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Strategies to improve engagement and inclusion of participants from culturally and linguistically diverse (CALD) communities in research involving patient-reported outcomes (PROs)

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Title:

Strategies to improve engagement and inclusion of participants from culturally and linguistically diverse (CALD) communities in research involving patient-reported outcomes (PROs)

Abstract:

Purpose

This study aimed to identify barriers, facilitators and resources currently used to engage participants from culturally and linguistically diverse (CALD) communities in studies with patient-reported outcome (PRO).

Methods

Australian researchers or health professionals using PROs in research or clinical practice were eligible to participate in an anonymous online survey. Quantitative data was summarised descriptively; qualitative data was analysed using critical content analysis.

Results

Forty-eight respondents were included in the analysis (56% female, 48% academic role). Common barriers included: lack of resources to translate study materials (77%) or to offer non-English questionnaires online (70%); tight funding deadlines (64%) and budgets (61%) precluding implementation of supports; and additional administrative work (59%). Inclusion strategies included engaging consumer advocates (85%), seeking advice from experienced colleagues (71%) and directly asking participants about support needs (63%). Seventy-three percent had participated in cultural sensitivity training. Respondents estimated a median of 1.5 hours and $300 per non-English-speaking participant, and 55 hours and $20,000 per study, would be required to adequately resource these supports, although estimates varied greatly.

Conclusions

Despite high cultural-sensitivity awareness and uptake of inclusion and engagement strategies, clear funding and time barriers were acknowledged, reflecting that community involvement, translation of study materials, collaborative study design, and implementing ongoing supports are resource-intensive endeavours. As Australia's CALD population continues to grow, funding bodies and research sponsors should support these needs by embedding dedicated funding, flexible timelines, and cultural safety frameworks to ensure genuine equity and inclusion of CALD communities in PRO research.

(Approved by University of Sydney HREC 2025/HEO00249).

Introduction

Over half of Australia's population was either born, or had a parent born, overseas(1) and 23% of Australians speak a language other than English at home (2). The term "culturally and linguistically diverse", or "CALD", is a heterogeneous construct referring to individuals and communities other than Anglo-Celtic (when used in the Australian context), and encompasses a diverse range of cultural traditions, languages, nationalities, migration histories, religions, and world views(3). It is well-established that participants from CALD communities are under-represented in health research, for various reasons, including lower English literacy, mistrust, economic and time constraints, poor communication between participants and research teams, and research teams that lack cultural competency(4-7). Problematically, individuals identifying as CALD often report worse health outcomes(8-11). The limited representation of CALD-identifying participants in patient-reported outcome (PRO) endpoints of clinical trials further increases health disparities, as their specific needs cannot be recorded or addressed.

PRO questionnaires provide data on the severity, frequency and burden of symptoms, and the impact of health conditions and treatments on functioning and health, in a standardised manner. Language and English literacy are primary barriers to CALD patient participation in PRO studies(5), however the authors have observed that offering validated translations of PRO questionnaires to non-English-speaking participants is often insufficient for meaningful, long-term engagement, as cultural barriers and potential issues with literacy in the primary spoken language remain unaddressed. Further, the diversity between individual CALD groups with respect to ethnicity, migration histories, languages, religions, culture, social structures(3), time in Australia, historic marginalisation, and mistrust of Australian systems, calls for a need for use of diverse, targeted and specific engagement strategies depending on the CALD community concerned, and this need is often underappreciated in research.

A range of strategies have successfully engaged participants from individual CALD communities in previous studies(6, 12-14), however their implementation requires substantial investment of resources(15). The engagement of people from CALD communities in research remains limited in general, and with respect to the completion of PRO questionnaires. The extent to which strategies are being implemented to improve inclusivity for PRO completion remains unknown in Australian studies.

This study of Australian health researchers and professionals aimed to determine the strategies used required resources, barriers and facilitators to engaging participants from CALD communities in PRO research.

Methods

This study involved a survey (or web-based interview option) of researchers and health professionals who had experience collecting PRO data from patients/participants from CALD communities. The questions addressed strategies used, barriers, facilitators and resources required to engage participants from CALD communities in health research involving PRO questionnaires, and were both quantitative and qualitative.

We hereafter use the terms "respondents" to refer to the researchers and health professionals who participated in our survey (as reported in this manuscript), and "participants" to describe the patients involved in health research.

