

ORIGINAL RESEARCH

# Consumer involvement in the development and dissemination of chronic kidney disease guidelines: a summary of a meaningful and sustainable approach developed by Caring for Australians and New Zealanders with kidney Impairment guidelines

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Accepted 18 March 2024; Published online 26 March 2024

## Abstract

**Objectives:** The involvement of consumers (people with lived experience of disease) in guidelines is widely advocated to improve their relevance and uptake. However, the approaches to consumer involvement in guidelines vary and are not well documented. We describe the consumer involvement framework of Caring for Australians and New Zealanders with kidney Impairment Guidelines.

**Study Design and Setting:** We used a descriptive document analysis to collate all relevant policies, documents, e-mails, and presentations on consumer involvement in our organizations. We performed a narrative synthesis of collated data to summarize our evolving consumer involvement approach in guidelines.

**Results:** We involve consumers at all levels of Caring for Australians and New Zealanders with kidney Impairment guideline development and dissemination according to their capacity, from conducting consumer workshops to inform the scope of guidelines, to including consumers as members of the guideline Working Groups and overseeing operations and governance as members of the Steering Committee and staff. Our approach has resulted in tangible outcomes including high-priority topics on patient education, psychosocial care, and clinical care pathways, and focusing the literature reviews to assess patient-important outcomes. The ongoing partnership with consumers led to the generation of consumer version guidelines to improve guideline dissemination and translation to support shared decision-making.

Funding: CARI Guidelines receives funding from Kidney Health Australia, Australian New Zealand Society of Nephrology, and National Health and Medical Research Council (NHMRC) Program Grant – BEAT-CKD (APP1092957). The funding organizations had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript. C.G. is supported by a National Health and Medical Research Council Postgraduate Scholarship (APP2014258). A.J. is supported by a National Health

and Medical Research Council (NHMRC) fellowship (APP1106716). D.J.T. is supported by an NHMRC Emerging Leadership 1 Investigator Grant (APP1197337).

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**Conclusion:** Meaningful consumer involvement can be achieved through a comprehensive approach across the entire lifecycle of guidelines. However, it must be individualized by ensuring that the involvement of consumers is timely and flexible. Future work is needed to assess the impact of consumer involvement in guideline development. © 2024 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

**Keywords:** Consumer involvement; Patient participation; Clinical practice guidelines; Knowledge translation; Shared decision-making; Health communication

### Plain language summary

Clinical practice guidelines (known as guidelines) provide recommendations for healthcare for conditions or diseases based on the best available evidence. Guidelines have traditionally been developed by and for healthcare professionals. However, it is increasingly recognized that the perspectives and values of consumers (people with lived experience of disease) are essential to developing acceptable guidelines to improve care and patient outcomes. Despite the importance of involving consumers in guideline development, there needs to be more guidance on what methods should be used and their potential outcomes. We describe the framework for involving consumers in the Australian and New Zealand guideline developers in chronic kidney disease (Caring for Australians and New Zealanders with kidney Impairment Guidelines). Our framework incorporates consumers at all levels, from identifying topics to include in the guidelines to ongoing involvement in writing guidelines and roles in our organization's administration and governance. The comprehensive approach we have developed has evolved and been adapted according to available resources and feedback from people with lived experience of chronic kidney disease.

## 1. Introduction

Clinical practice guidelines (referred to as guidelines throughout) aim to provide recommendations for management based on synthesized evidence and expert opinions, but the perspectives of ultimate recipients of care are often overlooked. The involvement of people with lived experience of disease, including patients or carers (referred to as consumers throughout), is recommended by peak guideline development organizations [1,2]. The Appraisal of Guidelines for Research and Evaluation II instrument for evaluating guidelines states that developers should seek consumers' views and input to improve the relevance of the guidelines [1]. Consumer involvement is defined as "being carried out 'with' or 'by' members of the public rather than 'to,' 'about,' or 'for' them" [3]. Consumer involvement can enhance the uptake and impact of guidelines by increasing acceptability and fostering self-management to improve health outcomes [4]. Consumer involvement provides opportunities for wider dissemination to the broader community through developing consumer versions using accessible language and formats [4,5]. However, the process is often not reported [6]. Benefits for consumers involved in guideline development include increased knowledge about their condition, the ability to connect with other consumers and health professionals, and an opportunity to provide insights from their lived experience [5].

