### SYSTEMATIC REVIEW

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# Interventions, programmes and resources that address culturally and linguistically diverse consumer and carers' cancer information needs: a mixed methods systematic review

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### **Abstract**

**Background** Culturally and linguistically diverse (CaLD) consumers and carers have been identified as experiencing high levels of unmet needs relating to information and support across the cancer journey. This review identified and evaluated the effectiveness of strategies to meet the cancer information needs of consumers and carers from CaLD backgrounds.

**Methods** This review followed Joanna Briggs Institute (JBI) methodology for systematic reviews. Databases searched included MEDLINE, CINAHL Ultimate, PsycINFO and AMED, ProQuest Dissertations and Theses, and GreyNet. Published and unpublished studies between 2013 - May 2024 on interventions, programmes or resources developed for adults (aged 18 years and over) from CaLD communities in relation to cancer prevention, cancer treatment or life after cancer were reviewed for inclusion. The review protocol was registered in PROSPERO (CRD42023451557).

**Results** One hundred and twenty papers were included in the review. The majority were quasi-experimental studies (n=52), followed by randomised controlled trials (n=38) and qualitative studies (n=25). The populations represented in the review included Latino (n=47), Chinese (n=28), Asian (n=19), Korean (n=16), and Vietnamese communities (n=7). Most studies focused on prevention activities (n=89) with a smaller number focused on active treatment (n=6) and life after cancer (n=20). Most studies focused on breast cancer (n=37), followed by cervical cancer (n=21). Engagement with community members was identified as an important requirement to develop and adapt interventions that were culturally acceptable, feasible and relevant to meet the communities' needs. The majority of interventions demonstrated a positive impact on the primary outcome measured. No studies reported on the experiences of consumers and carers from CaLD backgrounds in the development of interventions, programmes and resources to address their cancer information needs.

**Conclusions** This review supports a tailored approach to develop information, resources and interventions that leverage community resources and expertise to ensure that they are accessible and relevant to CaLD communities.

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Whitehead et al. BMC Cancer (2025) 25:599 Page 2 of 14

The onus for researchers and clinicians is the creation of information, resources and interventions that are both accessible in terms of language and comprehension and are culturally relevant.

**Keywords** Culturally and linguistically diverse, Cancer, Patient, Carer, Information needs

### **Background**

Cancer is the leading cause of death and disability worldwide [1]. Greater awareness of cancer and its risk factors, participation in screening programmes and improvements in cancer treatment and care have contributed to higher survival rates [2]. The development and delivery of services that are consumer-focused and strive to improve cancer outcomes for all are key goals for organisations around the world [3]. Culturally and linguistically diverse (CaLD) consumers and carers have been identified as experiencing high levels of unmet needs relating to physical, psychological and information needs across the cancer journey [2]. In this review, the term consumers is used to refer to people accessing services for the purpose of prevention or active management of cancer while carers are referred to as people providing unpaid care and support to family members.

Currently, there is no standard definition for CaLD status. CaLD status can be related to country of birth, speaking a language other than English (LOTE), speaking a LOTE at home, proficiency in English, ancestry, cultural background and length of time since migrating to host country [4]. People from CaLD backgrounds may also face greater challenges when navigating the cancer healthcare system, including language and cultural barriers and not knowing where to seek help or access services [2]. CaLD communities experiencing cancer can face greater barriers to accessing and understanding health information compared to non-CaLD communities. Language barriers and cultural differences can impact CaLD communities experiencing cancer from receiving health information, and lead to delayed treatment and poorer health outcomes [5, 6]. Disparities in health outcomes have, in part, been attributed to the absence of patientcentred care for CaLD communities living with cancer [7]. Targeted and culturally tailored interventions have been linked to improved screening rates and treatment outcomes, however, the evidence on the most effective approaches to increasing knowledge to support behaviour change has not been brought together in a comprehensive review.

A recent review found that resources specific to cancer and CaLD populations were minimal [8]. Another recent review of resources related to cancer internationally [9] found that few organisations provided information and resources in a LOTE. Where information and resources are provided in a LOTE, no information was provided as to whether the resource was a direct translation into another language or whether additional development

was undertaken to ensure cultural considerations were included. Without adaptation through community consultation, there is a risk that the resource will not acknowledge cultural ways of knowing and practices.

