Cross-Party Group on Heart and Circulatory Diseases

Tuesday 17th of September 6-7.30pm

Minutes

Present

MSPs

Alexander Stewart MSP
Colin Smyth MSP

Invited guests

Save a Life for Scotland
Resuscitation Council UK

Non-MSP Group Members

Vicky Joshi
Jonathan Roden
Amelia Lincoln
Marcus Loney-Evans
Lesley Hill
Gareth Clegg
Sandra Auld
MacLean MacLeod
Mike Parker
Lesley Giudici
James Cant
Michael Bradfield
Richard Forsyth

Agenda item 1

Welcome and introductions

Co-Convenor Alexander Stewart MSP

Agenda item 2

Minutes of last meeting

Minutes of meeting held on Tuesday 4th of June to be agreed

Proposed by Colin Smyth and seconded by James Cant

Agenda item 3

Topic Discussion: Out of Hospital Cardiac Arrests (OHCA) and Survivor Care Standards

Alexander Stewart MSP (AS) introduces speakers:

Alexander (AS) welcomed the attendees and introduced the agenda for the meeting. He stated that he meeting would focus on the importance of improving care standards for survivors of OHCA and discuss the quality care standards for cardiac arrest survivors. AS highlighted that over 3000 individuals experienced an OHCA each year. Despite considerable progress, which had been discussed in previous meetings, survival rates remained relatively low. AS noted that only 1 in 10 survivors accessed rehabilitation services and support, which was a significant concern. AS stressed the need for more support and attention from the sector and the government to manage this issue in the future.

AS thanked the speakers for taking the time to attend the meeting and discuss the topic, and introduced the first speaker, James Cant, CEO of Resuscitation Council UK.

Speakers:

James Cant from RCUK (JC) Presenting on 'My Right to Cardiac Arrest Recovery. Resuscitation Council UK's 'Survivor' Quality Care Standard"

James Cant (JC) expressed gratitude for the opportunity to share the work done by RCUK. JC began by providing a brief history of RCUK, which was established over 40 years ago by a group of committed clinicians. Their goal was to ensure that resuscitation training and standards were consistent across all four nations in the UK and to be a world leader in this field. JC explained that whenever resuscitation training was conducted within the NHS, it utilized RCUK training. This training is conducted by the NHS for the NHS, as RCUK instructors were almost always NHS employees. JC highlighted the strong, intertwined relationship between RCUK and the NHS. JC noted that a few years ago, RCUK realized the need to extend training beyond the hospital context. They aimed to take a more comprehensive approach, which was facilitated by the chain of survival concept. Over recent years, RCUK had focused on both the initial and final links in the chain of survival, supporting individuals affected by cardiac arrest in in any way shape or form. RCUK distil clinical expertise from across the UK into clinical standards. Many people on this call will already have been involved with this standard from a clinical point of view, and JC thanks them for their contribution, calling the standards a team effort.

James provided context on the complexities and challenges of surviving a cardiac arrest. JC explained that surviving a cardiac arrest was a highly complicated and messy situation and coping with the aftermath could be equally complicated. Survivors often suffered from brain injuries due to oxygen deprivation and might wake up from an induced coma with PTSD and flashbacks. JC noted that families and witnesses might also experience psychological impacts, including flashbacks and emotional distress. JC highlighted that cardiac arrest could lead to emotional, cognitive, and fatigue issues, with very few people emerging unscathed.

The impact extended beyond the individual, affecting bystanders, clinical staff, and family members. JC likened the effect to throwing a rock into a pool, creating ripples that impacted everyone around the survivor. Family and friends often observed significant changes in the survivor's personality and behaviour. JC emphasized the importance of providing bespoke, specialist care to those impacted by cardiac arrest, and stressed that such care was crucial for addressing the wide-ranging effects on survivors and their support networks.

James explained that RCUK took clinical excellence and lived experiences to create blueprints for developing clinical standards and service provisions. JC acknowledged the challenges but expressed optimism about the progress that could be made, particularly in Scotland due to it’s ideal size for a locally focused yet nationwide solution to public health problems. JC noted the high level of integration across health boards and the combination of urban and rural areas. The strong relationships between the government and NHS in Scotland were also emphasized as key factors for making significant progress. JC mentioned that the conversations within the CPG were a testament to Scotland's potential for improvement.

The importance of having a nationwide umbrella organization to bring together government, statutory powers, and non-profits was discussed. In Scotland, this role is filled by Save a Life for Scotland (SALFs), which is doing incredible work to increase the number of survivors. JC also highlighted the key partnership with Chest Heart and Stroke Scotland (CHSS), which provides amazing support for individuals affected by cardiac arrest through their existing phone support services. JC emphasized the importance of practical routes to ensure people received the support they needed. JC recognized that this was a small subset of the cardiac arena but incredibly important. The goal writing the standards was to build on existing services and develop bespoke services for individuals.

