

Commentary

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Values, principles, strategies, and frameworks underlying patient and public involvement in health technology assessment and guideline development: a scoping review

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Abstract

The importance of patient and public involvement (PPI) is recognized by agencies involved in health technology assessment (HTA) and guideline development. However, a comprehensive overview of the underlying PPI principles, values, strategies, and frameworks is lacking. This scoping review aimed to summarize the available evidence on principles, values, frameworks, and strategies underpinning PPI carried out by agencies involved in HTA and guideline development. A total of twelve records were included, of which four referred to guidelines and eight to HTA. Overall, this review demonstrated a lack of consistency in the definition and application of the concepts of values and principles to PPI in the context of guideline development and HTA. There was significant overlap between values and principles, with some broad themes emerging, such as representation, transparency, relevance, equity, fairness, and reconciling different types of knowledge. Frameworks were typically based on the stages of guideline development or HTA, despite heterogeneity in how stages were labeled and described. Strategies were also mapped to the stages of guideline development and HTA and varied substantially depending on the context and setting. Both strategies and frameworks demonstrated patients and the public can be involved, albeit to a variable extent, throughout the stages of guideline development and HTA. However, frameworks often failed to explicitly link the values and principles with the HTA and guideline development stages through actionable PPI strategies. Further research is warranted to better understand the values, principles, and frameworks underpinning PPI in guideline development and HTA.

The importance of patient and public involvement (PPI) in health and, to a lesser extent, social care systems is now recognized worldwide (1;2). PPI is rooted on the understanding that patients and the public are equal partners in the evaluation and decision-making processes underpinning these services (3). Public involvement in the design, conduct and dissemination of health research has become an expected norm and firmly enshrined in policy in the UK and internationally (4;5). Albeit with wide variation in extent, processes and practices, health technology assessment (HTA) and guideline developing agencies also engage in PPI, particularly the National Institute for Health and Care Excellence (NICE), which has been proactive in this area over the past years (6). The benefits of PPI have been established in these different settings, including improving patient-centeredness, integration, quality, safety, implementation, and the efficiency of health services (7). However, PPI implementation challenges remain including logistical barriers, knowledge and power asymmetry, and lack of resources (8;9).

Several healthcare or research institutions have developed PPI frameworks underpinned by values or principles (10–14). However, it is unclear how these apply to agencies, such as NICE, with broad remits, which include HTA and guideline development, due to differences in the purpose and practice of PPI in those settings (10). Whilst a framework of values and standards exist for HTA (e.g., equity, legitimacy, and capacity building) (15), there is no clear framework that links values and principles to PPI strategies. Organizations generally lack PPI aims (the “why”) that are mapped onto actionable PPI processes and strategies (the “how”), resulting in a gap between theory and practice (16). This limits their ability to implement a coherent and aligned PPI strategy and to evaluate the impact of PPI. A robust framework is needed, but a comprehensive overview of the underlying PPI principles, values, strategies, and frameworks within HTA and guideline development is lacking.

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NICE has long been recognized for the quality of its PPI activities (17). More than 200 lay members or patient experts take part in NICE's programs yearly. NICE commits to continuously improve its PPI policies and practices in line with the most recent evidence. This scoping review aims to summarize the available evidence on principles, values, frameworks, and strategies underpinning PPI in HTA and guideline development, to support NICE developing a comprehensive and evidence-based PPI program. Although the primary purpose of this is to inform the improvement of the PPI program at NICE, its findings will be applicable and helpful to similar guidance developers in other jurisdictions.

Methods

This scoping review was conducted in line with the PRISMA-Sc Guidelines for scoping reviews and the recommendations of the Cochrane Rapid Reviews Method Group (18;19). A scoping review was conducted due to the paucity and limited quality of the literature hitherto available.

Guiding Theoretical Framework

Values were defined as “The established collective moral principles and accepted standards of a person or a social group; principles, standards or qualities considered worthwhile or desirable” (13). Principles were defined as “fundamental norms, rules, of beliefs that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives and are meant to govern both” (10). Frameworks were defined as structured approaches, methods or processes underpinning PPI throughout the stages of guidance development (12). Strategies were defined as actions or interventions that would support the implementation of PPI and be embedded in

frameworks (20). The relationship between values, principles, frameworks and strategies is depicted in Figure 1.

