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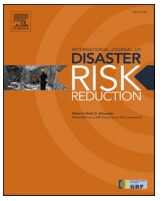

End user perspectives on design and conduct of health-related disaster research

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ABSTRACT

Individuals and communities are the intended beneficiaries of disaster research, and are ideally positioned to inform research aims, methods, desirable outcomes and implementation strategies. However, it can be challenging for researchers more familiar with quantitative methods to engage end users in study design and conduct. In an attempt to break down barriers involving end users in health-related disaster research, we outline how our research team conducted community consultations in the early stages of a bushfire-focussed health study, what we found and how this influenced our subsequent research. Participants (n = 76) were recruited by convenience sampling from five communities- one rural community which had direct experience of bushfire 5–10 years ago (n = 9), three communities located in high bushfire risk areas (n = 47) and one community in an urban centre (n = 20). Participants provided their perspectives on previous experiences of research participation and/or priorities/concerns about future health-related disaster research in two custom survey instruments and a focus group. Data analysis using conventional content analysis revealed four themes- 1) the importance of a holistic view of health that encompasses mental, physical, and social wellbeing; 2) appropriate study design/conduct with emphasis on inclusivity, scientific rigor, sensitivity to participants' needs/circumstances, minimised participant burden and responsiveness to participant feedback; 3) clear and regular communication; and 4) practical, participant-focussed study outcomes. We describe how these findings shaped the design of our subsequent prospective, longitudinal health-focussed disaster research study (the ISLAND Resilience Initiative). This work may support participant engagement in future research studies focused on end user needs following disaster experiences.

1. Introduction

Disaster events profoundly impact people across the globe, shaping their physical health, mental health and wellbeing in lasting and often devastating ways [1–3]. Therefore, improving outcomes for individuals and their communities following disaster is typically the central motivation for research studies in disaster risk reduction, resilience and recovery. Since individuals and communities are the intended beneficiaries, they are ideally positioned to inform relevant study foci, methods, desirable outcomes and implementation

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strategies, and as such it is vital that they are involved in the design and conduct of disaster-related research.

Research approaches that seek to engage intended beneficiaries in research design include participatory research (Cornwall & Jewkes, 1995), participatory action research [4] and co-design [5]. The aforementioned research approaches are increasingly employed in disaster-related health [6–9], risk reduction [10–13] and climate science [14,15] studies. Although participatory research approaches have unrealised potential in disaster-related health research, there are barriers to their utilisation. Researchers from many disciplines that use solely quantitative research methods may not be familiar with or trained in participatory approaches [16], which have typically been developed and used by qualitative researchers. In addition, many researchers investigating the impacts of disaster begin data collection after the disaster event, among communities with whom researchers have had no prior connection. Importantly, participatory approaches which involve end-users in detailed aspects of study design and conduct may not be appropriate or feasible in every discipline. Nonetheless, lack of involvement of participants and end users in study design, conduct and reporting has led to participants feeling that researchers have 'parachuted in' [17], which increases the risk of negative psychological outcomes [18].

In 2019, our research team began conceptualising a study of health, resilience and disasters in Tasmania, Australia. Across Australia, there is an ongoing unmet need for locally and regionally relevant strategies to improve health outcomes after disasters [1,2]. We envisioned a multidisciplinary research study that would increase knowledge of short- and long-term health outcomes after disaster in a Tasmanian context and the factors influencing them. This study would take a strengths-based approach where possible, framed around resilience (the ability to adapt to, cope with and/or recover from challenging life experiences). Although relevant to any disaster, the study was envisioned to capture particularly granular information on bushfires because this is considered the most significant natural disaster risk in Tasmania [19]. Our research team consisted of biomedical, psychology and natural sciences researchers. We recognised the importance of end user involvement in planning our study, so we set out to engage with community members and potential participants to learn about their previous experiences of and/or perspectives on research (including research on bushfires and natural hazards). Participatory research methods were not appropriate in our case because we were not equipped to involve participants in translating research findings into action. Therefore, we took a community engagement approach consistent with CDC principles of community engagement [20]. According to these principles, community engagement can be considered a continuum which encompasses different levels of community involvement depending on the extent of bidirectional communication, information sharing, trust and shared decision making [20]. Our engagement took the form of community consultation. We investigated participant perspectives on health-related natural hazard research, but also explored facilitators of, and barriers to, participant involvement so that we could integrate deeper levels of community engagement into future studies. Community consultation occurred in the early stages of research planning and imposed few study-specific constraints, so that findings would be broadly relevant to any research studies we might design in the future. The overarching research question was 'how do individuals in bushfire-risk and bushfire-affected communities think disaster-related health research could be best designed and conducted?'.

In an attempt to break down some barriers involving end users in health-related disaster research, particularly for researchers who may not have had experience with participatory methods, in this article we:

1) describe how our research team conducted community consultation and, based on our reflections on the co-design process, outline what we believe were the strengths and weaknesses of our approach;
2) outline what we learned about participants' perspectives on study design, conduct and participation in disaster research;
3) describe how these findings shaped the design of our subsequent health-focussed disaster research study (the ISLAND Resilience Initiative).

Through this work, we hope to support and facilitate participant engagement in future research paradigms focused on end user needs following disaster experiences.

Table 1
Informal activities undertaken to plan community consultations. These activities were independent of each other and undertaken simultaneously across a three-month period.

