Weaving the Threads



Training Panel Members in Guideline Development

Chloé Aymée de Mortier

Stellingen

Zonder training kunnen werkgroepleden geen waardevolle bijdrage leveren aan richtlijnontwikkeling (dit proefschrift).

Gelijkwaardige deelname aan richtlijnontwikkeling is alleen mogelijk als er aandacht is voor groepsdynamieken (dit proefschrift).

Alleen training is niet genoeg: zonder afspraken over verantwoordelijkheden, methoden en meer bewijs zullen kostenaspecten niet meegenomen worden in richtlijnen (dit proefschrift).

Training voor richtlijnwerkgroepen is waardevoller als deze wordt afgestemd op de context van de richtlijn (dit proefschrift).

Training voor richtlijnontwikkeling is het meest effectief wanneer leren gecombineerd wordt met directe toepassing in de praktijk.

Richtlijnen hebben niet alleen een klinische maar ook een maatschappelijke rol.

Zonder tijd, expertise en ondersteuning creëert de uitbreiding van de Evidence to Decision criteria een illusie van volledigheid.

Inhoudelijke expertise maakt iemand niet automatisch een goede docent.

'Ik heb het nog nooit gedaan, dus ik moet het wel kunnen.' – niet Pippi Langkous

"The world changes, and all that once was strong now proves unsure."
– J.R.R. Tolkien, Two towers.

Weaving the Threads

Training panel members
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Chloé Aymée de Mortier

The research presented in this thesis was conducted at Maastricht University | Maastricht UMC+



In the Care and Public Health Research Institute (CAPHRI), Department of Health Services Research, of Maastricht university. CAPHRI participates in the Netherlands School of Public Health and Care Research.



And in the School of Health Professions Education



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Weaving the Threads

Training panel members in guideline development

PROEFSCHRIFT

Voor het behalen van de graad van Doctor aan de Universiteit Maastricht,
onder gezag van de Rector Magnificus, Prof. Dr. Jan Smits,
overeenkomstig met het besluit van het College van Decanen,
te verdedigen in het openbaar op maandag 26 oktober 2026 om 10:00 uur.

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Table of Contents

Chapter 1	General introduction	7
Chapter 2	Unravelling education needs for clinical practice guideline development: a survey performed in the Netherlands	21
Chapter 3	Challenges and stimulating factors for incorporating economic considerations into clinical practice guidelines: a scoping review	83
Chapter 4	'We are the engine': A focus group study on clinical practice guideline development with European patient advocates for rare congenital malformations and/or intellectual disability	123
Chapter 5	From insecurity to confidence: evaluation of an innovative panel members' training for guideline development – a survey	145
Chapter 6	One size does not fit all: why guideline panels need context-tailored education	201
Chapter 7	General discussion	241
References		259
Impact		275
Summaries	English summary	282
	Nederlandse samenvatting	286
Addenda	Train the trainer guide	291
	About the author	309
	Dankwoord	313
	Publications and conferences	323
	SHE Dissertation series	329



Chapter 1

General introduction



The Importance of Guidelines

The accessibility of health care is under pressure due to rising healthcare expenditures, workforce shortages, and depletion of raw materials [1-4]. In response, growing attention is being paid to the efficient use of resources and to value-based health care [4-6]. At the same time, shared decision-making is an important principle in health care. It recognises that healthcare decisions should not only align with scientific evidence but also with patients' values and preferences. However, both patients and healthcare professionals face vast amounts of medical information that are not always reliable, accurate, or applicable [7, 8]. This increases the risk of misinformation and complicates decision-making. Consequently, there is a need for trustworthy, evidence-based guidance to support high-quality and value-based health care [9]. Guidelines can play an important role in supporting well-informed health care [10, 11].

Guidelines have long played a role in health care. For example, in the fifth and fourth centuries before the common era, early forms of guidelines are described in the Hippocratic Corpus [12, 13]. Today, guidelines are ubiquitous and have become an integral part of health care. Guidelines, including clinical practice guidelines and public healthcare guidelines, are defined as 'documents with recommendations aimed at improving the quality of care, based upon systematic summaries of scientific research and considerations of the advantages and disadvantages of various care options, supplemented with the expertise and experience of healthcare professionals and patients' [9, 14]. Guidelines can serve multiple purposes, with the primary purpose of supporting both healthcare professionals and patients in informed decision-making about appropriate health care for specific clinical circumstances [9]. Other purposes include reducing unwarranted practice variation, supporting evidence-based medicine, translating research into practice, and making knowledge accessible and manageable for healthcare professionals [9, 15, 16]. Furthermore, they support the effective and efficient use of healthcare resources, which is particularly important given current pressures such as rising expenditures and constrained resource availability [9, 16, 17].

Guideline Development

For guidelines to meaningfully impact health care, they must be methodologically sound, transparently developed, and implemented in practice [9, 18]. With the rise of evidence-based medicine in the 1990s, a paradigm shift was seen within guideline development. Guideline development shifted from primarily consensus-based

guidelines towards evidence-based guidelines, with the inclusion of systematic reviews [19]. The American Institute of Medicine (IoM), now known as the National Academy of Medicine (NAM), described trustworthy guidelines as guidelines that:

- are based on a systematic review of evidence;
- are developed by a multidisciplinary panel of experts and representatives from key affected groups;
- consider relevant patient subgroups and patient preferences, as appropriate;
- follow an explicit and transparent process that minimises biases, conflicts of interest and distortions;
- provide clear justifications for recommendations, explaining the relationships between interventions and outcomes, including ratings of the quality of evidence and the strength of recommendations;
- be periodically reviewed and revised when new evidence warrants adjustments. [9]

The introduction of the Appraisal of Guidelines for REsearch and Evaluation (AGREE) instrument in 2003 was a critical step in improving the transparency of guideline quality. It was subsequently updated in 2021, resulting in the current AGREE II instrument [18, 20]. This tool provided a standardised approach for assessing guideline quality and became the foundation for more structured guideline development [20]. Various manuals and guides have since been developed to support guideline development [21-24], with many of them using the widely accepted Grading of Recommendations, Assessment, Development and Evaluation (GRADE) methodology. This methodology was developed in 2008 by the GRADE working group [25] and provided a systematic way to assess the certainty of evidence, supporting guideline developers in making transparent and well-informed recommendations [19, 26].

Building upon the GRADE methodology, the GRADE Evidence to Decision (EtD) framework was developed [27-30]. This framework provides a structured and transparent approach to translate evidence into guideline recommendations. It systematically considers relevant factors such as the balance between the benefits and harms, certainty of the evidence, patient values and preferences, resource implications, cost-effectiveness, equity, feasibility and acceptability [28-31]. Considering these factors supports guideline developers in formulating recommendations suited to their context. The knowledge base to include when formulating guideline recommendations keeps evolving, with current discussions stating a need to consider planetary health [32, 33] and healthcare system capacity [34, 35] when formulating recommendations, further complicating guideline development.

While guideline development has become increasingly more rigorous and structured, fully operationalising all factors within the GRADE EtD framework remains challenging. There are still persistent challenges in fully incorporating key considerations like patient values and preferences, as well as economic considerations. The next two sections explore these important factors of guideline development in more detail.

Patient values and preferences

Healthcare decisions are preference-sensitive [36], making it crucial to consider patient values when developing guidelines. In this dissertation, the term "patients" is used. In other (research) fields this group may also be referred to as, for example, healthcare consumers, clients or citizens depending on the context in which the guideline is developed. It has been shown that patients and healthcare professionals often differ in how they assess the balance of benefits and harms of care. Additionally, healthcare professionals cannot predict individual patients' treatment preferences or outcomes [36-39]. Therefore, shared decision-making or patient-informed decision-making is essential, both in the (health)care setting and in guideline development. When guidelines align with patient values and preferences, their relevance, implementation, and adherence can be enhanced [37, 40].

The GRADE EtD framework states that patient values and preferences are a key factor in guideline development, but does not specify how to address them during the guideline development process [28, 37]. Various approaches exist, including patient representatives on guideline panels, literature reviews on patient preferences, investigating patient preferences during clinical trials, conducting surveys among patients and/or qualitative research (e.g., interviews, focus groups), and involving patient organisations [37, 40-43]. However, studies show that guidelines often lack patient preferences or fail to document explicitly how they shaped the guidelines [36, 37]. Barriers include limited funding, difficulties in recruiting patients to participate in panels, and healthcare professionals' reluctance to integrate patient preferences [37]. Facilitators include expertise in qualitative methods, educating healthcare professionals on the value of patient preferences, and educating patient representatives in (their role in) guideline development [36, 37, 40]. However, limited research has examined how education can best support panels in including the patient perspective in guidelines.

Economic considerations

Healthcare systems face increasing pressure due to limited monetary resources, shortages in the healthcare workforce, and depletion of raw materials [1-4]. Globally, healthcare expenditures have more than doubled since the start of this century, reaching $8.5 trillion in 2019 [44]. In many high-income countries, healthcare

costs are rising faster than their gross domestic product (GDP) [44], emphasising the need for well-informed and cost-conscious decision-making in health care. Integrating economic evidence into guidelines can help ensure efficient allocation of resources and support cost-conscious decision-making [45-47]. The terminology surrounding economic evidence in guidelines varies, with terms such as resource use, cost-effectiveness, and (monetary) costs often being used interchangeably, whilst they have different meanings [48, 49]. In this dissertation, the term 'economic considerations' encompasses all these terms and aspects of (health) economic evidence and methods.

Although the GRADE EtD framework and AGREE-II criteria acknowledge economic considerations, their integration into guidelines remains limited [20, 31, 50]. Addressing economic considerations could enhance guidelines' practical feasibility and improve implementation success [51]. Furthermore, incorporating economic considerations can raise healthcare professionals' awareness of resource constraints, encouraging more thoughtful resource use [11, 52]. However, challenges to integrating economic considerations in guidelines exist [45, 46], and the factors that could encourage broader adoption of economic considerations in guidelines remain unclear.

Guideline developers

Guidelines are developed by experts in a guideline panel, also known as the guideline development group or committee. These panels are often multidisciplinary, with panel members including healthcare professionals from all relevant healthcare disciplines, patient representatives, and sometimes researchers [9, 27]. They are supported by guideline methodologists and project leads, sometimes referred to as guideline advisors [53]. Panels may also consult additional experts, such as literature specialists, ethicists, implementation experts, and/or health economists. In this dissertation, when we refer to guideline developers, we mean any of the above roles and anyone actively involved in the development of guidelines.

Guideline development education

Guideline development requires competencies in a broad range of areas, as shown by the GRADE EtD framework. Despite their pivotal role, many panel members lack formal education in guideline development [54]. Although the fundamental steps of guideline development are well established [22, 27], little research has examined how best to teach the skills required to carry them out. Additionally, education has been shown to improve complex decision-making in healthcare settings, including cost-conscious care [42, 55-58].

Existing educational efforts have largely focused on guideline implementation rather than on the competencies needed for development [59]. A competency-based framework has recently been proposed by guideline methodology experts [60], but empirical evidence on the learning needs of panel members, project leads, chairs, and patient representatives remains scarce. Given the complexity of guideline development, understanding these needs is critical to ensure that all contributors are adequately prepared. While education has the potential to strengthen guideline development capacity, the most effective approaches to delivering education for guideline development are still unclear.

Given the complexity of guideline development and the need to gain practical skills, educational efforts should be guided by learning theories that support complex and real-world learning. In this dissertation, we have drawn on the principles outlined in Box 1.

Box 1: Design principles used in the educational intervention

Constructive learning emphasises active engagement with educational content rather than passive information uptake. It supports learners by linking newly introduced concepts regarding guideline development to their existing knowledge and experience [61, 62].

Collaborative learning focuses on learning through interaction with others by engaging in shared and complex tasks. This aligns with the collaborative nature of guideline development, where panel members build on one another's perspectives and contributions [63, 64].

Contextual learning connects educational content to authentic, real-world situations. It encourages learners to relate new knowledge to their own situation, in this case, the guideline development process, thereby supporting knowledge transfer [65, 66].

Blended design refers to the integration of face-to-face learning activities with online activities. It provides flexibility in timing and delivery of educational interventions [67, 68].

Just-in-time design involves delivering information in small segments at moments when the knowledge is applicable. It aims to enhance knowledge transfer by providing learners with timely, task-relevant input to support learners in their work and promote deeper engagement with educational content [69].

Research gaps, questions and approach

Although methodological rigour of guideline development has been strengthened by GRADE and the GRADE EtD, important gaps remain in how panel members apply key elements. In particular, this concerns patient values and preferences and economic considerations. Studies show that these factors are often insufficiently incorporated into recommendations [36, 37, 45, 50]. At the same time, many panel members have limited formal training in guideline development. Although some education initiatives do exist, these pay limited attention to the development of competencies for effective participation in guideline panels or the incorporation of economic considerations [54, 70]. Additionally, little is known about the practical educational needs of panel members or about how education could support more patient-centred and cost-conscious decision-making. These gaps highlight the need for an educational approach that is grounded both in the realities of guideline panels and in relevant theoretical insights.

This dissertation aims to address these gaps by examining the perspectives, experiences, and needs of guideline panel members regarding patient preferences, economic considerations, and guideline-development competencies. Therefore, this dissertation addresses the following research question: How can an educational programme based on practical needs and educational theory support panel members in guideline development?

To address this research question, we investigated the following research questions:

1. What are the (educational) needs of Dutch guideline developers to support clinical guideline development, with special attention to economic considerations and the patient perspective?
2. What are the challenges and potential stimulating factors for incorporating economic considerations in clinical practice guideline development?
3. How do patient advocates for rare congenital malformations and/or intellectual disabilities perceive:
    a. The relevance of key characteristics of clinical practice guidelines?
    b. Their involvement in clinical practice guideline development?
4. How can guideline development training with elements of constructive, collaborative, contextual, blended, and just-in-time learning support guideline panel members?
5. How do contextual factors affect guideline panel members during the guideline development process and influence their learning needs?

The overall design of this dissertation has been based on the design-based research (DBR) approach, also referred to as educational design research. This approach integrates theory and practice to shape educational design [71, 72]. It consists of three iterative phases: (1) analysis and exploration, (2) design and construction, and (3) evaluation and reflection. Design-based research is conducted in real-world settings and emphasises close collaboration with relevant stakeholders [73].

In the first phase of DBR, it is essential to understand the practical and educational needs of guideline panel members. These insights should then be integrated with relevant learning and design principles, such as constructive, collaborative, contextual, blended, and just-in-time learning (Box 1), to design an educational intervention accordingly. Involving relevant stakeholders in these steps enhances implementation success. In the final evaluation and reflection phase, it becomes crucial to understand how the intervention supports panel members during guideline development. The iterative nature of DBR allows emerging insights from practice to continually inform and improve the educational design. Figure 1 illustrates how the various studies in this dissertation are situated within the DBR approach.

Setting: Guideline Development in the Netherlands

Guideline development in the Netherlands began to take shape in the 1970s and 1980s. Today, every healthcare professional association has its own set of guidelines [19]. Currently, at least 30 organisations are involved in the development of Dutch guidelines [74]. Most of these organisations are part of the 'Guideline Dutch Network (Richtlijnen Netwerk Nederland (RNN))', which has been unified with the guideline networking community GENEVER [74].

These organisations use a shared methodological basis, the AQUA guidance document [22], based on the AGREE-II instrument [18, 20] and the IoM/NAM conditions [9], to develop their guidelines. The steps of guideline development are usually divided into three phases: preparation, development, and finalisation. In the preparation phase, the guideline's topic, target group(s) (i.e. users of the guideline) and target population (i.e. patient and client population) are defined. Next, the guideline panel is assembled and determines the specific scope of the guideline and formulates key questions based on problem areas to be addressed in the guideline. Additionally, potential conflicts of interest are reviewed [22, 27].

The development phase consists of systematically examining and critically assessing scientific evidence for the proposed key questions. When evidence is available, its quality is evaluated using the GRADE methodology [26, 75]. The recommendations that

answer the key questions are shaped by the literature findings and the experiential knowledge of clinical experts and patients. The strength of each recommendation is subsequently established with the help of the GRADE EtD framework [22, 29, 30].

In the finalisation phase, the draft guideline is shared with all relevant stakeholders for feedback during the commentary phase. Lastly, the guideline is submitted for authorisation or endorsement by all relevant healthcare professionals and patient organisations before publication [22, 27].

Dissertation Outline

The first part of this dissertation encompasses the analysis phase of the design-based research approach. Chapters two, three and four focus on mapping the practical and educational needs of guideline developers. **Chapter 2** investigates the educational needs of guideline developers, including methodologists, project leads, chairs and panel members (i.e. healthcare professionals, patient representatives). Their experiences and needs were collected through a mixed-methods survey. **Chapter 3** explores potential stimulating factors and challenges to incorporating economic considerations into guidelines. These factors were constructed through a scoping review, which allowed a broad investigation of diverse literature. **Chapter 4** focuses specifically on the needs and experiences of patient representatives during guideline development. This was explored through focus groups with patient representatives, highlighting their perspectives and experiences with guideline development.

Building on the insights of chapters two to four and the constructive, collaborative, contextual, blended and just-in-time design principles, we designed a training for guideline development. This training was developed in collaboration with guideline methodologists, educationalists and researchers to support panel members in developing high-quality guidelines. **Chapter 5** describes the design, implementation and evaluation of the guideline development training. The evaluation focuses on the suitability of the training and related design principles to support panel members in guideline development. **Chapter 6** examines how contextual factors affect the learning needs of panel members in guideline development projects. This creates insights into how educational initiatives can be further advanced to support varying guideline development panels. Interviews were conducted with panel members and project leads to capture their experiences regarding guideline development and education. Together, these last two chapters provide insights into how guideline development education can be designed to support guideline panel members.

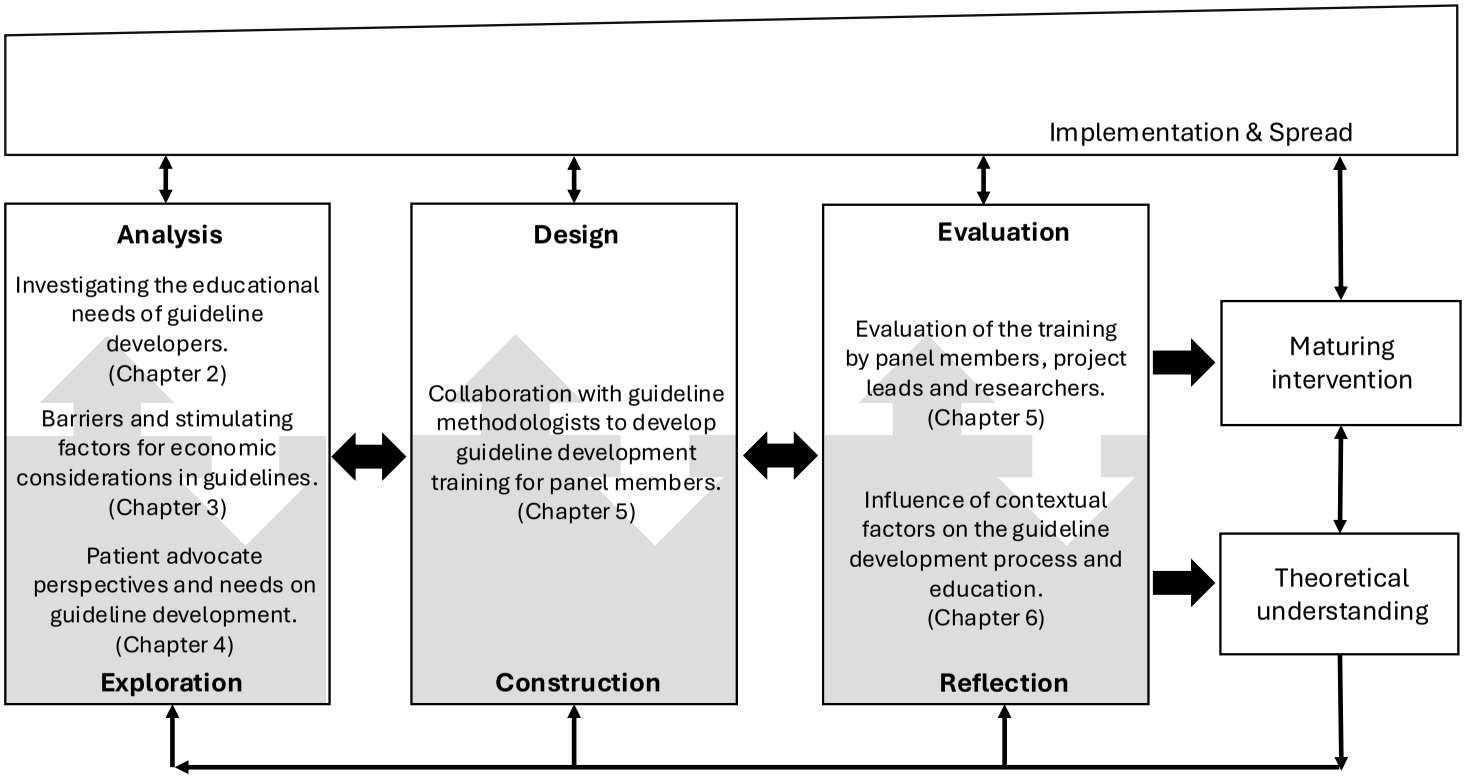

Figure 1. An adapted version of Mckenney & Reeves' generic model for design-based research for this dissertation [72].

Table 1. Overview of the dissertation.

	Chapter 2	Chapter 3
Title	Unravelling education needs for clinical practice guideline development: a survey performed in the Netherlands	Challenges and stimulating factors for the incorporation of economic considerations in clinical practice guidelines: a scoping review
Research question	What are the (educational) needs of Dutch guideline developers to support clinical guideline development, with special attention to economic considerations and the patient perspective?	What are the challenges and potential stimulating factors for incorporating economic considerations in clinical practice guideline development?
Methods	Mixed-method survey	Qualitative, scoping review
Participants	Guideline developers associated with various healthcare professions (n=271)	Various types of documents (n=33)
DBR-phase	Analysis	Analysis

	Chapter 4	Chapter 5	Chapter 6
	'We are the engine': patient advocate perspectives on clinical practice guideline development for rare congenital malformations and/or intellectual disability	From insecurity to confidence: evaluation of an innovative panel members' training for guideline development – a survey	One size does not fit all: why guideline panels need context-tailored education - a case study
	How do patient advocates for rare congenital malformations and/or intellectual disabilities perceive: a) The relevance and key characteristics of clinical practice guidelines b) Their involvement in clinical practice guideline development	How can guideline development training with elements of blended, just-in-time, constructive, contextual, and collaborative learning support guideline panel members?	How do contextual factors affect guideline panel members during the guideline development process and influence their learning needs?
	Qualitative, focus groups	Mixed-method survey	Qualitative, case study with semi-structured interviews
	Patient advocates of a European Reference Network (n=26)	Panel members (n=33) and project leads (n=9) of six guideline projects	Panel members (n=18) and project leads (n=10) of five guideline projects
	Analysis	Design, implementation and evaluation	Evaluation and Analysis



Chapter 2

Unravelling education needs for clinical practice guideline development: a survey performed in the Netherlands



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Abstract

Objective: The development of clinical practice guidelines (CPG) has evolved into a rigorous and complex process. There is a need for training of CPG developers including methodologists, panel members and patient representatives. This study explored the educational needs and experiences of CPG developers, with specific attention to the patient perspective and economic considerations.

Study Design and Setting: An anonymised mixed-method survey was distributed among CPG developers and panel members in the Netherlands. The survey, developed in collaboration with Dutch CPG development organisations and patient organisations, aimed to capture insights into the developers' roles, training needs, and the incorporation of economic considerations and patient perspectives in CPG development. Data analysis involved qualitative content analysis and descriptive quantitative analysis.

Results: A total of 271 responses were analysed. Respondents described role-specific tasks and tasks overlapping between roles. Experience, guidance, and training influenced the respondents' feeling of preparedness for their tasks. Respondents expressed the need for content-related training, including CPG development methodology. They also raised the importance of process-related topics in training, such as the inclusion of different perspectives and responsibilities during CPG development.

About half of the respondents (46%) indicated that economic considerations were included in their CPGs, however, there was no uniformity in approach. The patient perspective was included by 89% of the respondents, also in varying manners. Overall, respondents underscored the importance of both topics in CPG development (training) to ensure a future-proof healthcare system.

Conclusion: This study underscores the importance of tailored CPG development training programs addressing the specific competencies required for the different roles in CPG development. Thereby, recognising a holistic approach encompassing both content- and process-related aspects. Addressing economic considerations and the patient perspective in training will contribute to CPGs that support a patient-centred and a sustainable healthcare system.

Introduction

Guideline panel members (including healthcare professionals and patient representatives) are often not formally trained in clinical practice guideline (CPG) development [54, 76]. At the same time, the rigour and complexity of CPG development have evolved over the last few decades [77], for example, by including economic considerations and patient values [30]. CPG development by untrained panel members might strain the quality of the CPGs [54]. Research on education concerning CPGs has mainly focused on implementation training for healthcare professionals [59], with limited attention to the development of CPGs themselves.

Worldwide, numerous organisations dedicate themselves to supporting healthcare professionals and patients when developing CPGs [46, 78]. In the Netherlands, as in many other countries [9], CPGs are mostly developed by healthcare professional-specific organisations [19, 74]. Dutch CPGs are based on the AQUA agreement [22], which stems from the internationally used Appraisal of Guidelines for REsearch and Evaluation II criteria for CPGs [18]. While these CPG development organisations share a common methodological basis, differences in work processes exist. This complicates multidisciplinary collaboration and mutual understanding.

The strength of CPG recommendations is affected by various factors, including cost-effectiveness and patient values [30]. Economic considerations in CPGs support well-informed and cost-conscious healthcare decision-making [79]. This is important as providing healthcare is under pressure due to scarcity of resources (capital, labour, and natural resources) [2]. Worldwide, healthcare expenditures doubled in two decades and reached US$8.5 trillion in 2019 [44]. To allocate (financial) resources towards healthcare leads to a financial resource reduction elsewhere, such as education or safety [10]. Economic considerations in CPGs could promote cost-conscious decision-making among healthcare professionals by raising awareness of limited resources [11, 52].

Additionally, the value of the patient perspective in CPGs is widely recognised and supports the development of patient-centred CPGs [80]. Internationally, differences in patient involvement in CPG development are seen [41]. In the Netherlands, patient representative participation in CPG development increased [81]. However, the frequency and methods of incorporating the patient perspective into Dutch CPG development remains unknown. Implementation of CPG recommendations could be supported by the incorporation of patient perspectives and economic considerations [51, 80].

Given the complexity of CPG development, expertise across a broad range of areas is required [82]. Training would support CPG developers, including methodologists and panel members, to create CPGs and might enhance the communication and coordination between CPG developers from different domains. Currently, a single competency-based framework for CPG development training has been developed from a theoretical standpoint [60]. However, no empirical exploration has been undertaken to map the education needs expressed by guideline developers. Understanding these needs is crucial to support CPG developers in acquiring the skills to develop high-quality cost-conscious and patient-centred CPGs, especially as healthcare costs rise, CPG development becomes more complex and multidisciplinary [59]. The current study aims to yield insights into CPG developers' experiences and training needs, with a focus on the patient perspective and economic considerations, to improve design of future CPG development training.

Method

Design

An anonymised mixed-method survey, containing multiple-choice and open-ended questions, was distributed amongst CPG developers (i.e. panel members, methodologists and patient representatives). This approach allowed in-depth and breadth exploration, supporting the study's exploratory nature. Respondents were asked to reflect on their most recent experience in CPG development. The reporting of the study was guided by the COnsolidated criteria for REporting Qualitative (COREQ) research checklist [38] and CHEcklist for Reporting Results of Internet E-Surveys (CHERRIES) [83] (Appendices 1 and 2). This study was approved by the ethical committee of Maastricht University (FHML-REC/2022/080). Respondents provided informed consent by starting the survey after receiving clarification of its purpose and data usage on the survey's cover page.

Survey development

The survey was developed in collaboration with four Dutch CPG development organisations (Knowledge Institute of the Federation of Medical Specialists (FMS), the Dutch College of General Practitioners (NHG), the Royal Dutch Society for Physiotherapy (KNGF), the Mental Healthcare Quality Alliance (AKWA GGZ)), two patient organisations (Dutch Patients Federation and Burgerkracht Limburg), and education experts and HTA from the Maastricht University (MM, AP, SE, DS, GvM). The involvement of these organisations provided diverse perspectives and direct input from practice.

Representatives from the above-mentioned organisations piloted the survey. It contained 31 questions, divided into four categories: (1) general questions about experience with CPG development, (2) respondents' educational training needs to develop CPGs, (3) economic considerations in CPGs, and (4) inclusion of patient perspective during CPG development. The questions were presented in the same order, with certain questions following skip-logic and only being displayed after a certain response. Respondents could return to and skip questions. The survey, including skip-logic steps, can be found in Appendix 3.

Data collection

The survey was published via the online software Qualtrics^{xm} and available to anyone involved in CPG development, including CPG methodologists, panel members (healthcare professionals and patient representatives), literature specialists and project leaders. The survey was distributed via the researchers' personal LinkedIn pages. Additionally, it was distributed amongst CPG development organisations involved in developing the survey (FMS, NHG, NGF, AKWA GGZ, Dutch Patients Federation and Burgerkracht Limburg) and the Dutch Professional Nurses Organisation (V&VN). These organisations were asked to distribute the survey amongst their employees (including CPG advisors and methodologists) and their current CPG panel members (healthcare professionals and patient representatives). The survey was available from 27 October to 18 December 2022, and completion took approximately 15 minutes. Participation was voluntary and no directly identifiable information, such as IP addresses, was collected. Responses were anonymous and stored on a data-protected server at Maastricht University. Respondents interested in a follow-up study could leave their e-mail addresses at the end of the survey. These data were stored separately from the results to ensure anonymity.

Data analysis

Qualitative data analysis

The open-ended responses were analysed by two researchers (CdM and MKH) via inductive content analysis. The first step was familiarisation with the survey responses. Secondly, initial descriptive codes and potential categories were generated. Subsequently, data were reviewed to refine codes and categories. Lastly, the categories were defined by the research team [84, 85]. Upon disagreement, codes and categories were discussed with a research team member.

The initial five steps were conducted iteratively using MAXQDA (version 2022), wherein 50 responses were coded and re-evaluated in each iteration until 75% of the responses were analysed. Next, the final codebook was determined and assessed for saturation by analysing the final 25% of responses and re-analysing the initial 50 responses. The finalised codebooks and glossary can be found in Appendices 4 and 5.

Quantitative data analysis

Descriptive analysis of the quantitative data were analysed with SPSS (version 28.0.1.0). The quantitative data were categorised in two ways. The first categorisation was based on the respondent's indicated role(s) during the development of their latest CPG. The indicated role(s) were selected from pre-defined role names.

The second categorisation, for demographic information, was based on the affiliated healthcare organisation of the respondents, resulting in the following division: (1) medical specialist; (2) physical therapy-associated; (3) general practitioners; (4) patient; (5) mental healthcare; (6) nursing healthcare; (7) public health; (8) other; and (9) unknown. Further details on how (healthcare) organisations were (sub) categorised can be found in Appendix 6.

Research team and reflexivity

The research team consisted of the following experts: health economists & HTA (GvM, AP, SE), educational researchers (DV, AP, MM), a neurologist (MM), a senior advisor knowledge tools (DD), and two PhD candidates (CdM, MKH) in the field of CPG. Collaborations were established with guideline developers and patient representatives to capture different perspectives. To address the subjectivity of the researchers, the research team reflected on and discussed the coding schemes and interpretations at different stages. No personal relationships were known between researchers and respondents, as survey results were anonymised.

Results

General information

A total of 304 respondents participated in the online survey, of which 271 responses were included for analysis. Thirty-two respondents did not complete the survey beyond the general background questions and were excluded. One respondent was removed from the data upon request. Respondents were not obliged to answer all questions, therefore the number of respondents per question differs. The general characteristics of respondents are described in Table 1.

Most respondents aided the development of two or more CPGs (197/256 [77%]) and developed their last CPGs between 2017-2022 (250/271 [92.2%]). Respondents had different, and sometimes multiple, roles during the CPG development process. Most respondents were panel members (general and patient representatives) or advisors, while the least represented roles were implementation experts and health

technology assessment (HTA) specialists (Table 1). Respondents were affiliated with various healthcare professionals and/or patient organisations (Table 1). Respondents often collaborated with professionals from different healthcare and patient organisations within their guideline panels (217/255 [85.1%]).

Table 1. General information of respondents (n= 271).

Sex	***n (%)***
Female	185 (68.3%)
Male	84 (31%)
I'd rather not share	2 (0.7%)
Highest completed educational level	***n (%)***
Secondary school graduates	1 (0.4%)
Secondary vocational	1 (0.4%)
Higher professional graduates	50 (18.5%)
University graduates	221 (80.8%)
Type of organisation respondents were employee/member of [1]	***n (%)***
Medical specialist	97 (30.3%)
Nursing	50 (15.6%)
Physical therapy	42 (13.1%)
Patient representation	37 (11.6%)
Mental healthcare	14 (4.4%)
Public healthcare	3 (0.9%)
General practitioners	4 (1.3%)
Other	39 (12.2%)
Unknown	34 (10.6%)
Role of respondents in CPG development process [1]	***n (%)***
Panel member (General)	130 (38.5%)
Advisor	64 (18.9%)
Project leader	29 (8.6%)
Panel member (Methodologist)	26 (7.7%)
Panel member (Patient representative)	23 (6.8%)
Panel member (Chair)	21 (6.2%)
Literature specialist	7 (2.1%)
Implementation expert	4 (1.2%)
HTA-specialist	1 (0.3%)
Other	33 (9.8%)

[1] Multiple responses possible

The survey was divided into four categories and the content analysis resulted in the five topics presented in the next paragraphs. Illustrative quotes for each topic can be found in Table 2.

Table 2. Illustrative quotes by respondents on the open-ended questions.

	Respondents' role
Topic 1: Tasks	
Survey question 14: Could you briefly describe what your tasks were during the development of your last guideline?	
Respondent 57	Chair/general panel member
Respondent 41	General panel member
Respondent 141	General panel member
Topic 2: Preparedness	
Survey question 15: Were you prepared to perform the tasks you carried out for the development of your last guideline? Please indicate why or why not	
Respondent 76	General panel member
Respondent 176	General panel member
Respondent 188	Advisor/implementation specialist
Respondent 275	Patient representative
Topic 3: Economic consideration in CPGs	
Survey question 27: Were economic aspects considered during the development of the last guideline you helped with? Please indicate why or why not	
Respondent 4	Patient representative
Respondent 10	Advisor
Respondent 12	Advisor
Respondent 13	Advisor/methodologist/project leader
Respondent 25	Advisor
Respondent 84	General panel member
Respondent 190	Advisor/methodologist/project leader

	Quote
	'Formulating recommendations according to the predetermined framework.'
	'Conducting a literature analysis, review literature analysis of the guideline methodologist, and formulate recommendations.'
	'Participating in discussions about the findings related to my field of expertise and that of others.'
	'The first time and therefore less familiar with the format/procedure, but sufficient explanations were provided, and there was room to contribute my expertise.'
	'There was no communication about what was expected, so I just filled it in as I thought would be right.'
	'In advance, I was not told what was expected of me.'
	'I attended training sessions, knew what was expected, and had an advisory group I could rely on.'
	'So that it [the CPG] can also be applied. In case of no funding, the question remains whether the advice will be followed.'
	'I consider it [economic considerations in CPGs] important, but I often notice that there is insufficient expertise within the guideline panel to provide input on this matter. As a result, it becomes a mere formality.'
	'To better substantiate the cost aspect, it is ultimately essential for implementation.'
	'Awareness of costs is crucial, both for the patient and the healthcare provider.'
	'A budget impact analysis (BIA) is often beyond the budgetary possibilities.'
	'Ultimately, healthcare must remain affordable, and in doing so, the economic aspects must be considered in the recommendations.'
	'It is part of the Evidence to Decision Framework developed by the GRADE working group. Therefore, it is an argument that can (partly) determine the direction and strength of the recommendation.'

Table 2. Continued

	Respondents' role
Topic 4: Patients' perspectives	
Survey question 17 and 18: What was the reason for (not) including the patient perspective in the development of your last guideline?	
Respondent 250	Chair
Survey question 19: Could you briefly describe what the patient perspective looked like during the development of your last standard/guideline?	
Respondent 148	Patient representative
Respondent 169	Patient representative
Topic 5: Education topics	
Survey question 26: Indicate which topics you find important in training on guideline development	
Respondent 40	General panel member
Respondent 111	Advisor/methodologist
Respondent 148	Patient representative

Topic 1: Tasks respondents fulfilled during the CPG development process

Tasks in the CPG development process were reported to overlap and differ between different roles. General panel members indicated their primary responsibilities revolved around the literature analyses, giving input, and feedback. Patient representatives mentioned providing input and feedback as their primary responsibilities. Panel chairs indicated their key tasks were related to literature analyses, CPG recommendations, and project management (Table 3, Appendix 4.1).

CPG advisors, project leaders and methodologists indicated the same primary tasks: literature analysis, managing the project, and providing guidance. This is more related to process guidance for advisors and methodological guidance for methodologists. Tasks like formulating search questions, editing, updating the CPG, and implementation were less commonly reported (Table 3, Appendix 4.1).