Eligibility Criteria

Records of any type (e.g., original research, reviews, reports, and strategy documents published online or in paper) were included if they explicitly focused on PPI values, principles, standards, and frameworks in settings related to NICE's programs (e.g., public health, social care, or clinical guidelines; interventional procedures; highly specialized technology; technology assessments; and quality standards). Records that did not explicitly focus on values, principles and frameworks were excluded (e.g., records that presented evaluation of PPI programs or described the development of PPI programs without reference to values, principles, or frameworks). Records related to PPI in the context of research or healthcare delivery were also excluded because these have been explored in great depth by previous reviews (12–14). In addition, the differences between PPI in research and HTA and guideline development mean values and principles and frameworks may not be transferrable.

Search Strategy

The bibliographic databases Cochrane, Embase, and Medline were searched from Jan 2010 to Apr 2021. The search strategy was developed based on previously published reviews for values (13) and frameworks (12). Search terms included “lay,” OR “consumer,” OR “community,” OR “public,” OR “patient,” OR “service user” AND “Involvement,” OR “engage,” OR “participation,” OR “co-production,” OR “collaboration,” OR “represent.” Terms for framework included “Framework,” OR “Guideline” OR “tool” OR “toolkit” OR “checklist.” The terms “values,” “standards,” and “principles” were also used. Grey literature searches were carried

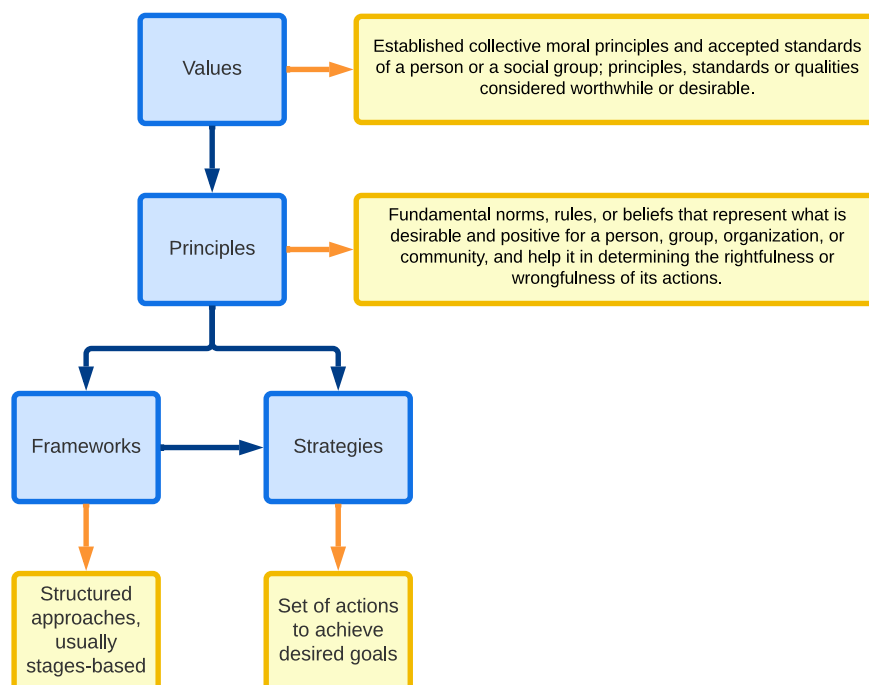


Figure 1. Diagram illustrating the definitions and relationships between values, principles, frameworks, and strategies.

out using a combination of relevant terms, such as “values,” “principles,” “frameworks,” and “patient and public engagement or involvement.”

This search was supplemented by grey literature searching through the Web sites of key HTA, guideline developers, and healthcare and public health institutions, including Health technology assessment International (HTAi), the King’s Fund, the European Patients’ Academy on Therapeutic Innovation (EUPATI), the Canadian Agency for Drugs and Technologies in Health (CADTH), and ProQuest. Those Web sites were searched using combinations of relevant terms, such as “values,” “principles,” “frameworks,” and “patient and public engagement or involvement.” Eligible records were extracted to a table and then added to records identified on bibliographic databases (details presented in Supplementary Table S1). Hand-search of lists of references from previous literature reviews was also carried out to identify additional records. These records were added to the list of records identified in bibliographic databases.

Selection of Records

After deduplication, titles and abstracts for all records were screened by two independent reviewers (J.S. and A.-C.P.-G.) based on the eligibility criteria. Full-text screening was then performed by A.-C.P.-G. and S.S. Any discrepancies in included records were resolved by consensus. The software EPPI-Reviewer 5 was used for reference management and screening.