The objective of this review was to report on approaches for developing interventions, programmes and resources to address the cancer information needs of consumers and carers from CaLD backgrounds and evaluate their effectiveness.

### **Review questions**

- 1) What approaches have been used to include the perspectives of consumers and carers from CaLD backgrounds in the development of interventions, programmes and resources to address their cancer information needs?
- 2) How effective are interventions that have been developed and implemented for consumers and carers from CaLD backgrounds in meeting their cancer information needs?
- 3) What are the experiences of consumers and carers from CaLD backgrounds in the development of interventions, programmes and resources to address their cancer information needs?

### **Methods**

The systematic review was conducted in accordance with the JBI methodology for mixed methods systematic reviews [10]. This review was conducted in accordance with an a priori protocol registered with PROSPERO (CRD42023451557). A systematic review was chosen over a scoping review where scoping reviews seek to identify and map the breadth of evidence available on a particular topic but do not report on effectiveness or make recommendations for practice [11].

### Search strategy

The search strategy included both published and unpublished studies, and this review utilised a three-step search strategy. First, an initial limited search of MED-LINE (PubMed) and CINAHL (EBSCO) was undertaken to identify articles on the topic. Secondly, titles and abstracts of relevant articles, and the index terms used to describe the articles, were used to develop a full search strategy for MEDLINE, CINAHL Ultimate, PsycINFO and AMED (Table 1). Step three involved the full search. The search strategy included all identified keywords and index terms and was adapted for each included database

Whitehead et al. BMC Cancer (2025) 25:599 Page 3 of 14

Table 1 Search strategy for MEDLINE (Searched on 29/05/2024; limited to 2013–29 May 2024)

Search number	Term searched	Number of hits
S1	Cancer n6 patient*	642,047
S2	Cancer n8 carer*	589
S3	Oncology n6 patient*	23,040
S4	Cancer n8 Caregiver*	4729
S5	MH Neoplasms+	3,969,037
S6	Information	1,900,811
S7	Resource*	859,867
S8	Intervention*	1,547,437
S9	Patient education	112,963
S10	Culturally and linguistically diverse	1036
S11	Non-english	4699
S12	Culturally diverse	2348
S13	Linguistically diverse	1284
S14	Low English	186
S15	Ethnic*	245,717
S16	Migrant*	41,259
S17	Immigrant*	47,802
S18	Emigrant*	17,315
S19	Language barrier	1289
S20	MH Cultural Diversity	13,113
S21	MH Transients and Migrants	14,207
S22	MH Emigrants and Immigrants+	15,577
S23	MH Ethnicity	75,825
S24	MH Limited English Proficiency	276
S25	MH Communication Barriers	7396
S26	MH Ethnic and Racial Minorities	523
S27	S1 OR S2 OR S3 OR S4 OR S5	4,112,761
S28	S6 OR S7 OR S8 OR S9	4,046,735
S29	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26	322,540
S30	S27 AND S28 AND S30	6597
S31	S30 Limit to 2013-29 May 2024	4243

and/or information source. The reference lists of all systematic reviews on the same or similar topic were reviewed. A search of ProQuest Dissertations and Theses and GreyNet was also conducted. The reference list of all included sources of evidence were hand searched for potential studies. Any references that appeared relevant were sourced and reviewed for inclusion.

### Inclusion criteria

The review included studies from peer-reviewed journal articles and peer-reviewed grey literature that reported on the outcomes of interest (Additional file 1). Papers were restricted to the publication period January 2013–May 2024, although any work considered seminal as found in the reference lists of the papers retrieved by the search, were considered for inclusion. Studies published in English, Vietnamese, Bhutanese and Mandarin were considered for inclusion. Interventions, programmes and resources developed for adults (aged 18 years and over)

from a CaLD background, either cancer consumers or carers with any cancer diagnosis and at any stage of cancer, were considered for inclusion.

### Types of studies

This review considered quantitative, qualitative and mixed methods studies. Quantitative studies included experimental and quasi-experimental studies. Qualitative studies included studies that used all methodological approaches. Mixed method studies were considered where data from the quantitative or qualitative components could be clearly extracted. This referred to the ability to extract specific details about the populations, interventions, study methods and outcomes of significance to the review questions for the quantitative component of mixed methods studies and for the qualitative component of mixed methods studies, specific details about the population, context, culture, geographical location, study methods and the phenomenon of interest

Whitehead et al. BMC Cancer (2025) 25:599 Page 4 of 14

relevant to the review questions. Opinion papers, text and reports with outcomes of interest relevant to the review were included.

