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CASE STUDY

‘My Wellbeing Journal’: Using experience-based co-design to improve care planning for older adults with multimorbidity

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SUMMARY

In this study, we investigated whether using an accelerated experience-based co-design (EBCD) approach is an effective way to involve multiple stakeholder perspectives in the development of a creative tool to support goal setting in care planning for older adults with multimorbidity. We describe the iterative multi-stage approach of developing “My Wellbeing Journal”, an innovative tool that incorporates consumer experiences and priorities and research evidence on goal-based shared decision-making. The EBCD process ensured stakeholders were involved in every stage of the design and development of the journal. We also discuss procedural and methodological considerations for others conducting similar co-design research.

Key Words

Experience-based co-design; aged; chronic illness and disease; shared decision-making; goal setting

ABSTRACT

Shared decision-making is integral to effective care planning for older adults with multimorbidity yet remains uncommon in routine practice. The development of tools designed with healthcare consumers can support shared decision-making because they align with consumer experiences. We used an accelerated experience-based co-design (EBCD) approach to enable stakeholder involvement in every stage of the development process. We describe the process of developing “My Wellbeing Journal”, a creative tool that incorporates consumer experiences and priorities and research evidence on shared decision-making with older adults. EBCD offered a valuable framework for developing user-centred personal health tools.

BACKGROUND

The prevalence of multimorbidity—defined as the co-existence of multiple medical conditions—and age-related conditions, including frailty, has negative consequences for older adults, including higher treatment burden, polypharmacy, increased use of healthcare resources, and a higher risk of mortality.[1] Shared decision-making (SDM) is central to the provision of patient-centred care.[2] Goal setting is a recommended approach when managing multimorbidity in primary care, yet it is often overlooked in SDM models.[3,4] Setting goals can help consumers (patients, families, and carers) and healthcare professionals (HCPs) define and agree on priorities and actions. Despite available guidelines, implementing SDM for older adults can pose challenges. Barriers to SDM with older adults include lack of perceived permission to participate in SDM, poor interpersonal skills among HCPs, and a lack of preparation for the SDM process, as well as barriers related to the wider social and organisational context, including lack of resources and policy factors.[5]

Decision aids are tools aimed to support SDM.[6] Decision aids contain information about treatment options and questions that can prepare consumers to discuss their preferences with others. Use of decision aids can improve decision participation, knowledge, informed choice, risk perception, and decrease decisional conflict.[7] However, such tools are rarely implemented in routine care, and many are not designed for people with multimorbidity. Generic tools are available, such as the Ottawa Personal Decision Guide and the Ask 3 Questions campaign, alongside tools aiming to support communication in the context of multiple chronic conditions.[8] Currently, there is limited evidence that these tools are being implemented widely or that they promote SDM from consumers' perspectives. Partnering with consumers and HCPs and incorporating their perspectives using an iterative co-design process may address issues related to limited uptake, relevance, and effectiveness.

There is increased interest in applying user-centred design principles to develop decision aids and other health tools. Experience-based co-design (EBCD) is a valuable method for engaging users in identifying ways in which services can be modified to improve user experiences.[9,10] EBCD is a form of narrative-based, participatory action research that was originally developed as a healthcare quality improvement method. In this study, we used an accelerated EBCD approach to engage stakeholders in co-designing a creative tool to support goal setting in care planning for older adults with multimorbidity that incorporated lived experience with other evidence resources.[11] Accelerated EBCD is an adapted approach where the co-design process is "accelerated" by using service user narratives from a pre-existing collection of interviews. We used an accelerated EBCD approach because it was cost-effective and could be completed in a relatively short period (4–8 months) compared to traditional EBCD (8–19 months).[9]

METHOD

We used an iterative five-step process to develop the tool (Figure 1). We have described Stage 2 in previous manuscripts[11,13,14] and therefore only briefly describe this stage here. We then describe Stages 3–5, which focus on the process of developing the tool. In the co-design process, we referred to the EBCD Australia Toolkit[15] (Table 1) and current recommendations for reporting EBCD research.[9] Ethical approval was granted prior to study commencement by the Flinders University Social and Behavioural Ethics Committee (Project Number 2772).

