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Broadening the diversity of consumers engaged in guidelines: a scoping review

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ABSTRACT

Background Guideline developers are encouraged to engage patients, carers and their representatives (‘consumers’) from diverse backgrounds in guideline development to produce more widely applicable guidelines. However, consumers from diverse backgrounds are infrequently included in guidelines and there is scant research to support guideline developers to do this.

Objectives To identify principles and approaches to broaden the diversity of consumers engaged in guideline development.

Design Scoping review and semi-structured interviews.

Methods We conducted comprehensive searches to March 2020 for studies, reports and guidance documents. Inclusion criteria included the terms ‘consumer’ (patients, carers and their representatives), ‘diversity’ (defined using the PROGRESS-PLUS mnemonic) and ‘consumer engagement’ (the active involvement of consumers at any stage of guideline development). We also conducted four interviews with consumers and guideline developers. We used descriptive synthesis to identify themes, and summarised information about implemented approaches used to broaden diversity of consumers in guidelines.

Results From 10 included documents, we identified eight themes. Themes covered general engagement concepts (Respectful partnerships; Recruitment; Expectations, process and review); specific concepts about guideline development group (GDG) engagement (Characteristics of guideline personnel; Consumers’ role, characteristics and prominence; Preparing and supporting consumers); and other (non-GDG) approaches (Online methods; Consultations and research-based approaches). The most commonly included PROGRESS-PLUS categories were Disability, Race/culture/ethnicity/language, Place of residence and Other vulnerable (eg, ‘disadvantaged groups’). Each theme included the views of both consumers and guideline developers. We found descriptions of 12 implemented engagement approaches to broaden diversity of consumers in guidelines.

Conclusions Relationship-building, mitigating power imbalances and meeting consumers where they are at underpin our findings. Engaging with diverse groups may require greater attention to building formal, respectful partnerships and employing inclusive engagement methods.

INTRODUCTION

Clinical practice guidelines (‘guidelines’) are statements that include recommendations for healthcare practice used by clinicians and patients to inform healthcare decision-making. However, guideline recommendations are not always universally applicable across populations and patient groups.1 2 For example, compared with more privileged populations, people from disadvantaged groups may experience different baseline risks of a particular condition, face more barriers to access the recommended treatment or hold different values about the treatment’s effects.1 In this way, guidelines may unintentionally result in poorer health outcomes (or health inequities) for people from disadvantaged groups.3 Health inequities are defined as differences in people’s health that are unnecessary, avoidable, unfair and unjust.4 They are derived from social and economic factors commonly termed PROGRESS-PLUS (Place of residence, Race/culture/ethnicity/language, Occupation, Gender and sex, Religion, Education, Socio-economic status, Social capital, Age, Sexual orientation and Disability).2 5

Guideline developers are encouraged to address health equity in guidelines,2 6 for example by prioritising equity-relevant questions and searching for evidence relevant to people from diverse backgrounds.5 7 Another
Consumer engagement in guidelines can be defined as the active involvement of consumers in a bi-directional relationship that results in informed decision-making at any stage of the guideline development process (adapted from Concannon et al.).

It may include having multiple consumers as members of the GDG, or involve a parallel process, for example, as participants in focus groups, interviews and workshops. However, consumers from diverse backgrounds may face additional barriers to participation, meaning guideline developers may need to adapt their approach and provide additional support. Despite the need for specific advice, guidance to address equity in guidelines typically includes little practical advice about how to do this. Guidance does exist for engaging specific groups in guidelines, such as children and people with mental illness or intellectual disability, and Indigenous Australians, but this may not be applicable across the spectrum of diversity. Further, there has been no rigorous and comprehensive synthesis of the relevant literature on which to develop such guidance.

Our aim was to identify principles and approaches to broaden the diversity of consumers engaged in guideline development. The findings will be relevant to guideline developers and guideline funders wanting to engage consumers from diverse backgrounds. Broadening the diversity of consumers engaged in guidelines may lead to guidelines that better address health equity, potentially supporting optimal healthcare delivery and health outcomes for consumers from diverse backgrounds.

METHODS
Context
This research was funded by Australia’s Stroke Foundation to inform refinements to the consumer engagement model used in their stroke living guideline. We conducted companion scoping reviews, one described here and one elsewhere.