### Study selection

Following the search, all identified citations were collated and uploaded into Endnote (version 20) and duplicates were removed. Following training and testing to ensure the team were similar in their approach, each title and abstract were screened by two reviewers against the inclusion criteria for the review. The full texts were retrieved for potentially relevant studies, and their citation details were imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI) [12]. The full texts were assessed in detail against the inclusion criteria by a team of five reviewers with two independent reviewers per paper. Reasons for exclusion of papers at full text that did not meet the inclusion criteria were recorded and reported in the systematic review. Any disagreements that arose between the reviewers at each stage of the selection process were resolved through discussion and assessed by an additional reviewer when required. The results of the search and the study inclusion process are reported in full in a Preferred Reporting Items for Systematic Reviews and Meta-analyses flow diagram [13].

### Assessment of methodological quality

All papers that met the inclusion criteria were assessed by two independent reviewers for methodological quality prior to final inclusion using the standardised critical appraisal instrument from JBI. Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer. The results of the appraisal are reported in narrative form and in a table (Additional File 2 Assessment of Methodological Quality).

All studies, regardless of the results of their methodological quality, underwent data extraction and synthesis.

### **Data extraction**

For the quantitative component, data were extracted from quantitative and mixed methods (quantitative component only) studies included in the review by two independent reviewers using the standardised JBI data extraction tool in JBI SUMARI. The data extracted included specific details about the participants, study methods, interventions, and outcomes of significance to the review objective. For the qualitative component, data were extracted from qualitative and mixed methods (qualitative component only) studies included in the review by two independent reviewers using the standardised JBI data extraction

tool in JBI SUMARI. The data extracted included specific details about the population, context, culture, geographical location, study methods and the phenomena of interest relevant to the review objective.

### Data synthesis and integration

This review followed a convergent segregated approach to synthesis and integration according to the JBI methodology for mixed methods systematic reviews using JBI SUMARI. This involved conducting a separate quantitative and qualitative analysis followed by integrating and generating quantitative and qualitative evidence.

### Quantitative synthesis

The pooling of statistical meta-analysis using JBI SUMARI would have been conducted if this had been possible and included sensitivity analyses. Meta-analysis was not possible and the findings were presented in narrative form with the inclusion of tables to aid in data presentation, where appropriate.

### Qualitative synthesis

Qualitative research findings were pooled using a metaaggregation approach. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation through assembling the findings and categorising these findings based on similarity in meaning.

### Results

### Study inclusion

The number of papers identified by the search strategy and the number of papers included and excluded at each stage of the study selection process are set out in the Preferred Reporting Items for Systematic Reviews and Meta-analyses flow chart as shown in Fig. 1. The main reasons studies were excluded on full-text review were ineligible phenomenon of interest or ineligible participant characteristics.

### Methodological quality

A small number of studies met all quality criteria according to the JBI critical appraisal tools. The details relating to each study design are described below with further detail provided in Additional File 2.

### Analytical cross-sectional studies

Critical appraisal scores for the four analytical crosssectional studies ranged from 6 to 8 out of a possible 8. Three studies did not report on whether confounding factors were identified and did not describe strategies to deal with confounding factors. Whitehead et al. BMC Cancer (2025) 25:599 Page 5 of 14

