**Strategies and checklist for designing and conducting palliative care research with family carers: EAPC international expert elicitation study**

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**Running Head:** Strategies for conducting research with family carers

**Abstract:**

Background: Palliative care services seek to improve the wellbeing of family carers of people living with serious and life-limiting illness. To help achieve this goal, systematic reviews have recommended priority areas for family carer research and the need to improve study design quality. Policy makers have also advocated for enhanced family carer support. However, there are specific methodological considerations and challenges in designing and conducting carer research conducted during the course of the serious illness trajectory and in bereavement.

Aim: To develop strategies to improve the design and conduct of research with family carers.

Design: Expert elicitation study using an adapted version of the ‘Identify, Discuss, Estimate and Aggregate’ elicitation protocol, supplemented with strategies in peer-reviewed literature.

Setting/participants: 9 members of the management committee of the European Association for Palliative Care’s Reference group on family carer research, comprising international senior research academics in family caregiving.

Results: A compilation of recommended strategies and checklist was created to: (a) help researchers plan research involving family carers focussing on: preparation, conduct and dissemination and (b) assist ethics committees and funding bodies to evaluate proposals.

Conclusions: The strategies and checklist for conducting research with family carers may enhance methodologically rigorous research. Consequently, researchers, practitioners and policy makers will not only gain a more comprehensive understanding of the unmet needs of family carers but also promote the development of empirically sound interventions.

**Keywords:** Palliative Care; Family; Caregivers; Research; Terminal care

**Key Statements:**

**What is already known about this topic**

* Improving the quality of life of family is a core element of palliative care. Systematic reviews have identified the need to improve study design quality.
* Methodological considerations and challenges associated with carer research have not been comprehensively detailed.
* Specific strategies for overcoming some of these challenges has not been published.

**What this paper adds**

* A detailed account of family carer research issues for consideration before embarking upon studies involving lay carers
* Specific strategies and recommendations for advancing scientific inquiry related to family carers and palliative care.
* A comprehensive checklist to help researchers and other key stakeholders plan for and conduct research involving family carers which can also be used by ethics committees and funding bodies to evaluate grant proposals.

**Implications for practice, theory and policy**

* In order for the strategies to be enacted, academic leaders will need to work strategically and collaboratively with policy makers, funding bodies and other key stakeholders.
* The strategies and checklist for conducting research with family carers may help to catalyse an increase in methodologically rigorous research.

**Introduction**

Palliative care services aim to enhance the quality of life of people living with serious and life-limiting illness and their families.1 However, despite palliative care policy, clinical and research guidelines highlighting the importance of a family carers, challenges have impeded development of optimal support and much of the scientific focus has tended to target interventions for patients with less attention given to family carers.2 Furthermore, many family carers find it difficult to access health professional support based on their needs 2 and others are not even aware that such services exist. 3 Moreover, family carers provide the bulk of care and support to patients receiving care at home, yet approximately 40% of carers may experience psychological distress 4 which is typically under-recognised. 5 Thus, despite consistent calls for the integration of a family approach to palliative care effective systematically applied psychosocial support for family carers is still underdeveloped. 6-8

It is not surprising, therefore, that more recently palliative care research priority setting initiatives have family carer research high up on the agenda. For example responding to the needs of family carers was rated 1st out of 32 topics 9 , 4th out of 10 topics10; 5th out of 10 topics 11 and was identified as 1 of 6 priorities in another research priority study.12 Reviews have also been undertaken which explore the priority topics specifically related to family carer research. 13-18 Additionally, we know that many family carers want to participate in research to benefit future palliative care provision. 19, 20

Thus, there is a strong policy, clinical, consumer and academic rationale for focusing on family carer research. Research in palliative care is commonly recognized as challenging and specific obstacles have been explicated. 21-24 However, there has been minimal exploration of the specific difficulties that may occur when conducting research with family carers who are supporting a person requiring palliative care. Researchers have acknowledged some complexeties such as gatekeeping and other recruitment related issues25, however a comprehensive appraisal is thus far lacking. Hence it is not surprising to find that recommendations for conducting research with family carers, that may accommodate such challenges, have not been formally established in the international peer reviewed literature.

Given this background, the European Association for Palliative Care’s International Reference group on family carer research (see [https://www.eapcnet.eu/eapc-groups/reference/family-carers/](about:blank)) set as one of its strategic aims, to develop and collate pragmatic strategies for designing and conducting research with family carers of people diagnosed with serious and life-limiting illness. The study described herewith outlines the empirical process and results linked to this aim.

