

Final Progress Report: 12/01/2026

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| Project Name: | Recovery from Spontaneous Coronary Artery Dissection: design and development of a recovery intervention and the development of a Patient Reported Outcome Measures (PROM) questionnaire. |
| Funder Reference: | SB\ZA\101010662\823949 |
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Introduction

Spontaneous coronary artery dissection (SCAD) accounts for approximately 4.0% of all acute coronary syndrome cases and mainly affects women [1-4]. The exact cause remains unclear but factors including sex, hormonal fluctuations, underlying arteriopathies, genetics and physical and emotional stressors are thought to play a role in its occurrence [1]. Management is usually conservative and long-term cardiovascular outcomes are generally positive [5]. However, around 10% of SCAD patients will go on to have another SCAD [6-8]. Patients report high levels of anxiety and psychological distress [9] and this is largely due to fear of recurrence and high incidence of post-SCAD chest pain, which is reported in up to 50% of patients and can last for up to two years post event [3, 10]. Patients report a lack of SCAD awareness by their general practitioners, local cardiologists and cardiac rehabilitation teams [11], leading them to feel isolated in managing their condition.

A recovery intervention for SCAD patients

Current United Kingdom (UK) practice is to offer SCAD patients cardiac rehabilitation to aid recovery and address risk factor management, however many feel that these services are not designed to meet their unique needs [3, 11]. Those with SCAD need to be provided non-atherosclerotic medication advice, access to SCAD specific exercise advice, psychological support, and menopause, pregnancy and contraception advice [12]. A SCAD specific recovery intervention is therefore required that is tailored to the largely female, aged under 60 and geographically dispersed population.

This project aimed to conduct 1) a co-design study to develop a recovery intervention to support physical and psychological recovery from SCAD and 2) a cohort study to test the co-designed intervention. During the co-design process we identified that spouses and partners of SCAD patients also had unmet support needs, therefore a further element was added 3) a qualitative study to explore the experiences and support requirements of the spouses and partners of SCAD patients.

A patient reported outcome measure for SCAD patients

Health-care providers often misdiagnose symptoms or underestimate their severity [13]. This could be because clinicians neglect to ask questions systematically, time constraints of busy clinical areas and placing a focus only on serious adverse events rather than the patient's symptoms [14, 15]. Understanding patients' experiences of health conditions and disability

along with those issues that are important, but less obvious, to healthcare professionals can be assessed through patient-reported outcome measures (PROMs) [16]. PROMs play a crucial role in both healthcare research and clinical practice, offering valuable insights into how patients view their health and the results of their treatments. PROMs are an evidenced-based, person-centred means of asking questions about people's perspectives of their own health. They are used to gather information directly from patients about symptom burden, functional status, and psychological and emotional well-being [17]. This information can then be collated, analysed and communicated to care providers to improve service delivery [18, 19].

These assessments provide a comprehensive perspective on a patient's well-being that goes beyond conventional clinical indicators and is especially valuable in the context of managing chronic illnesses, where understanding patient experiences and subjective outcomes is pivotal for making treatment choices and assessing the success of interventions or treatments [20]. While generic PROMs allow for comparisons between medical conditions, they can be too wide to fully assess the impact of one illness; disease-specific PROMs, although more sensitive, can miss the broader aspects of a disease [21]. Currently, no condition specific measures exist for SCAD. In the field of cardiovascular disease, many generic and disease-specific health and QoL assessment tools with varying degrees of validity, reliability and sensitivity are used [22]. However, none have been tested across the SCAD population.

The final objective of this study was 4) to develop a new pilot PROM for people diagnosed with SCAD to improve recovery.

What did the project involve

The project consisted of four phases:

Phase 1: A co-designed a recovery intervention to support physical and psychological recovery from SCAD.

Methods

The co-design study used The Person Based Approach [23] to guide intervention development in this study which included developing a programme theory about how the intervention would work [24]. This ensured that the intervention was grounded in perspectives and lived-experience of SCAD patients. The study involved, 1) a scoping review to develop an initial programme theory on how this intervention may or may not work, 2) the development of person-based approach guiding principles, 3) a survey and workshops with SCAD patients, and 4) the design and development of an intervention mapped to the COM-B behaviour change framework [25].

