'Making it Meaningful': Co-designing an intervention to improve medication safety for people from culturally and linguistically diverse backgrounds accessing cancer services.

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Abstract

This study reports on the process of using an adapted Experienced-Based Co-Design (EBCD) conducted with culturally and linguistically diverse (CALD) consumers and cancer service staff to co-design the novel 'Making it Meaningful'(MiM) instrument at a cancer service in Australia. Multi-source experiential and contextual information was gathered in phase 1 of the co-design and this evidence, coupled with knowledge gathered via a feedback event was used to inform three co-design workshops in phase 2. A series of meetings were conducted prior to and in between the workshops. Theory was progressively integrated into the workshop content. Two Mandarin speaking CALD consumers and three cancer service staff participated as co-design members. Workshops were supported by a multilingual fieldworker, co-facilitated by researchers and a consumer co-facilitator, and conducted using a hybrid model (face-to-face or online participation). In the first workshop members democratically selected to focus on a strategy to enable CALD consumers to make non-emergency urgent contact with the cancer service for medication related communication. The second workshop resulted in consensus to develop an accessible instrument that would identify appropriate contacts and information sources for medication management between appointments. In the third workshop, the prototype MiM instrument was developed and refined. The MiM is a novel instrument designed with CALD consumers to enhance their knowledge of medication management and empower them to contact cancer service staff about medication safety concerns. Feasibility testing is the next step with successful implementation requiring senior health leadership support and involvement of co-design members as change agents.

Introduction

Healthcare associated harms (such as medication related harm, healthcare acquired infections) are a pervasive challenge across all healthcare settings. International data demonstrates that 1 in 10 patients admitted to hospital are likely to experience a safety event, and that safety events occur in 2-3% of all health provision episodes in primary care.[1, 2] Recent evidence from a systematic review has highlighted that people from culturally and linguistically diverse (CALD) backgrounds - who are born overseas, have one or both parents born overseas, or speak languages other than the official national languages and/or have lower proficiency of native or national language[3] - are more often exposed to healthcare associated harms.[4]

Medication safety is a particular concern for CALD communities, with studies demonstrating higher incidence of medication related safety events among people from CALD backgrounds.[4-7] A cross sectional randomised controlled experiment identified that the rate of dosing errors was double among people with low English proficiency than those who were assessed as proficient in English.[8] Another systematic review also concluded that CALD patients were more prone to dosing errors and non-adherence.[9] Communication failures, patient-provider interactions and misinterpretation of instructions were found to be associated with risk of medication related safety events for people from CALD backgrounds.[8, 10-12]

Multiple factors contribute to inequities in patient safety for people from CALD backgrounds. These factors include communication barriers, access to services, health literacy, socio-economic factors, lack of cultural competency among health systems, services and staff and also limited patient and family inclusion and engagement in care processes.[4, 13, 14] Engagement with consumers (patients, their families and other informal care givers) in a patient's care has been identified as an essential element for the delivery of safe care.[15, 16] Evidence from multiple intervention studies suggests that consumer engagement can enhance safety by ensuring patient-centric allocation of resources at a service or system level,[17] by supporting care co-ordination and error detection through encouraging consumers to ask questions, and to contribute to shared agreement about care requirements and processes.[18-20] Many strategies have focused on improving face-to-face communication between patients and health care staff taking place at the clinical front line in either inpatient or outpatient settings.[18, 21, 22]

Recent studies have demonstrated that despite the increased risks of unsafe care for CALD communities, there is a lack of consumer engagement strategies designed with or for people from CALD backgrounds, and that current strategies are not well-suited to this population.[18, 23] Various challenges exist for application of these consumer engagement strategies to enhance patient safety for people from CALD backgrounds. These challenges include communication barriers, health service capacity, cultural competence of staff and different understandings of the concepts of patient safety and consumer engagement between and within CALD populations.[23] Cultural adaptations of existing interventions used with the general population that are developed collaboratively with CALD communities may provide relevant strategies that enhance their healthcare safety.[23] The present project sought to explore this by co-designing a consumer engagement strategy with CALD communities that aimed to address safety challenges arising for consumers in cancer settings.

We report the processes and outcomes of using an adapted Experienced-Based Co-Design (EBCD) process for CALD consumers and cancer service staff to co-design the 'Making it Meaningful'(MiM) intervention at a cancer service in New South Wales, Australia.

Project context
This research is part of a nationally funded project called the CanEngage Project, which was supported by two research grants led by RH. The CanEngage Project aims to improve patient safety for people from CALD backgrounds accessing six cancer services in two Australian states by enhancing their engagement in care. We report on the co-design processes and strategy designed at one of the participating cancer services which formed a component of AC's doctoral research.

Method

Ethics
This study received ethics approval from National Health and Medical Research Council (NHMRC) accredited Western Sydney Local Health District Human Research Ethics Committee: Reference number (2020/ETH0965) and (2021/ETH00532).

