

Diverse stakeholder engagement at the heart of co-designing cardiac arrest care



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In this article, Greg (a 48-year-old celebrated children's entertainer in the group "The Wiggles" and sudden cardiac arrest [SCA] survivor) and Jess (an engineer and new mother who lost her 31-year-old husband Bryan to SCA of unascertained cause) share their differing experiences of SCA and how they have targeted existing gaps in the medical landscape to contribute to a national program of research and advocacy to improve future outcomes (Figure 1).

Greg: "My name is Greg Page, and I am probably best known now as 'The Original Yellow Wiggle who survived a sudden cardiac arrest'—and I'm more than happy to own that!"

Jess: "While I was feeding our 3-month-old baby in the other room, my Bryan passed away from an unexplained cardiac arrest. The first responder on the phone talked me through providing CPR [cardiopulmonary resuscitation] until an ambulance arrived. The ambulance worked hard on trying to revive Bryan, but it was too late. Bryan did not wake up."

In modern cardiology there is increasing awareness that the incorporation of patient priorities into clinical and research agendas provides benefit.¹ Multiple international guidelines now recommend patient engagement as a strategic priority.^{2,3} SCA is a unique area of cardiovascular research, as the impact extends beyond the patient experiencing it, commonly affecting whole family units and the broader community. It is important to hear the voices of the heterogeneous array of people who experience SCA and recognize the diversity of experiences, needs, and

priorities when approaching patient engagement in the field of cardiac arrest.

Background

Greg: "When I collapsed at the end of a show—just one day after turning 48—I was incredibly fortunate that the Chain of Survival was strong for me that night. People around me recognized almost immediately that I was not responding and not breathing normally, so they called triple zero and began CPR. The venue we were performing at had a defibrillator and the bystander-responders used it to shock me twice to bring about return of spontaneous circulation just as ambulance crews were arriving 12 minutes into the event. I was taken to hospital, 1 stent was inserted into my left anterior descending artery, and I received great care in the hospital throughout my 5-day stay and excellent cardiac rehab."

Jess: "One day, Bryan went to work by train. He called me at about 4 pm to come pick him up, as he was not feeling well. This was very unlike Bryan, but Avie (3 months) and I happily went to collect him. Bryan did not seem to be too out of sorts, just very tired. We went about our usual routine, we had dinner, gave Avie a bath, and got her to bed. I was then up feeding Avie throughout the night. When I picked Avie up from her bassinet, Bryan reached out to me and held my hand. He said, 'I love you' and dozed back off to sleep. I was out in the living room feeding Avie when I heard a noise in the bedroom. It sounded like a cough from Bryan, I shouted out to ask if Bryan was okay but there was no answer."

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The unpredictability of SCA

Greg: "Prior to this event, despite the fact that my wife is a cardiac nurse and has worked in cath labs for the best part of 26 years or so, putting stents in people with blocked



Figure 1 Greg (top) describes his journey from performing in the Wiggles to surviving a cardiac arrest to advocating for widespread availability of defibrillators and universal cardiopulmonary resuscitation training in schools. Jess (bottom) lost her husband Bryan to cardiac arrest and has become a vocal campaigner for advancing research priorities and campaigning for funding.

arteries, I never knew much about the heart. I would listen to her talk about her day at work and try to understand the terminology she used but it went over my head—I was just a musician! Nor did I listen to her warnings about my diet, and how much red meat, sausages, chicken skin, and margarine I was consuming. Years ago, I had to do a stress test, during which I performed so well that the observing doctors actually asked me to stop even when I felt I could keep going. Based on that performance, I figured that the diet I was consuming was not playing havoc with my arteries because of how physically active I was right up until the point in time that I dropped dead. So, perhaps I was ill-informed (or in denial) about the state of my arteries!”

Jess: “Bryan was super fit, super healthy. and loved cycling. He grew stronger and stronger over the years and eventually was racing A-grade in road cycling... One of the hardest things is that Bryan’s death certificate says ‘unascertained.’ This leaves me without a clear support group and leaves me in limbo with regards to his diagnosis. It feels like it dilutes the number of people affected, and society’s awareness of the impact of the problem. That Bryan passed away in our bed, in our home, without a clear cause of death is terrifying. There is no longer a safe space. That it is not possible to identify people at risk means the fear that this could happen to either Avie or Jack [Jess and Bryan’s children] is very real.”