Quote
'The guideline is about the care for patients, and they themselves can best express what is essential for them to be heard and seen and thus be helped. '
'Asking for their input at each gathering as standard practice and at the beginning of the session. Patients are often tired during meetings. If the question regarding the patient's perspective is posed at the end, there's a big chance that the patient representative might not be able to express it adequately.'
'Supported by the chair and guideline facilitator, ensuring that the patient receives the proper support and empowerment.'
'Background of GRADE evaluation and conclusions based on this evaluation.'
'Clearly outlining role distribution and tasks.'
'How do you involve patients in such a way that they can and dare to express themselves among the other working group members? Respect for patient representatives is crucial in this regard.'

Topic 2: Preparedness

Respondents did not feel equally prepared for their role and tasks during the CPG development process. Panel members (general and patient representatives) most often indicated they felt unprepared when developing the CPG, while all methodologists and project leaders felt prepared (Table 4). The four emerging subtopics concerning feeling prepared were: having experience, being informed, having attended training, and receiving guidance during CPG development. Experience was explained in two ways: as CPG development being (part of) the respondent's job and as being a (content) expert in 'this field'. However, it was sometimes unclear whether respondents referred to being an expert in the CPG's subject or CPG development (Appendix 4.2). Furthermore, advisors, methodologists, literature specialists, and project leaders reported being adequately prepared for their tasks as this aligned with their job responsibilities.

Table 3. Overview of frequency of respondents per task and education topic category classified by panel members' roles (n=271). The percentage indicates the proportion of respondents within each role who addressed the respective topic in the survey, as revealed through the content analysis of the open-ended questions. Some respondents indicated they had double roles.

	Advisor (n = 64)		**General panel member (n=130)**	
n (%)	Tasks	Education topics	Tasks	Education topics
Phases of the CPG developing process	2 (3%)			2 (2%)
Question generation	4 (6%)	8 (11%)	8 (6%)	7 (5%)
Literature analyses	25 (39%)	12 (19%)	25 (19%)	29 (22%)
Grading of evidence	7 (11%)	10 (16%)	12 (9%)	21 (16%)
Search question	2 (3%)	2 (3%)	5 (4%)	9 (7%)
Considerations	3 (5%)	8 (13%)	3 (2%)	5 (4%)
Cost considerations		2 (3%)		5 (4%)
Recommendations	5 (8%)	17 (17%)	9 (7%)	7 (5%)
Implementation	3 (5%)	5 (8%)	2 (2%)	21 (14%)
Process general		10 (16%)		26 (19%)
Updating	1 (2%)	1 (2%)	6 (5%)	2 (2%)
Guidance	15 (23%)			
Process guidance	17 (27%)			
Methodological guidance	10 (16%)			
Different perspectives	2 (3%)	7 (11%)	18 (14%)	14 (11%)
Project management	13 (20%)	2 (3%)	1 (1%)	6 (5%)
Team dynamics				2 (2%)
Task division & responsibilities		9 (14%)		18 (14%)
Collaboration		2 (3%)		5 (4%)
Giving input	6 (9%)	3 (5%)	53 (41%)	4 (3%)
(Giving) Feedback/commenting	7 (11%)		43 (33%)	
Editing	1 (2%)		3 (2%)	
Methodology		15 (23%)		43 (33%)
GRADE		17 (27%)		13 (10%)

Patient representative (n=23)		Project leader (n=29)		Chair (n=21)		Methodologist (n= 26)	
Tasks	Education topics	Tasks	Education topics	Tasks	Education topics	Tasks	Education topics
	1 (4%)	1 (3%)				1 (4%)	
1 (4%)	1 (4%)	2 (7%)	2 (7%)		2 (10%)	3 (12%)	6 (23%)
	2 (9%)	12 (41%)	14 (14%)	3 (14%)	2 (10%)	14 (54%)	5 (19%)
	2 (9%)	4 (14%)		2 (10%)	3 (14%)	7 (27%)	4 (15%)
1 (4%)	1 (4%)	1 (3%)				1 (4%)	4 (15%)
		1 (3%)	5 (17%)	1 (5%)	2 (10%)	4 (15%)	2 (8%)
			1 (3%)				1 (4%)
	1 (4%)	4 (14%)	7 (24%)	3 (14%)	4 (19%)	4 (15%)	9 (35%)
	4 (17%)	2 (7%)	1 (3%)	1 (5%)	2 (10%)	1 (4%)	1 (4%)
	7 (30%)		8 (28%)		4 (19%)		5 (19%)
	1 (4%)		1 (3%)	2 (10%)			
2 (9%)		7 (24%)		2 (10%)		7 (27%)	
		8 (28%)				5 (19%)	
		6 (21%)				7 (27%)	
15 (65%)	11 (48%)		3 (10%)		2 (10%)		4 (15%)
	1 (4%)	9 (31%)	1 (3%)	4 (19%)	2 (10%)	9 (35%)	
	1 (4%)				1 (5%)		
	2 (9%)		5 (17%)		1 (5%)		4 (15%)
	2 (9%)		1 (3%)		2 (10%)		1 (4%)
7 (30%)	9 (39%)		2 (7%)	1 (5%)	1 (5%)		1 (4%)
12 (52%)		1 (3%)		1 (5%)		1 (4%)	
		1 (3%)		1 (5%)		1 (4%)	
	4 (17%)		7 (24%)		7 (33%)		4 (15%)
	2 (9%)		9 (31%)		5 (24%)		9 (35%)

Table 4. Overview of respondents feeling prepared for their tasks in the CPG development process and if they followed training.

	Respondents' preparedness for their guideline development role		*Respondents' participation in guideline development education*	
	n	Prepared *n* (%)	*n*	Followed training *n* (%)
General panel member	126	96 (76.2%)	125	68 (54.4%)
Advisor	63	57 (90.5%)	60	47 (78.3%)
Project leader	28	28 (100.0%)	26	23 (88.5%)
Methodologist	26	26 (100.0%)	26	23 (88.5%)
Patient representative	22	19 (86.4%)	20	15 (75.0%)
Chair	20	19 (90.5%)	19	12 (63.2%%)

Topic 3: Economic considerations in the CPG development (training)

Approximately half of the respondents reported incorporating economic considerations in their CPGs (113/245 [46.1%]). The results indicate some challenges for this endeavour. First, there was no uniformity in the method used to incorporate economic considerations in CPGs, with the GRADE Evidence to Decision framework being most often applied (Table 5). Furthermore, responsibility for this task was designated to the 'entire panel', followed by 'multiple panel members' and 'CPG advisor(s)'. To include an HTA expert or CPG advisor specialised in economic considerations was uncommon (Table 5). Furthermore, some respondents raised concerns about incorporating economic considerations into CPGs. They expressed that CPGs should describe the best care possible and that including economic considerations might be at odds with this view. Additionally, incorporating economic considerations requires additional resources, such as expertise, time, and budget. Finally, respondents stated that the lack of available economic evaluations posed a constraint (Appendix 4.3).

Despite these challenges, 79.8% (194/243) of the respondents supported incorporating economic considerations in CPGs. They indicated its importance for a future-proof healthcare system encompassing affordable, sustainable, and appropriate care. Furthermore, respondents emphasised that economic considerations could impact the decision-making for recommendations and affect the implementation success of CPGs. When asked, 78.0% (188/241) of the respondents endorsed including economic considerations in CPG development training. They emphasised its role in increasing awareness and knowledge about effectively integrating economic considerations into CPGs (Appendix 4.3).

Table 5. Overview of methods used to incorporate economic considerations during CPG development and by whom during the development of the last CPG respondent were involved.

Methods used to include cost considerations in guidelines (n=112)*	*n*(%)
Evidence to Decision Framework (EtDF) / considerations	38 (26.8%)
Naming costs of medicines/treatments	26 (18.3%)
Cost-effectiveness analyses	16 (11.3%)
Budget Impact analyse	11 (7.7%)
Cost-benefit analyses	9 (6.3%)
I do not remember	21 (14.8%)
Other	21 (14.8%)
Individual in charge of cost consideration inclusion (n=113)*	*n*(%)
The whole panel	37 (19.1%)
Multiple panel members	35 (18.0%)
Guideline advisor(s)	31 (16.0%)
Project leader	24 (12.4%)
Chair	18 (9.3%)
Panel member	13 (6.7%)
HTA-specialist	8 (4.1%)
Guideline advisor specialised in economic considerations	7 (3.6%)
I do not remember	11 (5.7%)
Other	10 (5.2%)

*Multiple responses possible

Topic 4: The inclusion of patients' perspectives in the CPG development process

Most respondents indicated that the patient perspective was included throughout the whole CPG development process (132/220 [60.0%]) or at specific moments (62/220 [28.2%]). Several reasons for the inclusion of patients' perspectives were expressed. Firstly, patients were considered end-users of the CPGs, and respondents argued that patient input offers a unique viewpoint that complements that of healthcare professionals. Additionally, involving patients was thought to enhance the success of CPG implementation and contribute to better healthcare practices. Lastly, including the patient's perspective was described as the norm or an obligation (Appendix 4.4).

The patient perspective was integrated into the development process in various ways. These encompassed including patient representatives as panel members and conducting focus groups or interviews. Patient organisations were also consulted to secure the patient's perspective. Patient representatives highlighted the importance

of boundary conditions for successful inclusion of the patient perspective during CPG development. This entailed dedicating adequate time to their input and respecting their contributions. Moreover, guidance and support were deemed crucial for effectively including patient perspectives (Appendix 4.4).

Topic 5: Education topics for CPG development training

Of the respondents, general panel members most often indicated they had not received any training (57/125 [45.6%]). The survey yielded a wide range of topics to be addressed in CPG development training. The main content-related topics mentioned were: literature analyses, grading of evidence/GRADE, recommendations, and methodology. Process-related topics encompassed: the general process, considering different perspectives, and task division and responsibilities. Certain topics were more emphasised per role, for example, methodologists showed interest in question generation, and panel members, including patient representatives, placed importance on giving input (Table 3, Appendix 4.5).

Discussion

Main findings

This study provided an overview of Dutch CPG developers' experiences and educational needs concerning CPG development, with attention to economic considerations and the patient perspective. Respondents described facilitating factors to successfully develop a CPG encompassed experience, training, and proper guidance. General panel members most often felt unprepared and least often followed training.

In corroboration with Sultan et al.'s internationally oriented competency framework for CPG development, the current findings highlight the importance of tailoring CPG development competencies to specific roles during the process [60]. These findings align with Sultans' framework, emphasising different roles during CPG development entail different responsibilities and educational needs [60]. Given the collaborative nature of CPG development, it is encouraging that this study noted a demand for attention to process-related next to content-related topics in CPG development training. Process-related topics included the general development process, considering different perspectives, and task division and responsibilities. The recently published twelve-phase integrated process framework for the co-development of CPG corroborated that training on how the CPG development process will proceed could be beneficial [86].

The patient perspective can be included in CPG development in various manners, as is supported in this study [87, 88]. A patient partnership is important to successfully include the patient perspective during CPG development [88, 89]. Patient representatives underscored this need and stated that successful collaboration required boundary conditions, such as time and respect for their contributions. Building upon these finding respondents stressed the importance of honouring diverse perspectives on the panel, not just the patient's viewpoint. There is a broader need for CPG developers to understand and appreciate each other's values and perspectives throughout the development process. To address this need the Guideline Participant Tool and the Guidelines International Network Public Toolkit: Patient and Public Involvement in Guidelines were developed [53, 90]. All CPG panel members would benefit from training to establish (patient) partnerships [87].

In this study, the incorporation of economic considerations in CPGs appeared less established than the inclusion of the patient perspective. Several factors might contribute to this finding. First, respondents expressed a lack of confidence in incorporating economic considerations citing a shortage of expertise. In line with previous research, the results revealed non-standardised approaches for incorporating economic considerations in CPGs [46]. However, frameworks such as the GRADE Evidence to Decision framework can offer guidance [6, 91]. Secondly, healthcare professional societies are often not directly accountable for CPG implementation. Consequently, they might be less aware of the resource use and economic consequences associated with a CPG recommendation [92]. This is supported by the low number of respondents reporting implementation of CPGs as one of their responsibilities. Lastly, other challenges identified in this study were consistent with existing literature, including resource requirements [93], limited economic evidence [91, 94], and the notion that incorporating economic considerations in CPGs is at odds with describing the best possible care [91, 94]. Despite the raised challenges, most respondents advocated the incorporation of economic considerations in CPGs, emphasising its importance for a sustainable and affordable healthcare system. Panel members play a crucial role in incorporating economic considerations in CPGs. Training them in basic economic evaluations could support them in this endeavour.

The findings of this study hold relevance to the broader CPG development community, extending beyond the Dutch context. CPG development in the Netherlands follows the AQUA agreement [22] following the international AGREE-II criteria [18] and Institute of Medicine guidance [9]. Dutch CPG development is primarily led by healthcare professional societies, similar to the process seen in e.g. the USA [9].

Furthermore, the study findings align with the previously mentioned competency-based framework for CPG development by Sultan et al. [60]. This suggests that the identified educational needs are not unique to the Dutch context but are relevant to the broader CPG development community.

Strengths and limitations

This study employed a bottom-up approach, engaging Dutch CPG developers directly to understand educational needs. Collaboration with representatives from different patient and healthcare professional organisations involved in CPG development enhanced the content validity of the survey. Distribution of the survey amongst various CPG development organisations in the medical and paramedical field helped ensure a broad and diverse sample of participants. The complexity of roles and responsibilities in CPG development was captured by allowing respondents to indicate their multiple roles but complicated the interpretation of results.

The voluntary participation of the survey raised the possibility of self-selection bias, as respondents who completed the survey might have been more invested and opinionated concerning CPG development. Whilst the survey was open to all individuals involved in CPG development, it is possible that some potential participants were not reached. The survey predominantly attracted academically educated CPG developers, potentially limiting the generalisability to panel members with vocational education or other educational backgrounds. Additionally, not all respondents completed the survey potentially creating a possible non-response bias in the last responses to the survey. This warrants consideration when interpreting the study's outcomes. Nevertheless, the mixed-methods approach, broad inclusion of participants, strong response rate and the explorative nature of the mixed-method survey allowed a comprehensive overview of the needs for CPG development training.

Implications for further research and practice

Tailoring and evaluating competency-based training programs for different roles in CPG development are necessary to advance practice. This study brings forth recommendations on what to address in CPG development training. It is recommended to address content-related topics, such as the GRADE (EtD) methodology. Additionally, the complex topics of economic considerations and patient perspectives in CPG development should be addressed. Lastly, the training must extend beyond only content-related topics and encompass process-related aspects, such as task division and responsibilities, regulating group dynamics and ways to ensure attention to different perspectives and equitable participation. To

ensure the training aligns with the most pressing needs of the end-users (in this case, CPG developers), it is essential to involve them in designing the educational program. Engaging other relevant stakeholders, such as educators and policymakers, can further enhance the program's feasibility and effective implementation. Whilst there is already some training on CPG development (e.g. INGUIDE [54]) we are unaware of training covering all the above-mentioned topics.

To ensure suitable training for all panel members, a follow-up study with non-academically educated panel members could be beneficial. This could create insights into the educational needs of the underrepresented groups in this study. Future research is needed to see how this holistic approach supports CPG development.

Conclusions

This study underscores the importance of tailored training programs that address the specific competencies required for different roles in CPG development. Training programs should recognise a holistic approach encompassing content- and process-related aspects. Addressing economic considerations and the patient perspective in training will contribute to CPGs that support a patient-centred and sustainable healthcare system.

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Declaration of Generative AI and AI-assisted technologies in the writing process
During the preparation of this work, the author(s) used ChatGPT 3.5 to receive guidance on the readability of the manuscript. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

Appendix 1: Consolidated criteria for REporting Qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/ facilitator? *e.g. Bias, assumptions, reasons and interests in the research topic*

	Remarks	Section, subsection
	N/A	N/A
	CdM: MSc, MkH: MSc, DV: Assoc. Prof., GvM: Asst. prof., AP: Prof., SE: Prof., DD: PhD, MM: Prof.	
	CdM: PhD candidate in the field of clinical practice guideline development, education, and health service research; MSc, Health Biology MkH: PhD candidate in the field of clinical practice guideline development and patient participation; MSc, Medicine & Clinical Research; MA Care Ethics and Policy DV: Assoc. Prof. instructional design and educational research GvM: Asst. prof. HTA and epidemiology AP: Full professor in Economics of Education and Healthcare SE: Full professor public HTA DD: Team lead & senior advisor knowledge tools, quality management/ improvement, knowledge translation/implementation, and patient participation/SDM MM: Full professor epilepsy and education; neurologist	Research team and reflexivity
	All researchers were female	
	All researchers had experience conducting different types (interviews, focus groups) of qualitative research and analyses.	
	None of the researcher was aware of personal relationships with respondents, as all survey results were anonymised.	Research team and reflexivity
	The respondents did not personally know the researchers. The primary researcher's name was known, and this researcher could be looked up by respondents. Additionally, the goals of the study were explained at the start of the survey.	Design and Research team and reflexivity
	Both researchers, CdM and MkH, are PhD candidates working in the field of clinical practice guidelines. Both have experience with quantitative and qualitative research.	

No	Item	Guide questions/description
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis.*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?

	Remarks	Section, subsection
	A thematic analysis was conducted from a pragmatic paradigm, with an aim to uncover what aspects are important for training of guideline developers from different healthcare professions.	
	Participants were found via distribution of the survey via LinkedIn and the participating guideline development organisations.	Data collection
	Participants were digitally approached by the guideline development organisation they are affiliated with or a post on LinkedIn.	Data collection
	282 respondents were included in the study	General information and Table 1
	It is not possible to know how many potential respondents did not respond to the survey. One participant asked to be removed as a responded, as they felt they were not the target audience of the survey. 21 respondents did not complete the survey and 33 respondents did not answer all question from the survey.	General information and Table 1
	Digitally via the program Qualtrics[xm] . This gave the possibility for respondents to fill in the survey at any place and time the preferred.	Data collection
	No. The researchers were also not present when the respondent filled in the survey.	N/A
	Educational level, guideline development organisation respondent is associated with, role in the guideline development process.	General information and Table 1
	N/A	N/A
	N/A	N/A
	N/A	N/A
	N/A	N/A
	N/A	N/A
	Yes	Qualitative data analysis
	N/A	N/A

No	Item	Guide questions/description
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g., participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

	Remarks	Section, subsection
	Two authors (CdM and MKH)	Qualitative data analysis
	Yes	Appendix 4 and 5
	Themes were derived from the data.	Qualitative data analysis
	For the qualitative part MAXQDA, version 2022 was used. For the quantitative part SPSS version 26.0 was used.	Qualitative data analysis and Quantitative data analysis
	The data was anonymised; therefore, participant checking was not possible. However, the results were presented to the stakeholders who were also involved in the development of the survey. They had the possibility to respond to the results.	N/A
	Yes, participants were identified by their respondent number and role during the development of their last guideline.	Table 2
	Yes	Results
	Yes	Results and Appendix 4 and 5
	Yes	Results and Appendix 4 and 5

Appendix 2: Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Checklist Item	*Explanation*	*Page Number*
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample? (In "open" surveys this is most likely.)	Design and Data collection
IRB approval	Mention whether the study has been approved by an IRB.	Design
Informed consent	Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?	Design and Appendix 3
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	Data collection
Development and testing	State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.	Survey development
Open survey versus closed survey	An "open survey" is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).	Data collection
Contact mode	Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)	Data collection
Advertising the survey	How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.	Data collection
Web/E-mail	State the type of e-survey (eg, one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?	Data collection

Checklist Item	***Explanation***	***Page Number***
Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site	Data collection and Strenghts & limitations
Mandatory/ voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?	Data collection
Incentives	Were any incentives offered (eg, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?	No
Time/Date	In what timeframe were the data collected?	Data collection
Randomization of items or questionnaires	To prevent biases items can be randomized or alternated.	Survey development
Adaptive questioning	Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.	Survey development and Appendix 3
Number of Items	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.	Survey development
Number of screens (pages)	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.	Survey development and Appendix 3
Completeness check	It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if "yes", how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as "not applicable" or "rather not say", and selection of one response option should be enforced.	Afterwards. Results and Table 1

Checklist Item	***Explanation***	***Page Number***
Review step	State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).	Survey development
Unique site visitor	If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.	N/A
View rate (Ratio of unique survey visitors/unique site visitors)	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.	N/A
Participation rate (Ratio of unique visitors who agreed to participate/ unique first survey page visitors)	Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called "recruitment" rate.	N/A
Completion rate (Ratio of users who finished the survey/users who agreed to participate)	The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition. Note that "completion" can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word "completeness rate".)	General information and Table 1
Cookies used	Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A

Checklist Item	***Explanation***	***Page Number***
IP check	Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A,Data collection
Log file analysis	Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.	N/A
Registration	In "closed" (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A
Handling of incomplete questionnaires	Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?	General information and Table 1
Questionnaires submitted with an atypical timestamp	Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined.	N/A
Statistical correction	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.	N/A

Appendix 3: the survey

Maastricht University

Dear reader,

For my PhD research, we would like to investigate education and training on guideline development and the inclusion of economic aspects in guidelines.

This survey will be distributed among a wide audience, including healthcare professionals, patient representatives, and guideline advisors. Your answers will help us develop a guideline development training program. Additionally, your answers will be used for the publication of a scientific article.

The questionnaire consists of 4 parts: guidelines, education/training on guideline development, economic aspects in guidelines, and patient representation.

Completing the survey takes about 10-15 minutes.

Participation is completely voluntary and can be stopped at any moment.
The survey is anonymous, and data will be stored and processed according to the Maastricht University regulations. Only the lead researcher, Marian Majoie and Chloé de Mortier can view the unprocessed data.

Any questions or comments can be directed to Chloé de Mortier at [e-mail address researcher].

When you start the survey, you automatically agree with the points mentioned above.

Thank you for your participation.

On behalf of Neurologist and professor Marian Majoie, PhD candidate Chloé de Mortier, the research team and other stakeholders.

You can fill out the questionnaire anonymously, and your data will be processed anonymously. The data will be stored and processed according to the regulations of Maastricht University.

More information about the PhD research can be found via the following link:
https://www.zonmw.nl/nl/onderzoek-resultaten/kwaliteit-van-zorg/programmas/project-detail/kwaliteitsgelden/leerplatform-richtlijnontwikkeling-toekomstbestendig-en-duurzaam/

General

1. What is your highest level of education?
   - Primary education
   - Secondary education
   - Vocational education
   - Higher vocational education
   - University education

2. What is your profession?

3. What is your gender?
   - Male
   - Female
   - Non-binary
   - I prefer not to say

4. How old are you?

5. I am a member of the following (professional) organisations (multiple answers possible):
   - Scientific or professional association. Please fill in the name of the association below...
   - Patient organisation. Please fill in the name of the organisation: ...
   - Umbrella organisation. Please fill in the name of the organisation: ...
   - Organisation (including self-employed) that supports guideline development. Please fill in the name of the organisation: ...
   - Other, namely: ...

Part 1 Guidelines

Healthcare professionals use guidelines. A guideline is a document with recommendations to improve the quality of care. These recommendations are based on scientific research and the experiences and expertise of healthcare professionals and users.

The first few questions are about your experience with guideline development.

6. Have you ever assisted in the development or revision of a guideline?
   - Yes →skip to question 7
   - No → skip to question 21
   - No, but I would like to do this in the future → skip to question 2

7. How often have you helped in developing/revising a guideline?
   A revision of a guideline is considered as the development of a guideline in this questionnaire. If you have developed a guideline and revised a guideline, you have helped in developing a guideline twice.
   - Never
   - Once
   - Twice
   - Three times
   - More than three times

8. In which year did you last develop/revise a guideline? …

9. For which (professional) organisation did you develop your last guideline? (Multiple answers possible)
   - Scientific or professional association. Please fill in the name of the association below…
   - Patient organisation. Please fill in the name of the organisation: …
   - Umbrella organisation. Please fill in the name of the organisation: …
   - Organisation (including self-employed) that supports guideline development. Please fill in the name of the organisation: …
   - Other, namely: …

10. Were the working group members who participated in the development of your last guideline from the same (professional) organisation?
    - Yes, from the same (professional) organisation
    - No, from 2 different (professional) organisations
    - No, from more than 2 different (professional) organisations
    - I don't remember

11. Was there a specific method/guide followed during the development of your last guideline?
    - Yes → skip to question 12
    - No → skip to question 13
    - I don't remember → skip to question 13

12. Which methodology/guide was followed in the development of your last guideline? (Multiple answers are possible)
    - Grading of Recommendations Assessment, Development and Evaluation (GRADE)

- Evidence-based guideline development (EBRO)
- Medical Specialist Guideline 2.0
- AQUA guideline
- Guideline for guidelines
- KNGF guideline methodology
- Development of NHG standards
- Own method/guide, namely…
- I don't remember
- Other, namely…

13. What was your role during the development of your last guideline?
    - Guideline development advisor
    - General working group member
    - HTA specialist
    - Implementation expert
    - Literature specialist
    - Methodologist
    - Project leader
    - Chair
    - Other, namely…

14. Could you briefly describe what your tasks were during the development of your last guideline?

15. Were you prepared to perform the tasks you carried out for the development of your last guideline? Please indicate why or why not.
    - Yes, because: …
    - No, because: …

Part 2 Patient Representation

16. Was there attention given to the patient perspective in the last standard/guideline you developed? What was the reason for not including the patient perspective in the development of your last guideline?
    - Yes, throughout the entire standard/guideline development → skip to question 18
    - Yes, at certain times during the development. → skip to question 18
    - No → skip to question 17
    - I don't remember → skip to 21

17. What was the reason for not including the patient perspective in the development of your last guideline?

18. What was the reason for including the patient perspective in the development of your last guideline?

19. Could you briefly describe what the patient perspective looked like during the development of your last standard/guideline?

20. In your opinion, what is a good way to incorporate the patient perspective into standard/guideline development? → this question is only visible to patient representatives.

Part 3 Education for Guideline Development

21. Have you followed any training(s) on guideline development? (Multiple answers possible)
    - Yes, I have followed training(s) → skip to question 23
    - Yes, it was included in my education. → skip to question 22
    - Yes, but in a different way. For example, by... → skip to question 24
    - No → skip to question 24

22. Which education included attention to guideline development?

23. The training I took on guideline development was:

24. What would motivate you to participate in a training on standard/guideline development? Multiple answers possible)
    - If I were to participate in a guideline panel
    - If it was mandatory to participate
    - If I were to become chair of a guideline panel
    - If I receive accreditation points
    - If the training is paid for/free
    - If the entire working group takes the training together
    - If no preparation is required
    - If this is necessary for my work
    - If this was part of my education
    - Personal interest
    - Other, namely...

25. When would you want to take a training on guideline development?
    - Before participating in a working group
    - During participation in a working group
    - After participation in a working group
    - It doesn't matter to me when

26. Indicate which topics you find important in training on guideline development
    - Topic 1: …
    - Topic 2: …
    - Topic 3: …
    - Topic 4: …
    - Topic 5: …
    - Topic 6: …
    - Topic 7: …
    - Topic 8: …

Part 4 Economic aspects in guidelines

Lately, there has been increasing attention to cost-conscious healthcare. Cost-conscious healthcare looks at how to best use resources, such as time, money, and personnel. The following questions are about incorporating economic aspects during guideline development. By economic aspects, we mean the cost of a treatment, but also economic evaluations where, for example, the costs of one treatment are compared to another treatment (cost-effectiveness analysis).

27. Were economic aspects considered during the development of the last guideline you helped with? Please indicate why or why not
    - Yes, because… → skip to question 28
    - No, because… → skip to question 30
    - I don't remember → skip to question 30

28. Who was involved with the economic aspects during the development of your last standard/guideline? (multiple answers are possible)
    - An expert in the field of economic aspects (HTA specialist)
    - The project leader Standard/Guideline advisor(s)
    - Guideline advisor specialised in economic aspects
    - The chairperson
    - A working group member
    - Multiple working group members

- The entire working group
- I don't remember
- Other, namely…

29. In what way were economic aspects incorporated into your last guideline?
    - Evidence to Decision Framework (EtDF) / in the considerations
    - Via a budget impact analysis (BIA)
    - Via a cost-effectiveness analysis
    - Via a cost-benefit analysis
    - By mentioning the costs of the medicines/treatment
    - I don't remember
    - Other, namely…

30. Do you think economic aspects should be considered in guidelines?
    - Yes
    - No
    - No opinion

30a. Would you like to explain your answer.

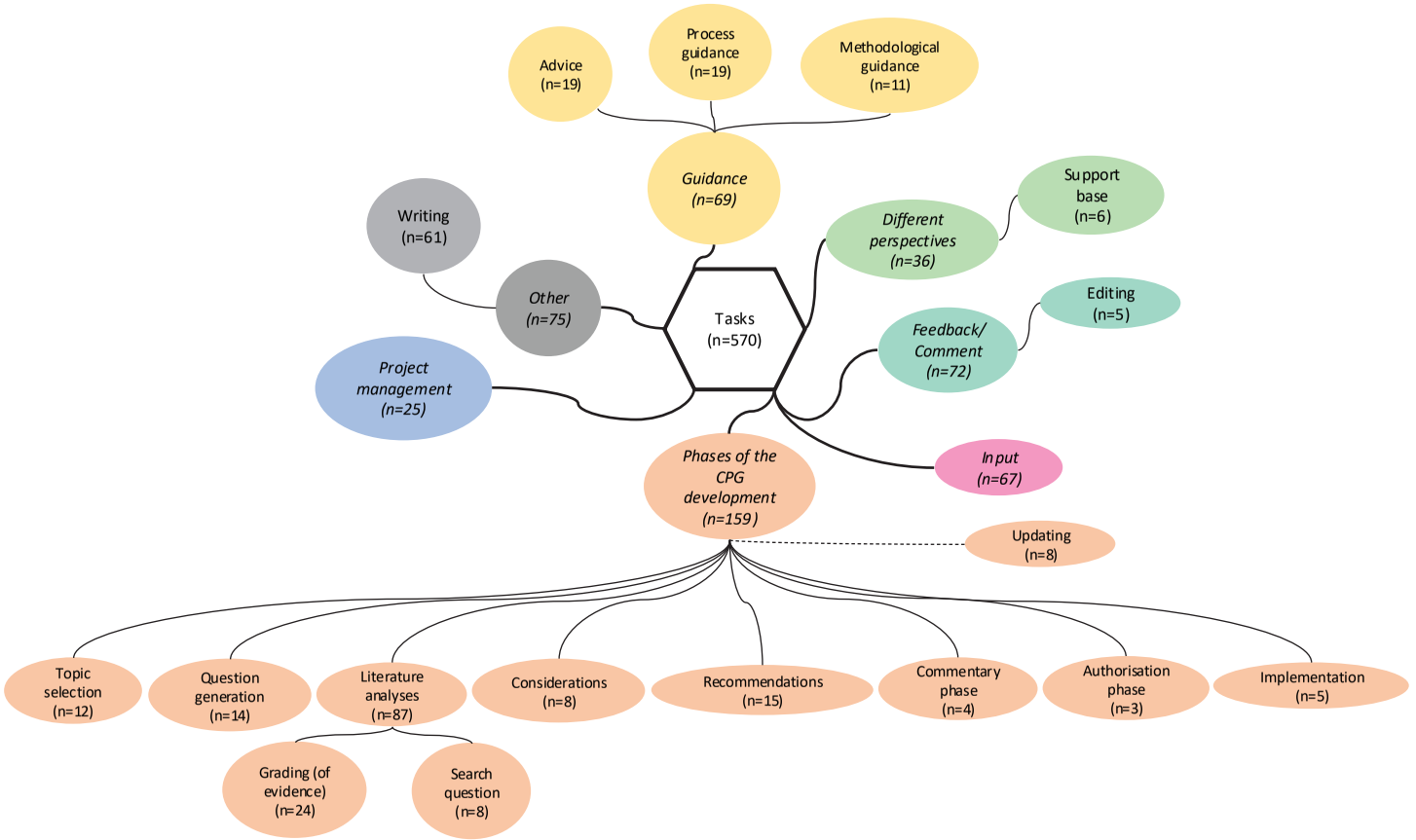
31. Do you think economic aspects should be included in training on guideline development?
    - Yes
    - No
    - No opinion

31a. Would you like to explain your answer.

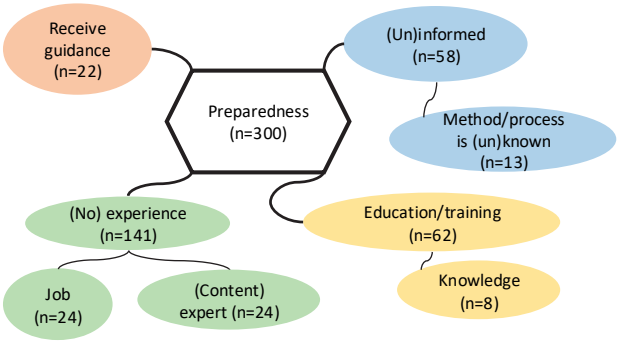
Thank you for completing the questionnaire. If you have any questions or comments, please feel free to post them below. For the continuation of this research, we would like to interview a few participants about their experience with guideline development. Would you be willing to participate in this? If yes, you can provide your email below.

The survey is anonymous, and data will be stored and processed according to the Maastricht University regulations. Only the lead researcher, Marian Majoie and Chloé de Mortier can view the unprocessed data.