The involvement of consumers includes active participation and critical input during the formation of recommendations, whereby consumers are valued and supported as

equal members of the Working Group. However, there is little description of effective and sustained consumer involvement in guideline development [6]. There are concerns that current approaches are tokenistic [7] and limited by inappropriate clarity of a consumer's role and power imbalances between healthcare professionals and consumers [8], as well as challenges of access to consumers and sustained engagement [9]. For consumers with chronic kidney disease (CKD), involvement can be challenging due to the intense, unpredictable, and unrelenting burden of treatment and illness, which may impact their capacity to contribute [10,11]. Meanwhile, for guideline groups that are often inadequately resourced, the involvement of consumers can often seem challenging. We aim to describe our approach to consumer involvement in developing and disseminating CKD guidelines, and the utility of methodological approaches undertaken to provide a framework for enriched guideline development.

## 2. Methods

Caring for Australian and New Zealanders with Kidney Impairment (CARI) Guidelines was established in 1999. We have documented CARI Guidelines processes and experiences to describe our approach and detail the outcomes, that is, achievements and outputs of consumer involvement in our organization. Authors (N.S.R., C.G., and D.J.T.) collated all documentation (e-mails from consumers, Steering Committee meeting agendas and minutes [3 per year

**What is new?**

- Consumer involvement in clinical practice guidelines has resulted in identifying patient-important outcomes to evaluate and high-priority topics to address in guideline development.
- Partnering with consumers has led to the development of consumer versions of guidelines, improving their dissemination and translation.

**What this adds to what was known?**

- Consumer involvement in guidelines is widely advocated, but there has been limited reporting of the methods and approaches undertaken.

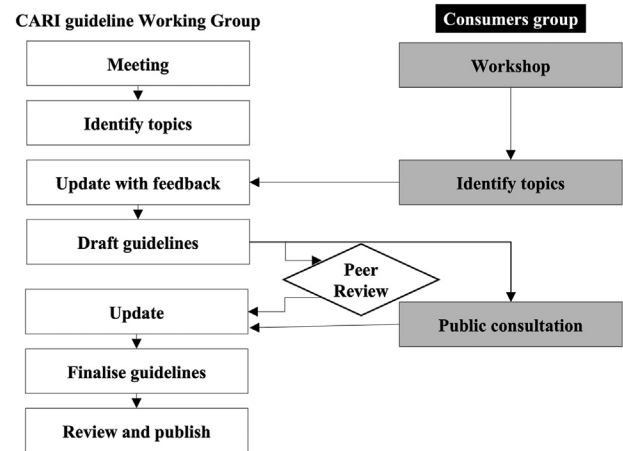
**What is the implication and what should change now?**

- Consumer involvement should be across all stages of guideline development, from governance, scoping, writing, and dissemination of guidelines.
- Tailoring consumer involvement into achievable, flexible tasks can ensure a more meaningful engagement that meets the needs and priorities of consumers.

since 2004], minutes from consumer meetings [1-2 per year since 2018]), policies documents since 2009, publications and transcripts from five consumer workshops, including illustrative quotations, and guideline development handbooks (30–50 pages) and undertook a descriptive document analysis [12] to avoid loss of organizational knowledge. The findings were summarized using narrative synthesis according to methods and outcomes to explore the relationships between organizational decisions, approaches, and outcomes individually by the consumer authors (N.S.G. and G.C.). Any differences were resolved with D.J.T. The resulting manuscript was reviewed by a multidisciplinary team and updated based on their feedback.

