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# A Call to Action to Improve Cardiac Arrest Outcomes: A Report From the National Summit for Cardiac Arrest



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Sudden cardiac arrest (SCA) represents a major cause of premature mortality globally, with enormous impact and financial cost to victims, families, and communities. SCA prevention should be considered a health priority in Australia. National Cardiac Arrest Summits were held in June 2022 and March 2023, with inclusion from multi-faceted endeavours related to SCA prevention. It was agreed to establish a multidisciplinary Australian Sudden Cardiac Arrest Alliance (AuSCAA) working group charged with developing a national unified strategy, with clear and measurable quality indicators and standardised outcome measures, to amplify the goal of SCA prevention throughout Australia.

A multi-faceted prevention strategy will include i) endeavours to progress community awareness, ii) improved fundamental mechanistic understanding, iii) implementation of best-practice resuscitation strategies for all demographics and locations, iv) secondary risk assessment directed to family members, and v) development of (near) real-time registry of cardiac arrest cases to inform areas of need and effectiveness of interventions. Together, we can and should reduce the impact of SCA in Australia.

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**Keywords** 

Sudden cardiac death • Arrhythmia • Resuscitation • Cardiac genetics • Cardiomyopathy • Heart attack • Defibrillator

#### Introduction

Sudden cardiac arrest (SCA) is when the heart stops meaningful contraction and life-sustaining output. Typically, this is the result of a rapid, unstable cardiac rhythm. This can be due to a primary or secondary electrical problem of the heart. Most commonly in adults, it is caused by a blockage of a heart artery (acute myocardial infarction or 'heart attack') or an abnormality in the heart structure or function (a cardiomyopathy). It is important to clarify that not all SCAs result from heart attacks, and not all heart attacks result in SCA; the two terms are commonly confused but are far from synonymous [1]. SCA may also have an underlying non-cardiac cause that typically leads to lack of oxygen and/or blood supply to the heart, such as asthma, choking, stroke, drug overdose or major physical trauma.

In Australia and New Zealand, there are more than 26,000 cardiac arrests occurring in the community every year, with a mortality approaching 90% in those treated [2]. In young and middle-aged populations of the developed world SCA is among the leading causes of death, resulting in more fatalities than road trauma, cancer, drug abuse or infectious diseases [3-5]. The incidence of sudden cardiac death (SCD) increases 100-fold from approximately 1-2 per 100,000 individuals in the young (age less than 30 years) [6,7] to approximately 1-2 per 1,000 individuals in middle-aged and older populations [8]. The health and economic burden of SCA is high, with annual losses approaching AUD\$2 billion in Australia, an amount comparable to productivity losses from all cancers combined [9]. Despite this, investment in SCA research remains low on a global basis, with American data indicating that SCA remains underfunded compared to all other leading causes of death [10].

Despite the substantial personal and societal burden, Australia lacks a national governmental strategy aimed at preventing deaths associated with SCA. There have been some promising state government commitments to addressing the burden of SCD through provision of automated external defibrillators (AEDs), education and awareness initiatives [11–13]. A pilot study with the Victorian State Government is also underway to provide teachers with the materials needed to educate high school students in basic life support [14]. These are an early start to addressing the significant gap between the economic and emotional impact of the disease versus the current level of attention given to the problem. This White Paper documents the proceedings,

outcomes, and aspirations of the inaugural National Summit for Cardiac Arrest<sup>1</sup>, where a diverse group of medical providers, academics, persons with lived experience, philanthropic groups, government and non-government health organisations met to discuss what more can be done to prevent SCA in Australia.

Reducing the impact of SCD is a multi-disciplinary problem that requires: (i) fundamental, clinical and translational research, (ii) continuous development and refinement of clinical standards related to risk identification and treatments of SCA, and (iii) awareness, education, and advocacy to address factors before, during and after a cardiac arrest (see Figure 1). These objectives cut across multiple specialties including, but not limited to, family medicine, cardiology, intensive care, emergency response services, forensic pathology, and allied health services.

The rationale underpinning the National Summit for Cardiac Arrest was that:

- SCD represents a major health burden, and its prevention should be a national priority;
- Current investment in research and implementation of preventive strategies is modest relative to the health burden and societal impact;
- Enhancing coordination among the wide range of groups working on the prevention and treatment of SCA is necessary.

The Summit sought to define the current status of SCD/SCA research and clinical care in Australia, to identify priorities for advancement, and explore innovative 'blue sky' ideas with potential for large impact.<sup>2</sup> As detailed in Supplementary Table S3, there were 65 attendees at the Summit representing a range of stakeholders and disciplines including medical practitioners (cardiologists, anaesthetists, forensic pathologists and family practitioners), paramedical practitioners (state-based and St John Ambulance services), epidemiologists, non-government organisations (including the National Heart Foundation [NHF]), philanthropic SCA organisations, public servants and persons with lived experience.

While resuscitation in Australasia is guided by the guidelines from the Australian Resuscitation Council [15], these guidelines do not address the prevention or follow-up care of SCA. After the National Summit for Cardiac Arrest, two key documents have been published that were directly pertinent to the Summit's objectives; The European Society of Cardiology (ESC) published guidelines for the management

<sup>&</sup>lt;sup>1</sup> The 1<sup>st</sup> National Summit for Cardiac Arrest was held in Canberra, ACT, Australia on 1 July 2022. The program for the Summit is provided in Supplementary Table S1. The Summit received sponsorship from several universities, medical research institutes and philanthropic groups (Supplementary Table S2) whilst all attendees were responsible for their own travel and accommodation costs. The list of attendees and the groups that they represented are detailed in Supplementary Table S3.

<sup>&</sup>lt;sup>2</sup> The program and sponsorship for the Summit is provided in Supplementary Table S1 and S2.