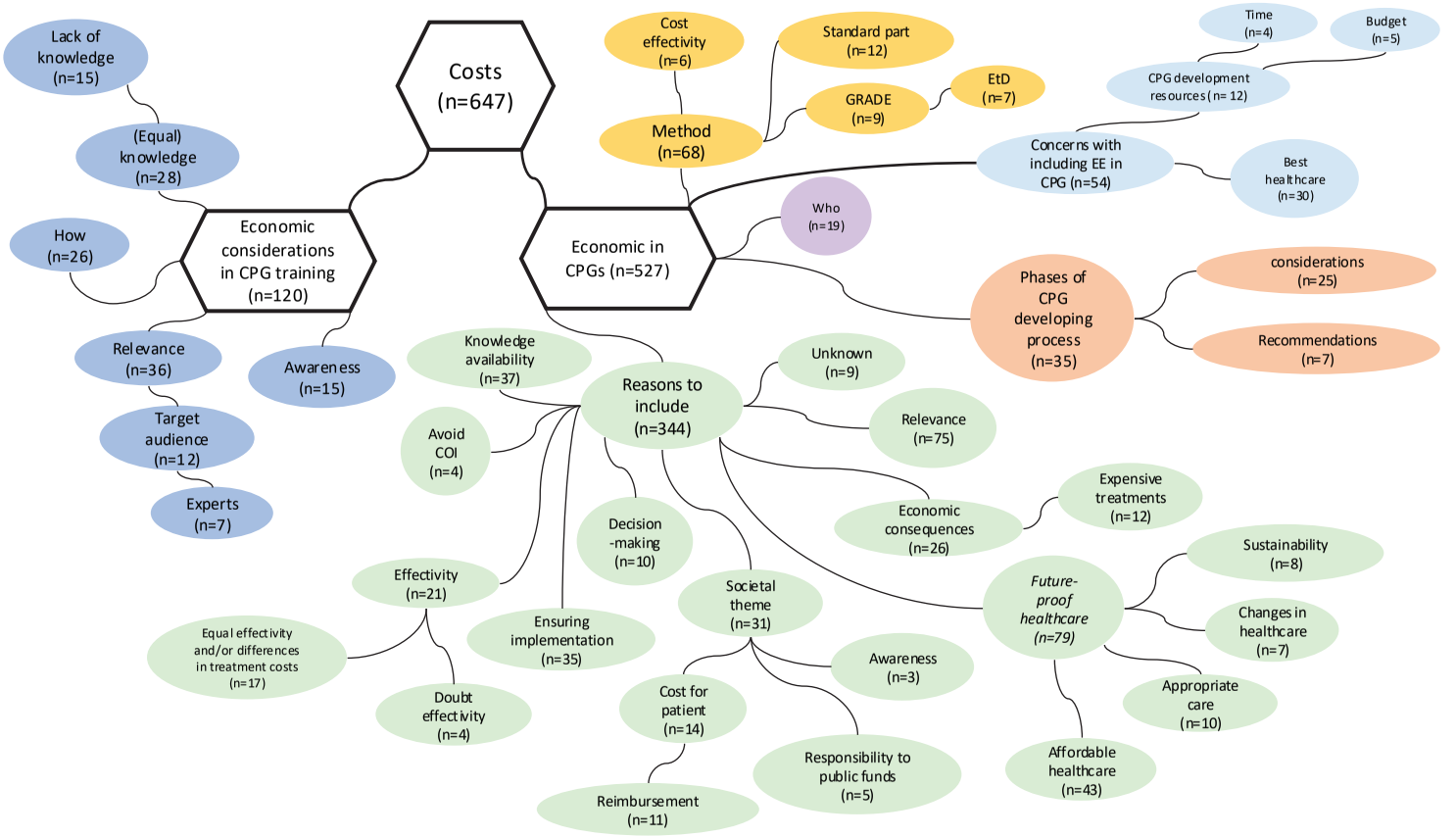
Appendix 4: Codebooks of the main five topics uncovered by the survey



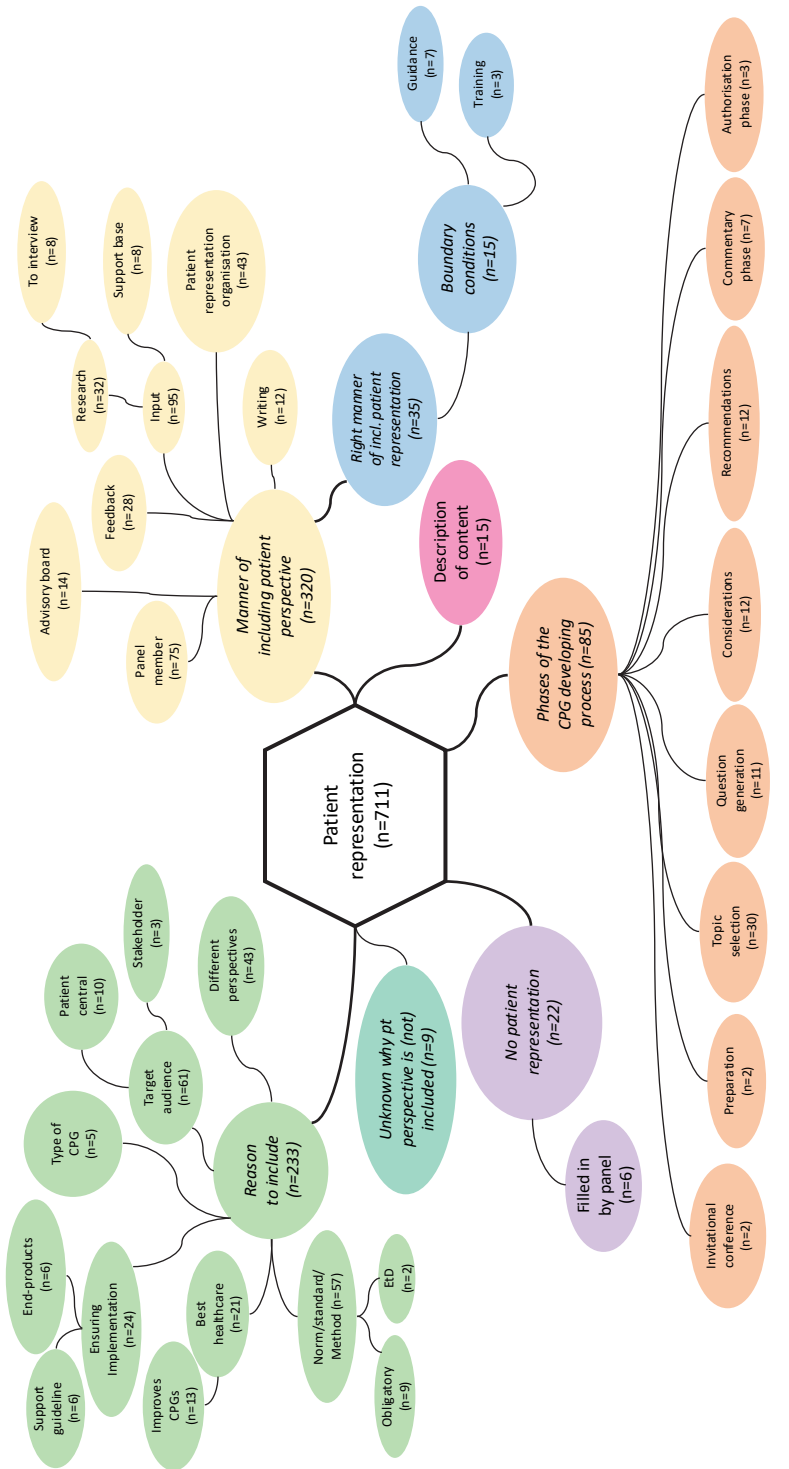
1. Codebook tasks



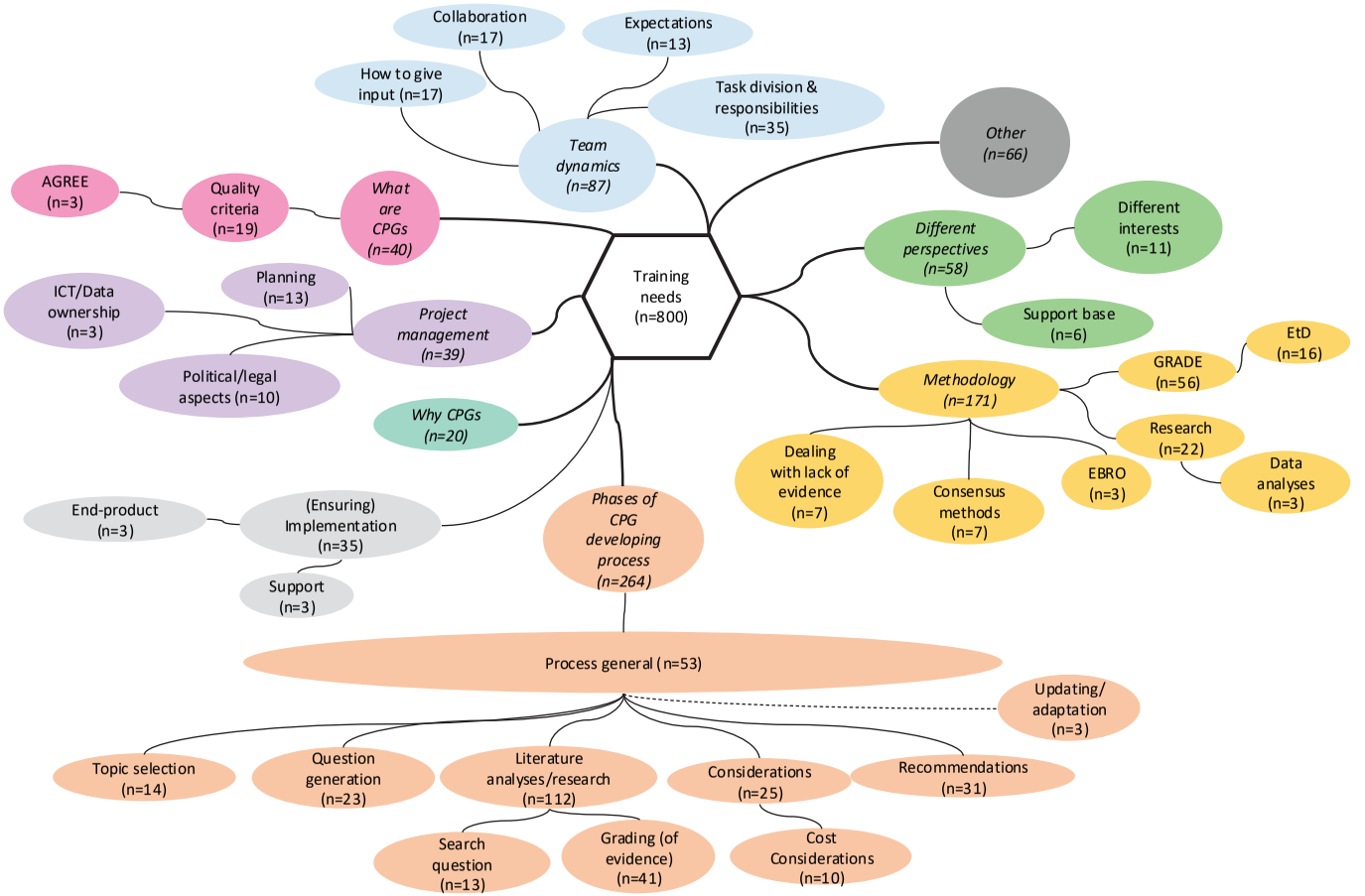
2. Codebook preparedness



3. Codebook cost considerations



4. Codebook patient representation



5. Codebook training needs

Appendix 5: Glossary of the codebooks

1. Tasks codebook glossary	
Code	**including**
Phases of the CPG development process	The different phases in the CPG development process where respondents indicated they had a task in. If respondents did not indicate more than development process, they only received this higher code
Topic selection	Dutch phrases related to code, such as: Knelpunten(analyse)
Question generation	Dutch phrases related to code, such as: Uitgangsvragen en uitkomstmaten
Literature analyses	Dutch phrases related to code, such as: literatuur analyse
Grading (of evidence)	Dutch phrases related to code, such as: Gradering, GRADE, and beoordelen
Search question	Dutch phrases related to code, such as: Zoekvraag and PICO
Considerations	Dutch phrases related to code, such as: Overwegingen
Recommendations	Dutch phrases related to code, such as: Aanbevellingen
Commentary phase	Dutch phrases related to code, such as: Commentaarfase
Authorisation phase	Dutch phrases related to code, such as: Autorisatiefase
Implementation	Dutch phrases related to code, such as: Praktijkbevoordering and implementatie
Updating	Dutch phrases related to code, such as: Herzien and update
Guidance	Dutch phrases related to code, such as: Help, ondersteunen and begeleiden
Process guidance	Specifically, if phrases referred to process guidance
Methodological guidance	Specifically in the context of methods, e.g., methodological advice or support
Advice	Advising specifically named. This can be in guidance context, but also in other ocntexts
Feedback/comment	Dutch phrases related to code, such as: Teksten beoordelen, feedback, tegenlezen and meelezen
Editing	Dutch phrases related to code, such as: Editing(aanpassen) or redigeren is specifically mentioned
Input	About giving input during the development process, and not feedback on draft version of the CPG.Dutch phrases related to code, such as: Meedenken, brainstormen and input geven

Project management	Task related to organizing of the CPG development process. Dutch phrases related to code, such as: Planning, voortgang bewaken, secretariele taken, organising, werkwijze werkgroep, panel composition
Role in development process	When participant did not specify the tasks' they had but named the title of the role they full filled during the process
Different perspectives	
Support base	Achterban
Other	Sections not fitting in any of the above codes
Unclear	Sections that were unclear
Writing	Dutch phrases related to writing, where it was unclear to what the writing reffered.For example: Meeschrijven, schrijven. Vormgeven aan..., opstellen and uitwerken

2. Preparedness codebook glossary

Code	Includes
(No) experience	State they have (no) experience. E.g., earlier done, experience
Job	State it is their job therefore experienced. (ingewerkt incl.)
(content) Expert	They state they are (content) experts, therefore prepared for their role.
(Un)informed	State they were (not) informed, there was (no) clear communication about what was expected of them
Method/process is (un)known	They state they are (not) familiar with the method or process of developing a CPG
Receive guidance	They (did not) receive(d) guidance during the process (e.g., begeleiding)
Education/training	The respondents (did not) follow(ed) training on CPG development before entering the CPG development process.
Knowledge	State they had (no) knowledge

3. Costs codebook glossary

Code	Including
Economic consideration in CPGs	
Phases of the CPG development process	If it is not clear when during the process attention has been given to cost considerations. Also includes segments stating not yet having looked at costs, or looked at costs after development.
Considerations	Dutch phrases related to code, such as: Overwegingen

Recommendations	Dutch phrases related to code, such as: Aanbevellingen
Method	Segments related to describing how respondents included costs considerations in their CPG
Cost effectivity	Segments where respondents specifically claim they used cost effectivity analyses
GRADE	Segments where respondents specifically claim they used GRADE method for cost considerations
EtD	Segments where respondents specifically claim they used EtD for cost considerations
Standard part	Segments where respondents specifically claim cost considerations is a standard part of CPG development
Who	Who has conducted the cost considerations or who the respondents think should look at the cost considerations
Reason for including EE (CPG)	Describes in which situation costs are relevant to considered or able to be considered according to respondents or describes the situation in which they did an EE
Unknown	If the respondent does not know why cost considerations should be considered
Avoid COI	To prevent conflict of interest to occur
Decision-making	Including cost considerations to support decision making discussions
Effectivity	
Doubt effectivity	If the effectivity of the treatment is unsure
Equal effectivity and/or differences of treatment costs	when there is a difference in medicine cost and/or equal effectivity of treatment
Economic consequences	When there are economic consequences expected or should be investigated
Expensive treatments	When the treatments are expensive
Knowledge available	If there is information about economic considerations
Ensuring implementation	Segments related to implementation of CPG. E.g., haalbaarheid, to ensure implementation, implementation
Societal theme	If the reason mentioned are related to bigger societal themes
Costs for patient	Segment about cost for patient
Reimbursement	Segments about reimbursement of care
Awareness	Segments about creating awareness for cost of healthcare
Responsibility to public funds	Segments related to the funding of healthcare is from public funds

Future-proof healthcare	Segments related to ensuring a viable, future-proof healthcare system
Changes in healthcare	That healthcare is changing
Appropriate care	Passende zorg
Sustainability	duurzaamheid
Affordable healthcare	Also incl. rising healthcare costs
Relevance	Include economic consideration if relevant, if stated that it is important/crucial,
Knowledge availability	Segments related to not having knowledge about how to approach this, as well as no scientific evidence/data available.
Concerns with including EE in CPG	Segments that raise concerns when including cost considerations in CPGs
Best healthcare	Segments that state that CPG is about the best healthcare i
CPG development resources	Segments related to (limiting) resources in CPG development process
Time	Specifically, the resource time
Budget	Specifically financial resources
Economic considerations in CPG training	
Relevance	Segments related to statements that inclusion of EE in CPG training depends on the relevance.
Target audience training	Segments related to who the training is for. Depending on the target audience EE inclusion is relevant or not.
Experts	Segments related to statement that EE in CPG should be devoted to experts/ specific panel members/advisors
Awareness	Segments related to improving awareness
How	Segments related to the manner of how EE should be included. A wish of what to have in the training on this aspect
	How ee should be included in CPG + how training about EE should look. Like, what it should address.
(Equal) knowledge	Segments related to improving (basic) knowledge of panel members
Lack of knowledge	Segments related to that training is relevant as there is no knowledge available now

4. Patient representation codebook glossary	
Code	Includes
No patient representation	When participant describes not including patient representation
Filed in by panel member	When participant describes the patient representation is done by the panel members who are not a patient representative
Unknown why pt perspective is (not) included	Participants indicated they are not aware why the patient perspective is (not) included in a guideline
Reason to include patient perspective	Different reasons that could not yet be subdivided
Ensuring implementation	Segments related to including patient perspective being beneficial for implementation success
End-products	Segments related to end-products focused on patients
Support guideline	Segments related to incorporating patient perspective ensures more support for the CPG
Type of CPG	Specific types of guidelines which seem to lend themselves more to the inclusion of the patient perspective
Different perspectives	Segments related to having different perspectives on the guideline/healthcare. For example, a healthcare professional's or patient's perspective
Best healthcare	If reason is related to improve the healthcare, literally stated best healthcare or 'passende' zorg
Improves CPGs	Segments related to statements that say it improves or results in better CPGs
Target audience	If mentioned someone is the target audience of guidelines, most often patients but sometimes also healthcare professionals. Can be phrased as, e.g., end-user, guidelines are about or for…,
Patient central	Segments that state that the patient stands central in the CPG or healthcare
Stakeholder	Segments that state that patients are 'belanghebbende', but not the most important stakeholder
The norm/standard/method	If mentioned that including patient perspective is the norm, included by default or it is in the method
EtD	If stated that patient perspective was included because it was part of the GRADE evidence to decision framework
Obligatory	If mentioned, it is obligatory to include patient perspective in the CPG.

Manner of including patient perspective	The way the patient perspective is considered during the guideline development. This category focuses on how it was, not how it should be done. This coded segments for this higher code contain the segments not specified for more specific codes.
Patient representation organisation	Everything that is associated with the mentioning of patient representation organization, except involvement in the panel. If explicitly stated that the patient representation organization was part of the panel this is coded as a panel member. e.g.: patient organisations reads along with the concept guideline.
Panel member	When a patient representative was present in the development process as a panel member. E.g.: Werkgroeplid, Vertegenwoordiger, Patientvereniging deelname in werkgroep, Vertegenwoordiger aanwezig alle vergaderingen.
Feedback	If the patient perspective was included in the form of giving feedback on already developed pieces. Described as e.g., feedback, commenting.
Input	If the patient perspective was included in during the CpG development. Described as e.g., input, thinking along, consultation, stated their views, shared experiences.
Support base	Asking the 'achterban' for their input
Research	Manner of receiving input during the development e.g., by holding surveys or focus groups
	Manner of receiving input by asking questions to patient representatives/organisations. E.g. with the Dutch phrase uitvragen
Advisory board	Including the patient perspective via klankboardgroup or steering committee or advisory board
Right manner of including patient representation	The manner patient representation should be done according to patient representatives
Boundary conditions	Segments related to allocating resources to including patient perspective inclusion
Guidance	
Training	
Phases of the CPG development process	The different phases in the CPG development process where something related with the patient perspectives occurred. When during 'all phases' is mentioned, it is categorized here. Also, if it is about the implementation phase.

Invitational conference	Segment related to including patient perspective via invitational conference
Preparation	Involved during the preparation before the development
Topic selection	Knelpunten(analyse)
Question generation	Uitgangsvragen en uitkomstmaten
Considerations	Overwegingen
Recommendations	Aanbevellingen
Commentary phase	Commentaarfase
Authorisation phase	Autorisatiefase
Description of content	About the content of the patient perspective in the CPG

5. Training needs codebook glossary

Code	including
What are CPGs	Segments related to what a CPG is, what components are to it (e.g., opbouw RL)
Quality criteria	What are the criteria of a guideline, e.g., Eisen aan een RL
Agree (criteria good guideline)	AGREE specifically named
Why CPG?	Goal/purpose of guidelines, why or when guidelines
Phases of the CPG development process	The different phases in the CPG development process where participants indicated they had a task in
Process general	process, how do you develop, all steps in the development process
Updating/adaptation	Segments that are related to updating ('herzien') or adapting guidelines
Topic selection	Dutch phrases related to code, such as: Knelpunten(analyse)
Question generation	Dutch phrases related to code, such as: Uitgangsvragen and uitkomstmaten
Literature analyses/research	Dutch phrases related to code, such as: literatuuronderzoek
Grading (of evidence)	Dutch phrases related to code, such as: Graderen, beoordelen data,/evidence
Search question	Dutch phrases related to code, such as: Zoekvraag, PICO
Considerations	Dutch phrases related to code, such as: Overwegingen
Cost considerations	Considerations specifically related to costs
Recommendations	Dutch phrases related to code, such as: Aanbevellingen
(Ensuring) Implementation	Codes related to implementation
End-product	How to get to usable end-product
Support	'Draagvlak'

Different perspectives	Segments related to different perspectives in CPG
Support base	achterban
Different interests	Segments related to intrests (belangen)
Project management	Task related to organizing of the CPG development process. E.g., Planning, voortgang bewaken, secretariele taken, organising, werkwijze werkgroep, panel composition
Planning	Planning, time investment, deadlines
Politcal/legal aspects	Segments related to political or legal components
ICT/Data ownership	Segments related to ICT or data ownership
Team dynamics	Components related to working in a panel. (boundary conditions). E.g. how a panel member group looks like
Task division & responsibilities	Task, roles, what responsibilities are related to the roles or tasks, task division
Expectations	Dutch phrases related to code, such as: Verwachtingen
How to give input	Segements relate to letting your voice be heard, topics related to giving input; how to give input, how to balance everyones input
Collaboration	Segments related to working together
Methodology	Including Evidence Based Medicine and other reference to methodology, e.g. methodiek, methode, werkwijze
Research	Anything related to research. E.g., statistics, scientific research, onderzoeksmethoden
Data analyses	
EBRO	Segments explicitly referring to the code
Consensus methods	Segments explicitly referring to the code
Dealing with lack of evidence	Segments related to limited evidence being available
GRADE	Segments explicitly referring to the code
EtD	Segments explicitly referring to the code
Other	

Appendix 6: Categorisation of respondents affiliated organisations

Respondent could work for or be a member of multiple organisations. One categorisation of respondents was made based on their affiliated healthcare or patient organisation. For respondents with multiple affiliations, the following criteria were applied: All healthcare-related organisations were categorised (1). Non-healthcare-related and unidentifiable affiliations were categorised as other (2). Additionally, the primary healthcare focus of societies or associations was leading in their categorisation. If the focus of the society or association was unspecified or general, they were classified as other (3). Healthcare-related organisations were leading in the categorisation above organisations categorised as other (4). Respondents who did not mention an affiliation were categorised as unknown (5).

Patient representation organisation		
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
BB4all	Bekkenbodem4all	
Behartiger bewonersparticipatie via VKKL, LVKK, NLZVE, koepel zorgcooperaties		
Burgerkracht limburg		
BVN	Borstkankerverneiging Nederland	
DON	Dwarslaesie Organisatie Nederland	
Duchenne Nederland		
EAT (we-are-eat.org)		
ESMO	European Society for Medical Oncology	This category as respondent indicate they were a patient representative/advocate.
EUPATI	The European Patients' Academy on Therapeutic Innovation	
Freya		Patient association for fertility problems
Hematon		Patient organisation for blood cancers
Hersenaneurysmaplatform		
Hoofdpijnnet		
Longfonds		
MaculaVereniging		

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
Nationale Vereniging voor mensen met Lupus, Antifosfolipidensyndroom, Sclerodermie en Mixed Connective Tissue Disease.		
NFK	Nederlandse Federatie van Kankerpatiëntenorganisaties	
Nierpatiënten Vereniging Nederland		
Olijf		
Osteoporose Vereniging		
Patiëntenfederatie		
Patientenfederatie Nederland		
Platform zeldzame kankers		
PlusMinus		
Psoriasispatienten Nederland		
PVHH	Patiëntenvereniging Hoofd-Hals	
ReumaNederland		
Reumazorg Nederland		
Schildklierorganisatie Nederland		
Spierziekten Nederland		
Stichting darmkanker		
Stichting FCIC	Stichting Family and patient Centered Intensive Care	
Stichting Zelfbeschadiging		
trainer voor patiëntvertegenwoordigers bij richtlijnontwikkeling		
Vasa Previa Foundation		
VOKS	Patiëntenorganisatie voor ouderen en kinderen geboren met een slokdarmafsluiting	

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
VSOP	Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (patiëntenkoepel in voor zeldzame en genetische aandoeningen)	
Medical specialist-associated organisations		
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
ARCH	Autoimmune Research and Collaboration Hub	Member of Knowledge Institute of Medical Specialists
EANS	European Association of Neurosurgical Societies	Focus is on neurosurgery and medical students
FMS	Federatie Medisch Specialisten	
KiMS	Kennisinstituut Medisch Specialisten	Knowledge Institute of Medical Specialists is part of Federation for Medical Specialists
NfN	Nederlandse federatie voor nefrologie	Focus clinicians and researchers
NIV	Nederlandse Internisten Vereniging	Member of Knowledge Institute of Medical Specialists
NOG	Nederlands Oogheelkundig Gezelschap	Member of Knowledge Institute of Medical Specialists
NOV	Nederlandse Orthopaedische Vereniging	Member of Knowledge Institute of Medical Specialists
NVA	Nederlandse Vereniging voor Anesthesiologie	Member of Knowledge Institute of Medical Specialists
NVALT	Nederlandse Vereniging van Artsen voor Longziekten en Tuberculose	Member of Knowledge Institute of Medical Specialists

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
NVDV	Nederlandse Vereniging voor Dermatologie en Venereologie	Member of Knowledge Institute of Medical Specialists
NVE	Nederlandse Vereniging voor Endocrinologie	Umbrella organisation of NIV, NVKC and NVK
NVGE	Nederlandse Vereniging voor Gastro-Enterologie	Primary focus: docters and other academici
NVIC	Nederlandse Vereniging voor Intensive Care	Member of Knowledge Institute of Medical Specialists
NVKC	Nederlandse Vereniging voor Klinische Chemie en Laboratoriumgeneeskunde	Member of Knowledge Institute of Medical Specialists
NVKF	Nederlandse Vereniging voor Klinische Fysica	Member of Knowledge Institute of Medical Specialists
NVKG	Nederlandse Vereniging voor Klinische Geriatrie	Member of Knowledge Institute of Medical Specialists
NVMDL	Nederlandse Vereniging van Maag-Darm-Leverartsen	Member of Knowledge Institute of Medical Specialists
NVMM	Nederlandse Vereniging voor Medische Microbiologie	Member of Knowledge Institute of Medical Specialists
NVMO	Nederlandse Vereniging voor Medische Oncologie	Focus on internist-oncologists
NVN	Nederlandse Vereniging Neurologie	Member of Knowledge Institute of Medical Specialists
NVOG	Nederlandse Vereniging voor Obstetrie en Gynaecologie	Member of Knowledge Institute of Medical Specialists
NVR	Nederlandse vereniging voor reumatologie	Member of Knowledge Institute of Medical Specialists
NVTH	Nederlandse Vereniging voor Trombose en Hemostase	Members are scientific researchers, physisians, clinical chemists and analysts

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
NVU	Nederlandse Vereniging voor Urologie	Member of Knowledge Institute of Medical Specialists
NVVC	Nederlandse Vereniging voor Cardiologie	Member of Knowledge Institute of Medical Specialists
NVVH	Nederlandse Vereniging voor Heelkunde	Member of Knowledge Institute of Medical Specialists
NVVN	Nederlandse Vereniging voor Neurochirurgie	Member of Knowledge Institute of Medical Specialists
NVZA	Nederlandse Vereniging van Ziekenhuisapothekers	Member of Knowledge Institute of Medical Specialists
Verenso	Vereniging van specialisten ouderengeneeskunde	Specialists in geriatric medicine
VKGN	Vereniging Klinische Genetica Nederland	Member of Knowledge Institute of Medical Specialists
VRA	Vereniging Revalidatie Artsen	Member of Knowledge Institute of Medical Specialists
VSG	Vereniging SportGeneeskunde	Member of Knowledge Institute of Medical Specialists
Physical therapy organisations		
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
AXXON	Beroepsvereniging voor kinesitherapeuten	
Ergotherapie Nederland		
Human factors NL	Ergonomie opleiding	
IOF Utrecht hartrevalidatie (etwork overleg fysiotherapeuten)		
IPT-HOPE	International etwork therapists for hope	

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
KNGF	Koninklijk Nederlands Genootschap voor Fysiotherapie	
krf kwaliteitskeurmerk fysiotherapie		
NFP	Nederlandse vereniging voor fysiotherapie volgens de psychosomatiek	
NVFK	Nederlandse Vereniging voor Kinderfysiotherapie	
NVFL	Nederlandse Vereniging voor Fysiotherapie binnen de Lymfologie en oncologie	
NVHT	Nederlandse vereniging voor handtherapie	
NVMT	Nederlandse Vereniging voor Manuele Therapie	
NVPMT	Nederlandse Vereniging voor Psychomotorische Therapie	
Oefentherapie Mensendieck		
Rugnetwerk		
VHVL	Vereniging voor Hart-, Vaat- en Longfysiotherapie	
VvBN	Vereniging voor Bewegingswetenschappen Nederland	
VvOCM	Vereniging van Oefentherapeuten Cesar en Mensendieck	
General practitioner organisation		
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
LHV	Landelijke Huisartsen Vereniging	
NHG	Nederlands Huisarts Genootschap	
Mental healthcare organisation		

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
Akwa GGZ		
ARKIN		
FVB	Federatie Vaktherapeurische Beroepen	
MIND Landelijk Platform Psychische Gezondheid		
NBVH	Nederlandse Beroepsvereniging van Hypnotherapeuten	
NIP	Nederlans Instituut van Psychologen	
NVGP	Nederlandse Vereniging voor Groepsdynamica en groepspsychotherapie	
NVP	Nederlandse Vereniging voor Pschyotherapie	
NVPMT	Nederlandse Vereniging voor Psychomotorische Therapie	Categorised at two places, also a physical therapist organisation
NVvP	Nederlandse Vereniging voor Psychiatrie	
Verslavingskunde Nederland		
VGVZ	Vereniging van Geestelijk VerZorgers	
Nursing organisation		
Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
CV&V	Continentie Verpleegkundigen & Verzorgenden	
DAEN (Dutch Assosciation of ECLS Nurses)		

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
ESPU(N)	European Society for Paediatric Urology Nurses Group	
Landelijk etwork VS long	Landelijk etwork Verpleegkundig specialist long	
etwork VSO	Netwerk Verpleegkundig Specialisten Oncologie	
NVHVV	Nederlandse Vereniging voor Hart- en Vaatverpleegkundigen	
NvvPO	Nederlandse Vereniging van Praktijkondersteuners en Praktijkverpleekgkundigen	
SIG Pijn bij kwetsbare ouderen	Werkgroep van V&VN	
Stoma, urologie, continentie en VS	Stoma, urologie, continentie en Verpleegkundig Specialist	
V&VN Diabeteszorg		
V&VN oncologie, urologie		
V&VN or VenVN	Verpleegkundigen & verzorgenden	
V&VN Pijnverpleegkundigen		
V&VN urologie verpleegkundigen		
V&VN VS		
v&vn wondexpertise		
V&VN-IC		
V&VN: CV&V/ VS/ stoma		
VenVS		
VS	Verpleegkundig Specialist	
Public health organisation		
Affiliation organisation abbreviation	**Affiliation organisation**	**Reason to include in this category**
AJN Jeugdartsen Nederland		
GGD	Gemeentelijke Gezondheidsdienst	
NJI	Nederlands Jeugdinstituut	

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
Other organisations		
Affiliation organisation abbreviation	**Affiliation organisation**	**Reason to include in this category**
AOB	Algemeen ouderen bond	
ASH	Ambulante spoedhulp	3rd association of respondent (NIV, ISTH, ASH, NVTH)
ASN		3rd association (NIV, NfN, ASN, ERA, VAS)
Docent klinische epidemiologie AUMC		
EASD	European Association for the Study of Diabetes	
EAUN	European Association of Urology	Umbrella organisation
ECCO	European Cancer Organisation OR European Crohn's and Colitis Organisation	
ERA	European research area	Type of members not specified
ERS	European respiratory society	Broad range of members: physicians, health professionals, scientists and other experts
ESE	European society of Endocrinology	Broad membership
ESSKA	European Society for Sports Traumatology, Knee Surgery and Arthroscopy	Target audience is clinicans ancd physical therapists.
ETA	European thyroid association	4rd association. Audience unclear
Expertisecentrum Pharos		
Genever		
Gezondheidswetenschappen		
GIN		
GRADE working group		
Guidelines International Network		

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
ICOH	International Commission on Occupational Health	
IKNL	Integraal Kankercentrum Nederland	
INS	Platform INS (niet echt zorg gerelateerd)	
ISMR	International Society for Maxillofacial Rehabilitation	
ISTH	International Society on Thrombosis and Haemostasis	Focus audience is clinicians, researchers, and educators. Also welcome to nurse and allied health professionals.
Kenniscentrum		Unclear what knowledge centre is referred to.
Kennisinstituut Mondzorg		
kennisinstituut NFU		
Keurmerk		
KNMG	De Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunde	
KNMP	Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie	
MASCC	Multinational association of supportive care in cancer	Broad orientation: doctor, nurse, allied health professional, researcher, industry representative, or simply have an interest in supportive cancer care
McKenzie Institute international		
Medewerker ziekenhuis		
NACGG	Nederlandse Associatie voor Community Genetics and Public Health Genomics	

Affiliation organisation abbreviation as written down by respondents	Affiliation organisation	Reason to include in this category
Ned Ver voor Klinische Arbeidsgeneeskunde, Human Factors NL, International Commission on Occupational Health		
Nederlandse Vereniging van Diëtisten		
Netherlands Association for the Study of Obesity		
Netwerk Transmurale zorg, Dementie Netwerk Haaglanden		
NRS	Netherlands respiratory society	
NVAB	Nederlandse Vereniging voor Arbeids- en Bedrijfsgeneeskunde	
NvBe	Nederlandse Vereniging voor Bio-ethiek	
NVDO	Nederlandse Vereniging voor Diabetes Onderzoek	
NvvA	Nederlandse Vereniging van Arbeidsdeskundigen	
NVVG	Nederlandse Vereniging van Verzekeringsgeneeskunde	
NWHHT	Nederlandse Werkgroep voor Hoofd-Hals Tumoren	Not clear which paramedics or medics
Onderzoeksinstituut TNO		
Palliactief	Multidisciplinaire beroepsvereniging voor professionals werkzaam in de palliatieve zor	
ParkinsonNet		
Pijn Alliantie Nderland		
Prinses Maxima Centrum		
PROVA		
PWHHT	Paramedische Werkgroep Hoofd-Hals Tumoren	Not clear which paramedics
PZNL	Palliatieve Zorg Nederland	

Affiliation organisation abbreviation as written down by respondents	**Affiliation organisation**	**Reason to include in this category**
qwerty		
Radboudumc		
RBCZ	Register Beroepsbeofenaren Complementaire Zorg	
Rescon		
RNN	Richtlijnen etwork nederland	
SKILZ		
Stichting Lagerhans, onderwijsinstituut eerste lijn DM zorg		
Universiteit		
Vrije Universiteit		
VvBW	Vereniging voor belastingwetenschap	
VVE	Vereniging voor Epidemiologie	
Zuyderland		



Chapter 3

Challenges and stimulating factors for the incorporation of economic considerations in clinical practice guidelines: a scoping review



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Abstract

Rationale, aims and objectives: The incorporation of economic considerations in clinical practice guidelines (CPG) could help promote cost-conscious decision-making in healthcare. Though healthcare expenditures increase, and resources are becoming scarcer, the extent to which economic considerations are incorporated into CPGs remains limited. This scoping review aims to identify the challenges and potential stimulating factors to incorporate economic considerations in CPGs.

Method: This scoping review was conducted following the Joanna Briggs Institute Methodology and findings were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines. A systematic search was conducted in eight databases considering literature published from July 2017 and onwards. Data extraction was conducted via an iterative and inductive approach to identify challenges and potential stimulating factors from the included reports. Included documents focused on the (para)medical field and reported on CPG development and economic considerations.

Results: The search identified 2445 documents from which 33 documents were included for analysis. The analysis identified five challenges: discourse surrounding economic considerations in CPGs, methodological ambiguities, scarcity of (high-quality) economic evidence, transferability of evidence, and resource constraints. Additionally, three potential stimulating factors were identified: acceptance, economic evidence knowledge, and guidance on incorporating economic considerations.

Conclusion: These findings reflect the complexity of incorporating economic considerations in CPGs. The identified challenges highlight the need for clearer guidance (i.e. by training) and standardised methodologies for incorporating economic considerations in CPGs. The potential stimulating factors provide a roadmap for future efforts to enhance the integration of economic evidence in CPGs. Collaborative initiatives between health economists, CPG developers, and other stakeholders are essential to drive progress in this area and promote cost-conscious decision-making in healthcare.

Introduction

The provision of healthcare is under pressure due to a scarcity of resources (financial, human, and material) [1]. Worldwide, healthcare expenditures have more than doubled in the last two decades, reaching US$8.5 trillion in 2019. In 29 high-income countries, healthcare costs grew more rapidly than the gross domestic product (GDP) [44]. Therefore, it is imperative to make well-informed and cost-conscious healthcare decisions to ensure affordable healthcare, for example regarding expensive innovations and long-term conditions [79, 95]. One potential avenue to support cost-conscious decision-making in healthcare is to enhance the (limited) incorporation of economic evidence in clinical practice guidelines (CPG) [45-47]. Economic evidence in CPGs is often referred to by various terms, such as costs and resource use. This scoping review categorises these under 'economic considerations', encompassing all related economic analysis methods (e.g. budget impact analysis and economic evaluations).

CPGs contain recommendations to support decision-making by healthcare professionals [17, 34] and patients. These recommendations are based on scientific evidence and the experiences/expertise of healthcare professionals and patients [9]. They are formed by a multidisciplinary CPG panel, consisting of guideline methodologists, patient representatives and healthcare professionals [78]. Addressing economic considerations in CPGs could improve the CPG's practical feasibility and implementation success [51]. Additionally, economic considerations in CPGs can enhance healthcare professionals' awareness of limited resources. Subsequently, this can encourage more thoughtful consideration of healthcare resource usage when making healthcare decisions [11, 52].

The formulation of CPG recommendations is guided by the strength of clinical evidence, incorporating several contextual factors such as equity and patient values and preferences [18, 20, 96]. Resource use is a contextual factor within the most common CPG development methodology, the GRADE Evidence to Decision framework [31]. In the Appraisal of Guidelines for Research and Evaluation II (AGREE-II) tool, a CPG quality appraisal tool, cost implication is one of the quality criteria for the applicability domain [20]. The incorporation of economic considerations in CPGs is still limited despite its importance and the explicit requirement for incorporation [50].

The limited incorporation of economic considerations in CPGs indicates barriers at play [45]. A review assessing the incorporation of economic considerations in CPG development handbooks and documents from different CPG development

organisations showed that CPG development handbooks and documents often lacked explicit guidance on how to incorporate economic considerations in CPGs [46]. Possible challenges to incorporate economic considerations in CPGs were lack of guidance, transferability of economic evidence, lack of expertise and added resources needed [46]. However, a comprehensive understanding of all the challenges hindering the uptake of economic consideration in CPG development is lacking. Moreover, an understanding of stimulating factors is unknown. To bridge this gap, this scoping review aimed to create a comprehensive overview of current challenges and potential stimulating factors for incorporating economic considerations when developing CPGs.