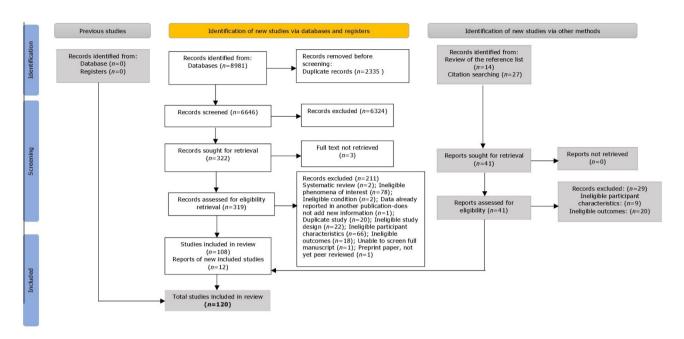


Fig. 1 PRISMA flowchart for study selection

### Randomised controlled trials

Among the 38 included randomised controlled trials, the scores ranged from 6 out of 13 (n=1) to 13 out of 13 (n=1). Almost half the studies reported that true randomisation was used for assignment of participants to treatment groups and only 9 studies reported that the allocation of participants to treatment groups was "blind" (concealed from those completing the allocation process). Two studies reported that those delivering treatment were blind to treatment assignment and the same two studies that participants were blind to treatment assignment. Six papers reported that outcomes assessors were blind to treatment assignment. These responses are not unusual for health and social science interventions where blinding is often not possible. All but two studies reported that follow-up was complete. Thirty-three studies reported that treatment groups were similar at baseline and in 38 studies, the trial design was assessed as appropriate, and that any deviations from the research protocol (individual randomisation, parallel groups) were addressed in the conduct and analysis of the trial. It was also noted that treatment groups were treated identically other than the intervention of interest in all studies. All studies reported that participants were analysed in the groups to which they were randomised, that outcomes were measured in the same way for treatment groups, that outcomes were measured in a reliable way and that appropriate statistical analysis was used.

### Quasi-experimental studies

The quasi-experimental studies (n = 52) ranged in score from 3 out of 9 to 9 out of 9, with the majority scoring 7

out of 9 and 8 out of 9. Eleven studies employed a control group and 25 studies either provided information on follow-up completion or adequately described and analysed the differences in follow-up between the intervention and control group. Thirty three studies reported that the participants included in any comparisons were receiving similar treatment/care (other than the exposure or intervention of interest), thirty one studies indicated that the participants included in any comparisons were similar in relation to key demographics and characteristics, and 35 studies indicated that multiple measurements of the outcome both pre- and post-intervention/exposure were completed. Fifty studies reported that the same methods were used to measure participant outcomes between comparison groups, that the outcomes were measured in a reliable way and applied appropriate statistical analysis methods. All studies clearly identified and described the "cause" and the "effect."

### Case reports

Only one case report was included and met all the criteria relevant to the study design (6 items out of a possible 8 items).

### Qualitative research

The scores ranged from 4 out of 10 to 9 out of 10 with the majority assessed as 7 to 9 out of 10. Only four studies included a statement locating the researcher culturally or theoretically in order to assess the cultural beliefs and values of the researcher as a source of bias, and only eight were assessed as having congruity between the stated philosophical perspective of the study, for example

Whitehead et al. BMC Cancer (2025) 25:599 Page 6 of 14

a constructivist approach and the research methodology, for example grounded theory. Twelve studies discussed the influence of the researcher on the research, and viceversa. The majority of studies were assessed as meeting the remaining criteria (items 2, 3, 4, 5, 8, 9 and 10).

### Characteristics of included studies

An overview of the characteristics of the included studies are set out in Additional file 3. The studies were conducted in 16 countries with the majority conducted in the United States of America (USA) (n = 101) and Australia (n = 12). The studies included people from a CaLD background across a diverse range of communities. The majority of studies (n = 47) focused on Latino communities, followed by Chinese (n = 28), Asian (n = 19), Korean (n = 16) and Vietnamese (n = 7). Other CaLD communities included in the studies were from Turkey, Morocco, Greece, the Philippines, Pakistan, Africa, Russia, Japan, Italy, the Middle East, Somalia and the Pacific Islands.

## What approaches have been used to include the perspectives of consumers and carers from CaLD backgrounds in the development of interventions, programmes and resources to address their cancer information needs?

The data from all studies contributing to this question have been synthesised and presented below. Where studies reported on the process of developing or adapting information, resources or interventions for CaLD communities, the process was documented (Additional file 4) and the key elements are summarised below. The majority of studies (n=84) reported engagement with communities to develop the intervention and described the approach and process of developing the information, resource/s or intervention. Nineteen studies did not describe engaging with the community to develop the intervention materials [13-31] and six referred to previous work, either their own or another research team as evidence of cultural adaptation but did not provide detail [32-37]. The majority of studies used face-to-face sessions, which often involved focus group interviews with members of the community for which the interventions were being developed for. The studies described multiple consultations with community members through focus groups or meetings to collect comprehensive feedback and to ensure that adaptations met the communities' needs. Advisory groups with consumers and expert representatives, often health-care professionals, were frequently featured among the included studies to inform the development of material and provide feedback on the same. Among the studies, the most popular methodology used to underpin intervention development was community-based participatory research.