Research approach
We conducted a scoping review, supplemented by key informant interviews with consumers and guideline developers. We selected scoping review methodology given our broad aim and the exploratory nature of the research, which necessitated the inclusion of evidence from a variety of sources (eg, research studies and guideline reports). Scoping reviews still adhere to core systematic review characteristics, such as an explicit, transparent search, inclusion criteria and data extraction process.

We also conducted interviews to augment review findings after our initial exploratory searches identified few documents which met the inclusion criteria. Key informants have special, often first-hand knowledge of a phenomenon and can provide a deeper insight into what is occurring. The scoping review was commenced first, with provisional results informing interview data collection.

We followed relevant guidance to conduct and report the review, but did not publish our protocol a priori.

Inclusion criteria
Participants
We included documents that pertained to consumers from diverse backgrounds. We defined consumers as patients and potential patients, carers and people who use healthcare services and their representatives, including organisational representatives.

We defined people from diverse backgrounds as those who might experience health disadvantage for reasons relating to the PROGRESS-PLUS categories, that is, Place of residence (ie, low-income country, or living in a remote area), Race/culture/ethnicity/language, Occupation (eg, being unemployed or working in a high-risk environment), Gender and sex (eg, transgender), Religion, Education (ie, limited education), socioeconomic status (ie, poor/limited money), Social capital (ie, social isolation and having limited networks), Age, Sexual orientation and Disability. The PROGRESS-PLUS acronym is a recommended framework used in guidelines to consider health equity.

Core concepts
Our core concepts were ‘consumer engagement’ and ‘ways to broaden the engagement’ of people from diverse backgrounds in guidelines.

We defined consumer engagement as the active involvement of consumers in a bi-directional relationship that results in informed-decision making at any stage of the guideline development process (adapted from Concannon et al.). We were interested in examples of engagement where consumers had some impact on decision-making, operationalised using the upper three levels of the International Association of Public Participation (IAP2) Spectrum of Participation. These include: Involve (work directly with consumers throughout the process); Collaborate (partner with consumers in each aspect of the decision) and Empower (place final decision-making in consumers’ hand).

We included documents if they described ways to support or increase the involvement of people from diverse backgrounds, or they described an implemented example of
consumer engagement involving people from diverse backgrounds. Where documents in the latter group also included non-diverse consumers, we included them if the majority of consumers were from diverse backgrounds, or the data or recommendations pertaining to people from diverse backgrounds could be differentiated.

Context
We defined guidelines as ‘statements that include recommendations intended to optimise patient care that are informed by a systematic review and an assessment of the benefits and harms of alternative options’,28 (p.4) although in practice we took a generous view of what constituted a guideline.

Evidence sources
To allow a comprehensive exploration of the topic, we included qualitative and quantitative research studies (primary and secondary), case reports, guidance and other reports, collectively referred to as ‘documents’.

Search sources and strategy
Using a search strategy developed by a specialist librarian, we searched the following databases in March 2020: MEDLINE (1946 to 20 March 2020) and Embase (1947 to 20 March 2020; see online supplemental material 1). We developed and ran additional searches in PsycINFO and CINAHL but they were not subsequently used as they yielded few additional citations and few unique citations corresponding to a reference set of potentially included studies that were already identified in the MEDLINE and Embase searches. We searched the websites of international organisations and networks specialising in guidelines or health technology assessments and those concerned with consumer engagement in healthcare. Examples include Guidelines-International-Network, Health Technology Assessment International, the National Centre for Health and Care Excellence, NIHR INVOLVE and the Consumers Health Forum of Australia. We emailed study information to individuals and organisations requesting they forward the details to relevant additional references, if provided.

Data charting items and process
To record document characteristics, one researcher (AS) charted the following key features using a standardised template: aim, country of origin, document type (ie, qualitative research, guidance document), research methods used (or other basis of their findings/recommendations), consumer type (ie, carer), PROGRESS-PLUS category and the views presented in the document (consumers or guideline developers). We added an ‘other vulnerable’ PROGRESS-PLUS category to capture groups that did not fit into existing categories, such as young people who had grown up in care.

To chart information relating to principles and approaches to increase diversity, we copied relevant text from any section of the included documents into a single Word document.