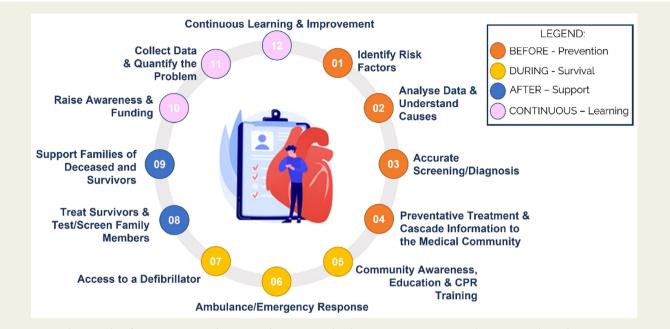


Figure 1 The 'Circle of Hope' encapsulating goals in research, discovery, awareness, advocacy, and implementation.

of ventricular arrhythmias and prevention of SCD [16], and The Lancet Commission report to reduce the global burden of sudden cardiac death was released in 2023 [17]. Although these articles post-dated the Summit and were therefore not referred to during the meeting, they will be referenced as important international standards of care against which we can benchmark Australian policy and practices.

# Setting the Scene-Definitions, Incidence and Cost of Cardiac Arrest

#### **Definitions**

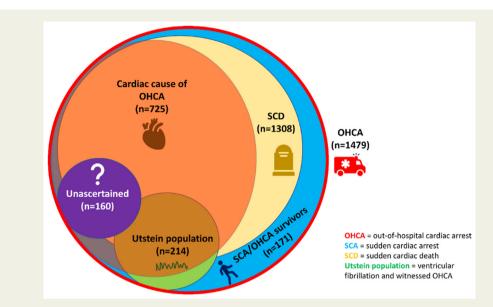
The term **sudden cardiac arrest** (SCA) is when the heart stops meaningful contraction and life sustaining output. This is usually due to an abnormal or chaotic heart rhythm followed by cessation of cardiac electrical activity.

Multiple terms are used to describe the problem and are sometimes used interchangeably but have quite different implications. The term 'heart attack' is a lay term that refers to when there is a sudden blockage to one of the arteries that provides blood supply to the heart which results in some heart muscle damage. In some cases, a heart attack can cause a rapid unstable heart rhythm disturbance resulting in cardiac arrest. In middle-aged and older populations, myocardial infarction ("heart attacks") are the leading cause of cardiac arrest. As a result, the term heart attack is often generalised as being interchangeable with cardiac arrest, but this should be avoided. Only a minority of heart attacks are complicated by cardiac arrest, and heart attacks are but one cause of cardiac arrest.

Differences in the terms used to describe cardiac arrest (or "arrest") have considerable effects on the size of the population under consideration (see Figure 2). Out-of-hospital cardiac arrest (OHCA) refers to people who have a cardiac arrest in the community (e.g., at home or in a public location). Sudden cardiac death (SCD) refers to approximately 90% of OHCA cases who do not survive to hospital [18,19]. These terms reflect the belief that the majority of these cases are due to a primary cardiac cause. However, recent data from large clinical registries (including Australian data), has demonstrated that in approximately 45% of OHCA cases the primary cause is non-cardiac (e.g., drug overdose, respiratory and neurological causes) [19-21]. There is some inherent linguistic inconsistency resulting from the historical medical assumption that a majority of sudden cardiac arrests are due to cardiac causes. This is illogical for the approximately 45% of SCAs caused by non-cardiac aetiologies resulting in the strange nomenclature of "non-cardiac sudden cardiac death" [19] (Figure 3).

Within reported discharge statistics, differing endpoints may also be used, raising further confusion. Overall, survival to hospital admission in OHCA in Australia is approximately 10%, while the proportion of OHCA victims who survive to hospital discharge with functional independence approximates only 5% [2,22–24]. Many of the aims of the Working Group address both improving survival to hospital admission and meaningful independent survival, and neurological recovery post-discharge.

The 'Utstein comparator group' refers to OHCAs that are witnessed and in whom the initial rhythm is documented as ventricular fibrillation (i.e., those with the optimal chance of successful resuscitation) (Figure 2). This group is useful for benchmarking and assessing the availability and effectiveness



**Figure 2** Impact of cardiac arrest definitions on the number of subjects that would meet criteria. Data obtained from 2 years of cardiac arrest cases aged 1–50 years in Victoria, Australia [19].

of treatments across the 'chain of survival' (see Figure 4). King County, in Seattle, WA, USA is quoted as the exemplar and world-leading with survival outcomes of up to 62% in 2013 in the Utstein group [25]. Whilst this is both inspirational and aspirational, this group of OHCAs represents only a minority of cases (11.3% in a United States cohort of more than 200,000 SCAs [26], 16.9% in Australia and New Zealand [2]).

For the remainder of this document, we will favour the term sudden cardiac arrest (SCA) as an umbrella term that includes all cardiac arrest cases presumed to be of cardiac aetiology, occurring in the community and in medical facilities, and independent of initial cardiac rhythm.