### How effective are interventions that have been developed and implemented for consumers and carers from CaLD backgrounds in meeting their cancer information needs?

The data from all studies contributing to this question have been synthesised and presented below. The majority of studies focused on cancer prevention (n = 56) with a smaller number focused on CaLD consumers in active treatment (n = 9) and life after cancer (n = 12). The majority of studies focused on breast cancer (n = 32), followed by cervical cancer (n = 18).

All educational programmes that sought to improve knowledge of cancer and risk factors among participants were reported as effective. The primary outcomes of seven studies related to awareness and decision-making related to attending screening services. One study [16] reported that the decision to take up screening was not only influenced by factual, medical information, but also by practical, emotional, cultural, and religious considerations. These findings were echoed in a study [38] that sought feedback on a brochure developed to improve knowledge of colorectal cancer and screening. Recommendations were made to address screening barriers faced by Latinos and included changes to wording, visual aids and content to make the brochure more culturally appropriate. These findings also resonated with Asian and Pacific Islanders living in the USA [39] who were cancer free to assess a liver cancer module. Participants indicated that they wanted more basic information about the hepatitis B vaccine and a desire for a summative brochure about the liver and liver cancer in general that would supplement two existing resources, on the hepatitis B vaccine and a general overview of liver cancer.

One study explored the use of comics [40] and found that they created awareness and discussion more readily compared to conventional didactic educational methods. Digital approaches were explored in three studies [41–43]. The key findings from these studies were the need for resources to be multilingual, to respect cultural considerations around modesty when using images, the need for resources to be easy to navigate, user-friendly, and easily accessible on the Internet.

The effectiveness of programmes to improve participants' screening intention and uptake of screening services were variable. Specifically, participants in many studies reported an increase in their intention to engage with screening services and engagement with screening services [14, 16–21, 23, 32, 33, 44–90]. However, some studies reported no change among participants' intention or actual engagement with screening services [21, 22, 91, 92].

One cross-sectional study [93] explored the information needs of 85 people from migrant backgrounds living with colorectal cancer. The key needs of participants were longer consultations (62%) and more time to ask

Whitehead et al. BMC Cancer (2025) 25:599 Page 7 of 14

questions (56.3%). The delivery of information through videos was favoured over attending a peer support group.

The studies that involved CaLD consumers and carers who were either undergoing active treatment involved the sharing of information to support people and a focus on reviewing resources developed for specific communities. The studies mostly used a series of questions to assess from the users' perspective whether the information or resource was fit for purpose. The key findings were that even when attention had been paid to the development of information and resources for specific communities, many further changes were recommended by consumers to make the resource more usable and relevant. In one study [94] seven rounds of feedback were required before the resources were deemed as ready to use.

The changes and adaptations required following consultation were cognitive-informational aspects, for example wording and sequencing including adaptation to regional lexicons and resolving vague or confusing phrasing [94] and the value of making recordings of consultations when English proficiency was low [95]. Affective-motivational aspects, for example cultural relevance [94, 96, 97] which included specific food examples and navigating cultural norms for example the power balance between patient and doctorand framing the information as complementary to the medical encounter and not challenging or replacing knowledge [98]. Two studies stressed the importance of moving beyond working with the individual and family alone to involve neighbourhoods [99] and community-based organisations [100].

Nine studies reported the effectiveness of interventions to support CaLD consumers living with cancer and were undergoing active treatment [25, 26, 34, 101–106]. The programmes in these studies aimed to provide support for people living with various types of cancer rather than focusing on a single type of cancer. Topics covered in these programmes varied from providing information on chemotherapy and strategies to managing negative emotions associated with a cancer diagnosis and treatment [25, 101, 102], using a translation device to facilitate communication between the CaLD patient and medical professional [26], and providing support related to endof-life care [34]. All studies reported that the intervention significantly improved participants' knowledge on treatment and treatment side-effects and reduced negative emotions associated with cancer and treatment.