Method

Protocol & Registration

The scoping review approach allows a broad investigation to help identify key characteristics or factors related to a concept, in this case, determining the challenges and potential stimulating factors to incorporating economic considerations in CPGs [97]. A scoping review iteratively narrows the focus in response to the found evidence [97]. This scoping review has been guided by the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis [98], an advancement on Arskey and O'Malley's original work [99]. This approach consists of nine steps: (1) defining the research question, (2) developing the inclusion criteria, (3) creating a research protocol, (4-7) searching, selecting, extracting and analysing the evidence, and (8-9) presenting and summarising the results. A scoping review has an iterative nature, allowing researchers to adjust the search strategy, inclusion criteria, and analysis in response to emerging evidence. As a result, the carried-out method slightly deviates from the protocol, prospectively registered with Open Science Framework in July 2022 [100]. Changes are explicitly addressed in the method section 'Synthesis of Evidence'. The findings are reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [101].

Eligibility criteria and search strategy

The inclusion of relevant documents was determined with the help of the Population-Concept-Context (PCC) framework in Table 1.

Population

Documents reporting on the development of CPGs for the (para)medical field were included. Documents on the endorsement of CPGs, CPG development handbooks, studies in progress, (conference) abstracts, CPGs, and CPG appraisals were excluded.

Concept

Economic evidence considered in CPGs tends to be referred to by different terms, such as (monetary) costs, resource use, and evidence from economic evaluations or health technology assessments (HTA). Whilst these terms have different meanings [48, 49], they are used interchangeably in the literature, making it an elusive subject. This scoping review considered every term related to (health) economic evidence as used or suggested by the authors of the included studies. Additionally, this scoping review included all economic analysis methods as suggested by the authors, such as cost-effectiveness analysis and budget impact analysis. See Appendix 2 for an overview of (health) economic evidence terms and economic analysis methods referred to under the term "*economic considerations*".

Context

This scoping review considered documents related to the CPG development phase. Documents related to the implementation phase were excluded. The review considered documents worldwide, limited to English and Dutch. Additionally, to capture the current challenges and potential stimulating factors, this review only considered literature published from July 2017 and onwards.

Search

An initial search in PubMed and OVID, NHS EED and EMBASE was conducted to determine index terms and keywords to develop search strings. In collaboration with a literature specialist, full search strings were designed for MEDLINE (PubMed & OVID), Cochrane Library, National Health Service Economic Evaluation Database (NHS EED), Google Scholar, Web of Science, International HTA Database (INAHTA), Embase (Elsevier) (Appendix 1). The initial search was conducted in July 2022 and repeated in November 2023.

Table 1. Description of the Population-Concept-Context (PCC) criteria applied for evidence selection.

PCC framework item	Inclusion criteria
Population	Documents devoted to CPG development
Concept	Documents that reported on challenges or stimulating factors for the incorporation of economic considerations in CPGs
Context	English or Dutch documents focused on CPG development for the (para)medical field, without any geographical limitation, that have been published since 2017

Screening and selection of data

Evidence selection was conducted via an iterative process by CdM and JY [98]. First, identified records were collated into the Clarivate reference manager EndNote and de-duplicated by the Bramer Method [102]. Next, records were imported into Rayyan [103] for the title and abstract screening. A pilot on 5% of randomly selected records was conducted by researchers CdM and JY. Pilot results were discussed amongst researchers CdM and JY, resulting in refined eligibility criteria to reflect the aim of the study. When consensus could not be reached a third researcher (AP or DD) was consulted. Once 90% agreement was achieved, all remaining records were screened for inclusion. The same method was used to complete the full-text screening.

Data items and extraction

The data extraction format was developed through an iterative and inductive approach in Microsoft Excel. The extracted data included bibliographic information (e.g. year, journal) and study characteristics (e.g. research approach). All segments relating to economic considerations were extracted from the included documents by the main researcher (CdM), and 10% by the second researcher (JY).

Synthesis of Evidence

The primary researchers (CdM and JY) thematically analysed 10% of the extracted data segments and categorised them inductively into challenges and potential stimulating factors [104]. The third researcher (AP) was consulted when consensus could not be reached. The main researcher categorised the remaining extracted segments and consulted the second researcher (JY) and third researcher (AP) when there were uncertainties regarding the categorisation or inclusion of segments. The final data extraction format can be found in Appendix 3.

Deviation from protocol

Due to the explorative and iterative nature of the scoping review, some deviations from the study's protocol were made [100]. The initial aim of the review was to explore the barriers and facilitators to incorporating economic evaluations during CPG development. However, the results did not yield any proven facilitators for increasing the incorporation of economic considerations. Consequently, the focus shifted to examining potential stimulating factors, which are suggestions to improve the incorporation but have not been proven effective (yet). Endorsements of CPGs, originally intended for inclusion, were excluded due to their limited content related to the CPG development process. Additionally, CPG development handbooks were excluded, as we felt the most valuable new information would be derived from different types of resources next to the CPG development handbook review from Sanabria et al. (2019) [46].

Results

This scoping review consulted eight databases to map challenges and potential stimulating factors for incorporating economic considerations into CPGs. Figure 1 shows the identification of 3617 records, of which 86 documents were fully screened. The scoping review process was iterative, with the research team refining the selection criteria as the review progressed, and ultimately data were extracted from 33 documents. The study characteristics are described in Table 2. The included records were published between 2017-2023, originating from five continents. Most articles were conducted in geographically unspecified areas (38%), then Europe (23%) and North America (21%). Documents from geographically unspecified areas often included methodological-oriented studies and their first authors were often from high-income countries. Various research designs are represented in the included articles, with most articles using a qualitative research design (90%). Appendix 2 shows an overview of all the terms authors used to refer to economic evidence and methods, referred to as economic considerations in this scoping review. Authors refer most often to costs or cost of and cost-effectiveness.

Five challenges and three potential stimulating factors for the incorporation of economic considerations in CPGs were identified (Table 2). The five challenges include (1) discourse surrounding economic evidence incorporation in CPGs, (2) methodological ambiguities, (3) scarcity of (high-quality) economic evidence, (4) challenges regarding the transferability of evidence, and (5) resource constraints. The three potential stimulating factors entail (1) acceptance and intent to incorporate economic considerations in CPGs, (2) knowing what evidence to consider and what evidence is missing, and (3) guidance.

Challenges for incorporation of economic considerations in CPGs

Challenge 1: Discourse surrounding incorporation of economic considerations in CPGs

A lack of consensus on whether to incorporate economic considerations into CPGs represents the first challenge. This partly stems from a debate on whether CPGs should describe the best patient care or best value-based care [91]. Resistance from healthcare professionals to incorporate economic considerations in CPGs was noted [94]. Furthermore, Garbi et al. (2021) noted that healthcare professional societies seem less concerned with resource availability or costs, and are often not directly responsible for CPG implementation [92]. Lastly, some plead that CPG's recommendations must be in line with the global healthcare professional societies' CPG recommendations, even in cases where economic evidence might give rise to a different recommendation [110].

Table 2. Characteristics of the included reports.

Author, year[reference]	Origin	Study design*	
		Qualitative	Quantitative
Alderson, 2018[105]	Europe	Unspecified journal article	
Alper, 2019[106]	n.a.	Communication	
Antioch, 2017[94]	Oceania	Review	
Barkham, 2017[107]	Europe	Original article	
Bettmann, 2018[108]	n.a.	Book chapter	
Braun, 2019[109]	North America	Roundtable discussion	
Briggs, 2021[110]	Europe	Commentary	
Capone, 2019[111]	North America	Research review	
Chou, 2017[112]	n.a.	Method	
Garbi, 2021[92]	Europe	Review	
Hurtado, 2020 [113]	Europe	Original research	
Kahale, 2021[114]	North Africa	Research	
Knies, 2018[115]	n.a.	Brief report	
Li, 2018[29]	Europe, North America, South America	Original research	
Maaløe, 2021[116]	n.a. (Low- or Middle-Income countries)	Viewpoint	
Marcucci, 2019[117]	n.a.	Correspondence	
Marx, 2020[118]	n.a.	Meeting report	
Mercuri, 2017[119]	n.a.	Original article	
Murano, 2022[120]	n.a.	Research	
Norlin, 2021[121]	Europe	Original article	
Ostrominski, 2022[122]	n.a.		Clinical research
Powell, 2022[123]	North America	Special contributions	
Qaseem, 2019[124]	North America	Update of methods	
Richter Sundberg, 2017[125]	Europe	Research article	
Riva, 2021[93]	n.a.		Review
Riva, 2022[126]	n.a.	(Systematic) review	

	Challenges to incorporations of economic considerations						Potential stimulating factors to incorporation of economic considerations		
	Discourse surrounding economic considerations	Methodological ambiguities	Scarcity of economic evidence	Transferability of evidence	Resource constraints	Acceptance and intent	Knowing what evidence to consider	Guidance
							x	
		x		x				x
	x	x	x	x		x		x
		x					x	
				x				
		x		x		x		
	x	x						x
			x					
			x					
	x							
			x					
			x	x				
						x		x
						x		x
								x
			x	x				
								x
		x						
			x	x	x			
		x	x	x				
		x	x	x		x	x	x
			x					
		x				x		
					x	x		x
		x	x		x	x		x
		x		x	x		x	x

Table 2. Continued

Author, year[reference]	Origin	Study design*	
		Qualitative	Quantitative
Scott, 2019[127]	n.a.	Conference presentation	
Shaker, 2020[82]	n.a.	Special series journal article	
Tuck, 2018[128]	n.a.	Journal article	
Wiercioch, 2022[129]	North America	Original article	
Wilson, 2019[91]	n.a.	Commentary	
Xie, 2023[6]	n.a.	Original article	
Yao, 2020[130]	n.a.	Editorial	
Total (33)		91% (30/33)	9% (3/33)

* Study design as reported by the authors themselves.

Challenge 2: Methodological ambiguities

When guideline panels decide to include economic considerations in their CPGs, they are faced with a new challenge: methodological ambiguities. There is a lack of clarity about how economic evidence should be incorporated into the CPG (development), as well as some limitations to economic evaluation methods. In general, the literature mentioned a lack of explicit guidance and clear or agreed-upon methodologies for various aspects of incorporating economic considerations in CPGs [93, 119]. More specifically, some studies noted that there is no clear guidance on how to integrate different concepts such as costs, benefits, and harms into the recommendations [93, 119]. Integrating these concepts is difficult because they use different outcome measures [119]. The interpretation of cost-effectiveness modelling is stated to be complex and attention might be paid to how economic evidence data might be presented to a CPG panel [106]. For example, Briggs et al. (2021) presented their cost-effectiveness results in a ranked manner to the CPG panel. They suspected that the ranking order might have influenced the panel's initial recommendations [110]. However, the panel must balance the cost-effectiveness concept with the other concepts that could affect the decision-making, e.g. patient values [110, 119]. When guideline panels incorporate economic evidence, implicitly and/or explicitly, this information is often limited and poorly described [93].

Challenges to incorporations of economic considerations						Potential stimulating factors to incorporation of economic considerations		
Discourse surrounding economic considerations	Methodological ambiguities	Scarcity of economic evidence	Transferability of evidence	Resource constraints	Acceptance and intent	Knowing what evidence to consider	Guidance
							x
				x			
		x		x	x		
				x			
x	x	x	x	x		x	
		x	x			x	x
							x
12% (4/33)	36% (12/33)	42% (14//33)	36% (12/33)	24% (8/33)	27% (9/33)	18% (6/33)	42% (14/33)

Furthermore, the literature highlighted some limitations of economic evaluation methods indicated by the authors. First, incremental cost-effectiveness ratio (ICER) analyses, can only be performed when the long-term outcomes are positive [109]. Secondly, it is thought cost-effectiveness acceptability curves may give misleading views on the strength of evidence as they use ordinal measuring [110]. Thirdly, cost-effectiveness analyses often use non-standardised methods [91] and a clear systematic review methodology for economic evaluations is believed to be lacking [93]. Lastly, it is stated that various assumptions must be made to conduct economic evaluations, large sample sizes are required, and the results may be paired with uncertainty [107, 110, 121, 122, 124]. These assumed limitations might partly be attributed to the finding that available economic evidence frequently fell short of the desired quality standards [91, 110, 119, 122, 124]. The quality of economic evidence studies can be determined with the help of study reporting checklists. However, it is noteworthy that cost-effectiveness study reporting checklists are not infallible. Sometimes, a well-reported but poorly conducted cost-effectiveness study can receive a high score on a checklist [126]. Lastly, there exists controversy concerning the usage of quality-adjusted life year measures, cost-effectiveness thresholds, and methods used to determine weights for decision criteria [91, 94].

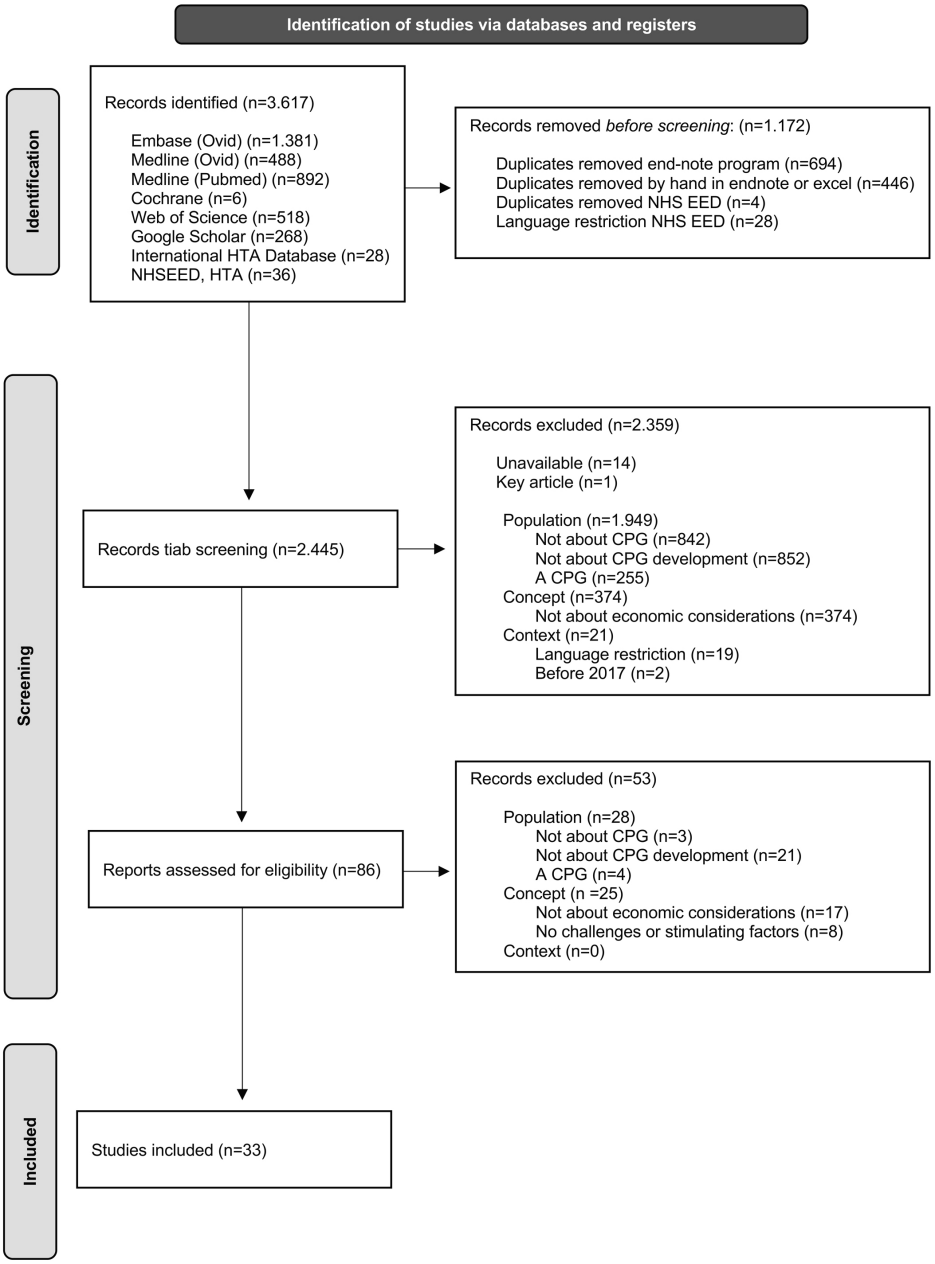

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Reviews (PRISMA-ScR) flowchart of included reports [101].

Challenge 3: Scarcity of economic evidence

Economic evidence must be available or developed to realise the incorporation of economic considerations during CPG development. The literature described a lack of available local data and (high-quality) economic evidence [6, 93, 111-114, 120, 122]. Additionally, it was described that economic evidence becomes outdated quickly and could already be so before a CPG is published [91, 128].

Challenge 4: Transferability of evidence

Given the limited availability of (high-quality) economic evidence, Kahale et al. (2021) sought economic information from panel members or investigated economic evidence from similar contexts [114]. However, if the economic evidence does not completely align with the context of the CPG, e.g. if it pertains to a different population or geographical region, a new challenge arises. This challenge is not solely recognised in economic literature, where it is referred to as the "transferability of evidence", but also in clinical studies. Within the CPG development community, in which there is also a focus on clinical studies, the challenge is known as the "indirectness of evidence" [91, 126].

Several factors that could constrain the transferability of economic evidence were mentioned [120]. For instance, disparities in the characteristics of populations in the economic study and target population of the CPG [6, 106, 121]. Additionally, the use of different perspectives in the CPG and the economic analyses [6, 94, 108], as well as the omission of elements in the economic analyses that were relevant to the CPG [117, 121]. Disparities in drug prices between countries were also mentioned to add to the transferability challenge [109, 122].

Whilst some researchers suggested that economic models could never be transferred from their original setting, it seems common to extrapolate effectiveness data from other contexts [126]. According to Riva et al. (2022) assessing the indirectness of certain transferability characteristics was easier than others, such as perspective, discount rate, cost approach, and comparable life expectancies. While, similar practice norms, health status (utilities), absolute and relative prices, technology availability, and acceptability are characteristics that were more challenging to transfer [122, 126].

Challenge 5: Resource constraints

The last challenge noted the increase in resource requirements to incorporate economic considerations in CPGs. The main additional resources mentioned were time [91, 93, 120, 125, 126, 128, 129], financial resources [91, 93, 126], and the need for specialised expertise to enable incorporating economic considerations in CPG development [82, 126].

Potential stimulating factors to incorporating economic considerations in CPGs

Potential stimulating factor 1: Acceptance and intent

The first stimulating factor described in the literature is a wider acceptance and intent towards the incorporation of economic considerations in CPGs. Richter Sundberg et al. (2017) highlighted that in the last few decades, more emphasis had been put on CPG recommendations being informed by cost-effectiveness studies [125]. Some organisations have been incorporating economic considerations in their CPGs, for example, the National Institute for Care and Excellence (NICE) in England and the National Board of Health and Welfare in Sweden [94, 109, 115, 122, 124, 125, 128]. Three studies indicated that economic considerations are a topic of interest to CPG panel members [29, 93, 94] and other stakeholders (e.g., healthcare providers, manufacturers, patients/families, and insurers) [94]. Knies et al. (2018) mentioned that national decision-making bodies ideally set boundaries and principles for economic considerations in CPGs, after which clinicians and health economists together specify the guidance [115]. The governments of Sweden and Australia required the incorporation of health economics evidence to inform decision-making [94, 125].

Potential stimulating factor 2: Enhancing knowledge on what evidence to consider for economic considerations in CPGs

When CPG developers embrace the idea of incorporating economic considerations in CPGs, they can consider various types of economic evidence. The literature proposed to describe in each CPG what economic evidence might have been able to enhance the CPG recommendations. Consequently, showing where economic evidence could be expanded, CPG developers and health economists can prioritise the generation of high-quality economic evidence [91, 122].

Additionally, some researchers have proposed broadening the range of economic evidence beyond randomised control trial (RCT) study results and considering evidence from different geographical areas [6, 107, 126]. Furthermore, to mitigate time and expertise constraints in conducting new economic evaluations for a CPG, it has been suggested to utilise previously published (high-quality) economic evaluations relevant to the CPG [105].

Potential stimulating factor 3: Guidance on how to incorporate economic considerations in CPGs

The scoping review revealed that CPG developers are in need of guidance on how to incorporate economic considerations during CPG development. Although no 'perfect' method for including economic considerations in CPGs was described [127],

several potential avenues were suggested in the literature. Firstly, CPG developers could look towards the approaches taken by organisations that already incorporate economic considerations within their CPGs [94, 109, 115, 122, 124, 125].

Furthermore, some literature suggested (international and broad stakeholders) that consensus upon a well-defined grading of evidence framework might help to incorporate economic considerations in CPGs [94, 118, 122]. For example, Riva et al. (2022) suggested a framework that includes an explicit step for prioritisation of research questions most benefiting from economic evidence [126]. The most mentioned framework in the literature was the GRADE Evidence to Decision (EtD) framework [6, 29, 93, 106, 130]. The GRADE methodology, which the EtD is part of, focuses on assessing and grading evidence for CPG recommendations and helps determine the strength of the recommendations [106]. The GRADE EtD framework explicitly requires consideration of resource use (cost) when determining the strength and direction of a recommendation [6, 106]. This framework employs predefined "Likert-type" questions for judgment, integrates research evidence and allows for the inclusion of additional cost-related information through free text fields [93]. Recently, the GRADE working group published an article on how economic evidence could be considered to inform CPG recommendations using the GRADE EtD framework [6].

The GRADE EtD framework is widely recognised and applied. However, Riva et al. (2021) proposed three simplified criteria to help apply the conventional GRADE criteria to economic evidence: (1) the transferability of economic evidence to the decision context, (2) identifying limitations of economic evaluations, and (3) assessing the consistency of findings across multiple cost-effectiveness models [93]. Hence, addressing their concern that the "Likert-type" judgements might become a "check box exercise" when the EtD framework was completed without supporting research evidence or additional considerations [93].

Next to the GRADE EtD framework, other frameworks and methods were mentioned in the literature, such as the WHO-INTEGRATE framework [116], the Swedish NBHW guideline development model [125] and the Australian National Health and Medical Research Council (NHMRC) methodologies [94].

Another suggested approach to guide the incorporation of economic considerations was including a health economist on the CPG panel or collaborating with one [94, 115, 122, 126, 127]. The literature proposed that it would be beneficial that economic evidence was presented in a simplified and understandable manner to panel

members, who often have no economic background. For example, using a graphical representation of the economic evidence, such as forest plots [110], and keeping economic models simple and transparent [127]. An additional suggestion to support the incorporation of economic consideration in CPGs was to develop an economic evidence indirectness tool to help determine the suitability of economic evidence for the CPG [93, 126]. Until the development of such a tool, it was recommended to use the GRADE indirectness criteria to determine the level of indirectness/transferability of the economic evidence [126].

Discussion

Overall review results

The incorporation of economic considerations in CPGs is still limited, even though CPGs could support cost-conscious decision-making in healthcare [45, 46]. This study is one of the first to provide a comprehensive overview of the challenges and potential stimulating factors to the incorporation of economic evidence in CPGs within the (para)medical field. The five identified challenges were: discourse, methodological ambiguity, scarcity of data, transferability of data, and resource constraints. The three potential stimulating factors were: acceptance, economic evidence knowledge, and guidance on incorporating economic considerations. The identified challenges and potential stimulating factors reflect the complexity of incorporating economic considerations in CPGs and may explain the limited extent to which this is undertaken [45, 46].

This extensive literature search identified a broad range of literature related to CPG development, but a narrower subset addressed the incorporation of economic considerations. This observation reflects the evolving nature of this topic in the field of CPG development. The included 33 documents were predominantly qualitative and originated from high-income countries or were from non-specified areas, of which the first author was often from a high-income country.

Main results and implications

Previous literature documented the challenges of methodological ambiguity, transferability of economic evidence, and requirement for added resources [46]. However, the broad scope of this review allowed the identification of an additional challenge: the discourse between prioritising best patient healthcare or value-based healthcare. There are various definitions of value-based healthcare, but they have in common that they place the patient centrally and define value ‘as health outcomes

for patients in relation to costs of the whole process of care'. CPG-developing healthcare profession societies might feel it is their responsibility to describe the best patient care and not to address economic considerations within their CPGs. Additionally, healthcare professionals may not be trained to consider resource impact in healthcare [131]. However, recognition of the need to effectively allocate resources in healthcare is seen as necessary due to growing resource strains [44, 132]. Various organisations address the importance of economic considerations in CPGs in their vision and guidance tools [6, 20, 92]. It has been shown that workplace culture and regional practice patterns can influence the attitudes of healthcare professionals regarding value-based healthcare [55, 133]. Thus, training CPG developers and guideline panel members regarding the importance of value-based healthcare might positively affect their attitudes on the incorporation of economic considerations in CPGs [51, 124].

Another novel challenge mentioned in more than half of the included studies was the scarcity of suitable economic evidence for CPG development. Reasons for this limited use of economic evidence included outdated data, relevance to different contexts (e.g. low- or high-income countries), and issues with data quality. Interestingly, this finding is contradicted by other researchers who argue that there is ample economic evidence available, citing cost-effectiveness studies from clinical trials [46, 134]. An explanation for these contradictory views may be that there is no clear definition of what should be considered under these economic considerations. This is reflected in the interchangeable terminology used when discussing economic concepts and the lack of a clear methodological approach to the incorporation of economic considerations in CPGs [46]. Additionally, most CPG developers lack training in health economics or related fields. Consequently, they might be unaware of what economic data could be considered during CPG development or where to locate such data. This lack of awareness is also reflected in the authors' perceived limitations of economic evaluations, which are not always recognised as such in health economics. For instance, it was noted that a large sample size is necessary, though, like randomised-controlled trials (RCTs), smaller sample sizes can be used, albeit with greater uncertainty. They also noted a lack of systematic review methods for economic evaluations, yet van Mastrigt et al. (2016) [135] and the ISPOR taskforce (2021) [136] have provided such guidance to conduct such reviews [137, 138]. These inaccurate assumptions reflect the importance of informing and educating CPG developers in basic health economics. Additionally, Wilkinson et al. (2021) suggested training health economists in the implementation and relevance of economic considerations for CPGs could be beneficial [132].

While the above-mentioned challenges pose hurdles, this scoping review identified three novel potential stimulating factors to guide the incorporation of economic considerations in CPGs. These factors were acceptance and intent, economic evidence knowledge, and guidance on incorporating economic considerations. Building on these factors, an initial step could be to define a shared concept of economic considerations in CPGs [132]. This may include consensus on the appropriate economic evaluation(s) and perspective(s) to utilise for CPGs. To develop such communal concepts, it would be beneficial to have acceptance and support on the micro (healthcare professionals and patients), meso (CPG development organisations and healthcare professional societies) and macro level (governments) [115]. There are several implementation strategies one could consider to stimulate acceptance and support [139]. One implementation strategy is education: educating stakeholders on the importance of economic considerations in healthcare decision-making might positively stimulate efforts to prioritise economic considerations in CPGs [132, 139].

Once these communal concepts are established a methodological approach to incorporate economic considerations in CPGs could be developed. This would guide CPG developers on what economic evidence they could consider for their CPG and how. The new approach might be an extension or adaptation of a current approach, for example, the GRADE EtD framework. Both developments should preferably be realised through interdisciplinary collaboration between CPG developers and health economists. This collaboration would help align their different methodological approaches and enhance practical feasibility.

When a new methodological approach is co-created, CPG developers would benefit from guidance on how to incorporate this approach into their CPG development. To support CPG developers the GRADE working group published a guidance paper on the incorporation of economic considerations in CPGs [6]. Other forms of guidance could entail training on basic economic concepts [132] and incorporation of economic considerations in CPGs or collaboration with a health economist or a CPG developer who specialises in this topic.

Strengths and limitations

This scoping review focused on publications from 2017 onwards, creating a comprehensive up-to-date portrayal of challenges and potential stimulating factors. Including previous reviews in this scoping review, potential earlier relevant literature was aimed to be included as well as all experiences and opinions concerning economic consideration incorporation into CPGs. When considering the results, it is important to realise different contexts may present distinct challenges and potential

stimulating factors. Most literature originated from high-income countries within North America and Europe, thereby creating a possible bias. Valuable insight might be found by understanding how middle- and low-income countries approach CPG development and economic considerations. These countries face more and different resource constraints and might heed resource use and implications more when creating clinical guidance.

There is much ambiguity surrounding the terminology for economic considerations. Differing terms were used in the literature to address economic considerations. These terms do not have the same meaning and are often used interchangeably. This scoping review covered the various terms under economic considerations, thereby recognising that this may introduce some level of generalisation of the results. However, singling out a specific term would have resulted in an incomplete picture of the current practice in CPG development. Despite the limitation, the broad scope of this scoping review allowed a comprehensive overview of the currently known challenges and potential stimulating factors to incorporate economic evidence in CPGs. Giving direction to future efforts to stimulate this endeavour.

Conclusion

The incorporation of economic evidence in CPG is complex and faces challenges on various levels, ranging from methodological ambiguities to acceptance. Consequently, the incorporation of economic considerations in CPGs is limited. Agreement on communal concepts and baseline terminology of economic considerations could be helpful. Future research could then focus on the development of practical methodologies and guidance tools for the incorporation of economic considerations in CPGs. Interdisciplinary collaboration between health economists and CPG developers could be beneficial to developing such approaches and tools. Furthermore, CPG (development) training programs addressing the importance of value-based healthcare could enhance the awareness and acceptance of economic considerations in CPGs, which is needed at the micro, meso and macro level. Additionally, specific training on economic basic concepts and how economic evidence could be considered during CPG development might help CPG developers realise the incorporation of economic considerations in CPGs.

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Appendix 1: Full search strains for the consulted databases

Appendix table 1. Search strain for database Embase (Ovid) and corresponding results.

Search Iteration	Query Run 15-07-2022 Run 24-11-2023	Results 15-07-2022	Results 24-11-2023
1	*practice guideline/ or guideline.pt. or (guideline* adj1 topic).ab,ti,kf. or "practice guideline*".ti,ab,kf. or (cpg adj1 guidel*).ti,ab,kf. or ("guideline develop*" or "guidelines develop*" or "health guideline*" or "healthcare guideline*" or "clinical guidance document*").ti,ab,kf. or ("clinical guidance" adj1 develop*).ti,ab,kf. or ("guidelines methodology" or "guideline methodology").ti,ab,kf. or methology.ti,kf.	126,475 (127,133)	n.s.
2	health economics/ or exp economic evaluation/ or exp health care cost/ or exp pharmacoeconomics/ or exp fee/ or budget/ or (economic* or pharmacoeconomic* or cost* or price* or pricing* or budget*).ab,ti,kf. or (value adj2 (money or monetary*)).ab,ti,kf. or (expenditure not energy not ((metabolic or energy or oxygen) adj1 cost*)).ab,ti,kf. or ("health economics" or "healthcare expenditure" or "health technology assessment" or HTA).ab,ti,kf. or RUC.ab,ti,kf.	1,714,495 (1,720,494)	n.s.
3	1 and 2	15,613	n.s.
4	limit 3 to yr="2017 -Current"	5,849	n.s.
5	limit 4 to (dutch or english)	5,783	n.s.
6	5 and "cost".mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	3,598	n.s.
7	5 and medical.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	2,081	n.s.
8	6 or 7	4,425	n.s.
9	limit 8 to (clinical trial or randomized controlled trial or controlled clinical trial or multicenter study or phase 1 clinical trial or phase 2 clinical trial or phase 3 clinical trial or phase 4 clinical trial)	279	n.s.

Appendix table 1. Continued

Search Iteration	Query Run 15-07-2022	 Run 24-11-2023	Results 15-07-2022	Results 24-11-2023
10	8 NOT 9		4,416	n.s.
11	10 and practice guideline.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]		3,622	n.s.
12	11 and cost*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]		3,179	n.s.
13	12 and develop*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]		1,057	324 via updates

Appendix table 2. Search strain for database Medline (Ovid) and corresponding results.

Search Iteration	Query Run 15-07-2022	 Run 24-11-2023	Results 15-07-2022	Results 24-11-2023
1	"Practice guidelines as topic"/ or "Guidelines as topic"/ or guideline.pt. or (guideline* adj1 topic).ab,ti,kf. or "practice guideline*".ti,ab,kf. or (cpg adj1 guidel*).ti,ab,kf. or ("guideline develop*" or "guidelines develop*" or "health guideline*" or "healthcare guideline*" or "clinical guidance document*").ti,ab,kf. or ("clinical guidance" adj1 develop*).ti,ab,kf. or ("guidelines methodology" or "guideline methodology").ti,ab,kf. or methology.ti,kf.		203,024	n.s.
2	((exp "costs and cost analysis"/ or economics/ or exp economics, hospital/ or exp economics, medical/ or exp economics, nursing/ or exp economics, pharmaceutical/ or exp "fees and charges"/ or exp budgets/ or ec.fs. or (economic* or pharmacoeconomic* or price* or pricing* or cost* or budget*).ti,ab,kf. or (value adj2 (money or monetary)).ti,ab,kf. or (expenditure not energy).ti,ab,kf.) not ((metabolic or energy or oxygen) adj1 cost$).ti,ab,kf.) or ("health economics" or "healthcare expenditure" or "health technology assessment" or HTA).ab,ti,kf. or RUC.ab,ti,kf.		1,154,760	n.s.

Appendix table 2. Continued

Search Iteration	Query Run 15-07-2022	Run 24-11-2023	Results 15-07-2022	Results 24-11-2023
3	1 and 2		20,572	n.s.
4	limit 3 to yr="2017 - Current"		3,915	n.s.
5	limit 4 to (dutch or english)		3,781	n.s.
6	5 and cost.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]		1,920	n.s.
7	5 and medical.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]		1,059	n.s.
8	6 or 7		2,471	n.s.
9	limit 8 to (adaptive clinical trial or clinical study or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial, veterinary or clinical trial protocol or clinical trial or controlled clinical trial or randomized controlled trial or randomized controlled trial, veterinary)		106	n.s.
10	8 NOT 9		2,365	n.s.
11	10 and (guideline or practice guideline).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]		793	n.s.
12	11 and develop*		349	139 via updates

Appendix table 3. Search strain for database Medline (Pubmed) and corresponding results.

Search Iteration	Query		Results 15-07-2022	Results 24-11-2023
	Run 15-07-2022	**Run 24-11-2023**		
1	Search: "Practice guidelines as topic"[Mesh] OR "Guidelines as topic"[Mesh] OR "Guideline"[Publication type] OR "guidelines as topic"[TW] OR "guideline as topic"[TW] OR practice guideline*[TW] OR (cpg[TW] AND guidel*[TW]) OR guideline develop*[TW] OR guidelines develop*[TW] OR health guideline*[TW] OR healthcare guideline*[TW] OR clinical guidance document*[TW] OR ("clinical guidance"[TW] AND develop*[TW]) OR "guidelines methodology"[TW] OR "guideline methodology"[TW] OR methology[TW] Sort by: Most Recent		227.533	233.101
2	Search: ("costs and cost analysis"[MeSH] OR "Economics"[Mesh:NoExp] OR "Economics, hospital"[Mesh] OR "Economics, nursing"[Mesh] OR "Economics, pharmaceutical"[Mesh] OR "Fees and charges"[Mesh] OR "Budgets"[Mesh] OR economics[Subheading] OR economic*[TW] OR pharmacoeconomic*[TW] OR price*[TW] OR pricing*[TW] OR cost*[TW] or budget*[TW] OR (value[TW] AND (money[TW] OR monetary[TW])) OR (expenditure[TW] NOT energy[TW]) NOT ((metabolic[TW] OR energy[TW] OR oxygen[TW]) AND cost*[TW]) OR "health economics"[TW] OR "healthcare expenditure"[TW] OR "Technology, High-Cost"[Mesh] OR "health technology assessment"[TW] OR HTA[TW] OR ("resource use"[TW] AND cost*[TW]) OR RUC[TW]) Sort by: Most Recent		1.311.980	1.434.268
3	Search: #1 AND #2 Sort by: Most Recent		22,095	22.551
4	Search: #3 AND (2017[pdat]:2022[pdat]) Sort by: Most Recent	Search: #3 AND (2022[pdat]:2023[pdat]) Sort by: Most Recent	4,512	731
5	Search: #4 NOT (Clinical Trial[Publication Type] OR Randomized Controlled Trial[Publication Type])		4,433	719
6	Search #5 Filter: Dutch, English		4,254	703
7	Search #6 AND NCBI Filter: cost*		3,089	148
8	Search #6 AND NCBI Filter: cost* AND guideline		2,554	65
9	Search #6 AND NCBI Filter: cost* AND guideline AND (medicine OR medical)		2,093	136
	Search #6 AND NCBI Filter: cost* AND guideline AND (medicine OR medical) AND develop*		859	33

Appendix table 4. Search strain for database Cochrane and corresponding results.

