

BMJ Open 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

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Including evidence from a variety of sources (eg, research studies and guidance reports) and data from interviews with consumers and guideline developers provided considerable depth and breadth to the findings.
- ⇒ We used a highly structured data charting process and rigorous descriptive synthesis to synthesise and summarise the findings.
- ⇒ It is likely we missed some descriptive reports about broadening diversity of consumer engagement in guidelines as they are sometimes published online in manuals and reports that are difficult to find or they remain unpublished.
- ⇒ Only a single researcher conducted the descriptive synthesis with checks by a second researcher, rather than independent double coding.

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.^{6,7} Another

approach is to directly engage consumers from diverse backgrounds (ie, those listed in PROGRESS-PLUS) in the guideline development process, for example, as guideline development group (GDG) members.^{6,8} The intention is not to aim for complete representation, but to ensure that a diversity of the lived experience of consumers, and those they may represent, is reflected in the guideline. However, it would seem this happens infrequently as there are few methodological or descriptive studies exploring how consumers from diverse backgrounds can be engaged in guidelines.^{9–11} Instead, recruiting and engaging diverse groups is commonly described as either a key challenge or limitation by guideline developers who have undertaken consumer engagement activities.^{9,12–14}

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*).¹⁵ 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.⁹ However, consumers from diverse backgrounds may face additional barriers to participation, meaning guideline developers may need to adapt their approach and provide additional support.^{16,17} Despite the need for specific advice, guidance to address equity in guidelines typically includes little practical advice about how to do this.^{6,8} Guidance does exist for engaging specific groups in guidelines, such as children and people with mental illness or intellectual disability¹⁶ and Indigenous Australians,¹⁸ 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.¹¹

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,⁸ potentially supporting optimal healthcare delivery and health outcomes for consumers from diverse backgrounds.³

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.¹⁹ We conducted companion scoping reviews, one described here and one elsewhere.²⁰

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 guidance reports).²¹ 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 findings²² 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.²³ The scoping review was commenced first, with provisional results informing interview data collection.

We followed relevant guidance to conduct²¹ and report²⁴ 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.²⁵ 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.^{2,5} The PROGRESS-PLUS acronym is a recommended framework used in guidelines to consider health equity.²⁶

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*).¹⁵ 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.²⁷ 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).²⁷

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 Health and Medical Research Council and the National Centre for Health and Care Excellence, NIHR INVOLVE and the Consumers Health Forum of Australia. We contacted experts in the area by email and via listservs asking if they could recommend potential documents for inclusion. Finally, we searched the reference lists of included documents.

We undertook a single search and screening process for the review reported here and the companion review.²⁰ More detail describing and justifying the terms used in the search strategy is provided in online supplemental material 1).

Selection process

We conducted two-person independent screening of titles and abstracts and full-texts (AS, AL, JH) using Covidence systematic review software.²⁹ Records were de-duplicated prior to uploading into Covidence. Discrepancies on title and abstract were resolved by AS, and for full texts, by discussion between the researchers or with input from another researcher (TT).

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 frameworks^{30 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.

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)³² and has been used in similar reviews (Tong 2018).³³ 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.²⁰ 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,³⁴ a qualitative interview study,³⁵ two

evaluation studies,^{36 37} one descriptive report,³⁸ a checklist,⁸ a toolkit chapter,¹⁶ two handbook modules^{18 39} and a discussion paper.⁴⁰ 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^{8 16 18 34 39 40}; provide an account of engaging diverse groups in a guideline^{36–38}; and explore the views of consumers from diverse backgrounds about engaging in guidelines.³⁵