#### Rates and Causes of SCA by Age and Sex

One of the largest influences on the underlying cause of the SCA is the age group studied. Studies in Australia and New Zealand are among some of the largest and most comprehensive worldwide [6,19,27–29]. The most common cause of death observed in individuals aged under 35 years is 'unexplained cardiac death', sometimes referred to as 'sudden arrhythmic death syndrome' because of the assumed underlying aetiology being an electrical problem predisposing to malignant ventricular arrhythmias. While inherited arrhythmia syndromes such as long QT syndrome have long been suspected as an important cause of unexplained SCA,

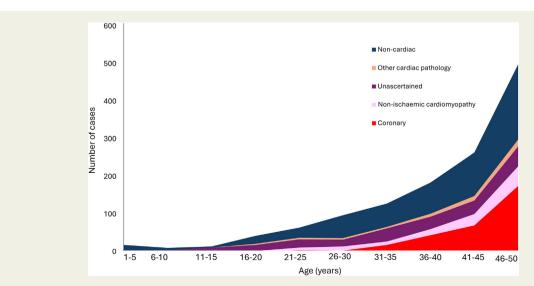
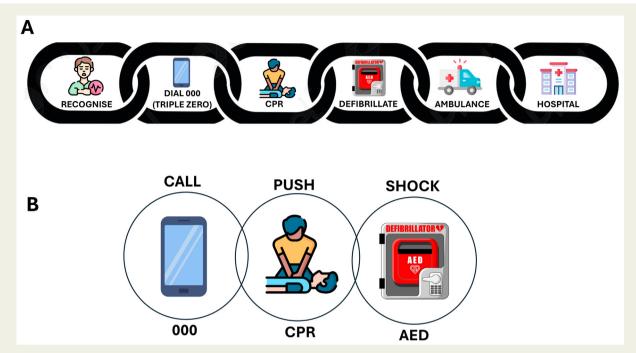


Figure 3 Causes of sudden cardiac arrest by age group in cases up to 50 years (modified from Paratz et al. [19] with permission).



**Figure 4** The Resuscitation Chain of Survival graphics display the series of actions or interventions in response to someone experiencing a sudden cardiac arrest. The graphics in A) begin with the bystander response and end with rehabilitation, and the graphics in B) provide simple messaging to the community to emphasise the important response by first bystanders. Abbreviations: AED, automated external defibrillators; CPR, cardiopulmonary resuscitation.

comprehensive genetic studies have recently identified causal variants in inherited cardiomyopathy genes leading to an arrhythmic phenotype that precedes overt structural disease, and which may account for approximately one in five cases of unexplained SCA in younger persons [30–32]. From the age of 30 years, particularly in men, ischaemic heart disease becomes the dominant underlying cause of SCA (Figure 3) [19]. Other important causes in the young and middle-aged groups includes cardiomyopathies, ion channel disorders, congenital and vascular cardiovascular anomalies. Despite community speculation, current evidence suggests that rates of SCA were not significantly influenced by the COVID-19 pandemic or vaccination [33,34].

It is important to recognise that statistics for older populations are likely to be less accurate as few older victims of SCA undergo a post-mortem examination and thus the underlying aetiology is more often assumed [35]. This is relevant in two respects; firstly, the evolving recognition that a substantial minority of SCA have a non-cardiac underlying cause and this may be even more pertinent in older populations in whom non-cardiac comorbidities are more prevalent. For example, a significant minority of those who suffer a presumed SCA are later found to have suffered a cerebrovascular accident or 'stroke' such as a ruptured intracerebral aneurysm or hypertensive haemorrhage, and this likelihood almost certainly increases with age [20]. Secondly, ischaemic heart disease is assumed to be the dominant cause of SCA in older individuals that have an underlying cardiac

cause [36]. Thus, the incidence of SCA attributable to cardiomyopathies and channelopathies in older populations is likely underestimated and less certain [37]. This lack of accuracy likely contributes to the variance in quoted statistics regarding incidence of SCA in the general population [38]. Given that SCA in the elderly (>80 years of age) is the fastest-growing segment of SCA in Australia and already the dominant population in countries such as Japan [28], it is important to better define the causes and management of SCA in this age group.

SCA is 3-5 times more common in men than in women [38–42]. This is true for most age groups, although there is an attenuation in sex disparity in later decades. The excess SCA risk in males is true for most underlying aetiologies; ischaemic heart disease, cardiomyopathies, channelopathies and even cases of uncertain causation. The reasons for the sex disparities are unknown and likely due to many factors including physiological, social, and individual [41]. While women contribute an overall smaller proportion of SCA, their events generally occur later in life, without a prior cardiac diagnosis, and are more likely to be due to nonischaemic causes, compared to men [43]. Numerous studies report lower rates of bystander cardiopulmonary resuscitation (CPR), defibrillator pad placement and/or bystander defibrillation in women experiencing SCA [44-47]. Determining the causes of these discrepancies may provide insights into protective factors that could assist in improved preventive strategies for both sexes.

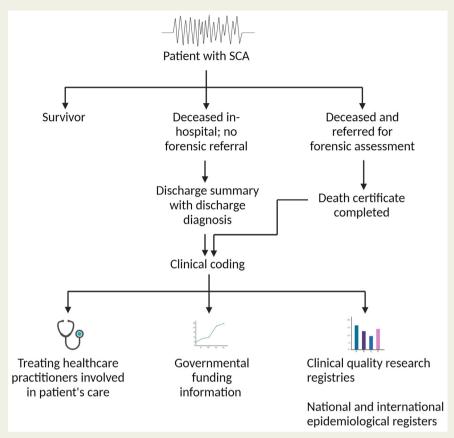


Figure 5 The impact of ambiguous hospital documentation on publicly available statistics related to sudden cardiac arrest (SCA) (adapted from Paratz et al. [48]).

It is notable that we have relatively scarce details on SCA in Indigenous populations, including the Australian and Torres Strait Indigenous populations. A greater understanding of the incidence and outcomes of SCA in the diaspora of Indigenous and ethnic groups is an important goal in the aim of reducing SCA burden.

# **Limitations in Public Statistics Regarding Cause of Death**

In Australia, cause of death statistics are compiled by the Australian Institute of Health and Welfare (AIHW). These rely upon hospital discharge summaries and death certification (Figure 5). As a large proportion of death certificates are completed with ambiguous or uninformative content, these statistics do not reliably enumerate the number of sudden deaths of the causes [48]. The potential harm of inaccurate diagnoses extends from the immediate counselling and care of surviving family members to the broader issue of estimation of burden of disease and resource allocation (Figure 5).