The study received a favourable ethical opinion from NHS West Midlands – South Birmingham Research Ethics Committee Reference: 23/WM/0169

Participant recruitment, data collection and data analysis

Participants were recruited via the patient support charity BeatSCAD in 2023. Participants signed up to take part in the study via a secure online system after reading all the study information. They were asked to complete a preworkshop online demographic and clinical questionnaire collecting demographic, health and SCAD experience information. They were then invited to join an initial workshop in December 2023. Three separate sessions were held to ensure that groups were of an appropriate size to allow for everyone to contribute. During workshop one, participants were introduced to their role as co-designers and there were open discussions about experiences, and psychological and physical recovery requirements. Researchers took extensive notes during conversations. Prior to the second workshops, the researchers thematically analysed [23, 26] the notes and drafted ideas for an intervention based on participant ideas. During workshop two, which took place in February

2024, the participants were presented with the key findings and proposed intervention. Time and space were provided for participants to feedback in detail on the proposed intervention. Participants were also asked to comment on proposed outcome measures for future intervention evaluation. As with workshop one, three separate sessions were held and researchers made notes about conversations. After workshop two, the researchers refined the proposed intervention to develop the final co-designed recovery intervention.

Results

Twenty-six participants completed the online consent form to attend the workshops. Of those, 21 (80.8%) participated in workshop one and 18 participants (85.7% of workshop one attendees) attended workshop two. The majority of participants were female (n=17, 85.7%), had experienced one SCAD (n=16, 76.2%), attended cardiac rehabilitation (n=16, 76.2%) and 87.5% (n=14) of these reported adhering. The most common age group was 51-60 years (n=10, 47.7%).

The final intervention (Figure 1) was a multi-component, virtual, person-centred programme designed to support recovery following a SCAD event by addressing medical, psychological, and physical activity needs. It began with an early one-to-one virtual consultation with a SCAD-informed healthcare professional who provided tailored education, reassurance, and emotional support, addressed common post-SCAD symptoms such as anxiety and fatigue, and ensured patients were appropriately referred to local cardiac rehabilitation services, with guidance to navigate referrals where needed. This was followed by an eight-week programme of individual virtual sessions with a clinical exercise specialist that focused on counselling rather than supervised exercise, using motivational interviewing and behaviour change techniques to explore concerns about physical activity, identify personal goals, and develop safe, meaningful, and sustainable activity plans. Optional components included mindfulness strategies, peer-support opportunities, performance-based outcome measures, and the use of a wearable activity tracker (such as a Fitbit or the patient's own device) to support reflective discussion.



Figure 1: Final Intervention for the SCAD Recovery Programme

Phase 2: A pilot cohort study to test the newly designed intervention

Phase 2 was mixed methods cohort study to test the feasibility and acceptability of a codesigned remote recovery intervention for SCAD patients. This involved 1) completion of pre and post intervention questionnaires, 2) participation in a codesigned exercise intervention that included an initial one-to-one session with a specialist nurse and an eight week exercise counselling intervention delivered by a clinical exercise physiologist, 3) a qualitative interview to discuss experience and acceptability of the intervention and acceptability of pre and post intervention questionnaires.

The study received a favourable ethical opinion from NHS West Midlands – South Birmingham Research Ethics Committee Reference: 23/WM/0169

Participant recruitment

Participants were recruited by the Leicester Hospital and NHS Forth Valley SCAD clinics between October 2024 and January 2025. Staff at the clinics identified potentially suitable participants from waiting lists and telephoned them to tell them about the study. Any interested patients were sent study information by post, and they returned a signed consent form via freepost to researchers at Edinburgh Napier University to register for the study. After consent, participants were contacted by researchers to arrange a convenient time for their initial consultation. Participation was voluntary and did not affect attendance at the SCAD clinic.

Data collection and analysis

Quantitative: Participants were asked to complete online surveys at baseline, and pre and post-exercise counselling intervention. These included demographic (age, sex, ethnicity, postcode used to calculate Scottish Index of Multiple Deprivation [SIMD] quintile) and health details (number of SCAD, date of last SCAD, risk factors, current medications and healthcare use during the intervention period), and validated questionnaires including the International Physical Activity Questionnaire Short Form [27], Cardiac Anxiety Questionnaire [28], Generalised Self-Efficacy Scale [29], Warwick Edinburgh Mental Wellbeing Scale [30], and the Seattle Angina Questionnaire [31]. Prior to the first and final exercise counselling session participants were asked to download a six-minute walk test app and asked to complete a remote test and to self-report the results during the session. Descriptive analysis of demographic, health and attendance data were conducted using SPSSv29. Data distribution of validated questionnaire and six-minute walk test repeated measures data were tested using the Shapiro Wilk test and a Wilcoxon signed-rank test (six minute walk test pre and post exercise counselling intervention) or Friedman tests with Bonferroni correction were used to examine whether there were significant differences at different time points (prior to the initial consultation, and pre and post the exercise counselling intervention).