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

Table 1 Characteristics of included documents

Document type (country)	Aim/objective	Methods, or basis of recommendations	Consumer group(s) (PROGRESS-PLUS)*	Views shared††
Checklist ⁸ (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 example: men who have sex with men and transgender people in LMICs) (P/S/G/OV)	GL
Toolkit chapter ¹⁶ (UK)	To show how it is possible to effectively involve people who may face additional barriers to participation	Published literature and authors' experiences	People facing barriers to participation (children, young people, mental illness, substance use, cognitive impairment, minority ethnic groups) (P/R/A/D/OV)	GL
Systematic review ³⁴ (International)	Practical considerations for using online methods to engage patients in guideline development	Rapid qualitative evidence synthesis (79 studies)	Various 'diverse' groups and 'specific patient populations'‡‡ (P/R/G/E/SES/A/D/OV)	C; GL
Handbook module ¹⁸ (Australia)	Practical advice to guideline developers about how Aboriginal and Torres Strait Islander people need to be involved in guideline development	Literature, and guidelines and methods experts and consumers	Aboriginal and Torres Strait Islander people (R)	C; GL
Handbook module ³⁹ (Australia)	Outline how guideline developers can engage with and support consumers in ways that help them make a meaningful contribution to guideline development	Literature, and guidelines/ methods experts and consumers	Consumers with a variety of needs (related to disability, medical conditions, cultural, language, social) (R/D)	C; GL
Discussion paper ⁴⁰ (Australia)	Assist in the implementation of culturally and linguistically diverse consumer, carer and community participation in the Victorian healthcare system	Literature and local health policies	Culturally and linguistically diverse consumers (R)	C
Evaluation ³⁶ (UK)	Outline the approach taken (involving people with learning disabilities in guideline development) and highlight lessons learnt	Reflections documented during process	People with learning disabilities (n=4) (D)	C; GL
Evaluation ³⁷ (US)	Describe participant experiences with a novel online, scalable approach for patient and caregiver engagement in guideline development	Surveys and interviews	People with Duchenne muscular dystrophy and carers (n=95) (D/P)	C
Descriptive report ³⁸ (Europe, n=8 countries)	Engage multiple sclerosis patients and caregivers in the definition of the key questions to be answered in the guideline on palliative care of people with severe multiple sclerosis	No evaluation; informal reflections only	People with multiple sclerosis and carers (n=970) (D)	GL
Qualitative research ³⁵ (US)	Investigate potential consumer perspectives on engagement in guidelines, including barriers and facilitators	Focus groups	African American research patient partners (n=10)(R)	C

*PROGRESS-PLUS categories: Place of residence, Race/culture/ethnicity/language, Occupation, Gender and sex, Religion, Education, Socioeconomic status, Social capital, Age, Sexual orientation, Disability, Other vulnerable.⁵

†Refers to whether the findings or recommendations made in the document were those of consumers (C) or guideline developers (GL). If classified as consumer, the document directly included consumer views via formal research, the author team included consumers, or consumers provided feedback on the document.

‡Full list: People with limited mobility or other travel limitations, age and sex, socioeconomic status, ethnicity and culture, patients living in geographically different areas, younger people, people with less education, people living rurally with limited internet access.

A, age; C, consumer; D, disability; E, education; G, gender and sex; GL, guideline developer; LMIC, low-income and middle-income country; N, number of participants; OV, other vulnerable; P, place of residence; R, race/culture/ethnicity/language; S, sexual orientation; SES, socioeconomic status.

Table 2 Principles and approaches for engaging diverse groups in guideline development