**3. Results**

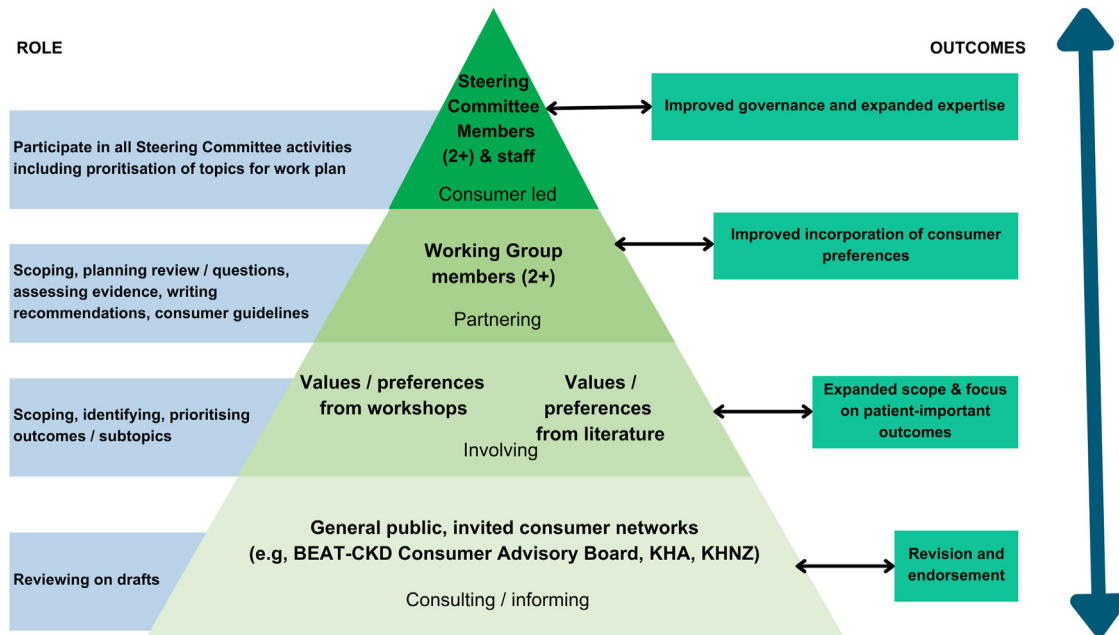
From the review of CARI Guidelines documents, we describe CARI Guidelines consumer involvement guideline framework (Fig. 1). A summary of consumer involvement in CARI Guidelines is provided in Table 1. CARI Guidelines criteria for consumer involvement are lived experience of disease and diversity of membership. Before 2009, consumer involvement in CARI Guidelines was limited to an individual consumer on the Steering Committee and usually, one consumer was asked to provide input on the subtopics of a guideline. However, the feedback



**Figure 1.** CARI framework for consumer involvement. BEAT-CKD, Better Evidence and Translation – chronic kidney disease; KHA, Kidney Health Australia; KHNZ, Kidney Health New Zealand.

from consumers was there was a power imbalance between consumers and healthcare professionals, and they required increased support and training for meaningful input. The model was limited by inexperience, lack of expertise, and resources to support engagement and lack of clearly defined consumer expectations. Since 2009, to address the concerns of power imbalance and tokenism, CARI Guidelines have undertaken a gradual approach in an externally funded low-resource setting to involve consumers in guidelines to ensure consumer time and priorities were valued by the organization according to the appropriate skills. Fundamental to expanding consumer involvement has been the establishment of the Better Evidence and Translation CKD (BEAT-CKD) national consumer advisory board of more than 40 consumers from around Australia in 2015. BEAT-CKD has allowed CARI Guidelines to engage with the kidney community [26,27], whereby consumers self-nominate to projects, including guidelines Working Groups, and are consulted to review of the guidelines. CARI Guidelines also engage with organizations focused on consumer advocacy for kidney disease, including Kidney Health Australia and Kidney Health New Zealand.