Qualitative: All participants were invited to take part in a qualitative interview post intervention to discuss their experiences. Data were collected via individual semi-structured interviews telephone interviews conducted by one researcher (CLH), who had more than 10 years' experience of qualitative research and had not been involved in the intervention delivery. Interviews were transcribed verbatim, anonymised, and imported into NVivo14, a data organisation tool and analysed thematically [23, 26].

Results

Participants: Sixty-one patients were screened for eligibility, and 51 information packs were posted to potential participants. Thirty-two patients consented, of whom two were ineligible to take part (one due to low ejection fraction and the other due to being diagnosed as not having had a SCAD between consent and the initial consultation) and two did not start (one

could not be contacted and the other withdrew due to mental health concerns). Twenty-eight participants started the study and 24 (85.7%) completed the intervention. Median attendance at exercise counselling sessions was 5 (IQR 0). The majority of participants were female (n=27, 96.4%) and mean age was 55.0±8.2 years. Participants had a range of traditional cardiovascular risk factors; 10 (35.7%) previously smoked, 14 (50.0%) were overweight/obese, 13 (46.4%) had a history of hypertension and 12 (42.9%) had hyperlipidaemia (table 1)

Table 1: Participant characteristics

| Characteristic | Category | Number | % |
|--|---|--------|------|
| Sex | Male | 1 | 3.6 |
| | Female | 27 | 96.4 |
| Age Group | ≤ 50 years | 8 | 28.6 |
| | 51-60 years | 12 | 42.9 |
| | > 60 years | 8 | 28.6 |
| Index of Multiple Deprivation Quintile | Most deprived quintile | 10 | 7.1 |
| | 21-40% | 8 | 28.6 |
| | 41-60% | 10 | 35.7 |
| | Least deprived two quintile | 8 | 28.6 |
| Ethnicity | White British | 25 | 89.3 |
| | Other | 3 | 10.7 |
| Education status | Secondary education | 5 | 17.9 |
| | Post 16 secondary education | 11 | 39.3 |
| | Bachelor's or master's degree | 9 | 32.1 |
| | Other | 3 | 10.7 |
| Employment status | Full time | 6 | 21.4 |
| | Part time | 11 | 39.3 |
| | Retired | 5 | 17.9 |
| | Other or unemployed | 6 | 21.4 |
| Caring responsibilities | Unpaid caring responsibilities | 9 | 32.1 |
| SCAD characteristics | 1 SCAD | 23 | 82.2 |
| | 2+ SCAD | 5 | 17.8 |
| Cardiovascular risk factors | Previous smoker | 10 | 35.7 |
| | Overweight/obese | 14 | 50.0 |
| | Previous history of hypertension | 13 | 46.4 |
| | Previous history of hyperlipidaemia | 12 | 42.9 |
| SCAD related risk factors | Migraine | 7 | 25 |
| | Other (connective tissue disorder, fibromuscular dysplasia, hypothyroidism) | 6 | 21.4 |
| Menopause status | Perimenopausal | 10 | 35.7 |
| | Postmenopausal | 14 | 50.0 |
| Cardiac rehabilitation attendance | Not referred | 3 | 10.7 |
| | Referred but did not attend | 8 | 28.6 |
| | Attended | 12 | 42.9 |
| Wearable use | Already had own wearable | 11 | 39.3 |
| | Accepted intervention wearable | 13 | 46.4 |

Outcome measures

6 minute walk test: 19 participants (67.9% of those who started) completed the pre-exercise counselling intervention 6 minute walk test and 15 participants (62.5% of completers) completed both pre and post-exercise counselling intervention 6 minute walk tests. Post-exercise counselling intervention 6-minute walk distance (median=594m, IQR 446-645m) was significantly greater than pre-exercise counselling intervention distance (median=499m, IQR 430-572m), $z = 3.41$, $p < .001$.