Data for every OHCA attended by paramedics is collected into registries by every Australian ambulance service. This data is then collated by the Australasian Resuscitation Outcomes Consortium (Aus-ROC) in the Australian and New Zealand OHCA Epidemiological Registry, known as the Aus-ROC Epistry [2]. Most ambulance services collect hospital or 30-day outcomes for patients that survive to hospital, and provide survival data for subgroups of OHCA in the Australian Government Productivity Commission Report on Government Services [49]. OHCA registries collect a presumed cause of the arrest based on international definitions [15], based on information available at the scene. The Victorian End-UCD registry is the only known Australian database to capture adjudicated data enabling accurate determination of aetiology of OHCA in young adults [50].

Improving the reporting of SCA is critical to defining priorities for how to improve outcomes and a National SCA Registry would allow greater appreciation of the incidence and burden of SCA in Australia. This Registry would complement existing initiatives, such as the Aus-ROC Epistry, in that it would include linkage with an adjudicated underlying cause, with reporting conformity to data captured by other international pathology beyond baseline International Classification of Diseases categories. In addition, the 11<sup>th</sup> International Classification of Diseases will have more nuanced diagnostic codes better aligned with capturing cause of

cardiac arrests [51]. There are challenges and limitations to a multi-source SCA registry. Access to post-mortems in rural and regional areas can be difficult and presents a geographic challenge in Australia, often affecting high risk populations such as Indigenous populations where reduced life expectancy is documented. However, some insights into the influences of Australian geography on SCA outcomes have been documented [52].

#### **Financial Cost of Cardiac Arrest**

The health and economic burden of SCA is substantial, predominantly underpinned by very high mortality. A study describing contemporary costs in the Australian setting estimated annual national losses approaching AUD\$2 billion (USD\$1.42 billion) in productivity losses alone [9], a cost exceeding that of all cancers combined. Another recent cost analysis using different methodology accounting for both direct and indirect costs estimated an upper boundary cost of up to AUD\$51 billion to the Australian economy [53]. Prioritising research and state-of-the-art care for SCA patients appears economically sound. For example, modelling various scenarios in which AEDs could be made more available has potential to provide net cost-savings [54].

# Bystander Response and Advanced Resuscitation

The Chain of Survival refers to a series of actions or interventions that can be made in response to someone experiencing a SCA [55]. These interventions traditionally begin with bystander response and end with rehabilitation (see Figure 4A). The first links in the Chain of Survival can be carried out by bystanders, regardless of age or the level of training in first aid or basic life support [14,56]. Simple messaging has been developed to help the community understand the role they can play, and graphics have been developed to emphasise the importance of these first bystander links (Figure 4B).

While each link in the Chain of Survival is important to achieving the best possible outcomes for the patient, the most important links are the first three [57]. Given these first three links (Recognise, Dial 000, CPR; Figure 4A) are usually carried out by members of the public, there exists an inherent responsibility on Governments and the community to ensure that lay-responders are well educated and practiced in resuscitation. In many cases where an AED is either not available or not indicated (due to absence of ventricular arrhythmia), CPR may be the only available strategy offering prognostic value in a cardiac arrest.

Defibrillation—the key link in the chain. CPR alone, whilst critically important, is not sufficient to restore a regular rhythm for most cases of cardiac arrest. Use of an AED in the early stages of a cardiac arrest (the first 3–5 minutes) more than doubles survival rates [58]. Thus, members of the community can have a substantial impact on SCA survival if they have received basic training and an AED is available [59]. Outcomes

in these settings are superior to those when bystander CPR is commenced but defibrillation is only performed after the arrival of emergency medical services (EMS) [58].

### **Modern Challenges for EMS**

The timely arrival of EMS and paramedics on the scene is a challenge in Australia due to many factors beyond the control of frontline paramedics [2]. There is evolving evidence that EMS delays are a world-wide phenomenon likely due to resource limitations and issues of transit times in built-up and increasingly congested urban environments [18]. As a result, there have been some innovative solutions for delivery of SCA care. In Victoria, Australia, for example, first responders are co-dispatched from Fire Rescue Victoria to maximise timely on-scene arrival [58]. A mobile phone-based app named 'GoodSAM' has been rolled out in multiple states of Australia for several years, and is continuing to expand coverage [60,61]. Internationally, some investigators have trialled the use of drones accompanied by video support to deliver AEDs [62]. Strategic approaches to AED placement are also becoming increasingly important to maximise availability and avoid the socioeconomic and other disparities seen in the availability of defibrillators [63-65].

Given that myocardial infarction is the most common cause of SCA in middle-age and older patients, several programs have been initiated that facilitate pre-hospital diagnosis of myocardial infarction and communication such that a patient can be transferred directly to the interventional cardiac catheterisation laboratory where percutaneous coronary intervention (PCI) can be undertaken to ensure myocardial reperfusion in the shortest period of time [66–69]. These strategies may be as simple as pre-notification of electrocardiograms to enable advance cardiac catheterisation activation, to dispatch of teams initiating mobile extracorporeal cardiac membrane oxygenation cardiopulmonary resuscitation (ECPR) in the pre-hospital setting [67,70,71].

### **Hospital Treatment**

Best practice in-hospital care has been informed by randomised controlled trial evidence, much of which has been conducted in Australia. Although a detailed discussion of current practice is beyond the scope of this White Paper, care inclusive of temperature regulation, oxygen supplementation, anti-arrhythmic agents, inotropic support and early coronary evaluation have all been the subject of major trials over the last decade [72–74].

Given only one in 10 SCA victims survive to hospital [75], delegates at the Summit involved with in-hospital care of SCA stressed that whilst optimised hospital care was essential, this formed the 'thin end of the wedge' in terms of improving overall outcomes and that SCA response times and pre-hospital factors had the greatest impact on overall survival and return to independent living [75].