To chart information relating to implemented examples of diverse consumer engagement, we devised a chart template based on relevant standards and frameworks30 31 to capture the number of consumers, guideline stages, key engagement features such as engagement methods, and the tasks given to consumers. We sourced some of this detail from relevant additional references, if provided.

One researcher (AS) conducted the data charting, with queries discussed and resolved with a second researcher (TT).

Interviews
We included English-speaking adults who identified as either a consumer from a diverse background(s) who had contributed (in any capacity) to one or more stages of guideline(s), or a guideline developer who had had a central role in guideline(s) in which consumers from diverse backgrounds were engaged in any stage or capacity.

Using purposive sampling, we recruited participants via the networks of the project team and those of international guideline groups, such as the National Institute for Clinical Excellence and Guidelines-International-Network. We emailed study information to individuals and organisations requesting they forward the details to relevant contacts, who could then get in touch with the researcher. We intended to conduct 10 interviews but ceased recruitment early as the data was adding some illustrative examples to the descriptive themes but few unique codes.

An experienced qualitative researcher (AS) conducted 60-min interviews over Zoom. Questions probed participants’ experiences of engaging consumers/being engaged in guidelines, whether they felt able to make an active contribution (consumers only), what worked well, what could have been improved and their recommendations (see online supplemental material 2). The interviews were audio-recorded and transcribed. Participants were sent a copy of the results.

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Synthesis

We conducted a descriptive synthesis of relevant text and transcripts. Descriptive synthesis, in the context of systematic reviews of qualitative evidence, allows the generation of themes from textual evidence that remain ‘close’ the primary studies (Thomas 2008) and has been used in similar reviews (Tong 2018). A more analytical approach was not possible given the limited data available in some included documents. As outlined by Thomas (2008), starting with the included documents, one researcher (AS) undertook line-by-line coding in Microsoft Word, applying free codes to the text. We reviewed the free codes, seeking like concepts, then merged and refined codes before grouping them under subthemes and then themes.

We used these codes, subthemes and themes as a framework to analyse the interview transcripts but created new codes in the few instances where new ideas or concepts were described. Once the document and interview data were integrated together, we refined and finalised the codes, subthemes and themes, and created overarching categories. A second researcher (TT) reviewed the data within each theme and subtheme, checking it was coded appropriately. The categories, themes and subthemes are presented in a table, along with the PROGRESS-PLUS categories they pertain to, the included source, and illustrative quotes.

Separately, we summarised information about the implemented approaches for boosting diversity of consumers engaged in guidelines, in a table and text.

Patient and public involvement

Patients and the public (in this paper, ‘consumers’) were not involved in developing or conducting this study or disseminating its results. This decision was made because of our tight time frames and the implications this would have had on our ability to meaningfully engage consumers and address their concerns. In a subsequent stage of the broader project we sought consumer input via a focus group to apply the review findings to the funder’s stroke living guidelines, however this step is not reported in this paper.

RESULTS

Selection of documents

We identified 15611 records from database searches and 87 records from additional sources. After de-duplication, we screened 11090 citations on title and abstract and subsequently reviewed 347 documents in full text. Of these, 337 documents were excluded from the review (see Preferred Reporting Items for Systematic Review and Meta-Analysis flow chart, online supplemental material 3, for reasons), with 10 documents included in the review.

Characteristics of included documents

The 10 included documents (see table 1) comprised a systematic review, a qualitative interview study, two evaluation studies, one descriptive report, a checklist, a toolkit chapter, two handbook modules and a discussion paper. They were from Australia (n=3), the USA (n=3), the UK (n=1), Europe (n=1) and from international groups (n=2).

The documents aimed to: provide guidance for developers about engaging diverse groups in guidelines; provide an account of engaging diverse groups in a guideline, and explore the views of consumers from diverse backgrounds about engaging in guidelines.

Across the documents, most diversity categories were mentioned including: Disability (intellectual, physical and mental illness; n=6), Race/ethnicity/culture/language (culturally and linguistic diverse backgrounds generally, and African Americans, and Aboriginal and Torres Strait Islander peoples; n=6), Place of residence (low-income and middle-income countries, n=3), Other vulnerable (young people who had grown up in care; n=3), Age (children and young people; n=2), Gender and sex (transgender men; n=2), Education (n=1), Socioeconomic status (n=1), Sexual orientation (men who have sex with men; n=1). No documents focused on the remaining categories (Occupation, Religion, Social Capital). Most documents focused on one or two of the PROGRESS-PLUS categories (n=6), while the remaining documents (n=4) included several categories, with a broader focus, for example on disadvantaged groups, or people facing barriers to participation.