Theme (sources)	PROGRESS-PLUS	Components	Illustrative quotes
<i>Category 1: General concepts about engaging diverse groups in guidelines</i>			
1. Respectful partnerships (5 documents, 3 interviews)	P/R/A/D/OV	<ul style="list-style-type: none"> Establish respectful partnerships with organisations that work with or represent diverse groups. ^{16, 18} Int-C; GL offer advice. ^{16, 18, 40} or actively support ^{16, Int-C} the engagement. Partner with individual consumers to plan the engagement and share core tasks. ^{38, 40} Int-GL acknowledging that they are the experts in how consumers should be engaged. ^{18, 38, 40} Establish and maintain respectful partnerships from the beginning. ^{18, 35} Int-GL 	<ul style="list-style-type: none"> "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} "Engage key people (...) such as Elders and community leaders in the early stages and respect their advice throughout the process." ¹⁶
2. Recruitment (3 documents, 2 interviews)	P/R/A/D/OV	<ul style="list-style-type: none"> Tailor recruitment strategy to the topic and the demographics (eg, age and language) of all diverse consumer groups sought. ^{16, 18} Int-C 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. ^{Int-GL} Organisations that work with or represent diverse groups can also assist, see Respectful Partnerships theme. 	<ul style="list-style-type: none"> "For some topics, it may be possible to recruit young people (aged 16–25) using targeted advertising and social media." ¹⁶ (p.54) "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." ¹⁶ (p.55)
3. Expectations, process and review (7 documents, 3 interviews)	R/A/D/OV	<ul style="list-style-type: none"> Ensure a clear purpose and role for consumers from diverse backgrounds, ^{16, 35} with well-defined recruitment and support processes to support this. ^{35, 40} Provide feedback and acknowledgement of participation (eg, a certificate), ¹⁶ cover expenses and consider providing compensation. ¹⁶ Int-C Review the engagement: ask consumers for their feedback, ^{8, 35, 40} or conduct a formal evaluation. ^{35, 40} Share examples of success. ¹⁸ Allow additional time for engagement. ^{16, 18, 35} Int-GL; GL Allow additional resources for engagement (eg, for interpreters or travel), ^{39, 40} Int-GL; GL, ¹⁶ but some adaptations (eg, alternate ways of running GDG meetings) are cost-neutral. ³⁶ 	<ul style="list-style-type: none"> "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) "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.60) "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." ^{Int-GL}
<i>Category 2: Engaging diverse groups in the guideline development group</i>			
4. Characteristics of guideline personnel (seven documents, 2 interviews)	R/A/D/OV	<ul style="list-style-type: none"> Ensure chair is skilled in facilitation and is able to actively support involvement of diverse groups, ^{18, 35, 36, 39} Int-C; C acknowledging some consumers from diverse backgrounds do not like direct questioning. ³⁵ Ensure the GDG is supported by people with skills and experience working with the diverse group(s). ^{8, 16} Ensure the chair and other guideline personnel are familiar with relevant history, cultural practices and safety measures ^{8, 16, 18, 39} and recognise the diversity of views and backgrounds within a single diverse group. ^{18, 35, 40} Make certain guideline personnel are sensitive to their own cultural beliefs and behaviours ^{18, 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. ^{35, 40} 	<ul style="list-style-type: none"> "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 maybe get a little bit more sway. He will say, what do you think?" ^{Int-C} "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 "When considering culturally diverse communities it is important to remain attuned to the tendency to homogenise differences in backgrounds, viewpoints and needs." ⁴⁰ (p.29)
5. Consumers' role, characteristics, and prominence (5 documents, 2 interviews)	P/R/A/D/OV	<ul style="list-style-type: none"> Most consumers from diverse backgrounds can and should be involved as full and equal GDG, even if this requires some adjustments. ^{8, 16, 18, 36} 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. ^{18, 35, 36} Consider smaller groups to make consumers feel more comfortable to share their views. ^{35, 36} Engaging consumers from diverse backgrounds can be tokenistic. ⁸ Int-C Consumers should have the skills and confidence to make an active contribution, ^{Int-C} C; ³⁵ however they can be intimidated by professionals ^{8, 35} Int-C and other consumers or carers. ³⁵ Use a consumer representative when people from the diverse group can't take part or for a different perspective. ³⁵ Int-C although including people with lived experience is ideal. ^{Int-C} 	<ul style="list-style-type: none"> "These findings indicate that people with learning disabilities can be included as full members of (guideline) groups with reasonable adjustments." ³⁶ (p.253) "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}