Figure 1: Overview of tool development process

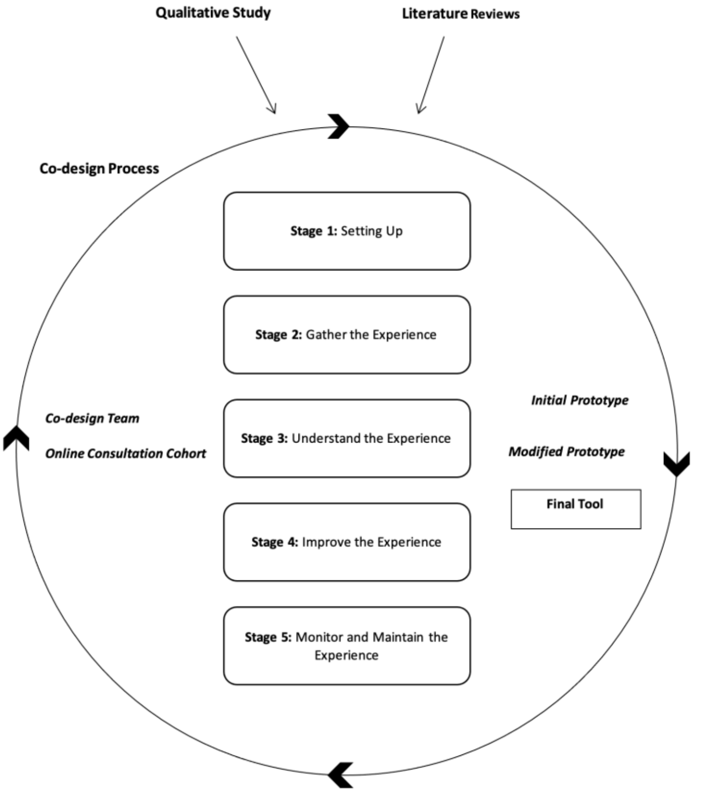


Table 1: Five-stage EBCD process (based on EBCD Australia Toolkit[14])

Stage	Strategy/Tool
1) Setting up	Engagement, planning the EBCD approach, project management, sustainability, leadership support
2) Gather the experience	Patient shadowing and observation, patient stories, staff interviews, video
3) Understand the experience	Feedback events, journey mapping, service touchpoints and hotspots
4) Improve the experience	Ideas group, stakeholder needs table, scenarios and personas, prototyping
5) Monitor and maintain the experience	Dissemination, celebration events

Stage 1: Setting up

Two researchers, ML and MAPP, coordinated recruitment of consumer representatives through the Consumer and Community Engagement Action Group of the South Australian Health and Medical Research Institute and Health Translation South Australia in January–March 2021. Recruitment involved posting a formal position description and call for expressions of interest. Inclusion criteria for consumer representatives were community-dwelling individuals with experience as an older adult (over age 65) with a chronic health condition or in a caring role for an older person. Academics and clinicians affiliated with three South Australian universities were purposefully invited to participate in the study (Table 2). Additionally, we established an online consultation cohort of consumers (n=10). ML engaged creative facilitator and co-author (MWS) to assist with facilitating the co-design workshops to support all team members to participate effectively. ML and MWS communicated on several occasions before the workshops to clarify the aims and scope of the project, develop workshop materials, and consider strategies and tools to enable mutual understanding and creative ideation.

Table 2: Description of co-design group

Team member	Affiliation and Representation	Justification for inclusion
Consumer Representative 1 (P1)	Community member	Combination of lived experience as an older person with chronic health conditions; advisory panel experience; experience managing care package programs; public service experience; knowledge of issues related to service access and information
Consumer Representative 2 (P2)		
Consumer Representative 3 (P3)		
Academic 1 (lead investigator) (P4)	Psychology, Nursing	Research experience in ageing and health communication with a focus on knowledge translation into policy and practice
Academic 2 (P5)	Marketing, Health promotion	Research experience in ageing and marginalised populations; prior experience as a consumer advocate and representative
Academic 3 (P6)	General practice	Research experience in ageing with a focus on frailty identification in primary care
Academic 4 (P7)	Medicine, Public health	Research experience in health services research with an emphasis on clinical effectiveness of frailty interventions
Clinician/Academic 1 (P8)	Physiotherapy	Relevant clinical experience as a therapist and educator; research experience investigating activity of older adults in residential care
Academic 5 (P9)	Health and social care economics	Research experience in health economics with a focus on understanding value to consumers of health and aged care services
Creative Facilitator (P10)	Strategy, Communications, Creative arts	Relevant experience as a creative facilitator with a focus on sustainability, wellbeing, ageing, and social enterprise