First, CARI Guidelines convened face-to-face consumer-involvement half-day workshops to identify consumer priorities for topics and outcomes to inform guideline scope, matching the staff’s qualitative research expertise. Consumers purposively sampled from participating hospitals are invited to participate. At the workshop, a facilitator provides a short introductory session on guidelines and the workshop’s aim. Focus groups are conducted with six to eight consumers to discuss perspectives of the disease and treatment to identify and prioritize guideline topics and important outcomes for evidence review. A plenary session is convened, whereby each focus group presents findings. The focus groups and plenary sessions are audio-recorded and transcribed verbatim. Workshop findings were synthesized, and a report is produced and



**Figure 2.** CARI guidelines consumer workshop framework. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

circulated to participants for feedback before being considered by the guideline Working Group (Fig. 2). To date, CARI guidelines have convened five consumer workshops (Table 1) for guidelines on (1) early CKD [15], (2) autosomal dominant polycystic kidney disease (PKD) [17], (3) infection control in hemodialysis units [20], (4) kidney biopsy [5], and (5) kidney stones. Due to limited resources, often only one workshop per guidelines occurs. The transferability of the workshops findings may be limited due to the participants often being from urban locations. All consumer workshops have expanded the scope of the five guidelines to include patient education and psychosocial care topics. For example, the isolation of people with infectious diseases in hemodialysis units led to distress and the need for clear guidance to inform expectations and improve communication between patients and healthcare providers.

*“The evidence might say you have to isolate them, but the guideline should say what you should do to make sure that the person isolated is not feeling stigmatized, upset, and alone.”* (Consumer, Infectious control in hemodialysis units workshop [20])

As a result, the infection control in hemodialysis guidelines included recommendations on education and communication regarding isolation and cohorting [18]. As another example, consumers involved in the kidney stones workshop suggested that care across medical specialties should be coordinated, particularly when first presenting to the hospital in an emergency, that is, for kidney stones—associated pain. Hence, the kidney stones guidelines have focused on education coordination across medical specialties and Allied Health across guideline subtopics.

*“I struggled to get care initially. It was really hard to get anyone to help me. I could not get any care.”* (Consumer, Kidney Stones Workshop, 2021—manuscript in preparation)

Across the workshops, consumers expressed the need for the management of their disease to be made explicit in terms that they could understand to facilitate their active involvement in shared decision-making. Additionally, two of the five workshops have resulted in different outcomes to those identified by the Working Group to be included in the evidence review process, such as life participation measures and social impact, that is, fatigue and quality of life measures [15,17]. The partnership developed between consumers and CARI Guidelines led to the continuing involvement in reviewing and endorsing the guidelines (Fig 1).

Feedback from consumers at the workshops focused on the need to translate guidelines to support shared decision-making, which led to developing a consumer version of the guidelines. Cocreated consumer-version guidelines in easy-to-understand language designed to meet the Centers for Disease Control eighth-grade reading level [28] and increased graphics were first developed for autosomal dominant PKD guidelines [16,29]. Eight people involved in the consumer workshops reviewed the proposed scope of the topics and the draft version of the guidelines. The guidelines were then disseminated via CARI Guidelines and consumer advocacy organizations Kidney Health Australia and PKD Australia consumer networks. Our work has led to ongoing projects in codesigning resources to support shared decision-making in autosomal dominant PKD [30]. However, in the development of these consumer-