The most common causes of young SCA are coronary artery disease or unascertained cause.⁴ Approximately half of patients do not have a known cardiac diagnosis prior to their SCA.⁵ This can create shock and ongoing psychological trauma owing to a lack of explanations as to why an SCA has occurred.⁶ The range of people affected by SCA is not limited to the index person who experiences the SCA but may encompass all involved.⁷ The impact is also influenced by factors such as whether the affected person has survived or died, whether they have administered lifesaving measures and if they were successful or not, and their relationship to the person.⁸

Optimal care for people affected by SCA is not limited to cardiologists performing evaluation, diagnosis, and ongoing care. Rather, it is a model of multidisciplinary care. Ideally, people affected by SCA should have access to a range of experts where indicated, including cardiologists, psychologists, genetic clinicians, forensic pathologists, prehospital support, and opportunities to participate in research (Figure 2).⁹

Inclusion beyond the patient who experienced the cardiac arrest: Experts with experience

Jess: “People talk about the importance of engaging ‘consumers’ rather than patients. I want to say, ‘what do I consume...cardiac death?’ I am not a patient and I am not a

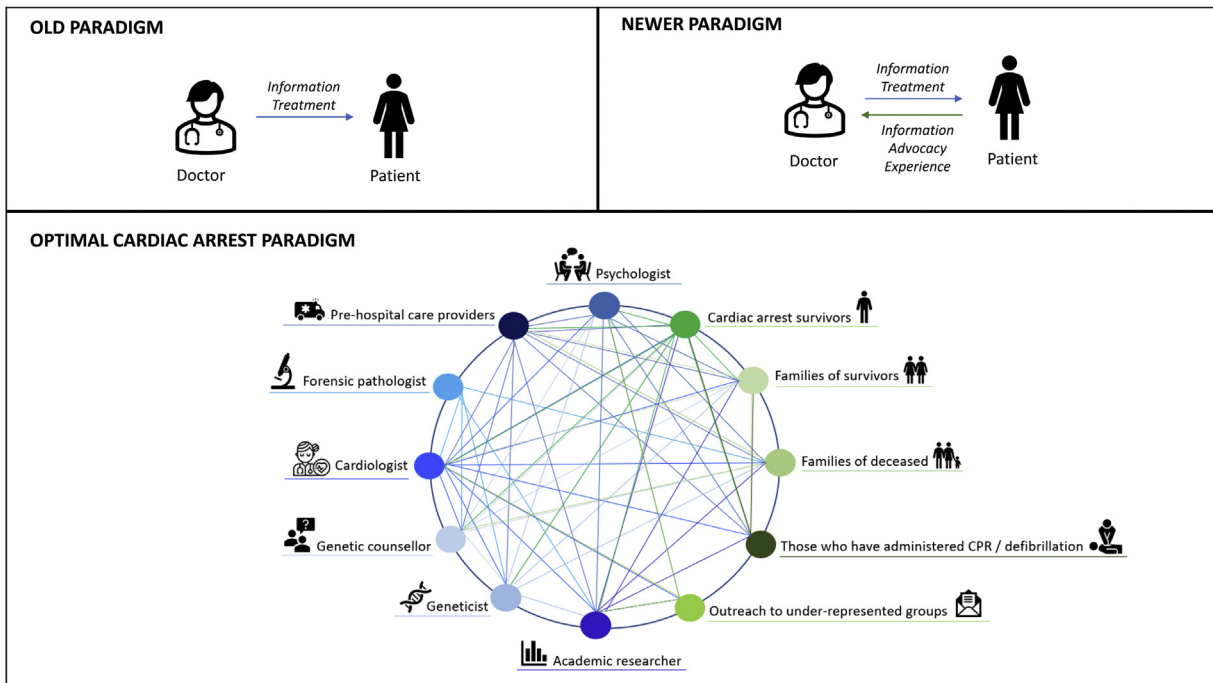


Figure 2 Patient engagement in cardiac arrest involves more than just a dyad of the cardiologist and the person who has experienced cardiac arrest. Ensuring multidisciplinary health teams and a representative array of people impacted by cardiac arrest all have “a seat at the table” promotes holistic care and community-driven research priorities and outcomes.

consumer, but I am still someone deeply affected by cardiac arrest who wants to contribute my voice and help make a difference.”

In many cardiac pathologies, patient engagement may primarily involve inviting index patients with the specified condition to drive research priorities, implement evidence, support patient self-management, and share their experience.² This is effective patient-centered care.

In the SCA model, however, in the majority of cases the index person is deceased and unable to share their voice. Furthermore, SCA’s impact usually extends beyond the initial patient, encompassing the original patient, their families, and even bystanders who have performed resuscitation and will have feedback to share (Figure 2). In some research programs, such as the Canadian Institute of Health Research, the term “patient” has therefore been broadened to include “individuals with personal experience of a health issue and also their informal caregivers.”¹⁰

There is really no ideal term to describe the heterogeneous array of stakeholders affected by SCA. The word “patient,” derived from the Latin *pator*, meaning to passively suffer, appears linguistically outdated.¹¹ The term “consumer” can likewise feel awkward in the context of SCA as described above, while the term “caregiver” defines a person’s role in terms of their relationship with the index person rather than as a person impacted by SCA with their own unique experience and needs. Perhaps the most inclusive terms are “experts with experience” or “persons with lived experience,” which is increasingly used in patient-centered documents.^{2,8}