Stage 2: Gathering the Experience

Developing the tool involved triangulating findings from a large qualitative study[12,13] and a systematic literature review,[14] reported elsewhere. The purpose of the qualitative study was to produce a detailed understanding of the experiences and perceptions of various healthcare provider groups and consumers regarding frailty and frailty screening.[12] As part of this study, we undertook seven focus groups with older adults (n=39) aged 62–99 years (M=80.6; SD=9.6) from community, assisted living, and residential aged care settings.[13] We used a collaborative process to produce a series of edited videos that reflected key themes and priorities from the consumer experience interviews that could be used to stimulate future co-design work.[11] Additionally, we conducted a literature review of observational research on communication between HCPs, older adults, and carers about self-management goals.[14]

Stage 3: Understanding the Experience

The co-design group consisted of academics and clinicians (n=7) and consumers (n=3). This sample size is consistent with previous studies describing the “small co-design team” stage of EBCD[9]. The same group met at three, two-hour workshops, which were conducted in-person at a central location in Adelaide, South Australia, and communicated between meetings via email. The overall aim of the workshops was to generate improvement ideas and review prototypes of those ideas for further refinement. All participants gave informed consent for the workshops to be audio-recorded for research purposes.

The first meeting (March 2021) focused on clarifying the purpose of convening the co-design group, introducing the background research, establishing a shared understanding of the issue, and discussing project objectives. The pre-recorded video was screened at the beginning of the workshop to stimulate discussion focused on authentic consumer narratives, derived from our earlier qualitative research. A key task of the first session was to identify enablers and barriers to older adults’ participation in discussions about goals in routine healthcare encounters and share ideas for improvements.

Stage 4: Improving the experience

In the second meeting (April 2021), we asked team members to complete a prototype mapping activity to review concepts and determine a set of possible solutions to bring forward for development and testing. The mapping activity involved identifying the most important moments or milestones of the consumer and HCP journeys. For each milestone, team members noted any improvements or shifts that were needed and proposed solutions. Then we mapped the concepts in relation to the corresponding improvements for consumers and HCPs, respectively, and we identified a range of potential prototypes. We generated prototypes following the agreed upon design principles informed by the co-design events and survey results. The purpose of the third meeting (May 2021) was to review prototypes, observe group reactions and responses, and discuss modifications and refinements to prototypes. At the end of the workshops, we clarified future directions and priorities and the meeting concluded with a reflection on the co-design process and discussion about future correspondence.

The co-design group communicated regularly throughout the prototype iteration process in a series of feedback and revision cycles (June–September 2021). We sought feedback from team members at two timepoints. First, after we produced a high-fidelity prototype, ML requested broad feedback on the design and aesthetic considerations, which informed the creation of a modified prototype. Second, ML sought and incorporated feedback on a complete, revised prototype, including comments that could be implemented into the design or noted for further team discussion before developing the tool's final design.

We surveyed the online cohort twice through the co-design process. We administered the first survey in April 2021 with 10 respondents. This survey provided information about respondents' experiences and attitudes towards discussing health goals and priorities with HCPs. We administered the second survey in June 2021 with six respondents. It provided information about how participants currently store and manage their health information, search terms and strategies participants might use to find health information, and considerations for designing new resources for older people and their advocates. We used this information to revise the prototype and inform the development of the evaluation and dissemination strategy.

Stage 5: Monitoring and Maintaining the Experience

We invited participants to a virtual celebration event to provide a summary presentation of the project and to acknowledge successes. Participants provided suggestions for further improvements to the tool and discussed project outcomes and future directions.

RESULTS

Following the EBCD methodology, we asked team members to think of ideas regarding improvements that will make a difference to consumers based on their experiences, which we subsequently used as the basis for prototyping solutions (Table 3). Following this, we mapped important moments or milestones for consumers and HCPs, identified improvement ideas, and suggested solution concepts.

