Zhou *et al.*
Research Involvement and Engagement (2025) 11:38
https://doi.org/10.1186/s40900-025-00707-1

Research Involvement and Engagement

REVIEW

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Supporting consumer engagement in health research about chronic conditions: a scoping review of evidence-based resources

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Abstract

Context and objective 'Consumers' refers to individuals with lived experience of health issues, as well as their carers or family members, who are often referred to as patients or service users. The recognition of consumers' expertise through lived experience is increasingly acknowledged as essential in health research design. Involving consumers in research enhances relevance and fosters high-quality, consumer-centric outcomes. While previous reviews have examined resources that support consumer engagement in health research, this review aimed to identify evidence-based resources specifically designed for engaging consumers in research related to chronic conditions.

Design We conducted a scoping review to map diverse resources, using the Arksey and O'Malley framework, enhanced by Levac et al. and the Joanna Briggs Institute.

Data collection A search strategy was developed using keywords related to consumer engagement and supporting resources, such as models, frameworks, and tools. Seven databases were searched: PubMed, Web of Science, Cochrane, Scopus, EconLit, PsycINFO, and ACM Digital Library, targeting peer-reviewed articles published between 2013 and 2023.

Analysis We conducted a qualitative thematic analysis by coding the results sections of each included study line by line. The codes were inductively grouped into descriptive categories, which were then synthesised into analytical themes and sub-themes.

Results From 15,245 identified articles, 15 met the inclusion criteria. An overarching framework for consumer engagement in health research related to chronic conditions was synthesised, comprising six themes: 1. Promoting reciprocal learning, 2. Fostering a supportive environment, 3. Providing training to build capacity, 4. Acknowledging consumer contributions, 5. Using resources to facilitate engagement, and 6. Evaluating engagement impact.

Conclusion This review integrates existing evidence-based resources for supporting consumer engagement in research about chronic conditions and presents an overarching framework. The findings offer valuable guidance for researchers aiming to effectively implement consumer engagement strategies tailored to individuals with chronic conditions.

Keywords Consumer engagement, Chronic conditions, Scoping review, Thematic synthesis, Health research

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Plain English summary

Consumers, a broad term that includes individuals with lived experience of a health issue and their carers, are often referred to as patients or service users in health research. Involving consumers in health research helps make studies more relevant and produce better, more meaningful outcomes. This is especially important for research on chronic conditions, where consumer involvement can contribute to long-lasting results, given the ongoing impact these conditions have on daily life. This review aimed to identify evidence-based resources, such as frameworks and toolkits, specifically designed to support consumer engagement in research about chronic conditions.

We searched seven databases and screened over 15,000 articles to find those that provided resources for involving consumers in research about chronic conditions. As a result of screening, we identified 15 relevant articles. From these, six key themes were identified: 1. Promoting reciprocal learning, 2. Fostering a supportive environment, 3. Providing training to build capacity, 4. Acknowledging consumer contributions, 5. Using resources to facilitate engagement, and 6. Evaluating engagement impact.

We further synthesised the findings to develop an evidence-based framework to inform the approach to consumer engagement in research about chronic conditions. This framework offers validated guidance to support researchers and consumers in building effective and collaborative research partnerships in research about chronic conditions.

Introduction

In health research, 'consumers' refers to individuals with lived experience of health issues, as well as their carers or family members, who are often referred to as patients or service users [1, 2]. Engaging consumers in research is considered essential to achieve high-quality and consumer-centred research outputs as their involvement in research leads to knowledge gain and empowerment, while for researchers, it enhances the relevance, quality, and dissemination of findings [3]. Consumer engagement refers to the active involvement of individuals with lived experience, their families, and carers in all stages of health research, from the development of research questions to dissemination of findings [4, 5]. It is variably referred to as consumer engagement, patient and public involvement (PPI), patient engagement, and consumer and community involvement (CCI).

Learning from the lived experience of 'experts by experience' is now being widely recognised and expected as a vital part of good research design, particularly in high-income countries such as the United Kingdom (UK), Canada, the United States of America (USA) and Australia [6]. Funding agencies in these countries increasingly require consumer engagement activities to be described in applications, as this will increase the likelihood of the research being relevant to those most affected [7–9]. Engaging consumers in research about chronic conditions, also referred to as chronic or noncommunicable diseases, is crucial, as these conditions contribute to 41 million deaths globally each year, accounting for 74% of all deaths [10]. Approximately 50% of adults in developed countries suffer from multiple chronic conditions, presenting a significant disease burden for both individuals and society [11, 12]. In Australia in 2023, approximately six in 10 adults were living with one or more chronic conditions, with over 90% of the non-fatal disease burden being attributed to these conditions [13].

Consumers with chronic conditions report various benefits of being involved in research, including improved access to information on the current treatment or management of their condition and a related enhanced problem-solving capacity [14]; increased confidence and empowerment through stepping into a role in the research community [15]; and the gaining of new skills, such as data collection and analysis [16]. It is important that research about people with chronic conditions is conducted 'with' or 'by' consumers with chronic conditions, rather than 'to', 'about' or 'for' them [1]. While consumer engagement offers significant benefits, there are also considerable barriers that prevent widespread adoption of this approach.

Despite the motivation from funding bodies and acknowledged benefits of consumer engagement, health researchers may face constraints within the frameworks they operate, which can limit their adoption of this approach. A primary concern is that effective partnerships in research require adherence to scholarly methodologies; hence, partnerships should serve research purposes, and thus, all activities should follow best practices grounded in evidence-based decision-making [17]. An absence of institutional policies, frameworks, or tools to guide the engagement process may constrain researchers from developing partnerships with consumers [4, 16, 18]. Other challenges frequently reported include having limited time to manage engagement activities [16] and

inadequate resources such as funding, costs, and training [16, 19]. These obstacles often result in sub-optimal or nominal engagement, which may be conceived by consumers as tokenistic, reflecting a simply 'ticking a box' exercise rather than genuine collaboration [20]. Many of these issues stem from a lack of knowledge or insufficient evidence-based resources to support meaningful consumer engagement in research [21].

Four systematic reviews have synthesized the literature on models, frameworks, and other resources to support consumer engagement in health research [4, 5, 27, 36]. However, none specifically addressed empirical research on chronic conditions [3, 4, 21] or offered a broad focus beyond a single condition [22]. While these reviews provide valuable insights—such as general frameworks for consumer engagement [21], patient engagement principles [4], models for health services research [3], and tools for promoting PPI [22]—they do not comprehensively cover evidence-based resources for engaging consumers in research on chronic conditions.

This review aimed to develop an evidence-based framework to guide the engagement of consumers in research focused on chronic conditions, thereby supporting health researchers in establishing meaningful collaborations with consumers. In order to achieve this, our objectives were to: (1) identify available evidence-based resources supporting consumer engagement in research about chronic conditions; (2) thematically synthesise the resources from included studies and present the findings in the form of a framework to support research about chronic conditions.

Methods

Guiding framework

A scoping review methodology was chosen to accommodate the diversity of resources available and to map the breadth of frameworks, models, and tools supporting consumer engagement. This approach prioritised breadth and inclusivity over the quality assessments of a systematic review.

The design of this review followed the framework initially developed by Arksey and O'Malley, which has been further enhanced by Levac et al. and the Joanna Briggs Institute (JBI) [22–24]. The review has been reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-SCRA).

Research question

The research question was developed using the PCC framework (Population, Concept, and Context) [24]. This approach, recommended by JBI for scoping reviews, ensures a structured yet broad exploration of existing evidence [24]. In this study:

- Population (P) refers to consumers (patients, service users, carers) with chronic conditions.
- Concept (C) focuses on evidence-based resources to support consumer engagement in health research.
- Context (C) relates to consumer engagement in health research.

For the term of chronic conditions defining Population in this review, we adopted the World Health Organisation's (WHO) definition of chronic conditions, which describes noncommunicable diseases (NCDs), or chronic diseases, as conditions of long duration resulting from a combination of genetic, physiological, environmental, and behavioural factors [10]. Given the Australian context of this study, we combined WHO's four main types of NCDs (cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes) [10] with the ten most common chronic conditions identified by the Australian Institute of Health and Welfare (AIHW) [25]. These include arthritis, asthma, back problems, cancer, chronic kidney disease, chronic obstructive pulmonary disease (COPD), diabetes, mental and behavioural conditions (e.g., mood disorders, substance use disorders, and dementia), osteoporosis, and selected heart, stroke, and vascular diseases [25]. The context of this review is health research, which is defined as "research aiming to improve our understanding of a human condition (i.e., basic science, clinical research, translational research, health policy etc.)" [26], and this includes medical and biomedical research.

Search strategy and information sources

Keywords were identified based on a preliminary scan of the relevant literature, and thereafter, a variety of search strategies were explored to test the feasibility. We used combinations of concepts as search terms (adapted from the strategies used by previous authors [27–29]) (Table 1), aiming to optimise the sensibility of the search while keeping the number of results manageable. We chose not to include the term "chronic condition" because it is a very broad term, and the literature was less likely to use it when referring to more specific conditions (e.g. mental health disorders or dementia) and preliminary testing demonstrated many irrelevant results were returned. The strategy was adapted to each database searched with the use of controlled vocabulary (e.g., Mesh terms for PsycINFO).