JC addresses how the CPG can help survivor care standards and emphasized the importance of incorporating their initiatives into Scotland’s national cardiac plan. JC noted that while rehabilitation is already mentioned in the national plan, survivors of cardiac arrest face unique challenges compared to those who have experienced a traditional heart attack. He stressed the need for innovative support solutions tailored to the clinical, emotional, and physiological experiences of cardiac arrest survivors. JC mentioned the importance of avoiding postcode lotteries and ensuring support is available across different regions. He cited examples of survivors from Findhorn and Lewis to illustrate the need for regional variation in solutions.

JC expressed the goal of ensuring every survivor has the best chance for recovery.

He acknowledged the great work being done by SALFs, CHSS, and other partners in supporting survival and emphasized the need to extend this support to recovery and thriving. He thanked the speakers following him, and the conveners for the opportunity to share this work. JC ends the presentation by nothing RCUK’s Parliamentary Reception the same week in Holyrood and extended an invitation to all on the call.

AS: Alexander thanked James Cant for his presentation and for the work done behind the scenes across the country and with government. He introduces the next speaker, MacLean

MacLeod, a survivor of OHCA and a campaign ambassador for RCUK. He hands over to MacLean

MacLean MacLeod (MM):

MacLean (MM) shared his experience of having a cardiac arrest on April 21, 2022. He attributed his survival to being in the right place at the right time with the right people, specifically mentioning a first responder in his rowing crew. He noted that for a person on their own, it's game over. It is important to have the right people around you, and that those people know how to react. MM describes his journey to the doctors in Elgin, and then on to Aberdeen, highlighting the severe physical trauma because of the CPR, including broken ribs, a fractured sternum, and a punctured lunch. He described the care he received from the NHS staff in hospital as 'second to none' and thanked everyone at the NHS for what they did for him.

MM notes that his problems began when he left hospital. He never experienced a pathway of care upon leaving hospital two years ago. He expected to hear from somebody to arrange a follow-up appointment but heard nothing. After chasing what was available locally, he discovered a cardiac nurse based in Elgin and a cardiologist there on an ad hoc basis. Upon contacting the nurse, she hadn't heard of him, no notes had followed him out of hospital. A few weeks later MM received a phone call from the cardiologist to discuss a halter monitor. That was the only contact he had with that cardiologist at Elgin, which was a telephone call.

MM recounted meeting another cardiac patient who was struggling to get necessary surgery whilst out walking the dog. MacLean later heard that the man had suffered a fatal cardiac arrest at Tesco, and this incident motivated MacLean to advocate for better care. MM detailed his efforts to get proper medical attention by contacting local representatives, Richard Lochhead and Douglas Ross. Their intervention led to an appointment in Elgin, where MM underwent various medical procedures and consultations with Dr Ryan, a cardiologist. The appointment consisted of several tests, after which MM could finally ask the cardiologist urgent questions about how to manage going forwards.

MacLean shared that Dr Ryan had declared him in remarkable health for a survivor and placed no restrictions on him. This news significantly alleviated his worries and was a 'game changer' although he still experiences daily concerns due to the sudden nature of his cardiac arrest, noting that there was no warning, no pain, he suddenly went from being alive to being dead for 20 minutes. MM emphasized the critical factors that contributed to his survival: being with the right people, having a defibrillator nearby, and the presence of someone who knew how to respond. He acknowledged that many others do not have such favourable conditions during a cardiac arrest.

MM expressed concern over the lack of follow-up care, both physically and mentally, since his discharge from the hospital. He highlighted that in over two years, he had only one meeting with a cardiologist and one telephone conversation. MM voiced his hope that new care pathways would better support cardiac arrest survivors, many of whom face significant challenges.

He contrasted his own quality of life with that of other survivors who may not be as fortunate.

MM expressed his gratitude to all those who helped him, from the first responders to the medical staff at Dr Grey's and Aberdeen.

He viewed his advocacy efforts as a way to give back and ensure better care for future survivors.

AS: Thank you on behalf of the group for your frank and fair assessment of where you are and how you've coped. Taking on this ambassador role is a challenge, so thank you for your time.

Alexander thanks MacLean on behalf of the group for his frank and fair assessment of his experience and hands over to Dr Gareth Clegg.

Agenda item 4

Topic Discussion: Out of Hospital Cardiac Arrests and Survivor Care Standards

Speakers

Dr Gareth Clegg and Dr Vicky Joshi from Save a Life for Scotland (SALFS)

Gareth Clegg (GC):

Gareth expressed gratitude for the opportunity to share the ongoing work related to Out-of-Hospital Cardiac Arrest (OHCA). He mentioned that he was speaking alongside Dr Vicky Joshi, a subject matter expert in cardiac arrest rehabilitation, and together they were developing a plan to address the issues highlighted by previous speakers.