Search Iteration	Query		Results	Results
	Run 15-07-2022	Run 24-11-2023	15-07-2022	24-11-2023
1	(guideline* NEAR/1 topic):ab,ti or "practice guideline*":ab,ti or (cpg NEAR/1 guidel*):ab,ti or ("guideline develop*" or "guidelines develop*" or "health guideline*" or "healthcare guideline*" or "clinical guidance document*"):ab,ti or ("clinical guidance" NEAR/1 develop*):ab,ti or ("guidelines methodology" or "guideline methodology"):ab,ti or methology:ti	(guideline* NEAR/1 topic):ab,ti or (practice NEXT guideline*):ab,ti or (cpg NEAR/1 guidel*):ab,ti or (guideline NEXT develop*) or (guidelines NEXT develop*) or (health NEXT guideline*) or (healthcare NEXT guideline*) or (clinical NEXT guidance NEXT document*):ab,ti or (clinical NEXT guidance NEAR/1 develop*):ab,ti or (guidelines NEXT methodology) or (guideline NEXT methodology):ab,ti or methology:ti	524 (525)	4362
2	(economic* or pharmacoeconomic* or price* or pricing* or cost* or budget*):ab,ti or (value NEAR/2 (money or monetary)):ab,ti or (expenditure not energy):ab,ti or ("health economics" or "healthcare expenditure" or "health technology assessment" or HTA):ab,ti or RUC:ab,ti	(economic* or pharmacoeconomic* or price* or pricing* or cost* or budget*):ab,ti or (value NEAR/2 (money or monetary)):ab,ti or (expenditure not energy):ab,ti or ("health economics" or "healthcare expenditure" or "health technology assessment" or HTA):ab,ti or RUC:ab,ti	86.145	97.961
3	#1 AND #2		93	857
4	#1 AND #2 with Cochrane Library publication date Between Jan 2017 and Jun 2022		60	573
5	#4 in Cochrane Reviews, Cochrane Protocols, Clinical Answers, Editorials and Special Collections		1	143
6		#5 (Limits: date from July 2022 to December 2023)		5

Appendix table 5. Search strain for database Google Scholar and corresponding results.

Search Iteration	Query	Results 15-07-2022	Results 24-11-2023
	Run 15-07-2022 **Run 24-11-2023**		
1	("guideline* as topic"|"practice guideline as topic"|"practice guideline"|(cpg guidel*)|"guideline development") (cost|economic|pharmacoeconomic|price|budget|expenditure|"health technology assessment"|hta|ruc)	296 (From 2017)	78 (from 2022)
2	Limited to the first 200 articles	200	
3	Search #2 Language: Dutch or English (picked by hand)	193	

Appendix table 6. Search strain for database International HTA Database (INHTA)) and corresponding results.

Search Iteration	Query	Results 15-07-2022	Results 24-11-2023
	Run 15-07-2022 **Run 24-11-2023**		
1	(("Guidelines as Topic"[mh]) OR ("Practice guidelines as Topic"[mh]) OR ("practice guideline*" or cpg or "guideline develop*" or "guidelines develop*" or "health guideline*" or "healthcare guideline*" or "clinical guidance document*" or "clinical guidance" or "guidelines methodology" or "guideline methodology") Year 2017 TO 2022	89	38
2	#1 Language Dutch & English	21	7

Appendix table 7. Search strain for database NHSEED, HTA and corresponding results.

Search Iteration	Query	Results 15-07-2022	Results 24-11-2023
	Run 15-07-2022 **Run 24-11-2023**		
1	(practice guideline* or cpg or guideline develop* or guidelines develop* or health guideline* or healthcare guideline* or clinical guidance document* or clinical guidance or guidelines methodology or guideline methodology). FROM 2017 TO 2022	36	0
2	Language and de-deduplication	4	

Appendix table 8. Search strain for database Web of Science Core Collection and corresponding results.

Search Iteration	Query
	Run 15-07-2022
1	TS=((guideline* NEAR/1 topic) or "practice guideline*" or (cpg NEAR/1 guidel*) or ("guideline develop*" or "guidelines develop*" or "health guideline*" or "healthcare guideline*" or "clinical guidance document*") or ("clinical guidance" NEAR/1 develop*) or ("guidelines methodology" or "guideline methodology"))
2	TS=((economic* or pharmacoeconomic* or price* or pricing* or cost* or budget*) or (value NEAR/2 (money or monetary)) or (expenditure not energy) or ("health economics" or "healthcare expenditure" or "health technology assessment" or HTA) or RUC)
3	#2 AND #1
4	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years)
5	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years) and English (Languages)
6	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years) and English (Languages) and Computer Science Information Systems or Computer Science Interdisciplinary Applications or Computer Science Artificial Intelligence or Mathematical Computational Biology or Computer Science Cybernetics or Computer Science Hardware Architecture or Computer Science Software Engineering or Computer Science Theory Methods or Biotechnology Applied Microbiology or Biochemistry Molecular Biology or Microbiology or Social Sciences Biomedical or Reproductive Biology or Cell Biology or Engineering Biomedical or Biochemical Research Methods or Biophysics or Biodiversity Conservation or Developmental Biology or Marine Freshwater Biology or Physics Applied or Physics Fluids Plasmas or Acoustics or Engineering Electrical Electronic or Engineering Environmental or Engineering Civil or Engineering Industrial or Engineering Chemical or Engineering Mechanical or Cell Tissue Engineering or Engineering Multidisciplinary or Engineering Geological or Engineering Manufacturing or Engineering Ocean or Metallurgy Metallurgical Engineering or Social Work or Telecommunications or Food Science Technology or Art or Thermodynamics or Transportation Science Technology or Transportation or Nuclear Science Technology or Water Resources or Plant Sciences or Regional Urban Planning or Archaeology or Architecture or Construction Building Technology or Mechanics or Family Studies or Geography or Entomology or Environmental Sciences or Environmental Studies or Chemistry Applied or Chemistry Multidisciplinary or Chemistry Organic or Electrochemistry or Chemistry Analytical or Law or Agriculture Multidisciplinary or Behavioral Sciences or Imaging Science Photographic Technology or Women S Studies or Urban Studies or Religion or Energy Fuels or Ecology or Parasitology or Business or Business Finance or Public Administration (Exclude – Web of Science Categories)

		Results 15-07-2022	Results 24-11-2023
Run 24-11-2023			
		54,208	60.476
		3,446,141	3.855.975
		6,172	6.746
#2 AND #1 AND DOP=(2022-07-15/2023-11-24)		2,580	594
#4 AND DOP=(2022-07-15/2023-11-24) AND LA=(English)		2,514	588
(#4) AND DOP=(2022-07-15/2023-11-24)) AND LA=(English) and	Computer Science Information Systems or Computer Science Hardware Architecture or Mathematical Computational Biology or Engineering Electrical Electronic or Engineering Geological or Engineering Biomedical or Engineering Civil or Biochemistry Molecular Biology or Biophysics or Biotechnology Applied Microbiology or Marine Freshwater Biology or Psychology Biologicalor Materials Science Biomaterials or Reproductive Biology or Biologyor Microbiology or Social Sciences Biomedical or Geography or Physics Applied or Regional Urban Planning or Mathematics Interdisciplinary Applications or Social Sciences Interdisciplinary or Chemistry Multidisciplinary or Geosciences Multidisciplinary or Social Work or Telecommunications or Water Resources or Chemistry Inorganic Nuclear or Nuclear Science Technology or Family Studies or Environmental Sciences or Construction Building Technology or Ecology or Energy Fuels or Hospitality Leisure Sport Tourism or International Relations or Law or Management or Meteorology Atmospheric Sciences or Nanoscience Nanotechnology or Political Science or Spectroscopy or Sport Sciences or Zoology or Soil Science(Exclude – Web of Science Categories)	2,336	526

Appendix table 8. Continued

Search Iteration	Query
7	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years) and English (Languages) and Computer Science Information Systems or Computer Science Interdisciplinary Applications or Computer Science Artificial Intelligence or Mathematical Computational Biology or Computer Science Cybernetics or Computer Science Hardware Architecture or Computer Science Software Engineering or Computer Science Theory Methods or Biotechnology Applied Microbiology or Biochemistry Molecular Biology or Microbiology or Social Sciences Biomedical or Reproductive Biology or Cell Biology or Engineering Biomedical or Biochemical Research Methods or Biophysics or Biodiversity Conservation or Developmental Biology or Marine Freshwater Biology or Physics Applied or Physics Fluids Plasmas or Acoustics or Engineering Electrical Electronic or Engineering Environmental or Engineering Civil or Engineering Industrial or Engineering Chemical or Engineering Mechanical or Cell Tissue Engineering or Engineering Multidisciplinary or Engineering Geological or Engineering Manufacturing or Engineering Ocean or Metallurgy Metallurgical Engineering or Social Work or Telecommunications or Food Science Technology or Art or Thermodynamics or Transportation Science Technology or Transportation or Nuclear Science Technology or Water Resources or Plant Sciences or Regional Urban Planning or Archaeology or Architecture or Construction Building Technology or Mechanics or Family Studies or Geography or Entomology or Environmental Sciences or Environmental Studies or Chemistry Applied or Chemistry Multidisciplinary or Chemistry Organic or Electrochemistry or Chemistry Analytical or Law or Agriculture Multidisciplinary or Behavioral Sciences or Imaging Science Photographic Technology or Women S Studies or Urban Studies or Religion or Energy Fuels or Ecology or Parasitology or Business or Business Finance or Public Administration (Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields)

	Results 15-07-2022	Results 24-11-2023
(#4) AND DOP=(2022-07-15/2023-11-24)) AND LA=(English) and Computer Science Information Systems or Computer Science Hardware Architecture or Mathematical Computational Biology or Engineering Electrical Electronic or Engineering Geological or Engineering Biomedical or Engineering Civil or Biochemistry Molecular Biology or Biophysics or Biotechnology Applied Microbiology or Marine Freshwater Biology or Psychology Biologicalor Materials Science Biomaterials or Reproductive Biology or Biologyor Microbiology or Social Sciences Biomedical or Geography or Physics Applied or Regional Urban Planning or Mathematics Interdisciplinary Applications or Social Sciences Interdisciplinary or Chemistry Multidisciplinary or Geosciences Multidisciplinary or Social Work or Telecommunications or Water Resources or Chemistry Inorganic Nuclear or Nuclear Science Technology or Family Studies or Environmental Sciences or Construction Building Technology or Ecology or Energy Fuels or Hospitality Leisure Sport Tourism or International Relations or Law or Management or Meteorology Atmospheric Sciences or Nanoscience Nanotechnology or Political Science or Spectroscopy or Sport Sciences or Zoology or Soil Science(Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields)	958	222

Appendix table 8. Continued

Search Iteration	Query
8	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years) and English (Languages) and Computer Science Information Systems or Computer Science Interdisciplinary Applications or Computer Science Artificial Intelligence or Mathematical Computational Biology or Computer Science Cybernetics or Computer Science Hardware Architecture or Computer Science Software Engineering or Computer Science Theory Methods or Biotechnology Applied Microbiology or Biochemistry Molecular Biology or Microbiology or Social Sciences Biomedical or Reproductive Biology or Cell Biology or Engineering Biomedical or Biochemical Research Methods or Biophysics or Biodiversity Conservation or Developmental Biology or Marine Freshwater Biology or Physics Applied or Physics Fluids Plasmas or Acoustics or Engineering Electrical Electronic or Engineering Environmental or Engineering Civil or Engineering Industrial or Engineering Chemical or Engineering Mechanical or Cell Tissue Engineering or Engineering Multidisciplinary or Engineering Geological or Engineering Manufacturing or Engineering Ocean or Metallurgy Metallurgical Engineering or Social Work or Telecommunications or Food Science Technology or Art or Thermodynamics or Transportation Science Technology or Transportation or Nuclear Science Technology or Water Resources or Plant Sciences or Regional Urban Planning or Archaeology or Architecture or Construction Building Technology or Mechanics or Family Studies or Geography or Entomology or Environmental Sciences or Environmental Studies or Chemistry Applied or Chemistry Multidisciplinary or Chemistry Organic or Electrochemistry or Chemistry Analytical or Law or Agriculture Multidisciplinary or Behavioral Sciences or Imaging Science Photographic Technology or Women S Studies or Urban Studies or Religion or Energy Fuels or Ecology or Parasitology or Business or Business Finance or Public Administration (Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields) and Cost* (Search within all fields)

	Results 15-07-2022	Results 24-11-2023
(#4) AND DOP=(2022-07-15/2023-11-24)) AND LA=(English) and Computer Science Information Systems or Computer Science Hardware Architecture or Mathematical Computational Biology or Engineering Electrical Electronic or Engineering Geological or Engineering Biomedical or Engineering Civil or Biochemistry Molecular Biology or Biophysics or Biotechnology Applied Microbiology or Marine Freshwater Biology or Psychology Biologicalor Materials Science Biomaterials or Reproductive Biology or Biologyor Microbiology or Social Sciences Biomedical or Geography or Physics Applied or Regional Urban Planning or Mathematics Interdisciplinary Applications or Social Sciences Interdisciplinary or Chemistry Multidisciplinary or Geosciences Multidisciplinary or Social Work or Telecommunications or Water Resources or Chemistry Inorganic Nuclear or Nuclear Science Technology or Family Studies or Environmental Sciences or Construction Building Technology or Ecology or Energy Fuels or Hospitality Leisure Sport Tourism or International Relations or Law or Management or Meteorology Atmospheric Sciences or Nanoscience Nanotechnology or Political Science or Spectroscopy or Sport Sciences or Zoology or Soil Science(Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields) and Cost* (Search within all fields)	768	164

Appendix table 8. Continued

Search Iteration	Query
9	#2 AND #1 and 2022 or 2021 or 2020 or 2019 or 2018 or 2017 (Publication Years) and English (Languages) and Computer Science Information Systems or Computer Science Interdisciplinary Applications or Computer Science Artificial Intelligence or Mathematical Computational Biology or Computer Science Cybernetics or Computer Science Hardware Architecture or Computer Science Software Engineering or Computer Science Theory Methods or Biotechnology Applied Microbiology or Biochemistry Molecular Biology or Microbiology or Social Sciences Biomedical or Reproductive Biology or Cell Biology or Engineering Biomedical or Biochemical Research Methods or Biophysics or Biodiversity Conservation or Developmental Biology or Marine Freshwater Biology or Physics Applied or Physics Fluids Plasmas or Acoustics or Engineering Electrical Electronic or Engineering Environmental or Engineering Civil or Engineering Industrial or Engineering Chemical or Engineering Mechanical or Cell Tissue Engineering or Engineering Multidisciplinary or Engineering Geological or Engineering Manufacturing or Engineering Ocean or Metallurgy Metallurgical Engineering or Social Work or Telecommunications or Food Science Technology or Art or Thermodynamics or Transportation Science Technology or Transportation or Nuclear Science Technology or Water Resources or Plant Sciences or Regional Urban Planning or Archaeology or Architecture or Construction Building Technology or Mechanics or Family Studies or Geography or Entomology or Environmental Sciences or Environmental Studies or Chemistry Applied or Chemistry Multidisciplinary or Chemistry Organic or Electrochemistry or Chemistry Analytical or Law or Agriculture Multidisciplinary or Behavioral Sciences or Imaging Science Photographic Technology or Women S Studies or Urban Studies or Religion or Energy Fuels or Ecology or Parasitology or Business or Business Finance or Public Administration (Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields) and Cost* (Search within all fields) and Develop*

	Results 15-07-2022	Results 24-11-2023
(#4) AND DOP=(2022-07-15/2023-11-24)) AND LA=(English) and Computer Science Information Systems or Computer Science Hardware Architecture or Mathematical Computational Biology or Engineering Electrical Electronic or Engineering Geological or Engineering Biomedical or Engineering Civil or Biochemistry Molecular Biology or Biophysics or Biotechnology Applied Microbiology or Marine Freshwater Biology or Psychology Biologicalor Materials Science Biomaterials or Reproductive Biology or Biologyor Microbiology or Social Sciences Biomedical or Geography or Physics Applied or Regional Urban Planning or Mathematics Interdisciplinary Applications or Social Sciences Interdisciplinary or Chemistry Multidisciplinary or Geosciences Multidisciplinary or Social Work or Telecommunications or Water Resources or Chemistry Inorganic Nuclear or Nuclear Science Technology or Family Studies or Environmental Sciences or Construction Building Technology or Ecology or Energy Fuels or Hospitality Leisure Sport Tourism or International Relations or Law or Management or Meteorology Atmospheric Sciences or Nanoscience Nanotechnology or Political Science or Spectroscopy or Sport Sciences or Zoology or Soil Science(Exclude – Web of Science Categories) and Guideline Or Practice Guideline (Search within all fields) and Cost* (Search within all fields) and Develop* (Search within all fields)	431	87

Appendix 2: Terminology

Appendix table 9. Talking about economic considerations in clinical practice guidelines. In the included reports, different economic terms and methods are used to refer to 'economic considerations' in CPGs. Terms are presented as reported by the authors of the included documents and reported alphabetically, along with the number of documents each term appeared in (*N*).

Term	n	Term	n
benefit-risk analysis	1	cost-effectiveness model: microsimulation model	2
budget impact	3	cost-effectiveness model(ing)	5
cost analysis	5	cost-effectiveness studies	5
cost and benefit evidence	1	cost-efficiency	2
cost-to-benefit ratio	1	cost-efficient	1
costs and benefits ratio	1	cost-minimization	1
costs and benefits value	1	cost-utility	4
cost and cost-effectiveness Likert-type judgments	1	cost-utility analysis	2
cost and resource implications	1	cost(s)	5
cost and value	1	cost(s) (of)	21
cost and value considerations	1	cost/value	1
cost consequence	2	cost/value citations	1
cost considerations	3	cost/value considerations	1
cost evidence	1	cost/value content	1
cost implications	1	cost/value data	1
cost information	2	cost/value evidence	2
cost literature	1	cost/value issues	1
cost modelling	1	cost/value methodology	2
cost of preventing an event (COPE)	1	cost/value statements	2
cost to benefits	1	cost/value studies	1
cost-benefit or cost/benefit	5	cost/value-related issues	1
cost-benefit analysis (CBA)	4	costs/burdens	1
cost-benefit ratio	2	discounting	2
cost-effectiveness or cost/effectiveness	23	economic analyses	2
cost-effectiveness data	3	economic arguments	1
cost-effectiveness (literature) review	2	economic aspects	1
cost-effectiveness analysis (CEA)	12	economic assessment	1
cost-effectiveness analysis (CEA) data	2	economic consequences	2

Term	n	Term	n
economic factors	1	markov cohort model or Markov process: cohort simulation	2
economic free text information	1	markov process	1
economic impact (statements)	2	markov process: Monte Carl simulation	1
economic implications	1	model-based economic evaluation	2
economic information	4	model-based economic studies	1
economic issues	1	multi-criteria decision analysis	1
economic justification (information)	1	net-monetary-benefit	1
economic literature	1	opportunity costs	5
economic methodologies	1	QALY comparison	1
economic model(ing)	5	resource allocation	4
financial consequence	1	resource and cost considerations	1
financial considerations	2	resource aspects	1
financial costs	1	resource considerations	1
financial impact	1	resource consumptions	1
financial implications	2	resource impact assessment	1
financial resources	1	resource implications	4
full economic evaluation	2	resource required	3
full incremental analysis	1	resource requirements	2
health economic analysis	2	resource use	11
Health economic assessment	1	resource use and costs	2
health economic considerations	1	resource use estimation and methodology	1
health economic evaluation	4	resource utilization	1
health economic evidence	2	resource utilization data	1
health economic model(ing)	2	resources	8
health economic review	1	scoping review cost-effectiveness evidence	1
health economic studies	1	systematic review including health economic studies	1
health economic thresholds	1	technology appraisals	1
health economics	1	trial-based economic evaluation	1

Appendix table 9. Continued

Term	n	Term	n
cost-effectiveness (analysis) evidence	3	economic considerations	4
cost-effectiveness (analysis) thresholds	2	economic data	6
cost-effectiveness calculations	1	economic evaluation	8
cost-effectiveness considerations	1	economic evidence	7
cost-effectiveness information	1	economic evidence profile	1
cost-effectiveness literature	1	economic evidence review	1

Appendix 3: Final data extraction form

Appendix table 10. Data extraction format.

Characteristics	Categories
Author	
Year	
Title	
Journal	
Type of Publication	Quantitative, qualitative
Location (study)	
Location (first author)	
Conflict of interest	Declared (as reported by the author), Declared None, NA
Challenges	
Discourse surrounding incorporation of economic considerations CPGs	As reported by the authors
Methodological ambiguities	As reported by the authors
Scarcity of economic evidence	As reported by the authors

Term	n	Term	n
health technology appraisals	1	trial-based economic studies	1
health technology assessment methods	1	value-based judgements	1
incremental cost effectiveness ratio (ICER) analyses	1	value-based recommendations	2
Incremental cost-effectiveness ratio (ICER)	5		
incremental costs	3		
incremental (net)-benefit	2		

	Defined as
	The type of article was described as reported by the authors. This investigation categorised them then as quantitative or qualitative in origin.
	City, country, continent
	City, country, continent
	There are various views on whether economic consideration should be incorporated in clinical practice guidelines. This investigation was open to all views on the incorporation of economic considerations in clinical practice guidelines.
	The challenge 'methodological ambiguities' was two-folded. First, ambiguity concerning the method of incorporating economic considerations in clinical practice guidelines. Second, methodological challenges concerning economic evaluation studies. This investigation was open to any challenges related to methods for economic consideration incorporation or economic evaluations.
	The incorporation if economic considerations require economic evidence. This investigation was open to any referral to a lack of (any type) of economic evidence (e.g. economic evaluation studies).

Appendix table 10. Continued

Characteristics	Categories
Transferability of evidence	As reported by the authors
Resource constraints	As reported by the authors
Potential stimulating factors	
Acceptance and intent	As reported by the authors
Enhancing knowledge on what evidence to consider for economic considerations in CPGs	As reported by the authors
Guidance on how to incorporate economic considerations in CPGs	As reported by the authors

	Defined as
	Transferability of evidence refers to if results from one area could be used in another area. Within the clinical practice guideline field this is referred to as the indirectness of evidence. This investigation was open to any statement concerning transferability of indirectness of economic evidence.
	The development of clinical practice guidelines requires resources. This investigation was open to any statement concerning limitations in any type of resource (e.g. time, finances or expertise) for clinical practice guideline development.
	To establish the incorporation of economic considerations into clinical practice guidelines requires acceptance and intent of clinical practice guideline developing organisations. This investigation was open to any positive reference related to the embrace of economic considerations in clinical practice guidelines.
	To establish the incorporation of economic considerations in clinical practice guidelines it must be known what economic evidence could be considered. This investigation was open to any statement describing what type of economic evidence could be considered in clinical practice guidelines.
	Clinical practice guideline developers need guidance on how to incorporate economic considerations in clinical practice guidelines. This article was open to any type of positive suggestion on guidance (e.g. methodological or by collaborations with health economist) to the incorporation of economic considerations in clinical practice guidelines.



Chapter 4

‘We are the engine’: A focus group study on clinical practice guideline development with European patient advocates for rare congenital malformations and/or intellectual disability



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Abstract

Background: Individuals living with rare congenital malformations and/or intellectual disability often face challenges in accessing appropriate healthcare. Clinical practice guidelines (CPGs) may serve as a tool to provide evidence-based care for rare diseases, but their development is complex, and the views of affected individuals and families often remain unknown.

Methods: Patient advocates of the European Reference Network ITHACA (Intellectual disability, Telehealth, Autism and Congenital Anomalies) participated in focus groups in which their experiences with and perspectives on CPG use and development were discussed.

Results: Patient advocates considered CPGs relevant to address information and care needs and support advocacy efforts. Important characteristics included representation of heterogeneity within conditions, a holistic approach in which and how topics are addressed, user-friendly availability for individuals and families, and reliability of information. Guideline development and implementation were described as challenging, iterative processes in which effective partnership between clinicians, patient advocates, and other stakeholders is essential.

Conclusions: Understanding the perspectives of patient advocates is essential to develop CPGs that meet the life-long and complex care needs of individuals and families living with rare conditions. Identified challenges include balancing the urgency of information needs with thorough guideline development processes, as well as the integration and interpretation of different types of knowledge.

Background

Individuals with rare conditions, such as rare congenital malformations and/or intellectual disability, often face long diagnostic journeys and unmet healthcare needs [140]. Healthcare professionals may lack the knowledge to manage these rare and complex conditions effectively. European Reference Networks (ERNs) have been established as virtual networks of healthcare providers to facilitate collaboration and improve care for rare diseases across Europe [141]. The development and implementation of guidelines are an important pillar of the ERNs to standardize quality of care and treatment, ensuring that it is effective, efficient, and people-centred [140, 141].

Clinical practice guidelines (CPGs) provide evidence-based recommendations to guide clinical decision-making and support healthcare professionals in providing optimal care. CPGs are developed by expert panels through systematic approaches. Recognition of patient involvement in guideline development is increasing, driven by political-ethical demands for patients to be included on a more equal level in health policy; moreover, patient involvement is thought to increase the relevance and applicability of guidelines by drawing attention to aspects that matter in daily life [41].

Currently, there is no standard approach for patient involvement in CPGs [40, 41]. Empirical evidence suggests that patient participation in CPG development does not necessarily result in more patient-centred guidelines [89, 142]. Still, few studies have explored the opinions and experiences of patient advocates concerning guidelines [80, 143], and it is unknown whether these results are transferable to rare disease contexts.

The development of CPGs for rare diseases poses notable challenges, due to a limited evidence base and small numbers of experts. In this context, persons living with rare conditions may contribute valuable insights into the challenges they face and potential solutions of which healthcare professionals might not be aware. As individuals and families often play active roles in orchestrating care in rare disease settings [144, 145], they are also important guideline end-users.

In this qualitative focus group study, experiences with and perspectives on the use and development of CPGs among patient advocates involved with ERN-ITHACA (Intellectual disability, TeleHealth, Autism and Congenital Anomalies) on Rare Congenital Malformations and Rare Intellectual Disability were explored. The

study describes (1) the relevance of CPGs to individuals and families living with rare congenital malformations and/or intellectual disability, (2) guideline characteristics that patient advocates consider important, and (3) their experiences and opinions on involvement in the guideline development process.

Methods

Study population and recruitment

The study population consists of the rare disease association representatives in the ERN-ITHACA Patient Council in the scope of rare (multiple) malformation syndromes and rare intellectual and other neurodevelopmental disorders of genetic, genomic/chromosomal or environmental origin, both diagnosed and undiagnosed. As appointed European Patient Advocacy Groups (ePAG) advocates, they represent the voices and interests of their patient community as a whole and have a mandate to represent their member organizations within the ERNs. These include organizations for conditions such as the 22q11.2 deletion, AGO2, Angelman, Coffin-Lowry, Cornelia de Lange, CTNNB1, Kleefstra, Noonan, Pitt-Hopkins, Prader-Willi, SATB2-associated, and Williams syndromes, KIF1A-associated neurodegenerative disorder, CDKL5 deficiency disorder, and spina bifida and hydrocephalus, as well as broader rare disease and/or intellectual disability groups. Patient representatives present at the annual ERN-ITHACA Board Meeting were invited to join during the meeting; all Patient Council members were invited through email.

Data collection

Data was collected through in-person and online focus groups moderated by M.K. and C.G., who both received prior training in interviewing techniques. The focus group guide (Supplementary data) was developed through discussions among the full research team and consisted of broad, open-ended questions to explore experiences and opinions regarding (1) using guidelines and (2) developing guidelines. The order of these two main topics was alternated between group discussions.

In-person focus groups were organized during the annual three-day ERN-ITHACA Board Meeting in Budapest in December 2022, after a brief presentation in which M.K. introduced herself and described ongoing CPG development efforts within the network. Two simultaneous focus groups with five and six participants respectively, lasting approximately 1,5 hours, were moderated by M.K. and C.G. in separate rooms at the meeting venue.

Three digital focus groups were organized to allow all ePAGs to participate and to further explore topics that arose in the two in-person discussions. These were conducted through Microsoft Teams in March 2023 with five, two, and three participants respectively, moderated by M.K. and lasting 1-1,5 hours. Although we aimed for four or five participants per online group, smaller sessions were also conducted to facilitate all interested patient representatives to participate in accordance with their professional and caregiver schedules.

Data analysis and reporting

Focus groups were audio recorded and transcribed verbatim; for digital focus groups, video recordings were available. Thematic analysis was conducted inductively. The analytic approach was based on the six-step approach of Braun and Clarke [146]: (1) familiarization with the data through reading and rereading; (2) generating initial, descriptive codes from the data; (3) grouping similar codes into potential themes to identify patterns in the data; (4) reviewing the data to refine the themes as necessary; (5) defining and naming the themes; and (6) presenting the findings by describing the themes, supported by quotations from all focus groups. MAXQDA 2020 software was used to manage and analyse the data [147].

Two researchers, M.K. and C.d.M., who had prior experience in qualitative data analysis, independently coded all focus groups. The initial themes were generated based on the two in-person focus groups. Subsequent digital focus groups were organized and coded iteratively until all interested ePAGs had participated. No new (sub)themes were identified in the last focus group, suggesting inductive thematic saturation [148]. The two researchers discussed the coding of each focus group until consensus was reached; emerging themes were discussed with all co-authors. Member checking was conducted by sharing a summary of the main themes and subthemes for commentary with all 21 participants through email, to which eleven participants responded. The overall thematic structure was confirmed by all respondents; six provided additional nuances that were integrated into the discussion and phrasing of the manuscript. The results of the focus group study were discussed at the Patient Workshop during the annual ERN-ITHACA Board Meeting in Dublin in December 2023. Consolidated criteria for reporting qualitative research (COREQ) guided the reporting of the study [38].

Research team and reflexivity

The study was planned and conducted by an interdisciplinary research team consisting of M.K. (PhD-researcher on guideline development, trained as a medical doctor and care ethicist), A.H. (ERN-ITHACA project manager with lived experience

as a parent, >30 years of active involvement in (inter)national patient advocacy, and experience in >25 rare disease guideline projects), M.C. (professor of community genetics and public health genomics), C.G. (ERN-ITHACA guideline methodologist with PhD in patient involvement in rare disease clinical trial design), and A.v.E. (ERN-ITHACA Guideline Working Group chair and intellectual disability physician). Data-analysis was conducted inductively by M.K. and C.d.M. (PhD-researcher on guideline development education, without involvement with ERN-ITHACA); during this process, the full research team discussed the themes and interpretations at different stages.

Results

Participant characteristics

In total, 21 participants joined the study. Five ePAGs did not participate; three did not have time due to the workload of managing national patient organizations and two did not respond to the invitations. One participant was a local patient representative attending the ERN-ITHACA Board Meeting who formally became an ePAG advocate after participation in the focus groups. Most participants were parents of a child with rare congenital malformations and/or intellectual disability; two participants were affected individuals. Participants came from 16 European countries; some had lived in multiple countries. All participants were active (board) members of associations representing rare diseases, intellectual disability, and/or specific conditions.

Research findings

Below is described (1) why CPGs matter to individuals and families living with rare congenital malformations and/or intellectual disability, followed by (2) which guideline characteristics patient advocates consider important and (3) patient advocate views on the guideline development process (Figure 1).

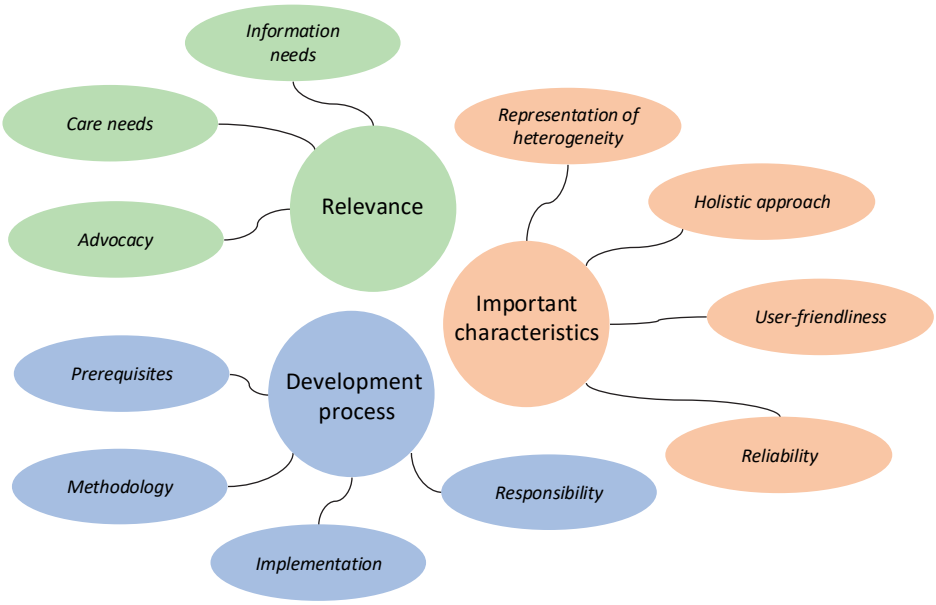

Figure 1. Themes with main subthemes.

Relevance of guidelines

Participants generally deemed guidelines important, describing their relevance with regard to (unmet) information and care needs as well as advocacy efforts (Figure 2). These needs were strongly intertwined: various participants described a need for information to actively demand care to address their (child's) needs.

> *"It is the most common thing, I would say, that patients ask us for, especially those who live (…) in countries, you know, like [in] eastern Europe (…) It is really, how can you get information to those families who are in severe lack of even a specialist doctor"* (P20)

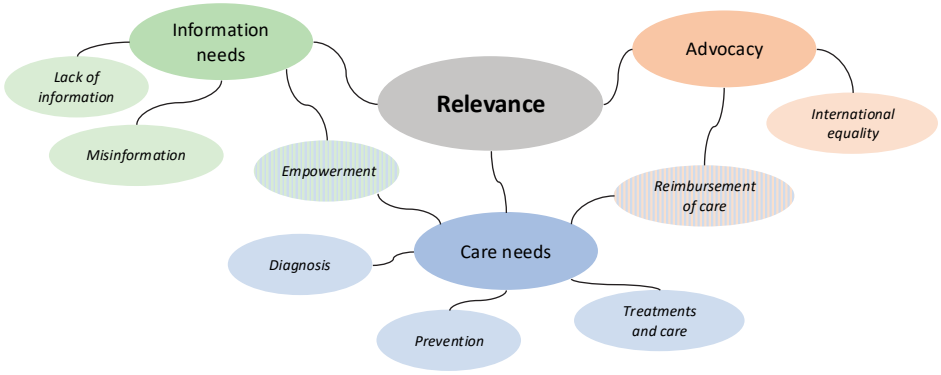

Figure 2. Relevance of clinical practice guidelines for individuals and families with rare conditions.

<u>*Information needs*</u> - Many participants described that being confronted with having (a child with) a rare condition brings uncertainty: "*Parents that have newly diagnosed children are always asking, what should I expect, how is going my child to develop*" (P8). Correct and comprehensive information about rare conditions may be difficult to find, and individuals and families often turn to each other in (online) support groups to share experiences. If available, guidelines may constitute a reliable information source. For example, one participant described referring to guidelines to moderate discussions in their support group:

> "*[In online] support groups, mainly Facebook, (…) different things are being said, and they are not necessarily correct, but for parents, that's the way it goes, there's this universe of information and when people hear it enough they think that's correct. Well, when I am able to say, the guidelines say or the consensus is, you know, it helps.*" (P6)

Additionally, guidelines represent a form of 'expert information', which is perceived as credible by the outside world. For example, one participant recounted the following interaction with their child's school: "*When I told the teacher not to do certain things, they would not listen, but when I brought some documents from clinicians, oh yes, that is something, so now we have to change*" (P5). Guidelines were described as "*useful for families to feel empowered*" (P10) as they can be used as reference documents in their contacts with healthcare professionals, social workers, and professionals in related fields. In this way, guidelines may support individuals and families in orchestrating care.

Care needs - Guidelines were described as helpful to address unmet care needs, including timely diagnosis, adequate treatment and follow-up, and reimbursement of care. For many conditions, there is a long diagnostic journey: "*Many people don't get to know the name of their disease in years* (…) *We had recently in our syndrome a girl diagnosed with 16 years old*" (P12). Participants suggested that guidelines might assist in receiving a diagnosis earlier, through raised awareness of rare diseases and indications for diagnostic testing. Guidelines might also contribute to appropriate treatment and follow-up, for example by setting a standard of care for all healthcare providers: "*We are visiting like three different hospitals* (…) *and each one of them will have [a] different specialist. So if you have like a general guideline, it would be easy for them to follow the same protocols*" (P17). Another reported purpose was early identification of and intervention for common comorbidities; for example, one participant explained how increasing scientific knowledge about their syndrome allows for preventative care:

> "*There is much more prevalence of psychiatric diseases* (…) *Researchers really did so much study for this syndrome in last twenty years, now we know much more* (…) *So, you check that, if it is not, okay, but if it is, you can do some things to prevent full-blown psychosis, for example,* (…) *you can introduce some pharmacotherapy or some psychotherapy.*" (P21)

Advocacy - Beyond the individual level, participants stated that guidelines support patient advocacy for better healthcare and social policy. Examples included recognition of rare conditions to receive social benefits and reimbursement of (para) medical therapies.

> "*If we have these guidelines* (…) *we can pursue more national, legal goals* (…) *For example, my child needs physiotherapy and speech therapy, one therapy per day, five days per week, then the government knows that they need to fund this amount of hours for this amount of children, but if there is no scientific proof that my child needs that, this need does not exist for the decision makers.*" (P8)

Guidelines were also mentioned as a tool for reducing international health disparities, as local patient groups might refer to the standard of care described in (international) guidelines to support their demands for better healthcare: *"If you go probably to South America and they see that they are not able to have kind of test, because the system they don't pay, they have some reason and some evidence what they can look for*" (P14).