Most documents (n=7) included the views of consumers from diverse backgrounds (of these, five also included guideline developer views). Three documents solely presented the views of guideline developers.

Interview participants

We interviewed two consumers and two guideline developers (three women and one man), based in Europe (n=3) and Australia (n=1). Consumers self-identified as belonging to a minority ethnic group (n=1) and being older (n=2) and had contributed to two or three guidelines. Guideline developers had engaged people with autism and people with a neglected tropical disease in one guideline each.

Both consumers were experienced as consumer members of a GDG. This involved semi-regular face-to-face meetings for the duration of the guideline’s development. For one guideline developer, the consumer engagement approach involved face-to-face interviews with consumers in low-resource settings. For the other, it included a consumer member on the GDG, online submissions about draft recommendations, an online survey to prioritise recommendations and multiple face-to-face workshops to review the draft guideline.

Principles and approaches to broaden diversity of consumers engaged in guidelines

We identified eight themes grouped under one of the three overarching categories (see table 2). Within each
| Document type          | Country        | Aim/objective                                                                 | Methods, or basis of recommendations                                                                 | Consumer group(s) (PROGRESS-PLUS)*                                                                 | Views shared††                                                                 |
|------------------------|----------------|-------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|
| Checklist              | International  | Guidance for guideline developers on how to consider health equity at key stages of the guideline development process. | Literature review, group discussions and consensus building.                                            | "Disadvantaged groups with specific patient characteristics. People facing barriers to participation (children, young people, people with disabilities, people with specific needs)." | GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/GL/G |
Table 2: Principles and approaches for engaging diverse groups in guideline development