The study was funded by Sydney Cancer Partners (2025) and approved by The University of Sydney Human Research Ethics Committee (2025/HE000249).

Survey and interview development

Our survey and interview questions were developed following a series of brainstorming sessions involving patient advocates, academic researchers, study coordinators, and clinicians to determine the topics to be addressed and cultural sensitivity of the questions.

A combination of multiple choice and short answer questions were then developed collaboratively by our multi-disciplinary research team, to address key topics and to capture diverse respondent demographics, training and experiences. Key topics included strategies used to recruit, engage or support participation of patients from CALD communities, the barriers they had encountered, and the nature of any collaboration with patient/consumer advocates representing CALD communities in the development of trials or other research with PROs. Additionally, respondents were asked to estimate the time required (hours), and the cost (Australian dollars), of implementing strategies to support participants from CALD backgrounds in four categories: per patient, questionnaire, language and study. (See Additional file 1).

The once-off survey was developed in REDCap and was anonymous, accessible by clicking a link. Alternatively, participants could provide informed consent via return email for a web-based (via Zoom) structured interview, using the same survey questions.

Eligibility and recruitment

Australian researchers or health professionals using PROs in research or clinical practice were eligible to participate in this mixed-methods study. The study was advertised through ten professional societies and local research groups. Experts (authors of relevant published literature), colleagues known to the research team with relevant research or clinical experience, and other colleagues identified by snowball sampling, were also invited to participate by direct email. In the final two weeks of recruitment, we advertised on social media (LinkedIn, X, Viva Engage, and BlueSky).

Analysis

Quantitative data was summarised descriptively using all available data for each question. Qualitative data was analysed by two researchers using critical content analysis. Discrepancies in coding were resolved through discussion.

Reflexivity: This research was led by a multidisciplinary team of academic researchers, clinicians, consumer advocates and clinical trials professionals who have an interest in equity, diversity and inclusion in clinical trials, some of whom are from CALD communities. The academics and clinicians involved regularly use PRO questionnaires in clinical trials and clinical practice. They have experienced some of the barriers to meaningfully engaging participants from CALD communities, and practiced some of the strategies, that are addressed in the survey questions. We acknowledge that our experiences motivated our research question and may have influenced our insights and interpretation of the findings(16).

Results

Our study was open to recruitment between 30 June and 10 September 2025; 63 respondents accessed the survey and 48 respondents with sufficient data were included in the analysis. Respondent demographics are included in Table 1; the average age was 42.8 years and 56% were female. Respondents had completed professional training a mean of 9.6 years ago. Almost half the sample (48%) had an academic primary employment role, 48% had experience leading PRO research. The most common clinical areas worked in or focused on were oncology (54%), kidney disease (8%) and mental health (6%). Half (50%) of the respondents could speak a language other than English, however among these, English was most commonly their primary spoken language.

Table 1. Demographics and professional training of respondents

		n	%
Age group	18 – 35 years	7	17
	36 – 55 years	32	78
	56 + years	2	5
Gender identity	Female	27	56
	Male	12	25
	Non-binary	2	4
	Prefer not to answer/ no response	1	15
Primary employment role	Academic	23	48
	Trial coordination/management	6	13
	Allied Health (e.g. exercise physiologists, physiotherapists, pharmacists, psychologists, nutritionist/dietitians, radiation therapists)	5	10
	Medical practitioners (e.g. medical or radiation oncologists, surgeons, general practitioners, psychiatrist, obstetrician, geriatrician)	5	10
	Nursing or midwifery (e.g. cancer nurse, clinical nurse specialist, registered nurse)	3	6
	Other	2	4
	Scientist	2	4
	Consumer/ patient advocate	1	2
	Student	1	2
Research area*	Health services	28	58
	Clinical trials	27	56
	Quality of life	23	48
	Implementation research	21	44
	Public health	12	25
	Research on specific cultural or demographic communities	11	23
	Behavioural science	10	21
	Epidemiology	8	17
	Translational research	8	17
	Health policy	7	15
	Psychology	7	15
	Decision making	6	13
	Health technology assessment / health economics	6	13
	Symptom management	6	13
	Exercise	5	10
	Research ethics	4	8
	Screening	4	8
	Biostatistics	3	6
	Other research area	3	6
	Genetics	2	4
	Imaging	1	2
Mean years since completing highest degree		9.6	6
Population focus	Oncology	26	54