Table 1 Summary of priority areas and framework to progress the goal of reducing the burden of sudden cardiac death (SCD) in Australia.

Priority areas for reducing the burden of cardiac arrest

- 1 Increasing community CPR training rates
- 2 Strategic and enhanced provision of AEDs in the community
- 3 Development of innovative solutions to improve EMS response times
- Development of nationwide family support services that encompass rehabilitation for survivors, genetic assessment of families and psychological support services
- 5 Better identification of patients at risk prior to a SCA
- 6 Personalised identification and care of high-risk or defined populations with unique needs

#### Framework for reducing the burden of SCD

- A multi-faceted SCD prevention strategy that includes:
   a. endeavours to progress community awareness;
  - b. fundamental mechanistic understanding;
  - c. preventive strategies;
  - d. best-practice resuscitation strategies for all demographics and locations;
  - e. secondary risk assessment directed to family members;
  - f. (near) real-time registry of cardiac arrest cases to inform areas of need and effectiveness of interventions.
- A new body that represents this multi-faceted agenda by:
  - a. bringing awareness to the issues;
  - b. advocating for resources that more closely match the burden of disease.

Abbreviations: AED, automated external defibrillators; CPR, cardiopulmonary resuscitation; EMS, emergency medical services; SCA, sudden cardiac arrest.

#### Rehabilitation

Without proper rehabilitation, the Chain of Survival is incomplete. Of those who survive SCA, standardised mortality rate is 5.6 times above baseline in the first year postarrest, primarily due to a combination of factors related to the aetiology of the arrest and complications of the arrest [24,76]. Rehabilitation can play an important role in supporting patients and their families through the first 12 months following an OHCA event and may assist to improve functionality and outcomes [77]. There is great benefit in ensuring emphasis is placed on comprehensive cardiac rehabilitation from a mental and physical perspective for patients and families [78].

Comprehensive, evidence-based cardiac rehabilitation programs will be multidisciplinary, and include cardiac, neurological and psychological aspects, as well as education and information that support both the patient, and the family members who will be supporting the patient at home [79]. Education about diet, healthy choices and exercise as well as CPR education are also important elements [80].

# Knowledge Gaps and Recommended Targets for High-Impact Interventions

The National Summit for Cardiac Arrest identified six key areas with potential to significantly impact survival from SCA (see Table 1).

#### 1. Bystander CPR

There was consensus that the greatest potential strategy to increase community rates of effective CPR is maximising the population that can perform CPR. Bystander CPR rates in Australia are suboptimal, and regions with higher rates have a greater proportion of their population trained in CPR [81]. Suggestions for increasing rates of CPR include (i) aiming to have all school children taught CPR and (ii) consider making CPR competency a requirement to gain a motor vehicle license (as it is in many European countries) [14,82–84]. Basic life support also needs to be 'de-medicalised' and made more a part of everyday responsibility [85,86]. There is a need for simplicity of messaging (e.g. Call, Push, Shock) and assurance that 'any CPR is better than no CPR'. CPR training should also be more readily available by bringing training to the worker with frequent refreshers [87]. Additionally, CPR training should be targeted to those at high risk of cardiac arrest and has been successfully trialled for family members of cardiac patients during cardiac rehabilitation programs [88].

# 2. Greater Provision and Uptake of Public Access Defibrillation

Availability and confidence of use were the two major factors identified as limiting the more widespread and prompt use of AEDs. While most Australians state they know what an AED is, only one in five individuals are confident to use one [89]. It is critical that AEDs are in close proximity to where events occur [63]. A majority of arrests occur in private homes and, thus, community devices are a priority. There are many successful programs for rolling out AEDs in the community however, funding remains a barrier [63].

Even when AEDs are available, bystanders and first responders may not be aware of their location. There should be standardised signage and greater efforts to identify standard landmarks at which AEDs could be placed [90]. For example, in the United Kingdom, decommissioned telephone boxes are used as a standard location in which to house AEDs [63]. The technology to rapidly locate AEDs using smartphone-application-enabled global positioning system guidance is available, but there is a significant gap in population education and uptake of this technology that needs to be addressed [91]. Significant resources need to be dedicated to

awareness and education such that lay responders have the skills, technology and resources immediately available to provide the best opportunity for SCA victims.

Ideally, all first responder services should be trained and enabled with AEDs. For example, calls to the Australian emergency hotline (Triple Zero, 000) for a person who is unconscious, not breathing or has no pulse, are responded to in Victoria by Fire Rescue Victoria (FRV) firefighters in addition to the nearest ambulance. The police force are often among the first to respond to emergencies but are not currently included in the cardiac arrest emergency response and not routinely equipped with AEDs, despite police being specifically named in Program 6 of the Global Resuscitation Alliance's Ten Programs to Improve Survival from OHCA [92].

Progression to smaller, cheaper devices with longer battery life and lesser maintenance requirement ('ultraportable defibrillators') was noted as a logical solution. There are some devices emerging that are small, portable and provide a solution that may be more appealing for some customers' needs [93]. Once again, the impact of this exciting technology is limited without accompanied education, awareness and data on efficacy [94]. There is also a need for centralised data on AED use, location, serviceability and resuscitation success rates to inform future resource allocation and identify barriers to care. A centralised registry identifying existing AED registries and patterns of use would be highly valuable [63].