Table 3: Summary of enablers and barriers identified during brainstorming

Theme	Example quote
Consumer characteristics	"*Lots of older people aren't terribly motivated because I think they get overwhelmed by their issues.*" (P1)
HCP characteristics	"*I think it all starts with the doctor. If you're not confident or you've got him on a pedestal, which many older people do, you don't really interact with him properly.*" (P2)
Interaction and communication factors	"*I think that's what's really important, that people are listened to and respected, and they're in the centre of what it is and they're offered choices and ideas.*" (P1) "*If you get a patient and ask, 'What are your long-term goals or short-term goals?" they might feel that they are back to school . . . that perhaps they need to answer in a correct way.*" (P5)
Preparation for goal setting and shared decision-making processes	"*My experience is with older people is that they struggle with coming up with what that goal is because they don't often think in that way.*" (P1)
Social context	"*With some of my longer-term issues, setting goals really had to involve my kids and my wife.*" (P3)
Economic and political context	"*There's nothing in the Medicare Benefits Schedule to allow doctors to spend time creating this dialogue with the patient.*" (P3)

Suggested ideas for solutions for consumers included:

- Information about goal setting and good communication with HCPs;
- A list of questions for consumers to support discussions about goals of care; and
- Text messaging reminder service or check-in process to prepare consumers for goal setting.

Suggested ideas for HCPs included:

- Group training or individual web-based training modules about goal setting, the importance of good communication, and who could benefit from goal setting;
- Documentation of goal setting discussions in the electronic health record; and
- Conversation guide or prompt questions, including a "How to start the conversation" script.

The most important shift for consumers focused on older adults' preparation and supports to participate effectively in SDM. For HCPs, the most important shift identified was the need for pathways that allow consumers to make an informed decision but also supports HCPs to align with current evidence or conventional medical practice. We noted the timing of HCP-patient interactions and patients' reasons for help-seeking as key factors impacting whether goal setting discussions occur. The online cohort also provided feedback on relevant information needs regarding goal setting (Table 4).

Given the resources and time available, team members opted to focus on consumer-oriented solutions aligning with the shifts and solutions generated during brainstorming. We agreed that the tool needed to allow for different kinds of goals to be set inclusive of physical care and emotional wellbeing. We agreed that the primary functions of the tool should be to assist older adults and their supporters to be more involved in goal setting and help people become better at communicating their goals.

Based on the discussions in the workshops, we created and presented an initial prototype to the co-design team for feedback on the content and design. They expressed that the tool should include language and visual elements that help users focus on the actions they want to achieve in relation to quality of life and keep track of their health conditions over time. Team members felt that the tool should not be too large so that it can be carried easily. A personal journal that can be used in conjunction with HCPs and supporters was identified as a useful format. Two representative comments were:

"*I think the tone of the whole logbook is great especially the piece 'your health and wellbeing are the most important things in life'. It's calming, thoughtful, personal, and encouraging.*" (P1)

"*One thing I wondered about is the risk of setting someone up to fail if goals or aims that are too ambitious and potentially leading to a difficult discussion with the healthcare provider.*" (P7)

We revised the initial prototype based on the suggestions from the third workshop and research literature. We shared the revised prototype with the co-design group for further feedback. Most team members found the prototype to be in accordance with their suggestions but made several recommendations regarding its functionality, particularly in relation to monitoring individuals' goal progress. Following this, we revised the prototype based on feedback from the co-design group and second online survey (Figure 2). In general, team members expressed positive sentiments about the co-design process and their involvement in developing the tool. Two examples of consumer feedback are:

"*I have really enjoyed being a part of the process and am happy to help in any way I can.*" (P3)

"*I also think the journal is indeed something we can all be proud of.*" (P2)

Table 4: Online cohort responses to items regarding the relevance of prompt questions about health goals, priorities, and treatments (n=10)