Continued

Table 2 Continued

Theme (sources)	PROGRESS-PLUS	Components	Illustrative quotes
6. Preparing and supporting consumers (7 documents, 3 interviews)	R/A/D/OV	<ul style="list-style-type: none"> ► Offer consumers training in the content and process.^{8 16 35} ► Provide an ongoing, proactive support person to provide practical, technical or emotional support.³⁵ Int-C; C; GL ► Ask consumers about their support needs and meeting preferences at the outset.^{35 39} Int-C This might include interpreters and translating services.^{16 39 40} a support person or carer attending meetings.^{35 39} and alternate ways of sharing their views (eg, written feedback subsequent to meetings).^{35 39} ► Send meeting documents (tailored to individual needs) in advance to give consumers time to prepare.^{16 35 39} Int-C ► Consider pre-meeting contact, for example, to discuss meeting documents or for venue orientation.^{16 36 39} although too much communication can be overwhelming.³⁵ ► Use understandable language during meeting and paperwork.^{16 35 36 40} ► Use accessible and structured formats for decision-making and sharing opinions.^{8 35 36} 	<ul style="list-style-type: none"> ► "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 ► "Ask if a communication support person will be attending, if they have difficulty understanding written or spoken language and what specific strategies would be most helpful for them." 39 ► "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." 39 ► "Multiple individuals mentioned the advantage of having an established process for making sure that everyone has a chance to share an opinion." 35 (p.3)
<i>Category 3: Other (non-guideline development group) engagement approaches</i>			
7. Online methods (5 documents, 4 interviews)	P/R/E/SES/A/D	<ul style="list-style-type: none"> ► Online methods preference the participation of well-educated, online-proficient consumers with internet access.^{34 36} Int-GL ► Online methods facilitate engagement for people with physical or social disabilities.^{34 37 39} Int-GL; C those in geographically dispersed areas in mostly high-income countries.^{34 37 38} and young people.³⁴ ► Online methods hinder participation for people with cognitive disability,³⁴ and people who are disadvantaged and living in low and low-middle income countries.^{Int-GL} ► 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 	<ul style="list-style-type: none"> ► "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." Int-GL ► "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 chit 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."
8. Consultations and research-based approaches (3 documents, 2 interviews)	R/A/D/OV	<ul style="list-style-type: none"> ► For some diverse groups it is impractical to include them in the GDG (eg, children, people with severe cognitive limitations),¹⁶ while others may prefer a separate consultation (eg, those with limited confidence or culturally and linguistically diverse groups).^{16 40} ► In these instances, families or advocates could join the GDG with additional consultation approaches (reference groups, advisory groups or expert testimony)¹⁶ used to capture consumer views. ► Consultation approaches can be used at key stages of the guideline development process to widen the range of views, address a specific issue and fill evidence gaps.^{16 18} ► Specific recommendations for reference groups: know your objectives and recruitment criteria, consider participant welfare, induction and support needs, provide participation rewards and feedback¹⁶ and ensure transparent report back to the GDG.^{Int-C} ► Research-based methods, including interviews, group-based methods or surveys (conducted in person, by phone or online) are appropriate in response to gaps in the evidence that cannot be filled by more participatory approaches.¹⁶ Int-GL ► Specific suggestions regarding research based approaches: tailor approach to the diverse group, use people with research expertise and experience working with the diverse group, and pilot tested¹⁶ Int-GL however this can be challenging and disadvantaged groups can't always answer questions framed in ways to feed into the guideline.^{Int-GL} 	<ul style="list-style-type: none"> ► "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."⁴⁰ (p.24) ► "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."¹⁶ (p.56) ► "The only problem (with seeking consumer views outside a GDG meeting) is that (...) they evolve from discussion. As long as those views are brought to each meeting in written form or whatever form (...) those would be added by patients or patient reps while they're there." Int-C ► "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
<p>.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.</p>			

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^{8 16 18 36-38} 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^{9 11 41} yield very little related to any aspect of diversity.⁹ Thus, 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).^{11 42} There is considerable overlap between our results and this literature. For example, partnering with diverse community groups to plan and undertake engagement is recommended,^{11 43} as

is ensuring the professionals involved view consumers as equal and possess linguistic and cultural competency.^{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^{17 42} and identifying and mitigating power imbalances.^{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,^{9 39} their contribution appropriately acknowledged and be given an opportunity to feed back about their experience.^{39 44} Further, consumers and guideline developers should be offered guidance and ongoing support in their respective roles.^{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^{16 18} yet only one⁴⁵ 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.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 analysis and interpretation, 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

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Patient consent for publication Not applicable.