The following databases were searched: Scopus, PubMed, Web of Science, Cochrane, EconLit, PsycINFO, ACM digital library. These were identified in

Table 1 Search terms

No	Concept 1	Concept 2	Concept 3
1	Public and patient involvement	Framework	Health*
2	Patient and public involvement	Model	Medical*
3	Patient partner*	Guide*	Biomedical*
4	Patient engagement	Tool*	
5	Patient-oriented	Checklist	
6	Consumer engagement	Resource*	
7	Consumer involvement		
8	Coproduce*		
9	Co-product*		
10	Co-design		
11	Codesign		
12	Concrete*		
13	Co-create*		

interdisciplinary team meetings, and with assistance from a university librarian.

The full search string used for PubMed was:

((("public and patient involvement"[Title/Abstract] OR "patient and public involvement"[Title/Abstract] OR "patient partner*"[Title/Abstract] OR "patient engagement"[Title/Abstract] OR "patient-oriented"[Title/Abstract] OR "consumer engagement"[Title/Abstract] OR "consumer involvement"[Title/Abstract] OR "patient involvement"[Title/Abstract] OR "public involvement"[Title/Abstract] OR "coproduc*"[Title/Abstract] OR "co-produc* "[Title/Abstract] OR " co-design"[Title/Abstract] OR "codesign"[Title/Abstract] OR "cocreat*"[Title/Abstract] OR "co-creat*"[Title/Abstract]) AND (resource*[Title/Abstract] OR tool*[Title/Abstract] OR framework[Title/Abstract] OR guid*[Title/Abstract] OR checklist[Title/Abstract] OR model[Title/Abstract])) AND (health*[Title/Abstract] OR medical*[Title/Abstract] OR biomedical*[Title/Abstract])) NOT ("clini*"[Title/Abstract]) in the last 10 years.

Eligibility criteria

This scoping review follows the JBI PCC framework (Population, Concept, Context) to identify evidence-based resources for consumer engagement in health research [30]. See Table 2.

Study selection

We followed a four-step process for study selection, using the inclusion/exclusion criteria identified in the previous section: (1) Ten articles were initially independently screened by four reviewers (MZ, MY, AP, JD), who then met to refine the inclusion/exclusion criteria and reach consensus. (2) Two reviewers (MZ and MY) independently screened title/abstracts after removing duplicates. Reviewers met every fortnight to compare results and resolve discrepancies. AP and JD acted as third reviewers to resolve any discrepancies. (3) MZ and MY conducted full-text screening, with AP and JD alternating as third reviewers to be consulted on disagreements. (4) These searches were supplemented by reference searches of the included articles.

We utilised Endnote (version 20) [31] to remove duplicates and Covidence, an online systematic review management software, to manage the selection of studies between reviewers [32]. We used NVivo 12 (a qualitative data analysis computer software package) [33] to store data and support analysis.

Data extraction

A standardised data extraction form was developed in collaboration with team members. The charting form included information about the study and more specific

Table 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Population:	
Consumers (patients, service users, carers) with chronic conditions	Consumers (patients, service users, carers) without chronic conditions
Concept:	
Evidence-based resources to support consumer engagement in health research	Resources that were solely focused on informing, educating, or gathering information from consumers, or those that describe or evaluate engagement rather than providing support
Context:	
Consumer engagement in health research	Clinical guidelines of engagement for treatment, service improvement (healthcare setting), and health technology assessment
Study type:	
Reviews, primary research (includes quantitative, qualitative, or mixed methods), and case studies Studies published in English or Chinese	Not peer reviewed. Ongoing studies Commentary or opinion articles Studies not published in English or Chinese Full-text paper not accessible

information about the resources to support consumer engagement (Supplementary Table 1). Data extraction was piloted for the first ten articles to ensure consistency among all reviewers (MZ, JD and AP). Extraction was completed by MZ and validated by JD and AP. If data items were not specified, the field was left blank.

Data analysis

Data analysis was conducted by MZ and validated by JD and AP. All selected articles were imported into NVivo software, where the results/findings section of each article was coded line-by-line. The background and discussion sections of the articles provided context but were excluded from the line-by-line analysis. The line-by-line coding and theme identification adhered to the thematic synthesis methods described by Tomas and Haden [34]. Codes were created inductively as new ideas emerged. Related codes were grouped into descriptive themes, which were then synthesised into analytical themes to provide a foundation for the final framework.

Consultation with stakeholders

Key stakeholders for this study were five people living with chronic conditions and one clinician, who were involved in a parallel research study, The Real Price of Health: Experience of Out-of-Pocket Costs in Australia [35]. Consultation occurred over key phases of this review through one online meeting and email correspondence. The meeting was held at the start of the data analysis phase, during which participants reviewed and provided feedback on the data coding framework. Participants were also given the opportunity to review the manuscript and provide feedback on the draft framework to guide consumer engagement in research about chronic conditions via email.

According to Arksey and O'Malley [22], this consultation stage is optional, although for our team, it was essential to ensure relevance and acceptability of the findings.

Results

The search yielded 15,244 articles, of which 14 studies were included in the review, with one additional study identified through a hand search of the reference lists of included studies. Figure 1 displays the flow of studies in a PRISMA flowchart.

The key characteristics of the 15 included studies are summarized in Table 3 (Appendix). Of these studies, seven were published between 2021 and 2023 [14, 36–41], and 11 originated from the United Kingdom [39, 42–45], Canada [37, 40, 46], and Australia [14, 47, 48]. The chronic conditions represented included mental health(n = 3) [44, 46, 47], dementia (n = 4) [42, 45, 48, 49], cancer-related

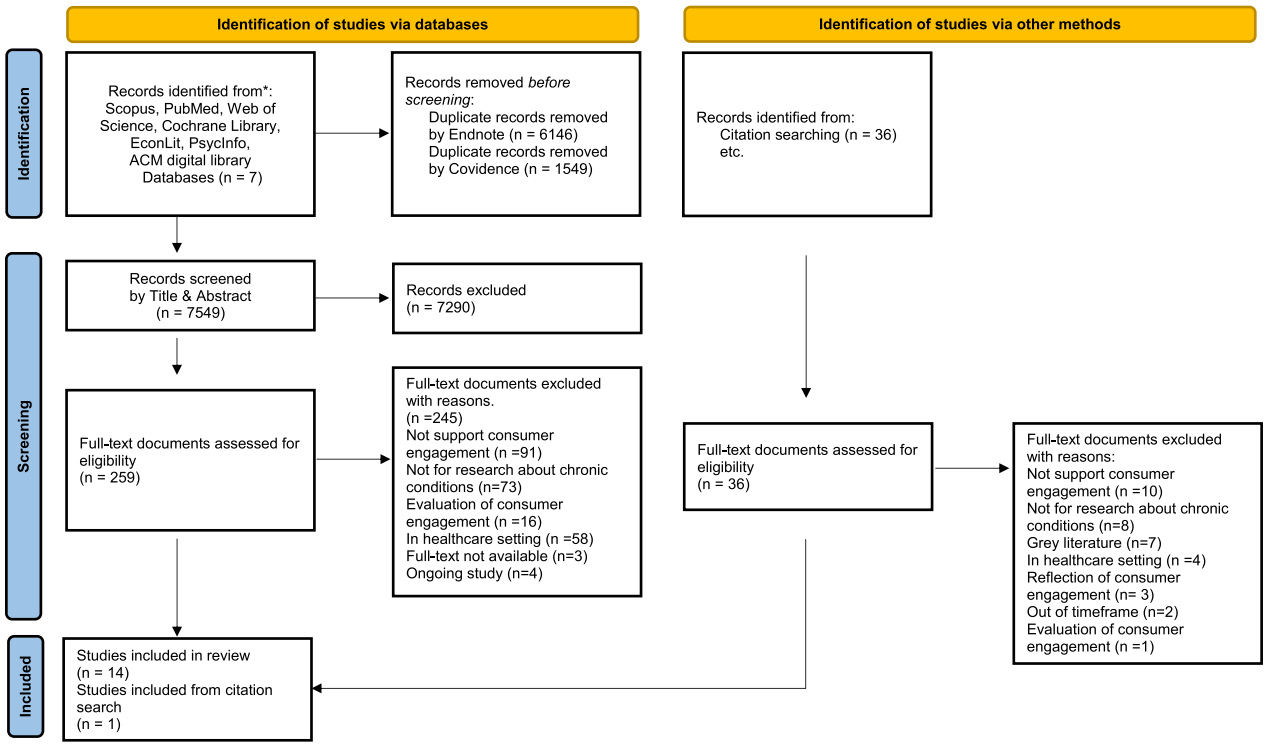

Fig. 1 PRISMA flowchart for study selection

diseases (n = 2) [40, 41], diabetes (n = 1) [14], chronic kidney disease (n = 1) [37], rheumatic and musculoskeletal conditions (n = 1) [36], chronic pain (n = 1) [38], cardiovascular disease (n = 1) [39], and multiple chronic conditions (n = 1) [43]. The resources identified in these studies included six models [42, 43, 45–48], three frameworks [14, 39, 44], three toolkits [37]/checklists [38]/booklets [40], and three other types: a whiteboard animation [41], core principles [49], and seven practical ways to engage in patient and public involvement in research [36].

