


# BMJ Open Using codesign focus groups to develop an online COmmunity suPporting familiEs after Sudden Cardiac Death (COPE-SCD) in the young

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**To cite:** Yeates L, Gardner K, Do J, *et al.* Using codesign focus groups to develop an online COmmunity suPporting familiEs after Sudden Cardiac Death (COPE-SCD) in the young. *BMJ Open* 2022;**12**:e053785. doi:10.1136/bmjopen-2021-053785

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-053785>).

Received 31 May 2021  
Accepted 24 June 2022



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## ABSTRACT

**Objective** To codesign an online support intervention for families after sudden cardiac death (SCD) in the young (<35 years).

**Design** Codesign of an SCD family intervention by stakeholder focus groups.

**Setting** Families and healthcare professionals with experience in SCD in the young.

**Participants** Semistructured online focus groups were held with key stakeholders, that is, family members who had experienced young SCD, healthcare professionals and researchers based in New South Wales, Australia. Guided discussions were used to develop an online support intervention. Thematic analysis of discussions and iterative feedback on draft materials guided content development.

**Results** Four focus groups were held (4–6 participants per group, 12 unique participants). Stakeholder involvement facilitated development of high-level ideas and priority issues. Creative content and materials were developed based on user preference for stories, narratives and information reflecting everyday experience of families navigating the legal and medical processes surrounding SCD, normalising and supporting grief responses in the context of family relationships and fostering hope. Emphasis on accessibility led to the overarching need for digital information and online engagement. These insights allowed development of an online intervention—COPE-SCD: A COmmunity suPporting familiEs after Sudden Cardiac Death—which includes a website and online support programme.

**Conclusion** Using codesign with stakeholders we have developed a support intervention that addresses the needs of SCD families and aims to fill a large gap in existing healthcare. We will evaluate COPE-SCD to determine whether this is an effective intervention for support of families following a young SCD.

## INTRODUCTION

Sudden cardiac death (SCD) is a tragic complication of many genetic heart diseases, often occurring with no prior symptoms.<sup>1</sup> Causes of SCD can include inherited cardiomyopathies and inherited arrhythmia syndromes.<sup>2,3</sup> These

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Healthcare providers and consumer representatives participated as stakeholders in support intervention design.
- ⇒ Codesign allowed development of a support intervention incorporating innovative ideas to meet user needs.
- ⇒ Focus groups were limited in size and cultural/linguistic diversity and may not fully represent the needs of the wider community affected by sudden cardiac death (SCD) in the young.
- ⇒ Consumer representatives were all patients from the one clinical service, the genetic heart disease clinic, Royal Prince Alfred Hospital (RPAH) in Sydney, Australia and may not share the experience of other families affected by SCD.
- ⇒ Healthcare professionals were from a range of disciplines and different states across Australia, but all worked within a specialised service in their respective states and their views may not reflect other healthcare professionals not surveyed, for example, general practitioners, private cardiologists.

inherited conditions are mainly autosomal dominant, meaning first-degree relatives are at a 1 in 2 (50%) risk of developing the same condition.<sup>4</sup> These conditions display clinical heterogeneity, with varying presentations from being asymptomatic through to heart failure and SCD.

Previous work has examined the psychological impact of SCD to the surviving family.<sup>5,6</sup> Indeed, up to one in two family members report symptoms of post-traumatic stress and prolonged grief requiring referral to a clinical psychologist, on average 6 years after the death.<sup>5</sup> More recently, McDonald *et al* performed a needs analysis of parents who had lost a child to SCD, showing medical information and support as the most important needs, and psychological information and

support (support from friends, family, community) as the most unmet needs.<sup>7</sup> Further work by Steffen *et al* identified four psychosocial needs to be addressed in future practice: a need for a safe environment, need to make sense of the death, need for affiliation and normalisation, need to find new meaning and ongoing connection with the deceased.<sup>8</sup> Community or peer-based bereavement support groups can enhance social support, including an increased sense of well-being and personal growth among participants, and improved feelings of personal growth and positive meaning in life among peer providers.<sup>9</sup>

Despite the need, in Australia, the ongoing support services for families after an SCD are limited. There are specialist multidisciplinary clinics in the majority of capital cities which provide clinical screening, genetic counselling and genetic testing for these families. Referral to clinical psychologists and grief counsellors is encouraged by these teams, but few have these healthcare professionals embedded in their clinical service. In addition, there are currently no Australian bereavement support groups specific to SCD.