Important characteristics

Representation of the heterogeneity of individuals, holistic approaches, presenting information in a user-friendly way, and providing reliable information were highlighted as requirements for guidelines to be useful to the patient community (Figure 3).

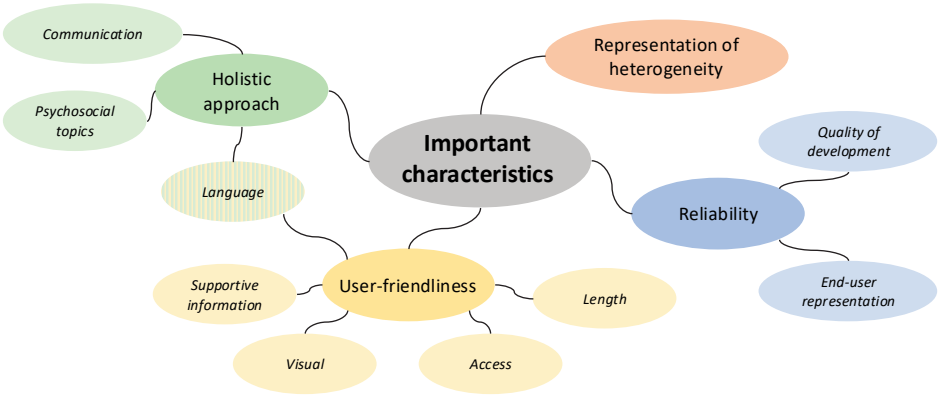

Figure 3. Important characteristics of clinical practice guidelines.

Representation of heterogeneity - Many participants stressed the importance of acknowledging the heterogeneity of manifestations within individuals with a particular condition in syndrome-specific guidelines. Phenotypic variability is common in genetic neurodevelopmental disorders, meaning that two individuals with the same condition may live different lives and have differing healthcare needs.

> *"We have mild, moderate and severe cases, (…) probably for all rare neurodevelopmental diseases this is the same, and all of the clinicians have to be aware of [these] unique Prader-Willi, unique Kleefstra, unique Rett patients (…) This exam, maybe it is not going to be applied for this unique person, because he is not experiencing [these] symptoms."* (P1)

Needs may also change throughout life, with different healthcare priorities per age and life phase. Various participants stated concerns about most expertise being centred on care for children, with a lack of knowledge regarding the transition to adult care and ageing:

> "*When it is a spectrum, it is very difficult to have one specific guideline to cover everything, especially when you have an aging group of people. Now, the paediatric guidelines are not working for me, for example. I need something else. And it is unfortunately not there.*" (P16)

Holistic approach - Participants highlighted that the life-long nature of these conditions and their varying needs in all areas of life emphasize the importance of a holistic approach: "*For our syndrome, that doesn't have a* (…) *pharmacological therapy, it is very important to look at the person as a whole and not a piece of them*" (P19). In this light, several participants disliked the term 'patient', as it refers to individuals based on their medical condition and does not recognize their identity beyond the diagnosis, but rather preferred the use of person-first language.

Living with a rare condition or disability was seen as intertwined with daily life, such that psychosocial topics including education, work, and relationships should be included in guidelines.

> "*A patient is, as all we are, human. We are very complex, and especially in terms of rare disease and* (…) *disabilities, non-functioning in some areas like school, work, social* (…) *relations* (…) *If the healthcare system is saying, I don't see all these other worlds, I want to focus in my world because I want to deliver good health for my patient, then the picture is not full.*" (P4)

Regarding the content and phrasing of recommendations, several participants referred to a "*life-disease balance*" (P4) between focusing on health outcomes and enjoying life: "*If [my child] has a little ice cream it will be okay, he will not die* (…) *The quality of life is what matters*" (P5). It was also suggested that strongly phrased recommendations could be experienced as stressful by caregivers: "*[When it] sounds imperative, it can make some parents very nervous, like am I not doing it right*" (P12).

User-friendliness - Participants considered individuals and families as active end-users, for whom guidelines must be made accessible and intelligible: "*If you have a patient [who isn't] so into medical language, they can read the lay version, but you should have the extra big one for those that like me want to know everything, every little ittybit*" (P15). Shorter summaries, easy-to-read text, and visual and/or video versions were suggested to improve the comprehensibility of guidelines. Free dissemination of both online and printed information was recommended. For international guidelines,

translations to national and local languages were mentioned as necessary. Finally, participants reported that guidelines should refer to further supportive information, such as contact information and websites of support groups and centres of expertise for the specific condition.

Reliability - Various participants, speaking as leaders of national family organizations, described the responsibility to their community to share reliable information: "*We feel responsible, as an association, all the information to be filtered, and of course checked with the doctors, in order to be sure that [it] is creditworthy and deserves to be communicated to the families*" (P11). Guideline reliability was seen as a necessity for its use: "*The quality is like, initial condition. The best possible or nothing*" (P4). Reliability of the guideline, derived from careful development in collaboration with all relevant experts, was also seen as a prerequisite for implementation: "*So it reflects expertise of the different groups, that also has a certain validity to it, so that that is adopted*" (P3).

Development process

The guideline development process was described with regard to its prerequisites, the employed methodology, implementation, and responsibilities for these processes (Figure 4).

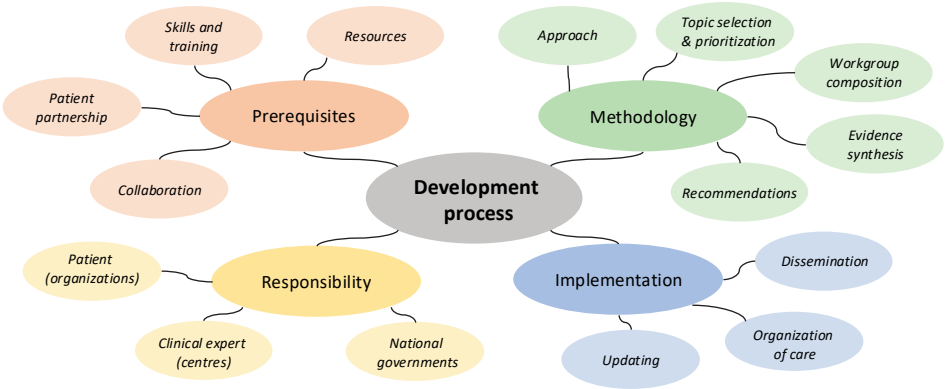

Figure 4. Development process of clinical practice guidelines.

Prerequisites - Several prerequisites for successful guideline development were discussed. These factors included collaboration on an international and multidisciplinary level, patient partnership, and having sufficient resources. Participants emphasized that guideline development for rare and complex conditions requires an inclusive approach involving clinical and scientific experts in various fields, affected individuals and families, and governance actors. The

participation of patient representatives as equal partners throughout the process was considered essential by all participants. The knowledge of families was seen as complementary to and equally valuable as clinical expertise:

> "*The perception of parents (…) is critical, but when we talk about pure clinical facts, the experts working with this kind of symptoms (…) have seen many cases, (…), [while] I don't have experienced further than my child (…) There [are] two parts, the clinical part which are facts that are supported by evidence, and then there is the part of prioritization for the parents (…) to be able to have a manageable family life, and these are two different perspectives.*" (P12)

The experiences of participants who had contributed to guideline development varied from being a valued partner in a successful project to being excluded from discussions or struggling to contribute effectively. Guidance and support were thought helpful to allow patient representatives to function optimally:

> "*I find it difficult to represent the whole community (…) There are very many manifestations and as representatives, we were two family members against (…) 18 or 20 specialists. Specialists all do a literature study for scientific proof. It might be an idea if (…) there would also be an analyst helping the representative analysing, for example, the [patient] stories.*" (P10)

<u>*Methodology*</u> - Participants with experience in guideline working groups described development as an iterative process, in which various methodological decisions needed to be made. Discussions included whether to develop syndrome-specific or more generic guidelines; to develop global minimum-standard guidelines or focus on the local level; and how to allocate efforts to guideline development versus clinical research when there is limited evidence. Several participants argued for the development of registries and research agendas to stimulate the generation of further information.

Participants suggested various contributions of affected individuals and families, including prioritization of topics that are important in everyday life, sharing information on (underreported) comorbidities and current care, and assessing the impact of recommendations on the patient experience. Both active collection of perspectives through surveys, focus groups, or patient stories, and the knowledge patient representatives implicitly derive from their work and daily life, were mentioned.

> "*As parents, we can fill the gaps that currently exist on the odyssey* (…) *of our rare disease* (…) *We can see, when we visit to the neurologist, there is a problem with the EEGs because they are not performed* (…) *so we can fill those gaps, and the rest can be [written] down by professionals, but we can say, hey, there is a gap here, there is a gap there.*" (P18)

Considering the large number of rare conditions and the scarcity of existing guidelines, efficiency of development was seen as important: *"Maybe we need new methodology to approve guidelines, in order for this generation to have a guideline, because somehow it takes so long"* (P9). In general, participants described a sense of urgency to provide information, which might conflict with the desire to make a reliable guideline:

> "*It takes us one year for making this [document], to read all the information, to ensure it is correct* (…) *so each time it is a discussion* (…), *it is important, and in the background you have the families asking, when, when, when, and I say, I prefer waiting maybe one, two, three months more to have a good information. If I give you something that is not correct, it is also my responsibility as a president of the organization.*" (P7)

Implementation - Participants considered guideline implementation as essential for individuals living with a rare condition to benefit from its development. This was seen as neither automatic nor straightforward:

> "*The guidelines are just an idea of what we have to do. Then, we have to write who is the leader* (…) *, who are the other actors who are involved in the pathway, and which hospitals or local units have to do that, in which time, when, and so on. So, there is a guideline, and then there is a translation on who, when, how.*" (P19)

Dissemination to both healthcare providers and affected individuals and families was perceived as crucial. Various participants described that they or their community members tend to receive care from healthcare providers with limited knowledge of their condition. Contacts with healthcare and government actors were reported to share information and raise awareness: "*The first step [is] to inform doctors*" (P2). On the other hand, dissemination of the guideline to affected individuals and families was highlighted as important, enabling them to actively demand care: *"It is the parents that are very often going to be the persons to take the guideline along. If they feel more part of them,* (…) *it is not beyond them to take them"* (P6).

Other mentioned challenges included differences in health systems between countries, limited funding and expertise on the local level, and the lack of strategies to update guidelines after initial development. Several participants stated that these challenges need to be discussed early on:

> "*How much in detail do you go, do you write very general and then you don't add much to the already existing* (…) *situation, or if you go in too much into details, let's say,* (…) *this examination must be done every three years or so, then you have a problem on the local level because the insurance doesn't cover this examination.*" (P13)

<u>*Responsibility*</u> - Participants described an active role for patient associations across the guideline development and implementation process. Through their networks, these organizations may provide access to the experiences and opinions of individuals and families. Subsequently, the associations may play a role in adapting guidelines to local settings and promoting dissemination and implementation among national actors.

> "*That is the importance of the association, because* (…) *we are the engine for this work* (…) *We are connecting people, connecting clinicians, putting them together to talk about the disease.*" (P19)

Some participants reported that the responsibility for guidelines should be shared across all stakeholders who are part of the guideline development process. For example, clinical experts and governance actors have access to different mechanisms and resources to promote implementation.

> "*A lot of centres only* (…) *start working with* (…) *guidelines if they are accredited* (…) *Once [accreditation] is in place, that means that you already have stakeholders there on a national level and on centre level. And then you have the patients who can actually furthermore advocate it, and then, top-down and bottom-up, you have two approaches that can work*" (P3)

Discussion

In this focus group study among European patient advocates for rare congenital malformations and/or intellectual disability, CPGs were considered important tools for information provision, improving care, and advocacy on national and international levels. Guideline development and implementation for this population were described as iterative processes that require collaboration between all

stakeholders, including the involvement of patient representatives as equal partners. It is important to recognize patient advocates' aims and priorities for guideline development, as their perspectives may differ from those of other stakeholders, and to ensure patient partnership throughout the development process, for which recommendations are provided in Table 1.

Balancing reliability and urgency to address unmet needs

This study identified a tension between reliability through rigorous methodology, associated with lengthy development processes, and a sense of urgency to make a wide range of information available as soon as possible. This contradiction may result from the multiple responsibilities patient advocates hold to address the unmet information and care needs of their communities. Guidelines were described as a tool to empower affected individuals and families in accessing appropriate healthcare and social support, in line with the role of the patient as an active partner in rare disease management [144, 145]. Although the burden placed on individuals and caregivers should not be overlooked, explicitly recognizing them as end-users means dissemination and user-friendliness for this audience are essential. A recent review of the information needs of caregivers of individuals with rare epilepsy syndromes and intellectual disability showed a diverse range of needs, from diagnosis-specific medical information to support in navigating health system organization and coping strategies [149]. In this light, it is important to assess which information and care needs are most pressing and to determine whether guideline development or other policy efforts are the best way to meet those needs.

Navigating diverse goals

The various goals patient advocates aim to achieve using guidelines may require different development strategies: for example, strongly phrased minimum-standard CPGs may be powerful tools to support advocacy, but may leave less room for sharing daily life experiences and freedom of choice in terms of the "life-disease balance". Patient advocate goals can also differ from those of other stakeholders: where guideline methodologists and clinical experts may aim to provide general recommendations for clinical management, participants highlighted the importance of personalized and holistic approaches to unique individuals, including psychosocial topics. Heterogeneity is a known challenge in rare disease research and may similarly complicate the formulation of clinical practice recommendations that apply to all individuals with a particular condition [150]. An existing framework that could help to comprehensively address all life domains is the International Classification of Functioning and Disability (ICF) [151, 152].

Harmonizing knowledge paradigms

Guideline development may reveal epistemic conflicts, as participants consider information from individual lived experiences to be highly valuable, while CPGs rely strongly on population-level evidence from scientific research [142, 153]. Ethnographic research of guideline development panels has described the difficulties of integrating different types of knowledge in CPGs, in which approaches focused on high-quality clinical evidence (e.g. defined as meta-analysis of randomized controlled trials) may conflict with more pragmatic understandings of relevant knowledge including clinical expertise, patient experiences, and real-world data [154]. As the perceived validity of CPGs is essential to the aims participants describe, including convincing healthcare professionals and policymakers and providing reliable information to families, the question as to which knowledge is considered reliable holds particular importance.

Table 1. Recommendations for patient partnership by guideline development stage.

Overall	Collaborate with patient representatives from the initial stages; Facilitate partnership through training, guidance, and/or support where necessary
Prioritization	Prioritize topics that are relevant to individuals and families living with rare conditions
Preparation	Create multidisciplinary guideline working groups in which patient representative input is facilitated and acknowledged
Data synthesis	Collect information from patient communities through quantitative (surveys, patient-led registries) and qualitative methods (focus groups, interviews, patient stories)
Formulation of recommendations	Include patient views in considerations to inform the content and phrasing of recommendations
Implementation	Collaborate with (national) patient organizations in guideline dissemination and implementation

Facilitating patient partnership

All participants consider patient partnership as a prerequisite for effective guideline development. Suggestions for collaboration at each stage of the development process are provided in Table 1. This continuous and broad conception of partnership confirms and extends upon previous research and policy reports that recommend combining consultation, deliberation, and co-decision methods throughout all stages of guideline development [87, 88, 155]. It is important to note that not every condition or country has a patient organization and that skills and experiences might vary between representatives. Training on guideline methodology and

terminology, guidance and support during the development process, and/or (financial) compensation for and practical consideration of the commitment required of patient advocates could help secure patient representation in guideline development [87, 89].

Strengths and limitations

By speaking to all interested members of the ERN-ITHACA Patient Council, who are both mandated to speak on behalf of their community and experienced in discussing policy issues, we believe our study holds high information power [156]. To accommodate participation of this international group, digital focus groups were a necessity; previous research supports the use of virtual focus group formats in rare disease contexts [157]. Most participants were parents of an affected child; all were officially mandated by their patient organizations, have professional working proficiency in English, and some have a professional or educational background in healthcare or research. Although these individuals represent larger patient communities through their organizations, their experiences may not reflect those of all individuals and families living with rare congenital malformations and/or intellectual disability. An important limitation is that no individuals with intellectual disability participated in the focus groups, and this work might not reflect their perspectives. The topic of patient representatives speaking as proxies on behalf of affected individuals was only briefly mentioned during the focus groups. Collaboration with individuals with intellectual disability in healthcare research and guideline development receives increasing attention [158] and needs to be considered in future efforts. Within a multiple-strategy approach to patient partnership, collaboration with patient organization leaders, families and caregivers, and affected individuals can coexist.

Conclusion

In this focus group study, patient advocate perspectives on guideline development for rare congenital malformations and/or intellectual disability were explored. Patient advocates viewed CPGs as a tool to meet information and care needs and support their advocacy work. Representation of heterogeneity, holistic approaches, user-friendly dissemination, and reliable development were considered important. The study identified tensions between evidence-based methodologies and the value placed on experiential knowledge as well as the speed of guideline development. The goals various stakeholders aim to achieve through guideline development deserve further attention in research and policy efforts. Supporting patient partnership is recommended to improve the relevance and implementation of guidelines.

Acknowledgments

We are very grateful to all members of the ERN-ITHACA Patient Advisory Board and Patient Council for their participation in this study, their support for the organization of focus groups during their annual workshop, and their ongoing contributions to the network's guideline development efforts. To learn more about the ERN-ITHACA Patient Advisory Board and Patient Council, and their members, please consult https://ern-ithaca.eu/for-patients-and-families/ern-ithaca-patients-representatives/

Supplementary data: Focus group guide

- Introduction (purpose and planning of the focus group, participants)
  - Introducing moderator; purpose ("*We are interested in hearing your opinions on the use and the development of guidelines*"); planning (duration); conversation rules (everyone's opinion is important; telephone on silent mode); recording for scientific article will be saved at Amsterdam UMC and deleted after 1 year; start recording.

- Introductory round: name and your role in ERN-ITHACA/PO.

- **Topic 1*:** Experiences in using guidelines within patient organization (PO) and needs regarding guideline end-products

  - Introductory round**:** short round to ask who has ever used a guideline.

  Possible questions:
  - Do(es) you/your PO have experience with using guidelines or guideline tools, such as decision aids?
  - What is important to you/your PO to use guidelines or guideline tools?

- **Topic 2*:** Experiences in participating in guideline development as part of patient organization/patient representative (PR)

  - Introductory round**:** short round to ask who has previously participated in guideline.

  Possible questions:
  - Do(es) you/your PO have experience with participation in the development of guidelines? Could you tell me about these experiences?
  - What is your opinion on participation of PR in guideline development?
  - In which phase(s) of guideline development should PR participate?
  - Through which methods should PR be involved in guideline development?

- Rounding up: any points that have not been mentioned yet?

- Closing: thanking participants and stopping recording

** The order of these two main topics was alternated between group discussions.*



Chapter 5

From insecurity to confidence: evaluation of an innovative panel members' training for guideline development – a survey



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Under review

Abstract

Background: Guidelines are essential tools for ensuring evidence-based healthcare and supporting decision-making. Their development is complex, yet many guideline panel members lack formal training. Existing training programs do not fully cover methodological and process-related educational needs expressed in a preliminary survey. Guideline panels involve diverse roles, each with unique responsibilities and skill sets, making tailored training essential. Therefore, this study aimed to investigate how a panel member-tailored program grounded in five educational design principles: contextual, constructive, blended, just-in-time and collaborative learning can support guideline panel members during guideline development.

Methods: The training was co-created with guideline methodologists, educationalists, and health economists. Intended learning outcomes were developed using the Responsible, Accountable, Consulted, and Informed (RACI) matrix. An anonymised survey with a Likert-scale of 1 (completely disagree) - 5 (completely agree) and open-ended questions based on the training design principles was used to evaluate the training. Data were analysed using descriptive statistics and qualitative content analysis.

Results: Six multidisciplinary guideline panels participated in the training. Half of the panel members (n=33) and 60% of the project leads (n=9) completed the survey. The training improved panel members' understanding of the guideline process (85%, 23/27) and their preparedness for their tasks (53%, 15/28). Contextual learning enhanced relevance by aligning the training to panel members' roles and tasks (82%; 23/28), and the examples were realistic (89%; 25/28). Constructive learning elements encouraged active engagement with the learning material (73%; 19/26).

The blended and just-in-time principles provided flexibility, allowing the training to accommodate the diverse development processes. However, the synchronous in-person components could be further strengthened. Approximately half of the participants indicated that the online modules provided sufficient knowledge to actively participate in the panel meetings (55%; 15/27). Furthermore, 80% (20/25) of the panel members agreed that combining online preparatory assignments and in-person training supported their learning. Lastly, the training raised awareness about the importance of cost considerations (55%;12/22) and encouraged consideration of how costs could be included in the guidelines (59%; 13/22).

Conclusion: Training grounded in blended, constructive, contextual, collaborative, and just-in-time design principles can meaningfully support guideline panel members during guideline development.

Background

Guidelines are essential tools that help ensure evidence-based healthcare by supporting healthcare professionals and patients in making informed healthcare-related decisions [9, 34]. High-quality guidelines shape healthcare delivery [54], and their development is a complex and rigorous process. Panels are expected to consider and weigh a variety of factors when developing a guideline, including the benefits and harms of treatments, certainty of effect, values and patient preferences, cost and resource use (economic considerations), equity, feasibility, and acceptability [28, 30]. Despite their crucial role in guideline development, formal training in guideline development is uncommon among many panel members, and many feel unprepared for their role within the guideline development process [54, 159].

Some training programs for panel members exist, such as the international INGUIDE training program [54] and the Dutch one-day EBRO (Evidence-based Guideline Development) training [70]. Additionally, there are trainings specifically for patient representatives' participation in guideline panels, for example, the two-day training by INVOLV [160]. However, these existing training programs do not fully address the educational needs expressed by panel members in a preliminary survey study [159]. This study underscored the need for training on methodological aspects as well as process-related aspects, such as:

- Grades of REcommenadation, Assessment, Development and Evaluation Evidence to Decision (GRADE EtD) methodology;
- Cost considerations;
- Including different perspectives (patient/healthcare professionals) during guideline development;
- Task division, group dynamics, and equitable participation [159].

Furthermore, guideline development panels comprise a variety of roles – guideline methodologists and panel members (such as chairs, patient representatives and healthcare professionals) – each with unique responsibilities and skill sets that can vary slightly per guideline project [53, 60, 159]. Therefore, educational programs must be tailored to meet the diverse needs of these roles, ensuring that all participants are equipped to contribute to the guideline development process [60].

In response to these needs, Dutch guideline development organisations collaborated to develop a joint tailored guideline development training program for panel members. Firstly, the training was developed by defining appropriate

intended learning outcomes (ILOs) and then applying five educational design principles: constructive, collaborative, contextual, blended and just-in-time. Constructive learning encourages learners to engage actively with educational content rather than passively absorbing information. The panel members actively connect their existing expertise and knowledge with new knowledge regarding guideline development [61, 62]. Collaborative learning fosters learning from and with one another by engaging learners in shared, complex tasks and building upon each other's contributions. This principle is fitting as panel members work together on developing their guidelines, thereby enhancing their collaboration [63, 64]. Contextual learning connects educational content to real-world situations by focusing on authentic problems. This motivates learners to relate new knowledge to their own situation, in this case, the guideline development process, and promotes knowledge transfer [65, 66]. In this study, blended learning is defined as 'the integration of face-to-face learning experiences with online learning experiences'. This provides flexibility in when the training can be delivered during the guideline development period [67, 68]. The last design principle, just-in-time, warrants that knowledge is delivered in small segments when the knowledge is needed [69]. This stimulates transfer, as panel members timely receive project-relevant knowledge to support their guideline development process, fostering deep engagement with educational content.

This study contributes to the limited educational research on guideline development training by detailing the design and evaluation of a training program for panel members [54, 60]. The research question guiding this study was: How can training that incorporates constructive, collaborative, contextual, blended and just-in-time design principles support guideline panel members in guideline development?

Methods

Guided by the preliminary identified educational needs [159, 161], the training was collaboratively developed by educationalists*, guideline methodologists from various guideline development organisations♦, and health economic experts▽.

* From Maastricht University, educational agency InnoWijs.

♦ From the Royal Dutch Society of Physiotherapy (KNGF), Dutch College of General Practitioners (NHG), Knowledge Institute of the Federation Medical Specialists (FMS), Knowledge Institute of the Dutch Association for Nursing Professionals (V&VN).

▽ From Maastricht University.

The training was evaluated using a survey containing open- and closed-ended Likert-scale questions. The reporting of the study was guided by the CHEcklist for Reporting Results of Internet ESurveys (CHERRIES) reported in Appendix 1 [83].

Study setting

This research was conducted in the Netherlands, where over 30 (healthcare professional) organisations are involved in the development of guidelines [74]. These guidelines are based on the AQUA agreement [22], which aligns with the international Appraisal of Guidelines for REsearch and Evaluation (AGREE) II criteria [18]. While these guideline development organisations share a common methodological basis, differences in work processes exist. Conventionally, guideline development requires approximately two years [17], usually conducted by panels with different healthcare disciplines and patient representatives [159].

In this study, we categorised guideline developers into four main groups: panel members, methodologists, project leads and supporting experts. Panel members can include healthcare professionals and patient representatives, researchers and chairs.

These panel members are supported by a project lead who is responsible for project management and process support, and may also serve as a guideline methodologist [159]. Guideline panels can be supported in their process by additional experts, for example, literature specialists, ethicists, implementation experts, and health economists.

The intervention

The intended learning outcomes (ILOs)

Based on the needs identified in the preliminary survey [159] and the guideline development steps outlined in the AQUA agreement [22], we conducted seven one-hour and one two-hour expert group meetings to define the training structure and formulate the ILOs.

The expert group comprised three senior guideline project leads/methodologists from various guideline development organisations, a health economist, an educationalist, a medical specialist with extensive experience as a guideline chair, a senior researcher/educator in epidemiology, and the lead researcher (CdM).

During the development of the ILOs, it became evident that guideline development processes varied across organisations, e.g. in task and role assignments. To address this, we used the Responsible, Accountable, Consulted, and Informed (RACI) matrix (a project management tool that clarifies role-specific responsibilities for a task) to help structure the training and corresponding ILOs [162]. Using the RACI matrix, we mapped RACI-specific responsibilities to guideline development tasks, helping to identify relevant competencies for panel members. Subsequently, ILOs were formulated per RACI category using Bloom's taxonomy [163, 164]. An example RACI application is shown in Table 1; the full overview of RACI-based ILOs is available in Appendix 2.

Structure of the training

The developed training for panel members consists of five modules, each with an asynchronous self-study e-learning and a synchronous training session, either physically or via videocall, designed to connect the educational activities to the panel's work. Four of the synchronous training sessions were held during the guideline panel meetings, while the session of the third module was conducted separately from these meetings. The training was based on five design principles: constructive, contextual, collaborative, blended and just-in-time learning, as explained in the introduction. Table 2 describes the training components and how the design principles were incorporated in the training. The digital component of the training was built by the educational agency InnoWijs [165] in Moodle Workplace [166].

Participants

All organisations involved in the development of the training were invited to pilot the training with one of their guideline panels. In total, six panels from five different guideline development organisations that started new guideline projects in the pilot timeframe volunteered to participate. Four panels were affiliated with organisations that co-developed the training, while two panels were affiliated with organisations that independently contacted the research team after learning about the training at a symposium. These panels represented guidelines from different healthcare sectors: allied healthcare, nursing, specialised medical care, and long-term care.

Participation in the survey and training was voluntary and did not influence whether participants could participate in the guideline development projects. Following the final synchronous in-person session, panel members and project leads were invited to participate in a post-training survey. Participation in the survey did not require panel members to have completed any or all of the (online) training modules. Although project leads were not the primary target group, they were invited to complete the survey to provide insights into the suitability of the training format and delivery.

All panels had a multidisciplinary composition, typically consisting of eight to twelve members, including healthcare professionals from various disciplines, a chair, and, when feasible, a patient representative. Each panel was supported by two to three project leads, ranging from junior to senior level.

Data collection and analysis

Data were collected via field notes during the panel meetings (taken by CdM, and by DD or DV during the first panel meetings), short surveys at the end of each digital module, and a post-training survey. The short surveys conducted in the Moodle workplace focused on evaluating the learning goals and providing an interim check (Appendix 3), completed between May 2024 and June 2025. The post-training survey, conducted in Qualtrics[XM], evaluated the five design principles underlying the training and participants' experiences. It contained 21 five-point Likert scale questions (1 (completely disagree) – 5 (completely agree)) and two open-ended questions and took approximately 15 minutes to complete (Appendix 4). The post-training survey was conducted between October 2024 and August 2025, after the completion of the last synchronous in-person training. The current study presents the post-training survey, using the field notes to aid in interpreting the results. Quantitative survey data were analysed using SPSS version 28 to conduct descriptive statistics. The open-ended responses were analysed with qualitative content analysis [84].

Panel members were informed about the training through the guideline panel recruitment letter, which clarified that participation in both the training and associated research was voluntary. Participation in the training did not require or imply participation in the study. Additionally, non-participation in the research or training did not influence partaking in the panel. End survey participants provided informed consent by starting the survey after receiving clarification of its purpose and data usage on the survey's cover page. Responses were anonymous, no directly identifiable information (e.g., IP addresses) was collected, and data were stored on a data-protected server at Maastricht University.

Table 1. Two examples of intended learning outcomes for modules one and two for the guideline development training. A complete overview of the intended learning outcomes is presented in the Appendix 2.

	Responsible	**A**ccountable
Module 1, Topic 2: Guideline development process		
ILOs	Participant is able to explain what the guideline development process will entail for their guideline project.	Participant is able to ensure that all tasks/roles that need to be fulfilled in the guideline development process are assigned.
Potential target audience	Project lead, guideline methodologist, chair	Project lead
Module 2, Topic 2: From topic selection to key questions		
ILOs	Participant is able to refine a problem area into a key question, while considering the perspectives and knowledge of the panel members.	Participant is able to assess if key questions (and PICO) and the related outcome measures are appropriate for guideline development. Participant ensures that all participants have the opportunity to share their input when formulating the key question and PICO.
Potential target audience	Guideline methodologist	Project lead

	Consulted	**I**nformed
	Participant is able to describe their task(s) in the guideline development process.	Participant understands how the guideline development process takes place.
	Panel member	Panel member, chair, junior methodologist
	Participant is able to explain how a problem area is formulated into a key question and the corresponding PICO. Participant is able to provide feedback on formulated key questions based on their content knowledge and expertise. Participant is able to share their perspective regarding the key question to be formulated.	Participant knows the researched topic in the guideline based on the key question.
	Panel member	End-users of the guideline

Table 2. Overview of the guideline development training for panel members. For each module, the table outlines the content, mode of delivery, and associated corresponding design principles—contextual, constructive, and collaborative. The training had a blended (asynchronous (e-learning) and synchronous (in-person or via videocall) format, and each module was delivered at a different stage in the guideline development process.

	Module 1: Guidelines	**Module 2: Key Questions**
Learning activities	**Asynchronous** Participants: • Complete a multiple-choice quiz on guideline myths and facts. • Read about the definition of a guideline. • Watch a video on guideline development. • Read about conflict-of-interests (COI) and practice identifying COI through case scenarios. • Complete a drag-and-drop task on the guideline development steps. • Fill out a personal COI form. • Reflect on their role in guideline development via an open-ended question. **Synchronous** Participants: • Introduce themselves, share their motivations, and experience. • Discuss their roles during the development process. • Establish collaboration agreements.	**Asynchronous** Participants: • Complete a multiple-choice quiz on priority setting. • Read and interact with a scenario-based story on priority selection with pop-up elements. • Read about formulation of key question. • Analyse examples of key questions and identify areas for improvement using multiple-choice questions. • Read about PICO format and apply it in a drag-and-drop task. • Draft key questions for their guideline. **Synchronous** Participants: • Participate in Q&A on theory. • Discuss and refine priorities and key questions for their guideline, drawing partly on their experiences.

Module 3: Summary of Scientific Evidence (GRADE)	Module 4: From Evidence to Recommendations	Module 5: GRADE EtD factor: Cost Considerations
Asynchronous Participants: • Watch an interactive video on meta-analysis basics. • Read about and practice literature selection using an abstract. • Read about applying PICO to said abstract. • Explore an interactive GRADE evidence table with pop-up explanations. • Reflect on their responsibility in summarising evidence with a multiple-choice question. **Synchronous** Participants: • Collaboratively review evidence tables. • Discuss the importance and the ranking of outcomes. • Receive a verbal explanation on clinical relevance.	**Asynchronous** Participants: • Watch a video and complete a multiple-choice quiz on formulating recommendations. • Read about the strength, direction and terminology of recommendations, as well as the GRADE Evidence to Decision (EtD) framework. • Practice assessing strength and direction of example recommendations in a multiple-choice task. **Synchronous** Participants: • Participate in Q&A on theory. • Discuss EtD considerations for their guideline, drawing partly on their experiences.	**Asynchronous** Participants: • Watch a video on the importance of addressing costs in guidelines. • Complete a quiz on types of costs. • Read about cost categories and perspectives. • Explore an interactive pop-up table about costs related to an authentic case. • Practice describing relevant costs for their guideline, • Watch a video on Quality-adjusted life year and Incremental cost-effectiveness ratio. **Synchronous** Participants: • Discuss the importance of cost considerations. • Describe and discuss potential costs related to their guideline using (digital) post its, drawing partly on their experiences. • Receive explanation about cost data sources and perspectives.

Table 2. Continued

	Module 1: Guidelines	**Module 2: Key Questions**
Contextual learning	**Asynchronous:** Participants work with an authentic narrative scenario of a guideline with a multidisciplinary panel, their own guideline, and their personal experiences. **Synchronous:** Participants work with their own guideline, a comparable guideline, and draw on both their own experiences and those of other participants.	
Constructive learning	Participants reflect on their understanding of guidelines and potential COI by completing a COI form. They define their role and motivation in the development process through written reflection and group discussion.	Participants build knowledge by analysing interactive scenarios and key questions. They identify PICO elements and formulate key questions. They deepen understanding by discussing their own priorities and key questions.
Collaborative learning	Participants share and discuss personal motivations and experiences. They jointly establish collaboration agreements through group discussion.	Participants collaboratively decide which priorities will be included in their guideline and co-develop corresponding key questions through discussion.

	Module 3: Summary of Scientific Evidence (GRADE)	**Module 4: From Evidence to Recommendations**	**Module 5: GRADE EtD factor: Cost Considerations**
	Participants construct knowledge by analysing abstracts and explore evidence tables through interactive formats. They reflect on their role in summarising evidence and practice selecting key outcomes relevant to their guideline.	Participants actively engage with knowledge by completing quizzes and practicing assessing authentic recommendation examples. They apply GRADE EtD to their guideline through discussion.	Participants engage in videos and quizzes exploring relevance of cost considerations, cost categories and perspectives. They practice with identifying relevant costs for their guideline.
	Participants discus potentially relevant outcomes and their importance for their guideline. They collaboratively review evidence tables.	Participants discuss the considerations for their key questions and their recommendation formulation, drawing partly on their experiences.	Participants discuss potential costs for their guideline from different cost perspectives and drawing on personal experiences.

Results

The survey provided an overall impression of how participants experienced the training and whether the design principles enhanced or hindered their learning. Six guideline panels from five different healthcare professional organisations participated in the training for seven to fifteen months. All panels were multidisciplinary, comprising healthcare professionals from various disciplines, and some included patient representatives and researchers. A total of 33 panel members (healthcare professionals, chair, patient representative and researcher) (52%; 33/64) and nine project leads (60%; 9/15) completed the survey, as shown in Table 3.

One panel discontinued participation after the third training session due to temporarily halting the guideline project by the guideline-developing organisation. Two panel members from panel three withdrew from the guideline development process due to personal circumstances. No drop-out was explicitly related to the training. In some panels, new members were added during the process. Five panels had changes in project leads, for example, due to job changes. Table 3 summarises the types and numbers of participants in the six guideline development projects at the time the survey was distributed, following the final in-person training session.

Of the panel members that responded to the survey, most (61%; 20/33) participated in a guideline project for the first time, as reported in Table 4. Among the responding panel members, five did not complete any online modules, while thirteen completed all of them, and fifteen completed some of the modules. Six project leads completed all modules, one partially and two did not complete any, as shown in Table 4. All participants who did not follow or partially followed the training indicated why they did not follow the training (completely). Twenty-seven (63%; 27/42) respondents used the final open field to provide written feedback.

Table 3. Summary of the panel compositions of the six guideline panels, from five different organisations, who participated in the study and the duration of the training accompanying the guideline projects.

		Panel 1*	Panel 2§	Panel 3§	Panel 4§	Panel 5§	Panel 6
	Duration of training with the project (months)	9	7	15	12	9	13
Panel members	Chair	X	X	X	X	X	X
	Vice-chair					X	
	Background of panel members						
	Patient representative			X	X**		X
	Healthcare professional	X	X	X	X	X	X
	Researcher	X	X	X	X	X	
	N	8	11	12	12	9	12
	Participated in the survey	4	7	6	7	4	5
Support	Guideline project lead	X	X	X	X	X	X
	Guideline methodologist	X		X	X		X
	N	2Ω	3	3Ω	3	3	2
	Participated in the survey		2	2	3	1	1

*The guideline project was discontinued after the completion of the first three training modules.