Overview of existing resources

Based on the thematic analysis of resources supporting consumer engagement from the included studies, an overarching resource framework to support consumer engagement in research about people living with chronic conditions (Fig. 2, appendix) was synthesized, comprising six themes: 1. Reciprocal learning, 2. Fostering a supportive environment, 3. Providing training to build capacity, 4. Acknowledging consumers' contributions, 5. Using resources to facilitate engagement, 6. Evaluating engagement impact. In this framework, reciprocal learning is positioned at the centre, representing the ongoing exchange between researchers and consumers throughout the research process. The remaining themes are arranged in a circular formation, reflecting their interdependent nature in supporting meaningful engagement. As illustrated in Fig. 2, these six themes are interconnected with each other. For instance, Fostering a supportive environment (Theme 2) is closely connected to Using resources to facilitate engagement (Theme 5), as accessible and tailored resources contribute to inclusive participation. Similarly, Flexible engagement strategies (a subtheme of Theme 2) directly supports Fostering an inclusive atmosphere by helping to address power imbalances and cultural considerations, ensuring that diverse consumer voices are equitably represented. Providing training to build capacity (Theme 3) reinforces these aspects by equipping both consumers and researchers with the skills needed for meaningful engagement, further enhancing inclusivity and participation. Additionally, Evaluating engagement impact (Theme 6) serves as a mechanism for assessing the effectiveness of these strategies, ensuring that engagement remains responsive to consumer needs over time. Supporting quotations from the included studies are presented in Tables 4, 5, 6, 7, 8 and 9 (Appendix).

Reciprocal learning

Reciprocal learning was identified in five studies [14, 37, 45, 46, 48]. Mutual learning was found to occur between researchers and consumers, irrespective of their age or hierarchical position [45, 46]. Some consumers experienced personal growth and improved management skills, while researchers developed a deeper understanding of the needs of those who would ultimately use the research outcomes [14]. For instance, involving young people in research was found to enhance their management strategies and enhanced researchers' focus on end-user needs [14]. Storytelling was noted as an effective method for enabling reciprocal learning, allowing both consumers and researchers to share experiences and perspectives [37, 46]. Through storytelling, both parties gained a clearer understanding of each other's experiences, fostering a sense of reciprocity and enhancing engagement [37].

Fostering a supportive environment

This theme included six aspects that described the range of activities identified in the included resources for facilitating a supportive environment: i) optimising accessibility, ii) fostering an equal and inclusive atmosphere, iii) promoting open discussion about consumer roles, iv) setting realistic expectations, v) employing flexible engagement methods, and vi) ensuring consumer health and safety.

i) Optimising accessibility—clear, jargon-free language is crucial to facilitating consumer engagement, especially for those with chronic conditions [36–38, 40, 42–45, 47–49]. Recommended practices included avoiding jargon [36, 42, 43, 49], conducting literacy checks [38], segmenting text [47], focusing on key trends [36], and minimizing ambiguity [44, 49]. Optimising accessibility involved using various formats, such as social media for recruitment [36, 38], visual aids for data collection [42], remote consent options [38], and community-based dissemination [47]. Implementing accessible design standards, such as booklets for individuals with visual impairments, and reducing reliance on scholarly publications were also noted [37, 38, 40]. Addressing specific needs, including travel and accommodation, was identified as necessary for engaging consumers with chronic conditions [38].
ii) Equal and inclusive atmosphere—widely recognised as fundamental to meaningful consumer engagement, studies emphasised the need to address power imbalances, enable autonomy, and promote mutual communication and cultural diversity [14, 37–40, 42–49]. Key to enabling this was: a) addressing power imbalances [37, 38, 42, 44], b) enabling autonomy in governance [38, 44, 46–48], c) fostering mutual communication and feedback [14, 37, 39, 43, 44, 47–49], d) facilitating a sense of being valued [14, 38–40, 43–49], e) promoting cultural diversity [37–39, 43], and f) respecting confidentiality [38, 47]. a) Power

imbalances, often due to unequal representation and involvement, were found to hinder effective engagement [37]. Addressing these imbalances led to more meaningful contributions from consumer partners [37, 42, 44]. b) Five studies referred to the value of embedding consumers in governance structures, underscoring the importance of listening to engaged consumers and tailoring relevant information to align with their individual needs and perspectives [38, 44, 46–48]. c) Strategies employed by researchers to optimise mutual communication and feedback included proactively seeking feedback from engaged consumers [39, 43, 49], conducting joint reflective exercises with them [44], and involving consumers in data collection and interpretation [38, 45]. These activities were integral to reciprocal learning and drawing on the value that consumers brought to the research. d) Respecting consumers' unique expertise was positively perceived by both consumers and researchers, fostering a sense of being valued in the research process [14, 45, 47]. e) Promoting cultural diversity involved fostering inclusivity and valuing contributions equitably [43], addressing biases and amplifying Indigenous voices [37], engaging diverse stakeholders and building culturally diverse teams [38], and ensuring participants were representative of target populations [39]. f) Respecting confidentiality included allowing individuals to decide on the level of disclosure, anticipating potential harms, and using pseudonyms and verbal consent to protect anonymity [38, 47]. Addressing these factors was found to enhance engagement and ensure a supportive research environment.

iii) Open discussions about consumer roles—highlighted as essential for ensuring clarity and flexibility in engagement, with studies recommending early and ongoing dialogue to define evolving roles in research [14, 36–39, 42–44, 46, 49]. Establishing clear, evolving consumer roles was suggested [14], with recommendations to begin role discussions early and maintain them throughout the engagement process [42]. The "involvement matrix" tool supported this approach by defining three research phases and five potential consumer roles: listener, co-thinker, adviser, collaborator, and decision-maker [36]. Seven roles were proposed in another study (see Table 5).

iv) Setting realistic expectations—identified as important for fostering a supportive research environment, with studies emphasising the need to consider consumers' time limitations, provide clear project information, and allocate manageable tasks [14, 37, 44, 47, 49]; three noted that individuals with chronic conditions often juggle various responsibilities, making it important to consider their time limitations [14, 44, 49]. Providing clear information about the project from the start was found to assist consumers to feel more at ease with its development [37]. Allocating well-defined and manageable tasks was also advised to prevent overwhelming consumers [44].

v) Flexible engagement methods—commonly recommended to accommodate consumer preferences, particularly in response to fluctuating symptoms of chronic conditions, with strategies including virtual participation, adjusted meeting times, and flexible working hours [37, 38, 43, 46, 47, 49]. Flexible engagement strategies included offering virtual participation options (e.g., Skype and phone) [43], adjusting meeting times to accommodate travel requirements [43], and adopting flexible working hours to meet consumers' unique needs [38, 46, 47]. Additionally, allowing consumers to opt in or out of specific research procedures assisted in addressing individual concerns [38].

vi) Ensuring consumer health and safety—a shared priority among consumers, researchers, and ethics committees, with studies highlighting the need for safeguarding well-being to support diverse participation and safe engagement [36, 37, 42, 46, 47, 49]. Studies across different conditions—including mental health[47], dementia[49], and musculoskeletal issues[36]—emphasised the importance of safeguarding well-being to promote diverse participation and ensure safe involvement of individuals with lived experience [46, 47, 49]. Ethics committees played a key role in this oversight as reported in one study about musculoskeletal and rheumatology research [36]. Providing counselling and emotional support in dementia research was recommended to reduce the risk of emotional distress among participants [42, 49].

Providing training to build capacity

Eleven studies described the role of training to enhance both consumer and researcher capacities to foster more effective engagement in research [36–42, 44, 45, 47, 49]. Key areas of focus included research skills, health literacy, cultural inclusiveness, and addressing individual needs.

Eight studies emphasized that training in research skills assisted consumers to develop academic competencies and a deeper understanding of the research process, improving their ability to contribute meaningfully to study design, data collection, and dissemination [36, 37, 39, 42, 44, 45, 47, 49]. By enhancing technical skills and building confidence, this training supported sustained

engagement and more equitable research-consumer collaboration throughout the research process [42].

Training aimed at improving health literacy benefited both consumers and researchers [40, 41, 49]. For consumers, it provided knowledge of key research concepts and terminology, enabling them to engage in discussions and decision-making more effectively. For researchers, it deepened their understanding of consumers' lived experiences and health conditions, promoting clearer communication and more responsive research designs. Accessible resources, such as booklets and tools for understanding Patient and Public Involvement and Engagement (PPIE) terminology, further supported this learning process [40, 41].

Training on cultural inclusiveness focused on cultural humility, implicit bias, and communication strategies to promote respectful and meaningful engagement with diverse consumer groups [38]. It encouraged researchers to critically reflect on their personal, professional, and research values, recognising how deeply underlying stereotypes and assumptions might influence interactions. Ongoing examination of these biases was emphasised as essential for fostering responsive and inclusive research practices.

Tailoring training to individual needs was also identified as a key factor in strengthening engagement. For example, adaptations made for peer researchers in dementia research helped address varied experiences, ensuring that training was accessible and relevant to all participants [42]. These tailored approaches supported long-term engagement by equipping consumers with the skills and confidence needed to participate actively in research, ultimately fostering a more collaborative and inclusive research environment.

Acknowledging consumers' contribution

Acknowledgements of consumers' contributions to research was documented in eight studies [36, 38, 39, 42–44, 47, 48], which identified both financial and non-financial recognition methods. All eight studies endorsed financial recognition and discussed justifications for remuneration [36, 39, 44, 47, 48], specific budget items to be remunerated [38, 42, 43], and factors influencing remuneration [36, 38]. Financial recognition included payments for advisory roles, meeting expenses, translation services, multimedia tools, and costs for transportation, childcare, and refreshments [38]. Remuneration was recommended to match the consumer's role and be accessible to all, including those with special needs [36, 38]. Non-financial recognition included appropriately acknowledging the contributions of consumer partners, such as offering co-authorship when eligible [36, 44]. Detailed descriptions of consumer engagement in publications enhanced the study's validity and encourage the adoption of engagement strategies by others [38].