Participants	Purpose of activity (from the point of view of researchers)	Type of consultation and venue
Residents of a community impacted by bushfire 5–10 years ago	Determine community interest in research consultation process; get to know community members and build trust	Informal discussions at neighbourhood Christmas lunch
Residents of a community at high risk of bushfire	Determine community interest in research consultation process; get to know community members and build trust; test a possible consultation approach (lunch); discuss research activities to consult about.	Informal lunch and discussion at a residential home within the community
Community engagement staff at the State Fire Service	Learn about methods of community engagement used by State Fire Service	Informal discussion over coffee/tea
Staff of community organisation in fire-affected region	Learn about community experiences of research participation; receive advice from community organisation staff on how to conduct community consultation	Informal discussion over coffee/tea
University of Tasmania (UTAS) academics in related disciplines	Learn about methods of community engagement used by UTAS academics	Presentation at local academic symposium; informal discussion over coffee/tea
Staff member of the State Department of Health involved in disaster recovery	Learn about health considerations in community-led disaster recovery	Informal discussion over coffee/tea
Staff member at local council involved in disaster recovery	Learn about local government initiatives in disaster recovery	Informal discussion over coffee/tea

2. Methods

2.1. Planning

Before formal community consultation was conducted, informal links with communities were developed to gauge levels of possible interest in co-designing/contributing to research focused on their needs, as an indicator of feasibility. A range of activities were conducted in informal settings, as described inTable 1, in which a researcher (DS) met with community members and staff of organisations involved in disaster response. These informal planning activities were also used to design community consultation survey instruments. For example, during lunch in the community at high risk of bushfire (Table 1), residents discussed with a researcher (DS) some research activities that they believed could be beneficial, such as an online course which would help participants build bushfire resilience and could be evaluated by researchers. When surveys for community consultation were developed, a question in survey B was included to seek participant perspectives on these research activities.

After these informal planning activities were conducted, a detailed plan for community consultation was developed and ethics approval for this community consultation study was granted by the University of Tasmania Human Research Ethics Committee (ref #H0017957).

2.2. Recruitment

Community consultation was conducted in five communities across Tasmania. One community had been impacted by a recent bushfire (cohort 1), three neighbouring communities were in urban fringe regions at high risk of bushfire (cohort 2) and one community was in an urban centre whose adjacent suburbs had varying levels (low, medium and high) of bushfire risk (cohort 3). The three communities varied in size from approximately 200–5300 residents and the urban centre had approximately 200,000 residents (2016 census, https://www.abs.gov.au). Within these regions, convenience sampling was used. Participation was open to those aged 18 and over and was advertised/recruited through various methods including noticeboard flyers, community newsletter information, community organisation Facebook pages and physical presence at community events (Table 2). Participants were provided with information sheets and the community consultation study was explained to them by investigators. Voluntary response sampling was used to recruit focus group participants from among survey responders. All participants provided written consent.

2.3. Data collection and analysis

Two custom surveys were used to collect data on participants' personal experiences of research participation in the past, and their perspectives about future participation in bushfire research in general (see Table 2). Survey A (Supplementary Material 1) was developed by the research team based on informal planning discussions (Table 1) in consultation with a community leader from a regional community affected by bushfire within the last 5–10 years. Survey A was used with members of this community (cohort 1, n = 9). Survey B (Supplementary Material 2) was developed by the study researchers for a broader range of participants than survey A, based on informal planning discussions (Table 1). It included one question from survey A and was used with members of three neighbouring communities at the bushland-urban interface who experience heightened high bushfire risk (cohort 2, n = 47) and also with people in an urban centre with interest in disaster preparedness (cohort 3, n = 20). With the exception of online survey B, researchers were on hand when surveys were completed so that respondents could ask questions about the research context and the

Table 2
Community consultation – study recruitment and data collection.

Participants	Number of participants	Advertising/recruitment method	Mode of consultation	Data collection method
Members of a community impacted by bushfire 5–10 years ago (cohort 1)	9	Flyer on noticeboard	In-person drop-in sessions at a local community centre (six occasions)	Survey A, paper version
Members of three communities in high bushfire risk regions (cohort 2)	11	Local community newsletters	In-person lunch at community hall	Survey B, paper version
	11	Letterbox drop	In-person lunch event at a residential home	Survey B, paper version
	3	Presentation/discussion at community association meeting	In-person at community hall	Survey B, paper version
	5	Discussion at local mothers' group	In-person at community hall	Survey B, paper version
	9	Table at local primary school fair	In-person at local primary school	Survey B, paper version
	8	Community associations' Facebook pages	Online, advertised via community social media pages	Survey B, online version
People in urban centre with interest in disaster preparedness (cohort 3)	20	Emergency Services Roadshow in an urban centre	In-person on outdoor city street	Survey B, paper version
Members of three communities in high bushfire risk regions, *and* people in an urban centre with interest in disaster preparedness	4	Participants who indicated they would consider helping design the health-focussed disaster research study (response item in survey B)	In-person lunch event at a residential home	Focus group recording

nature of research activities discussed in survey B. Data from two survey respondents were excluded because they did not complete a consent form. Both surveys featured one closed-ended question, to identify the extent of participants' prior experiences of research, two questions with ratings scales (1–10) and three open-ended questions giving participants an opportunity to expand on their ratings. For ratings scales, a higher score was more positive (1 = very bad, 10 = very good). Because they were tailored to different communities, the questions in surveys A and B differed. Demographic data was not collected because no analysis of data based on demographic characteristics was planned. Surveys took 2–10 min for participants to complete in-person or online (Table 2).