**Table 1.** Summary of consumer involvement for CARI guidelines

Guideline	Consumer involvement workshop/ Yarnings	Working group involvement	Consumer-version guidelines	Outcomes
Early CKD [14]	Two workshops with four focus groups [15]—15 people and caregivers with lived experience of CKD with introductory 30-min session on guidelines provided	No	No	<ul style="list-style-type: none"> <li>Identified consumer-important outcomes (social impact, long-term adverse events, test accuracy, discomfort and pain) to be examined in the evidence review.</li> <li>Included additional topics on consumer education on prognosis, symptoms, and expectations of disease.</li> <li>Developed lay summaries of the guidelines.</li> <li>Consumer endorsement of the guidelines.</li> </ul>
Autosomal dominant polycystic kidney disease [16]	One workshop with three focus groups [17]—13 people with autosomal dominant polycystic kidney disease and three caregivers with introductory 30-min session on guidelines provided	No	Yes—Developed (one-page and four-page summaries) by six patients and two caregivers involved in consumer involvement workshops	<ul style="list-style-type: none"> <li>Included outcomes focused on the wellbeing, such as quality of life.</li> <li>Added nonpharmacological management of disease, pain management, and psychosocial care topics.</li> <li>Guidelines were endorsed by consumers.</li> <li>A consumer version of the guidelines was developed.</li> <li>Ongoing funding for codesigned knowledge translation of guidelines</li> </ul>
Infection control in hemodialysis units [18,19]	One focus group [20]—eight people receiving hemodialysis and three caregivers with introductory 30-min session on guidelines provided	No	In development	<ul style="list-style-type: none"> <li>Topics on privacy and confidentiality, psychosocial care, quality of transportation, psychosocial care of patients in isolation, patient/caregiver education and engagement, and patient advocacy were topics added to the guideline.</li> <li>Guidelines were endorsed by consumers.</li> </ul>
Kidney biopsy [21]	One workshop with three focus groups [5]—10 people who have undertaken a kidney biopsy and seven caregivers with introductory 30-min session on guidelines provided	No	Yes—Developed by two people with lived experience and caregivers self-nominated from consumer organizations	<ul style="list-style-type: none"> <li>Topic on patient care and education were added to the guidelines.</li> <li>Guidelines were endorsed by consumers.</li> <li>Consumer version with summaries and infographics of the guidelines were developed.</li> </ul>

(Continued)



Table 1. Continued

Guideline	Consumer involvement workshop/ Yarnings	Working group involvement	Consumer-version guidelines	Outcomes
Kidney Stones <sup>a</sup>	Two workshops with five focus groups <sup>a</sup> —28 people with recurrent kidney stone disease with introductory 30-min session on guidelines provided and focus group lead by consumer member of Guideline Working Group	Yes—two people with kidney stone disease involved in workshops or self-nominated supported by consumer staff	In development	<ul style="list-style-type: none"> <li>• Focus on education incorporated throughout the guidelines.</li> <li>• Topic on clinical care pathways added the guidelines.</li> </ul>
Australian First Nations Guidelines [13]	Sixteen community consultations—Yarnings—Aboriginal and Torres Strait Peoples with CKD or caregivers/family with introductory session on guidelines.	Yes—three Aboriginal or Torres Strait Islanders with chronic kidney disease involved in Yarnings or self-nominated with support from consumer staff	Consumer summaries and infographics developed by consumer Working Group members	<ul style="list-style-type: none"> <li>• Incorporation of Indigenous Health Research Methods in analyses and synthesis [22].</li> <li>• Topics on Cultural Safety and recommendations on institutional racism.</li> <li>• Guidelines drafts were presented and discussed with communities involved in consultation</li> <li>• Consumer summaries and infographics were developed</li> </ul>
Aotearoa New Zealand Māori Guidelines [23]	Four community consultations (Huis)—Māori people with chronic kidney disease or Whānau with introductory session on guidelines.	No	In development	<ul style="list-style-type: none"> <li>• Incorporation of Indigenous Health Research Methods in analyses and synthesis.</li> </ul>
Living Guidelines—Cardiovascular disease and chronic kidney disease progression <ul style="list-style-type: none"> <li>• Cholesterol-lowering therapy [24]</li> <li>• Urate-lowering therapy [25]</li> <li>• SGLT2 inhibitors in CKD<sup>a</sup></li> </ul>	No	Yes—2-3 people with lived experience of CKD and therapy according to guidelines focus who self-nominated and supported by consumer member of staff	Infographics developed with consumer members of the Working Group	<ul style="list-style-type: none"> <li>• Patient preferences and values incorporated in guideline development.</li> <li>• Consumer-led infographics developed</li> </ul>

CARI, Caring for Australians and New Zealanders with kidney Impairment; CKD, chronic kidney disease.