Using resources to facilitate engagement

Ten studies noted the need for resources to support consumer engagement, including time investment, dedicated consumer engagement facilitators, and peer support [36–39, 42–45, 47, 48]. Allocating adequate time to facilitate engagement was noted in two studies as necessary for researchers to be made fully aware of the time spent in engagement with consumers, thereby enabling optimum engagement [38, 44]. Facilitators were delegated responsibility for distributing information, coordinating meetings, recruiting participants, and providing training [36–38, 43, 47, 48]. One study involving people with chronic kidney disease suggested that paid coordinators would be useful in managing daily operations and maintaining documentation [37]. Studies about chronic kidney disease, cardiovascular disease, and dementia found that peer and family support was important for providing emotional support, enhancing engagement and self-confidence [37, 38, 45]. It also assisted consumers in making informed decisions and provided a sense of security and well-being in the research process [38, 45].

Evaluating engagement impact

Two studies referred to the value of evaluating the impact of consumer engagement, focusing on the engagement process and research outcomes [39, 45]. Evaluation provided opportunities to improve the process and identified outcomes of consumer engagement for both consumers and researchers [39, 45].

Discussion

Summary of findings

This scoping review identified fifteen studies that provide resources to support consumer engagement for individuals with chronic conditions in health research from 2013 to 2023. To our knowledge, this is the most comprehensive and systematic summary of existing resources on this topic. As illustrated in Fig. 2, this review identified six key themes that informed the development of a framework to support consumer engagement in research about people living with chronic conditions: 1. Reciprocal learning, 2. Fostering a supportive environment, 3. Providing training to build capacity, 4. Acknowledging consumers' contribution, 5. Using resources to facilitate engagement, 6. Evaluating engagement impact.

Comparison with the existing literature

Reciprocal learning throughout the research project lifecycle emerged as a key theme in our review, highlighting its role in strengthening consumer engagement through mutual learning and collaboration, particularly for individuals with chronic conditions. This finding aligns with a review of models and frameworks for consumer engagement in health services research, where reciprocal learning is identified as a significant motivator for involvement [4]. For researchers, direct engagement with consumers provides deeper insights into the lived experiences of those affected by chronic conditions, allowing for the refinement of research questions and the alignment of study designs with real-world needs [21]. Consumers, in turn, gain knowledge from both researchers and peers, enhancing their understanding of the research process and enabling more meaningful contribution to study implementation [29]. Beyond these individual benefits, reciprocal learning fosters research that is more relevant, inclusive, and responsive to end-user needs [50, 51]. Storytelling and shared experiences further facilitate this exchange, fostering a sense of reciprocity that enhances engagement and strengthens the application of research findings in practice [14, 29, 46].

Our review emphasises the importance of building a supportive environment for consumers involved in research about chronic conditions, and resonates with previous reviews, which emphasize the importance of fostering equitable and transparent environments [4, 5, 27]. For example, Chudyk et al. highlight accessibility, transparency, and flexibility in patient engagement [4], while Harrison et al. stress the need for equitable power dynamics between consumers and researchers [5]. Greenhalgh et al. emphasise the importance of transparency in defining consumer roles and engagement goals [27]. The impactful roles of consumers in health research were initially elucidated by Croker et al. [52]. The value of discussing and expanding upon these has been highlighted in our review. Ensuring consumer health and safety—was unique to our review and fills a gap in the literature to date. As noted in a review of patient partners' experiences, chronic illness introduces challenges such as healthcare time constraints, low energy, and distress related to sensitive topics [29]. Therefore, as reiterated in this review, ensuring health and safety is critical when engaging consumers with chronic conditions.

A recent review of researchers' experiences highlighted recurring power dynamics between health researchers and patient partners [21]. In addition to two factors identified in our review, such as unequal representation and varying levels of engagement, this disparity often stemmed from differing values placed on academic versus experiential knowledge [21, 37]. Consumers frequently feel less influential due to hierarchical structures within research teams and benefit from strategies aimed at equalising these relationships [29]. The "ecology of engagement" framework [53] suggests that power dynamics arise from the differing authority between researchers, who rely on academic expertise, and consumers, who contribute experiential knowledge. This tension often affects decision-making, as research tends to prioritize academic over experiential knowledge. Similar challenges were identified in studies included in our review and proactive strategies were recommended to dismantle these power imbalances and foster a more inclusive and respectful environment for consumers. Similarly, Boivin [53] advocates for fostering cooperation through transparent communication, shared decision-making, and placing equal value on both knowledge sources. By addressing these power imbalances, researchers and consumers can collaborate more effectively, creating equitable and supportive engagement environments.

Many articles in this review emphasise the importance of training to build capacity for both researchers and consumers, covering research skills, literacy, cultural inclusiveness, and individual needs. Reviews of broader consumer engagement often highlight training in research skills, which Harrison et al. identified as a key principle of best practice for supporting engagement [5]. However, areas such as literacy improvement, cultural inclusiveness, and individualised approaches are less frequently addressed in broader contexts. Literacy training, supported by patient partners, enhances researchers' understanding of specific health conditions and engagement with affected consumers [29]. Similarly, training in cultural inclusiveness is vital, as cultural norms shape researcher-consumer interactions [21]. Individualized training, advocated by patient partners, ensures that engagement activities are tailored to participants' needs, availability, and abilities, particularly for those with fewer opportunities [29]. While research skills training is widely recognized, literacy, cultural inclusiveness, and individualized training are equally important for supporting consumer engagement, especially for individuals with chronic conditions.

Offering non-financial recognition or financial remuneration emerged as two key subthemes in acknowledging consumers' contributions to research. While supported by reviews from broader engagement contexts [5, 27], consumers often cite validation of their impact as the most desirable aspect [29]. Consistent with findings in a recent review on recognising patient partner contributions to health research [54], the most common form of non-financial recognition involved informal acknowledgements on research outputs and co-authorship. Such recognition fosters a sense of

value and respect, contributing to consumers' positive engagement experiences and their willingness to remain engaged in research over time [29]. Financial remuneration, where provided, plays a role in sustaining consumer engagement by mitigating barriers such as travel costs, time constraints, and competing responsibilities [55]. Additionally, feeling valued—whether through financial remuneration, co-authorship, or other forms of recognition—can foster a sense of belonging and encourage long-term participation in research [56]. To ensure equitable and accessible remuneration practices, particular attention should be given to consumers from diverse socio-economic backgrounds and those facing additional barriers, such as physical or cognitive impairments [42]. Offering transparent and flexible remuneration options, including direct payments or reimbursement for expenses, may help reduce disparities and promote more inclusive engagement [57]. Additionally, providing feedback on contributions is recommended as a strategy for enhancing the overall engagement experience and reinforcing the value of consumer engagement in research [51].

Our review identified resources supporting consumer engagement—such as time investment, facilitator support, and peer support—as a core theme. Although these factors are recognised as enabling contributors in broader engagement reviews, they are often reported as challenges in practice [4, 5, 21, 27]. A review of researchers' experiences highlighted barriers including inadequate time within their research timelines, insufficient administrative support, and a lack of infrastructure [21]. To address these challenges, researchers suggest that having dedicated roles, such as patient engagement coordinators, could enhance facilitation and improve overall engagement outcomes [21].

Two studies in our review addressed the evaluation of the impact of consumer engagement. This theme is more prominent in broader consumer engagement reviews and identified as a fundamental component, encompassing assessments of the engagement process [5], its impact on research outcomes [4], and consumer feedback [27]. Such evaluations are crucial for refining engagement efforts, ensuring sustained participation, and maintaining motivation among consumer partners. A recent umbrella scoping review identified eight measurable outcomes relevant to stakeholder groups in consumer engagement: (1) trust, (2) empowerment, (3) respect, (4) confidence in research outcomes, (5) transparency, (6) satisfaction with the engagement program, (7) knowledge and experiences, and (8) degree of engagement [58]. We believe these outcomes apply equally to engagement involving consumers with chronic conditions and would be of value to include in future evaluations of impact. Future research could also focus on ensuring that consumer engagement processes are meaningful, authentic, and mutually beneficial for both consumer and researchers. In addition to identifying impactful roles for consumers, participants in previous research believed that seeking individual feedback on the impact of engagement was an important driver for improvement and a motivator for future engagement [52].

Strengths and limitations

This review utilised a comprehensive search strategy across multiple databases and a rigorous methodology. It maps existing literature and synthesises resources to support consumer engagement in health research for individuals with chronic conditions. The large number of identified articles underscored the need for a thorough review, offering valuable insights for policymakers and researchers. Systematic screening, involving multiple reviewers, minimized bias, while incorporating consumer insights enhanced the relevance of the findings.

Limitations of the review include a potential oversight of studies due to variations in terminology and search queries. To address this, we consulted a health librarian, refined the search strategy through multiple tests, and employed reference tracking. Another limitation was the focus on peer-reviewed articles, which may exclude non-academic resources. The geographic concentration of studies in the United Kingdom, Canada, and Australia may limit the generalisability of the findings to other regions, where consumer engagement in research is influenced by different healthcare systems, policies, and funding structures. This geographic focus could affect the transferability of the synthesized framework to diverse global contexts. Additionally, while this review provides valuable insights into consumer engagement across a variety of chronic conditions, there is a notable lack of research on consumer engagement in conditions such as asthma, osteoporosis, and chronic obstructive pulmonary disease (COPD), which were underrepresented in the studies reviewed. Conversely, conditions like mental health and dementia were well represented, yet research exploring consumer engagement in conditions with more complex or overlapping symptomatology, such as multiple chronic conditions, remains limited. Despite these limitations, the review draws on a substantial number of studies and follows a transparent process, offering valuable insights for future research on consumer engagement.