Questionnaire data: 28 participants (100% of those who started) completed the baseline (prior to initial consultation) questionnaire, 25 (89.2% of those who started) participants completed the pre-exercise counselling intervention questionnaire 21 (87.5% of completers) participant completed all three questionnaires: (baseline, pre and post-exercise counselling intervention).

Warwick Edinburgh Mental Wellbeing Scale: Mental wellbeing significantly increased during the intervention, $\chi^2 (2) = 13.899$, $p < .001$, between baseline (46.0, IQR 35.0-54.0) and post-intervention (50.0, IQR 47.5-58.5) ($p = .008$) and between pre (44.0, IQR 40.0-50.0) and post-exercise counselling intervention (50.0, IQR 47.5-58.5) ($p = .004$).

International Physical Activity Questionnaire Short Form: Participants did not significantly increase their self-reported total activity (METS-min/week) $\chi^2 (2) = 4.880$, $p = .087$.

Generalised Self-efficacy Score: General self-efficacy significantly increased during the intervention, $\chi^2 (2) = 7.194$, $p = .027$, between baseline (30.0, IQR 29.0-34.0) and post-exercise counselling intervention (32.0, IQR 30.0-36.5) ($p = .041$). There were no significant changes between baseline and pre-exercise counselling or pre and post-exercise counselling.

Seattle Angina Questionnaire: Seattle Angina Questionnaire mean summary score significantly increased during the intervention, $\chi^2 (2) = 13.900$, $p < .001$, between baseline (66.9, IQR 53.0-84.0) and post-exercise counselling intervention (86.3, IQR 72.8-93.7) ($p = .001$) and between pre (73.5, IQR 62.0-82.0) and post-exercise counselling intervention (86.3, IQR 72.8-93.7) ($p = .034$).

Cardiac Anxiety Questionnaire: Mean cardiac anxiety score significantly decreased during the intervention $\chi^2 (2) = 12.937$, $p = .002$, between baseline (1.88, IQR 1.25-2.19) and post-exercise counselling intervention (1.22, IQR 1.09-1.59) ($p = .013$) and between pre (1.78, IQR 1.33-2.23) and post-exercise counselling intervention (1.22, IQR 1.09-1.59) ($p = .005$).

Qualitative findings

Eighteen participants who completed the intervention took part in qualitative interviews. Overall, the intervention was very positively received. Two main themes were identified: 1) Acceptability of the intervention and 2) Deliver skillset.

Acceptability of the intervention: Participants liked the intervention, valuing both the initial consultation and the exercise counselling sessions. They suggested that the flexibility of sessions times, the lack of transport requirements and the fact that the exercise counselling sessions were discussions rather than exercise reduced attendance barriers. Participants reported that a strength of the intervention was that it offered an individualised, pragmatic approach that helped them to incorporate physical activity into everyday activities, helped to reduce fear about exercise and increased confidence. This resulted in a return to at least previous levels of physical activity. Most participants were familiar with virtual meeting platforms and recognised that using Microsoft Teams allowed delivery to a geographically dispersed population. A few stated that they would have preferred an in-person intervention and for some who had also attended local cardiac rehabilitation, supervised exercise was reported to be reassuring. There were mixed views about the value of the fitness wearable.

Those who used one liked seeing daily step counts and some reported that it was reassuring to monitor exercise intensity. Some felt that it helped them to increase the amount of exercise that they did and/or exercise intensity. However, others stated that they just used the wearable as a watch or forgot to set it when they started a planned exercise session. One person had difficulties downloading the associated app. Views about the optional virtual coffee mornings were also mixed. Some participants found it very reassuring to talk to others with the same condition and share experiences, which built a sense of community and increased confidence. However, a few participants reported that they were shy or did not like group chats and that the coffee mornings were not for them. Times of coffee mornings were an issue for those who had returned to work, had caring commitments or who had medical appointments.

Deliverer skillset: Participants valued the expert SCAD knowledge of the intervention deliverers, their ability to listen well, being easy to talk to, their non-judgemental approach, and during the exercise counselling sessions being able to tease out what participants wanted to achieve and allowing them to set their own goals. These softer skills were considered particularly important. During the initial consultation, participants valued being able to talk to someone who understood what had happened to them, being able to ask more in-depth questions about medication and information they had found online and receiving reassurance about ongoing chest pain. One participant described it as cathartic. During the exercise counselling sessions, the expert knowledge of exercise after SCAD and the softer skills encouraged and motivated participants. This resulted in them increasing their understanding of appropriate heart rate levels during exercise, how to do strength training safely and how to rebuild exercise duration, intensity and confidence to be active. Participants highlighted the need for a consistent deliverer of the exercise counselling intervention to allow for the building of knowledge of personal circumstances and rapport.