In addition, a focus group discussion was held to gain insight into participants' perspective on resilience-focussed research activities, including how they could be designed and what they could include to achieve desirable outcomes for end users. Recruitment to the focus group was conducted by emailing all participants from cohorts 2 and 3 who indicated they would consider helping to design the study (response item in survey B). Two focus group session times were offered. By email, participants were notified about the questions that would be used to guide the discussion. Questions included 'What does resilience mean to you? How do you think your health might be affected by bushfire? What factors might influence your health or resilience? What roles might communities and organisations play in fostering resilience?'. This focus group was held with four participants from cohort 2 in one session and was audio-recorded.

Qualitative data from surveys and the focus group were analysed using a conventional content analysis approach [21] which involved summarising the data by coding similar information into categories generated from the data (inductive approach). Coding was conducted independently by two researchers experienced in coding qualitative data (AH and DS) and their consensus data summary was checked by another researcher with extensive experience in qualitative research methods (EL). Unless indicated otherwise, quotes used to illustrate the themes are from open-ended questions in the surveys. Quantitative data from surveys was not normally distributed so group differences were analysed using non-parametric Mann-Whitney *U* test.

3. Results

3.1. Overarching themes across all community consultation

Broadly, community consultation sought to address the overarching question "How do you, as a research participant and end user, think disaster-related research could be best designed and conducted?". Content analysis revealed four common themes among participants' responses.

1. Holistic view of health;
2. Appropriate study design and conduct;
3. Clear and regular communication;
4. Participant-focussed study outcomes.

Participants highlighted the importance of a holistic view of health that encompasses mental, physical, and social wellbeing for individuals and communities (theme 1). They indicated that research needed to be appropriately designed and conducted, with

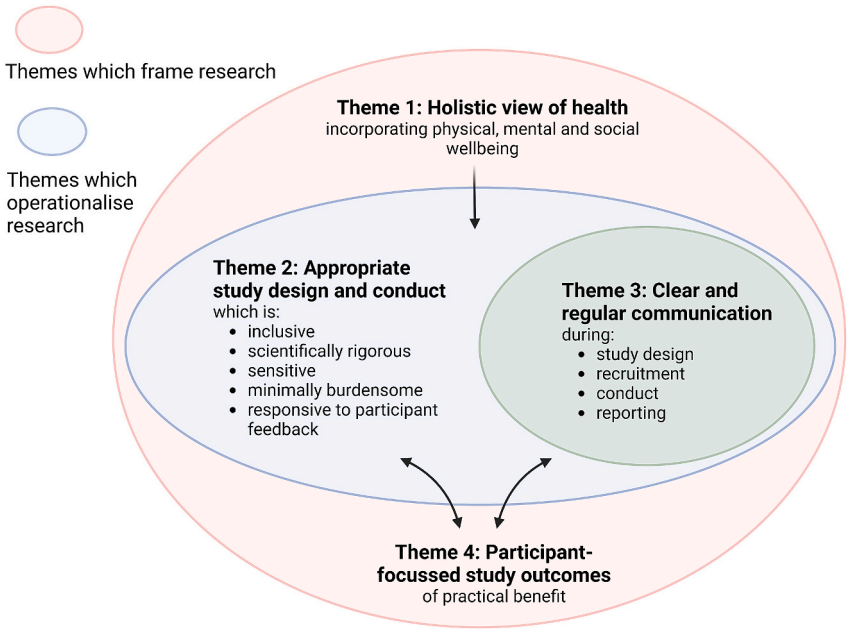

Fig. 1. Relatedness of four themes arising from consultation with participants about how disaster-related research should be designed, conducted and reported. Created with BioRender.com.

specific emphasis on inclusiveness of diverse individuals and communities, scientific rigour incorporating mixed methods approaches, sensitivity to participants' needs/circumstances, minimised burden on participants and responsiveness to participant feedback (theme 2). Participants valued clear, sustained communication, which occurs regularly throughout the study including during design, recruitment, conduct and reporting (theme 3). Finally, participants emphasised the importance of participant-focussed study outcomes which are of practical benefit to them (theme 4).

As illustrated in Fig. 1, these themes are closely inter-related. A holistic view of health that considers physical, mental and social wellbeing (theme 1) frames the research. It facilitates study design and conduct that are inclusive, sensitive, responsive, rigorous and minimally burdensome (theme 2). These theme 2 study design/conduct principles encompass clear and regular bidirectional communication (theme 3). They also lead to practical, participant-centred study outcomes (theme 4). While participant-focussed outcomes are a consequence of adoption of the study design/conduct principles in themes 2–3, a focus on these desired outcomes must also frame the research and inform all aspects of its design, conduct and communication.

3.1.1. Holistic view of health

The importance to participants of a holistic view of health, encompassing physical, mental and emotional health, together with education and family/community wellbeing, was revealed when participants from communities at high risk of bushfire (cohort 2), or who were from an urban centre and interested in bushfire preparedness (cohort 3), described the most important attributes for a research study to have:

> *"Various ways of measuring factors such as emotional/psychological health + well-being"*- participant 68 (cohort 3)

> *"Long term effects on mental + physical health"*- participant 62 (cohort 3)

> *"Starting point for [building resilience] is education, just giving people an insight … educating people with regards to the range of stresses around those things would be the first point of call."*- participant 13 (cohort 2, focus group) *"Community ability to support one another"*- participant 69 (cohort 2)

> *"Increasing individual resilience with flow on to rest of family/neighbourhood"*- participant 52 (cohort 3)

3.1.2. Appropriate study design and conduct

Appropriate study design and conduct was valued highly by participants, particularly with respect to five subthemes- inclusivity, scientific rigour, sensitivity, participant burden and responsiveness to participant feedback.

