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Experience-based codesign approach to improve care in Australian emergency departments for complex consumer cohorts: the MyED project protocol, Stages 1.1–1.3

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ABSTRACT

Introduction Emergency department (ED) care must adapt to meet current and future demands. In Australia, ED quality measures (eg, prolonged length of stay, representations or patient experience) are worse for older adults with multiple comorbidities, people who have a disability, those who present with a mental health condition, Indigenous Australians, and those with a culturally and linguistically diverse (CALD) background. Strengthened ED performance relies on understanding the social and systemic barriers and preferences for care of these different cohorts, and identifying viable solutions that may result in sustained improvement by service providers. A collaborative 5-year project (MyED) aims to codesign, with ED users and providers, new or adapted models of care that improve ED performance, improve patient outcomes and improve patient experience for these five cohorts.

Methods and analysis Experience-based codesign using mixed methods, set in three hospitals in one health district in Australia. This protocol introduces the staged and incremental approach to the whole project, and details the first research elements: ethnographic observations at the ED care interface, interviews with providers and interviews with two patient cohorts—older adults and adults with a CALD background. We aim to sample a diverse range of participants, carefully tailoring recruitment and support.

Ethics and dissemination Ethics approval has been obtained from the Western Sydney Local Health District Human Research Ethics Committee (2022/PID02749-2022/ETH02447). Prior informed written consent will be obtained from all research participants. Findings from each stage of the project will be submitted for peer-reviewed publication. Project outputs will be disseminated for implementation more widely across New South Wales, Australia.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A 5-year, staged, comprehensive study of experience and performance.
⇒ Engagement with diverse consumer, service provider, policymaker and research expertise.
⇒ Participant-oriented methods to promote inclusion and self-determination.
⇒ An incremental experience-based codesign approach to include multiple patient cohorts.
⇒ Translational methodology incorporating modelling of benefits and consideration of value.

INTRODUCTION

The demand for urgent hospital care is increasing in Australia[1] and internationally,[2] placing prolonged strain on emergency departments (ED). Overcrowding and access block arising from increased ED demand and inadequate hospital patient flow is associated with increased adverse events[3 4] and poor patient outcomes,[5 6] including increased mortality.[7] Integrated system-level approaches that incorporate evidence-based human factors and codesign are needed to adapt ED care to meet current and future demand.[8 9]

Demand for ED care, ED experiences and outcomes are not homogeneous within the community. For example, in 2021 in Australia, people aged ≥65 years represented 16% of the population of 25 422 788, accounted for 21% of presentations and 52% were admitted, compared with 28% for all patients.[10] In ED, a prolonged stay, pain

and some interventions contribute to delirium in older patients, associated with functional and cognitive decline and increased mortality.[11]

In 2018, it was estimated that 18% of Australians were living with a disability; 26% (639 000 people) visited an ED that year, a rate double that for all patients.[12] Chronic disease and behaviours of concern have been associated with frequent ED presentations for patients with intellectual disability, possibly exacerbated by an inability to communicate symptoms and unmet need such as pain.[13]

The number of consumers presenting to an ED with mental health conditions has increased annually by 1.5% over the last 5 years.[14] Of 309 657 presentations in 2020–2021 (representing 3.5% of all ED presentations), 71% were considered to require urgent or semi-urgent treatment.[15] Patients with a longstanding mental health condition were more likely to make multiple visits to EDs for any health issue and report poorer experiences.[16]

In 2016, Indigenous Australians represented an estimated 3.3% of the population (798 400 people).[17] In 2021, Indigenous Australians sought ED care for mental-health-related issues at a rate 4.5 times that of non-Indigenous Australians (478.3 and 106.4 per 10 000, respectively).[17] More Indigenous patients than non-Indigenous patients arrive at ED by ambulance.[18] In a 2018–2019 survey, 32% of Indigenous Australians who did not access health services when they needed to, indicated this was due to cultural reasons such as language problems, discrimination and culturally inappropriate care.[19] Many Indigenous patients leave ED before treatment is commenced or completed, even when they need immediate care.[18]

In 2021, it was estimated 27.6% (over 7 million) Australians were born overseas.[19] While specific ED statistics are not available, it is known that communication difficulties can impact care.[20–22] Culturally and linguistically diverse (CALD) consumers may also present later for care, with more severe illness than other Australians.[20–23]

In 2022, the MyED collaboration between a district health service, university researchers and stakeholder representatives was established to strengthen service performance, patient outcomes and patient experience for five adult cohorts in the catchment area. These were adults who are older, from a CALD background, have mental illness, live with a disability or are Indigenous Australians.

