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Practice case study

A co-design exemplar: how to align with community goals when developing data collection methods with communities from refugee backgrounds

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Abstract

Co-design in a research context is an approach that involves participants reflecting on their lived experience of a phenomenon to tailor research outcomes to their needs. It is empowering because it provides greater equity in the research process. However, minimal literature is available on ways to encompass co-design into research planning. This article aims to provide an exemplar of co-design research by describing how data collection methods and tools were developed in a participatory action research project through collaboration with community members with a lived refugee experience in Greater Brisbane, Australia. Eight people (aged 18 to 65) were recruited using convenience and purposive sampling, with four workshops held between January and April 2022. Workshops utilised co-design methods, including journey mapping, personas, brainstorming and experiential learning to capture the lived experience of accessing food, to collaboratively co-design data collection methods and tools, and to train community members as community researchers. Co-designing data collection

methods ensured that community members with no research experience could contribute towards the design of culturally appropriate data collection tools. Future research in public health should embed co-design into research/intervention planning, execution and outcomes, and align research goals with community goals by drawing on lived experience.

Keywords co-design; participatory action research; qualitative research; journey mapping; personas; experiential learning; refugee

Key messages

- Previous research has shown that there are often ambiguous descriptions of co-design terminology and inadequate explanations of co-design methods, making it difficult for researchers to understand how to embed co-design into their research.
- We present an explicit description of research activities (workshops) undertaken to co-design research tools with community members. The methods used in each workshop draw on the participants' lived experiences to develop culturally appropriate data collection methods and tools for the project.
- The article invites reflection on innovative ways (for example, journey mapping and personas) to embed co-design into the research planning process. It also incorporates ways of ensuring that community members (and community) benefit from their involvement in the research project, by incorporating reciprocity beyond financial reimbursement.

Background

When research project objectives do not align with the goals of the participating population, any outcomes, including interventions, may not be successful, and may result in wasted research time and resources (Slattery et al., 2020). Public health research is typically conducted in community settings, where a complex set of determinants affect lived experiences. This means that researchers may not be fully aware of the factors that lead community members to make decisions around their health, and therefore without input may set a research (or intervention) agenda that is not appropriate for those communities. Effective partnership building may overcome goal misalignment by involving community members in research goal setting, planning and designing research outcomes (Kerr et al., 2022; Liamputtong, 2020; Slattery et al., 2020).

Participatory action research (PAR) and co-design are two approaches in research where collaboration with community members is a core principle (Freire, 1972; Zelenko et al., 2021), and they could conceivably be applied in parallel during research. However, reviews of co-design articles have revealed ambiguous descriptions of co-design terminology, and inadequate explanations of co-design methods, making it difficult for researchers to understand how to embed co-design into their research (McGill et al., 2022; Slattery et al., 2020).

PAR is a methodology which was originally created through community development and social justice advocacy in the 1970s (Liamputtong, 2020). PAR aims to understand how social and political structures disempower people, and, ultimately, seeks to change these structures. In turn, it aims to improve experiences and outcomes of groups who are marginalised and oppressed by dominant systems through critical reflection and raising awareness about their experiences of exclusion and inequality. New awareness and change occur through continuous praxis of critical reflection and action. The underlying epistemology of this methodology is that knowledge is a social construction which is created by both the participant and the researcher, and that, therefore, the researcher, and research itself, cannot be

objective. Rather, the researcher is a participant in the research process, and engages in learning along with the other participants (Orlowski, 2019).

This epistemology gives rise to the idea that PAR creates a new shared reality between researcher and participant through understanding of the experiences of the participants and how these are socially constructed (Liamputtong, 2020). PAR involves participants becoming conscious of political and social ideologies, and their influence on the lived experience of exclusion and inequality to create social change (Liamputtong, 2020). It does this through a three-stage cyclic process: *planning*, where lived experiences of a phenomenon are shared, and the researcher and researched reflect on political and social structures which impact those experiences; *acting*, where a research plan is developed and implemented to affect those structures; and *evaluating*, where the changes are evaluated and goals reassessed (Kelly, 2005).

Co-design was originally described in the 1970s. It is a method where 'designers' collaborate with the end users of products or services to craft new and innovative ways to solve design problems (Zelenko et al., 2021). Sanders and Stappers (2008: 6) define co-design as 'the creativity of designers and people not trained in design working together in the design development process'. In research, the number of articles reporting on study designs with co-design methods has increased significantly in recent years (McGill et al., 2022). In these articles, co-design was generally applied when prioritising research topics, soliciting input from the target population on research protocols and outcomes, and contributing to the development of research tools (for example, generating culturally appropriate language for recruitment and consent documents) (Slattery et al., 2020).

Co-design is often used interchangeably with other 'co' words, such as co-produce, co-create, co-develop or co-construct (McGill et al., 2022). Although these terms are widely used, they are often not defined, leading to a vague description or understanding of the nature of co-design being undertaken (McGill et al., 2022; Slattery et al., 2020). An underlying epistemology has not been described for co-design; however, a number of co-design frameworks have recently been proposed (Bryan-Kinns et al., 2022; Pedersen, 2020; Real and Schmittinger, 2022; Zelenko et al., 2021). Real and Schmittinger (2022) discuss a co-create approach that includes a four-stage learning cycle: *concrete experience*, where a new or existing experience is examined; *reflective observation*, where the learner reflects on the experience; *abstract conceptualisation*, where new ideas are elaborated on or alternatives are envisioned; and *active experimentation*, where the new ideas are applied.