Setting
One cancer service located in a public hospital in New South Wales, Australia participated in this work. This cancer service provides a range of cancer specific care including inpatient, outpatient, day stay and palliative care services through a comprehensive cancer centre. This cancer service is located within a metropolitan area of a health district that serves a large population from CALD backgrounds. Almost 40% of the population residing in this health district were born outside of Australia with 30% of the population born in non-English speaking countries.[24] Almost 35% of the population residing in this health district spoke a language other than English at home with almost 6% reported being not able to speak English at all.[24] Of the 20 top countries of birth (other than Australia) for residents in this health district, China was most common.[24] Of the 20 top non-English languages spoken, Mandarin was most common.[24]

Experienced-Based Co-Design

Recognition that consumers are experts in their own care through their lived experiences has accelerated the use of experienced-based co-design (EBCD) when using co-design in healthcare to improve service delivery and enhance patient experiences.[25-27] EBCD seeks to democratically identify a problem(s) and develop solutions through a collaborative process.[28, 29] Increasingly, it is recognised that the success of EBCD is contingent upon creating conditions that foster meaningful engagement of co-design members in the process, which may require deliberate adaptations to the process.[30-32] An adapted EBCD process was developed and used in this project as described in the CanEngage Project protocol which is reported elsewhere.[33] Two adaptations were made that aimed to optimise the co-design for people from CALD backgrounds.[32, 33]

Firstly, we engaged with and trained consumer co-facilitators from CALD backgrounds to co-lead the design processes. Consumer co-leadership involved equal participation in planning and leading co-design workshops and the wider process, including planning for implementation.[34] We established the CanEngage Co-facilitator Network consisting of six consumer co-facilitators from CALD backgrounds with experience of cancer care, and five multilingual fieldworkers (health care service staff that spoke other languages including English

and were from diverse cultural backgrounds). The role of the multilingual fieldworker was to facilitate conversation between the participants who were from diverse backgrounds, act as translators or explain or describe certain terms and processes to the participants and support them by addressing language and cultural needs. The consumer co-facilitators and multilingual fieldworkers were recruited via consumer and community networks and organisations, the CanEngage consumer advisory group and multicultural health teams via webpages, online newsletters, and emails.

Secondly, we provided logistical, language and technological support to co-design members to optimise opportunities for equal participation in the design and output creation processes.[32, 35] Prior to co-design, consumer members were contacted to assess their communication preferences and support needs, members were matched with a relevant multilingual fieldworker, introduced to them and a process of working together was established. Logistical considerations included their preference for face-to-face or online meetings, venue choice, transport arrangements, testing of software such as Zoom and WeChat prior to use at the workshops and time allowances in session planning to account for translation and shared understanding.

Based on the preferences and abilities of group members, we ultimately adopted a hybrid approach, whereby co-design members were provided the opportunity to attend the workshops either face-to-face or online. Due to hybrid nature of the workshops, we took the following additional steps to mitigate the potential for online participants to be inhibited in their contributions: (1) co-design co-facilitators and multilingual fieldworker were provided with a dedicated training session for conducting the co-design workshops online; (2) consumer co-facilitator and multilingual fieldworker were present in the room (face-to-

face) at all times to facilitate conversation; and (3) participatory learning and action (PLA) techniques such as brainstorming, commentary chart and voting were used to support all members to contribute their experience and perspective meaningfully and to an equal extent in every stage of the process.[36] In the reported co-design, all co-design members attended the three co-design workshops.

Co-design procedure

The adapted EBCD was conducted in two phases (Figure 1). The two phases resembled the Double Diamond model developed by the Design Council.[37] Phase 1 explored the safety issues using various research methods to identify and consolidate the safety events. In phase 2, these safety events were further explored, and an intervention prototype was developed. Phase 1 is briefly described below. The focus of this manuscript is the co-design process (Phase 2).

Phase 1: Contextual and experiential data capture and exploration

Phase 1 used a multi-method approach (Supplementary File 1) to gather contextual and experiential data of patient safety challenges in the participating cancer service. Relevant data was identified in medical records as well as qualitative interviews with consumers and staff to inform the co-design of a solution. This was supported by wider evidence of the Australian health system context for consumer engagement for CALD communities[38] and the nature of patient engagement interventions and safety problems identified internationally for CALD communities.[4, 18] Phase 1 findings (Supplementary File 1) were then discussed via a feedback event, which were used to generate patient safety priorities and possible solutions via co-design in phase 2.

Figure 1. Visual of EBCD as two phases[37]

Discover and define safety issues through range of contextual and experiential studies

Determine Scope

Discuss ideas and develop prototype through three co-design workshops

Phase 1   Feedback event   Phase 2
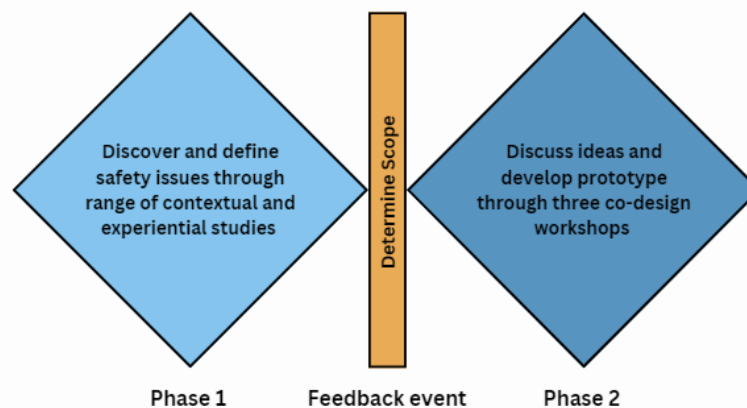
Feedback event

Feedback events are identified as an important component of EBCD by which the healthcare staff and consumers accessing the service come together to discuss the contextual and experiential data from Phase 1. The findings from these discussions are used to guide the content and context of the co-design process.[39, 40] An online feedback event was conducted as part of a cancer roundtable webinar at the participating cancer service, delivered by the project lead (RH). The feedback event was open to all consumers and staff at the participating cancer service. The invitation to participate in the feedback event was distributed through a flyer via the cancer service and the CanEngage consumer advisory group networks and by individual email to members who completed interviews in Phase 1. The attendees provided feedback through online discussion and chat forum. This feedback also guided the decision to conduct the language specific co-design workshops with Mandarin speaking CALD consumers accessing the cancer service.