Codesign is a collaborative change process that involves patients, family members, healthcare providers, researchers and others in working together to design, develop and improve healthcare services.<sup>10 11</sup> Involvement of end users in the deliberation and development of policy and programmes will lead to more inventive ideas that better address user needs.<sup>12</sup> As demands on services continue to grow and become more complex, codesign is increasingly being recognised as an important method in health service improvement and as a key vehicle for delivering a more efficient and patient-focused system,<sup>11</sup> including for care of the elderly, the young, family services and chronic disease.<sup>10 13–15</sup> Focus groups are an established research method that promote engagement of participants through a less intimidating manner than one to one interviews, and without the high literacy demands of written surveys.<sup>16</sup> They are helpful in

generating ideas in a cultural context, allowing a variety of forms of communication including jokes and debate, where participants can build off each other in the discussions. In recent years, focus groups have moved online, allowing participation from geographically diverse areas<sup>17</sup> and have included exploration of sensitive topics.<sup>18</sup>

There is much to consider in improving support for families after SCD. Multidisciplinary care is needed, recognising the complexity of information to be shared and changing support needs that might be experienced over extended periods of time. We believe codesign via focus groups is an appropriate method to ensure development of a programme that meets the needs of SCD families. We aimed to use codesign to develop an online support programme for families affected by SCD in the young.

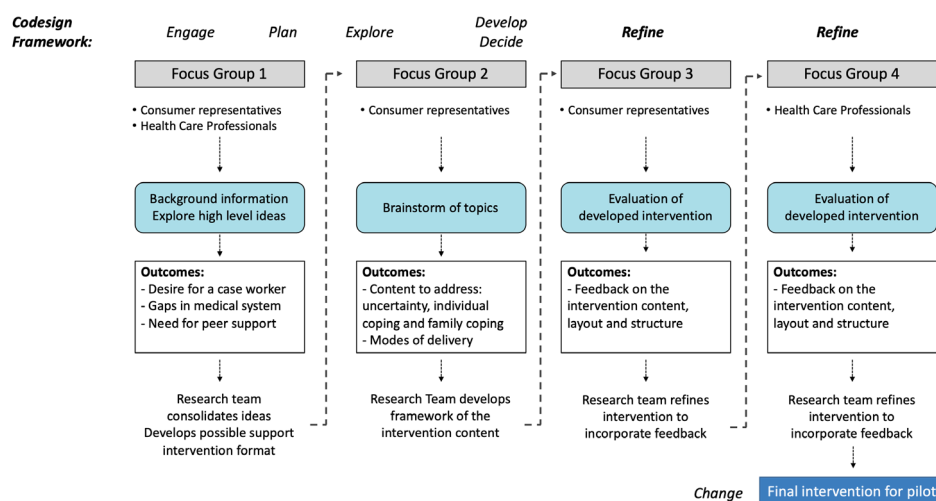
## METHODS

### Study design

We adapted the codesign framework of Boyd *et al* which uses six main elements: engage, plan, explore, develop, decide and change.<sup>19</sup> We incorporated an extra element of refine to allow participants the opportunity to provide feedback on the proposed intervention. Codesign was conducted over a series of four focus groups ([figure 1](#)). These groups involved (1) engaging stakeholders; exploring experiences, problems and current gaps in service delivery; (2) identifying new support options including topics to be included in such support options; (3) and (4) review of developed intervention, refining and working to tailor these to the service context; following a similar process as previously described<sup>20</sup> and used in cardiac research.<sup>14</sup>