It is obvious that PAR and co-design have several similarities. They were both developed during the 1970s, and they both involve reflecting on the lived experience of a phenomenon (Liamputtong, 2007; Zelenko et al., 2021). They require researchers to work with community members during the research process, so that people affected by research take part in making research decisions and are empowered with equity in the research process (Liamputtong, 2007; Zelenko et al., 2021). Therefore, both concepts result in a research project that is tailored to the needs of those being researched (Liamputtong, 2007; Real and Schmittinger, 2022). Finally, they are iterative and follow similar project cycles (see Table 1 for

Table 1. Comparison between participatory action research and co-design

Participatory action research cycles		Co-design cycles	
Planning	Lived experiences are shared and reflected on	Concrete experience	Experience is shared
		Reflective observation	Reflection on the experience
Acting	Research plan is developed and implemented	Abstract conceptualisation	New ideas explored, or alternatives envisioned
		Active experimentation	New ideas are applied
Evaluating	Changes are evaluated and goals reassessed		

a comparison). However, some noteworthy differences are also apparent. PAR is a methodology with a well-described epistemology (Orlowski, 2019), whereas co-design is an approach to research, with several suggested frameworks recently emerging (Bryan-Kinns et al., 2022; Pedersen, 2020; Real and Schmittinger, 2022; Zelenko et al., 2021). Additionally, PAR is specifically focused on actions affecting social and political ideologies to create social justice change, while co-design has a more generalised approach of collaborating with end users to design outcomes (products, services, research agendas) that meet their needs. Due to the similarities, it is feasible that a project with a PAR methodology could employ a co-design framework and methods into its research design.

This article provides an exemplar of co-design research by describing how data collection methods and tools were developed in a participatory action research project (Connecting with Cultural Foods) through collaboration with community members with a lived refugee experience in Greater Brisbane, Australia. The article first outlines the research context, summarising the objectives and programme of research, and the stakeholders involved, and then describes the structure of the workshops, the participants and recruitment processes. Next, it details the procedures and methods for each workshop, and the outcomes of those workshops. Finally, the article explores the challenges faced by the research team, and how they were overcome.

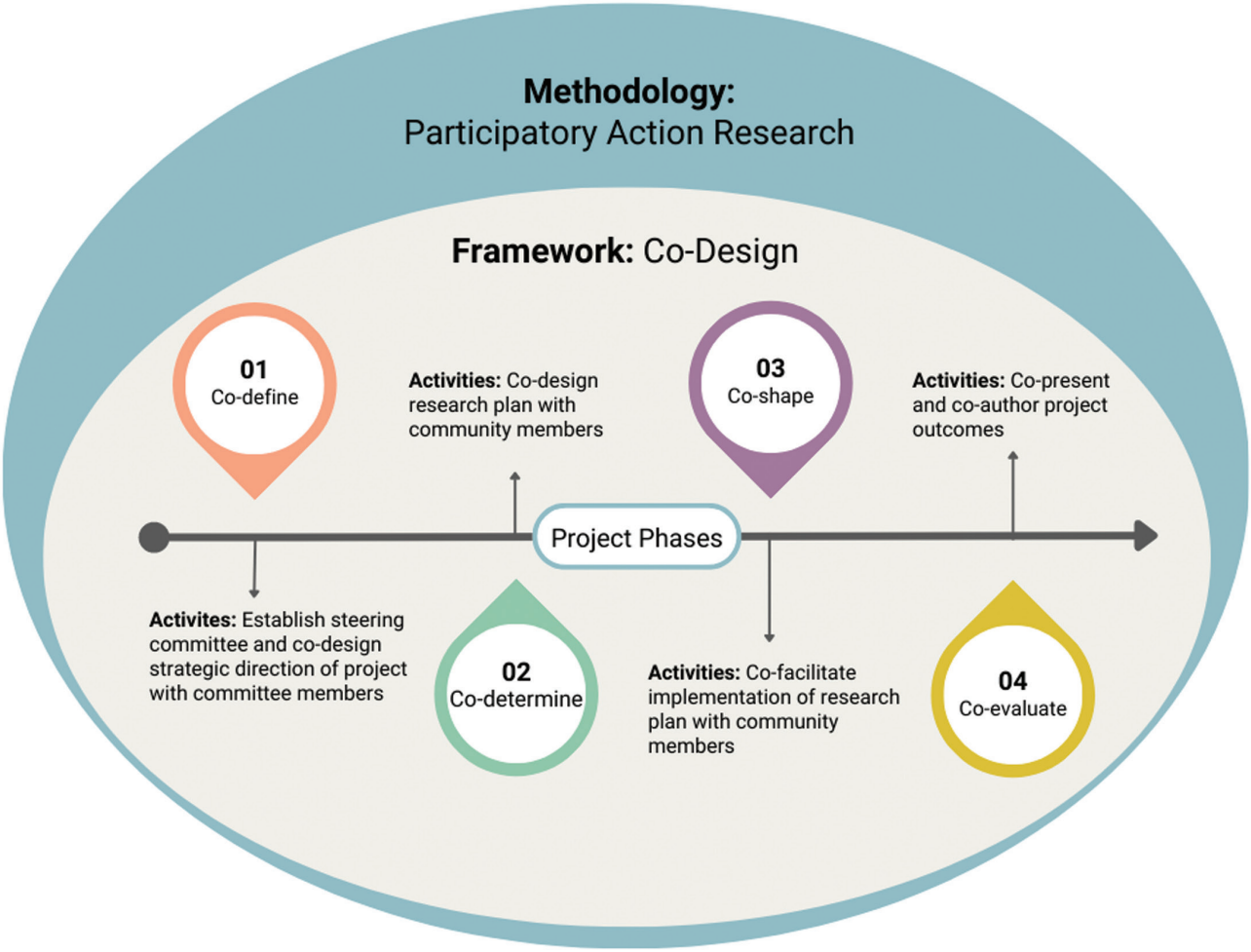
Research context: connecting with cultural foods project