Phase 2: Co-design workshops

Recruitment

Due to the many Mandarin-speaking consumers in the participating service, experiential data from phase 1 and conclusions of the feedback event, the co-design workshops were conducted with Mandarin speaking consumers. Individuals (healthcare staff and CALD consumers) who had participated in the semi-structured interviews as part of Phase 1 were invited to contribute to the co-design workshops. Following the interviews, one researcher (AC) contacted all individuals who expressed their interest to participate in the co-design. Consent was sought from participants prior to the session. Multilingual fieldworker was engaged where needed to provide language support. Through this process, two consumers with Mandarin as their first language (one consumer had good proficiency in English, another consumer had poor English language proficiency and required support from multilingual fieldworker), and three health service staff (one medical oncologist and two clinical nurses) became co-design members.

CALD consumers were eligible if; they were greater than 18 years of age, self-identified as CALD and were currently accessing the cancer service or had accessed cancer service in the past 5 years. Health care staff were eligible if; they were greater than 18 years of age and had worked in the cancer service as permanent employee for six months or more. Both consumer members participating in the workshop had controlled disease of more than 5 years duration, stable symptoms and had experienced medication related adverse events.
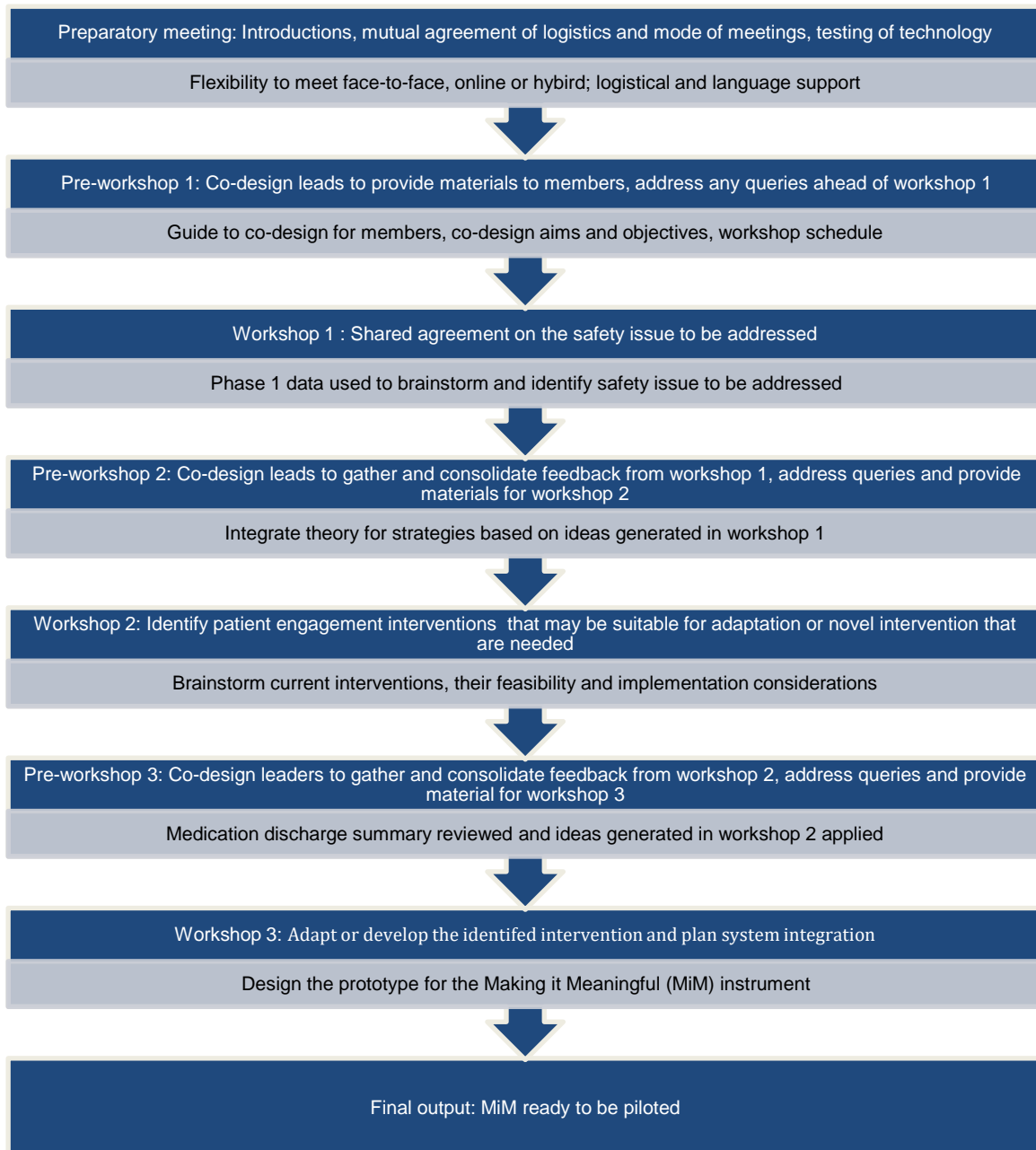
Procedure