Consumer expert group feedback

During our meeting with lived experience experts, the relevance of the studies and frameworks included in the review were confirmed. One of our lived experience team members (LW) reviewed the final draft of the review, including *the resource framework to support consumer engagement in research about people living with chronic conditions* (Fig. 2) and confirmed the relevance and applicability of this in relation to her experiences of being involved in research about people living with chronic and other health conditions.

Conclusion

In summary, this review has described the existing evidence-based resources and provided an overarching framework that synthesises these resources to inform consumer engagement strategies for research about chronic conditions. While resources for consumer engagement in health research are still evolving, more research is needed to develop, expand, and validate these resources further, thereby making them both evidence-based and inclusive in collaborations where consumers and researchers partner in research. We propose that future research could focus on evaluating engagement processes and outcomes, specifically considering the unique and varied chronic conditions of consumers. This approach would enhance the synthesis of existing data and contribute to advancing the resource framework for supporting consumer engagement in health research for individuals with chronic conditions.

Appendix

See Fig. 2 and Tables 3, 4, 5, 6, 7, 8 and 9.

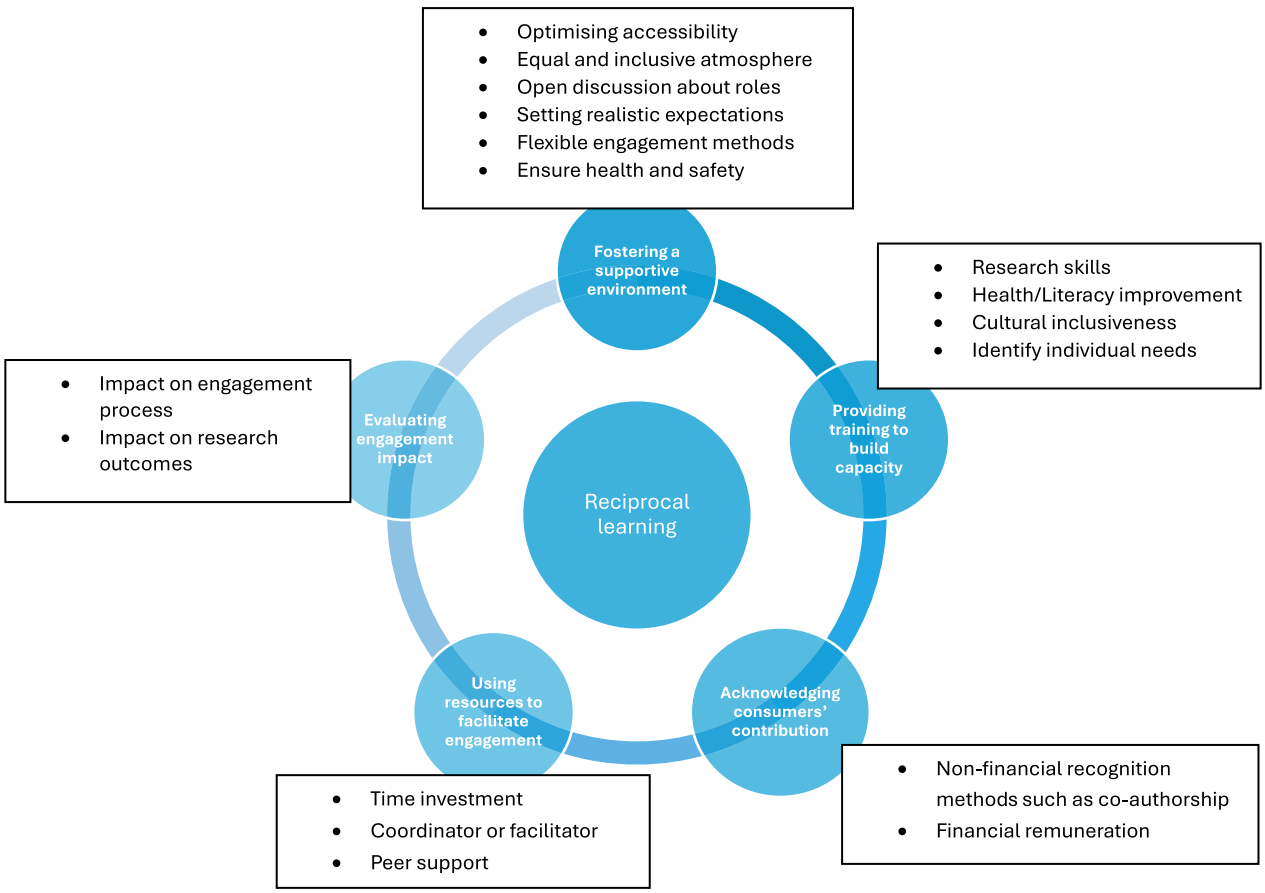

Fig. 2 Resource framework to support consumer engagement in research about people living with chronic conditions

Table 3 Characteristics of included studies

	Author, (year)	Title	Country	Research type	Discipline of resources	Identified Resources from the literature	Objectives of resources
1	Arumugam, (2023) [36]	Patient and public involvement in research: a review of practical resources for young investigators	United Arab Emirates	review	Public and patient involvement in rheumatic and musculoskeletal research	Figure 1 Seven practical ways to get started with patient and public involvement (PPI) in research	Provide a brief review of practical guidance in musculoskeletal and rheumatology research to increase the odds of successful and sustainable PPI in research
2	Banfield, (2021) [47]	Lived experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative	Australia	research article	Consumer engagement in mental health research	Figure 1 The ACT Consumer and Carer Mental Health Research Unit (ACACIA) model of lived experience-led mental health research	Provide a model for meaningfully engaging mental health consumers and carers throughout the research process
3	Desborough, (2021) [14]	A framework for involving coproduction partners in research about young people with type 1 diabetes	Australia	research article	Coproduction in research about young people with diabetes	Figure 1 Involving coproduction partners in research about young people with type 1 diabetes	Develop a theorized framework of mechanisms supporting the process of coproduction in T1DM research with young people
4	Di Lorito, (2017)[42]	A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia	UK	review	Peer research with people with dementia	Table 3 A model of good practice in peer research with people with dementia	Provide a model of good practice on how research studies have worked with people with dementia as peer researchers
5	Evans, (2019) [43]	A co-produced method to involve service users in research: the SUCCESS model	UK	research article	Coproduction in model development involving public members (including people with chronic conditions)	Table 2 Principles of effective involvement agreed by service users	Provide a method, co-produced model by service users to involve patients and carers in research
6	Getchell, (2022) [37]	Program Report: Can-SOLVE CKD Network Presents an Inclusive Method for Developing Patient-Oriented Research Tools	Canada	program report	Research involving people with chronic kidney disease	Figure 1 Can-SOLVE CKD Learning Tree; Table 1. Opportunities for Partnering with Patients in Research; Fig. 3 The knowledge-to-action framework; Fig. 4 Network-wide culture shift	Demonstrate how a diverse group of stakeholders working together can create tools to support high-quality patient-oriented research
7	Goeman, (2019) [48]	Partnering with people with dementia and their care partners,@@aged care service experts, policymakers and academics: A co-design process	Australia	research article	Research involving people with dementia and their care partners	Figure 1 Model for successful inclusion of consumers and community representatives (consumer representatives) in research	Demonstrate how can best support people living with dementia in the community setting

Table 3 (continued)

	Author, (year)	Title	Country	Research type	Discipline of resources	Identified Resources from the literature	Objectives of resources
8	Heffernan, (2017) [46]	Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes	Canada	viewpoint article	Youth engagement in mental health systems research	Figure 1 Model of youth engagement	Describe the development and implementation of a youth-adult partnership model in youth mental health systems research
9	Janevic, (2022) [38]	Making Pain Research More Inclusive: Why and How	USA	review	Consumer engagement in pain research	Table 2 Study Planning and Design Checklist; Table 3 Recruitment, Consent and Retention Checklist; Table 4 Measure Selection Checklist; Table 5 Data Collection Procedures Checklist; Table 6 Data Analysis Checklist; Table 7 Reporting and Dissemination Checklist	Provide guidance for the pain research community on how to adopt inclusive research practices
10	Jennings, (2018) [44]	Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement	UK	research article	Collaborative data analysis involving people with lived experience in mental health research	Figure 1 Best practice framework for collaborative data analysis involving people with lived experience in coding framework co-production	Develop a methodology for involving PPI co-researchers in analysis of qualitative data
11	Ramakrishnan, (2021) [39]	A brief guide to public involvement in cardiovascular research	UK	review	Public involvement in cardiovascular research	Figure 1 Ways that people can be involved in the research cycle	Provide a framework for researchers to use in practice
12	Ristevski, (2022) [40]	The Retinoblastoma Research Booklet: A Catalyst for Patient Involvement in Retinoblastoma Research	Canada	research article	Recruitment of patient partners in health research (cancer)	Figure 3 The Retinoblastoma Research and You! booklet	Provide a recruitment and educational tool to patient engagement in retinoblastoma research

Table 3 (continued)