The overarching programme of research, Connecting with Cultural Foods, was designed to improve food security of people with lived refugee experiences living in Greater Brisbane, by using PAR (Freire, 1972) methodology and a co-design framework. The project was split into four co-design phases based on the participatory design-led engagement framework (Zelenko et al., 2021): *Co-Define*, *Co-Determine*, *Co-Shape* and *Co-Evaluate*, and co-design methods were embedded in each phase of the project. During the *co-define* phase, a steering committee of community members was established, and the strategic direction of the project was co-developed. Steering committee members (n = 6) recruited were from diverse regional backgrounds (including from Africa, the Middle East and Southeast Asia), and they represented communities with lived refugee experiences found in greater Brisbane. The committee resolved that the project would be governed by a *mission* to identify best practice evidence for improving access to food for people with a lived refugee experience, by working with communities to learn how to create and share ways of accessing cultural foods (foods specific to countries of origin) in a culturally appropriate way. Underpinning this mission was the *value* that research is conducted in a way which benefits communities involved in the project. The *co-determine* phase involved co-designing the research plan with community members, the *co-shape* phase implemented the research plan, and the *co-evaluate* phase encompassed disseminating and assessing project outcomes. Figure 1 provides a graphical representation of the structure of the Connecting with Cultural Foods project.

Ethics

The project was approved by the Queensland University of Technology Human Research Ethics Committee (Project ID 5260). Initially, the workshops were not considered data collection, and therefore ethics approval was not deemed necessary. Participants were informed at the start of the workshop that a retrospective ethics application might occur later, if research data were identified. In July 2022, the university research team attempted to contact via email all participants to inform them an ethics application to use data from the workshops for research would commence. Seven (of eight) participants responded to confirm their consent to use the data from the workshop. Due to the collaborative nature of generating the data, a consent waiver for the final participant who did not respond to the email was sought and approved by the Queensland University of Technology Human Research Ethics Committee.

Figure 1. Graphical representation of the structure of the Connecting with Cultural Foods project