### Patient and public involvement and recruitment

Patients and the public were involved as focus group participants. Design of the study and focus group schedule



**Figure 1** Focus group summary highlighting key participants, aim of each focus group (ovals), outcomes (square boxes) and process to develop the final intervention. Elements of the codesign framework adapted from Boyd *et al* are in italics,<sup>19</sup> with additions to the framework highlighted in bold italics.

was based on previous research with patient and public involvement, but they were not involved in the specific study design period. Patient participants had a key role in the development of the final intervention through focus group participation. At the time of recruitment, participants were advised of the time burden of participating. Participants were informed that at the completion of the study, they would be updated on the final developed intervention.

Purposive sampling was used to recruit key stakeholders including consumer representatives (ie, family members who had experienced a young SCD), healthcare professionals with experience in caring for families after an SCD and a peer researcher was also recruited. Peer researchers are members of the research team who have personal experience of the topic being studied.<sup>21</sup> Family members were identified from a specialised genetic heart disease clinic (Sydney, Australia) and had a long-standing relationship with the clinical-research team. Family members were participating as individuals rather than representatives of any organisation (eg, support groups). Healthcare professionals were identified from the service network in which the specialised genetic heart disease clinic operates including forensic medicine departments, general clinical genetics departments, children's hospitals and general cardiology. In the first two focus groups, we focused on the codesign elements of engage, plan and explore, where participants contributed ideas for a support intervention including ideas for format and topics to be covered. The research team then used this information to develop and decide on the outline of the intervention content. This framework was presented to focus group 3 and 4 allowing feedback and further refinement (refine) and ultimately leading to change (figure 1). Participants differed from group to group. A number of members of the research team, with extensive experience in caring for families after SCD (clinical psychologists, cardiologist and genetic counsellors) attended the focus groups and helped support discussion.

Consumer representatives and the peer researcher were approached by an initial phone call from LY, with follow-up information sent via email. Healthcare professionals were approached via email. Nineteen individuals were approached to participate in one or more focus groups. Of these, 11 participated in at least one focus group with 7 declining due to other commitments/did not respond.

### Focus groups

Four guided discussion focus group sessions were held over videoconference. These were recorded using Quick-time Player but not transcribed. The sessions were semi-structured and moderated by JI (genetic counsellor) with input from members of the research team, primarily LA (clinical psychologist), LY (genetic counsellor) as required. Discussion prompters, for example, Jamboard (jamboard.google.com) were used in some focus groups to organise material from discussions, enhance feedback

on content of the intervention and guide content development.<sup>22</sup> Each focus group had a different overall aim and specifically approached the stakeholder participants who could contribute to that aim (figure 1). The focus group schedules are available in online supplemental information.

### Data analysis and theme development

Field notes were taken throughout each focus group session (LY—all groups, JD—groups 1, 2 and 4, GF—group 1 only). Field notes were reviewed by the research team and used to develop key themes from the discussion. In focus group 2, field notes were used in conjunction with feedback from the discussion prompter Jamboard. These were reviewed by LY and JD, categorised into 'intervention format' and 'topics to be covered'. Topics were then grouped into content themes to be covered by the support intervention and reviewed by the research team. In focus groups 3 and 4, field notes were used to collate feedback on the intervention.

### Prototype intervention development

Content themes (from focus group 2) were used as an outline in development of the proposed intervention, which comprised two parts: a website and an online support intervention. A draft intervention was then presented to focus group 3, which was composed of consumer representatives, where we invited discussion and feedback on the designed intervention. Between focus groups, the investigator team met periodically to discuss ideas generated during the codesign process. The intervention was further refined and presented to the final focus group 4 (healthcare professionals only), for final feedback.