**Methods**

Study Design

We utilized an expert elicitation methodology (adapted from26) . Expert elicitation relies on the expertise and opinions of people with significant experience and knowledge of a particular topic 26 and has been used in a wide variety of contexts 27, 28including palliative care.29

Ethical considerations

Advice regarding research ethics approval was sought from a research ethics committee at The University of Sheffield who noted that stakeholder engagement of this kind does not require research ethics approval. Nonetheless, participants were formally advised that consent to participate was voluntary and were informed of the implications of taking part and the option to withdraw.

Setting, Population, Sample and recruitment

We invited all members (n = 14) of the management committee of the European Association for Palliative Care’s Reference group on family carer(see [https://www.eapcnet.eu/eapc-groups/reference/family-carers/](about:blank)). This committee comprises international senior academics with independent programs of research in family caregiving. Nine members (co-authors of this paper) elected to take part and contribute as experts to the project. The remaining five were very supportive of the project and offered reasons for declining such as competing demands which precluded their capacity to actively participate`.

Data collection

We utilised the ‘IDEA’ (Identify, Discuss, Estimate and Aggregate) expert elicitation framework. 26 We followed these core steps but adapted the framework by excluding the quantitative (aggregate) component as our purpose was not to estimate probability. Notably, the intent of the discussion components of the IDEA protocol is not to mandate consensus but to resolve linguistic ambiguity, promote critical thinking, and share evidence and insights.

The elicitation methods literature suggests that experts should make judgements that ideally match empirical data. 27 Hence where evidence was available, we also asked experts to support their recommendations by citing peer reviewed literature.

In keeping with the IDEA elicitation protocol our data collection and analysis involved multiple steps (see Figure 1). The expert elicitation questionnaire (see Figure 2 for summary) was initially developed by the project facilitators (PH & CG) and then refined via sharing with the other experts and then sent out via email. The questions were commensurate with the study aims and focused on three key areas – preparing and designing research, conducting research, and disseminating and implementing research. In addition, all participants were asked to provide sociodemographic details including gender; country of residence; professional discipline; years of involvement in family carer research; and number of peer reviewed publications authored that focused specifically on family carers. The data were collected between June-August 2021.

Data analysis

Data analysis involved three rounds. First, responses were collated by CG and PH and core thematic categories were identified and used to developing a coding matrix. Codes were collated into potential themes, which were then checked against the coded extracts and the entire set of responses. Second, the draft analysis was circulated to all experts, and themes were refined based on their feedback. Finally, the subsequent analysis was presented at a group discussion meeting with all experts to finalise themes.

Patient and Public Involvement

Patient and public involvement (PPI) supported the development and refinement of the recommendations and checklist (Figures 3 & 4). PPI input was sought from the Cancer Patient Forum at the Royal Preston Hospital and the Palliative Care Studies Advisory Group at the University of Sheffield, UK. These two groups collectively comprise over 20 individuals with personal experience of palliative and end of live care services, including as carers. The groups have substantial expertise in contributing to national and international research in palliative and end of life care. Following feedback from three PPI representatives (two carers and one patient), one of the recommendations in figure 3 was amended, and one item was added and another amended in figure 4. Feedback from PPI representatives included that the recommendations and checklist appeared to be very helpful, with one representative remarking: “they are very comprehensive…and seems to cover all I would expect”. PPI representatives were offered authorship however preferred to be anonymously acknowledged instead.

Figure 1: Expert elicitation steps

1. Develop timeline
2. Form a project team of experts (as per above)
3. Appointed facilitators (PH & CG)
4. Draft the elicitation questions (PH & CG)
5. Conduct an inception discussion meeting (conducted virtually with facilitators and experts) to revise the elicitation questions and process for administering amongst the project team. Elicitations questions are outline in Figure 2 and were circulated electronically for completion (including facilitators).
6. Data analysis Round 1 (CG & PH)
7. Data analysis Round 2: results circulated to all experts electronically & then revised
8. PPI engagement and input
9. Data analysis Round 3: discussion meeting (conducted virtually with facilitators and experts) to finalise results

Figure 2: Summary of elicitation questionnaire

*Part 1 Preparing and designing family carer research*

When considering research related to family carers and palliative care what are the barriers and strategies related to: accessing grant funding; designing a research question(s); study design; involving key stakeholders (e.g consumers/end users); theories and conceptual frameworks; identifying primary outcome variable(s) and identifying suitable outcome measures?