Gareth explained that OHCA is a complex condition intersecting with his three roles: as a consultant in emergency medicine at the Royal Infirmary in Edinburgh, with the Scottish Ambulance Service, and with the research group at Edinburgh University. He emphasized that cardiac arrest is one of the most challenging medical emergencies due to its critical time dependency. Once a person's heart stops beating, immediate action within a few minutes is crucial for survival. This survival depends on the willingness of bystanders to help and the perfect alignment of a chain within the healthcare system.

GC described cardiac arrest as a "canary in the coal mine," indicating the overall effectiveness of patient care. When the system fails, success stories diminish. His career goal has been to eliminate the element of luck from survival outcomes. There is a plan to achieve this in Scotland: The OHCA National Strategy aims to optimize the chain of survival, like other global plans, and focusses on things like early recognition, early CPR, early defibrillation, and effective post-resuscitation care.

GC highlighted the modification of the chain of survival into a "cycle of recovery" to emphasize that the process begins and ends in the community. The community must be prepared to respond to cardiac arrests and support individuals in returning to a normal life post-recovery.

SALFS (Save a Life for Scotland) is a partnership of organizations dedicated to improving the community's readiness to respond to cardiac arrests. GC noted that this initiative has been active since the strategy's launch around 2015. He presented a graph illustrating the progress

made since then, highlighting the number of people trained in CPR with direct contact with SALFS members as well as the number of people given CPR by a bystander, this number has increased to close to 70% of people. The number of survivors from 2011-2023 is discussed, Gareth highlights that the figures for this year have yet to be released but are expected to peak at around 360,000, in comparison to 188,000 in 2011. Double the number of survivors means double the challenge in survivor care.

Gareth then handed over to Dr Vicky Joshi to speak about the initiative ‘Save a Life for Scotland: Recovery’. This initiative focuses on supporting individuals affected by cardiac arrest, including survivors, professional rescuers, bystanders, friends, and family members.

Dr Vicky Joshi (VJ):

Vicky expressed gratitude for the opportunity to speak, acknowledging the excellent groundwork laid by previous speakers. She emphasized the need for action to support survivors, noting that her role involves finding solutions and implementing quality standards.

VJ focused on the importance of post-discharge care, the final link in the chain of survival. She highlighted the increasing number of survivors and the significant impact on both survivors and their families. Drawing from her background as a physiotherapist in neurorehabilitation, Vicky shared her experience treating stroke and brain injury patients. She noted that cardiac arrest survivors were often excluded from rehabilitation programs, being classified solely as cardiac patients. Vicky challenged this notion, pointing out that while rehabilitation is standard practice for stroke patients, it is not the same for cardiac patients.

VJ discussed the gap in clinicians' understanding of the issues faced by cardiac arrest survivors, who often have numerous questions and are expected to be 'fine.' VJ referenced recent research on trauma, emotional impact, and brain injury, noting that approximately half of cardiac arrest survivors experience brain oxygen deprivation, with symptoms that may not become apparent until after hospital discharge. She stressed the importance of early information and support for both clinicians and survivors, as well as their families, to better manage expectations and outcomes post-cardiac arrest.

Vicky discussed the quality standards, which have consolidated research evidence from the past few years. She emphasized key elements: early support, ensuring follow-up at home, and making sure no one is forgotten. She highlighted a significant issue where survivors are discharged without proper tracking or follow-up.

VJ clarified that these standards do not require new technology or advanced interventions. Instead, they build on existing practices within the NHS. The main challenge from an organizational perspective is identifying cardiac arrest survivors, providing them with early information, ensuring they receive assessments, and facilitating access to NHS services. Vicky stressed the importance of not forgetting these patients once they are discharged home.

Vicky noted that the NHS and third sector organizations are already engaging with survivors and their families. She emphasized the need to integrate these efforts. She mentioned the establishment of SALFS Recovery, which builds on the success of SALFS, using a partnership model to unite organizations and individuals across the third sector and health service to create a clear pathway for survivors.

VJ pointed out that while some survivors might require minimal support, the absence of early intervention increases the risk of long-term and chronic issues. These issues can become more resource-intensive and may prevent survivors and their spouses from returning to work, thus having an economic impact. She stressed the importance of early identification, assessment, and support to prevent such outcomes.

VJ also highlighted the need for ongoing research to determine effective interventions. She noted that while there is substantial research on survival, there is limited research on successful interventions. She mentioned existing pockets of good practice, often driven by local clinicians' interests, which are not systematically integrated into the health service, both domestically and internationally.