### 3. Advanced Pre-Hospital Resuscitation

Worldwide data has suggested that improvements in OHCA survival rates are starting to plateau [1,2,95]. One factor is believed to be the increased urban congestion and resulting limitations in ambulance response times [95]. The time from OHCA to advanced resuscitation (inclusive of defibrillation) is the main determinant of outcomes with bystander CPR being an important factor in extending this window of success. The Summit attendees affiliated with emergency response organisations highlighted the need for advanced resuscitation responsibility to be shared among other groups if we are to meet aspirations of more prompt resuscitation and resulting improved outcomes. There was a call for innovative strategies to be investigated that could enable faster response times, particularly in areas of higher population density. The efficacy of diversifying the response to all emergency services and, potentially, to other community personnel should be investigated. Similarly, novel strategies such as drone delivery of AEDs, have been investigated in some sites throughout the world [96,97].

For refractory cases of SCA in which there is a failure to restore cardiac output with defibrillation, there is a need for advanced circulatory support. Traditionally, this has been performed in hospitals but there is evolving experience in the expedient use of circulatory support such as extracorporeal membrane oxygenation (ECMO) [70]. There are current trials underway in Australia in which a specialist ECMO team may be deployed into the community for out of hospital implementation of circulatory support [98,99], to

improve equity of access of this therapy in a cost effective manner.

#### 4. Recovery Phase

Rehabilitation and psychological support were recognised as being often overlooked in the care of the SCA survivor. The recovery journey is complex, lengthy and often incomplete [100]. There are no specific funding pathways for the complex physical and psychological support required.

For patients who die, it is important to undertake a thorough SCA evaluation as this can positively impact on the physical and psychological health of family members and the community at large [75]. Determination of the cause of SCA is of utmost importance in preventive strategies given that inherited causes of SCA are common especially among young people. Furthermore, a better understanding of the circumstances and cause of SCA can inform community risk identification screening policies. Strategies aimed at reducing the impact of SCA in the community must include pathways to optimise post-mortem evaluation, appropriate post-mortem sample collection and storage, data collection and care that extend to potentially affected family members, including access to genetic testing.

# 5. Preventing SCA Through Upstream Risk Identification

Recognition of higher-risk individuals and disease-specific symptoms should be recognised when present, to provide an opportunity for preventive care [101]. These issues were discussed under the following four broad categories: coronary artery disease, cardiomyopathies and channelopathies, acquired heart disease (e.g., myocarditis, sarcoidosis) and vascular causes (including aortopathies, spontaneous coronary artery dissection and anomalous coronary arteries). This topic constitutes the biggest challenge in SCA prevention.

Coronary artery disease (CAD) is the dominant cause of SCA in middle-aged and older age groups. The risk factors for CAD are well known, many of which are modifiable with lifestyle and pharmacological interventions. Awareness combined with public health and personalised interventions has seen a marked reduction in myocardial infarction and SCA rates, particularly among older populations. However, it was noted that the improvement in SCA rates has plateaued and, moreover, there is an increasing prevalence of SCA and myocardial infarct victims who have few or no modifiable risk factors [102]. For example, a recent study of SCA in Victoria reported that almost two-thirds of victims had no standard modifiable cardiovascular risk factors [19]. Delegates at the Summit reinforced the value of current 'heart check' tools that quantify risk based on an assessment of risk factors [103]. These are important for two reasons: they identify subjects at higher risk, and the factors that can be addressed to reduce that risk. However, the Summit delegates also noted that new strategies are greatly needed to assist in identifying those who are at risk of SCA who are not identified using these screening tools [3, 104]. It was noted

that the catch cry to 'go and get a heart check' was a common response to every high-profile case of SCA but that this approach fails to identify a majority of those at risk. A more transparent discourse would inform the public that our current risk identification tools are coarse and that there is need for improvement given the massive impact and societal impost that SCA carries [105].

As many as one in three first time ST-elevation myocardial infarction (heart attack) have no standard modifiable risk factors [106,107], and these individuals have a substantially higher likelihood of cardiac arrest following myocardial infarct than do comparative individuals with cardiac risk factors [107-109]. There is a clear need to move beyond probability algorithms, to the identification and treatment of the underlying CAD [104, 110]. Strategies to enhance risk identification could include coronary imaging with coronary artery calcium scoring and/or computerised tomography (CT) coronary angiography, which has proven value in risk stratification. Other evolving tools including polygenic risk scores and protein or lipid biomarkers warrant further investigation. There was consensus that substantial investment should be directed at novel strategies to better identify subjects at risk of SCA and promote efficacious interventions to prevent CAD-related events.

Inherited cardiomyopathies and channelopathies, while rare, are a major cause of SCA in the young and therefore assume considerable importance in the discussion of SCA prevention. A genetic predisposition to SCA is relevant for individuals with a clinical phenotype of disease. In addition, a likely causative genetic variant can be identified in 10%–40% of SCA victims who have apparently normal cardiac function and structure [6, 111] . Studies performed prior to more

rigorous gene and variant curation standards likely overestimated the diagnostic yield of post-mortem genetic testing, with the true rate likely being at the lower end of this range. The identification of a causal genetic variant indicating an inherited heart disease is important, as cascade genetic testing (i.e., genetic testing for the presence/absence of the genetic variant identified in the index case), in conjunction with clinical screening, can clarify risk among family members (Figure 6). This can allow more tailored diagnostics and interventions, which can prove lifesaving.

While world-leading models of care have been developed for comprehensive clinical, genetic and psychological assessment of families following a SCA, these have not been uniformly practiced [112]. Indeed, financial and geographical constraints have been highlighted for their potential to magnify health disparities in the assessment of patients post SCA. Multidisciplinary models of care enable grieving families to receive case-specific information regarding their family member's cause of arrest, psychological support and informed advice regarding the heritability of the disease leading to diagnostic and therapeutic options need to be made more accessible throughout Australia.