Data Extraction and Analysis

Data were extracted by three independent reviewers (A.-C.P.-G., J.S., and S.S.) for variables related to the article (title, author, year, settings, and methods), values, principles, and frameworks. Data for values, principles, frameworks, and strategies were summarized in tables. Due to the inconsistent reporting and description of principles, thematic analysis was performed by one reviewer (S.S.) to group principles by similarity based on the labels and operational definitions used across HTA and guidelines. Triangulation was performed and themes were reviewed by another reviewer (J.S.) with 93 percent agreement. Disagreements were resolved by consensus and further themes created if identified.

Results

Overall Findings

In total, twelve records were included (out of 6,199), of which ten were identified through electronic databases and two through a grey literature search (Figure 2). Four records referred to guidelines and eight records related to HTA (Table 1).

Values and Principles

Six values were identified, namely capacity building, equity, fairness, legitimacy, relevance, and transparency/openness (Supplementary Table S2). These were mentioned by three records, all of which related to HTA and adopted consistent definitions of those values. For instance, relevance was defined as “Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA” and fairness as “Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective

engagement.” Transparency/Openness was mentioned by one record but not defined.

Seven records described forty principles in total, underpinning PPI in guidelines (six principles), HTA (twenty-five principles), and both guidelines and HTA (nine principles) (Supplementary Table S3). Principles were variably framed as values, objectives, or even methods for undertaking PPI. Although principles were often labeled and defined differently by different authors and agencies, HTA and guidelines shared many principles, such as transparency, representation, support and training, commitment to engage and involve patients, reconciling different types of knowledge, and improving relevance and applicability of guidance.

The thematic analysis of the forty principles identified some common themes that were framed differently, for example “engage a range of patients” and “multiple inputs” were mapped to the theme “representation” based on the similarity of their label and description. In total, principles were categorized into sixteen main themes, such as transparency, representation, support/training, resources, and fair and equitable. A full list of themes of the core principles is provided as Supplementary Table S4. Interconnections between themes existed with some principles and operational descriptions coded within the same theme (e.g., timeliness and transparency).

Overall, the concepts of values and principles were used interchangeably, with no clear and agreed definition of what values and principles meant. For instance, transparency, relevance, equity, and fairness were labeled as either values or principles depending on the author. The lack of a clear distinction between values and principles is well illustrated by the EUPATI, which stated in its PPI strategy: “These values are the underpinning principles that indicate why it is important to involve patients in HTA.”

Frameworks and Strategies

Seven records described seven frameworks in total, of which two were related to guideline development and five to HTA (Supplementary Table S5). All but one of the frameworks were based on the stages of development of guidelines or HTA and included guidance on how to involve and engage with patients and the public as well as examples of activities to be undertaken at each stage. The exception was a framework of factors influencing choice of public engagement in HTA mapped onto three types of participation: communication, consultation, and participation (21).

Two records described strategies for undertaking PPI in the context of guidelines, which were also mapped to different stages of guideline development (Supplementary Table S6). Four records described strategies to embed PPI into the stages of HTA development (Supplementary Table S7). Some stages were common to both HTA and guideline development, such as selecting and prioritizing topics, scoping, evidence review and analysis, drafting recommendations, dissemination, and evaluation of PPI. However, the recommended strategies within each stage varied between authors and agencies from different countries (e.g., Spain and Canada).

Discussion

Overall, this review highlighted the key values (e.g., transparency), principles (e.g., representation), and frameworks in the context of PPI in guideline development and HTA. However, the review demonstrated a lack of consistency in the definition and application of the concepts of values and principles to PPI. There was