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Provenance and peer review Not commissioned; externally peer reviewed.

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SUPPLEMENTARY MATERIAL

‘Broadening the diversity of consumers engaged in guidelines: A scoping review’

Supplementary material 1. Search strategies

We used a single search and screening approach for this scoping review and its companion review¹ hence the search strategy was necessarily broad to encompass both topics. The search also includes terms related to health technology assessments (HTA), as the scoping review originally include this additional context. HTA documents were later excluded based on the number of included documents in guidelines, as they better reflected the review’s aim. The full search records are presented for completeness.

Embase Classic+Embase (1947 to 20 March 2020)

1. *practice guideline/
2. guidelin*.mp.
3. exp Technology Assessment, Biomedical/
4. (health technology adj2 assess*).ti,ab,kw.
5. or/1-4
6. Patient Participation/
7. exp Community Participation/
8. ((consumer? or patient? or communit* or stakeholder? or user? or lay or citizen? or public) adj (particip\$ or involv\$ or represent\$ or collaborat\$ or consult\$ or contribut\$ or engage or engagement or deliberat\$ or dialogue or opinion?)).ti,ab,kw.
9. or/6-8
10. and/5,9
11. limit 10 to english language

Ovid MEDLINE® ALL (1946 to 20 March 2020)

1. *"Practice Guidelines as Topic"/
2. guidelin*.mp.
3. exp Technology Assessment, Biomedical/
4. (health technology adj2 assess*).ti,ab,kw.
5. or/1-4
6. Patient Participation/
7. exp Community Participation/
8. ((consumer? or patient? or communit* or stakeholder? or user? or lay or citizen? or public) adj (particip\$ or involv\$ or represent\$ or collaborat\$ or consult\$ or contribut\$ or engage or engagement or deliberat\$ or dialogue or opinion?)).ti,ab,kw.
9. or/6-8
10. and/5,9
11. limit 10 to english language