While Australia has pioneered research and policy to enable effective evaluation of young SCD, including establishing comprehensive post-mortem evaluation of young SCD with forensic autopsy, and collection and storage of a sample appropriate for DNA extraction and genetic testing in future [113], the Summit attendees highlighted the significant challenges in families routinely accessing post-mortem genetic testing. Forensic services in Australia in general have reported challenges in infrastructure and resourcing, with state-by-state variation on access to services such as post-mortem imaging

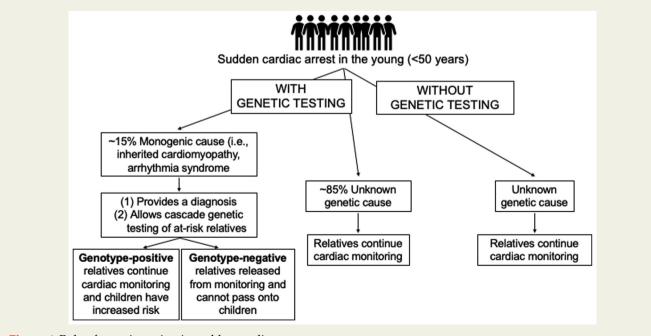


Figure 6 Role of genetic testing in sudden cardiac arrest.

[114]. Excitingly, in recent years genetic testing for inherited cardiomyopathies and inherited arrhythmia syndromes have been added to the Medicare Benefit Schedule. For family members of someone who has experienced SCD, however, the index case's Medicare number cannot be billed for genetic testing due to their death, precluding subsidised access to this testing. Therefore, families must deal with very long wait times via already stretched clinical genetics services, or access testing via research studies which can take >6 months for a result. The marked value where a genetic diagnosis can be made, allowing a cause of death and a powerful tool for risk stratification of family members, is clear [115]. However, the low diagnostic yield of genetic testing highlights the large gap in knowledge that exists in understanding the genetic causes of young SCA, which likely include complex polygenic and moderate effect size variation in combination with non-genetic factors. Taken together, very large datasets will be required to achieve sufficient statistical power to untangle such associations that might explain causes of SCA in young people or predict future events [116,117].

Several causes of acquired cardiac disease (e.g., myocarditis, sarcoidosis) can predispose to SCA. Often, diagnostic evaluation is commenced in a patient presenting with chest pain, palpitations or breathlessness and the diagnosis may be supported by the release of markers of myocardial injury. Cardiac magnetic resonance (CMR) imaging assumes a key role in the diagnostic workup of such patients. CMR can be used to identify myocardial inflammation and injury with high sensitivity and specificity and, moreover, the nature of the CMR abnormalities (such as pattern of late gadolinium enhancement) can be used to discriminate between the various disease entities commonly responsible [118]. An accurate diagnosis is critical in determining appropriate treatments that can help to prevent SCA recurrence in the individual. In some cases, the CMR findings will help identify familial heart disease thereby providing information of relevance to the family of the patient. Whilst CMR is an essential tool in the evaluation of patients who have suffered SCA or are at risk of SCA, access to this technology in Australia is limited. For most relevant indications, there is no current Medicare rebate and patients may be left to cover the cost. In addition to the cost, CMR is only available at specialist centres, and, in most cases, there are substantial waitlists. As a result, appropriate CMR tests are not available to many patients with a suitable indication.

Vascular causes of SCD (e.g., anomalous coronaries, coronary dissection, aortopathies, aortic dissection) can also result in SCA. Anomalous coronary arteries are a recognised cause of myocardial infarction, arrhythmias and SCA while spontaneous coronary artery dissection (SCAD) is an increasingly recognised cause of myocardial infarction, particularly in young-middle-aged women. Diseases of the major blood vessels can result in aneurysmal dilation, dissection, and catastrophic rupture. The extent to which these less common entities contribute to the burden of SCA remains incompletely resolved. There is a need for research to better quantify risk and prevention in these conditions.

#### 6. SCA in Sports

At the Summit, note was made that SCA during sports activity has received significant attention because i) deaths in professional athletes are often seen by large audiences and so receive significant media attention and ii) the high profile of sports and high level of sport participation in Australia makes it an ideal environment to engage with the community. It was noted that Registries are being created with the aim of understanding the relationship between sports trauma and traumatic brain injury and this could provide an opportunity to leverage that experience and specifically evaluate the hypothesis of a link between trauma and cardiovascular injury.

# International Efforts to Improve Prevention and Outcomes Following SCA

European Society of Cardiology (ESC) guidelines for the management of ventricular arrhythmia and prevention of SCD were released in August 2022 [16]. These were not available for reference at the time of the National Summit on SCA but are very pertinent to the aims and objectives of the Summit. Some of the key recommendations pertinent to the prevention of SCA are listed in Table 2. Each of these is listed as a Class I recommendation meaning that it is "recommended or is indicated".

The Lancet Commission to reduce the global burden of sudden cardiac death was published August 2023 [17] and likewise was not available at the time of the Summit, but reinforces key discussion points arising on the day. The commission highlights the substantial burden of SCA, with outcomes largely not improving in recent decades. Recognising the increased risk of SCA among certain high-risk populations, including those with inherited causes or with previous SCA, has been critical in curtailing future events, however in absolute numbers these individuals account for the smallest number of events. Most SCA occur in those in the general population with few or no known risk factors, highlighting the critical need to bring together multidisciplinary expertise in first-response, post-arrest care and research to identify new markers that could predict events. A complete revamp of existing approaches to SCA are needed to make a transformative impact to this problem, with countries encouraged to take this document and consider local applications.

## National Strategy for a Multi-Faceted Approach to Prevent Sudden Cardiac Arrest

As evidenced throughout this report, Australian researchers and practitioners have contributed significantly to the evidence base underpinning SCA risk identification, prediction and response. However, the Australian community remains

# Table 2 Summary of European Society of Cardiology (ESC) Guidelines recommendations (n=11) [16] with Class 1 evidence.

#### Public basic life support and access to AEDs

1. It is recommended that public-access defibrillation be available at sites where cardiac arrest is more likely to occur (shopping malls, stadiums, public transport stations and casinos).