| Theme (sources) | PROGRESS-PLUS | Components | Illustrative quotes |
|----------------|---------------|------------|--------------------|
| Category 1: General concepts about engaging diverse groups in guidelines | | | |
| 1. Respectful partnerships | P/R/A/D/OV | ▶ Establish respectful partnerships with organisations that work with or represent diverse groups. They can assist with recruitment,16,18, Int-C: GL offering advice,16,18,40 or actively support the engagement. | “Employ an adult autistic researcher, and a caregiver researcher, as members of the GDG so that they’re on staff and involved in the day-to-day work (...), it would have been really important.” Int-GL |
| | | ▶ Partner with individual consumers to plan the engagement and share core tasks,16,18, Int-GL acknowledging that they are the experts in how consumers should be engaged.16,36,40 | “Engage key people (...such as Elders and community leaders in the early stages and respect their advice throughout the process.”18 |
| | | ▶ Establish and maintain respectful partnerships from the beginning.18,35, Int-GL | |
| 2. Recruitment | P/R/A/D/OV | ▶ Tailor recruitment strategy to the topic (eg, age and language) of all diverse consumer groups sought.8,16,40, Int-C | “For some topics, it may be possible to recruit young people (aged 16–25) using targeted advertising and social media.” |
| | | ▶ Health and other professionals working with your target group can assist with recruitment,16, Int-G but relying on third parties can be challenging as you cannot follow-up with consumers directly.8,16,40 | “Professionals working in the field can also play a role. This turned out to be a successful route for recruiting young adults (aged under 25) for the NICE ‘looked after children’ guideline development group.” |
| | | ▶ Organisations that work with or represent diverse groups can also assist, see Respectful Partnerships theme. | |
| 3. Expectations, process and review | R/A/D/OV | ▶ Ensure a clear purpose and role for consumers from diverse backgrounds,16,35 with well-defined recruitment and support processes to support this.36,40 | “Make your purpose of the group clear. Like, this is what we’re here to do, this is why you are here, this is the overall goal, why this is important.”35 (p.9) |
| | | ▶ Provide feedback and acknowledgement of participation (eg, a certificate),16 cover expenses and consider providing compensation.16, Int-C | “It is important to formally thank participants, for example with a letter or certificate (…). It may be possible to accredit certain forms of participation, which could be useful (for people) with limited work experience.”16 (p.66) |
| | | ▶ Review the engagement: ask consumers for their feedback.8,36,40 or conduct a formal evaluation.35,40 Share examples of success.18 | “The key takeaway that I had was in the very early stages when you’re negotiating the guideline to happen just asking for enough money and enough time.”18 (p.42) |
| | | ▶ Make additional time for engagement.16,18,35, Int-GL: GL | |
| | | ▶ Allow additional resources for engagement (eg, for interpreters or travel).9,40, Int-GL: GL; GL,18 but some adaptations (eg, alternate ways of running GDG meetings) are cost-neutral.39 | |
| Category 2: Engaging diverse groups in the guideline development group | | | |
| 4. Characteristics of guideline personnel | R/A/D/OV | ▶ Ensure chair is skilled in facilitation and is actively support involved of diverse groups.16,35,36,39 Int-G: C acknowledging some consumers from diverse backgrounds do not like direct questioning.35 | “The chair I’ve got is in no way patronising to patients. We are treated the same as any other committee member. In fact, sometimes we might get a little bit more away. He will say, what do you think?” |
| | | ▶ Ensure the GDG is supported by people with skills and experience working with the diverse group(s).16,18 | “Take the time to learn about local history and traditions including traditional names for the lands and languages and the local families. Local Aboriginal community-controlled organisations can be contacted to ask about local protocols and how to follow them.”18 |
| | | ▶ Ensure the chair and other guideline personnel are familiar with relevant history, cultural practices and safety measures18,35,41 and recognise the diversity of views and backgrounds within a single diverse group.18,36,41 | “When considering culturally diverse communities it is important to remain attuned to the tendency to homogenise differences in backgrounds, viewpoints and needs.”36 (p.28) |
| | | ▶ Make certain guideline personnel are sensitive to their own cultural beliefs and behaviours18,35,40 Int-C as misperceptions and stereotypes hinder engagement.35,40, Int-C | |
| | | ▶ Make sure there is diversity among GDG members, reflecting the ethnic or racial diversity of the consumer group.39 | |
| | | | “These findings indicate that people with learning disabilities can be included as full members of (guideline) groups with reasonable adjustments.”36 (p.323) |
| | | | “These (meetings) are very important; you have a duty and responsibility to other patients. I fully believe in equality of access, but if you’re not able to do it then somebody who can has to do it. Because that voice is not going to be heard and it has to be heard.” Int-C |
| | | | “It’s not necessarily the person themselves, as much as someone who has experience of what these people are going through. Because it would be quite difficult to have someone of a certain age be there and contribute and be there all the time.” Int-C |
| 5. Consumers’ role, characteristics, and prominence | P/R/A/D/OV | ▶ Most consumers from diverse backgrounds can and should be involved as full and equal GDG, even if this requires some adjustments.8,16,18,39, Int-C For priority topics, they might co-chair the GDG.18 | |
| | | ▶ Include at least two consumers on the GDG, but potentially four or more.16,35,39 | |
| | | ▶ Consider smaller groups to make consumers feel more comfortable to share their views.16,18 | |
| | | ▶ Engaging consumers from diverse backgrounds can be tokenistic.8,16,18,39, Int-C Consumers should have the skills and confidence to make an active contribution, Int-C, GL however they can be intimidated by professionals,8,36, Int-C and other consumers or carers.41,53 Use a consumer representative when people from the diverse group can’t take part or for a different perspective.8,16, Int-G although including people with lived experience is ideal.41 | |
| | | | “These findings indicate that people with learning disabilities can be included as full members of (guideline) groups with reasonable adjustments.”36 (p.323) |
| | | | “These (meetings) are very important; you have a duty and responsibility to other patients. I fully believe in equality of access, but if you’re not able to do it then somebody who can has to do it. Because that voice is not going to be heard and it has to be heard.” Int-C |
| | | | “It’s not necessarily the person themselves, as much as someone who has experience of what these people are going through. Because it would be quite difficult to have someone of a certain age be there and contribute and be there all the time.” Int-C |
There was one particular person who coordinated things. I had contact with her regularly. She would ring and say, how are things going? (…) We would discuss quite a lot of things, so the support was there if one wanted it.” Int- C

Send copies of agenda papers well in advance. Check if they want to have a chat about the content prior to the meeting and arrange main topic points in bullet list.” Int- C, C; C; GL