	Other	5	10
	Kidney disease	4	8
	Mental health	3	6
	Infectious diseases	2	4
	Diabetes	1	2
	General practice	1	2
	Haematology	1	2
	Obstetrics and gynaecology	1	2
	Paediatrics and child health	1	2
	Pain	1	2
	Psychiatry	1	2
	Rehabilitation medicine	1	2
	Respiratory diseases	1	2
	Surgery	1	2
Involvement in PRO Research*	Co-investigator/collaborator	35	73
	Chief (lead) investigator/ Study chair	23	48
	Principal investigator at recruitment site	9	19
	Research assistant	9	19
	Clinical trial coordinator	8	17
	Ethics committee	7	15
	Research manager	4	8
	Data manager	4	8
	Research nurse	2	4
	Clinical trial operations lead	2	4
	Biostatistician	2	4
	Consumer advisor/ Patient partner	1	2
	Health economist	1	2
	Sponsor	1	2
	Data collection [other]	1	2
Cultural background	Anglo-Celtic	15	31
	European	12	25
	Southeast Asian	6	13
	South Asian	5	10
	Middle Eastern/North African	2	4
	East Asian	2	4
	Other cultural background	2	4
	Aboriginal or Torres Strait Islander	1	2
	Latin American	1	2
	Prefer not to say which cultural background	1	2
Language other than English spoken		24	50
Primary language spoken among those who speak multiple languages	English	14	29
	Hindi	2	4
	Arabic	1	2
	Bangla	1	2

Malayalam	1	2
Mandarin	1	2
Phusto	1	2
Spanish	1	2
Tamil	1	2

*Respondents could select more than one answer

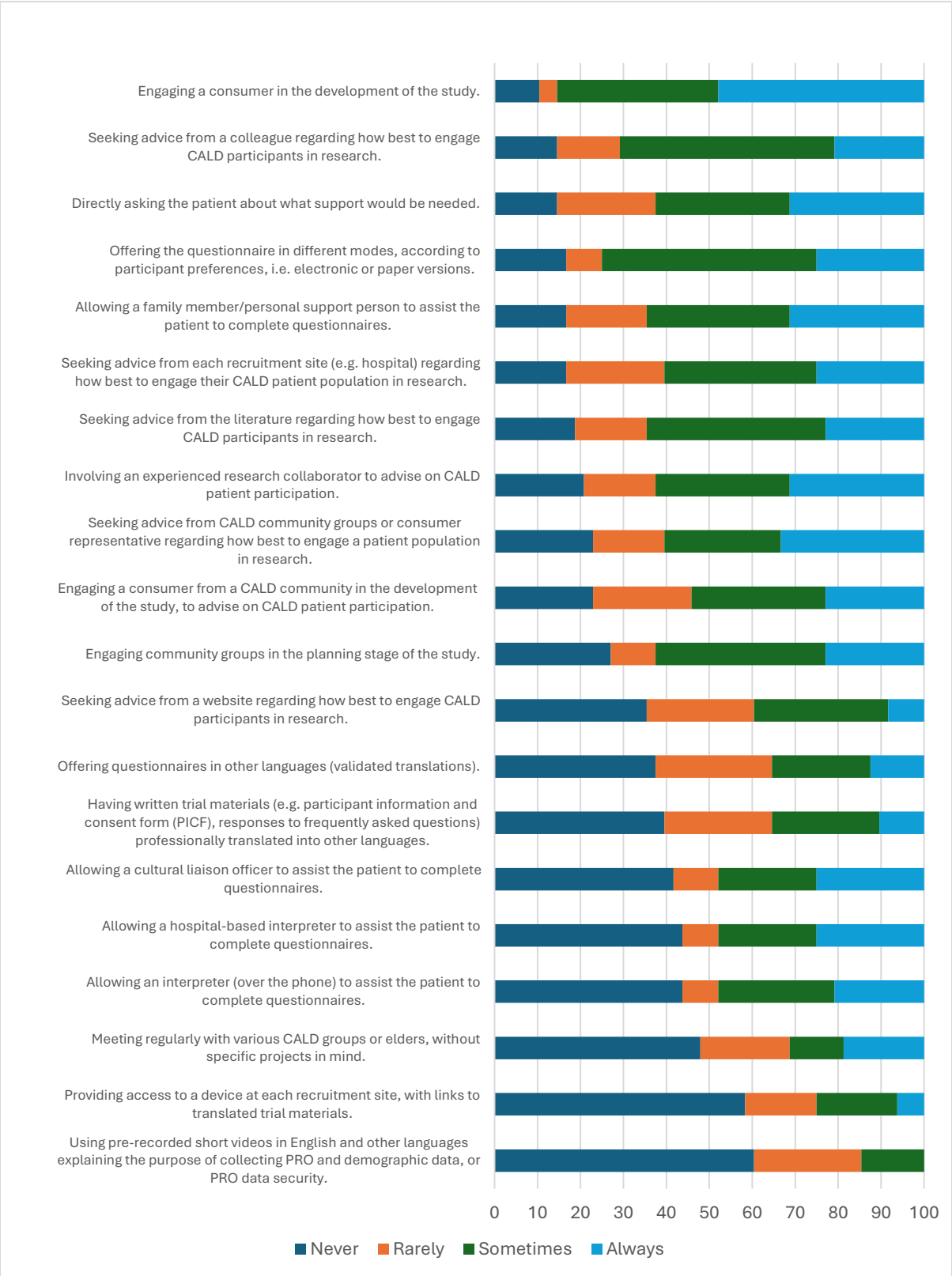
Facilitators to engaging participants from CALD communities in PRO research