*Part 2 Conducting family carer research*

When considering research related to family carers and palliative care what are the barriers and strategies related to: identifying family carers for potential involvement in research; recruiting family carers; collecting and analysing data from family carers?

*Part 3 Disseminating and implementing family carer research*

When considering research related to family carers and palliative care what are the barriers and strategies related to: disseminating research findings (e.g., publishing, presenting at conferences, media) and implementing research findings into practice?

*Part 4 Most important strategies*

When considering research related to family carers and palliative care what are the most important strategies for

improving the preparation and design of family carer research; conducting family carer research; the dissemination of family carer research and for improving the implementation of family carer research?

**Findings**

Sociodemographic profile of participants

Responses were received from 9 experts (5F, 4M). Respondents were based in UK (n=4), Sweden (n=2), Australia (n=1), USA (n=1), Netherlands (n=1). The main disciplines of respondents were nursing (n=6), psychology and health psychology (n=2), social work (n=1). Respondents were involved in family carer research for between 10-25 years each and had published a median of 30 family carer research focused manuscripts each.

Responses from experts identified both pragmatic strategies for facilitating family caregiver research, and barriers to successful family caregiver research. These are presented according to stage of the research process namely preparing, conducting, and disseminating/implementing research.

Barriers and strategies for preparing and designing family carer research

Experts felt that both palliative care research, and specifically family carer research in an international context, were not prioritised by funding bodies. In addition, funders were perceived to prioritise interventional research and this had implications for family carer research, which often uses non-interventional methods particularly when trying to ascertain carer needs and/or the impact of the carer role. Experts suggested that engagement with funding bodies to highlight the impact of carer research on patient outcomes, alongside work to establish research priorities for family carer research,30 may help develop priority driven agendas for funders. One example is the United States-based National Cancer Institute who, in 2019 had a specific grant call for research projects measuring the impact of caregiving on patient outcomes and service utilization.

A major issue identified by the experts was a lack of a clear operational definition of the term ‘family carer’, with many carers not identifying with the term. 31 This was perceived to contribute to a lack of research prioritisation from funders but more broadly led to challenges with defining the population of interest, and thus difficulties with preparing and designing research. Other challenges were identified relating to research design, with some designs including longitudinal 24 or randomised controlled trials 32 often not considered to be feasible in this population. There was also some suggestion that insufficient attention is given to research designs exploring the positive aspects of caregiving. 33 The involvement of family carers in co-designing research from inception to dissemination may help mitigate some of these issues, likewise a greater focus on mixed methods, and more broadly inclusive, research designs (such as participatory and stakeholder engagement approaches). In addition, the carer research realm appears to lack specific methodological training for investigators focussing on this population.

Gaining ethical approval for research involving family carers was deemed to be challenging, with evidence of gatekeeping by ethics committees and patients 22, 34, 35 and a reluctance to approve studies deemed ‘sensitive’ can present a barrier. In response, proactive efforts should be made to educate ethical committee members that carers value the opportunity to participate in research (e.g.,20, 34). Patient and Public Involvement (PPI) is integral to developing research designs, and PPI support can be extremely persuasive in ethical review.

A final barrier to the planning of research relates to the limited theoretical framing of family carer research in the palliative care context.36 This leads to a reliance on generic caregiving literature which may not be appropriate, and which can result in interventions with unclear theoretical constructs. Researchers may want to consider the adaptation of existing family caregiver theories 37 to the palliative care context, in order to support the theoretical foundations of projects.