“Multiple individuals mentioned the advantage of having an established process for making sure that everyone has a chance to share an opinion.” 35, 36

The online submission probably had the least barriers to participation (…) and we probably had a little bit more diversity. It was the easiest. You didn’t need to go anywhere. You didn’t need to be in a social situation. It was all anonymous. Whereas with our workshops I don’t think we got as much participation.” 34, 37, 39

“There’s something about meeting face to face and having coffee breaks and a preamble. It seems on Zoom quite formal and you can’t chat with anybody. You’re there and you’re down to business. (…), there’s no room for, what sort of weekend did you have? (…) So it puts off all the informalities, which are part of group bonding.” Int- C

Online Delphis facilitate community building and sharing of experiences, with their staggered contribution reducing participation burden. 37

Online GDG meetings offer less opportunity for explanation, less team building, and shorter meetings. Int- C, C Multiple, in-person meetings may help build group dynamics. 35

It may be appropriate to have CALD (culturally and linguistically diverse) specific (…) initiatives or to integrate CALD consumers and their experiences within the more generic process. 36, 37

“We recommend you consider alternative approaches to involving people with the condition or from the affected population. One option is to have a reference group or panel to help the guideline group identify patients’ perspectives and priorities at key stages of guideline development, and beyond to dissemination and implementation.”

“The second challenge is if you ask patients to give the best treatment outcome from their point of view, some cannot think what you are trying to ask. If you identify your four best treatment outcomes (…) this is what you want to formulate your recommendation. But that’s not the response you get from the patient.” Int- GL

A, age; D, disability; E, education; G, gender and sex; GDG, guideline development group; Int- C, interview with consumer; Int- GL, interview with guideline developer; NICE, National Institute for Clinical Excellence; O, occupation; OV, other vulnerable; P, place of residence; R, race/culture/ethnicity/language; Re, religion; SC, social capital; SES, socioeconomic status; SO, sexual orientation.
theme, the description pertains to multiple PROGRESS-PLUS categories; with Race/culture/ethnicity/language, Age, and Disability the most commonly represented. We describe the components of each theme derived from (documents and interviews) and provide illustrative quotes. Each theme contains the views of consumers and guideline developers.

Three themes relate to general concepts about engaging diverse groups in guidelines. Establish respectful partnerships (theme one) at the outset with organisations and individuals who represent diverse groups to facilitate a range of different activities. Recruitment (theme two) should build on partnerships and be tailored to the topic and demographics of consumers. The expectations of consumers’ role and review processes should be clear (theme three).

Three themes relate specifically to engaging diverse groups in the GDG. Characteristics of guideline personnel (theme four) should include relevant skills, experience and understanding about working with diverse groups, sensitivity to their own cultural beliefs and they should reflect the racial or ethnic diversity of consumers involved. Regarding consumers’ role, characteristics and prominence (theme five), most consumers from diverse backgrounds can be GDG members. They need sufficient skills and confidence, but also benefit from having more than two consumers in the group and smaller group meetings. Consumers need to be prepared and supported (theme six) through training and ongoing support, with many potential meeting adaptations such as using understandable language in meetings and paperwork.

Two themes relate to other (non-GDG) engagement approaches. Online methods (theme seven) can facilitate the participation of some diverse groups (eg, social disability) and hinder participation for others (eg, cognitive disability). Consultations and research-based approaches (theme eight) may be necessary or preferred for some diverse groups.

Summary of implemented approaches for boosting diversity of consumers in guidelines

Six documents included a description of one or more implemented engagement approaches to boost diversity of consumers in guidelines (see online supplemental material 4).

These 12 engagement activities occurred in the UK (n=5), Australia (n=3), Europe (n=2), unspecified low-income and middle-income countries (n=1) and the USA (n=1). The following PROGRESS-PLUS categories were included: Age (n=4), Disability (n=4), Other vulnerable (n=3), Race/culture/ethnicity/language (n=3), Place of residence (n=2), Sexual orientation (n=1) and Gender and sex (n=1).

Broadly, the engagement approaches included: consumer members of the GDG (including as chair; n=3); consumer members of the GDG plus other activities, such as a workshop (n=2); and consumer advisory groups external to the GDG (n=2). In these examples, consumers were likely involved across all guideline development stages. The remaining examples (n=5) used consultation approaches, such as workshops and online surveys, in which consumers might be engaged in one guideline stage (developing recommendations, or priority setting and topic selection) or multiple stages. The reports for nine of the 12 implemented approaches provided a description of the engagement methods used with no additional reflections or recommendations from those involved.