Working together: innovation to improve ED performance and patient outcomes and experience for five complex cohorts—the MyED project

Our overall objective is to codesign, with users and providers, new or adapted models of ED care that improve ED performance (eg, shorter wait times, reduced length of stay), improve patient outcomes (eg, fewer re-presentations and people who did-not-wait to be seen) and improve patient experience (eg, satisfaction, respect and feeling safe). The selected cohorts all experience various social and systemic barriers to accessing healthcare that can be under-appreciated. Overlooking factors that influence consumer decisions about how they access healthcare has previously been attributed to failed health policy,[24–26] and delivering outcomes that matter to patients is a central tenet of value-based healthcare systems.[13]

Experience-based codesign (EBCD) was selected as the methodology as it privileges change on behalf of the consumers or providers of the service, rather than traditional change orientations around organisational processes and indicators.[27] The defining feature of EBCD is the emphasis on the subjective experience of consumers and providers to understand and improve 'touchpoints', or moments of common concern, to improve their overall experience of that service.[28] Whereas the experience of consumers may create momentum for change, sustaining the change also relies on the value proposition to providers and the implementation strategy, both of which must also be addressed in the translational methodology.

This 5-year project (MyED) comprises three stages:

Stage 1: Engage with consumers, providers and observe the service to understand the interface of care and identify touchpoints in models of ED care.

Stage 2: Establish shared priorities for codesign of new or adapted models of ED care; simulate and develop the value proposition to guide decision-making about viable improvement; and implement and evaluate selected options in the study EDs.

Stage 3: Disseminate findings and output with ongoing evaluation of wider implementation.

Due to the project size and complexity, an incremental design has been adopted to maximise learning within and between stages, to maintain stakeholder engagement and to minimise change fatigue in the clinical setting. Research will begin at the care interface, then with each of the cohorts separately. We will engage with two cohorts at a time, progressing to subsequent codesign, then continue with the remaining cohorts, progressing to codesign. Modelling and testing of codesigned strategies for each cohort will be drawn into an integrated and streamlined implementation strategy for those selected (figure 1). Study protocols for individual studies will be developed concurrently over the life of the project.

Special considerations

To ensure respectful and ethically sound representation of Indigenous knowledge systems, world views and interests and privilege Indigenous perspectives in research methods and methodological frameworks, an Indigenous Health Advisory Committee (IHAC), chaired by an Indigenous chief investigator, has been established to guide all aspects of design involving the Indigenous Australian cohort.

Guidelines for ethical research advocate strongly for allowing autonomous decision-making of patients and caregivers regarding their engagement with research[28 29] and to avoid limiting participation through inappropriate gatekeeping and paternalistic attitudes.[30] We have