Inclusive study design was described as important when participants reflected on the most important attributes for a research study to have:

> *"A wide selection of people, people groups, culture and needs to be statewide"*- participant 60 (cohort 3)

> *"Flexibility for involving broad age groups; broad cross-section of socio-economic groups"*- participant 44 (cohort 2)

> *"Accessibility for disabled people to participate"*- participant 70 (cohort 2)

When asked about their experiences of research and/or suggestions for research improvement, participants who had specific experience of bushfire research described a lack of inclusivity, which arose because research was too localised, poorly advertised or inaccessible:

> *"Spread the researchers out so that they also cover surrounding affected areas. Everything was at [location A] after the bushfires, but [location B] had a lot of residents who had severe losses also"*- participant 1 (cohort 1) "

> *There was a lack of communication, advertising if there were forums or there would be individual researchers asking questions"*- participant 6 (cohort 1)

> *"I … would have liked to give feedback on the bushfire especially in response to the welfare of livestock, domestic pets + wildlife + their welfare"*- participant 7 (cohort 1)

> *"More accessible. i.e., online. [If] Paper surveys [then] being delivered to households"*- participant 65 (cohort 3)

This inclusivity sub-theme was also reflected by participants when asked what they thought could have been done better in the non-disaster related research study/studies they participated in previously:

> *"Sometimes it is difficult for disabled and chronically ill people to attend things outside of their home"*- participant 61 (cohort 3)

A second study design/conduct subtheme expressed by participants related to scientific rigour. Research designs incorporating novelty, qualitative methods and longitudinal data collection were highlighted by participants when asked what the most important attributes for a research study would be, or what they thought could have been done better in the non-disaster related research study/studies they participated in previously:

> *"Sound methodology; new area of research/contribution"*- participant 46 (cohort 2)

> *"Yes-no answers that research often asks for often are irrelevant to how I see things"*- participant 28 (cohort 2)

> *"There needs to be an opportunity for participants to explain their answers rather than just ticking a box"*- participant 13 (cohort 2)

"Already had a 'preferred' outcome … too prescriptive – didn't allow for alternative views"- participant 20 (cohort 2)

"Evidence based; longitudinal study- building of resilience skills from a young age rather than focusing on support after the event"- participant 19 (cohort 2)

"There needs to be research before as well as after"- participant 33 (cohort 2)

To explore respondents' perspectives on specific research methods, their openness to participating in specific research activities was explored in survey questions for cohorts 2 and 3. The majority of respondents indicated they would consider filling in questionnaires/providing feedback (92%), participating in research activities measuring physical health (86%), brain health (76%), stress (85%) and breathing (73%) and participating in an online resilience course (70%; Fig. 2A). Thirty six percent of participants indicated they were open to helping to design a research study. Sixteen participants (24%) were open to filling in questionnaires but not to undertaking an online resilience course or helping design a research study (which were the more time-consuming options presented; Fig. 2B).

Sensitivity to participants' needs/circumstances, or lack thereof, was highlighted as a contributor to positive or negative experiences of post-bushfire research. One participant described interpersonal interactions with researcher(s) which were helpful, though challenging for some individuals:

"[I had a] need to unload to someone … it helped me as a pressure release valve … opening up to strangers or official bodies can be hard for some who are used to looking after themselves"- participant 5 (cohort 1)

However, some participants did not believe the bushfire research they experienced was conducted sensitively- either they had experienced negative interpersonal interactions with researchers or felt research was conducted too soon after the disaster event:

"*Some [researchers] failed to appreciate the impacts on fire victims"*- participant 6 (cohort 1)

"Immediately after [there were] too many interfering people asking questions"- participant 2 (cohort 1)

" *People need time immediately after a disaster to get their mind around what has happened"*- participant 2 (cohort 1)

Sensitivity to participants' needs, for example for privacy, was highlighted by participants from communities at high risk of bushfire, or who were interested in bushfire preparedness, when they were asked if they had any reservations or concerns. The term 'concerns' was intentionally ambiguous to allow for consideration of all relevant concerns participants may raise.

"Respecting people their privacy"- participant 54 (cohort 3)

"Privacy is important to me, in some areas. Knowing about community resilience is vital, so my need for privacy is relative to the importance of the community's [sic] having this knowledge"- participant 76 (cohort 2)

"I [have] concerns about the effect of [on] the people who lost their loved ones and property"- participant 56 (cohort 3)

"No [concerns] as long as it is not too intrusive"- participant 26 (cohort 2)

"Being contacted at inopportune times (during work or time with family)"- participant 71 (cohort 2)