** Patient representative who discontinued participation in the panel meetings but remained available for consultation when needed.

§ Panel composition changed during the development process due to member dropout or additions.

Ω One individual served as the project lead for both panels one and three. The project lead completed the survey after both panels were completed.

Table 4. Experience of panel members and project leads across six guidelines, from five different organisations, with guideline development projects and their completion rate of the guideline development training.

	Panel members (n=33)	Project leads/guideline methodologists (n=9)
How often participated in guideline development		
First time	20	2
Second time	6	1
Third time	1	
More than three times	6	6
Followed the online modules		
Followed all modules	13	6
Partially followed modules	15	1
Did not follow modules	5	2

Supporting panel members through constructive and contextual learning

Figure 1 shows that the training helped panel members understand the guideline development process better (85%, 23/27; median = 4) and over half of them indicated the training made them feel better prepared for their tasks in the development process (53%, 15/28; median = 4). Additionally, Panel members felt stimulated to actively engage with the learning material (73%,19/26; median = 4) and reported that applying the gained knowledge to their guidelines helped their learning (64%, 18/28; median = 4). The examples in the training were perceived as realistic (89%, 25/28; median = 4), and the training suited the roles and tasks of most panel members (82%, 23/28; median = 4).

Although panel members indicated that examples were realistic, participants suggested in the open-ended question that tailoring examples specifically to the guideline healthcare discipline(s) or topic could be beneficial.

> *Quote 1: 'I think it would be great if you could submit questions through the platform, and if the content could be tailored to [specific healthcare professional x] topics, or if multiple options were available. I can imagine that not all panel members will always be [specific healthcare professional x].' – Project lead, panel 4*

Fostering collaboration within diverse panels

Each panel consisted of panel members from diverse backgrounds, including various healthcare disciplines and occasionally patient representatives (Table 3). Panel members indicated that this diversity helped them view the guidelines' content from multiple perspectives (85%, 23/27; median = 4). The panel members indicated that they were able to express their thoughts (92%, 25/27; median = 4). However, responses were more neutral regarding the extent to which the training supported their discussions about different ideas and opinions (46%, 13/28; median = 3), as shown in Figure 1.

A project lead stated in the open-ended question that the training enabled panel members to start on a more equal footing and can contribute to a more equal input in the guidelines.

> *Quote 2: '... I did learn a lot about how the process can go differently and how designing a training process can influence the panel members and change the dynamics. Those who are less equipped at the start are given good tools. This allows you to start the development on a more equal footing, and the input incorporated into the guideline modules becomes more balanced.' – Project lead, panel 6*

Blended training can support panel members if the content is fitting

The training contained a blended format in which digital modules were alternated with synchronous in-person sessions. About half of the participants indicated that the online modules provided them with the knowledge needed to actively participate in the panel meetings (55%, 15/27; median = 4). Whereas 80% (20/25; median = 4) of the panel members indicated that the combination of online preparatory assignments and synchronous in-person training supported their learning, as presented in Figure 1.

In the open-ended feedback, panel members indicated that the content of the training was not always fitting, possibly due to the nature of the guideline, or because they lacked explanation on specific topics. For example, a diagnostic key question requires different expertise than intervention questions. Additionally, participants indicated that the in-person component of the training could be strengthened.

> *Quote 3: 'In fact, the knowledge was rarely used in the meetings. This is probably also due to the nature of the guideline itself.' – Panel member, healthcare professional, panel 5*

> *Quote 4: 'I missed a recap, for myself, about how research is structured and what types of articles exist.' – Panel member, healthcare professional, panel 2*

> *Quote 5: 'I missed one team session, but the other one about costs did give me food for thought and taught me new things. I found this more useful than the e-learning modules. During the panel meeting, I didn't think about the training. Perhaps the chair or the board could have referred to the training when relevant. As it stands (despite the good timing), it was somewhat disconnected from the guideline process.' – Panel member, healthcare professional, panel 5*

The timing of training delivery is complex

The training was set up as just-in-time training, where participants would receive knowledge when needed. Fifteen (61%, 16/26; median = 4) panel members responded that the training was delivered at the right time, and 59% indicated the timing of the training benefited their learning (16/27; median = 4) (Figure 1).

In the open feedback question, some panel members indicated they would have preferred to have followed the modules before the start of the guideline development process.

Quote 6: '…. It would have helped me if I could have taken this training earlier, say 2-4 weeks before the first panel meeting. Before that first meeting, I searched the [organisation] website/YouTube myself to find out what a guideline panel entails. If I had been able to take this training immediately after my participation was confirmed, I would have saved myself some extra work and been able to prepare even better.' – Panel member, healthcare professional, panel 1

Quote 7: '… In addition, I would prefer to read the information from the modules at a time of my own choosing before the start of the panel…' – Panel member, healthcare professional, panel 5

However, other panel members indicated they had difficulty retaining the training content after a long period had passed.

Quote 8: 'I completed all the modules before the guideline development process began, as that is how I understood it. Therefore, a lot of knowledge had faded by the time the module was supposed to be completed. I probably misunderstood, but it was not entirely clear.' – Panel member, healthcare professional, panel 2

Quote 9: 'I understand just-in-time method from an educational point of view, but I notice that months later, I no longer remember what the previous modules were about. – Panel member, healthcare professional, panel 6

The training stimulated cost consideration inclusion

The training seemed beneficial in raising awareness about the importance of incorporating cost considerations in guidelines. Panel members indicated the training created awareness about why cost considerations are important (55%,12/22; median = 4) and encouraged them to think about how cost considerations could be included in their guidelines (59%, 13/22; median = 4) (Figure 1).

Experience with guideline development

Panel members had varying levels of experience with guideline development, as presented in Table 4. In the open-ended feedback response, a panel member indicated that the training was less relevant for them due to their extensive experience in guideline development.

Quote 10: 'As a scientist on the subject-matter (and having already developed several guidelines), the training added little new information for me, but I can imagine that the training was very valuable for others.' – Panel member, researcher, panel 1

However, panel members with prior experience in guideline development generally respond positively to the training. Their responses were sometimes less pronounced compared to those with no experience, as seen in Table 5.

The project leads' point of view

As expected, most project leads indicated that they did not acquire new content knowledge (median = 2, n = 6), nor did the training enhance their understanding of guideline development (median = 2.5, n = 6), as they were not the primary target audience of the training. Nevertheless, their perspectives on the suitability of the training format and delivery were valuable. They expressed that the training was valuable for panel members, and agreed the assignments encouraged active engagement (median = 4, n=6) and the examples were realistic (median = 4, n=7) (Table 5).

> *Quote 11: 'The training is not intended for guideline advisors, of course, so I definitely think it has added value for panel members. As an advisor, I already had more knowledge, and I don't think I've learned anything new (fortunately).' – Project lead, panel 4*

Additionally, they stated the training was valuable in understanding how the development process could be structured in different ways. Finally, they highlighted that the training supported project leads in explaining aspects of the process to panel members.

> *Quote 12: 'As a project lead, I did not learn much about the content (GRADE methodology, etc.), but I did learn a lot about how the process can go differently and how designing a training process can influence the panel members and change the dynamics. …. In addition, it also takes a lot of explanation that would fall on the project lead out of their hands.' – Project lead, panel 6.*

Challenges in completing the training

Panel members who did not follow the training (n=5) indicated time constraints, experience with guideline development, and difficulty with the login process and finding the online training platform as reasons. Fourteen additional panel members only partially completed the online modules. Reasons for this included time constraints, prioritising preparation for the meeting content over the training, and the premature end of a guideline project. Contradictory, only two panel members indicated that the training took too much time on the Likert-scale question (8%, 2/26; median = 3) (Figure 1). In the open feedback field, some panel members indicated they had difficulty finding the link to the training and had difficulties with the interface of the training, as it was unclear which parts had been completed.

Table 5. Summary of Likert-scale survey results from panel members (both first-time and recurring participants) and project leads across six panels from five organisations. The table presents responses to the training's design principles—including constructive, contextual, collaborative, and just-in-time learning—as well as cost considerations in guideline development and the general impressions of the training.

General questions
The time investment for the training was too much
The training helped me better understand the CPG development process
Constructive design
The assignment challenged me to actively engage with the learning material
Applying the knowledge I gained to my CPG helped me learn better
Contextual design
The training suited my role and tasks in the development of the CPG
The examples in the training were realistic
The training made me feel better prepared to perform my tasks in the development process
Collaborative design
The diverse backgrounds of the panel members helped me view the CPG content from multiple perspectives
I was able to share my thoughts with the panel
The training helped facilitate discussion about different ideas and opinions during the panel meetings
Blended design
The combination of online preparatory assignments and in-person training during the panel meetings supported my learning
The online modules provided me with the knowledge needed to actively participate in the panel meetings
Just-in-time design
The online modules and in-person training sessions were delivered at the 'right' time
Receiving the training at the 'right' moment helped me apply the knowledge I had learned
cost-considerations in guidelines‡
The training helped me better understand why it is important to include cost considerations in CPGs
The training encouraged me to think about how cost considerations can be included in my CPG

‡ The responses of the panel members of the prematurely stopped guideline project were removed from the cost questions, as they did not reach this module.

Panel members						**Project leads**		
First time participating in guideline			**More than 2 times participating in guideline**					
N	**Mean (SD)**	***Median***	***N***	**Mean (SD)**	***Median***	***N***	**Mean (SD)**	**Median**
18	2.61 (0.70)	3	9	2.56 (0.73)	2	7	2.00 (1.16)	2
18	4.06 (0.80)	5	9	3.78 (0.44)	4	6	2.50 (0.55)	2.50
17	4.12 (0.78)	4	9	3.44 (0.88)	3	6	4.00 (0.63)	4
18	3.83 (0.71)	4	10	3.30 (0.68)	3	5	3.20 (0.84)	3
18	4.06 (0.80)	4	10	3.90 (0.57)	4	6	2.83 (0.98)	3
18	4.11 (0.83)	4	10	4.30 (0.48)	4	7	4.14 (0.69)	4
18	3.94 (0.80)	4	10	3.30 (0.82)	3	6	2.50 (1.05)	2.50
18	4.22 (0.65)	4	9	4.22 (0.83)	4	6	4.17 (0.75)	4
17	4.41 (0.51)	4	10	4.30 (0.82)	4.50	6	4.50 (0.55)	4.50
18	3.78 (0.73)	4	10	3.10 (0.88)	3	7	3.86 (0.69)	4
17	4.06 (0.66)	4	8	3.88 (0.64)	4	6	3.00 (0.63)	3
17	3.71 (0.77)	4	10	3.30 (0.68)	3	5	2.80 (0.84)	3
17	3.53 (0.94)	4	9	3.78 (0.97)	4	7	3.71 (0.48)	4
17	3.59 (0.71)	4	10	3.70 (0.68)	4	5	3.40 (0.55)	3
14	3.86 (0.95)	4	8	3.50 (0.76)	3	7	3.29 (0.76)	3
14	3.71 (0.83)	4	8	3.63 (1.06)	3.50	7	3.71 (0.49)	4

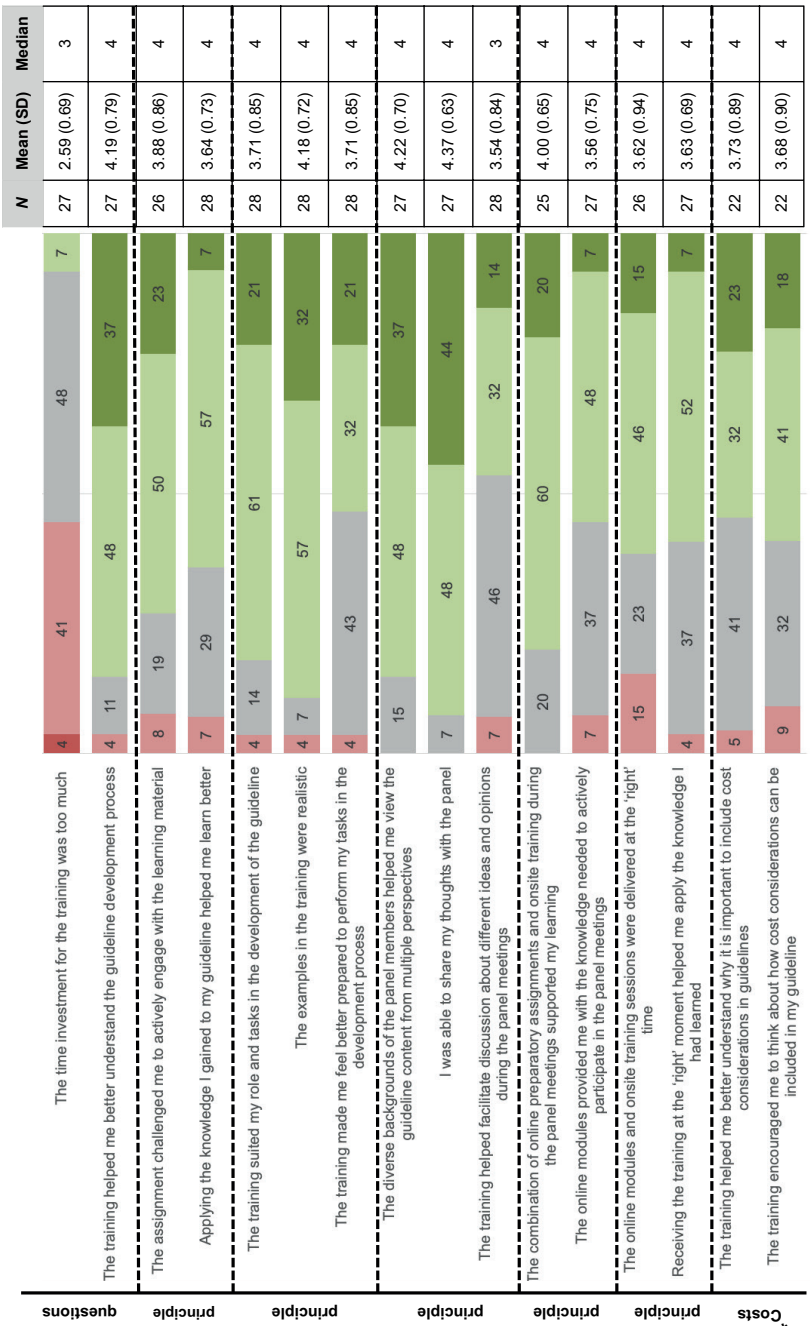

Figure 1. Summary of Likert-scale survey results from panel members across six panels, from five different organisations. The panel members reflected on the overall impression of the guideline development training, the design principles, and the effect of the training on cost considerations in guideline development. *The responses of the panel members of the prematurely stopped guideline project were removed from the cost questions, as they did not reach this module.

Discussion

This study demonstrates that training based on constructive, contextual, collaborative, blended and just-in-time design principles can support panel members in guideline development. The training enhanced panel members' understanding of the development process and was relevant to their roles. The training's blended design – combining asynchronous e-learnings with synchronous in-person sessions – was positively received. Panel members also appreciated actively engaging with authentic learning material and applying concepts directly to their guideline development process, reflecting constructive and contextual learning.

More than half of the panel members reported feeling better prepared for their roles after the training, while others responded neutrally. This highlights the potential to refine the training to meet the diverse needs and contexts of panel members. While the just-in-time delivery was appreciated, some panel members indicated the training did not align perfectly with their progression in the development process. Variations in subgroup timelines, scheduling conflicts, and mismatches between module content and current panel tasks likely contributed to this perception. The modular approach of the training supported flexibility, but future iterations could potentially benefit from further segmenting training content into smaller modules. This would make them more adaptive to better align with the panel's needs. Additionally, a just-in-time design was introduced to address the lengthy timelines of guideline development. However, panel members reported forgetting earlier content due to the long gaps between training moments. These long intervals are inherent to the guideline development process, which typically spans about one to two years. Incorporating brief recaps could therefore reinforce learning, consistent with the effective learning strategy of spaced and repetitive learning, known to enhance long-term retention [167, 168].

A distinctive component of this training, compared to initiatives such as INGUIDE or EBRO [54, 70], is the blend of asynchronous and synchronous learning, where the whole panel can follow the training together. Design principles worked in tandem in the training; for example, just-in-time is more valuable when linked to real-life complex tasks (contextual learning) [169]. However, some participants perceived a disconnection between training and their guideline development process. Explicit efforts were made to link the learning material to the guideline development process – e.g., through guideline-specific examples in the synchronous in-person sessions of modules three and five – reflecting both the blended and contextual design principles. But, these links were not always translated into immediate, actionable

steps within the guideline development, thereby limiting the just-in-time effect [169]. Limited time for learning activities during panel meetings constrained integration. Strengthening the connection between learning materials and guideline tasks during the synchronous in-person sessions, through assignments directly aligned with current panel activities, could enhance engagement and reinforce constructive, contextual and collaborative learning.

Panel members valued seeing the guidelines from different perspectives by working in multidisciplinary panels. Li, et al. (2024) showed that social dynamics in a panel can influence the final recommendations made in a guideline [170]. Therefore, it is important that panel members can express their thoughts. Fortunately, most panel members indicated they were able to share their thoughts. However, about half of the panel members responded neutrally to whether the training helped facilitate discussion within the panel (collaborative learning). This suggests that contextual factors might have played a role in panel members being able to share their thoughts, and the contribution of the training was limited.

Globally, guideline panels struggle with including cost considerations in guidelines [46, 161]. However, current resource shortages make their explicit consideration increasingly relevant. The training raised awareness about the importance of cost considerations in guidelines, encouraging panel members to actively reflect on how to include these in their guidelines. Stimulating panel members to consider cost considerations via training can enhance its incorporation in guidelines [11].

Some experienced panel members did not participate in the online training because of their prior guideline development experience. Interestingly, those with experience who did participate in the training still responded positively, although their feedback was sometimes slightly less pronounced than that of non-experienced panel members. Project leads were positive about the format of the training and the value for panel members, but understandably less positive about how the training improved their own guideline development knowledge, as the training was targeted towards panel members.

The design principles used in the development of this training are transferable across settings [61, 62, 64-69] and can also be valuable to international guideline panels. This study demonstrated that guideline development training based on these principles can support panel members within Dutch guideline development. At the same time, the effectiveness of the training appears to be affected by contextual factors, including timing and alignment of training content with the workflow

of the development process, available time, and prior experience with guideline development, and possibly country-specific circumstances. Accounting for and adapting to contextual factors could be key in optimising the training's impact and effectiveness. A greater understanding of the contextual landscape could help create more tailored and impactful guideline development training programs. Thus, a better understanding of contextual factors affecting the guideline development process is needed [171].

Strengths and limitations

A strength of this study lies in the co-development of the training with guideline methodologists from various healthcare professional organisations. They provided a broad perspective on guideline development processes, ensuring the training aligned with the core steps and processes of guideline development [20, 22].

A limitation of this study, however, is that co-creation with panel members was not feasible due to the extreme diversity within panels. Making it challenging to determine a representative group. Additionally, only one patient representative participated in the survey, limiting the extent to which the findings reflect the views of all stakeholder groups in guideline development. Furthermore, not all panel members who participated in the panels completed the survey, introducing a risk of non-response bias, as those with more positive experiences may have been more likely to respond.

A unique strength of this study is its longitudinal follow-up of six guideline panels, an uncommon approach given the lengthy duration of guideline development. This approach provided valuable insights into the guideline development process and practical barriers to implementing the training. The diversity of the research team (researchers, educationalists, guideline methodologists from various guideline development organisations, and health economic experts) brought complementary perspectives to the data analysis and interpretation.

Conclusion

This study demonstrates that training grounded in blended, constructive, contextual, collaborative, and just-in-time design principles can meaningfully support guideline panel members during guideline development. Contextual learning enhanced relevance, while blended and just-in-time principles offered flexibility to accommodate the training to diverse development processes. Constructive learning

tasks fostered deepened engagement with the learning material. However, the synchronous in-person components could be further strengthened by stimulating collaborative and contextual learning. The impact of the training was influenced by contextual factors, highlighting the need for further investigation to optimise alignment with panel needs.

Abbreviations

AQUA = Advisory and Expertise Group Quality Standards (Advies- en expertgroep Kwaliteitsstandaarden)
AGREE = Appraisal of Guidelines for REsearch and Evaluation
CHERRIES = CHEcklist for Reporting Results of Internet ESurveys
EBRO = Evidence-Based Guideline Development (Evidence-based richtlijnontwikkeling)
GIN = Guidelines International Network
GRADE EtD = Grades of REcommenadation, Assessment, Development and Evaluation Evidence to Decision
ILO = intended learning outcomes
RACI = Responsible, Accountable, Consulted, and Informed

Declarations

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Authors' contributions

All authors contributed to the study conceptualisation and design. CdM, DD, MM, AP and DV contributed to the methodology and investigation. CdM carried out the formal analyses, visualised the data, administered the project and prepared the original draft. All authors contributed to the review and editing of the manuscript and approved the final version. MM acquired the funding.

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Data availability

The survey conducted in this study is included in the Appendices. The data set analysed in this study is available on request from the corresponding author.

Ethics approval and consent to participate

This study was reviewed and approved by the Maastricht University Faculty Health, Medicine and Life Sciences Ethics Review Committee (ID: FHML-REC/2023/120). All participants were informed of the purpose of the study at the start of the survey and gave their consent. This manuscript has been compiled in accordance with the CHERRIES checklist (Appendix 1).

All authors gave consent for publication.

Competing interests

The authors declare no competing interests.

Appendix 1: Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Checklist Item	*Explanation*	*Section*
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample? (In "open" surveys this is most likely.)	Participants and Data collection and analysis
IRB approval	Mention whether the study has been approved by an IRB.	Declarations
Informed consent	Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?	Data collection and analysis
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	Data collection and analysis
Development and testing	State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.	Data collection and analysis
Open survey versus closed survey	An "open survey" is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).	Closed survey
Contact mode	Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)	Participants and Data collection and analysis
Advertising the survey	How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.	N/A
Web/E-mail	State the type of e-survey (eg, one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?	Participants and Data collection and analysis

Appendix 1: Continued

Checklist Item	*Explanation*	*Section*
Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site	N/A
Mandatory/ voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?	Participants
Incentives	Were any incentives offered (eg, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?	N/A
Time/Date	In what timeframe were the data collected?	Data collection and analysis
Randomization of items or questionnaires	To prevent biases items can be randomized or alternated.	N/A
Adaptive questioning	Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.	Appendix 4
Number of Items	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.	Appendix 4
Number of screens (pages)	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.	Appendix 4
Completeness check	It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if "yes", how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as "not applicable" or "rather not say", and selection of one response option should be enforced.	Participants could follow their progress via a bar at the top of the survey. All questions were non-mandatory to answer.

Appendix 1: Continued

Checklist Item	*Explanation*	*Section*
Review step	State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).	Yes
Unique site visitor	If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.	Each participant got their own participation code.
View rate (Ratio of unique survey visitors/ unique site visitors)	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.	N/A
Participation rate (Ratio of unique visitors who agreed to participate/ unique first survey page visitors)	Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called "recruitment" rate.	N/A
Completion rate (Ratio of users who finished the survey/users who agreed to participate)	The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition. Note that "completion" can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word "completeness rate".)	All participants completed the survey.
Cookies used	Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A

Appendix 1: Continued

Checklist Item	*Explanation*	*Section*
IP check	Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A
Log file analysis	Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.	N/A
Registration	In "closed" (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?	N/A
Handling of incomplete questionnaires	Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?	N/A
Questionnaires submitted with an atypical timestamp	Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined.	N/A
Statistical correction	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.	N/A

This checklist has been modified from Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res. 2004 Sep 29;6(3):e34 [erratum in J Med Internet Res. 2012; 14(1): e8.]. Article available at https://www.jmir.org/2004/3/e34/; erratum available https://www.jmir.org/2012/1/e8/. Copyright ©Gunther Eysenbach. Originally published in the Journal of Medical Internet Research, 29.9.2004 and 04.01.2012.

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Appendix 2: Intended learning outcomes

Appendix two describes the developed intended learning outcomes (ILOs) at the different levels of the RACI-matrix. The ILOs used to create the guideline development training for panel members are highlighted in green.

Module 1: Guidelines		
Topic 1: What Are Guidelines and Their Purpose		
	R	A
ILO		
Potential audience		
Topic 2: Guideline Development Process		
	R	A
ILO	Participant is able to explain what the guideline development process will entail for their guideline project.	Participant is able to ensure that all tasks/roles that need to be fulfilled in the guideline development process are assigned.
Potential audience	Project lead, methodologist, chair	Project lead
Topic 3: Guideline Quality Criteria Based on AGREE-II/AQUA Criteria		
	R	A
ILO	Participant understands the integration of the AGREE-II criteria into the different phases of the guideline development process.	Participant can describe the AGREE-II criteria that a guideline must adhere to. Participant is able to determine if a guideline meets the AGREE-II criteria.
Potential audience	Methodologist	Project lead

	C	I
	Participant understands what a guideline entails and what the intended purpose of a guideline is.	Participant understands what a guideline entails and what the intended purpose of a guideline is.
	Panel member, chair, junior methodologist	Interested parties

	C	I
	Participant is able to describe their task(s) in the guideline development process.	Participant understands how the guideline development process takes place.
	Panel member	Panel member, chair, junior methodologist

	C	I
	Participant understands that a guideline must adhere to the AGREE-II criteria and understands the criteria.	Participant is able to state that a guideline must adhere to AGREE-II criteria or the AQUA guideline.
		Panel member

Topic 4: Conflicts of Interest		
	R	A
ILO	Participant understands the importance of declaring interests and the consequences of not declaring them (regarding the guideline development process). Participant is able to declare their interests and to identify potential conflicts of interest.	Participant is able to discern possible conflicts of interest for the guideline development process on the basis of the declaration of interest forms. Participant is able to determine (counter) measures to eliminate (the appearance of) conflicts of interest in the guideline development process.
Potential audience	Panel member, chair	Project lead, conflict of interest committee
Topic 5: Division of Tasks in Guideline Development		
	R	A
ILO	Participant is able to describe their role and responsibilities as guideline panel members, as well as those of the other members.	Participant is capable of moderating dialogue about the task/role allocations/division for the guideline development process.
Potential audience	Panel member	Chair, project lead
Topic 6: Good Communication and Bringing Perspectives Together		
	R	A
ILO	Participant ensures all panel members has the chance to speak and participate. Participant is able to analyse, summarise, and weigh the panel members perspectives so that the panel can reach a well-balanced consensus.	Participant ensures all panel members has the chance to participate/speak. Participant is able to summarise the viewpoints expressed by the panel members.
Potential audience	Chair	Project lead, methodologist

	C	I
	C	I
	C	I
	Participant understands how active listening and constructive dialogue between panel members enhances guideline quality. Participant is capable of expressing their own perspective while taking into account the perspective and input of their stakeholders (e.g., patient and/or healthcare professional societies). Participant remains open to perspectives of other panel members and can engage in constructive and respectful dialogues.	
	Panel member	

Module 2: Key questions		
Topic 1: Identifying and Prioritising Problem Areas		
	R	A
ILO	Participant is capable of collecting relevant problem areas to the guideline by consulting their stakeholders (e.g., patient and/or healthcare professional societies).	Participant can verify that the collected problem areas are suitable to include in the guideline.
	Participant is able to make a prioritisation of the collected problem areas for the guideline.	
Potential audience	Methodologist, guideline development organisation, project lead, panel member	
Topic 2: From Topic Selection to Key Questions		
	R	A
ILO	Participant is able to refine a problem area into a key question, while considering the perspectives and knowledge of the panel members.	Participant is able to assess if key questions (and PICO) and the related outcome measures are appropriate for guideline development. Participant ensures that all participants have the opportunity to share their input when formulating the key question and PICO.
Potential audience	Guideline methodologist	Project lead

Module 3: Summary of Scientific Evidence (for interventions using GRADE)		
Topic 1: Summary of Scientific Evidence		
Topic 1.1: Summary of Scientific Evidence – Literature Search		
	R	A
ILO	Participant is capable of performing a systematic literature search based on the formulated PICO question.	Participant verifies systematic literature searches are conducted in line with the PICO question.
Potential audience	Literature specialist	Project lead, methodologist

	C	I
	Participant contributes subject-matter expertise during the collection of problem areas.	Participant understands how the problem areas are identified and collected. Participant can indicate considerations to contemplate when prioritising problem areas.
	Relevant stakeholders	Panel member, relevant stakeholder

	C	I
	Participant is able to explain how a problem area is formulated into a key question and the corresponding PICO. Participant is able to provide feedback on formulated key questions based on their content knowledge and expertise. Participant is able to share their perspective regarding the key question to be formulated.	Participant knows the researched topic in the guideline based on the key question.
	Panel member	End-users of the guideline

	C	I
	Participant can provide input to help shape the systematic literature search strategy.	Participant understands the purpose and process of a systematic literature search.
	Panel member	Panel member, methodologist

Topic 1.2: Summary of Scientific Evidence – Literature Selection		
	R	A
ILO	Participant is able to select appropriate literature for the guideline using the established in- and exclusion criteria based on the PICO.	Participant verifies that the literature selection has been performed correctly.
Potential audience	Panel member (sometimes), methodologist	Methodologist, project lead
Topic 1.3: Summary of Scientific Evidence – Data Extraction/Summarising Study Characteristics		
	R	A
ILO	Participant is capable of extracting and summarising relevant information/study characteristics from the selected studies.	Participant ensures relevant study information is extracted and summarised correctly.
Potential audience	Methodologist	Project lead
Topic 1.4: Summary of Scientific Evidence – Meta-Analysis		
	R	A
ILO	Participant is able to conduct a meta-analysis based on the included studies.	Participant oversees whether a meta-analysis has been correctly performed based on the included studies.
Potential audience	Methodologist	Project lead
Topic 2: Appraising and Grading the Evidence with GRADE		
Topic 2.1: Determining the Quality of Evidence		
	R	A
ILO	Participant is capable of assessing the quality of included studies using the GRADE methodology.	Participant ensures that GRADE assessments are correctly conducted.
Potential audience	Methodologist	Project lead, methodologist

	C	I
	Participant understands why certain studies are included based on the PICO.	
	Panel member	

	C	I
		Participant is able to describe how and why relevant information/study characteristics were extracted.
		Panel member

	C	I
		Participant is able to explain what a meta-analysis and why it is used. Participant is able to interpret the results of a meta-analysis.
		Panel member

	C	I
		Participant understands how studies quality is collectively assessed using the GRADE methodology. Participant can name the five GRADE criteria for downgrading evidence (risk of bias, imprecision, inconsistency, indirectness, and publication bias).
		Panel member

Topic 2.2: GRADE Evidence Table		
	R	A
ILO	Participant is capable of formulating conclusions from literature using GRADE and the panel members subject-matter expertise.	Participant ensures that literature conclusions are made using GRADE.
Potential audience	Methodologist	Project lead

Module 4: From Evidence to Recommendations (GRADE EtD)

Topic 1: GRADE Evidence to Decision (EtD) Framework		
The various factors that need to be considered to develop a recommendation according to the GRADE EtD: (1) quality of evidence, (2) balance of desirable and undesirable effects, (3) values and preferences of patients (and professionals), (4) cost considerations, (5) acceptability, (6) feasibility and (7) equity.		
	R	A
ILO	Participant is able to formulate considerations/judgements for each factor of the EtD framework together with the other panel members. Participant can listen to and discuss considerations/judgements brought forward from other perspectives.	Participant checks whether considerations/judgments have been formulated for each EtD factor.
Potential audience	Panel member	Methodologist

	C	I
	Participant is able to discuss the literature conclusions, e.g. in the GRADE evidence table, from the perspective of their expertise.	
	Panel member	

	C	I
	Participant knows the GRADE EtD factors used to formulate considerations/ judgments in a guideline.	

Topic 2: Formulating Recommendations		
	R	A
ILO	Participant is able to describe the appropriate strength of a recommendation based on the EtD framework. Participant is capable of drafting recommendations using the EtD framework and the panel members' (subject-matter) expertise. Participant can weigh the perspectives of the panel members and integrate them into a recommendation. Participant can discuss the recommendations with the panel members, using their relevant expertise and the EtD framework.	Participant moderates the dialogue on the strength and wording of the recommendations. Participant verifies whether all components of the EtD framework have been described. Participant is able to judge whether the formulated recommendation answers the key question.
Potential audience	Panel member, methodologist	Methodologist, project lead

Module 5: GRADE EtD Factor: Cost considerations

In the GRADE Evidence to Decision framework, one of the factors is *cost considerations*—sometimes also referred to as *resource use*. In guidelines, cost considerations are examined to refine recommendations, provide stronger justification, or differentiate them for specific subgroups of care users [22].

Cost considerations may involve various components, such as the economic/financial costs of an intervention or the resource capacity it requires [22]. Economic evaluation studies can provide insight into the relationship between the effectiveness of an intervention and the (economic/financial or capacity-related) costs needed to achieve that effect [172]. Examples of such studies include cost-effectiveness analyses and budget impact analyses (BIA).

	C	I
	Participant is able to explain how the EtD framework is used to formulate recommendations.	
	Panel member	

Topic 1: What are Cost Considerations		
	R	A
ILO	Participant knows the basic principles of how cost information is reported in studies (study design, outcome measures, reporting of results) relevant for decision-making in guidelines. Participant is able to explain potential cost considerations relevant for decision making in guideline development. Participant is capable of contributing their (clinical) expertise toward identifying potentially relevant cost aspects for the guideline.	Participant ensures that cost considerations are properly included in the guideline.
Potential audience	(Specialised) methodologist	Project lead
Topic 2: Why Include Cost Considerations in Guidelines		
	R	A
ILO	Participant is able to explain how cost considerations contribute to how guideline recommendations are substantiated.	Participant is able to explain why cost considerations are included in guidelines.
Potential audience	Methodologist	Project lead

	C	I
	Participant knows the basic principles of how cost information is reported in studies (study design, outcome measures, reporting of results) relevant for decision-making in guidelines. Participant is able to share ideas about potential cost aspects relevant for the guideline.	Participant knows potential cost aspects affecting decision-making in guideline development.
	Panel member	Interested party

	C	I
	Participant understands the importance of considering costs in guidelines. Participant understands how cost considerations help the justification and formulation of guideline recommendations.	Participant understands the importance of including cost considerations in guidelines.
	Panel member	Interested party

Topic 3: How to Include Cost Considerations in Guidelines		
Topic 3.1: Conducting Economic Evaluations		
	R	A
ILO	Participant is able to collect relevant cost-related data for the guideline from the chosen perspective. Participant is able to conduct economic evaluations to assess the impact of different interventions and diagnostic options from the chosen perspective.	Participant ensures that cost considerations are included in the guideline. Participant ensures that cost considerations are accurately reported in the guideline.
Potential audience	Methodologist, project lead, chair	Project lead
Topic 3.2: Considering Costs in Formulating Recommendations		
	R	A
ILO	Participant is able to interpret and appraise economic evidence (e.g., using the CHEC checklist) and relate it to clinical practice. Participant is able to incorporate the results from cost-effectiveness studies (e.g., ICER, QALY) into judgments on the strength and direction of the recommendation.	Participant ensures that cost considerations are included in the guideline.
Potential audience	Panel member, methodologist, project lead, chair	Project lead

	C	I
	Participant is familiar with the different perspectives (e.g., societal, patient) that can be applied to cost considerations. Participant knows when and how cost considerations can be included during the guideline development process.	Participant knows how cost considerations have been included in the guideline.
	Panel member, health economist	Interested party

	C	I
	Participant is capable of explaining the limitations and uncertainties of economic models and evaluations. Participant is able critically appraise economic evidence (using the CHEC checklist).	Participant knows how cost considerations have been included in the guideline.
	Methodologist, health economist, specialised methodologist	Interested party

Appendix 3: Digital interim module surveys

Likert-scale questions based on the learning goals are at the end of each digital module. Likert-scale: completely disagree, disagree, neutral, agree, completely agree.

Module 1: Guidelines

1. The e-learning taught me the purpose of a clinical guideline.
2. The e-learning provided insight into the steps of clinical guideline development.
3. The e-learning provided insights to the various roles and tasks involved in guideline development.
4. The e-learning helped me understand what my role and tasks will be during the clinical guideline development process.
5. The e-learning has helped me understand what conflicts of interest may arise in the context of guideline development.

Module 2: Key questions

1. The e-learning has helped me understand the various ways in which practice-related issues/barriers can be identified.
2. The e-learning has helped me indicate the considerations involved in prioritising the practice-related issues.
3. The e-learning helped me to understand how key questions are formulated based on a practice-related specific issue.
4. The e-learning has helped me indicate what the PICO elements are of a key question.

Module 3: Summarising Scientific Evidence (for interventions using GRADE)

1. The e-learning enabled me to understand why a systematic literature review is necessary.
2. The e-learning enabled me to understand how a systematic literature review is conducted.
3. The e-learning enabled me to understand the selection of relevant scientific literature is determined by the PICO.
4. The e-learning enabled me to describe what information about outcomes and study characteristics are essential in a study.
5. The e-learning enabled me to name what can be investigated using a meta-analysis.
6. The e-learning enabled me how to interpret the results of a meta-analysis.
7. The e-learning enabled me to indicate how scientific articles are assessed using GRADE.