Twenty one studies related to cancer survivorship [27–29, 31, 35, 36, 105, 107–120]. Three studies described the challenges for cancer survivors in relation to engaging with available resources and information. Practical issues identified [121] were technology literacy and preferences, language issues, staff competence, security and

confidentiality issues, time and geographical constraints, and cultural attitudes, beliefs and values. The research team recommended future research using culturally tailored technology-based interventions among racial and ethnic minorities to address the issues identified.

The barriers to accessing cancer information on Australian cancer-related websites for CaLD communities were explored to guide the development of appropriately translated resources [122]. Beliefs about fate had a significant impact on behaviours. The study reinforces the need to fully explore cultural beliefs and structural barriers to accessing cancer information and to incorporate both into the process of developing and accessing information resources.

The use of interpreters to support cancer survivors to communicate with health-care providers was described as frustrating in one study [115] when interpreters did not speak the same dialect, causing linguistic and cultural discord.

Eight studies reported a need to focus on aspects of the cancer experience that were not included or perceived as not covered enough in the information provided, for example healthcare system navigation, employment concerns and sexuality [116], emotional and social challenges [123] and the need for a transition plan (to survivor) [117]. Culturally appropriate adaptations were also reported in relation to programmes [31, 118, 124] with some specifying the importance of including family [119] and spirituality in programmes [116].

The production of material and delivery of information in English and the native language of participants were highlighted [119, 125]. The evidence favoured faceto-face sessions and the use of advisory groups which often included a mix of consumers, health professionals and experts in the filed were reported. The methodology most commonly used or referred to was community-based participatory research.

Thirteen studies reported interventions developed to support cancer survivors [27–29, 35, 36, 102, 107, 109– 111, 113, 114]. Most programmes focused on breast cancer survivors. The programmes predominantly aimed to provide cancer survivors with the knowledge and skills to manage physical symptoms and negative emotions associated with living with cancer [27, 28, 102, 108–111]. Some programmes aimed to support cancer survivors to live a healthier lifestyle through diet and increased physical activity [29, 35, 113, 114]. Most programmes were delivered using technology, such as an app, online chat function, website or telephone [28, 29, 35, 107, 110, 111, 114]. The authors reported that the interventions were effective in supporting cancer survivors to reduce negative emotions (e.g., stress and depression), improve their lifestyle and improve overall quality of life.

Whitehead et al. BMC Cancer (2025) 25:599 Page 8 of 14

### What are the experiences of consumers and carers from CaLD backgrounds in the development of interventions, programmes and resources to address their cancer information needs?

No study directly addressed this question. The evidence presented in relation to objective 1 indicated that the process of involving and working with consumers and carers from a CALD background was effective, no study directly reported on consumers and carers experience of the process.

### Discussion

This systematic review identified and synthesised the international literature on the development of interventions, programmes and resources that address CaLD consumers' and carers' cancer information needs. Most of the literature related to materials that were developed in the USA for Latina populations and focused on cancer prevention.

In relation to objective 1 of the review, developing and adapting materials intended for CaLD communities, the majority of the studies overwhelmingly promoted and supported the need for consumer engagement or codesign with members of the community for whom the intervention was intended for. Whilst intervention studies referred to the latter, the qualitative studies were able to detail the level of community engagement involved in developing and adapting information and other intervention materials.

The majority of studies used face-to-face sessions rather than on-line intervention and described multiple consultations with community members through focus groups or meetings to gain comprehensive feedback and to ensure that adaptations met the communities' needs. Advisory groups with consumers and expert representatives, often health-care professionals, were frequently featured among the included studies to inform the development of material and provide feedback on the same. Among the studies, the most popular methodology used to underpin intervention development was community-based participatory research.

A key finding of this review was the importance of community evaluation of information, resources and intervention programmes to identify cognitive informational and affective-motivational revisions to optimise the "fit" of information, resources and interventions for the communities they were targeted for. Involvement of the community at all stages of development aligns with the World Health Organisation's recommendations on strategies to assist the health literacy needs of migrants and includes involving migrants in the planning, implementation and evaluation processes [126]. In the majority of the studies reviewed, community members generally advised on multiple changes to materials to improve

comprehension. This included language where literal translations of the English materials created nonsensical content, or where the translated language was vague and lacked clarity and specificity. In response to the feedback, researchers simplified the English script, corrected out-of-context translations and removed words that contributed to creating text that lacked clarity. Additionally, abstract terms or catchphrases in English that lack a direct equivalent in the language being translated require particular attention.