Question		1* *n* (%)	2 *n* (%)	3 *n* (%)	4 *n* (%)	5 *n* (%)
1	"What is goal setting?"	0 (0)	1 (10)	3 (30)	4 (40)	2 (20)
2	"What do I need to do?"[a]	0 (0)	0 (0)	2 (22.2)	5 (55.6)	2 (22.2)
3	"What is currently happening with my health?"	0 (0)	0 (0)	1 (10)	3 (30)	6 (60)
4	"What does goal setting involve and how can it help with my health and care?"	0 (0)	0 (0)	3 (30)	4 (40)	3 (30)
5	"What can I expect in the future?"	0 (0)	0 (0)	2 (20)	6 (60)	2 (20)
6	"What options are available to treat my health condition(s)?"	0 (0)	0 (0)	1 (10)	3 (30)	6 (60)
7	What are the pros and cons of different treatments for my condition(s)?"	0 (0)	0 (0)	1 (10)	3 (30)	6 (60)
8	"What do the advantages/disadvantages of different treatments mean for my other health condition(s)?"	0 (0)	0 (0)	2 (20)	2 (20)	6 (60)
9	"Will these actions make me feel better or worse?"	0 (0)	1 (10)	1 (10)	3 (30)	5 (50)
10	"What options are available to control things like pain, nausea, stress, anxiety etc.?"	0 (0)	0 (0)	3 (30)	4 (40)	3 (30)
11	"How can I make the most of my life living with my health condition(s)?"	0 (0)	0 (0)	0 (0)	3 (30)	7 (70)
12	"Are there any lifestyle changes that could help me make the most of my life, living with my health condition(s)?"	0 (0)	0 (0)	2 (20)	5 (50)	3 (30)

13	“What support is available for me?”	0 (0)	0 (0)	1 (10)	2 (20)	7 (70)
14	“How can I help my spouse and family understand what is happening to me?”	1 (10)	0 (0)	4 (40)	2 (20)	3 (30)
15	“What support is available now or in the future for my carer, my spouse, and my family?”	0 (0)	0 (0)	2 (20)	4 (40)	4 (40)

* (1 = “not relevant at all”; 5 = “extremely relevant”); [a] Incomplete data (n=9)

DISCUSSION

We designed the final “My Wellbeing Journal” prototype to empower consumers to identify, record, and discuss their health and wellbeing goals with HCPs, family members, and others. It is a 26-page A5 booklet and digital eJournal divided into four main sections: (1) Exploring what matters: understanding health and wellbeing; (2) Doing what matters: setting meaningful goals; (2) Discussing what matters: communicating with your healthcare team; and (4) Journal entries. Version 1 is available to download.

We developed “My Wellbeing Journal” in response to the need for user-centred tools to support consumers to participate actively in goal setting during care planning. The EBCD process enabled the co-design group to identify important shifts and related improvement ideas that will make a positive impact for older adults with multimorbidity, with the resulting prototypes targeted to this population’s needs and experiences.[9] Benefits associated with using EBCD included the adaptability of engagement activities, the ability to integrate diverse perspectives and evidence sources, and the high level of engagement and responsiveness of the co-design team. Challenges included time and funding constraints, difficulties in recruiting participants from minority communities, and the risk to fidelity due to the need to adapt stages to satisfy the unique needs of the project. This study adds to the literature on patient-centred innovation in health communication by presenting an exemplar of co-designing a creative tool with transdisciplinary and community partnerships using a facilitated, structured, and time-limited EBCD process. It adds to the EBCD literature by illustrating the value of an accelerated EBCD approach in designing and developing tools that integrate research evidence with consumer experiences and priorities.