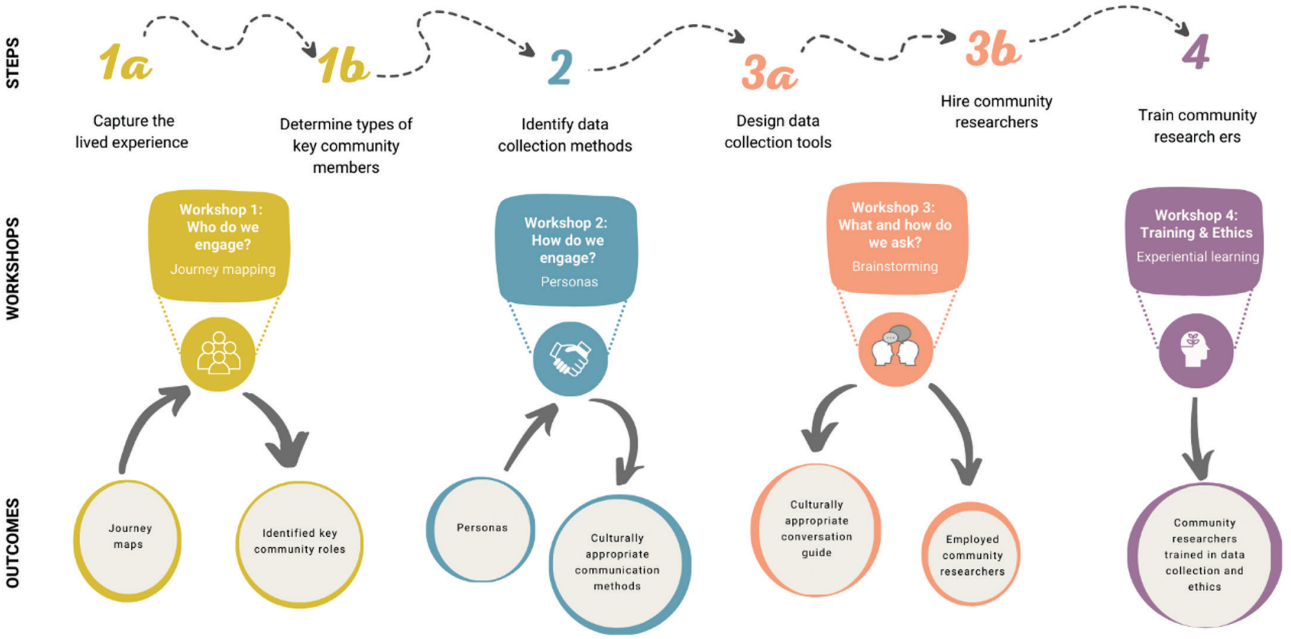
Overview of workshops

Four workshops were undertaken during the *co-determine* phase of the project, when the research plan was being developed. The aim of the workshops was to co-design culturally appropriate data collection methods and tools with community members with a lived refugee experience. Workshops were planned and facilitated by the lead investigator (TG). The lead investigator was a steering committee member, an academic researcher and a PhD candidate who identifies as White Australian.

The workshops followed a series of steps, with the outcomes from each workshop forming the basis of activities for the following workshop. Figure 2 provides a graphic representation of the structure of the workshops. Each workshop lasted between two and three hours. Data were collected through the first three workshops, each designed using methods that align to PAR methodology and the co-design framework to solicit specific outcomes, which informed the following workshop. Data analysis occurred throughout the workshops, as the group collaboratively determined and agreed the outcomes for each workshop. A fourth workshop was then held with participants agreeing to become community researchers to be trained in data collection and ethical conduct of research.

Participants had the option of attending workshops face-to-face in a central location convenient for all participants, or by joining online via Zoom™ video conferencing software to accommodate individuals unable to travel or who were self-isolating due to Covid-19 symptoms. The three co-design workshops

Figure 2. Graphical representation of the structure of workshops



were audio recorded using Zoom™ functionality, and participants provided consent for this to occur prior to each workshop. The fourth workshop was a training workshop and was not audio recorded.

Participants and recruitment

Purposive and convenience sampling methods were used to recruit four youths (aged 18 to 24) and four adults (aged 25 to 65) from a community likely to have a lived refugee experience. All persons approached agreed to participate. Participants were from Myanmar, Afghanistan, Iran, Burundi and Sudan. One participant had previous research experience (data collection). Youths represent the future of communities, and were therefore specifically recruited to ensure that they had agency over how the project was conducted. Additionally, by adhering to the project's *value*, it was planned that community researchers would be recruited from the workshops, and it was agreed by the steering committee that youths would obtain the greatest benefit from building their research skills through this employment.

Youth participants were purposively recruited from the Future Leaders Advocacy Group (FLAG). FLAG is a Brisbane-based group of young leaders from diverse communities, including people from refugee backgrounds, who advocate for young people's voices in their communities. The organiser of FLAG (a steering committee member) recruited four youth participants by distributing a flyer and details about the research to members. Adults were invited to participate by emailing steering committee members from the Connecting with Cultural Foods project, and people that had attended previous activities (focus groups) of the project and had expressed ongoing interest in the project. Participants were provided with a $100 gift card for each workshop attended (representing between $30 and $50 AUD an hour), and a certificate of completion for attending a minimum of three workshops.

Workshop procedures and outcomes

Four workshops were held between January and April 2022. All participants attended all workshops, except one participant who missed Workshop 2, and one participant who declined to become a community researcher and therefore did not attend Workshop 4.