## RESULTS

### Focus groups

Four focus groups were held (range: 4–6 participants per focus group) over a period of 4 months. These groups were composed of a selection from a pool of five healthcare professionals, six consumer representatives and one peer researcher (table 1). There were 12 unique participants, 8/12 were female and ages of the consumer representative and peer researcher ranged from 32 to 65 years. Fifty per cent of consumer representatives attended more than one focus group and 60% of healthcare professionals attended more than one focus group; the peer researcher attended all focus groups. Consumer representatives/peer researcher included parents and one sibling. Overall, group dynamics were productive and respectful, with participants building and brainstorming ideas raised by other participants. Moderation ensured each participant had an opportunity to speak and groups functioned well, even when a mixture of healthcare professionals and consumer representatives were present.

### Focus group 1: exploring high level ideas

The first focus group included both healthcare professionals and consumer representatives and introduced the

**Table 1** Characteristics of the focus group participants

Participants N	Focus group 1	Focus group 2	Focus group 3	Focus group 4
Consumer representatives	1	3	5	0
Genetic counsellor	1	0	0	2
Cardiologist	1	0	0	2
Forensic nurse	1	0	0	1
Peer researcher*	1	1	1	1
Total participants	5	4	6	6

\*Peer researchers are members of the research team who have a personal experience of the topic being studied.

rationale for the development of a support intervention. Participants then had the opportunity to engage in high-level discussion about their experiences and areas they felt needed to be addressed by a support intervention. Three key themes emerged from this session:

#### The desire for a caseworker

Participants reported a 'directionless' period following the sudden death of their family member and how a caseworker or a nominated contact would have provided them with general information as well as grief support. Healthcare professionals in this session, while supportive of this idea, acknowledged this would be an aspect of work needing significant commitment to funding.

#### Gaps in the medical system

Participants recognised the limits of the current medical system and confusion about the referral pathways to access specialised multidisciplinary genetic heart disease clinics. Participants suggested a website could assist in providing accurate information for families and healthcare professionals after SCD, showing the pathways to finding appropriate specialists and in addition may be a platform to allow families to connect.

#### The need for peer support

Participants expressed a desire for peer support from families with shared and similar experiences. This was echoed by the healthcare professionals who recognised that appropriate support groups specific to SCD in the young could be a powerful mode of support. Participants expressed a preference for 'something they can drop in and out of' acknowledging their support and information needs varied at different times and easily accessible resources meant they could access as required.

#### Focus group 2: brainstorming content

The second focus group included consumer representatives and sought to brainstorm topics to be covered by a support intervention. Participants gave suggestions on content as well as different modes of delivery. Using discussion prompters and notes taken throughout the session, feedback was summarised into broad categories: connecting, information, coping and mode of delivery (table 2). Participants gave suggestions for topics to be addressed, highlighting areas where information was

difficult to access or where they experienced gaps in the care they received. This feedback was used to develop the intervention content, ensuring topics raised were addressed where possible by multiple modes of the intervention recognising the need for easily accessed information in different formats.

Further structuring of content topics was collated and grouped into three key themes (figure 2).

#### Uncertainty

Including coping with uncertainty due to the cause of the SCD, uncertainty in the next steps for the participant and their family, the chance of reoccurrence of an SCD event in another family member.

#### Individual coping

Including normalising different grief responses, coping with general life and returning to work/vocation.

#### Family and systems coping

Understanding how people grieve differently within the family unit, change in family dynamics, practical support.

#### Focus group 3 and 4: evaluation of proposed intervention

In the final two focus groups, the proposed intervention was presented to the group comprising consumer representatives (focus group 3) and healthcare professionals (focus group 4), inviting further feedback. Both groups gave constructive feedback on the overall content of the proposed intervention and the layout and structure, allowing further refinement of the interventions after each focus group.

#### The support intervention: COPE-SCD - an online COmmunity suPporting familiEs after Sudden Cardiac Death in the young

The support intervention comprises two parts: a website and 'online support sessions' (figure 3). The website provides written and video content for families after an SCD. It contains both information on the causes of SCD, practical processes including the coronial process, as well as general information on grief and loss, individual and family coping and accessing further help. The website also has an area for family stories and information on the second part of the intervention, the online sessions.