	Author, (year)	Title	Country	Research type	Discipline of resources	Identified Resources from the literature	Objectives of resources
13	Scottish Dementia Working Group Research Sub-group, (2014) [49]	Core principles for involving people with dementia in research: innovative practice	Scotland	research article	Research involving people with dementia	Experience one: I never heard what happened; Experience two: Knowledge comes from all sorts of places; Experience three: We need to be in a safe and secure environment; Experience four: keep it simple … less is best; Experience five: Why should anyone be let loose, who hasn't had the training …? Experience six: Keep to 'dementia time'	Co-create core principles for involving people with dementia in research
14	Swarbrick, (2019) [45]	Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice)	UK	research article	Involvement of people living with dementia in research	Figure 2 The CO-researcher Involvement and Engagement in Dementia (COINED) Model	Demonstrate how people with a lived experience have been and will be involved in the research process
15	Weiler-Wichtl, (2023) [41]	Good to know—This is PPIE! Development of a training tool for public and patient involvement and engagement in pediatric oncological research	Austria	research article	Implementation of public and patient involvement and engagement (paediatric oncological research)	A white-board movie: "Good to know! That's PPIE (English)"	Develop a training tool for public and patient involvement and engagement in paediatric oncological research

Table 4 Theme 1 results on 'reciprocal learning'

Subthemes	Description
Important component of consumer engagement	Reciprocal learning is an important Y-AP (Youth–Adult Partnerships) component that can facilitate personal and/or professional growth. Reciprocal learning occurs when each party is considered an expert in an area and able to teach the other members, regardless of age or "power." Both youth and adults are "teachers" and "students" in different areas [46] Among the constant learning opportunities for YEFs (Youth Engagement Facilitators), co- authors GC and JH provide context and guidance on navigating oftentimes confusing organizational structures, in addition to practical skills in proposal writing and research. As teachers, YEFs show adult partners how to engage youth more effectively, effective technology use, and strategies for enhancing "youth- friendliness." [46]
Benefits for both consumers and researchers	For the young people (consumers), personal learning was wide-ranging, including empowering one to change and enhance their management strategies… Working with the young people prompted researchers to consider what is important to people who will use the outcomes of their research, and for one participant, created a sense of urgency, reinforcing the value of their work. [14] Knowledge exchange was regarded as fundamental to the advancement of learning for all. There was a general feeling that the process of translating research into practice was often disparate and fragmented. Subsequently, group members advocated the involvement of people living with dementia in presenting research findings alongside academic colleagues in ways which would be creative, accessible and meaningful to all. [45]
A tool to support reciprocal learning	Storytelling was deemed an effective strategy to help research teams and others better understand the patient experience. TMC (Training and Mentorship Committee) patient partners also voiced an interest in hearing researchers' stories, noting that the sharing of stories by patients and researchers alike could create a sense of reciprocity and help build trust. [37]

Table 5 Theme 2 results on 'fostering a supportive environment'

Subthemes	Description
Optimising accessibility	
Simplicity in language	Explain it to your audience—do not supply too much or too little detail when discussing your research. Let people know what is important to them, and do so in a language they understand. [36] These strategies include using simple and jargon-free language, reducing abstract language or concepts, considering non-verbal language as a valid communication tool, avoiding making assumptions, resisting the temptation to finish the peer researcher's sentences and maintaining a relaxed and unhurried attitude. [42] It is important that researchers speak in layman's language. Please keep in simple. Researchers should explain terms each time they use them. Don't use abbreviations and acronyms…All documents about research, for example proposals, information sheets and consent forms that researchers want people with dementia to engage with need to be in clear, accessible language. Researchers should use language which is supportive of people with dementia and consider ways in which language can offend people with dementia. [49] 'Accessibility' featured at the very heart of effective communication, particularly in terms of language and terminology used. [45] Be accessible (including venue, location, language, information, format). [43]
Multiple formats	Choose pictures—understandable pictures can communicate much more information than a column of data. When possible, present data with visual representation (e.g. an infographic). [36] Memory difficulties can be overcome by using visual prompts, such as laminated cards, to aid the peer researchers during the administration of interview questions. [42] Consider the needs for community- and public-facing dissemination products, including graphic design, translation, event/ hosting expenses, video production, etc. [38] Use recruitment videos to explain the study. This can offset potential in-person bias such as spending less time with patients from minoritized groups during recruitment [97]
Multiple channels	Use a variety of channels to disseminate results to participants, communities, and the public. It is important to disseminate beyond scholarly publications; it is a way to give back and helps foster ongoing relationships between academic and community partners. Stakeholder/community advisory board should be involved in dissemination efforts and can help to identify appropriate channels [38] Use mHealth and social media channels for recruiting geographically dispersed groups. These methods can help reach dispersed and invisible communities, e.g., sexual and gender minorities [38] Stakeholder/community advisory board should be involved in dissemination efforts and can help to identify appropriate channels. Examples include: social media, webinars, community talks, "research cafes", and hosting events in accessible locations like faith communities, libraries or movie theaters [38] The brochures are included with bright, eye-catching flyers to advertise research participation opportunities, and as suggested at the forum, the team has expanded its recruitment methods to include social media and nongovernment organizations in addition to consumer and carer organizations [47] They strongly favoured providing feedback on the findings to the community using a variety of methods such as community organization newsletters, public seminars and websites [47] Dissemination of the tools within the network was made possible through the Can-SOLVE CKD (Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease) monthly newsletter and social media, as well as through presentations at the various scientific meetings of the kidney community (i.e., the Canadian Society of Nephrology) and beyond (e.g., diabetes and Indigenous health) [37]

Table 5 (continued)

Subthemes	Description
Reduce transport burden	Consider ways to reduce/offset travel burden for data collection visits. Provide travel funds, transportation, and/or options to collect data remotely (including via sensors). Both recruitment materials and consent forms should state that accommodations are available for people with disabilities, offering the name of a contact person with whom they can discuss their participation [38] Stakeholder/community advisory board should be involved in dissemination efforts and can help to identify appropriate channels. Examples include: social media, webinars, community talks, "research cafes", and hosting events in accessible locations like faith communities, libraries or movie theaters [38] Make clear in the consent form that accommodations are available for participants with disabilities [38]
Equal and inclusive atmosphere	
Addressing power imbalances	Equality and self-determination among members of the research team were felt as fundamental conditions for meaningful involvement…In order to facilitate the process of involvement, academics should re-evaluate the concept of partnership and commit to fully involve peer researchers in order to avoid the type of one-off consultation that would give the impression that academics only want to tick the user-involvement box [42] As the number of patient partners and the scope of their involvement in the network increased, there was a natural shift from historically perceived power imbalances between patients and clinicians/researchers to the development of true partnerships… To further achieve its goals of creating a collaborative environment, the TMC adopted and expanded upon Kirkness and Barnhardt's 4 Rs, which include Respect, Relevance, Reciprocity, and Responsibility. The iterative nature of the TMC's ((Training and Mentorship Committee)) work resulted in an additional R, Reflection. These core values were critical for ensuring equitable partnerships between researchers and non-researchers and challenging the dominance of "expert knowledge" by actively engaging, exchanging, incorporating, and valuing diverse perspectives from all stakeholders on the TMC (Training and Mentorship Committee) [37]. Be mindful of labelling: people hold multiple identities, and categorisation can cause inter-group tensions. Be vigilant for power imbalances, which may occur even with the best of intentions…Listen to and explore differences of opinion. When non-consensus occurs, try to create novel synthesis to acknowledge the range of perspectives…Clearly set out the PPI (Patient and Public Involvement) co-researcher role and expected time commitment, and how their contributions will be valued and incorporated [44].
Enabling autonomy in governance	Advisory groups are one of the better-established methods of involvement and a very good method for embedding partnerships at the research governance level. ACACIA's (ACT Consumer and Carer Mental Health Research Unit) Consumer and Carer Advisory Group is a core element of our model [47]. The research team worked with people with dementia and/or their care- partners to ensure that consumer representatives were embedded at research governance levels, that all members were listened to, received information that was accessible and suited to their individual needs and that involvement was not unreasonably costly [48]. Working and reference group teleconferences focused on the progress and aims of the study with the aim of guaranteeing everyone, including consumer representatives, an opportunity to participate equally which was identified as critical for consumer involvement [48]. Authentic decision- making opportunities were built into NYAC (National Youth Advisory Committee) including on- going open dialogue with members about NYAC structure and operations which has resulted in recommendations that have been implemented [46]. Ensure there are people with lived experience in the research team [44].
Fostering mutual communication and feedback	As part of ACACIA's development in partnership with the broader mental health consumer and carer community, our inaugural event was a research priority-setting forum. The forum had two main components: (i) to identify and prioritize consumer and carer topics for research and (ii) to explore consumer and carer views on methods of active involvement in research (described in the next section) [47]. An important outcome for PPI contributors was responsive design, where they were able to see their advice and suggestions incorporated into device prototypes. This demonstrated the value of their input and fed into their sense of being listened to, contributing towards their continued readiness to contribute [14]. Through a two-way process, individuals involved in research projects as SUCCESS (Service Users with Chronic Conditions Encouraging Sensible Solutions) members shared information about their activities with the Panel, who in turn provided contributions based on their experiences to enhance the input of each individual [43]. TMC (Training and Mentorship Committee) members were motivated to ensure all voices around the table were equally heard, and everyone's opinion was valued. One effective approach for bringing members of the team together as equals was the use of the "talking circle." [37] We want researchers to come back and tell us the outcome of research that we have been involved in. Please be honest and don't bury 'bad' findings." [49]