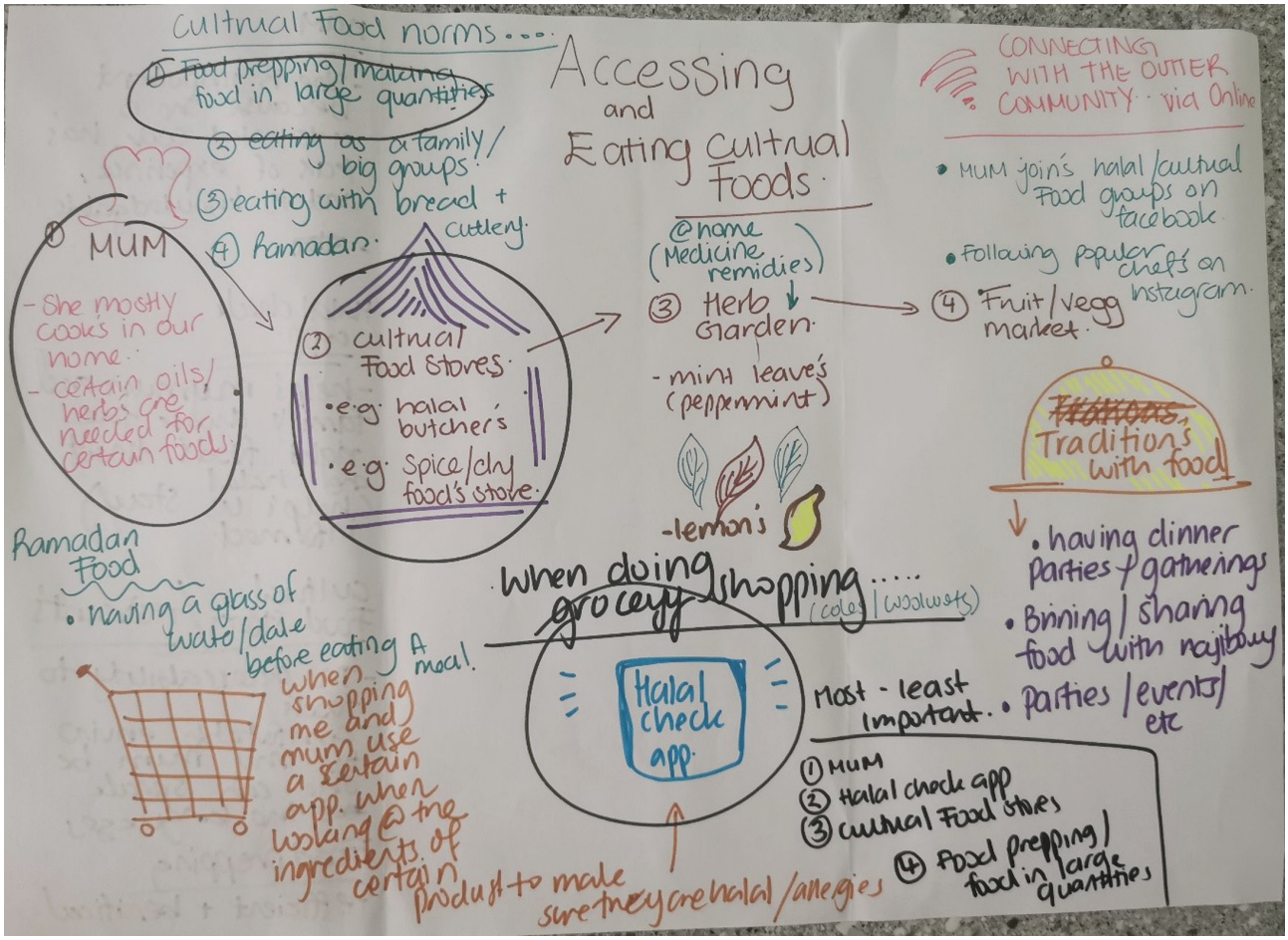
At the start of the first workshop, the facilitator (the lead investigator) introduced the Connecting with Cultural Foods project, and provided an overview of the workshops. The ensuing workshops included a brief overview of this information and a recap of outcomes from the previous workshop. At the end of each workshop, the facilitator provided a summary of the workshop outcomes to all participants via email. The methods used in each workshop are described in detail below.

Workshop 1: 'Who do we engage?'

Journey mapping methods (McCarthy et al., 2016) were used to explore participants' experiences of accessing food in Brisbane. Journey mapping is a method of capturing lived experience, incorporating the physical and emotional aspects of that experience, and it aligns to both PAR and co-design approaches. This method helps to transfer knowledge and insights concisely and visually from the participant to the researcher (McCarthy et al., 2016). It was used as a discussion point to explore individual experiences and commonalities shared across the group of participants. Each participant was asked to: (1) draw their journey of accessing cultural foods; (2) highlight parts of the journey that they considered to be culturally important; and (3) identify people that made those parts possible. An example of a journey map created during Workshop 1 is provided in Figure 3.

Participants were then invited to describe their journey map to the group, specifically, the parts of the journey they had chosen as important and why, who they identified, and how those people facilitated access to food. The group was encouraged to discuss shared and differing experiences, and why this

Figure 3. Example of participant journey map from Workshop 1 (Source: © Huda Akhlaki, used with permission)



might be the case. Using the journey maps as a guide, the final part of the workshop was to collaborate and identify the types of key community roles from which the project would probably gather data. At the conclusion of the workshop, five key food-related community roles had been identified: retailers, stall owners, community leaders, restaurant owners and gardeners/farmers.

Workshop 2: 'How do we engage?'

This workshop utilised user persona methods (McCarthy et al., 2016). These methods identify target groups, and allocate a graphical representation and background information to help researchers understand and empathise with the group. These personas direct researchers to create ideas which are tailored to the unique needs of that group, and to dynamically create solutions across different target groups (McCarthy et al., 2016). This method has previously been used with multiple stakeholder groups to solve wicked problems (Kerr et al., 2022). A wicked problem is one which is difficult to solve due to complex interdependencies that go beyond the capacity of any one organisation or government department to understand or address (Australian Public Service Commission, 2007). Low rates of food security in this population (Gallegos et al., 2008) could be described as a wicked problem due to complex and multifaceted determinants, such as political and social structures that disrupt cultural practices of procuring and consuming foods (Gingell et al., 2022).

Participants identified five personas that aligned with the key community roles identified in Workshop 1: Bob was a food retailer, Mary had a food market stall, Sue was a community leader, Said owned a restaurant and Fred was a food grower. Based on the participants' experience of people in their community, each persona was provided with contextual information that typified people performing those community roles in greater Brisbane, which was important to consider when engaging with that persona. Some examples included language skills, age range, communication preferences (for example, telephone, face-to-face, social media), technology skills, work schedules and availability, and potential motivation for involvement in the project. Initial engagement and ongoing communication strategies were then collaboratively identified and agreed for each persona. Figure 4 provides an example of a persona created during Workshop 4, and Figure 5 provides an overview of how the outcomes from Workshop 1 informed the development of personas in Workshop 2, with details of their identified background and communication methods.