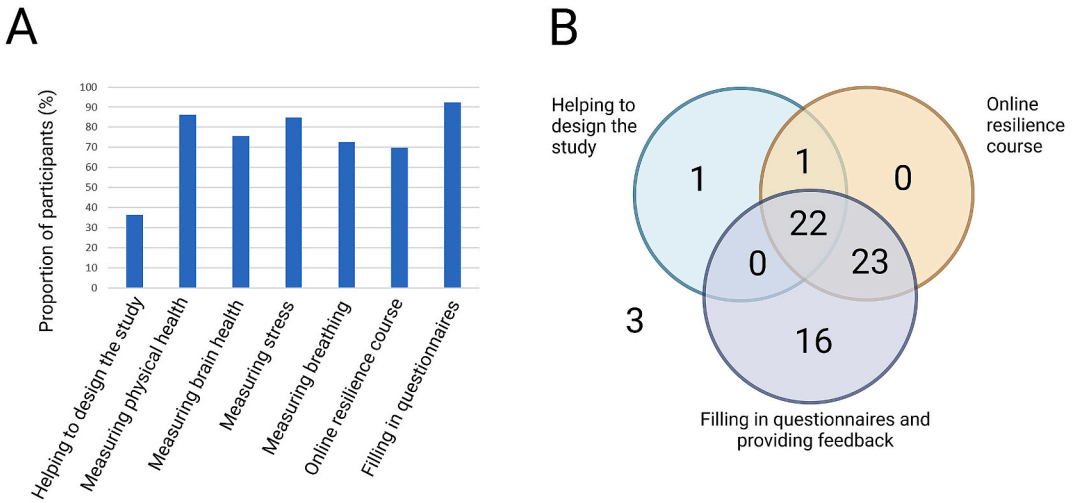

Fig. 2. Research activities that participants reported they would consider participating in. A) Percentage of participants who would consider participating in each of the activities. B) Number of participants interested in least (questionnaire completion) and most (online course and study co-design) potentially demanding or time-consuming forms of research participation. Numbers in overlapping sections of Venn diagram indicate participants interested in multiple activities. Three participants reported they would not consider participating in any of the three activities described in panel B. Created with Biorender.com.

"Concern about possible … stressful responses by participants"- participant 64 (cohort 3)

An additional subtheme within the study design/conduct theme related to participant burden. Participants expressed concern that research could be time-consuming and burdensome:

"I don't have a huge amount of free time, so something that doesn't take too much time would suit"- participant 46 (cohort 2)

"Time – commitments – may not always be available when the research [data collection?] times are happening which is why online can be helpful"- participant 68 (cohort 3)

"Lots of repeat questionnaires over time [is] tedious"- participant 45 (cohort 2)

Finally, some participants felt that an important attribute for research studies to have was responsiveness to participant feedback during the conceptualisation, design and conduct of the research study or future studies:

"Responding carefully to feedback & input"- participant 13 (cohort 2)

"Participant involvement at all stages"- participant 31 (cohort 2)

"Helping to direct where research is headed"- participant 50 (cohort 3)

Participant interest in assisting with study design was explored further in cohorts 2 and 3. Participants were asked if they were 'interested in helping to design the study'. Preamble text on the survey indicated that 'the study' was a study of health and resilience after bushfire or other disaster (Supplementary Material 2). Over a third of participants (36%, 24 respondents) indicated they would consider helping design the study (Fig. 2B). Most of those who would consider helping design the study (22 of 24 respondents) were also amenable to participating in an online course and filling in questionnaires (Fig. 2B). Only one of the 24 respondents who were open to helping to design the study highlighted participant burden as a concern. Our participant burden subtheme indicated this was a concern for many participants, illustrating the heterogeneity of participant cohorts and highlighting the challenge of simultaneously meeting diverse participant needs.

To explore focus group participants' attitudes to involvement in designing a research study, they were asked whether there was a place for participants to be involved in decision-making about a future research study:

"I feel like, you know, without having thought about it much either, that you may be better off starting with a top-down approach just to get it off the ground. And then see how that's working, and people can know what you're on about and what's gonna [sic] happen and then it can eventually maybe become community driven"- participant 12

"The fundamental issue … is that whoever the audience is, the audience has to have sufficient trust in the person [who is making decisions]. You know, if it's coming from a reputable organisation or reputable individual or community or particular group … people will … be more or less open to taking in that information and also taking it on in different ways depending on the credibility"- participant 13

Participants felt that end user involvement in study design and decision making may be most appropriate after the study was established by a credible research team and organisation. Participants felt this would enable them to understand their potential contribution. This researcher-led initial approach may be more appealing to many end users because it would be less demanding of time. Our focus group findings suggest that it is important to establish a clear framework for their involvement so that study credibility is maintained and participants understand their potential role.

3.1.3. Clear and regular communication

Clear and regular communication was emphasised by participants as important, particularly when they were reflecting on ways in which the research study/studies they participated in previously could have been improved:

"Practical activity clearly described BEFORE a person makes the time + effort to turn up … know what I am asked to do. (e.g. research where there may be some degree of ethical consideration … let people make a choice in advance)"- participant 68 (cohort 3)

"Being kept informed as study progresses, + of any outcomes + publications, result etc. along the way"- participant 18 (cohort 2)

"The final technical report was sent without a general statement of value; it was left to the recipient to plough through the statistics and graphs"- participant 26 (cohort 2)

"They said they would let us know their findings – but never heard back – so follow up would have been good"- participant 25 (cohort 2)

"The papers took years to write up. Too long in my view"- participant 13 (cohort 2)

3.1.4. Participant-focussed study outcomes

The final theme was about participant focussed study outcomes. Participants emphasised that study outcomes needed to be practical and relevant to their lives:

"It should have a positive benefit to all those who live in the area under investigation as well as those who live in similar areas elsewhere"- participant 13 (cohort 2)

"Focus on providing practical outcomes that can benefit the study group"- participant 22 (cohort 2)

"To be relevant to the Tasmanian community; practical implications for the research"- participant 71 (cohort 2)

This theme also emerged when participants were asked if they had any reservations or concerns related to research participation:

"What would be the benefit once the study is completed? Would there be the funding to actually help those deemed needing psychological help through these times?"- participant 53 (cohort 3)

"Keen to have individual feedback/data re. study measures e.g., from health assessments"- participant 18 (cohort 2).

3.1.5. Effects of respondents' concerns on their level of comfort in research participation

We explored whether participants who expressed concerns about research felt a decreased level of overall comfort in taking part in a research study. Across the whole cohort, participants in the study expressed a high level of comfort in study participation (average 9.2/10). Individuals who noted a specific concern ($n = 25$) had significantly lower levels of comfort in research participation than those who did not ($n = 41$; Mann-Whitney $U = 379$, $p < 0.05$, Fig. 3). This suggests that our survey data was broadly capturing participant insights which could be relevant to their future research engagement. However, some variability in participants' level of comfort was still evident for those who did not describe their concerns, suggesting that meaningful concerns among a small number of our participants were not captured in our qualitative data.