Table 5 (continued)

Subthemes	Description
Facilitating a sense of being valued	This sense of being valued was echoed in comments from Advisory Group member and author SH, who characterized her experience with ACACIA as 'unique'. 'I don't know of anywhere else I could volunteer which is within a research institute or is focused on research. There doesn't seem to be volunteer opportunities in the academia space, so this is really special. Gives us more credit for our abilities. Even just having people truly listen to us in this space, is important and can be therapeutic in itself I feel [47]. Young people felt respected and listened to in meetings, enabling them to feel free to express their ideas. They knew that their ideas would be considered seriously by the researchers, who was present at a meeting was a condition that supported participants' contribution, influencing how comfortable they were with others in the group, also linked to a sense of respect for their expertise. All participants recognised the value of lived experience [14]. They encouraged service user involvement in research and demonstrated that they valued their contributions by: proactively seeking service users to join research projects; making involvement a standing agenda item in meetings to ensure service users contributed and to give status to their involvement; creating an accessible environment with non-jargon meetings, a welcoming atmosphere and meeting times to allow travel arrangements; directing research and administrative staff to involve and support service users [43]. Viewing everyone as having expertise, NYAC (National Youth Advisory Committee) members have collaborated with YEFs to create webinars on topics they feel comfortable teaching to others and broadcasting to NYAC members [46]. Involve Stakeholder/ Community Advisory Board in data interpretation. Board members can bring new perspectives to data interpretation, and the process of examining data can strengthen partnerships [38]. Research team amend preliminary framework on the basis of PPI co-researcher contributions: Research team circulate to PPI co-researchers for further comment and refine to develop coding framework… Final coding framework is shared with PPI co-researchers for further comment and refinement. Undertake a joint reflective exercise on the CDA (Collaborative Data Analysis) process, identifying amendments [44]. It is important that researchers use the views and experiences of people with dementia as 'knowledge'. The process of setting research agendas should happen in a mutual relationship between people with dementia and researchers. This should include people with dementia being involved in setting research priorities, for example researchers asking people with dementia what a positive outcome would look like for them [49] The data collected by a co-researcher would inevitably provide different levels of richness, depth and context compared to data collected by an academic researcher." [45]
Promoting cultural diversity	Exhibit a culture which is inclusive and equally values the contributions of all participants including service users and researchers [43] This fourth branch (of training) aimed to enhance researchers' and network members' knowledge and awareness of racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health, and promote cultural safety [37] Engage a wide range of stakeholders where feasible: patients, family members, community members, representatives of professional organizations, advocacy groups, clinical staff including social workers and chaplains, and/or health department staff and representatives from insurance companies. Build cultural and language diversity on the research team [38] Consider whether the people you are involving are truly representative of the population you are targeting. Diversity is key [39]
Respecting confidentiality	We encourage safe, reflexive use of personal experience when conducting research projects and training, but the level of disclosure of specifics is a decision for each individual [47] Undocumented individuals may have concerns about the legal consequences of participation. Anticipate potential sources of harm and mitigate them appropriately. Use pseudonyms and consider obtaining verbal consent to minimise the risk of a breach of anonymity [38]
Open discussion about roles	
Provide role descriptions	Provide clarity about roles and responsibilities [43] Develop roles, expectations, and accountability mechanisms for engaged stakeholders [38] Co-develop a detailed session plan incorporating success characteristics and specifying timings, content and roles (narrative & group dynamic facilitators, data recorders / field note-makers, timekeeper). Explain the PPI co-researcher role, and why their input is valued [44] This learning branch was designed to support the development of teams composed of patient partners and health research team members (primary investigators, research staff, KT brokers, etc.). It involved the development of a toolkit with a suite of resources targeted to help teams communicate, create a shared vision and common goals, and define roles for patients within the research team [37] Ensure people are clear about their roles by providing role descriptions/ ground rules/terms of reference [39]
Multiple expert roles	Participants identified seven expert roles in the first part of the interviews: 'lived experience expert', 'professional expert', 'research implementer', 'teacher/translator', 'being present', 'free speaker' and 'supporting another'…Participants believed that one expert role could be enacted by multiple individuals, or one individual could enact multiple expert roles." [14]
Evolving roles	The discussion should ideally continue throughout involvement, as research roles should be flexible and renegotiable according to the presenting circumstances…" [42]
Time of discussion	Defining each researcher's involvement and role at the initial stage of collaboration helps create the conditions for effective involvement of peer researchers." [42] Researchers should ask people with dementia how they want to be involved in research, including at what points and in what ways they want to be updated. Different people will have different views on this [49]

Table 5 (continued)

Subthemes	Description
A tool to facilitate discussion	Tools that encourage conversation and provide clarity regarding roles and expectations may be useful for PPI in research. The "involvement matrix" use a participatory research methodology in which meaningful conversations between patients and researchers are made possible. Five separate roles—a listener, cothinker, adviser, collaborator, and decision maker—have been recognised, despite the matrix including three phases of research (preparation, execution, and implementation). The engagement matrix enables researchers to categorize and quantify patient roles in the progression of research studies. Patients might specify their preferred role when speaking with the researcher. The participation matrix is likely one of the best available tools for facilitating PPI in research [36]
Setting realistic expectations	
Be mindful about consumers' and other experts' priorities	Having expertise of living with T1DM (Type 1 Diabetes Mellitus) carried a sense of responsibility to people with T1DM more broadly, but such responsibility had to be balanced with managing competing priorities for their time. For example, professionals referred to work commitments, whereas the young people referred to sport and homework impacting their capacity to contribute to the project." [14]
Appropriate time for discussion	It was also important to discuss these expectations at the outset to ensure individuals were comfortable with the evolution of ideas [37] Researchers need to consider 'dementia time' in their expectations of research, including finding out the best time and how each individual keeps track of time. Researchers should always re-cap on previous conversations or interviews each time they meet with people with dementia [49]
Assigning manageable tasks	Keep the data set relatively small and do not present people with too much raw data. Ensure the data analysis process is adjusted to take into account the strengths and needs of PPI co-researchers and is 'failure free' [44] Focus on specific tasks to which consumers and carers can easily contribute. One such task was non-academic input on participant information sheets to ensure their suitability for consumers and carers. Several participants commented that the information sheet for the forum, which was developed from a compulsory university template, was too long and not particularly engaging. They felt it could have been improved with feedback from people in the groups it targeted [47]
Flexible engagement methods	
Requested needs from consumers	Even though respondents experienced a range of different health conditions, their requirements for being involved in the workshop were similar. They asked for: meeting times which allowed for relaxed travel arrangements; good parking at venues; preconfirmed meal times so they could manage medication; access to a quiet room or option to leave early if needed [43]
Flexible arrangements	Recruit and engage participants in ways that work best for them. Forum participants were interested in strategies for making research more engaging, from recruitment through to the communication of findings. They suggested that many mental health consumers and carers prefer 'personal' methods of participation, such as face-to-face interviews, and suggested rapport was better with other consumers or carers, particularly for relating personal stories. A key message from the discussion on methods of involvement was that no one size fits all. Participants indicated that the optimal strategy was to employ a variety of methods and to identify opportunities to partner with consumers, carers and organizations throughout the research process [47] Skype and phone participation was arranged for individuals unable to travel to meetings. Meeting times were altered to suit train travel times. Briefing sessions were held, with the facilitator or research staff, to provide extra information requested by service users. Administrative staff were encouraged to support and ease processes by booking carparking spaces and overnight accommodation, arranging suitable refreshments, processing paperwork and taking phone calls [43] Regarding work hours, the team adopted a flexible approach, trusting YEFs (Youth Engagement Facilitators) to determine their own schedules with manager approval. These steps addressed YEFs' unique needs, and were also important to the task of engaging youth most often available evenings and weekends [46] When considering all of the above, researchers should consider creative methods and new ways for creating new knowledge in partnership with people with dementia [49]
Allowing opt—in or opt—out	Allow opting in or out of specific study procedures on the consent form. This may be helpful where some components of the study might be culturally non-congruent, invasive or painful procedures, or particularly time-consuming elements [38]
Ensuring health and safety	
Safeguarding well-being supported by researchers	Many of the participants made suggestions for safeguarding participant well-being to ensure a wide range of people with lived experience has the opportunity to share their perspectives in research. A key suggestion was to offer interview and focus group participants the opportunity to bring a support person with them to provide solidarity and help participants feel comfortable sharing their perspectives in a research setting [47] Due to concerns about possible effects on headaches and mental health, especially during Canada's dark winter months, YEFs used light therapy lamps at their desks and were permitted daily use of nearby meeting rooms with large windows [46]
Ethics committee's role	The ethics committee verifies that the safety, integrity and rights of the participants in a research study are safeguarded, to provide opinions and create training opportunities on the ethical aspects of practice and research in biomedical sciences [36]
Providing emotional support	The research team should make some form of counselling and emotional support available to peer researchers, who may feel distressed when hearing their peers' stories during the interview sessions [42] People with dementia taking part in research should always be offered counselling or emotional support: (Researchers) Find out where 'safe zones' are (both physically and emotionally) and meet us there. Be aware that research has the potential to take people with dementia outside of their 'safe zones' and be ready to respond [49]

Table 6 Theme 3 results on 'providing training to build capacity'