<sup>a</sup> Guidelines in development.



**Figure 3.** Map of consultations across Australia for indigenous guidelines [13]. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

version guidelines, we recognize a high attrition of participants from the workshops. Some consumers said their workshop participation was unclear, lacked tangible outcomes, and declined ongoing involvement.

To overcome these challenges, reduce development time, and improve outputs, the kidney biopsy consumer-version guidelines and COVID-19 evidence summaries Working Group included self-nomination of members from the workshop [5] and BEAT-CKD Consumer Advisory Board to ensure involvement is tailored to consumers’ capacity to ensure sustainability. The consumer members were also supported by CARI Guidelines consumer staff, and the Working Group included a nephrologist who could provide expertise and answer the consumer Working Groups’ relevant clinical questions. To best accommodate all consumers and their informational needs, one-page summaries [31], infographics [32], and a four-page document [33] were produced and widely distributed via consumer advocacy networks. Videoconferencing allowed the Working Group to collaborate seamlessly and forge critical relationships for the teams to be productive.

*“Virtual connections helped us to save time and travelling and also the ability to have a diverse opinion really worked well”* (Transplant recipient, COVID-19 consumer summary)

*“There was excellent communication in between our online meetings so that everyone was kept informed and involved and the meetings themselves were well facilitated with a clear path to follow”.* (Transplant donor, COVID-19 consumer summary)

In response to the disparity in the prevalence and burden of CKD between Aboriginal and Torres Strait Islander Peoples, and Māori compared to non-Indigenous peoples in Australia and Aotearoa New Zealand, CARI Guidelines have developed First Nations Guidelines [13,23,34]. The expert Working Group recognized consumer involvement workshops as insufficient for community engagement for these guidelines, and hence community yarnings were undertaken. A targeted consultative process was conducted with Aboriginal and Torres Strait Islanders [35–37] (Fig. 3) and Māori communities to identify the guideline scope through informal conversations in culturally safe environments. Ongoing community engagement was maintained to review draft recommendations during the COVID-19 pandemic; continued involvement was achieved by employing Aboriginal and Torres Strait Islander Peoples consumers to organize community feedback. The community consultation organized by partner organizations Kidney Health Australia and Menzies School of Health Research [23,34] identified a deficit of methodological approaches toward

guideline development for this topic. Hence, CARI Guidelines methods were adapted to incorporate a holistic view of health and Indigenous health research methods, such as yarnings, to build rapport and trust with communities as well as the critical appraisal of the literature using the CREATE [38] and CONSIDER tool [39] to identify how research has been conducted with and led by First Nations Peoples. The rationale for guideline recommendations was underpinned by both the synthesis and appraisal of the literature and the findings from the community consultations due to the limited scientific assessment of issues of importance for kidney health in First Nations Peoples [22,40].

The workshops' and yarnings' success led to consumers' natural inclusion as equal and valuable members of guideline Working Groups. Ideally, three or more consumer members are part of the Working Group to address power imbalances and ensure meaningful contribution [26]. Ongoing training on guideline development is provided by dedicated staff through short videos and exercises. Separate consumer-only discussions are offered before and after meetings as required. All consumers are offered a sitting fee to adhere to local standards [41] and to recognize their time and expertise. To date, CARI Guidelines have involved consumers in six guidelines Working Groups (three published [13,24,25] and three ongoing) and guideline commentaries [42]. Consumer Members in guideline Working Groups have proven invaluable to guideline writing. For example, they have raised tolerability concerns and transportability of liquid citrate salts in managing kidney stone recurrence, which has directly informed practice points to indicate a preference for tablets over liquids. Consumers Working Group members have identified pertinent topics to be covered in guidelines, such as ketogenic diets for autosomal dominant PKD guidelines.