Supplementary material 2: Question guide for interviewsConsumer participants

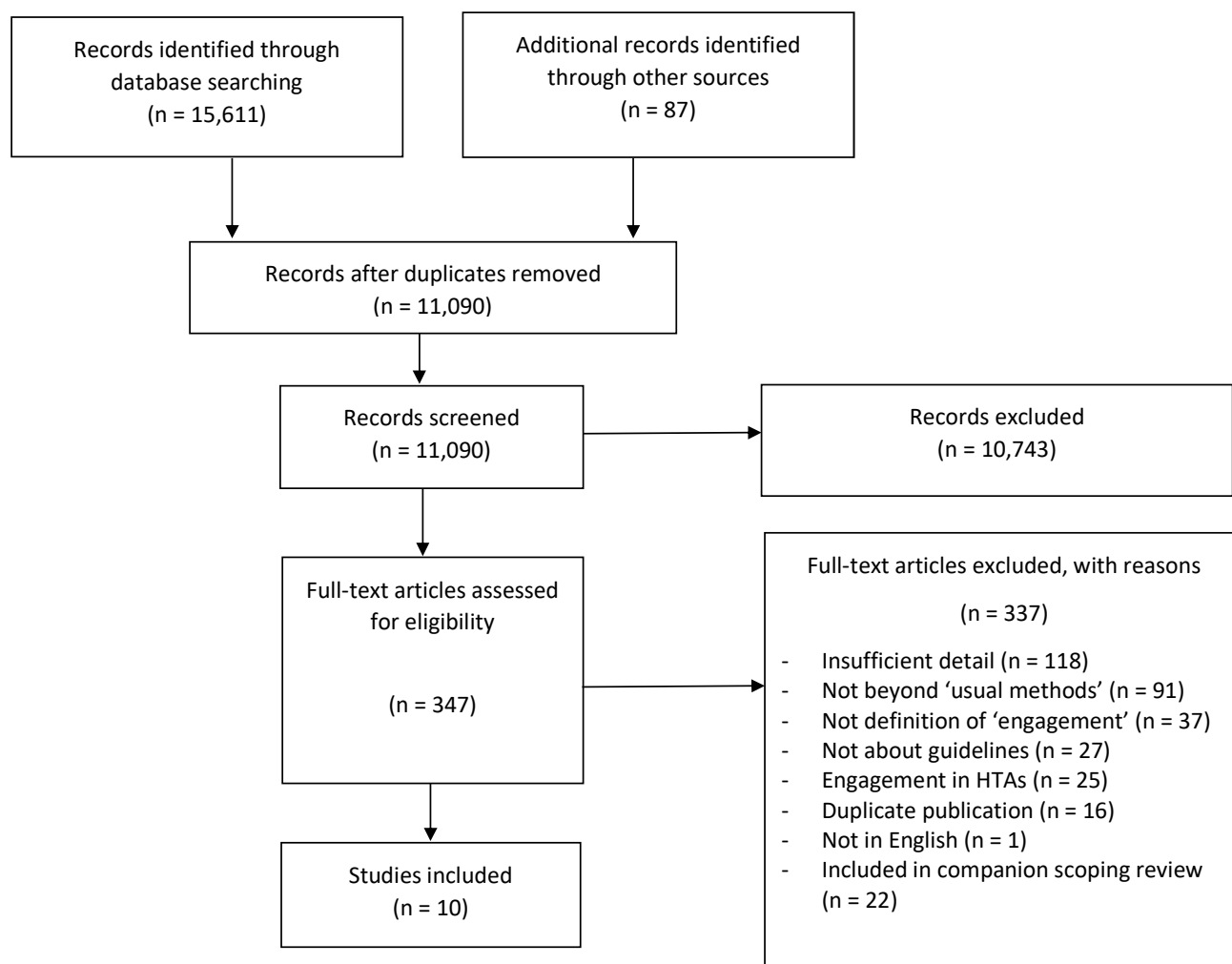
1. Please introduce yourself and tell me a little about how you came to be involved in guidelines (e.g. motivations).
2. Briefly describe your experience as a patient/consumer contributor to healthcare research or guidelines. Please describe which PROGRESS-PLUS diversity category(ies) you fall into (see descriptions on the next page).
3. Please describe how you (and any other patients/consumers from diverse backgrounds) were involved in the guideline(s)
Prompts (if not covered off)
 - What types of consumers (ie. lived experience, representative) and how many people?
 - How did you hear about the opportunity to get involved?
 - What tasks were you asked to do? What did you like most/least and why?
 - How were you involved (meetings, workshops etc)? How did you feel about the level/extent of involvement?
 - What sort of support were you offered to participate (e.g. training, additional meetings with a support person, financial reimbursement)? What did you think about these – what did you like, what could have been improved?
4. Were you able to make the contribution to the guideline that you had hoped? Why or why not? Do you have any examples?
5. To what extent do you feel you were able to make an active contribution – why? Was this shaped or influenced by anything the guideline developers did/say? What are some examples?
6. What could have been done differently to improve your experience and ability to contribute as a patient/consumer from a diverse background?
7. What strategies would you recommend to guideline developers who are seeking to involve people from diverse backgrounds in guideline(s)?
8. Is there anything else that you would like to mention or add that we haven't covered?