Subthemes	Description
Research skills	
Training for consumer partners	The principal investigator must ensure that patient research partners receive information and training appropriate to their roles [36] Conduct skill-building workshops to facilitate greater involvement of consumers and carers in the research process. Participants commented that a barrier to involvement was a lack of knowledge on how to effectively conduct data collection such as interviews and surveys [47] Training of peer researchers was identified as essential in all papers. Offering practical research training represents an invaluable opportunity for the peer researchers to develop their research skills and familiarise with a project. Research training could also be instrumental for peer researchers to develop their confidence to take on the responsibility of doing research (Rose, 2003), to become aware of their own capacities and limits, to understand the context of social research and the practicalities of the study (Clough et al., 2006) and to discuss the questionnaire and exercise interviewing skills (Tanner, 2012) [42] Provide training that ensures people can successfully complete the CDA they have been asked to do [49, 50]. Do 'warm up' activities that align with the CDA tasks people are being asked to undertake [48]. Use practical, visual aids like post-it notes and flip chart paper to support analysis tasks [44, 48, 49] Ensure those involved and those facilitating are trained and supported adequately. [39] Researchers should create opportunities for us (patient researchers) to develop our research skills so that we can be involved in influencing knowledge about dementia [49]
Providing ongoing training throughout project	Underpinning the COINED (CO-researcher INvolvement and Engagement in Dementia) Model is training and support for co-researchers, which we recommend should be provided for the duration of the research [45]
Health/Literacy improvement	
Training for researchers	We are going to create some training resources for researchers. They should read these before coming to meet with us as a group. These will include training about dementia and about how researchers should support people with dementia. It is important for researchers to know that we are all different. This includes the fact that there are lots of different types of dementia that can affect people differently [49]
Training for consumers	The resultant Retinoblastoma Research and You! booklet (Fig. 3 provided in a hard copy and digital version was created to be accessible to those with low and impaired vision by incorporating accessible design standards. The booklet outlines how individual patients' lived experiences and skills can influence retinoblastoma research with their participation in CRRAB (Canadian Retinoblastoma Research Advisory Board) activities [40] This tool aims at explaining the basics PPIE terminology, the various roles patients and the public can adopt, and the various possibilities its implementation [41]
Cultural inclusiveness	Provide training for research team members in cultural humility, implicit bias, and communication strategies. This includes an examination of personal, professional, and research values that may guide actions. Include implicit bias training that helps researchers recognise how stereotypes and biases can be deeply embedded in their assumptions and cognitions and require ongoing examination to change these assumptions and related behaviours [38]
Identifying individual needs	Given that dementia can be experienced very differently among different individuals, the training sessions should be tailored to the peer researcher's needs in order to maximise the results [42]

Table 7 Theme 4 results on 'acknowledging consumers' contribution'

Subthemes	Description
Non-financial recognition method	
Co-authorship or acknowledgement on publication	The contribution of patient research partners to projects should be appropriately recognised, including co-authorship when eligible [36] In publications, describe stakeholder engagement in detail. This adds validity to the study processes and will also promote the adoption of engagement strategies by other pain researchers [38] PPI co-researchers are offered the opportunity to be co-authors in project outputs [44]
Financial remuneration	
Reason for remuneration	Patients have the right to remuneration and that the level of remuneration should be equitable, optimal, and suitable for the services offered without exceeding the market value. Many patients are willing to volunteer without remuneration; yet equity, diversity and inclusive input is best achieved with PRPs as part of the remunerated research team [36] Financial support provided to enable consumer attendance at meetings [48] In accordance with best practice for consumer and carer involvement (National Health and Medical Research Council and Consumers Health Forum of Australia, 2005, 2016), any members of the group who are not in receipt of a salary for their participation are paid a reimbursement in recognition of their contributions [47] Pay people for their time in addition to travel expenses and refreshments in line with NIHR INVOLVE guidance [39]
Budget items for remuneration	Budget items related to stakeholder engagement: payments for patient advisors/partners and other Advisory Board members time and input, funds to hold meetings in community locations. Budget items related to inclusive recruitment and data collection practices: materials for community-engaged dissemination, translation of research-related materials into other languages, tablets for multimedia informed consent, transportation and child/elder care costs, and snacks/refreshments [38] Be well resourced (including travel and carer costs, support, training) [43] Resource implications. Adopting good practice in peer research can significantly increase research costs due to providing training or financially compensating peer researchers, to refunding travel expenses or to paying support workers to accompany the peer researchers on research activities [42]
Factors affecting remuneration	Involvement levels may change accordingly throughout the research phases/process. Payment of PRPs (Patient Research Partners) should reflect expertise level, time commitment, responsibility, type of work involved, and the extent of participation considered [36] Ensure that compensation and incentives are appropriate and accessible. Compensation should adequately reflect time investment and disruption to daily life. If it is not possible to offer cash, consider electronic cash transfers, as checks and gift cards may present barriers to individuals without bank accounts or transportation. Incentives should not require a social security number or other proof of citizenship [38]

Table 8 Theme 5 results on 'using resources to facilitate engagement'

Subthemes	Description
Time investment	Ensure sufficient resources exist, e.g. time and money to organise and facilitate CDA (Collaborative Data Analysis). Do not underestimate this. Academic researcher facilitators felt that more time was needed for PPI co-researchers to complete the CDA tasks, especially regarding areas of ambiguity and achieving rationalisation and reconciliation in the analyses [44] Allocate time and money in budget for meaningful engagement with stakeholders and to support inclusive recruitment and data collection practices [38]
Coordinator or facilitator	
Role of facilitator	The facilitator role was identified by service users as necessary to coordinate and support the operation of the model. The role included: distributing information to the SUCCESS (Service Users with Chronic Conditions Encouraging Sensible Solutions) Panel; convening SUCCESS Steering Group meetings; promoting the SUCCESS Panel to researchers; and recruiting service users for research activities. The facilitator also provided training within the SUCCESS meetings about research skills, structure and organisations within the research setting. The facilitator provided briefing sessions about research studies for individuals who became involved in research opportunities as a SUCCESS member [43] The forum facilitator invited participants to suggest ways of ensuring that consumers and carers actively participated in the research process across the five stages of research as conceptualized by the National Health and Medical Research Council and Consumers Health Forum (National Health and Medical Research Council and Consumers Health Forum of Australia, 2005, 2016): deciding what to do, deciding how to do it, doing it, letting people know the results and knowing what to do next [47] Consider engaging a trial navigator. For outreach to marginalized populations, lay navigators can help address participants' practical and logistical barriers to clinical trial recruitment and retention [38]
Impact of facilitator	These aspects of the facilitator's role enabled many of the principles of effective involvement (Table 2) to be achieved, such as: instilling inclusive and respectful values; resourcing involvement; ensuring accessibility and mutual communication [43]
Payment of coordinator/facilitator	Given the competing demands on volunteer committee members, the involvement of a paid coordinator became necessary for overseeing day-to-day activities and following up on outstanding actions. Among the coordinator's responsibilities were detailed note taking and retaining of all documentation so that the group discussions and decision-making would be tracked at every stage. This ensured the necessary work was accomplished and the committee stayed on track [37]
Peer support	
Reason for peer support	Decisions about participation are often linked to family and community involvement and costs. Partner with institutions that have a historical bond with community. These might include local physicians, businesses, advocacy groups, and/or faith-based communities. Accommodate understandably protective attitudes of family members/community leaders. Invite family members to information sessions/screenings so that they can also ask questions and express concerns. Hold townhall meetings or newsletters to ensure transparency and allay fears. Consider providing incentives to family caregivers of research participants (e.g., compensated for time off work) [38]
Importance of peer support	The importance of peer support in providing a community network is essential in maintaining wellbeing, self confidence and a sense of security within an ever-changing environment [45]

Table 9 Theme 6 results on 'Evaluating engagement impact'

Subthemes	Description
Impact on engagement process	Develop a strategy for evaluation and capturing impact early on. Keep a log of involvement activities and detail how you plan to evaluate their impact [39]
Impact on research outcomes	Discussions extended to narrative of 'evaluation', which was regarded as an integral mechanism of the research in 'measuring' impact, which was necessary to ensure that we are 'getting it right'. It was felt that the processes and outcomes of any evaluation would be crucial to our learning and should be embedded within further decision-making [45]

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40900-025-00707-1.

Supplementary material 1.

Acknowledgements
The authors gratefully acknowledge the contributions from the team of lived experience experts from The Real Price of Health research project [35]: Ms Kamania Butler (Lived experience expert), Ms Fiona Hodson (Chronic Pain Australia), Ms Samar Ibrahim (Lived experience expert and cultural advisor), Ms Jillian Kingsford Smith (Lived experience expert), Ms Julie Veitch (Lived experience expert).

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Mingming Zhou: conceptualisation, methodology, data collection, data analysis, writing—original draft, review and editing. Anne Parkinson: supervision, methodology, data collection, data analysis, validation, writing—review and editing. Mengyu Lyu: data collection, writing—review. Hanna Suominen: data analysis, writing—review and editing. Leanne Watts: lived experience expert, data analysis, writing—review. Jane Desborough: supervision, conceptualisation, methodology, data collection, data analysis, validation, writing—review and editing.

Funding
This project was funded by the Australian Research Council, Discovery Early Career Researcher Award #DE220100663, The Real Price of Health: Experiences of Out-of-Pocket Costs in Australia.

Availability of data and materials
No datasets were generated or analysed during the current study.

Declarations

Ethical approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Received: 23 December 2024 Accepted: 29 March 2025
Published online: 29 April 2025

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