Barriers and strategies for conducting family carer research

Challenges were identified with involving family carers in research and recruiting to studies. 24 Alongside the definitional issues described above, family carers in palliative care are often too busy, tired, unwell or pre-occupied with care tasks to participate in research. This is compounded by a comparative absence of international advocacy organisations and/or national databases from which to recruit carers. Patient focussed data bases also typically lack the family carer detail required. Carers are frequently positioned as ‘appendages’ of patients and therefore under the control of health services rather than as people in their own right, with autonomy to consent or not to participate in research. Gatekeeping from health professionals or from patients (whose consent is often required before a carer can be contacted) who worry about overburdening these family carers hampers recruitment and ultimately efforts to better support and lessen the burden on family carers. More imaginative and flexible recruitment channels may therefore be required to achieve a target sample, for example use of social media, support groups, charities and patient organisations with family carer sub-groups. Direct recruitment via researchers, rather than through health professionals/patients may also bypass some gatekeeper issues, however it is important to continue to engage with both clinical teams and patients as partners in the research process. 38 An ‘opt out’ rather than an ‘opt in’ approach allowing all family carers to be contactable about research to make their own decisions regarding research participation, may also support recruitment. 22, 34

Some sub-populations of family carers may be particularly difficult to identify and are at risk of being excluded from research. 39 For example, ethnic and cultural minorities36, non-spousal carers (friends, children), carers who are employed37, socio-economically deprived carers and same sex couples.21 Similarly, most carer research assumes the presence of a single primary carer where each patient is presumed to have a single carer providing all or the majority of support; however there are often multiple carers involved and research is needed that takes a broader view of the patient’s carer network.21 It is important to promote greater collaboration with groups and communities representing sub-populations, and where possible involve researchers from sub-populations, in order to maximise inclusivity and equity in research design and recruitment. Similarly, longitudinal studies that capture the complexity of caregiving relationships and the evolution of relationships over time 40 may be valuable.

When conducting research with family carers, data collection may be influenced by the values and expectations that are associated with the carer role. Some carers may be unwilling to be critical of the patient,31 or may be uncomfortable discussing their own needs and concerns in front of the patient. Legitimising the family carer role and recognising carers as recipients of care as well as providers of care, may help reframe the carer role within research paradigms. 41The development of innovative protocols to specifically support family carers in research (i.e. minimising distress due to research participation) may also be useful in further legitimising the carer role and supporting their engagement in research. For bereaved carers, a challenge often encountered is how much time to leave after a patient’s death, before the carer is invited to participate in research. There is little consensus on the most appropriate timeframe, however the decision should be informed by the research question(s) and consideration given to minimizing potential distress while maximising accuracy of recall. 42 As long as the research is warranted and deemed ethically sound; family carers can decide if they want to participate as opposed to someone else making assertions about when is the ‘right’ time to contact them in the bereavement period.

Barriers and strategies for disseminating and implementing family carer research

The dissemination of family carer research was not perceived to be particularly problematic, with experts even noting that carer research was gaining more prominence at palliative care conferences and in journals. 43 However, the implementation of research findings and generating impact can be more challenging. Translating research findings into practice and wider society can be difficult when the patient is often seen as the primary focus 44 42 and internationally there is a lack of staffing, training and funding to deliver family carer support. Similarly, there can be differing opinions on whose responsibility it is to support family carers, with implications for where to direct research findings. Utilizing family carer support knowledge in non-specialised palliative care settings might also be challenging, since including family support is less clear in these services as comparted to specialised palliative services.

An obvious strategy for improving dissemination and impact is to design research with implementation as a core outcome, rather than an afterthought. 45 Alongside this, closer working between researchers, clinicians and policymakers 41 will help emphasise the importance of the family carer role, and the significance of research focused in this area. Working with policy colleagues from the project outset has many advantages but getting help to distil the key findings into policy areas is vital to maximising impact . 46 Researchers in palliative care may also consider aligning their research with the wider family carer agenda, potentially leading to collaborations with more influential advocacy organisations, for example Carers UK. The World Health Organization could potentially take a lead in advocacy for family caregiver research particularly in resource poor countries.47

Strategies and recommendations for advancing scientific inquiry in family carer research

To complement the aforementioned approaches and based on responses related to what were considered the most important elements for overcoming research challenges, we developed a summary of strategies for advancing scientific inquiry related to family carers and palliative care (see Figure 3). Palliative care: researchers, advocacy groups and leaders could ideally influence uptake of these steps.