A co-design team was formed and consisted of three research co-facilitators (AC, RH and BN), one consumer co-facilitator (ER), one Mandarin speaking multilingual fieldworker, three healthcare staff from the cancer service and two CALD consumers (who were born in mainland China and spoke Mandarin as their first language). The consumer co-facilitator and multilingual fieldworker were engaged to support CALD consumer participation in the co-design process and workshops. Prior to the co-design workshops, two training workshops were provided for consumer co-facilitators and multilingual fieldworkers to support their co-design practice. The training is subject to ongoing process evaluation and the first component of this has been reported elsewhere.[41]

A schedule was developed that outlined series of meetings (preparatory, introductory and in-between workshop meetings) and workshops between co-design members as agreed by the cofacilitator network members (Figure 2).

A preparatory meeting was held (online and face-to-face) prior to the first workshop with all co-design members. This meeting was intended to introduce members to each other, test the feasibility and usability of the hybrid nature of the workshops, and develop a shared understating of the project aims and objectives.[35] Prior to this preparatory meeting, members were provided with materials to facilitate understanding of the aims of the co-design workshops, purpose and the guide for co-design workshops. These materials were: 1) A guide to co-design outlining membership, expectations, workshop schedule, contact points etc; and 2) one page summary of project aims of each workshop. The information outlined in these documents was explained to the Mandarin speaking consumer by the multilingual fieldworker. Through this preparatory meeting, any questions and queries were answered and the usability of conducting workshops through a hybrid medium was tested as acceptable by the members. During this process, the need to provide an agenda and draft plan for each workshop prior to its commencement was identified to facilitate members preparation for each workshop. This information was provided to members via email and was verbally communicated by the multilingual fieldworker to the Mandarin speaking consumer member prior to each workshop. Verbal communication with the multilingual fieldworker was preferred by the consumer who spoke Mandarin as it allowed the consumer to ask questions directly as they arose. This process also allowed the multilingual fieldworker to check consumer's understanding of the information provided by using strategies such as teach back. This process was also used due to time and resource constraint.

Following the preparatory meeting, three workshops were conducted using an interactive discussion approach

Figure 2. Schedule of workshops and meetings

Preparatory meeting: Introductions, mutual agreement of logistics and mode of meetings, testing of technology

Flexibility to meet face-to-face, online or hybird; logistical and language support

Pre-workshop 1: Co-design leads to provide materials to members, address any queries ahead of workshop 1

Guide to co-design for members, co-design aims and objectives, workshop schedule

Workshop 1 : Shared agreement on the safety issue to be addressed

Phase 1 data used to brainstorm and identify safety issue to be addressed

Pre-workshop 2: Co-design leads to gather and consolidate feedback from workshop 1, address queries and provide materials for workshop 2

Integrate theory for strategies based on ideas generated in workshop 1

Workshop 2: Identify patient engagement interventions that may be suitable for adaptation or novel intervention that are needed

Brainstorm current interventions, their feasibility and implementation considerations

Pre-workshop 3: Co-design leaders to gather and consolidate feedback from workshop 2, address queries and provide material for workshop 3

Medication discharge summary reviewed and ideas generated in workshop 2 applied

Workshop 3: Adapt or develop the identifed intervention and plan system integration

Design the prototype for the Making it Meaningful (MiM) instrument

Final output: MiM ready to be piloted

incorporating various activities that promoted open discussion and democratic decision making.[42] Content was guided by the workshop objectives. Integration of theory in co-design may clarify the mechanism by which co-design works and provide success measures.[43] Theory was progressively introduced into the co-design process whereby the ideas generated by the members were explored by research co-facilitators to develop a toolkit of strategies that were then presented in subsequent workshops.[43] The co-facilitators developed the workshop content prior to each workshop. In each pre-workshop meeting, the co-facilitators clarified content and discussed which aspect of the workshop each facilitator would lead. Members agreed that the workshops would be conducted in a university meeting room (with online options due to Covid-19) that was not affiliated with the cancer service. Consumer members were also encouraged to bring a carer or support person as they wished. Workshop processes were designed to foster positive connections between members to allow different perspectives to contribute to a