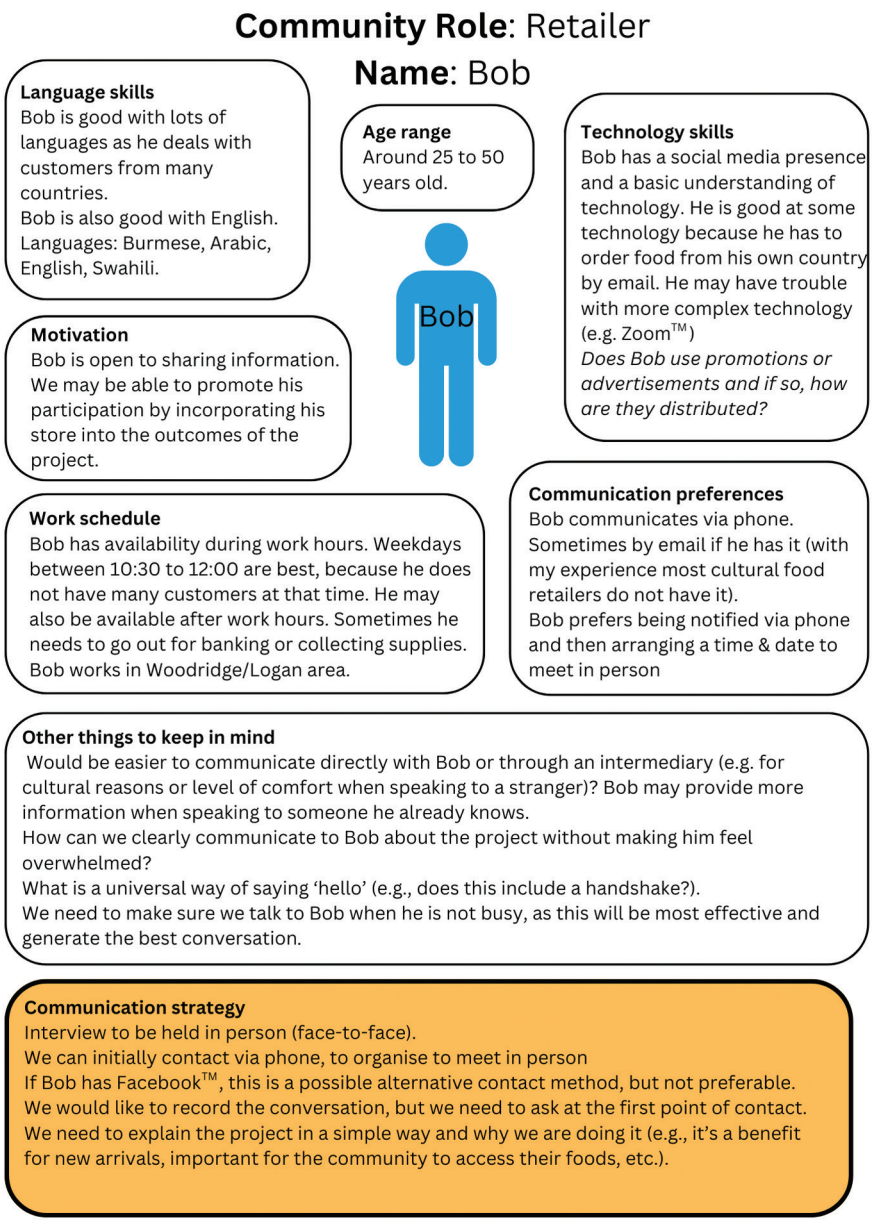
Workshop 3: 'How do we ask?'

This workshop utilised brainstorming (Boddy, 2012) methods, specifically the nominal group technique, to determine the information to be collected from each persona, and to develop culturally appropriate questions to collect this information. Nominal group brainstorming utilises individual creative thinking to generate ideas, followed by structured feedback from the group to evaluate those ideas for feasibility and usefulness (Boddy, 2012). Participants were first asked to collaboratively decide the type of information the project should collect, while considering the project objectives and community goals. The participants then discussed each individual persona from Workshop 2, to identify specific information to be collected that is relevant to that persona. During these discussions, participants constructed culturally appropriate questions to solicit the data. Finally, participants identified other data collection tools which may be required during the data collection phase of the project.

During this workshop, participants developed a recruitment template for the initial contact with potential participants, research team profiles to be provided to participants so they can select a community researcher to interview them, and a conversation guide containing interview questions, which were generalised and specific for personas. These tools can be found in supplementary materials (Gingell et al., 2024a).