Moving into action

Greg: “Why was I so fortunate to survive when only around 12% survive to discharge, and even fewer to 1 year after discharge? Because I suffered an SCA that was witnessed by people who could enact the specific chain of events that was required to save my life. For me, from what I have read, researched, and come to understand since, from my own experience and that of others, is that one of the biggest reasons why our survival rate is so low is because our rate of early defibrillation in the first 3–5 minutes is so incredibly low. This has driven me to create an organization called Heart of the Nation, which lobbies for widespread defibrillator availability and increased community capabilities in CPR.”¹²

Jess: “Even though it is very hard to identify someone at risk of an event happening, I keep wondering how Bryan could have been saved. The only way to really ensure Bryan’s survival would have been to detect the problem prior to his SCA occurring. The way you will save the most lives is to identify and prevent the event from occurring in the first place. In Bryan’s case, since I did not go into the room when the event occurred, when I did CPR it was too late and the paramedics could not save him with a defibrillator. The reality that life can be so short and taken away in a moment gives the perspective that I need to do something that is meaningful. I can think of nothing that is more important and that gives more meaning than being part of the solution to ending unexplained cardiac death. I now work with a group called EndUCD to help raise awareness and funding for SCA research.¹³ I want to do my best to help ensure a

BENEFITS TO CLINICIANS AND ‘EXPERTS WITH EXPERIENCE’ FROM CO-DESIGNING CARDIAC ARREST CARE



Clinicians

- Insight into patient preferences to design pragmatic interventions optimizing adherence
- Enhanced patient engagement in self-care
- Improve communication between scientific community and the public
- Improved public outreach and recruitment



Experts with experience of SCA

- Advocacy
- Provide new insights
- May contribute unique skillsets
- Identification of patient-centred priorities
- Empowerment following a life-changing experience
- Fulfilment in improving future patients’ experiences

Figure 3 The benefits of co-design incorporating multidisciplinary medical care and an array of experts with experience in sudden cardiac arrest (SCA) are bidirectional.

robust screening process is created so people at risk can be identified before it is too late.”

There are an array of ways in which experts with experience of SCA may become involved in clinical care and research. For example, predefined protocols to ensure continuous patient engagement in the co-design of clinical trials are now recommended.^{2,3} In a less formalized manner, experts with experience may identify gaps and initiate their own programs, as described by Greg and Jess. Ultimately, supporting the inclusion of a diverse array of people impacted by SCA in the manner that is most meaningful to them alongside a multidisciplinary team of healthcare professionals helps best promote personalization of future SCA care.

Transforming trauma into research and advocacy

Greg: *“I have gone from being a student at school, to a teacher, then a performer in my first life—it has been incredibly rewarding and fulfilling to see the many lives I have touched through the work I have done with The Wiggles. Now I am an advocate for the Chain of Survival in an attempt to give others a second chance at life, as I have had. I know just how incredibly fortunate and grateful I am to understand more about the heart. And how I can use it to give back.”*

Jess: *“When Bryan passed, I had no control. The entropy in the world increased exponentially for me. Somehow, this feels like a way to bring order to the chaos. It won’t bring Bryan back, but it will help me do something, rather than being a victim. It helps me to think I am doing something constructive, that may help prevent the same thing from happening to Avie and Jack or someone else’s family. I guess to me it is a mark of respect, it is one of the few ways I can say Bryan’s life was important and that it is not okay that he died and no one knows why. Somehow in my mind it gives value to Bryan’s life, that we cared enough to find out what happened rather than just accepting it as a tragedy that is too hard to figure out. My way of dealing with it is by becoming involved and advocating for more*

research, using my skillset as an engineer and project manager to help in any way possible.”

People affected by SCA show high rates of interest in inclusion in cardiac arrest research.¹⁴ Experiential sharing and creating initiatives to improve SCA outcomes may be a positive method of deriving meaning from a traumatic event, in line with the philosophy of Viktor Frankl that “suffering ceases to be suffering at the moment it finds a meaning.”¹⁵ Importantly, in SCA there are still large evidence gaps and systematic processes that can strongly benefit from community identification, promotion, and advocacy (Figure 3).^{16,17} In a condition with 90% mortality, there is such self-evident scope for improvement that there is real benefit from the opting-in of willing “experts with experience” of SCA to share their priorities and drive new projects.

The importance of ensuring diversity in co-design

In this article we present the voices of 2 people impacted by SCA who have identified gaps in the existing system of cardiac arrest care and created new initiatives. It is important to reflect that many experts with experience face systemic barriers to inclusion in studies, clinical evaluation, and patient engagement.¹⁸

When designing engagement strategies, identifying groups who have not participated or who face barriers to inclusion is highly recommended. If active identification and outreach is not undertaken, then there is a real risk of amplifying only the voices of selected experts with experience of cardiac arrest, unintentionally reinforcing existing barriers.^{11,19} Incorporating a diversity of voices and representations is likely to support the most equitable cardiac arrest care in the future.

Conclusion

SCA is a condition benefiting from multidisciplinary medical collaborations and diverse input from patients, their families, and their communities (“experts with experience”). When anticipating patient engagement in SCA programs, it is

important to ensure all voices are heard. This will most effectively drive multidirectional insights into advancing equitable cardiac arrest care and research.

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