Figure 3. Patient safety issues at participating cancer service
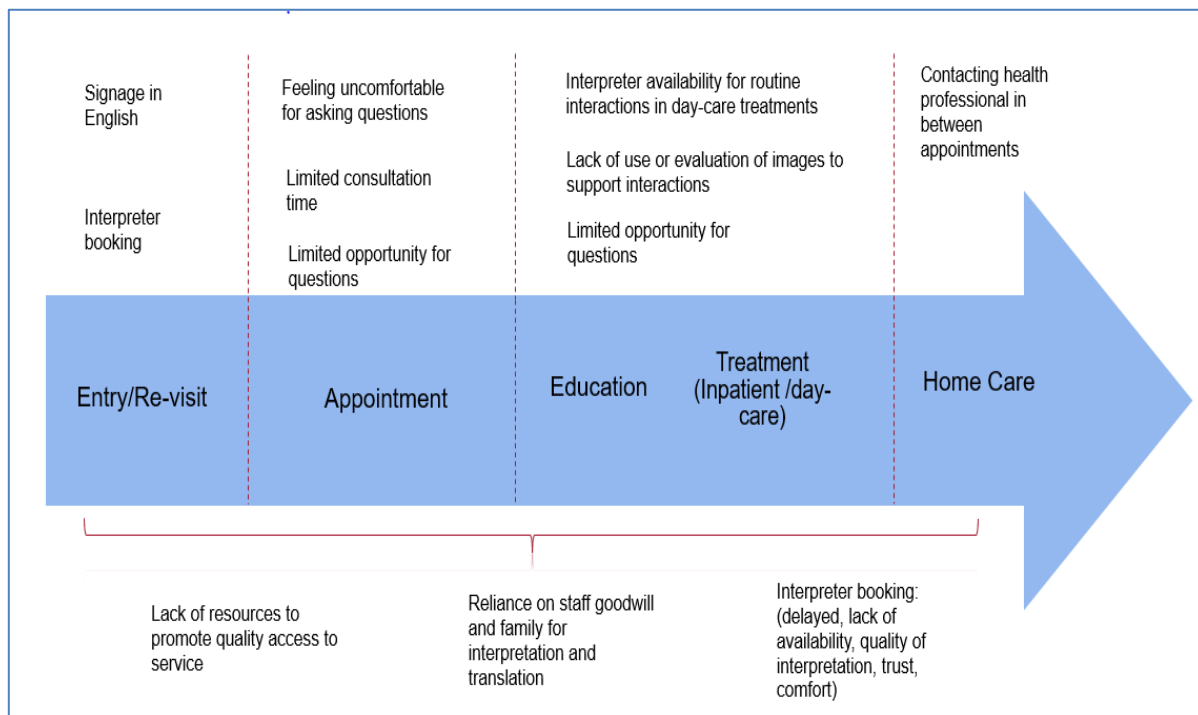
shared decision-making process.[44, 45] In addition to the workshops and preparatory meetings, informal phone and email conversations occurred between co-design members and the project team.

Results

The process resulted in the development of the Making it Meaningful (MiM) instrument, which is a modified medication management summary for CALD consumers in cancer services. The key information and decisions resulting from each workshop are documented below, followed by the MiM instrument.

Workshop 1 aimed to collectively identify the patient safety problem to be addressed. A range of patient safety issues were identified at the participating cancer service in Phase 1, with medication concerns featuring prominently (Figure 3). Following discussion of these, two group activities were conducted to facilitate prioritising a patient safety issue and to establish the scope of issue that would be feasible to tackle in our co-design. Members discussed and debated their perspectives, facilitated by the co-facilitators, with language support from the multilingual fieldworker. Members collectively agreed that a lack of shared understanding between consumers and staff about medication management was a central problem leading to poor safety outcomes. This problem was exacerbated by a large volume of instructions in cancer services and

instructions that were not in accessible language or formats. The management of medications in outpatient settings was identified as the priority patient safety problem. We agreed to address gaps in support for CALD consumers when they had non-emergency, urgent questions regarding medication instructions, side effects or adverse effects when not in inpatient care. The group wanted to enable consumers and healthcare professionals to gain a mutual understanding of how medications were to be managed at home, and clarity about who consumers could contact for medication concerns as an outpatient.

Preparation between workshops 1 and 2: Following selection of the issue during the first workshop, the co-facilitators conducted a literature search to identify evidence of strategies to enhance shared understanding about medication management for outpatients. Three broad strategies were found that could be relevant; (1) making existing medication information more accessible; (2) improving communication by health professionals about medication instructions and management; and (3) enabling consumers to initiate contact with service providers between appointments about their medications. These strategies were discussed in a pre-workshop meeting and used as a basis to develop activities for the second workshop.

Workshop 2 aimed to create shared agreement on a patient engagement intervention that is suitable for

adaptation, or whether a novel intervention was needed. The co-facilitators provided brief overview of the first workshop and issue selected, along with an overview of existing strategies used to manage medication safety. Following this, members were grouped in pairs to brainstorm how they might consider addressing the patient safety issue, what adaptations were needed or if a new strategy was required. Each group presented their ideas. Through brainstorming, it was revealed that the current process in place to make non-emergency urgent contact between appointments is not accessible for non-English speaking patients. Members also agreed that the new consumer engagement intervention should encourage consumer-initiated contact as required outside of clinic visits or hospital stays. Members agreed that translated information for appropriate contacts needs to be available along with information about medication management in simple and accessible language.

Preparation between workshops 2 and 3: Prior to the third workshop, the existing medication discharge summary used by the cancer service was retrieved. Members were asked to consider examples of specific concerns they may have regarding medication management that would warrant making contact with the service. Co-facilitators conducted a literature search for strategies used to improve outpatient non-urgent contact with health services. The project lead (RH) fed back the workshop progress to date with cancer service lead to ensure that a co-designed solution would be acceptable for use in the service.