Figure 1 presents the strategies used previously by respondents to recruit, engage, or support participants from CALD communities. The most common strategies used were engaging a consumer in the development of the study, which was utilised "always" by 48% of respondents and "sometimes" by 38%; seeking advice from a colleague "always" by 21% and "sometimes" by 50%; "directly asking the patient what support would be needed" was "always" done by 31% and "sometimes" by 31%. The least-used strategies included "using pre-recorded short videos in English and other languages explaining the purpose of collecting PRO data, demographic data, or PRO data security", which was "never" done by 60%; "providing access to a device at each recruitment site, with links to translated trial materials", which was "never" done by 58%. 10% had never "engaged a consumer for advice about involving CALD participants in research"; 23% had never "engaged a consumer from a CALD community"; 40% had never "translated trial or study materials into another language", 38% had never "offered questionnaires in another language", and 65% "allowed participants' primary support person to assist the participant (patient) to complete questionnaires".

Of the capacity building strategies recommended for engagement in the literature, 73% self-reported having completed cultural sensitivity training themselves, 52% had hired CALD-identifying and/or multilingual staff, 40% had offered cultural sensitivity training for their research team, 35% had offered cultural sensitivity reading material for their research teams and 25% had offered community engagement or cross-cultural volunteering opportunities for staff.

Figure 1. Strategies used to recruit, engage, or support participation of CALD-identifying patients, and their frequency.

Respondents could select up to 3 strategies



Respondents could select up to three strategies that would be most helpful to them to engage participants from CALD communities in future. "Specific funding for extending study to CALD participants" was the most-endorsed option, selected by 33 respondents, followed by "guidance on obtaining funding and budgeting for specific strategies to engage CALD participants" (selected by n=21), "specific training for engaging CALD participants in research" (n=20), "a website with dedicated resources to support CALD engagement" (n=16), "consultation with an expert" (n=15), "checklist of strategies to

consider when developing a research proposal" (n=14) and "specific CALD competency training for research" (n=9).

Barriers to engaging participants from CALD communities in PRO research

Respondents selected barriers they had ever experienced from the list. Of the four barrier categories, barriers within the "lack of resources/time" category were most frequently endorsed overall, with 6 of the 7 listed barriers endorsed by more than half the sample and only 3 (7%) respondents reporting never having experienced any time/resource barriers. Staff/ institutional barriers were next most frequently experienced, with 16% never experiencing barriers in this category, followed by participant-level barriers (23% had never experienced) and community/cultural-level barriers (45% never experienced).

The most common barriers overall were: lack of resources to translate the study materials (77%), lack of resources to offer the online questionnaire in languages other than English (70%), tight research funding deadlines - could not implement procedures to support CALD participation within the study funding period (64%), minimal budget to fund additional procedures to support CALD participation (61%), additional administrative work associated with engaging CALD participants (59%), lack of staff capacity due to workload (overworked, understaffed) (54%), questionnaires not available in required languages (52%) and inability of CALD-identifying participants to participate, as required supports were not available (48%). The full list of barriers is included as Table 2.