To support this expanding and ongoing consumer involvement and partnership developed over the years, CARI Guidelines Office has established paid staff positions for consumers. Consumers are involved in administrating and developing CARI Guidelines through the engagement of the CKD community, support, and training of consumer Working Group members, contributing to evidence review, guideline writing, and administrative tasks, such as remuneration of consumer members supported by administration from our host institution. Additionally, CARI Guidelines have consumer membership on the Steering Committee, providing oversight and direction to ensure appropriate consumer involvement. Consumer Steering Committee Members are supported by consumer staff according to their specific needs. We ensure involvement is manageable and can fit within their capacity, and consumers are offered a sitting fee for their contribution. The involvement of consumers in the administration and governance of CARI Guidelines has increased the diversity of expertise. While the lived experience was the initial selection criteria for membership or employment, breadth and depth of knowledge and skills have improved CARI Guidelines potential to attract funding through nonmedical sources, better

outputs through improved graphical design and marketing, and community engagement through codesigning strategies for dissemination with tailored communication plans.

There have been challenges, as guideline development can often be lengthy, and the capacity of consumers in Working Groups may fluctuate due to the unpredictability of their condition or changing life circumstances. Feedback from consumers has highlighted that providing support in the form of peer mentoring from consumer members of staff and offering a sitting fee has allowed strong engagement, ensuring that their time and contribution are valued and purposeful. Furthermore, tailoring their involvement to suit their capacity by one-off workshops, community meetings, or ongoing engagement in Working Groups conducted via video-conferencing or reviewing draft guidelines or outputs can ensure flexibility according to their needs and well-being and ensure that consumer involvement is not onerous and will continue into the future.

#### 4. Discussion

Implementing the consumer involvement framework for CARI Guidelines has increased the number of consumers contributing and broadened the diversity in skills, backgrounds, and experience of consumers by offering different types of involvement opportunities that are well supported and remuneration. It has also led to a range of outcomes, which include changes in the guideline scope and improved methods for guideline development, including the addition of topics on patient education, psychosocial care, and clinical pathways, as well as focusing the systematic evidence review process to include patient-important outcomes, such as life participation measures. Our consumer involvement framework has resulted in the development of consumer-version guidelines, which have expanded our dissemination and the incorporation of additional professional expertise within the governance and operations of CARI Guidelines.

Despite consumer involvement in guidelines being advocated [1,2,43], a wide variety of options are available to guideline developers, but the reporting of methods used and the outcomes are limited [6]. Hence, further research to inform knowledge on the utility and application of consumer involvement approaches in guidelines is needed [43,44]. Additional guidance on consumer involvement in guidelines is being developed [4]. The lack of resources has been recognized as a critical barrier to meaningful consumer involvement in guidelines [45]. In contrast, others have described reservations about the value of consumer involvement in guideline development [46]. Further research, both quantitative and qualitative, may provide answers on the best processes to address barriers, such as power imbalances, lack of clarity on consumer contribution, and tokenism [8]. Our framework describes some similarities as other models, such as the importance of consumer-only forum to nominate and prioritize topics [47,48], and systematic review planning



[48] as well as active consideration of patient preferences [49] through the involvement of consumers in drafting recommendations [48] and dissemination and implementation of guidelines [48]. However, we do uniquely describe an active role of consumers in the administration and governance of guideline development.

Using a descriptive document analysis as the only data source is a limitation that may result in insufficient detail and a selective retrieval of documents. Still, the approach has allowed a comprehensive description of our consumer involvement framework over time despite numerous changes in staff and governance over our 20-year history, through documentation of organizational process, employment of consumers, staggered governance terms, and a belief in the importance of consumer involvement. Our consumer involvement approach is impacted by low resources, such as only conducting one workshop, which limits geographical diversity and may affect the transferability of the findings. However, the experiences of consumer involvement expanded staff skills and formed vital networks with community and consumer advocacy organizations. The result has been an iterative expansion of consumer framework in guideline development achieved in a low-resource environment. The partnership with like-minded organizations, that is, Kidney Health Australia, Kidney Health New Zealand, and BEAT-CKD, has snowballed the number and diversity of consumers involved.