3.2. Implementing participant feedback during the community consultation process

Throughout the community consultation process, participants highlighted the importance of researchers acting on their feedback. Therefore, as the community consultations drew to a close, a number of actions were taken by the researchers in response to participants' input and suggestions. These actions related to the theme of clear, regular communication (theme 3). As soon as data analysis was finalised (approximately six months after community consultation data collection was completed), a personalised email was sent to all participants with a summary of results (Supplementary Material 3). One year later, as soon as further funding was received, an email was sent to all participants with an update of progress. Lastly, approximately three years after community consultation data collection was completed, participants were invited by email to contribute to manuscript preparation by providing feedback on findings or readability, co-writing the discussion or proofreading. This offer was taken up by one participant who proofread the manuscript.

3.3. Implementing participant feedback to design a future research study

Actions based on participants' insights were also taken in the design and implementation of a bushfire-focussed health and resilience study, called the ISLAND Resilience Initiative, which commenced in 2021. This study has recruited ~1300 participants. It was in the earliest stages of conceptualisation when community consultation commenced in 2019 and has incorporated recommendations across all four themes which emerged from community consultation findings. These actions are described in Table 3.

4. Discussion

4.1. Reflections on our community engagement approach

Our community engagement took the form of consultation and used diverse approaches to learn about how individuals from multiple communities believe future disaster research should be conducted. This yielded valuable insights in the form of four themes

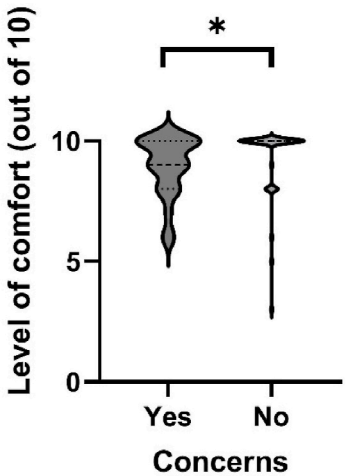

Fig. 3. Relationship between participants' level of comfort and whether or not they described specific concerns. *$p < 0.05$, Mann-Whitney *U* test.

Table 3
Actions taken to implement participants' suggestions from community consultations.

Theme	Actions taken [or pending]
Holistic view of health, that encompasses mental, physical and social wellbeing (theme 1) and Careful study design, which is inclusive, conducted sensitively and maintains scientific rigour while minimising burden on participants (theme 2)	Designing prospective, longitudinal study with input from participants -A prospective, longitudinal study was designed to accurately and ethically evaluate impacts of *future* disaster events. Study launch was timed so that it did not coincide with, nor was it connected to, a specific disaster event -Extensive state-wide recruitment was undertaken to ensure study is adequately powered and available to people across diverse geographic regions -Baseline data encompassing physical health, mental health, social networks, quality of life and other variables were collected -Surveys were administered online to increase availability for people with limited mobility -Short versions of surveys have been chosen whenever they were available and validated -Participants can pause between surveys and resume at a later date, or skip surveys -Qualitative data collection (online and in-person) with a community focus will be conducted in the future to complement existing quantitative data collection -Alongside qualitative data collection, participants will be invited to participate in co-design of future post-disaster research activities
Clear, regular communication during the entire study, from planning and delivery to reporting (theme 3)	Communicating about study demands -Detailed participant information sheets were provided outlining all research activities for first two years of study -Guidance has been provided before each survey of estimated time to complete Communicating about study progress -Regular updates have been provided to participants via email newsletters -A hard-copy update on progress was posted to participants 6 and 18 months after study commencement -Email newsletters have been made available via Print Radio Tasmania for those who prefer to listen to, rather than read, study updates
Participant-focussed study outcomes (theme 4)	Ensuring benefits/outcomes are relevant to real life -A free online short course called 'Bushfires and Your Health' was developed and offered to participants to help them build their bushfire knowledge, preparedness and understanding of health impacts of bushfires. Data on the impact of this short course has been collected, analysed and is in preparation for publication.

which have shaped the establishment of a health-focused disaster research study. Engagement with prospective participants before a disaster is not widespread in health-related disaster research, but our experience and findings suggest it can be beneficial and should be conducted wherever possible, depending on the research context.

Our community consultation took place early in the planning process, which meant that participants' perspectives could shape the overall direction of the research and provide insights which would be broadly applicable to our research studies in the future. However, deeper involvement of participants in study planning and decision-making during establishment of the ISLAND Resilience Initiative was not undertaken. According to CDC principles of community engagement [20], deeper participant involvement would necessitate greater cooperation and bi-directional communication. To reach the deepest level of community engagement, shared decision-making and formalised partnership would be required [17,20,22]. Researchers formed the opinion that increased engagement of this nature would not be suitable in this study's context, at least initially. This decision was informed by focus group findings, which revealed that participants preferred a researcher-led design process during establishment of the research. In addition, as highlighted in theme 2, many participants were concerned about study burden, which likely contributed to low focus group participation and limited appetite for greater involvement. This barrier to increased engagement was evident when researchers invited participants to contribute to preparation of this manuscript in whichever way they felt comfortable (example ways to contribute were provided). One participant assisted with proofreading, but two other participants who expressed interest in contributing were unable to do so because of their own time constraints. Since the ISLAND Resilience Initiative consists of baseline data collection and additional longitudinal research activities, we are endeavouring to engage participants in the ISLAND Resilience cohort ($n = \sim 1300$) more deeply in design of upcoming research activities, specifically a post-disaster research protocol. Plans are underway for sustained involvement of a group of interested participants in design and decision making of the research protocol and future research activities.