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

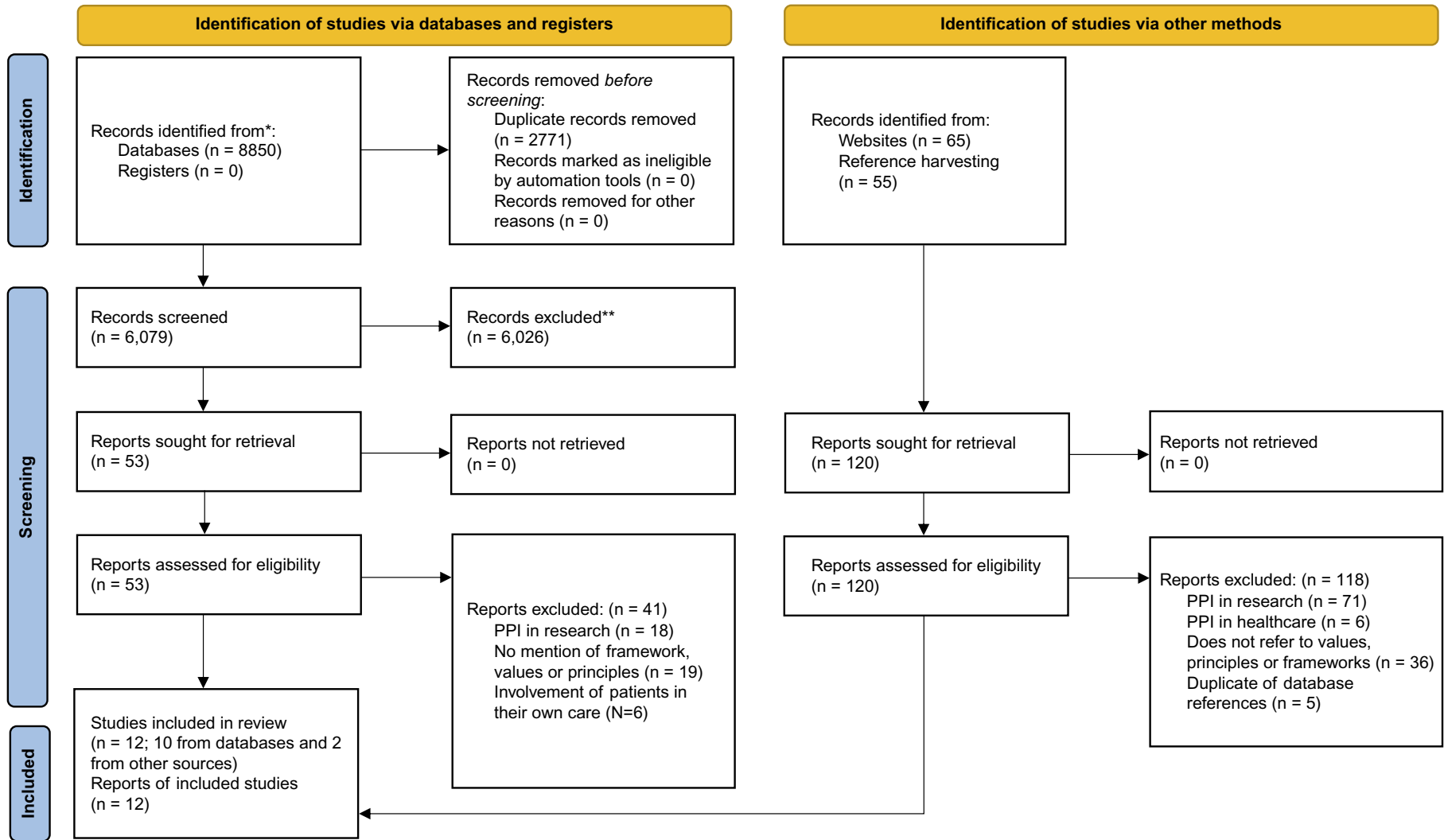


Figure 2. PRISMA flow diagram. The diagram illustrates the process of screening and selection of eligible records, including number included and excluded at each stage.

Notes: *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Source: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

Table 1. Summary of Records Included in This Review

Primary author	Methods	Country	Setting
Björkqvist, 2021	Systematic review and interviews with key stakeholders; Delphi survey		Guidelines
Armstrong, 2017	Proposal of framework		Guidelines
de Wit, 2019	Expert panel		Guidelines
Harding, 2011	Analysis of mental health guideline development	UK	Guidelines
Abelson, 2016	Synthesis of international practice and published literature, a dialogue with local, national, and international stakeholders, and the deliberations of a government agency's public engagement subcommittee	Canada	HTA
Wortley, 2016	Framework proposal		HTA
Hunter, 2018	Guidance based on expert consensus		HTA
Gagnon, 2015	Semistructured interviews with stakeholders on applicability of framework developed based on systematic review and interviews with stakeholders	Canada	HTA
Toledo-Chavarri, 2019	Systematic review, qualitative study through interviews with RedETS members to analyze the perceptions of patient involvement (PI) among HTA managers in the Spanish context; a Delphi consultation with three large platforms of patients, carers, and consumer organizations in Spain; a consensus process with the members of the RedETS Governing Council to define the final strategy	Spain	HTA
Perfetto, 2018	Survey and focus group		HTA
CADTH Framework for Patient Engagement in Health Technology Assessment, 2021	This framework is available on the CADTH Web site but there is no information on how it was developed		HTA
Values and quality standards for patient involvement in HTA, EUPATI, 2014	In 2014, HTA international worked with a wide range of stakeholders internationally to develop values and quality standards for patient involvement in HTA		HTA