Workshop 3 aimed to design the medication management solution. In the third workshop, the existing medication discharge summary was reviewed along with discussion of common medication concerns that members brought to the workshop. These concerns included identifying common side effects of the medications, understanding of the severity of side effects and information about how to contact relevant health care staff (when and whom). A prototype adaptation was made to the existing medication discharge summary that included several new features; the adapted version was called Making it Meaningful (MiM) (Figure 4). Adaptations to the existing tool included translations of medication side effects into Mandarin (and potentially further non-English languages), with common side effects listed for health care staff to circle relevant to a specific treatment. MiM would also contain a separate notes section for relevant information to be drawn or noted for the consumer e.g., drawing an image to enhance understanding and accessible information about the appropriate points of contact for different types of medication issues and their contact details. The MiM primarily aims to improve timely communication about medication concerns from people from CALD backgrounds to healthcare staff in between their appointments. The instrument aims to achieve this by

improving CALD patients' self-efficacy in medication management by increasing their knowledge of the purpose of each medication, potential side effects and relevant point of contact at health service if any side effects, urgent concerns or questions arise.

The instrument is intended to be used at the point of discharge from inpatient to home or at the end of an outpatient appointment. The MiM instrument could be used as a conversation starter, to educate patient on the purpose of the medication, highlight potential common side effects and outline when to contact relevant healthcare staff regarding any side effects. The 'notes' section can be used by the consumer or the healthcare staff in a way that they would like to use it to further enhance understanding (for example, healthcare staff could draw a simple figure or consumer could use it to write a question for their next visit). The intention of this intervention is that the CALD consumers at the end of the session will be able to recognise the side-effects and have knowledge of who to contact with medication management related queries. Following the third workshop, we refined the prototype MiM instrument with co-design members and members of the CanEngage Consumer Advisory Group and made edits to enhance language, layout, clarity, and ease of use.

Discussion

This study reported on the process and development of a novel co-designed intervention, the MiM instrument, to enhance medication safety by improving consumer engagement and their ability to make timely communication about medication concerns. The MiM, to our knowledge, is the first co-designed medication management instrument developed with consumers from CALD backgrounds aimed at enhancing medication safety. This work has implications for both improving safety of care but also for processes of co-design with CALD communities.

Consumer engagement in medication management can enhance patient safety and ascertain accurate two-way information flow between consumers and healthcare staff.[46] Various barriers such as language proficiency, consumer-provider relationship, consumers' knowledge of, ability and willingness to engage and health providers' unconscious bias may limit these accurate two-way information sharing.[4,47,48] The MiM may address these issues by providing consumers with a medication management instrument in their own language to enhance their ability to identify medication related side effects, support them in identifying relevant contact points and to facilitate timely contact.

Engagement interventions have highlighted the use of medication management lists as valuable instruments to

Figure 4. Making it Meaningful (MiM) Instrument

Name: MRN:
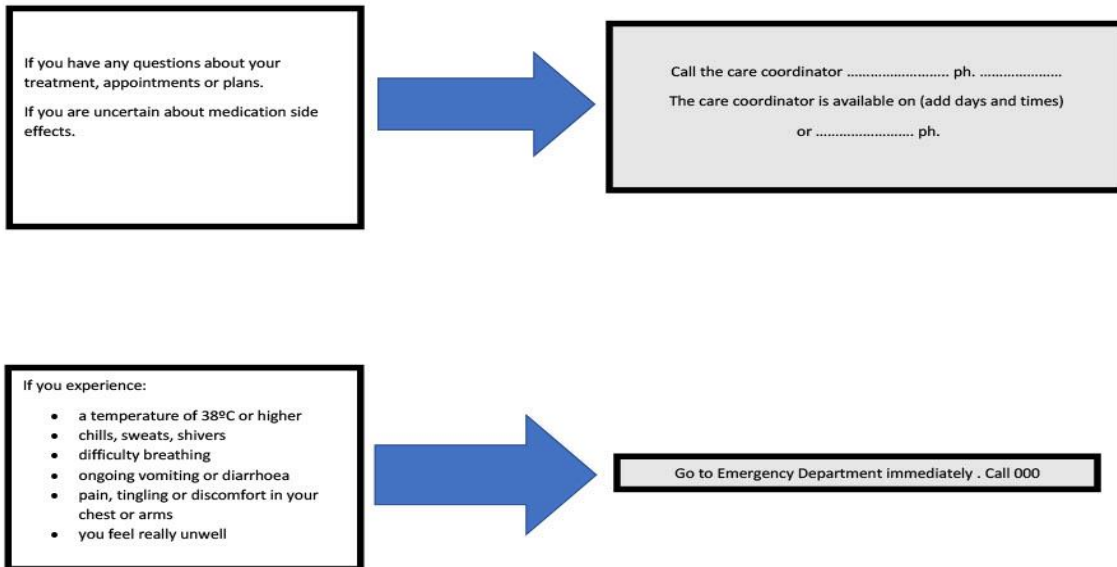
Health Care Practitioner:

SECTION 1 provides translated list of common side effects as a conversation tool and gives space for practitioner notes about specific treatment plans (in English)

Possible side effects (Translated)	**NOTES:**
English Russian/Chinese	
Nausea/vomiting	
Headaches	
Itchy/Rash	
Confusion	
Reflux/heartburn	
Dizziness	
Diarrhoea	
Shortness of breath	
Swelling	
Chest pain	

PLEASE TURN OVER FOR PAGE 2

Medication used to treat cancer can sometimes cause serious problems. It is important to get medical help immediately if you become unwell.

If you have any questions about your treatment, appointments or plans.

If you are uncertain about medication side effects.

→

Call the care coordinator .... ph. ....
The care coordinator is available on (add days and times)
or .... ph.