Additional strengths and weaknesses of our community consultation approach, as we (the research team) perceive them, relate to two themes which subsequently arose from participant consultation - inclusive study design (theme 2) and participant-focussed

outcomes (theme 4). Inclusivity and accessibility were areas of strength of our community consultation approach, but there remained room for improvement. A broad range of stakeholders, including community members, community leaders, academics and experts from the state fire service and health service, were consulted in the planning of the consultation process. Such rigorous planning is vital, since poor planning has been identified as a key barrier to effective community engagement in disaster risk reduction [23]. Recruitment was by convenience sampling in targeted geographic regions, specifically three peri-urban high bushfire risk communities, an urban centre and a rural community who had experienced bushfire in the past. By targeting these regions, we garnered perspectives of people who have extensive relevant experience and are personally invested in the research area, which we believed strengthened our findings. Online surveys, publicised and distributed via community social media pages, were used to increase accessibility for those who could not attend events in person. There was still room in our approach for improved inclusivity. We conducted our consultation activities in five communities, but were unable to consult Tasmanians in many other diverse geographic and socioeconomic areas of the state. This meant many potential end users' views were not considered. We also did not specifically tailor our consultation approach to minority groups including First Nations people, disabled people and those from culturally and linguistically diverse backgrounds. Greater efforts to engage individuals from these groups in culturally safe ways, for example using community panels [24], will be important for our future community engagement activities.

We believe the participant-centred nature of our consultation (theme 4) was a strength of our approach. We held events in community venues which were familiar to participants, such as community centres, and took advantage of community events such as a local primary school fair and Emergency Services Roadshow. Many face-to-face activities included an informal lunch, which we believe created a relaxed and appealing atmosphere which participants seemed to enjoy. Furthermore, our approach enabled researchers to draw on community links (as these were some of their own communities), increasing participation. The community consultation also led to tangible, practical outcomes for participants as our research team implemented findings in all key themes, as discussed below.

4.2. What we learned about participants' perspectives on study design, conduct and participation

The rich lived experience of participants was reflected in their priorities for research design and conduct as encapsulated by the four themes-holistic view of health; appropriate study design and conduct; clear and regular communication; and participant-focussed study outcomes. These themes revealed participants' high levels of health- and research-literacy. A body of Australian research has highlighted the physical, mental, social and community impacts of bushfire [1,2,25–27] and our findings suggest that participants are aware of the diversity of these impacts. To effectively research these diverse impacts, it will be important to employ creative, multidisciplinary approaches including both quantitative and qualitative methods as requested by participants. The barriers to research participation that we identified were consistent with findings from a recent international study of the inclusion of local knowledge in disaster risk reduction across the developing world [23]. In the 'Views from the Frontline 2019' study of 750 at-risk communities across 50 countries globally, the top three factors that community members felt prevented their inclusion in disaster risk reduction policy processes were time constraints and inaccessibility (theme 2) and poor communication (theme 3) [23]. Participants in the 'Views from the Frontline 2019' study also highlighted that planned outcomes of disaster risk reduction policies and initiatives in their communities often did not align with their perceptions and needs (theme 4) [23]. Importantly, the four themes identified were often inter-dependent. For example, the requirement for participant-focussed study outcomes (theme 4) determines many aspects of study design and conduct (theme 2), which then strongly reciprocally influences the delivery of participant-focussed outcomes. Effective two-way communication (theme 3), from researchers to participants and vice versa, is a conduit for important information about study design and conduct (theme 2). It is vital that a two-way communication strategy is embedded within the study from the outset, and that throughout the study participants can provide feedback about how it is being conducted. A commitment to regular communication increases accountability of researchers to participants and may increase researcher motivation and productivity. It may also increase participant motivation to remain engaged with the research, lowering attrition and increasing research sample sizes. Effective communication (theme 3) is motivated by the same respect for participants that underpins the desire for participant-focussed outcomes (theme 4). Effective communication is vital for participant-focussed outcomes to be achieved. Overall, we believe the four themes communicated by participants establish a solid foundation for research design and conduct and may be widely applicable across various research fields.

4.3. Using community consultation findings to shape the design of subsequent disaster research

Our findings highlighted the importance of researchers seeking and acting on feedback to ensure optimised outcomes for end users. Adopting a community engagement framework, we implemented feedback in a number of areas during our planning of a longitudinal research study about health, resilience and disasters in Tasmania (the ISLAND Resilience Initiative, see Table 3). One area which we believe was particularly important, and which was often emphasised by participants, was the importance of research leading to practical benefits to participants (theme 4). Therefore, as part of our subsequent research study we partnered with another research group who developed, offered and evaluated a free online (pilot) short course, called 'Bushfires and Your Health', which provided easy-to-access information about health impacts of bushfires and ways to increase preparedness. A third (32%) of ISLAND Resilience study participants took part in this short course, and qualitative feedback about the course indicated that participants felt it was useful and beneficial for them. Research into the impact of this course on bushfire knowledge and preparedness has revealed that it led to increased bushfire knowledge and contributed to a range of new actions by participants (manuscript in preparation). Subthemes which emerged from our findings related to study design (theme 2) were sensitivity to the needs and circumstances of participants and rigorous study design incorporating a prospective, longitudinal approach which commences before any specific, large-scale disaster event. Therefore, we adopted this research design approach in our subsequent study. This approach will build relationships with participants, yield baseline data, and importantly ensure that we are not requesting initial research consent from traumatised

individuals nor are seen as "interfering people asking questions" (quote from participant 2) after a disaster event. We believe our community engagement approach substantially strengthened our subsequent research study and will increase the likelihood of impactful, beneficial outcomes for end users and study participants.