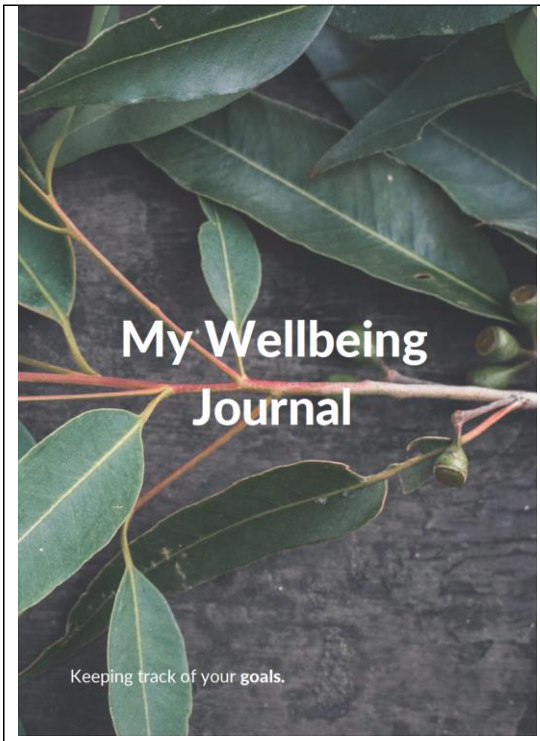
Limitations

The number of consumer representatives invited to participate in the co-design group may be considered small compared to similar EBCD studies.[15] However, the inclusion of the online cohort provided additional data from participants representing a greater experiential and socio-demographic diversity than was possible using just the main co-design group. The tool may not be transferrable to other communities and jurisdictions in its current form. We therefore plan to conduct usability testing among a larger sample of consumers to enhance the relevance and uptake of the final version.

Future directions

The next stage of the research involves usability testing of the My Wellbeing Journal and will be reported in a forthcoming manuscript. The results of this evaluation will provide necessary insight into the usability and translatability of the tool. Following this, we plan to evaluate the feasibility of using the journal in primary care and assess its impacts on clinical care. We also intend to repeat the EBCD process with HCPs to develop and test education and communication training materials related to care planning for older adults with multimorbidity and frailty.

Figure 2: Final version of "My Wellbeing Journal"




DATE: CHECK-IN

My overall quality of life right now:

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
(worst) (best)

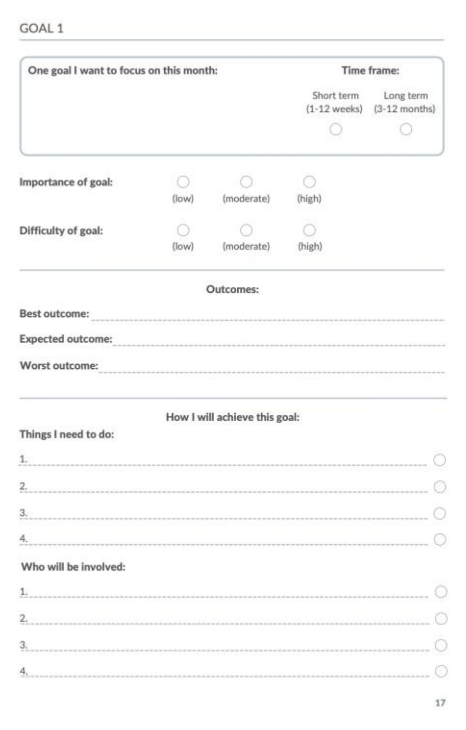
Are any of these things a source of stress?
(choose or write down your own)

○ Being active
○ Feeling tired
○ Sleep
○ Falls or balance
○ Eating well
○ Weight
○ Medications
○ Pain
○ Other (please specify):
○ Depression
○ Anxiety
○ Feeling alone
○ Vision or hearing
○ Memory changes
○ Alcohol or drug use
○ Smoking
○ Urinary continence
○ My health conditions
○ My house
○ My neighbourhood
○ Money
○ Work or volunteering
○ Getting around
○ My family
○ My friends
○ Caring for others

How this affects my life:

What I hope my health care team can do for me:

15


GOAL 1

One goal I want to focus on this month:

Time frame:
Short term (1-12 weeks) ○
Long term (3-12 months) ○

Importance of goal: ○ (low) ○ (moderate) ○ (high)

Difficulty of goal: ○ (low) ○ (moderate) ○ (high)

Outcomes:

Best outcome:
Expected outcome:
Worst outcome:

How I will achieve this goal:

Things I need to do:
1. ○
2. ○
3. ○
4. ○

Who will be involved:
1. ○
2. ○
3. ○
4. ○

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CONCLUSION

Using an accelerated EBCD process was feasible in terms of the available time and resources and ensured that stakeholder perspectives were incorporated at every stage. Other investigators developing personal health tools and other tools using consumer engagement might benefit from a structured and facilitated co-design approach. Including academics and clinicians from various disciplines and engaging an extended online consultation cohort ensured a broader range of perspectives were incorporated despite resource constraints.

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PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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ETHICS COMMITTEE APPROVAL

Ethics approval was received from Flinders University Social and Behavioural Ethics Committee (2772).