Awareness of, and accommodation for, dialects were also highlighted as important. Recognition and incorporation of culturally sensitive beliefs and practices and alignment of these with key concepts in the framework guiding the work should be recognised. For example, Latino populations have identified the concepts of 'personalismo' (a personal and empathetic way to relate to another person), 'respeto' (a feeling of high esteem and respect for others), and 'confianza' (the trust in the relationship) as vital in Latino cultural theory [89]. The development of information and resources that include a visual format and plain language are recommended. Beyond language proficiency, other barriers to seeking and using health-related information involve culturally based values and beliefs, including a preference to use folk remedies or Chinese Medicine, particularly if Western medicine was perceived as ineffective. Many CaLD consumers in the studies expressed interest in complementary and alternative medicines and this needs to be recognised in information, resources and intervention programmes, whether or not support or access to them are incorporated. The lack of familiarity with Western healthcare systems and processes was a recurrent theme. Multimedia resources attempted to fill these gaps by including in-language information about the Western health systems and what to commonly expect when attending hospital for cancer treatment. Awareness of language and culture are vital and include issues such as stigma associated with a cancer diagnosis and community perceptions about cancer (e.g., a cancer diagnosis is fatal or contagious).

The process of introducing, delivering and evaluating information, resources and interventions is critical. Feedback from participants in the studies included in this review highlighted that resources should be responsive and flexible. Resources need to be consumer-focused with flexibility for consumers to engage with resources that meet their needs. The involvement of bilingual speakers, with consideration of professional qualifications in translation and interpretation, are important if cultural synergy is to be achieved.

In relation to the effectiveness of interventions, the included studies primarily centred on prevention rather than active treatment or survivorship. They focused on

Whitehead et al. BMC Cancer (2025) 25:599 Page 9 of 14

screening and improving the uptake of screening, either during the course of the study or to promote future uptake, through awareness raising of screening services and the benefits of screening. The components of effective cancer screening programmes, that aimed to improve knowledge and beliefs about cancer and screening, screening intentions and uptake rates, included using theories to guide intervention development, delivery of services in community settings, using culturally relevant and linguistically appropriate materials, content that highlighted key messages about cancer and screening measures, and adopting multiple intervention strategies.

The interventions were mostly reported as effective in improving the primary outcome of the study. The findings support the value of creating culturally targeted information, resources and interventions to increase engagement with services, change behaviours and improve screening uptake. Of key importance was the consideration of the implementation of the intervention. Structural barriers were identified in the majority of studies and had an ongoing and pervasive impact on the ability and confidence of CaLD consumers and carers to engage with screening services. Barriers included low health literacy, socioeconomic status, language barriers, cultural beliefs and transportation issues. CaLD consumers and carers face many challenges and these share common underlying causes linked to the inequitable distribution of resources that affect social, structural, economic, political, environmental and commercial determinants of health [123]. It is also important to create awareness of both the benefits and the impacts of digital technologies. These create both opportunities for digital health solutions but also to widen equity gaps in access to health care. Currently few studies consider equity of access in relation to digital interventions [127].

A number of approaches were described to support the delivery of the intervention. These included a peer support model and using ethnically concordant interventionists who had an innate understanding of the cultural and social contexts of participants to help "bridge the gap" between cultures and improve communication. A key recommendation from this review is that both the content of an intervention and the implementation are carefully considered at the outset and use cultural- and language-specific outreach strategies into the community.

No studies reported on the experiences of CaLD consumers and carers in the development of interventions, programmes and resources to address their cancer information needs. This is an area for future focus. At this point in time there is no evidence to guide researchers and clinicians on how best to engage with consumers and carers in the field of cancer care to ensure that the process is acceptable, equitable and productive.

This review has highlighted that there is a paucity of interventions to support knowledge and behaviour change for cancer patients undergoing active treatment and cancer survivors. CaLD communities are a priority population and growing in size in many countries, including Australia. CaLD consumer engagement in decision-making is a vital part of patient-centred care. The provision of culturally competent care is well recognised as a priority issue in health care and is characterised as the integration of culture into the delivery of health services through staff who have the knowledge and ability to deliver culturally competent care in an environment that supports this [128].