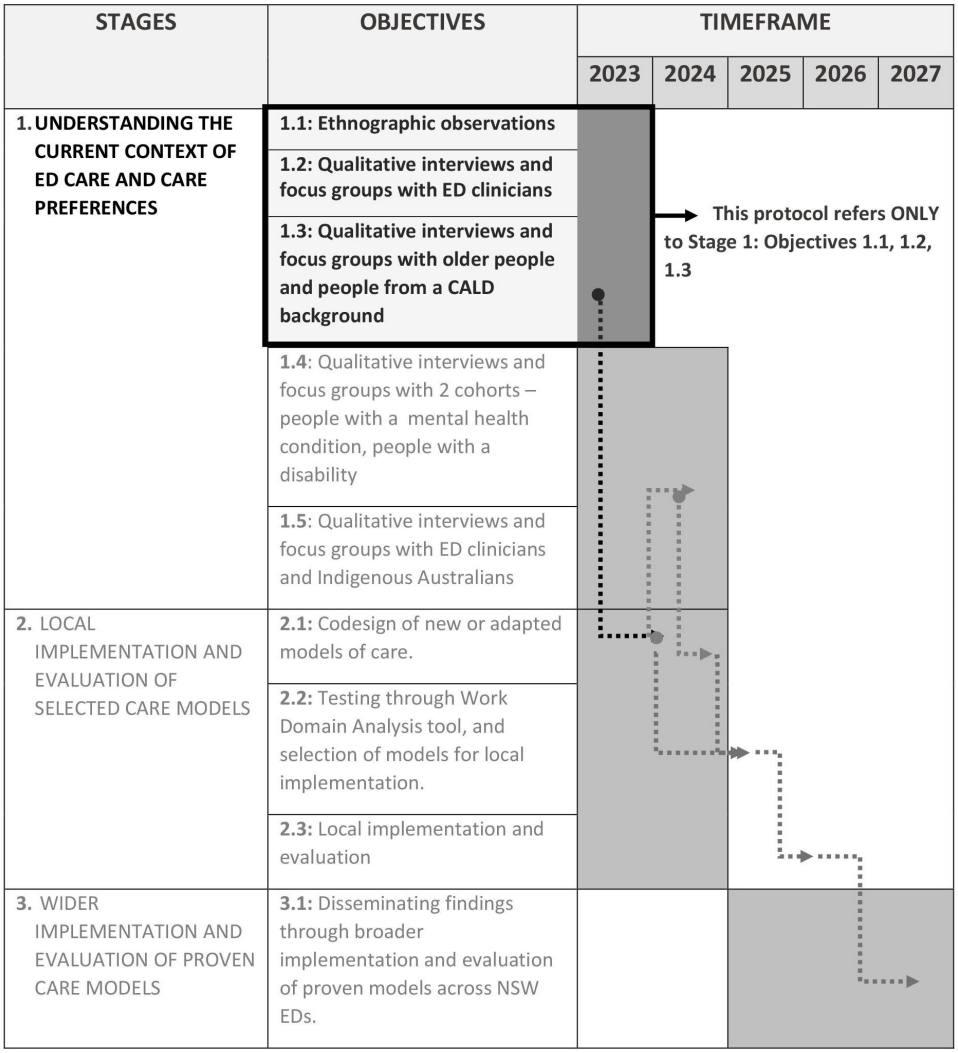

Figure 1 Schematic diagram of the proposed 5-year timeline of the MyED study and Steps 1.1–1.3 (this protocol). CALD, culturally and linguistically diverse; ED, emergency department; NSW, New South Wales.

adopted considered approaches to promote inclusion and self-determination, to capture nuanced participant accounts of emergency care and to represent this view while ensuring participant care and safety. This work also assists the researchers to embrace critical, reflexive practice to understand standpoints and epistemological frameworks that will impact relationships with participants throughout the project.[31]

The three specific objectives of this Stage 1 protocol are:

1.1. To understand the current context of ED care for four of the target cohorts (older adults, adults from a CALD background, mental health condition or a disability; Indigenous research pending IHAC advice).

1.2. To understand the knowledge or service gaps clinicians perceive in providing ED care for adults within these four target cohorts.

1.3. To elicit the needs and preferences for future ED care of two patient cohorts—older adults and adults from a CALD background.

METHODS AND ANALYSIS

Setting

The research will be conducted from February 2023 to June 2027, in collaboration with a health district in New South Wales (NSW) (public health delivery), the NSW Agency for Clinical Innovation (Emergency Care Institute) (public health delivery), Health Consumers NSW (registered health charity representing consumers), the Australian Government Department of Social Services (Federal Government Department) and the National Disability and Insurance Scheme Quality and Safeguards Commission (Federal Government Department). The 2022 health district population of over almost 1 million people has been growing annually, and is culturally and socioeconomically diverse[32] (text box 1).

EDs at three of the five hospitals in the district will participate in Stage 1 and 2 of the study. The methods for Stage 1, Objectives 1.1, 1.2 and 1.3 are aligned with the research aims and detailed in the following three subsections.

Box 1 Characteristics of the health district community stakeholders. *Source:* Australian Bureau of Statistics

- ⇒ Around 1.5% (~13 400 people) identify as Indigenous Australians.
- ⇒ About half of the population were born overseas.
- ⇒ Fifty per cent of people speak a language other than English at home, and 8.5% of people do not speak English well or at all.
- ⇒ The top five languages used at home other than English: Mandarin, Cantonese, Korean, Hindi and Arabic.
- ⇒ Whereas some neighbourhoods enjoy relative socioeconomic advantage, others are among the most disadvantaged, in terms of education, occupation, employment income and housing.
- ⇒ The number of people aged ≥70 years is forecast to grow by 54% by 2026.
- ⇒ Major long-term health problems in the area include arthritis, asthma, diabetes and mental health conditions.