DISCUSSION
From 10 included documents and four interviews with consumers and guideline developers we devised eight themes summarising principles and approaches to broaden the diversity of consumers engaged in guidelines. Three themes related to general concepts about engaging diverse groups in guidelines, including respectful partnerships, recruitment and expectations, process and review. Three themes relate to engagement in the GDG, including characteristics of guideline personnel, consumers’ role, characteristics and prominence and preparing and supporting consumers. The final two themes related to other engagement approaches, including online methods, and consultations and research-based approaches. Across themes, the most commonly included PROGRESS-PLUS categories were Disability, Race/culture/ethnicity/language, Place of residence and Other vulnerable (eg, ‘disadvantaged groups’). Each theme included the views of consumers and guideline developers. In addition, we found descriptions of 12 implemented engagement approaches to boost diversity of consumers in guidelines. They included a mix of methods, such as GDG membership, consumer advisory groups and different consultation approaches, but included limited information about how they did this (eg, partnerships, recruitment, support to consumers). We found very little information about engaging consumers from diverse backgrounds in guidelines in low-income and middle-income countries, and scant or no information relating to the PROGRESS-PLUS categories of Education, Socioeconomic status, Sexual orientation, Occupation, Religion, Social Capital. We also found very little research exploring the perspectives of consumers from diverse backgrounds, nor many descriptive reports or evaluations about implemented engagement approaches.

The few existing systematic and related reviews on consumer engagement in guidelines yield very little related to any aspect of diversity. This review provides the first in-depth exploration of how to include people from diverse backgrounds in guidelines, with examples of how this has been done in practice. There is substantially more literature exploring diversity in consumer engagement in the broader areas healthcare and research (which includes guidelines). There is considerable overlap between our results and this literature. For example, partnering with diverse community groups to plan and undertake engagement is recommended, as
is ensuring the professionals involved view consumers as equal and possess linguistic and cultural competency.\textsuperscript{11 43} Two important factors in the diversity literature that are supported by our findings (while not being standalone themes) are the importance of trusting, long-term relationships\textsuperscript{17 42} and identifying and mitigating power imbalances.\textsuperscript{11 43}

Many of our findings are not unique to engaging people from diverse backgrounds in guidelines, but reflect recommended practice in consumer engagement in guidelines more broadly. For example, consumers should be set up with clear role expectations,\textsuperscript{9 39} their contribution appropriately acknowledged and be given an opportunity to feed back about their experience.\textsuperscript{9 44} Further, consumers and guideline developers should be offered guidance and ongoing support in their respective roles.\textsuperscript{9 39 44} However, compared with our findings, there is less emphasis in this literature on building formal and respectful partnerships with individuals and organisations, and on the use of engagement methods beyond membership of the GDG, where often only a small number of consumers are involved.

Considered together, we believe there are three overarching concepts that underpin our findings and speak to where attention should be paid when engaging diverse groups in guidelines. First, the importance of establishing trusting, long-term relationships, where consumers’ expertise is respected and valued (eg, respectful partnerships and expectations, process and review themes). The second is mitigating power imbalances, giving consumers every chance to make an active contribution (eg, preparing and supporting consumers and guideline developer characteristics theme). Third is meeting consumers where they are at, through the use of flexible and tailored engagement methods and practices (eg, consumers’ role, characteristics and prominence theme and non-GDG methods category).

The strengths of this study are that we included evidence from a variety of sources (eg, research studies and guidance reports) and augmented review findings with interviews to provide the greatest depth and breadth of the findings. We also used a highly structured data charting process and rigorous descriptive synthesis to synthesise and summarise the findings.