At the conclusion of the workshop, participants were invited to become community researchers who would collect data by using the tools and methods they had developed across the three co-design workshops. Hiring community researchers from the workshops provided several advantages. Participants

Figure 4. Example persona containing contextual information created during Workshop 2

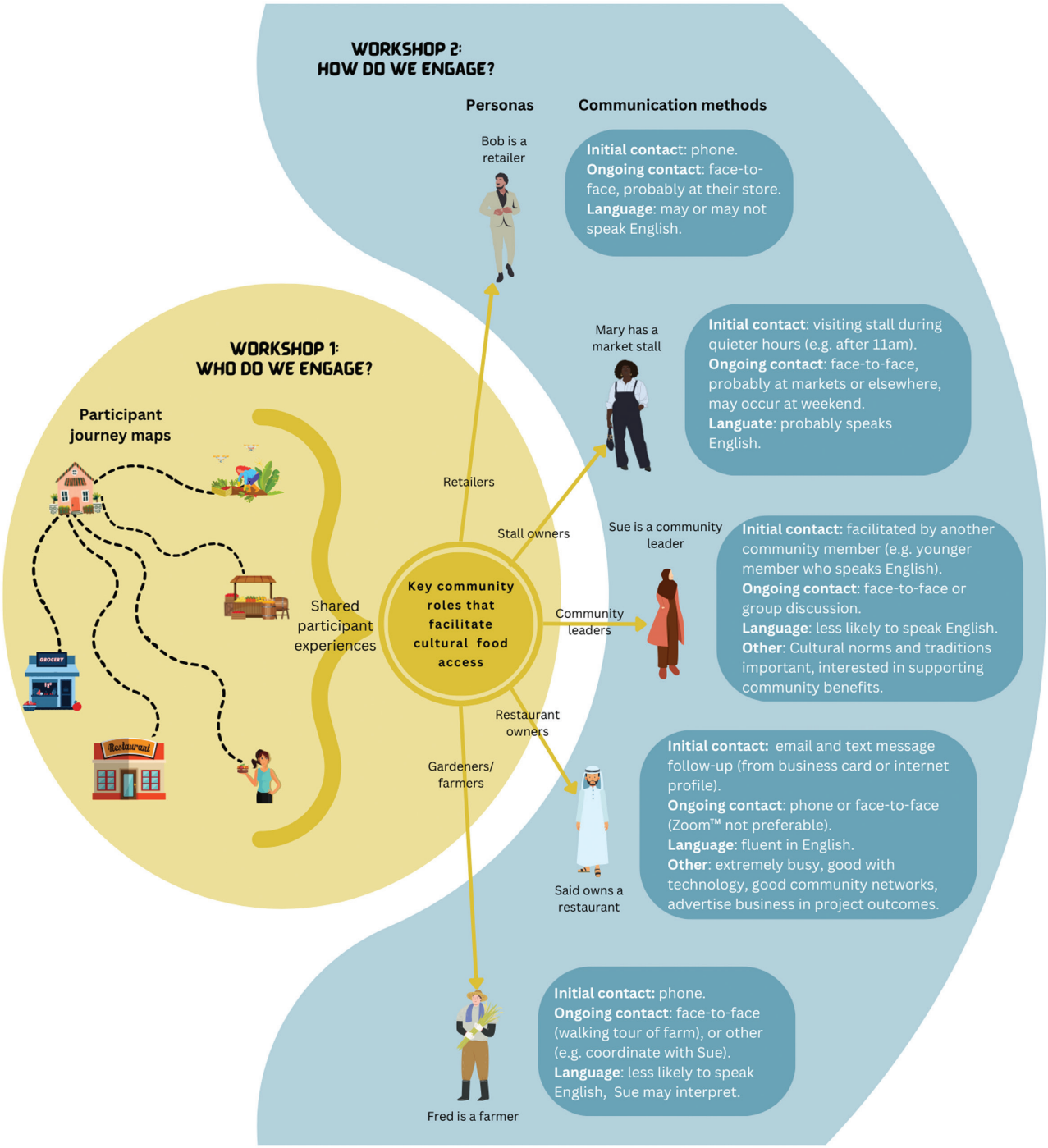


were familiar with the project objectives and invested in the success of the project. They were from the project's target communities and had a deep understanding of the cultural nuances of those communities, and they therefore aided the project in conducting research in a culturally appropriate manner. Finally, this strategy provided reciprocity to communities by enhancing the skills of community members to conduct research, and by remunerating them for their involvement in the project. Seven (of eight) participants agreed to continue working with the project as community researchers. The eighth participant reported that they were disappointed that they could not commit to the project further, and they cited competing interests as the reason for declining.

Workshop 4: Training and ethics

This workshop aimed to prepare participants that had agreed to be community researchers for data collection. Experiential learning (Beard and Wilson, 2018) methods were employed to train participants in

Figure 5. Overview of outcomes from Workshops 1 and 2



interviewing techniques for research and ethics. This is a method where experience is embedded in the learning process, and learning occurs simultaneously for teacher and student (Beard and Wilson, 2018). Experiential learning aligns to PAR and co-design, as there is shared understanding fostered about the lived experience.

Participants were first provided with information about interview techniques. They were then placed into pairs (interviewer and interviewee), and they took turns asking each other questions from

the conversation guide. Participants also discussed, individually and as a group, their learnings, and they provided feedback to others. Additionally, participants were presented with moral and ethical scenarios that could arise during data collection. These included issues around community members providing and withdrawing consent to participate or audio record interviews, and queries raised by community members, which, if answered, could potentially breach confidentiality. They were then asked to discuss appropriate responses to challenging questions specific to the target population. These were generated from a systematic literature review conducted previously (Gingell et al., 2022), and from discussions with the steering committee about difficult situations that may arise during data collection. Participants were encouraged to discuss each scenario and to decide how to respond.