CADTH, Canadian Agency for Drugs and Technologies in Health; EUPATI, European Patients' Academy on Therapeutic Innovation; HTA, health technology assessment.

substantial overlap between values and principles, with some broad themes emerging, such as representation, transparency, relevance, equity, fairness, and reconciling different types of knowledge. This review also identified useful frameworks and strategies to support PPI. Frameworks were typically based on the stages of guideline development or HTA, despite heterogeneity in how stages were labeled and described. Strategies were mapped to the life cycle of guidelines and HTA and varied substantially depending on the context and setting. Both strategies and frameworks demonstrated patients and the public can be involved, albeit to a variable extent, throughout the stages of guideline development and HTA. However, frameworks often failed to explicitly link the values and principles with the HTA and guideline development stages through actionable PPI strategies. Taken together, the findings of this review highlight the need for greater consistency and clarity on the reporting of PPI values, principles, and frameworks implemented in both guideline development and HTA.

Although this review identified values and principles shared between guidelines and HTA, a key finding was the lack of consistency on how "values" and "principles" were defined. This resulted in values and principles being used interchangeably, making it impossible to fully understand the values and principles underpinning different PPI programs. The variable and unclear definition of values and principles in this context reflects a broader lack of consistent and clear definitions in the literature (22;23). We adopted the definition of values as "established collective moral principles and accepted standards of a person or a social group; principles, standards or qualities considered worthwhile or desirable" (13) and principles as "fundamental norms, rules, or

beliefs that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives and are meant to govern both" (10). However, even those definitions conflate values and principles by defining values as "moral principles." Based on those definitions, we interpreted values as well-established, widely accepted, overarching ideals, and principles as norms, rules, or statements that describe those ideals in more detail and help establishing the right or desirable course of action. Values can be considered as abstract, whilst principles are concrete and linked to action and, potentially, a context (13;24). Adopting standard or consensual definitions, rooted on theory, is essential to ensure comparability of PPI programs. Unless there is a common understanding between those involved in PPI programs, evaluating, and sharing good practice, which is essential for continuous improvement, will not be possible.

On the other hand, there was lack of clarity on how to apply principles in practice. Assuming principles should "help determining the rightfulness or wrongfulness of actions" as per the aforementioned definition (10), then the frameworks and strategies underpinning PPI programs should enact those principles. This means that the definitions of principles should be operationalizable to ensure there is a binding thread from theoretical principles to practical frameworks and strategies, thus enhancing the clarity and accountability of PPI programs (25;26). If principles are defined as values, which are inherently abstract and intangible, it is difficult to embed them into frameworks and strategies. Although principles are not "how to" guides, they should clearly identify what is desirable and ideal and be linked to action so that frameworks

and strategies (i.e., “how to” guides) can be developed based on those foundational principles.

Some of the values and principles identified by this review were in keeping with those underpinning PPI in research and healthcare, such as transparency, equity, and relevance (12;24). This may reflect similarities between the purpose of PPI in research, healthcare, and the development of HTA and guidelines (27;28). For example, patients and the public are seen as equal partners in research and healthcare (24;29). Their lived experiences contribute additional expertise and give valuable, novel insights that can significantly enhance the relevance and impact of research outputs as well as improve patient-centeredness of services (30). Similarly, some guideline development and HTA organizations, such as NICE, recruit and involve patients and people using health and care services into their guideline development committees as equal members with voting rights in the decision-making process (17). Patients and the public are also invited to provide testimony or submissions of their lived experience of health conditions, medications, interventional procedures, technologies, or health services (31;32). These commonalities suggest agencies involved in HTA and guideline development may borrow shared values, principles, frameworks, and strategies from research, where PPI is better established and documented (33).