Additional barriers were highlighted in the qualitative responses. Respondent ID59 acknowledged the additional time required to acquire validated language translations:

> *"licensed instruments often have study specific licensing, so for translations, it is reasonably quick to obtain if the language is already to be used in another country doing the trial. But if not, it can take a long time to obtain the license for that language… many PRO instruments do not allow for interpreter support".* ID59

A lack of awareness, training or confidence among clinicians recruiting to trials is another key barrier to recruitment of CALD participants in clinical trials, thus preventing their involvement in PRO studies:

> *"Investigators not identifying participants as they speak another language - opted not to give them a PICF."* ID57

> *"While it may be true some of the time, I think clinicians often assume that CALD participants are not interested in research. They also often do not have the time and resources needed to enrol."* ID54

Another respondent highlighted the importance of involving consumer panels to identify how best to engage CALD communities, but acknowledged a lack of diversity among consumer advocates, which may be perpetuating issues of limited participation:

> "(there is a) *lack of trained consumer panels from CALD community(ies) to provide feedback in general" ID58.*

Eighteen respondents agreed they had experienced barriers specific to particular language, religious or cultural groups, and 16 offered qualitative comments, which were coded into four unique categories: lack of trust (n=5), stigmas reporting certain PRO domains (n=4), uncommon languages (n=4), religious beliefs that restrict participation (n=3). When asked how these barriers were overcome, in many instances, respondents noted they were still working towards solutions. The solutions were coded into 10 unique categories, with improving community engagement (n=6), hiring bilingual staff (n=3) and allowing more time (n=2) being the most common. Please see **Additional file 2** for quotes related to each category.

Table 2. Barriers to engaging participants from CALD communities in PRO research

Barrier category	Barrier	N who had experienced the barrier	%
Participant level	Inability of the CALD participants to participate, as required supports were not available	21	48
	Lack of trust in the research or research team, from CALD participants	14	32
	Lack of interest from CALD participants in research	11	25
	Lack of interest from CALD participants family members/support persons in the research	9	21
	Lack of capacity from CALD participants, as dealing with diagnosis/management is overwhelming enough for the participants	7	16
	Lack of capacity from CALD participants, due to health, mental health or cognitive challenges	7	16
	Other relating to participant level barrier	5	11
	None of the above relating to participant level	10	23
Community/ cultural level	Inability to find a consumer from a particular CALD community to advise on recruitment and participation in PRO studies	13	30
	Questionnaires covering topics that are culturally inappropriate to ask about	11	25
	Lack of interest from CALD community groups in research	8	18
	Religious barriers	5	11
	Community groups declining to support your specific project	3	67
	Other relating to community/cultural	2	5
	None of the above relating to community/cultural barriers	20	46
Resource/time	Lack of resources to translate the study materials	34	77
	Lack of resources to offer the online questionnaire in languages other than English	31	71
	Tight research funding deadlines - could not implement procedures to support CALD participation within the study funding period	28	64
	Minimal budget to fund additional procedures to support CALD participation	27	61
	Additional administrative work associated with engaging CALD participants	26	59
	Questionnaires not available in required languages	23	52
	Challenges setting up patient database access to support CALD participants	18	41
	Other relating to resources/time barrier	1	2
	None of the above relating to resources/time	3	7

Staff/institutional barriers	Lack of staff capacity due to workload (overworked, understaffed)	24	55
	Limited CALD-identified staff and/or multilingual staff	19	43
	Lack of personal awareness about how to support CALD participation	17	39
	Lack of staff/team member awareness about how to support CALD participation	13	30
	Limited cultural competency training for staff/team member, leading to unintentional exclusion or misunderstandings	9	21
	Never personally completed cultural competency training, leading to unintentional exclusion or misunderstandings	8	18
	Lack of staff/team member interest in implementing procedures to support CALD participation	7	16
	Lack of support from senior colleagues or management to implement programs to support CALD research participation	7	16
	Other relating to staff/institutional barriers	2	5
	None of the above relating to staff/institutional barriers	7	16