An area where we feel we had mixed success in implementing our community consultation findings was in participant communications (theme 3), relating to both the community consultation and the subsequent prospective longitudinal study. We invested substantial effort in communicating the findings and progress of our community consultation- we emailed participants a plain language summary of our consultation findings (Supplementary Material 3) approximately six months after completion of data collection, and emailed updates when funding was secured for our prospective longitudinal study and when the prospective longitudinal study launched. Communication with participants in our prospective longitudinal ISLAND Resilience study has been consistent and varied and has included monthly email newsletters and two end-of-year summaries accompanied by greeting cards. The key area where we did not meet expectations was in publishing findings; the findings of the community consultation have taken approximately three years to write up for publication which our findings indicated may be considered overly long by some participants. This reinforces the need to find ways to offer more contemporaneous communication of data outside formal publication contexts, because it is common for research to take years from inception to publication.

There were two additional areas where we deem that we fell short in responding to participants' feedback. Firstly, the research activities in our longitudinal ISLAND Resilience study are likely to be more time-consuming and repetitive than some participants would have liked. Throughout the study, the research team tried to balance the need for rigour with the desire to minimise participant burden. The fewest possible surveys which would address the study aims were administered, and only the most important surveys were re-administered on follow-up. The shortest validated forms of key surveys were chosen to minimise responder burden. Nonetheless, participants were still requested to spend approximately 36 min (baseline) and up to 18 min (follow-up) completing surveys. We have tried to mitigate this burden by making all surveys optional and allowing participants to save surveys and return to them at a later date within the survey period. Participants in our prospective longitudinal study were also involved in another broader project, the ISLAND Project, which is a public health program targeting dementia risk reduction. Our research team has worked closely with the ISLAND Project team to coordinate activities, but it is an ongoing challenge to work together to minimise participant burden and communicate with participants effectively, in order to achieve study goals and maximise participant engagement.

A second area where we have not been able to fully respond to participants' feedback was with respect to desired outcomes (theme 4). Some participants indicted that they would like personal outcomes from the study which we found difficult to deliver, such as improved mental health service funding or individual data from health assessments. Our research team is not affiliated with a health provider or positioned to directly influence health funding, and our surveys are not administered for diagnostic purposes so we have not provided participants with individual feedback on their scores. However, we have included information about mental health impacts of disaster in the free online short course we developed for participants. While information relevant to personal outcomes, such as individual health data from surveys, were desired by some participants, our conversations with participants during consultation and during conduct of our longitudinal research study indicate that many other participants do not want to receive individual data from their surveys. This highlights that in some domains, participant desires will differ and a degree of compromise and/or flexibility is required by all stakeholders when planning and conducting participant-centred research, and this needs to be communicated transparently.

4.4. Limitations

There are limitations of the work reported here. Short surveys and a single, small focus group were used in this study, which may have limited the depth of data generated. The generalisability of findings in this study which relate to specific aspects of research design is limited because of bias in sampling methods used, particularly self-selection bias. Quantitative data indicated that respondents typically felt a high level of comfort in research participation (average 9.2/10), and it is likely that greater challenges to participation in research are experienced by those who did not participate in this study. Finally, we cannot determine how much diversity was represented in our sample. We did not collect information about demographics such as gender, age and household composition because our study was not designed or powered to analyse the impact of these factors. It may be valuable to collect such demographic data in future to consider relationships with disaster planning and willingness to participate in future research. We do recognise that we could have taken steps to increase the diversity of participants in this study. Our community consultation took place in Southern Tasmania and did not include communities in Northern and North-Western Tasmania, nor were they tailored to engage with minority groups such as people from culturally and linguistically diverse backgrounds.

4.5. Recommendations

Our experience suggests that consultation with prospective and/or enrolled participants throughout the research process is feasible, appropriate and highly valuable for health-focussed disaster research and, potentially, disaster research more broadly. We recommend incorporating participant consultation into research study design, conduct and reporting as an avenue to:

-increase research rigour, productivity and impact by increasing accountability and participant engagement.
-increase the likelihood of participant-focussed research by identifying outcomes that are most important to the study cohort and wider community.
-respect and empower participants by conducting research sensitively and embedding effective communication.

While the ways in which participant consultation are conducted will vary depending on context, our experiences highlighted that:

-early advice from potential participants and other stakeholders, such as local council staff, community engagement professionals within emergency services organisations and other academics in related disciplines can be valuable so that consultation activities are effective and complement existing community activities and research initiatives.
-if conducting convenience sampling of prospective participants during the study planning phase, it can be mutually beneficial to build and leverage connections with community groups and networks.
-a combination of in-person activities, such as catered lunches at community venues, and online data collection can be used to maximise inclusivity and engagement.

We believe that the process of community engagement while designing health-focused disaster research study will generally be mutually beneficial for participants and researchers by improving study design and conduct across multiple domains. In different contexts and disciplines, the community engagement approach should be tailored to balance demands on participants and researchers. We would encourage research groups to incorporate participant consultation, engagement or co-design into their research process, according to their capability and context.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Duncan Sinclair reports financial support was provided by Commonwealth of Australia.

Data availability

Data will be made available on request.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijdrr.2023.103919.

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