Phase 3: A qualitative study with the partners of SCAD patients to explore their experiences and support needs

During the co-design workshops participants shared that they felt their partners had experienced greater levels of post-SCAD anxiety than them, with two participants describing how their husbands have now been diagnosed with PTSD. It was highlighted that no support existed for partners or advice on how best partners could support loved ones following SCAD. Therefore, the steering group decided that additional qualitative work should be undertaken to explore the experiences of partners following SCAD and to use this information to develop family related support resources.

Methods

A qualitative study using individual semi-structured interviews via Microsoft Teams was conducted between May

Participant recruitment, data collection and analysis

Participants were recruited via BeatSCAD social media advertising and participants consented to the study after reading the participant information via an online link. Participants were invited to take part in an online, Microsoft Teams meeting at a convenient time. Interview topics included their experiences of partner's SCAD events, impact and support requirements. Interviews were recorded, transcribed verbatim and thematically analysed [23, 26].

Results

Fourteen participants were recruited. The majority were male (n=12, 85.7%) and the median age was 52 (interquartile range 16) years. Three overarching themes were developed: 1) Emotional trauma. The unexpected nature of SCAD, often in the absence of cardiovascular risk factors and at a young age, resulted in shock, fear of recurrence, and anxiety about

ongoing chest pain and the impact of SCAD on their loved one. This was exasperated by the unknown causes of SCAD and limited understanding of medication regimes. 2) Extreme coping responses. Participants did not want to leave their partners alone and struggled to maintain normal work/routines. This resulted in measures like tracking the SCAD survivor's location via mobile phone, giving neighbours access to their home and purchasing a defibrillator in case of further events. Partners took on more strenuous household tasks and childcare responsibilities. 3) Support and information needs. Participants required clear explanations from healthcare professionals about their partner's event and access to informative resources including information about what SCAD is, what treatments are appropriate and what to expect during recovery.

Phase 4: The development of a Patient Reported Outcome Measure (PROM) for SCAD patients

Methods

The pilot PROM was developed in four distinct phases: item generation, pilot questionnaire development, SCAD patient feedback on the pilot questionnaire, revision of the pilot questionnaire. Testing of validity and development of scoring were not within the scope of this funding, and more funding is required for these stages.

Item generation

Item generation involved a multi-stage co-design process: 1) review of the literature, 2) examination of currently available and relevant PROMs and 3) focus groups with patients and further individual feedback. All stages were overseen by the steering group and patient representatives.

An initial scoping review of available SCAD literature, including previous systematic review and qualitative interviews conducted by members of the steering group, was used to guide the identification and development of potential PROM domains. Patients with lived experience helped to further help identify important topics to this population via the project steering group and the intervention co-design workshops. This information informed a larger literature search to identify previously existing PROMs used with other cardiovascular populations (e.g., coronary artery disease, heart failure and valve disease), existing general quality of life PROMs, and PROMs used for women's specific conditions (e.g., gynaecology and pregnancy). A Google search was undertaken by one researcher in June 2023. Existing PROMs were screened for relevance by two researchers and reviewed and categorised by one researcher to assess their relevance. Relevance screening was based on two criteria: 1) whether the PROM would be helpful to the SCAD population, and 2) whether they met the domains relevant to the SCAD population identified during the initial development work. Relevant PROMs then underwent PROM item extraction, grouping potentially relevant individual questions to a SCAD population into a corresponding domain(s), to create an initial bank of questions and interesting areas of discussion to take to a SCAD co-design workshop for further item refinement.

Two researchers independently assessed the quality of the identified PROMs using the checklist to operationalise measurement characteristics of PROMS [32]. Any discrepancies were discussed and if a solution could not be found, a third researcher provided an independent assessment.

Participant recruitment and data collection

SCAD participants who took part in the co-design project were invited to be involved in the development of the PROM. They consented to this at the same time as they consented to take part in the codesign study. After the co-design process was completed, participants were invited to attend a fourth online workshop. The workshop included an introduction to what a PROM was, examples of relevant PROMS. Prior to the workshop, researchers had

created a suggested PROM based on the item generation and the co-design work. Participants were also shown examples of excluded PROMS and asked whether the reasoning behind exclusion was acceptable or whether they felt that these PROMS should be considered in the development of the SCAD PROM. Participants were also asked to comment on terminology, positive and negative framing of questions, readability and length of the proposed PROM. They were provided with examples for comparison throughout.