Objective 1.1 ethnographic observations

The purpose of this ethnographic study is to document the current model of ED care for people within four of the target cohorts (older adults, adults with a CALD background, mental health condition or a disability).

Sampling

Six members of the research team aim to spend 4×12 hours shifts in each of the three participating hospital EDs. Observations will occur for up to 288 hours in total over a 3-month period. For each shift, a research pair will be pre-allocated to nursing triage (initial patient assessment and urgency of care classification), navigator (facilitating the patient journey through the ED) or patient flow (facilitating communication among staff and patient movement through the ED) roles, to attain an overview of workflow and processes. Observations of the ED environment will include how the ED staff work, the flow of work and practice patterns. Researchers will identify themselves openly to staff and patients, and comply with all hospital protocols and directives. Staff interactions will only be described in general terms, and subject to written consent.

Data collection

A validated Cognitive Work Analysis (CWA) question framework will be used to guide researcher data collection.[33] CWA is a framework used to identify and describe constraints that limit or control complex sociotechnical systems.[33] This framework was previously developed for the participating EDs by our team,[33–35] and we anticipate using CWA to model proposed solutions in Stage 2. Fieldnotes will be taken throughout the day, on different days of the week, aiming to observe naturalistic behaviour patterns. We aim to produce a detailed examination of work-as-done, and the use and influence of existing models of care on routine, daily healthcare practices. Only generalisable workflow and researcher perspectives will be collected, not individual or personal health information.

Data analysis

Fieldnotes will be aggregated and uploaded into NVivo V.20 software and analysed using thematic analysis.[36] Qualitative analysts will independently code the data, then discuss major and minor themes and their concomitant categories and arrive at consensus opinion if variance occurs.

Special considerations

Site governance processes will be completed for each research team member. Researchers will comply with ED staff directions including leaving in an emergency. Researchers will provide inquiring patients with written explanations of their presence. If a patient objects to or is distressed by the researchers' presence, the researchers will remove themselves from the patient area.

Outcomes

The data from this step will be triangulated with data from Step 1.2 to build a picture iteratively of the work process in line with the research aim.

Objective 1.2: qualitative interviews to understand the experience and perspectives of ED participants at the study EDs

The purpose of this phenomenological study is to understand the knowledge or service gaps clinicians and support staff (ED participants) perceive in providing care in the ED for persons within four of the target cohorts (older adults, adults with a CALD background, mental health condition, or a disability).

Sampling and recruitment

Up to 50 interviews with staff from each ED setting will be conducted onsite face-to-face or online. Participant perspectives about delivering ED care for the four cohorts (older adults, adults with a CALD background, adults with mental illness or adults with a disability), will minimise repeated participation and help define the target cohorts for the qualitative studies in Step 4 of the MyED study.

We will include clinical (eg, medical, nursing and allied health professionals) and non-clinical staff (eg, clerks, orderlies) who have worked in the participating EDs for at least 3 of the previous 12 months and who:

- ► Deliver direct patient care or support clinical care in the ED, or
- ► Manage patient care delivery in the ED.

We will exclude staff who:

- ► Attend ED as part of a wider hospital organisational role, but do not provide or support direct ED patient care.

Data collection

Initial demographic information will be collected before commencement of the audio-recorded semi-structured interviews. Interviews (30–40 min) will be conducted over a period of approximately 12 weeks, continuing until the target sample number is reached or data saturation occurs.

Data analysis

All audio recordings will be transcribed verbatim and once checked against the audio recording, imported into NVivo V.20 software for data organisation. The transcripts will be analysed using data-driven thematic analysis as previously described.[36]

Outcomes

The data will be used in conjunction with the ethnographic data from Step 1.1 to construct the mapped models of ED care, and in conjunction with data from Step 1.3, to identify and illustrate touchpoints.

Objective 1.3: qualitative interviews with two patient cohorts – older adults and adults with CALD backgrounds

The purpose of this phenomenological study is to understand the experience of ED care and elicit the needs and preferences for future ED care, for these two patient cohorts.

Sampling and recruitment

We intend to undertake up to 10 focus groups (FGs) of 5 persons for each cohort but will supplement FGs with semi-structured interviews based on the needs and preferences of potential participants. Sampling and recruitment have been tailored to these different cohorts.