On the other hand, some key values and principles outlined by previous reviews on PPI in research and healthcare did not appear in the context of HTA and guideline development, for instance autonomy and empowerment (12;13). This may reflect fundamental differences between the rationale for and purpose of PPI in research and healthcare in comparison to development of guidelines and HTA. In keeping with the definition of PPI in research as research being carried out “with” or “by” members of the public rather than “to,” “about” or “for” them, patients and the public are seen as cocreators (2;24). In healthcare, PPI often means sharing information and empowering patients to make autonomous decisions supported by clinicians, in contrast with the old paradigm of paternalistic medicine (14;34). This is dramatically different from the role of PPI in HTA and guideline development. NICE and other agencies are accountable for producing impartial, equitable, evidence-based guidance that maximizes population health within the constraints of limited healthcare resources. Such decisions are made following rigorous, transparent, quality assured methods and processes that are relatively inflexible (31;32). This is distinct from research, where subjective, individual testimonials can shape how studies are designed and carried out, and healthcare, where patients make decisions that impact mostly on their own healthcare either at individual or collective level (e.g., commissioning of local healthcare services). In guideline production and HTA, PPI needs to be conciliated with the rigid methods and processes that guarantee decisions are equitable, unbiased, and evidence-based (35), thus limiting the ability to adopt principles, such as empowerment and autonomy. Therefore, some values and principles are and should be distinct in HTA and guideline development in comparison to research and healthcare.

All but one of the frameworks were based on the stages of guideline development and HTA and included specific actions for each stage (21). Likewise, strategies were mapped to specific stages of guideline development and HTA. These findings have two important implications. First, these frameworks and strategies demonstrate PPI is feasible and beneficial throughout the process of guideline development and HTA, from topic selection and prioritization through to dissemination and implementation. Importantly, both in guidelines and HTA, strategies were also

identified to engage patients and the public in the evaluation of the PPI processes and outcomes. Therefore, it seems broadly accepted that PPI should be embedded into all steps of development of guidelines and HTA. Second, despite some similarities between guidelines and HTA, the stages of development do not exactly overlap. This means developing a single stages-based framework that could be applied to both guideline development and HTA may not be feasible. On the other hand, it may be possible to develop a generic stages-based framework, which includes slightly modified strategies specific to the setting of guidelines or HTA. This may be particularly suited for agencies, such as NICE that produce multiple types of guidance (e.g., guidelines and HTA) and, hence, would rather benefit from developing a unified framework that could be applied in both contexts for clarity and transparency in PPI programs.

The heterogeneous description of frameworks and strategies, particularly the discrepancy in how stages of guidance production were labeled and conceptualized, suggests frameworks and strategies need to be tailored to the specific context, setting, population, and topic (20;36). On one hand, a PPI program should be embedded into a broader organizational mission and vision (37). This means PPI strategies should be guided by core institutional values and principles, which are part of the organizational culture. In addition, strategies may need to be adjusted to the topic as well as the target population (38). For instance, strategies to engage with children and young people and their carers are likely to be different to those required for involving older people (39). PPI strategies may also vary according to how sensitive, controversial, or uncertain the topic and/or recommendations are. On the other hand, PPI strategies are likely to differ between countries due to different societal values (6). NICE and similar agencies in other jurisdictions are ultimately accountable to the society they serve and, thus, are expected to adopt strategies that fit with wider societal needs and preferences.

This is the first review to comprehensively explore the linkage between values, principles, strategies, and framework components for PPI in multiple types of guidance and guideline development. The main strengths of this review are the comprehensive literature search, including grey literature, and the in-depth data extraction and thematic analysis, which provided a new insight into values and principles often hidden amidst complex papers describing PPI programs. There are, though, some limitations to acknowledge. First, it is possible that some papers may have been missed, particularly if values, principles, and frameworks were not clearly mentioned in the title or abstract. In addition, restrictions were placed on the date range and number of databases searched in line with recommendations for rapid reviews (19). Second, publication bias cannot be excluded, as preprint databases were not searched and, due to the enormity of the task, we did not contact all guidance developing agencies globally to enquire about whether they had their own unpublished frameworks and principles.

Conclusion

PPI is widely recognized as an intrinsic component of HTA and guideline development. However, consensual definitions of values and principles underpinning PPI are lacking. Frameworks are commonly mapped to the stages of HTA and guideline development, thus emphasizing PPI should be embedded throughout the process from scoping to implementation and evaluation. However,

the extent and strategies may vary across the stages of HTA and guideline development. Further research is warranted to better understand how values and principles shape PPI programs and are reflected in frameworks and strategies used by agencies involved in HTA and guideline development.

Supplementary Material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S0266462322000289>.

Conflicts of Interest. The authors declare that they have no conflict of interest.

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