Resources required

Participants estimated that a median of 1.5 hours and $300 per participant; 1 hour and $400 per questionnaire; 5 hours and $2000 per cultural or language group; and 55 hours and $20,000 per study would be required to adequately resource the support required for participants from CALD backgrounds to be involved in studies with PRO questionnaires (**Table 3**). There was a high level of variability in responses across all resource categories. The highest cost per study was estimated at $600,000, and the highest cost per participant was estimated at $4,800. Many study participants made comments that this question was difficult to answer as it depended on individual CALD participant variables, such as the availability of interpreters in that specific language, the number of participants involved from each CALD community, the nature of the research, the centre, the number of questionnaire completions required and the literacy levels or capabilities of the participants.

Table 3. Resources required to accommodate participants from CALD communities in PRO research

	Time required in hours				**Cost in Australian dollars**			
	Per Participant	**Per Questionnaire***	**Per language or cultural group**	**Per study**	**Per Participant**	**Per questionnaire**	**Per language or cultural group**	**Per study**
Mean	3.2	6.1	37.2	123.6	986.5	1,202.4	2,692.7	73,069.7
Standard deviation	4.3	9.4	102.4	211.4	2,243.5	1,663.2	2,544.9	133,934.1
Highest	12	35	500	1000	4,800	6,000	7,680	600,000
Lowest	0.2	0.1	0.25	1	5	2	50	1,000
Median	1.5	1	5	55	300	400	2,000	20,000
Mode	1	1	1	100	500	1000	2,000	5,000
N responders	28	30	26	24	22	20	16	23
N unsure/ left blank	20	18	22	24	26	28	32	25

*approximately 30 questions

Community involvement

Seventeen (38% of 45) respondents had engaged with members of the general public for advice or support in recruiting research participants from CALD communities, and only four respondents belonged to the same CALD community they were attempting to engage. When asked how these individuals or groups were identified, responses were coded into six groups: contacted an agency (n=6), reached out to community groups (n=3), attended community sessions (n=2), personal communication (n=2), social media (n=1), and snowball methods (n=1).

Agencies from where CALD-identifying consumers were identified included Health Consumers NSW, the cancer clinical trials groups, undisclosed peak CALD representative bodies, the consumer group of the respondent's research centre, and the Diaspora Community. Examples of community sessions attended and how advocates were engaged included: cancer information community evenings, volunteering to run community health education sessions at community health groups, and hosting community consultation forums.

When asked whether and why the respondents sought to involve representatives from specific CALD communities in their research development, six respondents reported a need to engage the particular CALD group due to high numbers in the local health district or in the particular clinical population being studied. This reflects a strategy to direct resources for maximum impact – by prioritising CALD groups to receive support based on the number of participants that may potentially benefit.

> *"My research is primarily related to co-designing interventions with the community to implement such interventions for the community. Therefore, I think it is important to earn their trust by being seen as a member of the community before going further into developing a research project with the particular group."* ID15.

> *"Because of 1) prevalence of these communities in the health service I work. 2) Because of the documented inequities in health outcomes experienced by these communities. 3) Because members of the communities themselves have asked for targeted approaches to support their community."* ID60.

Five respondents sought to involve and prioritise particular CALD groups with high levels of unmet health needs.

> *"High diabetes and high mortality rate of complications. 7 times more likely to be hospitalised"* ID61.

Two respondents highlighted the need to engage under-represented groups*:*

> *"Health resources should be accessible to all, maintaining health equity and avoiding disparity."* ID07.

Two respondents reported a personal connection with the CALD community, and one participant stated their involvement with a particular CALD community was opportunistic in nature:

> *"(the) opportunity presented itself. I didn't seek out the particular groups, it was a case of being in the right place at the right time"* ID13.

Barriers and facilitators to CALD community engagement in research development

Barriers to involving CALD-identifying advocates or collaborating with CALD community groups were coded into 10 unique categories. Language (n=7), cost (n=5), time (n=4), systemic barriers (n=2), communication barriers (n=2), need for family involvement (n=2), making connections (n=2), representatives being over-utilised (n=1), health literacy (n=1), building trust (n=1).

The resource-related barriers highlighted in engaging with consumers with PRO research design reflected the ongoing challenges in conducting research:

> *"Sometimes it can be difficult explaining the challenges you experience as a researcher to community groups. I believe there is a perception among the community that we have an endless supply of time and money to accommodate all wishes, but this could not be further from the truth."* ID13.