After the workshop, the proposed PROM was amended based on the feedback and then circulated via email to workshop participants for in-depth feedback. Participants could suggest edits to the document, which were incorporated into the pilot PROM if appropriate.

Results

Item generation: We identified 107 PROMS. Fifty-one were not accessible and two did not meet any of the required domains, leaving 54 PROMs to be analysed further. Thirty-three were excluded due to: assessing physical activity and not the impact of an event (n=2), being an assessment tool (n=7), being culturally irrelevant (n=1), not being relevant to SCAD (n=8), being too general (n=2) and being too condition specific (n=1). The remaining 33 PROMs were used to form an initial bank of questions for the workshops.

Participants: Six SCAD patients from the co-design group attended Workshop 4 and all commented via email on the proposed pilot PROM.

Final pilot PROM: The pilot prom consisted of 40 questions, divided into six sections: SCAD specific questions, illness beliefs, physical impact, emotional impact, social impact and quality of life (table 2).

Table 2: Pilot SCAD PROM

| Section 1 SCAD specific questions | | | | | |
|---|----------|----------|----------|----------|----------|
| Please rate the following statements on a scale of 1 to 5, where: 1 = Not at all, 2 = Slightly, 3 = Moderately, 4 = Very, 5 = Extremely | | | | | |
| Question | 1 | 2 | 3 | 4 | 5 |
| 1. I am fully recovered from my SCAD | | | | | |
| 2. Because of my SCAD I experience ongoing chest pain or discomfort | | | | | |
| 3. Because of my SCAD I experience ongoing fatigue | | | | | |
| 4. I understand why I need to take medication after my SCAD | | | | | |
| 5. Taking medication for my SCAD helps me to control my symptoms | | | | | |
| Section 2: Illness beliefs | | | | | |
| Please rate the following statements on a scale of 1 to 5, where: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree, 5 = Strongly Disagree | | | | | |
| Question | 1 | 2 | 3 | 4 | 5 |
| 6. If I keep myself active, I can stay healthy | | | | | |
| 7. I am concerned about having another SCAD | | | | | |
| 8. If I exert myself, I will experience chest pain | | | | | |
| 9. I should take life easy because of my SCAD | | | | | |

| 10. There's nothing I can do about my SCAD symptoms | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|----|
| 11. If I have chest pain, I think I am having another SCAD | | | | | | | | | |
| 12. If I have chest pain, I think it is causing permanent damage | | | | | | | | | |
| 13. Too much stress will cause another SCAD | | | | | | | | | |
| 14. Being relaxed will help control my SCAD symptoms | | | | | | | | | |
| Section 3: Physical Impact (Activity and ADLs) | | | | | | | | | |
| Please rate the following statements on a scale of 1 to 5, where: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree, 5 = Strongly Disagree | | | | | | | | | |
| Question | 1 | 2 | 3 | 4 | 5 | | | | |
| 15. I have been able to engage in physical activity/hobbies that I enjoy/previously enjoyed | | | | | | | | | |
| 16. I have had difficulty performing daily activities due to my SCAD | | | | | | | | | |
| 17. I have been able to maintain my preferred daily structure and routine | | | | | | | | | |
| 18. I have had chest pain or tightness when undertaking physical activity | | | | | | | | | |
| 19. I have changed the type of exercises I undertake | | | | | | | | | |
| 20. I feel deconditioned since my SCAD | | | | | | | | | |
| 21. I understand what physical activity is appropriate after my SCAD | | | | | | | | | |
| 22. I have made positive lifestyle changes as a result of my SCAD diagnosis (e.g., diet, exercise, stress management). | | | | | | | | | |
| 23. I feel confident undertaking activities alone without support from friends or family | | | | | | | | | |
| 24. Over the past four weeks, how would you rate your overall physical wellbeing: (1= very poor, 10= Excellent) | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Section 4: Emotional Impact | | | | | | | | | |
| Please rate the following statements on a scale of 1 to 5, where: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree, 5 = Strongly Disagree | | | | | | | | | |
| Question | 1 | 2 | 3 | 4 | 5 | | | | |
| 25. My SCAD diagnosis has caused anxiety or depression. | | | | | | | | | |
| 26. I feel supported in managing my emotional well-being. | | | | | | | | | |
| 27. I feel frustrated after my SCAD | | | | | | | | | |
| 28. I am frightened I will have another heart attack | | | | | | | | | |
| 29. Ongoing chest pain impacts on my mental health | | | | | | | | | |
| 30. My confidence is as good as it has ever been | | | | | | | | | |
| 31. I am worried or anxious about the prospect of travelling away from home | | | | | | | | | |
| 32. Over the past four weeks, how would you rate your overall emotional wellbeing: (1= very poor, 10= Excellent) | | | | | | | | | |