Guideline developer participants

1. Please introduce yourself and tell me a little about your specific experience in patient/consumer engagement and guideline development.
2. Please describe how patients/consumers from 'diverse backgrounds' (see PROGRESS-PLUS diversity categories – next page) were included in your guideline(s)
Prompts (if not covered off)
 - a. Who was involved (which PROGRESS-PLUS diversity category – see next page), what types of patients/consumers (i.e. lived experience, organisational representative) and how many people? Why did you focus on these specific groups?
 - b. How did you find/recruit people?
 - c. In what guideline stages and why in these particular stages?
 - d. What were the methods of involvement, why did you use these methods and were there any challenges – if so, how did you overcome them?
3. What, if anything, did you do differently from usual to facilitate involvement of patients/consumers from diverse backgrounds? How did you come up with this approach?

Prompts (if not covered off)

- a. Recruitment
 - b. Support/preparation for consumers or guideline panel
 - c. Structure/logistics/support at meetings/consumer input
4. Reflecting on your own experience, what worked well to involve patients/consumers from diverse backgrounds and why?
5. What would you do differently next time to increase or support involvement patients/consumers of from diverse backgrounds?
6. What would you recommend to other guideline developers seeking to involve this group(s)?
7. Is there anything else we should know?

Supplementary material 3. PRISMA flow diagram

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Supplementary material 4. Summary of implemented approaches for boosting diversity of consumers engaged in guidelines

Guideline topic (and country)	PROGRESS-PLUS¹	Consumers (number and description)	Guideline stages	Engagement methods / partnerships / support to consumers	Tasks given to consumers
HIV in men who have sex with men and transgender persons ² (LMICs)	SO; G; P	N > 16 (Men who have sex with men community/representatives n > 14; community members n = 2)	Likely all (NR)	<u>Engagement methods</u> : Members of 'core working group' and consensus panel (community/organisational representatives); Involved in review of final drafts (community members) <u>Partnerships</u> : NR <u>Support to consumers</u> : NR	-Likely contributing to all GDG tasks
Learning disabilities ³ (two guidelines; UK)	D	N = 4 (people with learning disabilities)	Likely all (NR)	<u>Engagement methods</u> : Members of GDG <u>Partnerships</u> : NR <u>Support to consumers</u> : Simplified documents; Pre-meeting catch ups; Skilled support staff during meetings	-Contributing to all GDG tasks
Management of volatile substances ⁴ (Australia)	R	N = NR (Aboriginal researcher n = 1; reps from Aboriginal organisations in community n = NR)	All	<u>Engagement methods</u> : Chair of guideline committee (Aboriginal researcher); Guideline committee members (Representatives from Aboriginal organisations) <u>Partnerships</u> : NR <u>Support to consumers</u> : NR	-Committee chair -Direct contribution to guidance
Health and wellbeing of 'looked after' children and young people ⁵ (UK)	A; OV	N = NR (Children and young people who grew up in care)	All	<u>Engagement methods</u> : Members of GDG (young adults); Workshops (children and young people in public care); Involved in two online resources to support guideline implementation (young people) <u>Partnerships</u> : NR <u>Support to consumers</u> : NR	-GDG: direct contribution -Workshops: Comment on relevance, acceptability -Implementation: Interview young people for a film and help develop a website
'Dual diagnosis': Psychotic illness and substance use problems ⁵	OV	N = 19 (people with psychotic illness and substance use problems, n = 9; user organisation representatives, n = 10)	All	<u>Engagement methods</u> : Members of GDG (people with lived experience; 4 and 5 on the respective GDGs); Working group (user org reps) <u>Partnerships</u> : NR <u>Support to consumers</u> : Working group members were paid for time and travel	-GDG: Scoping most important topics and formulating recommendations -Working group: Planning guideline implementation