> *"I don't speak a language other than English, nor identify with a CALD community, therefore have to work closely with and budget for collaborators with language and cultural expertise."* ID60.

> *"A lot of the community engagement approaches take considerable time and as a clinician-researcher this is not included within my core role provisions."* ID60.

Other respondents highlighted challenges in identifying and making the changes needed to adapt studies suitably for CALD participants.

> *"We could get CALD people involved, but they were typically frequent research participants, and hence potentially not representative."* ID26.

> *"Research design based upon white European imperialistic assumptions/ lack of cultural awareness"* ID21.

Respondents highlighted specific communication challenges and cultural differences in decision-making processes, which may slow progress in developing PRO research studies and may lead to misunderstandings.

> *"People may nod or smile out of politeness, even when they don't understand."* ID61.

> *"Not speaking the language can be one (barrier) as it means you will need to take a longer time to complete your work with the help of an interpreter. Often interpreters may also not fully understand what you are trying to convey and meaning can be misunderstood"* ID15.

> *"Some health or technical terms may not have direct translations"* ID61.

> *"More family orientated decision making, something some clinicians are not fully aware of."* ID57.

> *"Hierarchical decisions may defer to senior members"* ID61.

Facilitators to working with specific CALD communities highlighted a need for building trust, respect and open communication. Respondents emphasised the need to build trust before engaging in research-related discussions.

> *"To build trust, it is essential to engage with communities to find out their perspectives on the needs within their communities, what research priorities are important to them in order to co-design research that addresses their needs, and that the findings are communicated and translated"* ID21.

> *"1. Build in time for establishing trust and rapport with community BEFORE asking for anything research related. 2. Listening to communities and shaping research questions around their needs and interests. 3. Having study provisions to include community members as research advocates and members of the research team"* ID60.

> *"Listening, making them feel comfortable and safe, acknowledging that their opinion is valued and is exactly the reason we sought to talk with them"* ID13.

> *"Going to them. Listening. Engaging them on their terms."* ID30.

Respondents reported the frequency of meetings with CALD-identifying advocates and communities in various formats, which were re-coded for analysis. Seven reported meeting with their consumers more than five times, while five met less than five times.

When asked what specific feedback had been provided by CALD consumer advocates about questionnaires in these discussions, two respondents noted they had received feedback about the length of questionnaires, six received feedback about the content: "*The wrong questions were being asked*" ID21; one received feedback about the response scale: "*Yes/no responses would be more appropriate than Likert scales*" ID13; and one received feedback about how to collect PRO data from participants of this CALD community.

Discussion

This study documents the strategies currently being used by Australian researchers to engage participants from CALD communities in PRO research. Respondents reported high levels of awareness and uptake of strategies to support the inclusion and engagement of research participants from CALD communities in PRO studies, however clear funding, time and resource barriers were acknowledged. Respondents reported that they actively sought out advice or education from various sources to support CALD participants with PRO research. A majority had participated in cultural sensitivity training, sought advice from colleagues, actively read literature and directly asked participants about how they could best support participants with PRO research. Previous studies have recommended the need for professional development in this area(12, 14, 16).

Respondents acknowledged the importance of building trust, making study materials accessible, co-designing research with communities, and involving CALD research participants in PRO studies. Providing access to study materials in other languages addresses a primary barrier to access - language (5), however additional steps must be taken to address persisting trust, safety, religious, power, literacy, or communication barriers that may differ between and within cultural and language groups. Such barriers can only be addressed by actively engaging with individual CALD communities, an din many cases, with individual patients, to identify and address support needs. The complexity and range of challenges faced by individual CALD-identifying trial participants must be acknowledged. Individuals who belong to well-established migrant communities may have access to networks, both formal and informal, and other supports (e.g. hospital translation service to support understanding of trial information, community representation on consumer advisors committees), whereas those who have only recently migrated or who speak an uncommon language may not.