Implementing consumer involvement in CARI Guidelines has enabled varying degrees of consumer engagement, providing consumers flexibility in time and commitments. It is essential to be adaptable and support those who want or can commit to a one-off attendance at workshops and those who want to commit to being a part of Working Groups or the Steering Committee, providing oversight and direction to CARI Guidelines. The process of including consumers in developing and writing guidelines is evolving. However, it must be individualized to each guideline topic. Some topics may require specific skills or subject knowledge, such as Indigenous health expertise and extensive community consultation in the First Nations guidelines. For future guidelines, involving consumers at the start of guideline development is critical, along with a clear and realistic setting of expectations of contribution, effective communication, and adequate support and resources. Future work is needed to assess the impact of consumer involvement in guideline development, including the effect of consumer-version guidelines have on knowledge gain and confidence in shared decision-making.

### Consumer involvement in this paper

N.S.R., C.G., and I.R. are all people with lived experience of chronic kidney disease who have worked on consumer guideline development and are authors of this paper.

### CRedit authorship contribution statement

**Nicole Scholes-Robertson:** Writing – review & editing, Writing – original draft, Visualization, Formal analysis, Conceptualization. **Chandana Guha:** Writing – original draft, Formal analysis, Data curation, Conceptualization. **Talia Gutman:** Writing – review & editing. **Martin Howell:** Writing – review & editing. **Adela Yip:** Writing – review & editing, Project administration. **Brydee Cashmore:** Writing – review & editing, Project administration. **Ieyasha Roberts:** Writing – review & editing, Project administration. **Pamela Lopez-Vargas:** Writing – review & editing, Project administration. **Germaine Wong:** Writing – review & editing, Supervision. **Robert MacGinley:** Writing – review & editing. **Anneliese Synnot:** Writing – review & editing. **Jonathan C. Craig:** Writing – review & editing, Project administration, Funding acquisition, Conceptualization. **Allison Jauré:** Writing – review & editing, Supervision, Funding acquisition. **Rathika Krishnasamy:** Writing – review & editing, Project administration, Funding acquisition. **David J. Tunnicliffe:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Vincent Lee:** Writing – review & editing, Funding acquisition. **Jane Boag:** Writing – review & editing, Funding acquisition. **Helen Coolican:** Writing – review & editing, Funding acquisition. **Vanessa Cullen:** Writing – review & editing, Funding acquisition. **Debbie Fortnum:** Writing – review & editing, Funding acquisition. **Hicham Hassan:** Writing – review & editing, Funding acquisition. **Min Jun:** Writing – review & editing, Funding acquisition. **Kelly Lambert:** Writing – review & editing, Funding acquisition. **Casey Light:** Writing – review & editing, Funding acquisition. **Thu Nguyen:** Writing – review & editing, Funding acquisition. **Suetonia Palmer:** Writing – review & editing, Funding acquisition. **Carla Scuderi:** Writing – review & editing, Funding acquisition. **Emily See:** Writing – review & editing, Funding acquisition. **Andrea Viecegli:** Writing – review & editing, Investigation. **Rachael Walker:** Writing – review & editing, Funding acquisition.

### Data availability

No data was used for the research described in the article.

### Declaration of competing interest

None relevant.

### Acknowledgments

We wish to thank the consumers who contributed to CARI Guidelines.

CARI Guideline Group Steering Committee Investigators: Rathika Krishnasamy (Chair), Vincent Lee (Deputy Chair), Jane Boag, Helen Coolican, Vanessa Cullen, Debbie Fortnum, Hicham Hassan, Min Jun, Kelly Lambert, Casey Light, Thu Nguyen, Suetonia Palmer (Member 2013-2017; Previous Chair 2018-2020), Carla Scuderi, Emily See, Andrea Viecelli, and Rachael Walker (Member 2018-2021).

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