The synthesis of the findings has informed some of the key steps that researchers and clinicians can engage with to support the creation of information, resources and interventions for CaLD communities in relation to cancer care. The most important finding was the need for engagement with a methodology that supports consultation and cycles of feedback, for example, a community participatory approach. Community-based participatory research is an approach to research that involves collective, reflective and systematic inquiry in which researchers and community stakeholders engage as equal partners in all steps of the research process with the goals of educating, improving practice or bringing about social change [129, 130]. Community-based participatory research questions the power of relationships that are inherently embedded in Western knowledge production, advocates for power to be shared between the researcher and those being researched, acknowledges the legitimacy of experiential knowledge, and focuses on research aimed at improving situations and practices [131]. This approach to research is recognised as particularly useful when working with populations that experience marginalisation.

A small number of studies used a theoretical framework to guide the theoretical and therapeutic components of the engagement and evaluation process. A recommendation from the review is the use of a framework to create a bridge between the operational elements of a project and the key theoretical drivers. The frameworks used in the studies included in this review were: the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) [132, 133], the Health Belief Model [133, 134] the PRECEDE-PROCEED model [134, 135], Transtheoretical Model of Change [135, 136], Ottawa Decision Support Framework [136, 137] and the Tipping Point Model [137, 138]. Theoretical frameworks can support understanding of the critical elements of an intervention that contribute to effectiveness [138, 139].

Whitehead et al. BMC Cancer (2025) 25:599 Page 10 of 14

### Limitations

The review employed a systematic approach to searching and securing the relevant studies for this review. The team included members who were bilingual in several languages, however, all studies included were published in English. The majority of studies included in the review were conducted in the USA and the population most commonly involved were Latinos/ Hispanic Americans. This limits the generalisability of the findings to other health care settings and populations. In line with the JBI approach to conducting systematic reviews all papers were included regardless of methodological quality. Whilst few papers were lower quality these have not been highlighted in the review and caution must be taken in the interpretation of results where some studies were pilot interventions with small sample sizes, which limit both the statistical power and generalisability of the findings. The heterogeneity of the studies included in the review meant that a meta-analysis could not be undertaken, and a narrative synthesis was completed.

### **Conclusions**

The review provides directions for practice, policy and future research.

The outcomes and findings of this review can support and guide progress towards achieving key policies and strategies, including the priorities of Cancer Plans internationally with specific reference to providing consumers with reliable information about their cancer care. The review provides insight into the gaps in the field, key considerations and the next steps.

Before developing information, resources or interventions, understanding and addressing the contexts, motivation and preparedness of CaLD communities for change is needed. This includes screening services, lifestyle, health behaviours, opportunity (e.g., their household environment and access to food and exercise), competing priorities, health and technological literacy, readiness to change, and clinical characteristics. The review supports a tailored approach to develop information, resources and interventions that leverage community resources and expertise to ensure that CaLD communities have the best opportunity possible to engage with them to achieve effective outcomes.

### **Abbreviations**

CaLD Culturally and linguistically diverse

SUMARI System for the unified management of the assessment and review

of information

LOTE Language other than english USA United states of America

### **Supplementary Information**

The online version contains supplementary material available at https://doi.or g/10.1186/s12885-025-13931-5.

Supplementary Material 1
Supplementary Material 2
Supplementary Material 3
Supplementary Material 4

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### **Author contributions**

LW contributed to conception and study design, database search, data analysis and interpretation, literature review, writing of the manuscript. DK contributed to conception and study design, database search, data analysis and interpretation and critical revision of the manuscript. PC and WL database search, data analysis and interpretation and critical revision of the manuscript. MN contributed to conception and study design, database search, data analysis and interpretation and critical revision of the manuscript. CB, CL and ME contributed to data interpretation and critical revision of the manuscript. The authors read and approved the final manuscript.

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### Data availability

All data generated or analysed during this study are included in this published article [and its supplementary information files].

### **Declarations**

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### **Competing interests**

The authors declare no competing interests.

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Whitehead et al. BMC Cancer (2025) 25:599 Page 14 of 14

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