Figure 3: Strategies for advancing scientific inquiry in family carer research

|  |  |
| --- | --- |
| Preparation and design of research | * Lobby funding bodies to prioritise family carer research, and educate them on the value of a range of research methodologies (including qualitative and mixed methods approaches) * Promote conceptual clarity and clearer operational definitions of the term ‘family carer’ * Support greater involvement of family carers throughout the research process and as research partners; embedding Patient and Public Involvement (PPI)/ Community Engagement & Involvement (CEI) in all research designs * Liaise with national/ key ethics committees to educate them on research in palliative care and family carers * Promote community awareness of the impact of the family carer role and the need for investment in research |
| Conduct of research | * Support the development of more flexible and imaginative recruitment channels to minimise carer burden e.g. social media, advocacy groups, opt out rather than opt in designs * Greater commitment to equity and diversity - recruiting sub-populations by collaborating with groups and communities representing sub-populations, and where possible involving researchers from sub-populations * Encourage legitimisation of the carer role with carers acknowledged as recipients of care as well as providers * Develop protocols to specifically support family carers in research i.e. flexible data collection, managing distress, providing practical support so they can take time away from patient. * Recognise that family carers have more to contribute to research than as proxies for patients * Advocate that bereavement data collection can potentially take place soon after death has occurred as long as the time point and data collection method are justified and processed for managing risks are approved by ethics review board. |
| Dissemination and implementation of research | * Lobby funding bodies to include resources that optimise implementation and uptake of family carer research findings and interventions both in specialised and non-specialised palliative care services * Work closely with those who are able to influence implementation, impact and uptake e.g. clinicians, policymakers, commissioners, advocacy and lobbying organisations * Consider aligning palliative care family carer research with the wider family carer research agenda, to maximise influence 43 * Encourage family carers to collaborate in preparing and delivering (co-design) project dissemination |

Drawing upon the data from the expert elicitation questionnaire we also developed a comprehensive checklist (see Figure 4) to (a) help researchers plan research involving family carers focussed on the aforementioned core areas: preparation, conduct and dissemination and (b) assist ethics committees and funding bodies to evaluate proposals.

Figure 4. Checklist for research involving family carers: for researchers, funding bodies and ethics committees

***Preparation and design***

1. What is the rationale for involving family carer(s) as participants in the research?
2. Has a literature review been undertaken to justify the study?
3. If pertinent has input been sought from family carers with regard to the aims and design and if so has their role been distinguished from that of research participants?
4. What theoretical or conceptual framework related to family carers underpins the study?
5. How are family carers defined for the purposes of the study? Has a clear definition been included in the study materials?
6. Which family carer(s) are involved and why? (Primary family carer(s) only or entire carer network)
7. What strategies are being employed to promote diverse and inclusive family carer representation, for example including minority and disadvantaged groups?
8. Will the research focus solely on the family carer(s) or both the carer and the person they are supporting (e.g dyadic research)?
9. If the study involves an intervention what are primary and secondary outcome(s)? To foster implementation: how is feasibility, acceptability and scalability being assessed?
10. How many family carers need to be recruited, has this been justified and is this feasible?
11. Is there a plan for minimising and managing missing family carer data?

***Conduct of research***

1. What specific approaches will be used to identify relevant family carers? (e.g via the patient/health professional? Next of kin? via medical record? social media, advocacy groups etc)
2. What specific strategies will be used to optimise recruitment of family carers? (e.g if the family carer works full time, how will you optimise access).
3. Have partnerships with clinician and other stakeholders (e.g health professionals) been sought to assist with promoting the study to optimise recruitment and also to keep them informed on progress throughout?
4. Is consent of the patient required prior to approaching their carer?
5. How will the study be introduced to the family carer prior to formal consent? (e.g a via a health care professional? In person or remotely?)
6. Who will formally recruit the family carer(s)? (e.g research staff; In person or remotely?)
7. What strategies have been incorporated to minimise potential gatekeeping by health care professionals and/or the person the family carer is supporting?
8. How will data be collected? (In person or remotely?)
9. What time commitment do carers need to allocate for data collection? And will payment for expenses be offered?
10. If the study design involves administration of questionnaires, how has it been determined that they are not overly burdensome and easy to understand?
11. How frequently will data be collected and how long will it take to complete?
12. How will confidentiality of personal data be assured?
13. If data collection includes after bereavement, how will this be sensitively conveyed to the family carer(s) and how soon after death data will be collected and has this been justified?
14. What plan is in place to assist the family carer should they become distressed during or after participation in the study?
15. What are the implications if the person the carer is supporting dies before data is collected? And how will these be managed?