Guideline topic (and country)	PROGRESS-PLUS ¹	Consumers (number and description)	Guideline stages	Engagement methods / partnerships / support to consumers	Tasks given to consumers
(2 guidelines; Norway)					
Social care for child abuse and neglect ⁵ (UK)	A	N = NR (young people who have experienced child abuse and neglect)	Likely all	<u>Engagement methods</u> : Reference group (convened and supported by external agency) for ongoing consultation <u>Partnerships</u> : External agency with expertise / experience convened and support reference group <u>Support to consumers</u> : NR	-Share perspectives and priorities at key stages of guideline development and dissemination
Pregnancy care ⁴ (Australia)	R	N = NR (consumer representative, health workers from Aboriginal community-controlled health organisations)	All	<u>Engagement methods</u> : Expert advisory committee <u>Partnerships</u> : NR <u>Support to consumers</u> : NR	-Provision of advice and guidance throughout the guideline
Kidney disease care in Aboriginal and Torres Strait Islander peoples and Māori ^{4,6,7} (Australia)	R	N = NR (engagement ongoing) (Aboriginal and Torres Strait Islander peoples with kidney disease and carers, in 16 communities across Australia) ²	-Priority setting and topic selection -Dissemination and implementation	<u>Engagement methods</u> : Face-to-face community consultations: Project team, and local facilitators included Aboriginal and Torres Strait Islander Peoples and professionals; Individual workshop structure co-designed locally; Draft reported presented in person <u>Partnerships</u> : Local community members & patients as cultural brokers; Partnerships with stakeholders in Indigenous health and local community contacts <u>Support to consumers</u> : Held open and closed meetings for cultural safety	-Feedback and advice on scope, content and priorities -Approach for translation into consumer information, tools and education materials
Autism ⁵ (UK)	D; A	N = NR (Children and young people on the autism spectrum)	-Developing recommendations	<u>Engagement methods</u> : Focus groups and interviews (numbers not reported) <u>Partnerships</u> : National Autistic Society conducted consultations <u>Support to consumers</u> : NR	-Validate and comment on draft recommendations derived from literature

Guideline topic (and country)	PROGRESS-PLUS ¹	Consumers (number and description)	Guideline stages	Engagement methods / partnerships / support to consumers	Tasks given to consumers
Sedation for procedures in children and young people ⁵ (UK)	A; OV	N = NR (children in hospital)	NR	<u>Engagement methods</u> : Survey delivered via a hand-held touch screen; Children and young people previously contributed to data collection system <u>Partnerships</u> : Local hospital <u>Support to consumers</u> : NR	NR
Duchenne Muscular Dystrophy care ⁸ (US)	D; P	N = 95 (carers n = 71; People with Duchenne Muscular Dystrophy n = 24) ³	-Developing recommendations	<u>Engagement methods</u> : Online modified Delphi (3 rounds: (1) rating; (2) review and discuss; (3) revise <u>Partnerships</u> : NR <u>Support to consumers</u> : Voucher after completed round	-Share views on importance and acceptability of 19 care considerations
Palliative care in MS ⁹ (Europe)	D	N = 970 (People with MS n = 776; carers n = 193; Person with MS who was member of MS org n = 1) ⁴	-Priority setting and topic selection	<u>Engagement methods</u> : Taskforce member (n = 1); Online survey: Consumers (n = 934) presented with 9 guideline questions and asked to rate agreement; 5 focus groups: Consumers (n = 35) online survey results. Explored additional topics and related outcomes. <u>Partnerships</u> : NR <u>Support to consumers</u> : NR	-Taskforce member: “a bridge between MS patients and developers” -Online survey/focus group: Prioritising questions, suggested new questions and outcomes

Footnotes

¹Full list of PROGRESS-PLUS equity categories include: place of residence, race/ethnicity, occupation, gender, religion, education, socioeconomic status, social capital, age, sexual orientation and disability ¹⁰. We added an ‘other vulnerable’ category to capture groups who did not fit into the existing categories, such as young people who’d grown up in care and people with substance use problems.

²At the time of writing, this consumer engagement activity was ongoing. The engagement approach described includes their planned methods and a report of the first three consultation activities.

Abbreviations

GDG = guideline development group, HIC = high income country, LMICs = low- and middle-income countries, MS = Multiple Sclerosis, P = Place of residence; R = Race/culture/ethnicity/language; O = Occupation; G = Gender and sex; Re = Religion; E = Education; SES = Socio-economic status; SC = Social capital; A = Age; SO = Sexual orientation; D = Disability; OV = Other vulnerable

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