If you experience:

- a temperature of 38ºC or higher
- chills, sweats, shivers
- difficulty breathing
- ongoing vomiting or diarrhoea
- pain, tingling or discomfort in your chest or arms
- you feel really unwell

→

Go to Emergency Department immediately . Call 000

enhance medication safety and user experiences,[49] but there is no evidence of use of such resources for people from CALD backgrounds.[18] A recent mixed -method study examined 103 (paper-based, digital and smartphone application based) medication management tools that delivered range of medication management information to consumers.[50] This study identified that paper-based tools that provided opportunity for consumers to easily customise the information were more acceptable. Having a 'notes' section that consumers or service providers could use to write information in a way they want to enhance their understanding was considered more useful by participants (both service providers and service users).[50] MiM instrument offers one such approach to improve medication safety and user experiences for people from CALD backgrounds.

Implications
There are two main medication related implications of our research. Firstly, understanding of medication management and secondly who to contact and where to go. Medication management is a key concern for people from CALD backgrounds.[51] This is particularly relevant for cancer care where increasingly care is delivered outside of the hospital with patients and families responsible for management of medication at home. Poor medication management and poor recognition of side effects related to medication management may result in people from CALD backgrounds not accessing services they need at appropriate time or may access emergency department (ED) for non-critical matters.

Policy organisations nationally and internationally have proposed use of medication management plans to enhance patient safety by fostering consumer engagement in their care.[52, 53] The Australian Commission on Safety and Quality in Health Care (ACSQHC) have highlighted the importance of using (a) medication list(s) to reduce medication management related safety events by making it part of the Medication Safety Standard.[54] The Medication Safety Standard requires healthcare staff to provide a medication list to consumers, with information on current medications and any changes made.[54] Similar resources have been developed in other developed countries with focus for their use with patients with low health literacy and translated in non-English languages. The Agency for Healthcare Research and Quality (AHRQ) in the United States had commissioned 'Pill Card' as a medication management resource for consumers with low health literacy.[55] Similarly, the Canadian Patient Safety Institute have recommended use of medication lists as resources to enhance medication safety with this resource translated in non-English languages.[56] In NSW, a patient friendly medication list (PFML) is also developed by Clinical Excellence Commission that provide information regarding medication management in a patient friendly format.[57] These instruments contain information for

names of the medication, dosage, purpose of the medication and any changes made. The MiM has potential to complement these existing resources to enhance patient comprehension and engagement in their care to improve their medication safety with particular focus on recognition of side effects and appropriate contact point. Understanding when and how to access health services is an ongoing challenge for many CALD communities, reflected in the vast literature on this subject.[58-60] In phase one of this work, we identified that for non-English speaking patients, the process of making contact with services between visits was not clear for people from CALD backgrounds, putting them at risk of medication problems and contributing to emergency department pressures. The lack of suitable support structures at the service level, in terms of care co-ordinators who could manage non-English speaking patients and connect with interpreter services, was a critical problem.

Our work also has implications for engaging in co-design with CALD communities, which has been documented elsewhere.[32] Key learnings were in relation to the conditions (logistical, financial and technological) that support optimal participation and engagement for CALD consumers in co-design processes. Our research highlighted the resources required to generate such conditions, including the extensive preparatory work needed.[32] These findings have implications for funders to ensure that there is an avenue for high quality co-design processes to underpin grant applications in which patient and public involvement in research is emphasised. This is in addition to allocation of funding for engagement activities during the research process.[61, 62] Future research relate to evaluation of the MiM instrument and the adapted EBCD process. We aim to conduct this as the next stage of the CanEngage project.

Limitations
Due to COVID-19 related restrictions, potential risks associated with acquiring COVID-19 for the target population and associated challenges with recruitment of CALD individuals in research, four consumer interviews were conducted during the experiential data collection stage. While this may have shaped the findings from Phase 1 of the study, the democratic process employed during Workshop 1 to select a particular issue of concern meant that members were able to select an issue that most concerned them. Further, the co-design workshops were only conducted with Mandarin speaking consumers. CALD populations are super-diverse groups with individual experiences shaping their needs and requirements for engagement.[32, 48] Further, inter- and intra-group variations exist between and within this diverse populations.[4, 48] We focused on one group which limits the generalisability of the tool but there are opportunities to explore its perceived relevance for other non-English speaking groups. As the issue identified was applicable to

non-English speaking consumers, we aim to test this instrument with another non-English sub-group (Russian speaking) in conjunction with Mandarin speaking consumers as a feasibility pilot study. The co-design workshops were conducted using a hybrid approach. Whilst it may be harder to mitigate the barriers to communication when hybrid approach is used, it enabled people who had limited support or health concerns to attend and contribute. The adapted EBCD process may have applications with members from multiple cultural and linguistic backgrounds and possibly to further population groups. This application would require evaluation with members of the target population groups to determine suitability.

Conclusion

The MiM is a co-designed medication management instrument that aims to increase engagement among people from CALD backgrounds with cancer services to improve medication safety. Feasibility pilot testing with two population sub-groups will determine whether MiM requires further refinement ahead of use, and the implementation support required. Co-design members will continue to be engaged as change agents in this process.

Conflict of interest

Authors declare no conflict of interest.