Cohort (1) – older adults

Four participant models will be available:

1. FG with up to five individuals.
2. One-on-one interview with individuals who cannot or do not wish to participate in an FG.
3. One-on-two interview with individuals who wish to participate in a supported model with a family member or friend.
4. One-on-one interview with individuals who have supported an older person in ED, who meets the inclusion criteria, who may or may not have the capacity to participate themselves. These participants will be consenting to their own participation, providing their own perspective. Related participant accounts may also enable corroboration, increasing the trustworthiness of collected data.

Through prior consultation with domain experts and project investigators, we understand that ED presentations by older adults may increase markedly during a 6-month period prior to their needing more supported living or 24-hour care.[37] In Australia, the Federal government subsidises home care packages (HCP) at four levels—from level 1 for basic care needs to level 4 for high care needs, to enable people to remain living in the community. Older people who can no longer live at home and need ongoing help with everyday tasks or healthcare may move into residential aged care facilities (RACF) . Our recruitment thus targets adults aged ≥65 years:

- Who have presented at least once to one of the three EDs within the previous 12 months and are:
  - Living in the community and have been assessed as requiring an HCP at Level 3 or 4, or
  - RACF residents.
- Who can understand the nature of the research to provide informed consent to participate individually or with support.

For support persons who wish to participate, we will include those who have attended ED with a person who meets the inclusion criteria, are aged ≥18 years and can provide informed consent. We will exclude those who are unable to understand or speak English (although they may be referred to the CALD cohort). Recruitment material will be disseminated through RACFs and community-based healthcare services in the catchment who have agreed to participate.

Special considerations

Patient participants will be identified to researchers by a person who knows them well—RACF carers or family members and community services. The researcher will approach the individual identified in the community setting and ask their permission to tell them about the study. If the individual indicates their willingness to participate and their understanding of the study through talking to the researcher about the study, asking pertinent questions or commenting appropriately, and understands the instructions for consent, capacity to consent to participate in the study will be assumed. Participant information will be left with the resident to consider or to discuss with their family member, carer or support person. At the time of telling an individual about the study, the researcher will draw the individual's attention to the interview questions that are listed in the participant information so the individual can make notes before the interview if they wish.

The researcher will revisit the individual and check that they remember the introductory meeting, understand the nature of the research and want to participate, with or without support. If the potential participant or the RACF or other carer indicates cognitive decline, consent will be witnessed by a person external to the research team to provide independent confirmation of the participants' understanding of the study. Acknowledging that individual capacity may fluctuate, the researcher will include in the consenting process a discussion about what would happen if the individual's capacity to participate was in doubt at the next visit. The planned strategy is that the researcher will reschedule the interview twice, before withdrawing the individual from the study. If the individual's preference differs from this plan, this will be noted on the consent form.

Cohort (2) – adults with a CALD background

A person with a CALD background will be considered to be: 'the non-Indigenous cultural and linguistic groups represented in the Australian population who identify as having cultural or linguistic connections with their place of birth, ancestry or ethnic origin, religion, preferred language or language spoken at home'.[31] For CALD participants, the interview or FG may be conducted in English or one of the five languages that are most prevalent in

the catchment (Arabic, Mandarin, Cantonese, Hindi or Korean).

We will include individuals:

- Aged ≥18 years with a CALD background, who
- Have sought care at one of the three EDs within the last 12 months, and
- Can provide informed consent to participate individually or with support.

We will exclude individuals who do not speak or understand English if an accredited translator is unavailable.

Special considerations

A registered recruitment agency has been engaged for recruitment as they have existing relationships with the CALD community and can complete the full recruitment process in the preferred language of the participant. Up to 50 participants, targeting 10 from each language group will be recruited. An initial meeting with the agency will be conducted to provide a clear vision for the proposed research. Using their key contacts and community networks, the Human Research Ethics Committee (HREC) approved recruitment material will be used to recruit participants for FG (and interviews if preferred). Once a potential participant is identified they will be assisted, as required, to register. The research team will liaise with the agency to arrange the schedule for interviews or FG and the agency will inform participants of their appointed interview or FG date and time. The agency will manage participants and guide them throughout the research process in their preferred language. This includes liaising with participants to partake and complete the study, addressing any questions, scheduling, communications and technical support.

Data collection

Descriptive demographic details will be collected for each participant prior to commencement of the audio-recorded interviews. Focus groups (<2 hours), or semi-structured interviews (<60 min), will be conducted by a member of the research team in English. If one of the five languages other than English is preferred, an FG will be conducted by a member of the research team with an accredited bilingual interpreter to translate to and from the language preferred by those participants. If there are ≥5 people from the same language group outside of the five language groups nominated who wish to participate, an FG will be conducted pending availability of an accredited translator.