The online sessions are a series of four live, virtual sessions held over video conference (eg, Zoom) and

**Table 2** Summary of feedback from focus group 2, including examples and where these examples will be addressed in the intervention

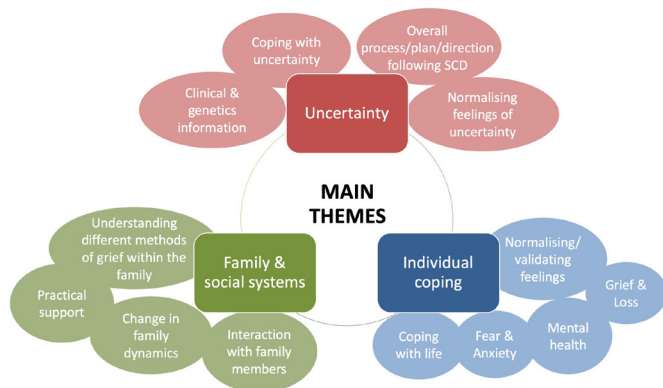
Content feedback	Overview	Examples	Addressed by COPE-SCD
Connecting	Participants raised the desire to meet with other SCD families recognising the benefit of peer support	Connecting with other families	Website and online session 1
		Tell your story	Website and online session 1
		Learning from the experience of others	Website and online sessions
Information	Participants discussed the need for information, particularly around causes of death, coronial process and next steps for their family.	Medical information: causes of sudden death	Website and online session 2
		Coronial process (expected timeline)	Website and online session 2
		Next steps/plan for family	Website and online session 2
		Information for GP and health professionals	Website
		Referral pathways	Website and online session 2
Coping	Participants sought help with coping after a sudden cardiac death	Dealing with questions from family/ friends	Website and online session 3
		Returning to work/school	Website and online session 3
		Coping with life	Website and online session 3
		How to talk about death	Website and online session 3
		Phases of grief	Website and online session 3
		Fear of repeat event	Website and online session 2
	Participants sought help with coping in the context of the wider family	Helping your family/ children grieve	Website and online session 4
		Different grief processes	Website and online session 3 and 4
		Addressing inaccurate assumptions of family/friends/community	Website and online session 4
		Reaching milestones: birthday, anniversary, other family events	Website and online session 4
		Coping as a family	Website and online session 4
		Family communication	Website and online session 4
		Question and Answer sessions	All online sessions
Mode of delivery	Participants discussed the different ways they would like information presented	Interactive	Online sessions
		Personal Stories	Website and online session 1
		Written information	Website
		Other information formats, for example, video	Website
		Sessions for different family members (siblings, parents)	Online sessions
		Practical help	Website and all online sessions
		Support information for wider community	Website

COPE-SCD, COmmunity suPporting familiEs after Sudden Cardiac Death; GP, general practitioner; SCD, sudden cardiac death.

facilitated by a clinical psychologist and/or a genetic counsellor, with input from other health professionals. Each session has a specific focus (figure 3) and provides a space for peer support and expert input from healthcare professionals. The sessions are interactive, encouraging participant input. Participants register for a set of sessions and the same group of individuals attend each of the four sessions through to completion.

The website and support sessions are complementary aspects of the intervention, and allow for flexibility of access, acknowledging that the benefit of joining an

online session group and the timing of such a group will differ from individual to individual. The combined intervention incorporates the consumer stakeholder priorities and their preference for stories, narratives and information reflecting everyday experience of families navigating the legal, medical, social and psychological processes surrounding SCD.