Author contribution

Ashfaq Chauhan, Reema Harrison and Bronwyn Newman conceptualised the study. Ashfaq Chauhan, Reema Harrison and Bronwyn Newman completed data collection and the co-design workshops with assistance of Elsa Roberto. Ashfaq Chauhan completed the initial draft of the manuscript. All authors discussed the draft and provided intellectual contributions to the manuscript. All authors approved the final version for submission.

Data availability

The data is not publicly available due to privacy or ethical restrictions.

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Supplementary File 1. Synthesis of studies from Phase 1

Study Type	Level of knowledge	Summary of Study	Key findings contributing to co-design
Systematic Review (Chauhan et al)[4]	• Contextual data • Broader health system level	• Examined the nature of safety events for CALD patients and factors that impact on their safety. • Five databases searched. • Review was conducted using PRISMA. • Narrative synthesis undertaken	• Forty-five studies included in the review. • People from CALD backgrounds had higher rates of hospital acquired infections, surgical complications, adverse drug events and medication dosing errors. • Factors including language proficiency, beliefs about illness and treatment, formal and informal interpreter use, consumer engagement, and interactions with health professionals contributed to increased risk of safety events for CALD patients. • There is a lack of knowledge of patient safety events for people from CALD backgrounds in cancer settings
Systematic Review (Newman et al)[18]	• Contextual data • Broader health system level	• Examined the strategies used to engage patients in safety during direct care, explores who is engaged and determines the mechanisms that impact effectiveness. • Review was conducted using PRISMA guidelines. • Seven databases searched. • A narrative review and realist synthesis was undertaken.	• Twenty-six studies included reporting on 27 patient engagement strategies for improving patient safety. • Collaborative strategy development, a user-friendly design, proactive messaging and agency sponsorship were identified strategies to improve engagement about safety. • Participants characteristics and description of interactions between people using various strategies were limited in detail. • No patient safety interventions have been designed with people from CALD backgrounds to enhance their safety in healthcare.
Document Analysis (Chauhan et al)[38]	• Contextual data • Local health system level	• Examined how consumer engagement is conceptualised, operationalised and what are the implications of these for engagement with CALD consumers. • Altheide's document analysis approach was used. • Websites of federal, state and territory level health departments and agencies searched for engagement frameworks. • Narrative synthesis was undertaken.	• Eleven consumer engagement frameworks were identified and analysed. • The frameworks focused on attaining to language needs and providing culturally sensitive services. • Limited discussion of what culturally sensitive services looks like. • Lack of knowledge on efficacy of various engagement activities to enhance engagement with people from CALD backgrounds. • Lack of knowledge on mechanisms to enhance involvement of people from CALD backgrounds in healthcare decision-making.
Retrospective Medical Record Review	• Experiential data • Local health service level	• Examined nature and rate of safety events for CALD patients accessing participating cancer service and any association between CALD indicators and number of safety events. • An adapted version of a validated cancer specific trigger tool used for data collection. • Quantitative data analysis completed using SPSS. • Qualitative data analysis of clinical notes conducted using a basic content analysis approach.	• A total of 150 patient records reviewed. • 47/150 of the patient records had at least one safety event with a total of 73 safety events recorded. • Medication related safety events occurred most (22/73; 30.1%) in both inpatient and outpatient settings. • Content analysis of the fieldnotes indicated poor communication between healthcare staff and people from CALD backgrounds as likely contributing to safety events.

Supplementary File 1. Synthesis of studies from Phase 1 (Cont'd.)

Study Type	Level of knowledge	Summary of Study	Key findings contributing to co-design
Observations	• Experiential data • Local health service level	• Examined how opportunities for consumer engagement are generated through physical environment of the participating health service. • Data collections was completed by two researchers (AC; BN) using a validated ACE tool[39]	• Five common areas (one inpatient and four outpatient) audited. • Limited amount of health information available in non-English languages • Signages and navigation displayed in English. • Information for interpreter booking available in 10 common non-English languages in outpatient setting. • Incorrect information for interpreter booking displayed in inpatient common area. • Feedback and complaint forms only displayed in English
Semi-structured interviews	• Experiential data • Local health service level	• Explored experiences of healthcare staff and people from CALD backgrounds for consumer engagement to enhance healthcare safety. • Semi-structured interviews were conducted using an interview guide. • Data analysed using a Framework Analysis method.[40]	• Fifteen interviews completed with range of healthcare staff (nurses, oncologists, administrative staff, and managers (clinical and service) • Four interviews completed with consumers from three different countries (China, Russia, and Lebanon). Two participants were born in China. The other two participants were informal carers who were born in Australia. • Two consumers were English speaking and two were non-English speaking. • Staff and consumers identified lack of mutual understanding of instructions as common theme. • Staff highlighted lack of appropriate language support services beyond consent and education with lack of interpreter use noted during daily treatment sessions in ambulatory care. • Consumers highlighted disconnect with use of interpreters as they were often inconsistently used, did not have trust in interpreters or they did not speak patient's dialect. • Consumers identified building trust and positive relationship as essential to create condition for asking questions. • Staff identified importance of cultural sensitivity and to avoid monoculturalism. • English speaking consumer highlighted importance of care co-ordinators as contact point for care related queries – non-English speaking consumers relied on treating oncologist for care related queries. • Patient delayed care seeking or asking for interpreters due to lack of knowledge of who the appropriate person is to make the contact, feeling of shame or guilt as they thought they were often a burden on the doctor.