Reviews by Hughson(12) and Kasahara(17) highlighted the need to address language and literacy barriers to improve the recruitment rate of people from CALD backgrounds by incorporating multimedia into consent and research procedures. Wells reported that use of a multimedia intervention in Spanish was feasible and effective in educating Hispanic cancer patients about clinical trials(18). This suggests that such practices are being used internationally, however our results suggest the high costs involved or the number of different CALD groups or participants requiring support may be prohibitive in the contemporary Australian setting (60% had never attempted this). Respondents acknowledged that community involvement, translation of study materials, collaborative study design, and implementing ongoing supports are resource-intensive endeavours, particularly given the diversity of Australia's CALD population. Whilst many respondents aspire to partnership and co-design with consumers representing individual CALD communities, there are limits to what can be achieved within the constraints of individual trials, given the number of different, diverse CALD communities within Australia. Respondents also noted high variability in the cost of these endeavours, both financially and in terms of time required, reflecting the diverse, multifactorial variation in individual study designs, questionnaire licensing fees, individual patient needs and access to diversity support from recruiting centres.

Strengths of this study include a robust design, informed by input from a diverse range of collaborators and stakeholders. The survey was anonymous, allowing respondents to disclose their challenges honestly without risk of being identified. We recruited using multiple targeted strategies, and the diversity of participation is highlighted by a range of professional backgrounds being represented.

Recruitment was challenging, with few participants accessing the survey in response to mail-outs from professional societies; however, we acknowledge that our selection criteria required respondents to have had experience with PRO research in which participants from CALD backgrounds were involved. This inherently excluded anyone who had possibly tried and not succeeded in involving CALD participants due to barriers. Additionally, researchers who have used other forms of self-report data (e.g. diaries) may have deemed themselves ineligible. Respondents were self-selected and we presume they represent highly motivated researchers who are making more effort towards supporting the inclusion and engagement of people from CALD communities than colleagues.

Our estimate of resources required is limited as this was an optional question with lower completion rates than other questions within our survey. Respondents appeared to be considering diverse aspects of study participation, despite the context provided within the question. For example, some noted that their response was on the basis of a cross-sectional survey (single completion) as opposed to repeated-measures, which may have impacted the variability seen in the "per-participant" costs reported. Some noted that they assumed questionnaires were free to use in their reports. Some questionnaires are subject to licensing fees for English and additional languages, which would have impacted all time and cost estimates. Although the response variation made it difficult for us to provide a summary of the resources data, it reflects the range of costs (both financial and time) faced by Australian researchers and suggests it may be difficult to predict the resources required in a study's planning stages, i.e. when writing a grant application. Additionally, in the interests of minimising responder burden, we limited this question to four response categories (per participant, 30-item questionnaire, CALD group and study), however the responses to an earlier question on what was included in previous study budgets to support CALD participation reflect the range of additional costs that may not have been considered. These include: costs to run consumer advisory panels; community advisors; community engagement workshops; bicultural research personnel or interpreters; translation (and cultural adaptation) of additional study resources such as participant information, brochures or advertorial materials; licences for validated translated questionnaires; production costs of videos to explain the study; travel fee reimbursement for CALD participants and staff and social media costs. Further research into the average costs of these additional components is needed in order to adequately budget for future studies. Furthermore, resources required, and budgeted for, were self-reported in our study, and future studies may wish to audit these costs by examining study records.

Our findings highlight the very real challenges that even the most enthusiastic researchers face in trying to make Australian studies more inclusive, diverse and equitable. Our study focused on PROs – the outcomes that give patients a voice. As noted previously, language, literacy, cultural and other barriers make it difficult for people from many CALD communities to complete PRO questionnaires. Researchers must continue to make attempts to support the involvement of people from CALD communities in PRO endpoints so that specific health needs may be reported and addressed. Failing to do this will perpetuate health inequities. We hope that this study will shed light on what supports are needed to assist researchers to this end. Funding bodies and study sponsors must become aware of the struggles and supports needed and provide dedicated funding. They must also allow sufficient time for meaningful community consultation, discussion, informed consent and decision making, translation of all study materials (including participant information and questionnaires), ongoing communication and feedback, and co-design where appropriate. Additionally, researchers require time and support to educate themselves, to attend training, to implement their learnings and address the specific barriers that impact individual CALD groups.

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Statements and declarations

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Competing interests

None to declare

Author contributions

RMB, AT, MH, NEK, MS contributed to the study conception and design. All team members contributed to material preparation. RMB and JC coordinated data collection and analysis. The first draft of the manuscript was written by RMB and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the University of Sydney HREC 2025/HEO00249.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Supplementary Files

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