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
|---|---|---|---|---|---|---|---|---|----|---|
| Section 5: Social Impact | | | | | | | | | | |
| Likert Please rate the following statements on a scale of 1 to 5, where: 1 = Strongly agree, 2 = Agree, 3 = Neither agree nor disagree, 4 = Disagree, 5 = Strongly Disagree | | | | | | | | | | |
| Question | | | | | | 1 | 2 | 3 | 4 | 5 |
| 33. My ability to work or pursue my career has not been affected by my SCAD diagnosis | | | | | | | | | | |
| 34. My ability to meet the needs of my family has not been affected by my SCAD diagnosis | | | | | | | | | | |
| 35. My social life has not been affected by my SCAD diagnosis | | | | | | | | | | |
| 36. My libido (sex drive) has been reduced after my SCAD | | | | | | | | | | |
| 37. I feel that I am a burden to others | | | | | | | | | | |
| 38. Over the past four weeks, how would you rate your overall Social wellbeing: (1= very poor, 10=Excellent) | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| Section 6: Quality of Life | | | | | | | | | | |
| 39. On a scale from 1 to 10, with 1 being the worst possible quality of life and 10 being the best possible quality of life, how would you rate your overall quality of life since your SCAD diagnosis? | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| 40. If you had to spend the rest of your life with your health following your SCAD the way it is right now, how would you feel about this? (1= very poor, 10=Excellent) | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |

Dissemination

Current Outputs:

- 1) As part of the project, we developed a collaboration with Australian researchers to assess the quality of online information about SCAD. This resulted in a publication in an international journal: Weddell, J., Jawad, D., Buckley, T., Redfern, J., Mansur, Z., Elliott, N., Hanson, C., & Gallagher, R. (2024). Online information for Spontaneous Coronary Artery Dissection (SCAD) survivors and their families: a systematic appraisal of content and quality of websites. *International Journal of Medical Informatics*, 184, 105372. <https://doi.org/10.1016/j.ijmedinf.2024.105372>
- 2) British Association for Cardiovascular Prevention and Rehabilitation annual conference 2025: Poster presentation “*Designing a recovery intervention for spontaneous coronary artery dissection: a person-based approach co-design study*”. Presented by Alice Pearsons and published in Heart: <https://doi.org/10.1136/heartjnl-2025-bacpr.47>
- 3) British Association for Cardiovascular Prevention and Rehabilitation annual conference 2025: **Winner of the Best of the Best Oral Abstract Session** “*A remote recovery intervention for spontaneous coronary artery dissection: a cohort study*”. Presented by Coral Hanson and published in Heart: <https://doi.org/10.1136/heartjnl-2025-bacpr.2>
- 4) British Association for Cardiovascular Prevention and Rehabilitation annual conference 2025: Oral Poster Presentation Session “*Supporting recovery from*

spontaneous coronary artery dissection: a qualitative study of partners perspectives". Presented by Andrew Steven and published in Heart: <https://doi.org/10.1136/heartjnl-2025-bacpr.8>

- 5) The co-design and cohort study results were presented at the BeatSCAD conference in Leicester in October 2025. This is a patient facing conference.

Planned Outputs:

- 1) The co-designed SCAD recovery intervention manuscript will be submitted for publication in February 2026. The target journal is the European Journal of Cardiovascular Nursing.
- 2) The cohort SCAD recovery intervention manuscript has a planned submission date of April 2026. The target journal is the European Journal of Cardiovascular Nursing.
- 3) The Partners SCAD manuscript is still in development with a planned submission to British Journal of Cardiac Nursing.

Expenditure:

This is provided on an attached document.

Principal Investigator:

| | | | |
|------------|--|-------|------------|
| Signature: |  | Date: | 29/01/2026 |
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