Data analysis

The English portion of all audio recordings will be transcribed verbatim and entered into NVivo V.20 software for data organisation. A social constructionist grounded theory[38] approach will be used to gain an interpretive understanding of the ED experience for patients that accounts for their unique context but amplifies their presence and voice throughout analysis and presentation of findings. While data collection from cohorts occurs separately, the intersectionality between cohorts will contribute to a picture of the whole and reflects constructionist grounded theory constant comparison and theoretical sampling methods. Coding and analysis of interview data will occur as it is collected. Researchers will listen to recorded interviews alongside written transcripts paying attention to the individual, their life contexts and emotional tone. A preliminary descriptive code will be assigned to each line incorporating active 'in vivo codes' where possible.[38 39] The analysis will cycle through collection and initial coding, analytical memo-writing[39] and supervision sessions by researchers to reflexively examine interpretation, divergent cases, focus coding and refinement of categories and consider theoretical care concepts. Assisted by hermeneutical interpretation,[40] a 'patient story'—one that represents the lived experience of participants (but no individual participant)—will be crafted to make visible the human experience.

Other considerations

Research material will be provided in an alternative large font format for patients who have visual impairment. The interviews will also be conducted in a quiet environment. For older adults, a ½-hour window between interviews will be scheduled, acknowledging some residents may wish to have a general chat about other things (not recorded or included as part of the study). Our prior consultation indicates the older person cohort are likely to prefer a face-to-face interview, whereas the CALD cohort are likely to favour an online forum.

While participant upset is not anticipated, in this event the researcher will manage this at the time by: stopping the interview (if online during the FG, the participant will be moved into a virtual break-out room attended by a second researcher), providing time for the participant to self-manage, using a strengths-based approach to draw attention to the internal resources of the participant and giving the person the option to withdraw or return to the interview. At the interview end, all participants will be reminded of resources listed in the participant information should difficult thoughts arise from the subject matter.

Outcomes

The data from this step will be used in conjunction with the data from Steps 1.1 and 1.2 to elicit touchpoints to inform opportunities for codesign in Stage 2. The life story will be used prior to codesign to draw ED staff from their clinical orientation of ED care into the human experience of the consumer.

Data management

We will use REDCap (Research Electronic Data Capture), a secure web platform for building and managing Australian-based online databases and surveys. Macquarie University REDCap will be used to provide online study information, electronically register study participants and to capture electronic consent and demographic

information. The platform provides the registrant with a downloadable copy of the participant information, and electronic acknowledgement of their successful registration. The REDCap site can be navigated by participants independently, or the researcher can assist the participant via phone, online or face-to-face with a portable electronic device.

A Data Management Plan was created to map data flows and explicitly identify methods to mitigate risk to the security of the data and the privacy and confidentiality of participants.

Ensuring study quality

The success of codesigned project initiatives for ED care will be judged by their utility, safety and actual use, directly impacting evaluated outcomes. While the research project team conduct the day-to-day work, all chief investigators and associate investigators and project partners comprise a Steering Committee that meets quarterly and is responsible for governance, including the overall project direction, monitoring quality and high-level decision-making to assure utility, feasibility and quality standards. A Core Research team meets biannually and via email between meetings comprising all university project researchers to provide oversight of research strategy and quality, and to monitor potential changes and their impact on the correctness, completeness and integrity of output from a research perspective.

Patient and public involvement

Experience-based codesign champions user participation; the project team includes representation from consumer groups and services, people with a CALD background, and those with lived experience as carers. Over a 3-month period the research team consulted epistemic experts to inform methods for engagement, recruitment and participation and strategies to assure inclusivity and self-determination. The constructivist grounded theory and hermeneutical approaches have been chosen to elevate lived experience. Research participants may opt to participate in subsequent codesign.

Ethics and dissemination

The overall project was peer-reviewed by the Australian National Health and Medical Research Council. An Ethically Defensible Plan was created to consider the ethical implications of this research and guide strategies to minimise harm to participants, manage power differentials, offer flexibility to account for differences and fluctuations in ability to participate and compensation to minimise financial barriers to participation. This plan was considered in conjunction with the protocol and approved by the health district HREC.

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Competing interests None declared.

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