Workshop feedback and next steps

At the end of each workshop, participants were encouraged to provide feedback. All participants provided positive remarks, and commented that they enjoyed the activities. All participants were also active contributors in workshop activities, and significantly contributed to the final data collection tool. Furthermore, nearly all participants (87 per cent, $n = 7/8$) agreed to continue working with the project as community researchers. This indicates that participants were satisfied with their level of contribution and involvement, and that the project was run in an inclusive and accessible manner. At the end of the final workshop, participants were also asked an open question about their perception of how prepared they were to conduct data collection. Participants stated that they felt prepared to commence data collection and were eager to use the tool in their communities.

After completing the co-design workshops, the hired community researchers piloted the tool in the community, and feedback was incorporated. Between August and December 2022, the community researchers conducted interviews with community members in key community roles. Community researchers then analysed the data, and some researchers also co-authored an article on the findings (Gingell et al., 2024b).

Challenges beyond the research team's control

Workshops were planned to be held in-person; however, this was not always possible due to the Covid-19 pandemic and significant weather events. The Omicron variant of Covid-19 was spreading through greater Brisbane from December 2021, and mask mandates were reinstated by the state government at that time (Queensland Health, 2021). Additionally, between November 2021 and April 2022, heavy rainfall and flooding occurred across greater Brisbane, with widespread damage due to water inundation of homes and businesses (Queensland Reconstruction Authority, 2022). In late February 2022, significant flooding caused local public transport to shut down, and residents were asked not to travel. Communities with refugee backgrounds were probably affected to a greater extent, as they often reside in more affordable low-lying areas. The university research team had to be flexible to deal with these challenges, and workshops were moved to a multimodal format, with a video conferencing (Zoom™) option made available to participants.

The multimodal format created new challenges for those activities designed to be face-to-face. For example, during Workshop 2, it was planned that each persona would be drawn on paper, and displayed in the room, and that participants would attach background details using sticky notes. However, the computer video could not capture the room adequately, and therefore those online were not able to view the persona. This issue was overcome using Zoom™ functionality: a document was created, and the facilitator shared it using screenshare; each participant provided background information as sticky notes (those in the room) or in the chat (those online); and the facilitator added those comments into the screenshared document for everyone to see.

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Conclusions

This article details the procedures and outcomes of a series of workshops that utilised co-design methods embedded within a PAR methodology to develop research tools that collected data that aligned with the goals of local communities. Additionally, participants were trained to undertake data collection for the next phase of the project. The methods described are unique and specific to the objectives of this study, and therefore may not be appropriate for other research goals. Rather, this article is designed to provide researchers with a framework for how co-design methods could be embedded into the research planning process.

There are some limitations when using a co-design approach. It can be time-consuming, with some researchers highlighting that collaboration often takes longer than anticipated (Kirk et al., 2021; Pirinen, 2016). It requires commitment from community members, who may have limited availability due to personal, community and work responsibilities (Stewart and Liabo, 2012). When co-design is undertaken improperly, and engagement is 'tokenistic' or culturally insensitive, it can damage the reputation of the researcher and research organisation, and cause frustration among community members, who may refrain from engaging with further research (Kirk et al., 2021; Pirinen, 2016). However, despite these limitations, co-design can increase rigour in the research process, improve the credibility of the findings, and enhance the impact of outcomes in the community (Stewart and Liabo, 2012). This occurs through a fairer research process that empowers the researched, and that increases their sense of ownership of the outcomes, thereby creating sustainability (Kirk et al., 2021; Zelenko et al., 2021).

There were also other limitations in the way the study was conducted. Participants were purposively and conveniently sampled, and they were required to speak English. Therefore, they may not represent the broader communities' views and perceptions of accessing foods, particularly for specific groups not represented, such as older people or people from cultures not present at the workshops. The study also did not formally measure other outcomes for participants, such as skills development, improved social capital, increased self-efficacy or new knowledge acquired. It is therefore difficult to assess whether these factors changed for participants.

In this study, co-design methods created a collaborative environment that developed tangible outcomes from each workshop, which were used as the basis for activities in the following workshops. It ensured that community members with no research experience were able to draw on their lived experience of accessing cultural foods in greater Brisbane, and contribute towards the design of culturally appropriate data collection tools that met their goals and those of the community. Further, it fostered a team of trained community researchers from the target population that were invested in the success of the project and were eager to support it. Additionally, the research team was able to overcome challenges resulting from circumstances beyond their control by being flexible and innovative, and utilising communication technology.

It is recommended that future research in public health embed co-design into research/intervention planning, execution and outcomes, and align research goals with community goals by drawing on lived experience. Further, researchers should report not just on research outcomes, but should explicitly describe the way co-design was used throughout their project, to guide others embarking on public health research.

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Declarations and conflicts of interest

Research ethics statement

The authors declare that research ethics approval for this article was provided by QUT Human Research Ethics Committee (Project ID 5260) ethics board.

Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

The authors declare the following interests: Danielle Gallegos has received research support from the Children's Hospital Foundation via a philanthropic donation from the commercial funder Woolworths. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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