2. It is recommended to promote community training in basic life support to increase bystander CPR rate and AED use.

#### Recommendations for evaluation of sudden death victims

- 1. Investigation of unexpected SD, especially in case of suspicion of inherited disease, should be made a public health priority.
- 2. In cases of SD, it is recommended to collect a detailed description of circumstances of death, symptoms prior to death, the family history, and to review prior medical files.
- 3. A comprehensive autopsy is recommended, ideally, in all cases of unexpected SD, and always in those <50 years of age.
- 4. In cases of SCD, it is recommended to retain samples suitable for DNA extraction and consult a cardiac pathologist when an inherited cause is suspected, or the cause of death is unexplained.
- 5. For SCD where the cause is known or suspected to be heritable, genetic testing targeted to the cause is recommended.
- 6. Following SADS, post-mortem genetic testing targeted to primary electrical disease is recommended when the decedent is young (<50 years) and/or the circumstances and/or family history support a primary electrical disease.
- 7. When an autopsy diagnoses possible heritable cardiac disease, it is recommended to refer first-degree relatives for cardiac assessment in a specialised clinic.
- 8. In non-autopsied cases of SD where inherited cardiac disease is suspected, it is recommended to refer first-degree relatives for cardiac assessment in a specialised clinic.
- 9. Familial evaluation of SADS decedents is recommended:
  - a. for first-degree relatives;
  - b. for relatives who must carry a mutation based on analysis of the family history;
  - c. for relatives with suspicious symptoms;
  - d. when the decedent's age is <50 years, or if there is other circumstantial data or family history to suggest heritable disease.

Abbreviations: AED, automated external defibrillators; CPR, cardiopulmonary resuscitation; SD, sudden death; SCD, sudden cardiac death; SADS, sudden arrhythmic death syndrome.

relatively naïve to the incidence, burden of disease, health care costs and the successes in improving outcomes to date. At the SCA Summit, there was agreement from all stakeholders that there was a clear need to increase awareness of this condition and optimism that awareness and advocacy would serve to partially address the marked mismatch between burden of disease and funding directed toward SCA research and preventive strategies, some of which could be instituted with immediate impact.

There was also agreement at the Summit that the 'sum of the parts' may prove synergistic. In a system in which funding has proved elusive, some attendees at the Summit voiced the concern that this had led to competition within SCA groups. For example, people debated whether limited money should be spent on AEDs when a large proportion of arrests are unwitnessed and the sentiment that prevention through mechanistic understanding may be better than incomplete treatment strategies. The general consensus was that the best strategy for a condition with such substantive burden of disease was for there to be sufficient funding to direct to all elements of the 'Circle of Hope' depicted in Figure 1. Fundamental discovery should not be competing with epidemiological science, implementation of best practice and subsequent auditing of survival. To re-state, the primary agreed outcome of the SCA Summit was to advocate

for all elements of science and practice aiming to reduce the incidence and impact of SCA. It was felt that there was rationale to form a new 'umbrella organisation' that could represent all bodies in SCA science with broad representation and membership that would aim to advocate for awareness of SCA and improvement in SCA outcomes through greater resource allocation to the sector.

The Summit attendees recognised the important work that had been undertaken that sought to address the complimentary elements of the Circle of Hope in Australia and New Zealand. In the ideal world, the preventative strategies would be completely effective and resuscitation responses rendered obsolete. However, in a more realistic scenario, optimisation of emergency responses, post-arrest care, data collection for quality control, education and awareness are all critical elements of the ultimate challenge of saving lives. Thus, each element of the Circle of Hope strengthens, but does not replace, a need for a national strategy that addresses the whole of the SCA agenda.

The community currently working to reduce the burden of SCA in Australia risk being under-recognised for their contribution because most researchers and practitioners address SCA as only part of their remit. Again, using the example of the paramedic services, world-leading innovations in resuscitative care are only part of the

requirements of a modern ambulance service. Similarly, few researchers have funding enabling them to focus solely on addressing SCA causes, preventions and treatments.

### The Agreed Framework

The framework to progress the goal of reducing the burden of SCA in Australia was agreed as follows:

- The SCA prevention strategy should be multi-faceted, including:
  - a. endeavours to progress community awareness,
  - b. resource fundamental research aimed at improving the mechanistic understanding of SCA and its causes,
  - c. develop and implement SCA preventive strategies,
  - d. implement best-practice resuscitation strategies for all demographics and locations,
  - e. ensure secondary risk assessment for family members,
  - f. (near) real-time registry of cardiac arrest cases to inform areas of need and effectiveness of interventions.
- A new body be formed that represents this multi-faceted agenda, bringing awareness to the issues and advocating for resources that more closely match the burden of disease, equally across all areas of need.

#### **Conclusions**

- 1. SCA is a major cause of death with a considerable cost to the Australian public.
- Prevention of SCD is possible. Gains can be made in risk identification, investigation of SCA, resuscitation, postarrest care and assessment of family members.
- 3. The prevention of SCD should be a national health priority.
- There is currently a substantial gap between the large burden of disease and the modest investment into its prevention and treatment.
- Recent international guidelines provide a framework for the prevention and management of SCD that is evidencebased and impactful but are not currently in routine practice in Australia.
- 6. It was resolved at the Summit that the multi-faceted endeavours related to SCD prevention in Australia are impressive in aggregate. However, a centralised voice that could provide focused advocacy to support research into preventing sudden death as well as improved resources and legislation to support best care in resuscitation interventions was deemed a critical need. The Summit attendees resolved to commence work on establishing a central SCA/ SCD focus group. Following the Summit, the Australian Sudden Cardiac Arrest Alliance (AuSCAA) was formed to address this manifesto.

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# **Appendices**

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