Vicky concluded by expressing optimism about the SALFS Recovery initiative. She hoped that by raising awareness of cardiac arrest recovery, more could be achieved collectively than individually.

Agenda item 5

Discussion and questions

Richard Forsyth (RF), Health and Care Lead, BHF Scotland: Richard Forsyth reported that BHF Scotland is conducting significant work with rehabilitation services to initiate an audit through the Scottish Cardiac Audit Programme (SCAP). RF noted that there is anecdotal evidence of variation in eligibility criteria among different health boards, largely influenced by service capacity.

He highlighted the challenge of the "postcode lottery" due to the lack of uniform data on cardiac rehabilitation. Anecdotal evidence suggests variations in eligibility criteria across different health boards, often driven by service capacity.

RF noted that there is anecdotal evidence of variation in eligibility criteria among different health boards, largely influenced by service capacity. Over the next 8-10 months, data will be collected with the aim of expanding the audit to all 14 health boards by the new financial year in 2025.The goal is to ensure accessibility to cardiac rehabilitation services across Scotland.

Gareth Clegg: Confirmed that the SCAP programme will be around cardiac rehab in general and OHCA as a subset that can be flagged as a reason for referral.

RF: Confirmed this is correct. In England, Wales and Northern Ireland, cardiac rehab is audited using the national audit for cardiac rehab. The BHF have been working closely with the SCAP team to develop a national framework which all 14 health boards will refer to, and one of the dropdowns will be on OHCA. It will look at the number of people referred into rehab and track when they drop out, hoping that they don’t.

GC: Commented that one of the challenges is looking at patients who don’t get referred into rehab, who haven’ had an MI… those who have implantable defibs that don’t get followed up in the system at all.

AS on behalf of Lesley Hill: Do we have knowledge of the age demographics of people in Scotland who suffer an OHCA?

GC: Confirmed we do, and brings up a slide showing the age breakdown, taken from the cardiac arrest report published every year on the Scottish Ambulance website. A diagram showed the female/male distribution by age, the peak age was in the 60s-80s, but it can

happen at any age. With sudden cardiac death, the under-49s are the interest group. The median age is 67.

Colin Smyth (CS): Asked whether we are on track to reach the strategy's 2021 target to increase survival rate to 15% in Scotland by 2026. He appreciated that 1 in 10 is an improvement, but are we on track? Additionally, CS asked if we have accurate data on the causes amongst those age groups?

GC: Commented that in 2015, Scotland cardiac arrest survival was low, at about 7%. That progressed to 12% and was knocked back down to 7.7% by COVID. We're now recovering from that drop.

There is a problem using percentage outcomes as a figure, as it depends on how many patients we resuscitate. If you resuscitate everyone, the percentage drops. You cannot manipulate the number of survivors each year, which can be expressed as a number of survivors per year per million, which is independent of the proportion of people resuscitated. The Global Resus Alliance recommends this as a more helpful measure. In this year's figures, we are about to break the 60 per million level for the first time in Scotland, which is great. And that 15% target might not be reached, but it's more helpfully translated into survivors per million, and that should be around 70.

Answered the question on data of causes of cardiac arrest: the short answer is we don't have an accurate record of what causes cardiac arrest. There is work in the sudden cardiac arrest group to focus on that younger age group, because if it's a genetic cause, that will have wider ramifications for the family. There are conversations happening this week about marrying up postmortem reports with cardiac arrest deaths figures to support more comprehensively those families across Scotland.

CS: Asked whether screening is part of the strategy

GC: Screening isn't tacked specifically in the strategy. It's not focused on that genetic group. GC commented that there are discussions around that issue, but it's not something he has an expertise in.

Sandra Auld (SA): recently began supporting Cardiomyopathy UK and has identified issues regarding access to screening, ECG, and echocardiology.

She shared a personal experience as a carer for her younger brother, who is terminally ill with skin cancer. Her brother's immunotherapy was unsuccessful, and before starting other treatments, he required a baseline echocardiography. Unfortunately, the echocardiography was cancelled twice due to staff sickness, and the backlog could not be addressed. SA emphasized that the lack of access to screening affects multiple clinical areas, not just one. She suggested that the group consider the screening aspect in future discussions, linking it back to previous comments on cardiac rehabilitation and its connection to cardiac arrest.

AS: Comments that the CPG does have a view on that and may choose to have more dialogue within the group and within parliament.

Alexander ends the meeting by thanking the commitment of all on the call. A lot of areas were raised to be unravelled in parliament, and AS notes that the CPG has an in-depth knowledge of the problem, and many on this call are working towards that solution. His MSP

colleagues and he look to pull these strands together and rise to the challenge of pulling organisations up and having them listen. He thanked all our speakers from this evening.

Agenda item 6

Next meeting of the CPG

11th March 2025, 6pm-7:30pm on Microsoft Teams.