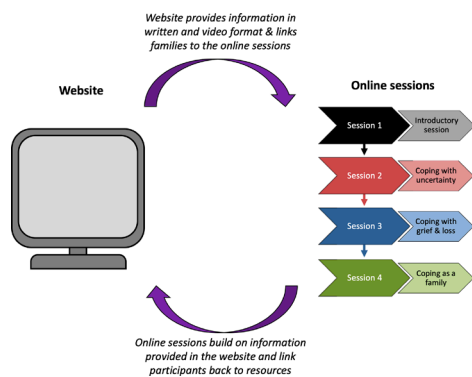


**Figure 2** Key themes derived from the focus groups. SCD, sudden cardiac death.

## DISCUSSION

Codesign is a method that promotes the preference of the end users by engaging them in the development process.<sup>10 12</sup> We report our experience in using a codesign approach to develop a support intervention for families affected by SCD in the young. By engaging consumer representatives and healthcare professionals as stakeholders, we were able to integrate not only broad ideas, for example, help with coping, connecting with other families, but also specific aspects of the user needs (stories and narratives) into multiple aspects of the intervention (table 2). Codesign is becoming increasingly popular in health intervention design across a wide range of clinical areas<sup>23</sup> and was invaluable in this process allowing us to shape and develop a support intervention that aims to fill a gap in clinical care and directly address user needs.

Peer support specific to SCD was identified by participants as a significant gap in current support services. Peer support is a recognised intervention across healthcare and has been shown to be of benefit to adults after the death of a family member.<sup>9</sup> It is underpinned by the premise that supportive interactions with people who have experienced similar difficulties can give individuals a sense of empowerment, increase self-efficacy and enhance coping skills.<sup>24</sup> Peer support programmes come in many different forms and can be led by professionals or volunteer peers.



**Figure 3** Overview of the COPE-SCD support intervention. COPE-SCD, COmmunity suPporting familiEs after Sudden Cardiac Death.

Volunteer-led groups involve people with similar backgrounds providing emotional, social or practical support to each other.<sup>25</sup> Participants in these groups draw on their shared experiences to provide empathic understanding, information and advice to those they are helping. A key aim is to promote hope, recovery from illness or trauma, improve life skills, psychological well-being and social integration.<sup>26</sup> Professionally led groups are therapeutic in nature, and focus on developing treatment goals within a group setting.<sup>27</sup> They provide participants with both peer and professional support, encouraging sharing of experiences and feedback to facilitate greater insight and personal change.<sup>28</sup> Participants in this study raised the specific need of a shared experience of SCD, when they sought peer support. Recognising the impact of a previously well person dying suddenly with no apparent cause/undiagnosed genetic heart disease, was very different to death by long-term illness or an external cause such as motor vehicle accident.

Including bereaved patient groups in research has been previously discussed, with many studies reporting bereaved research participants find therapeutic value in their research participation and are motivated by the desire to help others going through a similar situation.<sup>29</sup> In our study, the patient group had a long-standing relationship with the clinical-research team. The process of engaging end users was straightforward as long-term trusting relationships had already been established over many years. The desire to meet and help others in a similar situation appears to be a strong motivator in this unique group and established trust relationships made it possible to provide a codesign space for open and honest discussion. While various levels of codesign have been described in the literature, from involving end users in the design phase to involving them in the delivery,<sup>30</sup> this codesign process was focused on design. Some participants expressed a view that involving peers in delivering support programmes would also be a welcome addition to care. Further discussion of such options may be addressed as the programme develops, is tested and becomes established.

A family affected by SCD will encounter a number of healthcare professionals as they seek to determine the cause of death of their family member.<sup>31</sup> While referral to key services such as a specialised multidisciplinary genetic heart disease clinic, support services and connection with research centres seems a straightforward process, participants described this as confusing, slow and difficult. Navigating the legal and medical processes surrounding SCD, normalising and supporting grief responses in the context of family relationships, and fostering hope were key priorities for SCD families, yet they often describe the difficulty in accessing services. Variability in access to service was experienced across residential locations, where those out of major cities had greater difficulty accessing specialised clinics, information and support. Thus, the aim of COPE-SCD (A COmmunity suPporting familiEs after Sudden Cardiac Death) is to provide a centralised source of information that connects a family

who has experienced SCD with other families, and with the appropriate services. Online delivery means there can be access to information that can be revisited as needed and supports equitable access for those in rural and remote areas. Coupled with this is the peer support component which comprises family stories housed on the website and access to the online sessions. COPE-SCD aims to provide families and communities with resources and support, and aims to fill an existing gap in the care of families after SCD.