***Dissemination and implementation***

1. Has a dissemination strategy for informing key stakeholders about the results been developed (for example health care professionals who may have assisted with recruitment?)
2. Has a plan been developed to foster implementation and uptake of the intervention or key recommendations?
3. How will information about project outcomes be delivered in accessible language and formats to family carers, and the public? (including social media strategy)

**Discussion**

Main findings

We set out to develop and collate pragmatic strategies for designing and conducting research with family carers of people diagnosed with serious and life-limiting illness and end of life contexts. In addition to a descriptive overview of challenges and strategies identified via the expert elicitation process, two key outcomes are presented: (1) a summary of strategies for advancing scientific inquiry related to family carers and palliative care and (2) a comprehensive checklist to help researcher’s plan for research involving family carers which can also be used by ethics committees and funding bodies to evaluate proposals.

Implications

We anticipate that in order for the strategies and recommendations to be enacted, academic leaders will need to work strategically and collaboratively with policy makers, funding bodies and other key stakeholders. Policy makers, for example, could promote engagement with family carers when setting agendas and standards. These steps will require leadership and investment in identifying organisations and specific people responsible for pertinent components.

With regard to the checklist; the key to its uptake will be through raising awareness of its existence not only amongst academics but also funding bodies, ethics committees, clinicians and others who may only occasionally be involved in family carer research. In order for this to be achieved, in addition to conventional approaches such as publication and conference presentation, other contemporary initiatives such as social media and engagement of key palliative care advocacy groups. From a research perspective, it will be important for others to utilise, adapt and critique the checklist to determine if it has utility.

There appears to be a lack of evidence regarding evaluating the success of different recruitment and data collection strategies.48 Novel approaches need to be considered that focus on fostering participation retention. 49 Although there has been an increase in family carer research 43; as noted, more attention also needs to be directed toward research strategies to engage diverse carer cohorts and the potential uptake and implementation of interventions. 43

To move forward, researchers, health care organisations and policy makers will need to make substantial changes in their processes. Moreover, changes should not be made in isolation. The pathway to true engagement involves working in partnership with patients and families. 50 Ultimately, in order to enhance family carer research in palliative care a multicomponent approach with engagement from all key stakeholders is required. 51 This could incorporate ‘call to action’ type forums and initiatives that focus on specific activities with policy makers and other key collaborators along with explicit actions and outcomes. 51

Strengths and limitations

One of the key strengths of our study is that is appears to be the first of its kind to explicitly outline the challenges of conducting research with family carers and moreover outlining strategies to attempt to overcome them informed by international engagement. This was undertaken via an expert elicitation process that was pragmatic but also robust and incorporated an international team of multidisciplinary experts with considerable experience of research in this topic. The expert elicitation method worked well given it was pragmatic and flexible enough to respond to project constraints including our limited resources given the project was unfunded and the need for international engagement to occur virtually (video conferences) and electronically (email). Nonetheless there were several limitations with the method and therefore our results. For example, we adapted the IDEA protocol, and the efficacy of this design for future studies should therefore be critically appraised by other researchers in order to enhance its potential legitimacy. For example, we advocate that there should be an independent review of the pros and cons of this method in a prospective study(ies).

There was not an open call for experts across the world to contribute; the participants were recruited directly from a reference group of the EAPC which means comprehensive widespread input was not undertaken. In addition, whilst experts were from five countries, these were all high income countries all of which have palliative care integrated into their national healthcare structures and findings may have less relevance for those undertaking research in low and middle income countries. Furthermore, patient and public involvement was limited to representatives from one country; hence broadening input to multiple countries is strongly advocated. Lack of family carer involvement is a major limitation. Unfortunately, as the project was unfunded, we did not have the resources to engage with carers in all stages moreover, we could not involve carers from multiple countries and different languages and also offer to remunerate them for their time.

**Conclusion**

The strategies and checklist for conducting research with family carers can potentially enable an increase in methodologically rigorous research resulting in more robust findings. In so doing, researchers, practitioners and policymakers may not only gain a more comprehensive understanding of the unmet needs of family carers but also the development of much needed empirically sound interventions to better support them. We strongly advocate greater family carer involvement in the evolution of the strategies.

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**Declarations**

Authorship:

PH, CG & SP for leading facilitation of the research with a particular focus on data collection, analysis; presentation of results and discussion. AA; J D; JO; EC; RH; & EW for contributing to research questions, method, analysis; interpretation of results and discussion.

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Data management and sharing: Relevant additional data which informed the findings of this manuscripts can be sought from the corresponding author: Peter Hudson.

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