computer file stored on computers belonging to either Swansea University or the students. All paper records will be stored in a locked filing cabinet (Room A114, Engineering East, Bay Campus, Swansea University). Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous, at the point when your data is stored (i.e. on the first day of your participation in the study protocol), thus it will not be possible to identify and remove your data at a later date, should you decide to withdraw from the study. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before you leave.

Data Protection Privacy Notice
The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet.
Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Engineering Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?
We will hold any personal data and special categories of data for six months following the end of the study. Anonymised data will be kept for five years following the end of the study.

What are your rights?
You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer:-

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP

Email: dataprotection@swansea.ac.uk

How to make a complaint
If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details above.

If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

8. Declaration of interests

Two members of the research team are directors of Cardiac Health Diagnostics Ltd., a provider of SCD screening services. This provider will not be promoted in any way during the study. If asked for details of SCD screening service providers the research team will make available details of all know providers, of which two are currently known to us (Cardiac Health Diagnostics and Cardiac Risk in the Young).

9. What if I have any questions?

If you have any further questions, then please don't hesitate to contact the students using the contact details at the top of this document. The project has been approved by the College of Engineering Research Ethics Committee, Swansea University. If you have any questions regarding this, any complaint, or concerns about the ethics of this research please contact Dr Andrew Bloodworth, Chair of the College of Engineering Research Ethics Committee, Swansea University: coe-researchethics@swansea.ac.uk . The institutional contact for reporting cases of research conduct is Registrar & Chief Operating Officer Mr Andrew Rhodes. Email: researchmisconduct@swansea.ac.uk. Further details are available at the Swansea University webpages for Research Integrity. http://www.swansea.ac.uk/research/researchintegrity/.

PARTICIPANT CONSENT FORM
(Version 1.1, Date: 07/01/2020)

Project Title:

Barriers and facilitators to introducing a screening programme for sudden cardiac death in various sporting populations.

Contact Details:

Ed Couzens
[redacted]

Please initial box

1. I confirm that I have read and understood the information sheet dated 09/10/2019 (version number 1.1) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation in this study is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that sections of any of data obtained from me during this study may be looked at by responsible individuals from Swansea University or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to these records. ☐
4. I understand that data I provide may be used in reports and academic publications in an anonymous fashion. ☐
5. I have no known cardiovascular (e.g. heart), metabolic (e.g. diabetes or pre-diabetes) or renal (e.g. kidney) disease. (Not applicable for medical professionals) ☐
6. As far as I am aware, I have not experienced any signs or symptoms of cardiovascular (e.g. heart), metabolic (e.g. diabetes or pre-diabetes) or renal (e.g. kidney) disease. (Not applicable for medical professionals) ☐
7. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

PARTICIPANT DISTRESS

Procedures to follow in the event of participant distress during Interviews/Focus

Groups

Prior to the interview:
Prior to conducting interviews, pilot interviews will be conducted in liaison with the supervisor. These interviews will provide the researcher with an opportunity to identify any questions that might lead to distress and where appropriate, take steps to rephrase or change these questions.

Before conducting the first formal interview, the student will meet with their supervisor to discuss to procedures that are in place in case a participant becomes distressed during an interview. The supervisor will also ensure the student feels prepared for the interview. The supervisor must be satisfied that the researcher is competent in conducting interviews before giving approval for the commencement of data collection.

Students will inform their supervisor where and when they are completing all interviews and in turn the supervisor will ensure the student has a means of contacting them when they are conducting interviews.

During the interview:
At the beginning of the interview the student will remind the participant that they can stop the interview at any time, that they can choose not to answer questions, and that there are no right or wrong answers to questions (so there is no fear of 'saying the wrong thing').

Once the interview begins, the researcher will be required to be aware of any potential indications of distress (e.g., withdrawing, visible upset, declining to answer numerous questions, shifting in seat, looking away from the interviewer, asking for the interview to end) and should air on the side of caution in all instances. If there is even the slightest indication that participants might be distressed students must immediately follow the procedure below:

1) The recording will be immediately stopped and the participant will be asked if they are ok. At this point the participant will be asked if they want to take a break/end the interview/continue talking – the participant's decision will be final. If the participant decides to take a break and continue with the interview, confirmation will be sought that the participant is actually comfortable continuing and they will be reminded there is no penalty for withdrawing.

2) If the participant wishes to continue but remains distressed, the interviewer will make the decision to drawn the interview to an end. At this point, the interviewer will commit to providing the participant with an opportunity to talk and ensure the participant is not visibly distressed when leaving the interview.

3) If the participant remains distressed and the researcher does not feel capable of managing the situation they will contact their respective supervisor who will be available at all times during interviews by phone contact. Depending on the situation, the supervisor will either provide guidance to the student, speak

directly to the participant over the phone, or make attempts to go and meet with the researcher and the participant.

4) If the participant has become distressed at any point in the interview, the student will ensure the participant has the contact details of the rest of the research team and remind them that they are free to contact any member of the research team if there is anything further they would like to discuss.

The interviewer will also offer to provide the participants with a list of local contacts (e.g., counselling services, sport psychology services)