A key benefit of the codesign approach was the identification of priority areas (focus group 1) for a support intervention and topics of greatest need (focus group 2), allowing their prioritisation into the designed intervention and ensuring they were covered by multiple modes of the intervention. The sequential nature of the focus groups allowed us to maintain momentum and work through the adapted Boyd elements of codesign in a relatively short time period.<sup>19</sup> In addition, involving both healthcare professionals and consumer representatives, enabled the process to identify gaps and problems in the current care system provided to SCD families, from the perspective of both the recipients and healthcare providers.<sup>32</sup> This collaborative approach gave wider scope to design a programme that potentially fulfils the needs of families affected by SCD, while ensuring a practical and complimentary addition to current services.

One drawback of codesign is recognising the diversity of opinion, with the possibility that different participants could continually introduce new areas for consideration. While efforts were made to include a range of participants through purposive sampling of family members and healthcare professionals, we acknowledge that a different group of participants may have had different ideas for a support intervention, particularly in focus groups one and two. Diversity in participants is critical to ensure a wide range of ideas are presented and discussed.<sup>20 22</sup> In this study, the consumer representatives had a wide age range, mixture of male/female gender and representation of the sibling/parent relationship. We also had a number of different healthcare providers represented. However, our study did lack cultural and linguistic diversity which will need to be addressed as the intervention is piloted. Another drawback is the availability of resources. Many good ideas may be designed to improve the healthcare service, however the lack of funding may result in the codesigned solutions failing to be put into practice.<sup>20</sup>

Codesign was incorporated into the development of this support intervention with relative ease. The motivation of the stakeholder groups, including both consumers and healthcare professionals, to engage and be involved in the research has produced, in a relatively short time frame, a great depth of insight into the needs of families and their priorities for support. The result is an intervention that families believe will be of assistance in the most tragic of circumstances and one that will equip healthcare professionals with practical and helpful tools so they may provide better support.

## CONCLUSION

SCD in the young is a devastating event which has a lifelong impact on the family and supporting community. Support interventions that better care for families following SCD are highly sought after and currently are an existing gap in clinical care. Using codesign with stakeholders, we have developed a support intervention that directly addresses the needs of end users and fills a gap in existing healthcare. The service providers and end user group in this codesign process were highly motivated to participate and deep insights into the experiences of families following SCD have shaped the priorities and specific interventions developed. Next steps will include evaluation of the intervention with a culturally and linguistically diverse group.

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**Acknowledgements** We would like to thank the focus group participants.

**Contributors** LY wrote the majority of the first version of this manuscript as a PhD student under the supervision of JI, CS and AM. KG wrote sections of the first version of the manuscript and assisted in supervision of the project. JI, LA, JD and LvdH conceived the study design. LY collected field notes on all focus groups, JD collected field notes on focus group 1, 2 and 4, GF collected field notes on focus group 1. GF and AM were involved in thematic analysis of focus group 1. LY and JD conducted thematic analysis of focus group 2. LY, KG, LA, JD, LvdH, CS and JI contributed to analysis of each focus group and development of the intervention between groups. JI was the senior author and oversaw the entire project and is the guarantor of this study. All authors reviewed and gave their approval for the final manuscript prior to publication.

**Funding** LY is a recipient of a cofunded National Heart Foundation of Australia/National Health and Medical Research Council (NHMRC) PhD scholarship (#102568/#191351). CS is the recipient of a National Health and Medical Research Council (NHMRC) Practitioner Fellowship (#1154992). JI is the recipient of an NHMRC Career Development Fellowship (#1162929).

**Competing interests** JI receives research grant support from Myokardia. All other authors report no competing interests

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by Ethics review committee (RPAH Zones) of the Sydney Local Health District (protocol



number X19-0405). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request.

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