One limitation is that we are unlikely to have captured all relevant evidence. Some of our included documents (specifically guidance manuals and reports) were found via online searches, rather than bibliographic databases, where it is difficult to ensure comprehensive searches. We also suspect there are many examples of consumer engagement with diverse groups in guidelines that remain unpublished. For example, we found eight brief descriptions of implemented consumer engagement approaches in two included documents\textsuperscript{16 18} yet only one\textsuperscript{45} had been published separately in full. However, given the breadth of issues we identified, this may not have altered the results but rather strengthened specific findings or provided additional illustrative examples. A second limitation is that only a single researcher conducted the descriptive synthesis (with checks by a second researcher). If we had conducted independent double coding the interpretation and organisation of synthesis concepts may have been different, meaning the final conclusions may have differed. In terms of implications for policy and practice, our findings have relevance to guideline organisations and funders. Creating an environment in which consumers from diverse groups are valued and included in guideline development requires organisational support and commitment, such as policies and procedures and additional resources, for example, to train and support guideline developers. Such organisations may need to develop the capacity in this area before encouraging guideline developers to engage with diverse groups. For guideline developers, the general principles of consumer engagement (eg, planning, identifying who to include, training, support, attention to inclusive practices) still apply but careful attention should be paid to building formal partnerships with organisations and individuals representing diverse groups and working with them to plan the engagement activities. Further, the skills, experience, attitudes and backgrounds of the GDG should be carefully considered, and developers should be prepared to be flexible and inclusive in the specific approach (including non-GDG methods, if appropriate). While this review identified that most consumers from diverse backgrounds can be included in the GDG (with adaptations), other engagement approaches will be preferable for some consumers and some guideline contexts. Not all concepts and approaches we identified will be relevant to all diverse groups. Instead, the ideas could help shape or refine their engagement plans and make it a more satisfactory experience all round.

Researchers could build a more complete picture of ways to boost diversity of consumers engaged in guidelines with more reports detailing how consumers from diverse backgrounds have been engaged in guidelines, along with parallel evaluations, or standalone research, exploring the perspectives of consumers and guideline developers. Particular settings (low-income and middle-income countries) and diversity categories (Education, Socioeconomic status, Sexual orientation, Occupation, Religion, Social Capital) warrant attention. The inclusion of more illustrative examples, or providing more depth to some of the descriptive themes, would allow the results to be turned into more comprehensive guidance for guideline developers, for example, building on the existing work of Guidelines-International-Network in this area.\textsuperscript{16}

CONCLUSIONS

Guidelines must be developed in a way that ensures they support equitable decision-making and health outcomes. Engaging consumers from diverse groups is one way to do this, however these groups are often excluded from guideline development. In a scoping review, we found 10 documents and conducted four interviews with consumers and guideline developers, identifying eight themes describing...
principles and approaches for boosting the diversity of consumers engaged in guidelines. The themes speak to the importance of relationship-building, mitigating power imbalances and meeting consumers where they are at. Many themes reflect good practice in consumer engagement in guidelines, more broadly, but engaging with diverse groups may require greater attention to building formal, respectful partnerships and employing inclusive engagement. Both guideline organisations and funders have a role to play in creating a supportive environment. These findings offer guideline developers many ideas to shape or refine their approaches regarding consumers from diverse backgrounds, and therefore provide all parties with more meaningful and valuable experience and outcomes.

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Contributors

AS led the study design, contributed to search development, conducted study screening and the interviews, conducted the analysis and interpretation, drafted the manuscript, and is responsible for the overall content as guarantor. SH contributed to the study design, critically reviewed the analysis and interpretation, provided supervision throughout the review process, and critically reviewed the manuscript for important intellectual content. AJ contributed to the study design, critically reviewed the analysis and interpretation, provided supervision throughout the review process, and critically reviewed the manuscript for important intellectual content. BM contributed to the study design, and critically reviewed the manuscript for important intellectual content. KH conceived the original idea and contributed to the overall study design, critically reviewed the analysis and interpretation, and critically reviewed the manuscript for important intellectual content. PB contributed to the study design, and critically reviewed the manuscript for important intellectual content. AL contributed to the study design and conducted study screening, and critically reviewed the manuscript for important intellectual content. TT conceived the original idea and contributed to the overall study design, contributed to study screening and validated the data charting and analysis, provided supervision throughout the review process, critically reviewed the analysis and interpretation, and contributed to drafting the manuscript. All authors approved the final version of the manuscript before publication.

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Competing interests

None declared

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication

Not applicable.

Ethics approval

This study involves human participants and was approved by Monash University Human Ethics Committee (reference number 23693) and La Trobe University Human Ethics Committee (reference number 23693). Participants gave informed consent to participate in the study before taking part.

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Supplemental material

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