Module 4: From evidence to recommendations (GRADE EtD)

1. The e-learning has taught me which Evidence to Decision (EtD) factors must be considered when drafting a recommendation.
2. The e-learning enabled me to explain how the EtD framework assists in formulating recommendations.
3. The e-learning enabled me to determine the strength of a recommendation.
4. The e-learning enabled me to indicate the appropriate formulation of a recommendation, depending on its strength.

Module 5: GRADE EtD Factor: Cost considerations

1. The e-learning taught me which cost-related aspects are relevant to clinical guidelines.
2. The e-learning helped me understand why it is important to include cost-related aspects in clinical guidelines.
3. The e-learning enabled me to understand how cost-related aspects can support recommendations.
4. The e-learning enabled me to identify the various perspectives for determining cost-related aspects (e.g., societal perspective, patient perspective).
5. The e-learning enabled me to interpret economic evidence.
6. The e-learning enabled me to incorporate economic evidence into a clinical guideline.

General Questions for each module

1. Which element of the e-learning module x did you find the most valuable, and why?
2. Which element of the e-learning module x did you find the least valuable, and why?
3. Is there anything you would like to add about your experience with e-learning module *x*?

Appendix 4: The post-training survey

Dear panel member,

In recent months, you have been involved in the development of a guideline supported by the just-in-time guideline development training. This training is part of a research project on training for guideline development.

With this survey, we would like to gain insight into your experiences with the training.

Your responses will help improve and further development of the training.

The survey consists of five general questions and 18 multiple-choice questions specifically about the training.

When you did not follow the training, your input is still valuable, as the survey includes six questions for participants who did not attend the training.

Completing the survey will take approximately 10–15 minutes.

Participation is entirely voluntary and may be discontinued at any time.

Responses will be anonymised and cannot be traced back to you.

The data will be stored and processed in accordance with Maastricht University's regulations. Only the principal investigators, Marian Majoie and Chloé de Mortier, will have access to the raw data.

If you have any questions or comments about the research or the survey, please contact Chloé de Mortier at: c.demortier@maastrichtuniversity.nl

By completing the survey, you automatically agree to the following points (click for info) *

Thank you in advance for your time and participation.

On behalf of,

Chloé de Mortier (PhD Candidate), Marian Majoie (Neurologist and Professor, Academic Centre for Epileptology Kempenhaeghe/Maastricht UMC+), the research team and your guideline development organisation

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1. What was your role in the guideline development process?
- o Guideline methodologist
- o Project lead
- o Panel member: healthcare professional
- o Panel member: chair
- o Panel member: patient representative
- o Other: …

2. For which organisation did you develop the guideline:
- o Option 1
- o Option 2
- o Option 3
- o Option 4
- o Option 5

3. How often have you participated in a guideline development process?
- o This is the first time
- o This is the second time
- o This is the third time
- o More than three times

4. Which digital module(s) did you follow? Select all that apply. [multiple options]
- Module 1
- Module 2
- Module 3
- Module 4
- Module 5
- None

5A. [display logic: If 'None' is not selected and fewer than five options are selected at question 4] Could you indicate why you did not follow all digital modules? (open-ended question)

5B. [display logic: If 'None' was selected at question 4] Could you indicate why you did not follow any digital modules? (open-ended question)

----

6. [Display logic: After question 5B; Skip logic: to the end of the survey] What would be a reason to follow the training? (open-ended question)

Below are three general statements about training. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

1. The training taught me something new
2. The time investment for the training was too much
3. The training helped me better understand the guideline development process

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Below are three statements about training. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

4. The training suited my role and tasks in the development of the guideline.
5. The examples in the training were realistic
6. The training made me feel better prepared to perform my tasks in the development process.

Below are three statements about training. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

7. The diverse backgrounds of the panel members helped me view the guideline content from multiple perspectives.
8. I was able to share my thoughts with the panel.
9. The training helped facilitate discussion about different ideas and opinions during the panel meetings.

Below are two statements about training. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

10. The combination of online preparatory assignments and in-person training during the panel meetings supported my learning.
11. The online modules provided me with the knowledge needed to actively participate in the panel meetings.

We tried to offer the training elements at the moment you needed them during the development process. We call this the "right" moment.

Below are two statements about training at the 'right' time. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

12. The online modules and in-person training sessions were delivered at the 'right' moment.
13. Receiving the training at the 'right' moment helped me apply the knowledge I had learned.

Below are four statements about training. Please indicate to what extent you agree with the following statements. [Likert scale; Completely disagree – disagree – Neutral - Agree – completely agree – Not Applicable]

14. The assignment challenged me to actively engage with the learning material.
15. Applying the knowledge, I gained to my guideline helped me learn better.

16. The training helped me better understand why it is important to include cost considerations in guidelines.
17. The training encouraged me to think about how cost considerations can be included in my guideline.

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25. Do you have any tips, tops or other comments in regards to the training? Please feel free to share your feedback below. [open-ended question]

Thank you for completing the survey!

Your input will help us further develop the training.

**1. I have read the participant information for this survey. I have had the opportunity to ask questions. My questions have been answered. I have had enough time to decide whether or not I want to participate in the survey. 2. I understand that my participation is entirely voluntary. I understand that I may stop completing the survey at any time, without giving a reason. 3. I understand that the survey is anonymous. 4. I understand that the principal investigators (Marian Majoie and Chloé de Mortier) have access to my submitted data. 5. I give permission for the use of my data for the purposes described. 6. I give permission for my responses to be stored for future research for a maximum of 15 years after the conclusion of this study. 7. I agree to participate in this study*



Chapter 6

One size does not fit all: why guideline panels need context-tailored education – a case study



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Under review

Abstract

Introduction: Guideline development is a complex, multidisciplinary process in which panels formulate recommendations. Many panel members have limited formal training before participating in a panel, even if this can enhance their competencies. There is a wide variety in guidelines and healthcare contexts for which guidelines are developed. Currently, it is unclear how contextual factors shape guideline development processes and panel members' learning needs. This study examined how contextual factors influence the learning needs of panel members in guideline development.

Methods: We conducted a qualitative multiple-case study of five Dutch multidisciplinary guideline projects supported by a newly developed training programme. Panels were followed longitudinally from their first meeting to the final training session (March 2024–June 2025). Semi-structured interviews were conducted with eighteen panel members and ten project leads. Data were thematically analysed using an iterative inductive–deductive approach, with the levels of Bronfenbrenner's social-ecological model as sensitising concepts.

Results: Three interrelated themes shaped learning needs. First, the guideline topic influenced panel composition, methodological choices, and the extent to which panels had to rely on expert judgment due to limited or low-certainty evidence. Second, participation dynamics**,** including individual characteristics (i.e. confidence and prior experiences), hierarchy, and psychological safety, affected engagement and whose expertise was integrated into the guideline. Third, task allocation varied substantially between projects, particularly regarding involvement in evidence appraisal and drafting recommendations, resulting in different competency requirements. Meeting formats (online versus in-person) further shaped interaction and learning. Importantly, the themes interacted; for example, topic-driven methodological demands shaped task allocation and participation, while participation dynamics influenced topic (key question) prioritisation.

Discussion: Methodological competence alone is insufficient for effective participation in guideline development. Learning needs arise from the combined influence of the guideline topic, participation dynamics, and task allocation. Training initiatives should therefore adopt a flexible, context-sensitive, and role-specific approach.

Practice points

- Guideline training should be flexible, modular and context-sensitive, addressing methodological and social aspects of development.
- Training needs vary per guideline project.
- Guideline topics influence panel composition and methodological approach. The amount of available evidence varies per guideline topic.
- Psychological safety, hierarchy, self-confidence and experience affect participation. Chairs can enable inclusive dialogue.
- Task allocation varies across projects, creating different competency requirements and learning needs.

Introduction

Guideline development is a complex process involving expert panels composed of healthcare professionals and patient representatives. However, many guideline panel members lack formal training in guideline development, whilst training can help them be better prepared for their roles and tasks [54, 173]. A previously developed training, focusing on methodological and process-related aspects of guideline development, was positively received, and panel members reported they felt better prepared [173]. Guideline projects vary because they are developed for different healthcare contexts [30, 173]. However, it remains unclear how contextual factors in these different projects shape the learning needs of panel members. A better understanding of these factors is essential to tailor training to diverse guideline projects, strengthening panel members' preparedness and ultimately improving the quality of guidelines.

Over time, the guideline development methodology has changed [77, 174]. The Grading of Recommendations Assessment, Development and Evaluation Evidence to Decision (GRADE EtD) framework, widely used in guideline development, requires consideration of factors such as benefits and harms of the options, cost-effectiveness, patient preferences, and equity [30, 33]. In addition, recent discussions have emphasised the inclusion of planetary health considerations when formulating recommendations [32, 33]. These developments have broadened the range of competencies expected of guideline panel members, who must now consider multiple non-clinical factors alongside their (clinical practice) expertise when making recommendations.

Context is a dynamic concept that affects both education and guideline development. Educational theory emphasises that learning is more effective when adapted to learners' contexts, a principle known as contextual learning [65, 169]. Contextual learning underlines the importance of authentic tasks that bridge knowledge and practice, encouraging learners to transfer knowledge to real-world settings [65, 169]. To facilitate contextual learning in guideline development, it is essential to understand the contextual factors that influence the guideline development process. The Bronfenbrenner's social-ecological model, originally developed to understand child development, has been widely applied in health and social sciences to help understand contextual factors [175, 176]. The model conceptualises the interplay of interconnected systems operating at multiple levels: individual, interpersonal, organisational, community, and public policy [177]. The model highlights that contextual factors across levels are interdependent: changes at higher levels, such as policy, can cascade down to affect individuals and generate new training needs [178]. In this study, we define contextual factors as the (in)voluntary elements that

influence the work/role(s) and educational needs of panel members during guideline development. These contextual factors define the conditions training must consider to align with the real-world practice of guideline development.

Despite the increasing complexity of guideline development and recognition of the importance of context-sensitive training, there is limited understanding of how contextual factors shape guideline development processes and, in turn, influence the training needs of guideline panel members. Adapting training to project-specific circumstances helps maintain core learning objectives while ensuring relevance to panel members' learning needs. By contrast, rigid adherence to a fixed training design may hinder learning when training elements do not align with panel members' needs [178]. A context-sensitive approach can therefore enhance support for panel members without compromising the overall aims of the training [178]. To address this gap, this study aimed to answer the following research question: How do contextual factors affect guideline panel members during the guideline development process and influence their learning needs?

Methods

Design

We adopted a qualitative multiple-case study approach to explore how contextual factors shape the learning needs of guideline panel members during guideline development [179, 180]. This approach was chosen as it enabled an in-depth description and analysis of guideline development processes of Dutch multidisciplinary guideline panels situated in their real-life setting. The Consolidated Criteria for Reporting Qualitative Research (COREQ) were used to guide the reporting of the methods and results (Appendix 1) [38].

Setting

In the Netherlands, panel members, methodologists, project leads and supporting experts collaboratively develop guidelines. Commonly, the panel members form a multidisciplinary team that includes healthcare professionals from various disciplines, patient representatives, researchers and chairs. The project leads support the panel regarding project management and the development process; they can also fulfil a role as guideline methodologist [159]. Additionally, external experts (e.g., literature/information specialists, ethicists, implementation experts, and health economists) may provide additional support. In some guideline projects, a sounding board provides input at certain stages during the development process.

Dutch guidelines are developed according to the AQUA agreement [22], based on the international Appraisal of Guidelines for REsearch and Evaluation (AGREE) II criteria [18] and the Institute of Medicine [9]. The guideline development process includes three phases: preparation, development, and finalisation. During the preparation phase, the guideline topic and target audience are defined. Next, the guideline panel is assembled, and potential conflicts of interest are reviewed. Problem areas to be addressed in the guideline are selected and formulated into key questions [22, 27].

In the development phase, evidence to answer the key questions is systematically searched. If relevant literature is available, it is assessed using the GRADE methodology [26, 75]. The scientific evidence is complemented by clinical practice and patient input. The strength of recommendations is determined by considering factors such as the balance of benefits and harms, patient values and preferences, quality of evidence, resource use, cost-effectiveness, equity, acceptability, and feasibility [22, 29, 30].

In the finalisation phase, the draft guideline is shared with relevant organisations (e.g. healthcare professional societies, patient organisations and healthcare insurers) for written feedback. Finally, the guideline undergoes an authorisation process, requiring approval from the relevant healthcare professionals' organisations and patient organisations before publication [22].

Participants

The guideline development projects included in this study were multidisciplinary and initiated by different healthcare professional societies. All projects were supported by a newly developed training program for panel members. Healthcare professional societies enrolled their panels in the training program after participating in its development or hearing about it at conferences [173]. The training was developed based on five design principles: active, blended, contextual, just-in-time and collaborative learning. The training consisted of five e-learning modules alternated with in-person training moments during the panel meetings. The modular structure allowed the training to be aligned with the varying guideline project timelines [173].

The panel members and project leads of included guideline projects were invited to participate in an interview via e-mail two weeks before the final in-person training session, with face-to-face reminders during the final live session and two e-mail reminders afterwards. The goal of the study was explained during the first training session, as well as in the invitation to the interviews. Participation in both

the training and study was voluntary and had no bearing on their involvement in the guideline development projects. Participants did not have to complete any or all training elements to participate in an interview.

Data collection

Participating guideline panels were attended by researchers CdM, DD and/or DV from their first meeting until the final in-person training session, between March 2024 and June 2025. During these meetings, field notes were taken. Individual semi-structured interviews with healthcare professionals and project leads were conducted approximately two months after the training's final meeting, between March and July 2025, by CdM. Two patient representatives were interviewed together by CdM in November 2025 with the support of two representatives of Dutch patient societies. The interview guides, one for panel members and one for project leads, were based on the guideline development phases (Appendix 2).

Three pilot interviews were conducted to test the interview guides with project leads unrelated to the participating guideline panels. Project leads assumed their usual role or were asked to imagine themselves as a panel member. No changes to the interview guides were made after the pilots. Interviews were conducted via videoconference (Microsoft Teams). All interviews were audio-recorded, transcribed verbatim, and anonymised to ensure participants' anonymity. Participants provided both oral and written informed consent. Participants were allowed to review and correct their interview transcripts.

Data-analysis

In this study, Bronfenbrenner's social-ecological model was utilised as a sensitising concept to analyse and construct contextual factors affecting panel members during the guideline development process and their training needs [181, 182]. The framework provided a holistic lens to analyse the complex reality of guideline development, rather than a narrow focus on only the direct factors related to the individual panel members. Table 1 describes how we operationalised the different levels of the socio-ecological model for the current study.

The interviews were thematically analysed using an iterative inductive-deductive approach guided by the principles of Braun and Clarke [183]. CdM conducted the interviews simultaneously with the first data familiarisation and coding. As an initial analytical step, all interviews were coded independently by CdM and MKH, using the guideline development steps and the levels of the socio-ecological model [181] as sensitising concepts to organise the data [184].

Table 1. The different levels of the socio-ecological model as operationalised in this study.

Individual	This level refers to personal characteristics that influence behaviour, such as knowledge, attitudes, motivation, skills, beliefs, and demographical characteristics.
Interpersonal	This level concerns the social relationships and interactions between the individuals involved in the guideline development process.
Organisational	This level concerns the role guideline development organisations have in relation to setting structures for the guideline development process.
Community	
Guideline	This level captures the broader community of guideline development, including collaborative networks, methodological standards and norms for evidence use.
Healthcare profession	This level refers to the professional communities of healthcare practise, encompassing shared norms, disciplinary traditions, and collective needs/expectations of guidelines.
Public policy	This level relates to the wider policy environment, including (inter) national policies, legalisation, political priorities and funding structures.

Subsequently, coding moved beyond these primary codes through iterative discussion, continuous comparison of codes and engagement with the reflexive notes. Disagreements between CdM and MKH were resolved through discussion and by consulting an additional researcher (DV and/or DD). Themes were constructed inductively beyond the initial coding scheme, capturing patterns grounded in participants' experiences. The constructed themes were discussed first within a smaller team (DD, DV, MKH and CdM), then with the whole research team, and further refined.

The refined themes and codes were applied to subsequent interviews, and earlier transcripts were revisited to ensure coherence. Finally, the written report was developed, during which the themes were further shaped and linked to the learning needs of panel members as interpreted by the research team [146, 183]. The analysis was conducted in Atlas.ti, version 25.

Reflexivity

The research team brought diverse disciplinary backgrounds that shaped the design and interpretation of this study. CdM, AP, MM, and DV are trained in educational sciences. CdM, MKH, DD, and MM had previous experience in guideline development research, and DD had expertise in implementation science and knowledge translation within healthcare settings. MM was a full professor in epilepsy and education, with extensive experience as chair of guideline development projects. AP is a full professor with experience in healthcare research, economics, and education.

All researchers except MKH were involved in developing the training programme that supported the guideline projects. CdM held multiple roles in this study: coordinating and delivering the training, observing panels, and acting as the main researcher. DD and DV acted as trainers and observers during the guideline training programme, which positioned them as partial insiders to the setting. Field notes were made to support reflexivity. MKH, a physician and care ethicist with experience in European guideline development and related research, contributed a broader international perspective on this study. Together, these different backgrounds functioned as complementary interpretive lenses during the study, with some researchers working closely with the data and others providing more analytical distance.

We recognise that our backgrounds might have influenced what we noticed during observations and how we interpreted panel members' experiences and learning needs. To enhance reflexivity, we engaged in regular team discussions to examine our assumptions, challenged early interpretations, and considered alternative explanations. Themes were therefore constructed through an iterative and collaborative process.

Results

Five multidisciplinary guideline panels across allied healthcare, nursing, specialised medical care, and long-term care participated in the newly developed training. In total, 28 interviews of 30-60 minutes were conducted with 18 panel members and 10 project leads from those projects. Part of an interview was excluded at the request of a participant due to the sensitive nature of that part. Most participants followed (part of) the training (86%) and had previous experience with guideline development (61%) or scientific research (82%). Each panel was composed of eight to twelve members representing diverse healthcare disciplines, and in some cases, a patient representative. Two to three project leads supported each panel. The composition and characteristics of the panels and interview participants are described in Tables 2 and 3.

Three main themes were constructed that shaped the learning needs of guideline panel members across the five guideline projects. The themes are the guideline topic, participation dynamics and task allocation and are interrelated as depicted in Figure 1. The following section will elaborate on each theme.

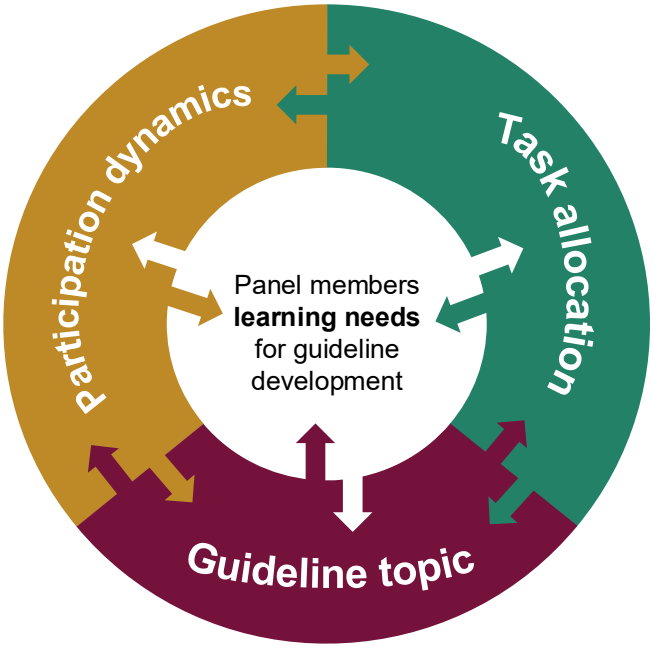

Figure 1. A visual representation of the three themes that affect the learning needs of guideline panel members in multidisciplinary panels.

Table 2. Case descriptions of the five guideline projects participating in this study.

	Description
Panel 1	This guideline focused on a psychosocial topic in both institutional and home care settings. It was the first time the initiating healthcare profession society produced a guideline on this topic. The panel consisted of twelve members from various healthcare disciplines. They were supported by two project leads at all times, with the role fulfilled by three different individuals over the course of the project. Finding a chair was challenging, and the panel initially started without one. A panel member agreed to take on this role on the condition that responsibilities would be shared with a project lead. The panel represented a mix of academically trained and practice-oriented professionals, including one member who had transitioned from clinical practice to research. The first panel meeting was held in person, while all subsequent meetings were conducted online.

Table 2. Continued

	Description
Panel 2	This guideline was jointly initiated and developed by two healthcare professional societies. It was a newly developed guideline focusing on a specific mobility-related condition. The panel included eleven members representing various healthcare disciplines, a representative of a patient organisation and was supported by two project leads, each affiliated with one of the initiating societies. During the development process, both project lead positions experienced turnover in the individuals fulfilling these roles. This influenced the continuity and coordination within the project, as well as extensive discussions on the definition of the guideline topic. The panel was chaired by a chair experienced in both guideline development and research. Most panel members were practice-oriented professionals, with a smaller group of academically schooled members. The patient representative had a prominent role in the patient organisation and a background as a healthcare professional. The first meeting was held in person, and subsequent meetings took place online.
Panel 3	This guideline was collaboratively developed by two healthcare professional societies and focused on conditions of an infectious nature affecting two patient populations. It concerned an update of an existing guideline. The panel consisted of nine panel members from multiple healthcare disciplines, supported by two project leads, one from each society, and alternating trainees. To ensure balanced representation, the project was co-chaired by representatives from both healthcare professional fields: one an experienced chair, the other assuming the role for the first time. The panel included both academically and practically educated members, as well as some members without a healthcare professional background. A slight delay occurred in the development process from waiting for the results of the literature review and an ongoing study. All meetings were conducted online.
Panel 4	This guideline addressed (in)formal care in both institutional and home settings, focusing on a holistic approach. The project consisted of a partial guideline update. The panel included twelve members from a range of healthcare disciplines, most with practical experience, complemented by researchers with clinical backgrounds. A patient representative joined the panel for one online meeting. The panel was supported by a senior project lead and two less experienced project leads. After half a year, the senior project lead was succeeded by a senior colleague. The chair was familiar with guideline development but had not previously chaired a panel. During the project, additional funding was secured to expand the guideline's scope, allowing more healthcare professionals to join several months after the project's start. This expansion resulted in a slight delay in the development process. Additionally, the expansion resulted in a more balanced mix of academically trained and practice-oriented members. The first panel meeting was conducted in person, followed by online sessions.

Table 2. Continued

	Description
Panel 5	This guideline concerned a partial guideline update on a condition requiring surgery, focusing on hospital-based care and subsequent aftercare. The panel consisted of twelve members from diverse healthcare disciplines, most of whom held a university-level education, and a patient representative with lived experience. The panel was supported by two project leads. The chair was experienced in leading guideline projects. All meetings were conducted online to enable participation across different regions in the Netherlands.

Table 3. Characteristics of the study participants.

	N	%
Guideline development panel (n=28)		
1	7	25
2	4	14
3	5	18
4	8	29
5	4	14
Role guideline development project (n=28)		
Project lead	10	36
Panel member (chair)	2	7
Panel member (healthcare professional)	12	43
Panel member (researcher)	2	7
Panel member (patientt representative)	2	7
Healthcare field of the healthcare professionals (n=12)		
Allied	2	7
Nursing	3	11
Mental	2	7
Medical specialist	5	18
Followed e-learning (n=28)		
Yes	17	61
Partially	7	25
No	4	14
Experience in guideline development (n=28)		
Yes	17	61
No	11	39
Experience in scientific research (n=28)		
Yes	23	82
No	5	18

Theme 1: How the guideline topic shapes learning needs

The topic of a guideline shaped guideline development in multiple ways. For example, it affected the methodological approach taken and the composition of the guideline panel. In our cases, healthcare professional societies initiated the development of a guideline in response to perceived needs in practice or the recognition that an existing guideline required updating. Potential problem areas were identified through input from professional and patient societies, surveys, focus groups, or panel members. Topic selection or prioritisation of key questions was sometimes affected by existing (inter)national guidelines, as alignment with these guidelines was actively sought. Furthermore, broader national policy also played a role in topic selection. Some participants noted that political priorities and funding conditions could influence which problem areas panel members chose to address. This was mentioned particularly in relation to preventive care. Training was noted to help discuss the impact of policy on guidelines.

> *"And this clashes a bit with the way things are right now, especially when it comes down to government funding. … That the preventive side of things, which we talked about yesterday, is really under pressure." (Panel member, healthcare professional, panel 1).*

> *"What I liked about the last [live training] session was that we also briefly discussed things like: what does this imply for possible societal changes, or what are the financial factors? … it was still good to realise: oh right, those are also factors we should take into account." (Panel member, healthcare professional, panel 1).*

Once a guideline topic was chosen, it directly shaped which perspectives and types of expertise were crucial to the guideline and, therefore, needed to be represented in the panel. Project leads described contacting relevant healthcare professionals and patient societies to ensure appropriate representation. Diversity across healthcare disciplines, as well as a balance in research- and practice-oriented expertise, was seen as a complementary strength. In some cases, a guideline was jointly initiated by two healthcare professional societies. One panel appointed a chair and vice-chair, each representing one society. *"So that they complement each other." (Project lead, panel 1)."*

Panel members were either directly invited or recruited through open calls issued by their professional or patient societies. During the early phase of panel formation, project leads sometimes discussed the panel composition with the chair

and/or existing panel members to assess whether all relevant perspectives were represented. These discussions occasionally resulted in the inclusion of additional disciplines later in the development process.

> *"I could not identify myself in all the problem areas. I almost started to think, like: gosh, is it [type of care] different in the north of the Netherlands than in the west or something? As you are dealing with different contexts, so to speak." (Panel member, healthcare professional, panel 3).*

Participants noted that the diversity within panels required training to be adaptable to the different (professional) backgrounds of the panel members.

> *"I have the idea that you already adjusted the training a bit for our panel and made it more accessible and not only medical specialist oriented." (Panel member, healthcare professional, panel 1).*

In addition to shaping panel composition, the guideline topic also influenced methodological choices during development. Participants described that the suitability of the GRADE approach depended strongly on the type of questions the panel chose to address. Conventionally, this method is well-suited for intervention-focused questions, where clinical trials or other quantitative evidence can be systematically assessed. However, participants described that when they wanted to address topics regarding diagnostics, prognostics, prognosis or organisation of care, this approach was less suited. Therefore, participants valued the adaptability of the training towards the type of questions they addressed.

> *"It was a topic that we already knew beforehand would be a difficult one, that defining its scope would be very challenging, and that there would also be many issues around diagnostics and prognosis. Which does not always neatly fit within the guideline methodology." (Project lead, panel 2).*

> *"We often first need to create an overview of: what risk factors are there? Or what treatments even exist? Before we can say: is A better than B? Or how should care be best organised? Those kinds, yes, those are the kinds of questions we are answering. And then it is just really difficult if you follow a training with that standard A–B comparison. To then translate that to these kinds of questions." (Project lead, panel 1).*

All guideline projects encountered challenges related to limited evidence. This was linked to, e.g., limited research within the patient population or care settings which the guideline covered. Additionally, it was stated that this was inherent to how guidelines are developed in the Netherlands, namely by focusing on problem areas. Limited evidence created uncertainty amongst panel members about whether recommendations could still be made, as a guideline often became more (clinical practice) expertise-informed. Participants indicated that training might help increase confidence when formulating recommendations if evidence is limited.

> *In the guideline, we focus on the things that are under debate, where there are still questions, and where the best course of action is uncertain. And that uncertainty, well, where does it come from? Because even internationally, and in the literature, it has often not been sufficiently studied." (Project lead, panel 5).*

> *"We try to indicate that the literature is not sacred. But I think that more emphasis might be needed on: how does the literature relate to expert opinion? And what if there is no literature? What does that then mean? Can we do nothing anymore? So, that should be really clearly explained, and they [panel members] can be made more comfortable with it [expert opinion]." (Project lead, panel 4).*

Theme 2: How participation dynamics shape involvement and learning needs

While the guideline topic influenced who participated in a panel, participants described that the way panel members participated was shaped by a combination of personal characteristics, interpersonal and group dynamics, and the formats through which contributions were organised.

Panel members noted that personal characteristics influenced their ability to engage in panel discussions. Confidence played an important role in participation, particularly in methodological discussions. Panel members without an academic or research background described difficulties in following methodological discussions concerning scientific methods and/or guideline development, which limited their contributions during meetings. A patient representative described similar challenges, as well as unfamiliarity with medical terminology. Prior experience with guideline development or research was described as strengthening self-confidence, as was perceiving oneself as a subject-matter expert. Training was seen as particularly valuable for panel members with less experience in guideline development or research.

> *"It really helped a lot to have already developed a guideline, because I remember at the start, I was really thinking what am I supposed to do here, what are they expecting from me, and what does this all mean." (Panel member, healthcare professional, panel 1).*

> *"In earlier guidelines, I have experienced that it could be really difficult if you were not academically schooled. Without putting science on a pedestal, because I mean, not every article is equally good. But understanding that better, as a non-academically trained professional, that is, I think, a major added value of this training." (Panel member, chair, panel 4).*

Beyond methodological familiarity and confidence, individual characteristics also shaped participation. More outspoken panel members were more likely to contribute during plenary discussions, whereas those who described themselves as modest or shy reported contributing less. "*The training is, of course, quite content-focused, but maybe a bit on soft skills might be handy. Yes, I can imagine that some might benefit from a piece on assertively." (Project lead, panel 4).* Panel members also indicated that their emotional state could affect their engagement, for example, during periods of stress or grief. Participants further described differing motivations for joining guideline panels, ranging from advocacy-oriented goals for patients or healthcare professionals to personal professional development goals, which may have shaped how they engaged in discussions.

> *"Yes, I think it is also my kind of modesty or shyness or inexperience, that makes me think: yes, do I really have anything important to say?" (Panel member, researcher, panel 1)*

> *"And in [healthcare field], we are with a smaller group, so that is also why I feel a bit more strongly that: Oh right, if I hear something that does not apply [to our healthcare field], then yes, I think it is important I speak up." (Panel member, healthcare professional, panel 1).*

Group dynamics within panels played a central role in shaping participation. Participants emphasised the importance of a psychologically safe environment in which differing perspectives could be expressed and taken seriously. The first live session of the training addressed collaboration agreements and norms between the panel members. Additionally, it supported setting clear expectations at the beginning of the project, which was seen as helpful for building initial trust. Participants indicated that the training thereby helped create a more psychologically safe environment.

> *"I have the feeling that, also because we talked about it [that everyone brings valuable perspectives] so explicitly, a safe environment was created in which everyone feels comfortable contributing their input — even if you completely disagree with each other in terms of opinions. I think that really worked. And I have to say that the chair also plays an important role in that." (Project lead, panel 2).*

> *"What I found very strong about the training is that at the beginning, we really took the time for it [getting to know one another]. Specifically: how will we collaborate? And what agreements are we making?" (Project lead, panel 2).*

Chairs were seen as key players in fostering a safe and inclusive environment by actively encouraging contributions, managing dominant voices, and legitimising diverse forms of expertise. For example, a patient representative noted that early reassurance and explicit acknowledgement of the value of their lived experience supported a feeling of belonging. In contrast, panels in which chairs dominated discussions by steering them towards their own viewpoints were described as less inclusive and characterised by stronger feelings of hierarchy. In some cases, this led to panel members reducing or withdrawing their participation. To prevent this, some guideline development organisations deliberately appointed a subject-matter independent chair.

> *"What really stands out compared to the other guidelines is that we have a chair who is not from the subject-matter side. So, they are very conscious about giving everyone a chance to speak, hearing everything, asking good follow-up questions, and therefore, I think, does not bring in their own conclusions, findings, or judgments." (Panel member, healthcare professional, panel 3).*

Being a chair may require additional competencies. For example, a first-time chair indicated they would have benefited from training specifically for this role and associated responsibilities.

> *"Maybe indeed a short module: what is actually expected from you as a chair? You know, something that focuses a bit more on that role." (Panel member, chair, panel 4).*

Panel members themselves could also influence the participation of other panel members. Participants noted that dominant behaviour by some panel members could limit others' willingness to share perspectives, while positive and constructive responses supported a safer environment for discussion. Trust between panel members was described as particularly important, as guideline development was often divided into sections requiring reliance on one another's professional judgement.

Pre-existing relationships (e.g., from previous collaborations) further shaped group dynamics. They facilitated communication and mutual understanding, but could also create perceived hierarchies within the panel. In a few cases, members joined later in the process, entering panels where relationships were already established.

> "*So even though [chair] leads them [the meetings] well and everything, you still sometimes think, well, I will just keep quiet for now, because others have not had a chance to speak yet." (Panel member, researcher, panel 4).*

> *"I feel that with [this guideline] there are already some existing relationships, or that some people might have already earned their place or whatever." (Panel member, healthcare professional, panel 3).*

Participation was not limited to plenary meetings. Project leads described offering multiple avenues for contribution, including subgroup work, written feedback via online platforms, surveys, email correspondence, and one-on-one consultations. These formats enabled participation by members who were less comfortable speaking during meetings. Panel members were expected to represent the broader perspective of their professional or patient communities. They described consulting their societies to inform their contributions and feel more secure in their role, although limited engagement from these societies was noted.

> *"I find that a pleasant way of working. Also, for example, when new things are introduced, you still have time to look at them calmly at home or at work later and give your input. … That you can sometimes still send in things afterwards, once you've thought about them a bit more or looked up some additional information." (Panel member, healthcare professional, panel 3).*

Finally, participants described how meeting formats influenced participation. Online meetings lowered practical barriers such as travel time, beneficial for panel members with limited availability. At the same time, in-person meetings were valued for fostering informal interactions and social cohesion, which were perceived as important for building trust and a sense of belonging.

> "*The interaction is easier. … If you have had a discussion and then you go have a cup of coffee together, you talk about something else for a bit. That creates a different kind of relatedness." (Panel member, healthcare professional, panel 4).*

Theme 3: How variation in task allocation shapes learning needs

Although guideline panels followed similar methodological steps, participants described variation in how tasks were assigned. These differences shaped the competencies required of panel members in the development process and, consequently, their learning needs.

> *"Sometimes those nuances [in approaching guideline development] can also differ from project to project within the same organisation, because each project may have slightly different needs." (Project lead, panel 4).*

Panels varied in the way panel members were involved in specific tasks such as literature searching, evidence appraisal, and drafting recommendations. In some projects, these tasks were largely undertaken by project leads or external organisations, with panel members providing feedback on draft outputs. In other panels, members were more directly involved in searching and appraising evidence or drafting written recommendations. Some project leads expressed a preference for greater involvement of panel members in the literature review or drafting recommendations, as they felt this enhanced panel members' sense of ownership and accountability for the guideline. *"You immediately place ownership with the panel." (Project lead 2, panel 2).* Such an approach required panel members to possess more extensive knowledge regarding scientific research and guideline development. On the other hand, a strong emphasis on academic competence was seen as a risk of overshadowing the practical insights of healthcare professionals who bring an essential practical-based perspective to the guideline.

> *"We want to develop guidelines for [healthcare professions]. You should not fill that process only with academics; you also need people who are really in the field, literally doing the work, even if they might not be that scientifically trained." (Project lead, panel 2).*

Decisions regarding task division depended on several factors, including the available budget, the expertise within the panel or healthcare professional society, and the preferences of individual members. Panel members' prior experience with guideline development or research influenced their willingness to take on certain responsibilities. As mentioned in Theme 1, most projects also organised subgroups for specific key questions. Project leads described actively seeking diversity within subgroups in terms of academic and practice-oriented perspectives and representation of relevant healthcare fields.

> "*This was basically done based on: who finds which topic the most interesting, so to speak. And also a bit of a division based on the types of clients people work with, so that you get a somewhat diverse picture, and on the healthcare professions themselves, as well. So, it is all a bit varied and mixed." (Project lead, panel 1).*

Furthermore, participants noted that task distribution is not static but evolved as guideline methodologies and organisational processes changed over time. In some panels, guidelines were developed using updated methodological approaches, requiring panel members to adapt to new processes. Shifts towards new guideline methodologies or procedural steps required panels to adapt to changing roles and patterns of involvement.

> *"There are panel members who have been [healthcare professionals] for many years. … So, they join a panel with certain expectations based on those older guidelines. But the way we now develop guidelines is very different from what they are familiar with." (Project lead, panel 2).*

Finally, multiple participants underscored the importance of establishing clear agreements and expectations at the start of the project regarding task allocation, time commitment, and responsibilities. Training and preparation materials helped clarify expectations and reduced feelings of uncertainty and inequality, supporting both healthcare professionals and patient representatives to understand their responsibilities within the panel. Explicit training on this helped:

> *"I really felt that we went through the process step by step, and that the training, the modules, fitted very well with each next step we took. So, if you know very little to begin with, it was set up in a really good way to still be able to follow it and, as a result, increase your sense of involvement. And when you feel more involved — even better — it also becomes easier to contribute, to share your views." (Panel member, patient representative, panel 2).*

> *"Well, for example, the first module was about: what is expected of me as a panel member? How often will we meet? How much time will it require? How will we communicate? And that it is made explicit that you do not always have to agree. So, I… and that, attention was given to how we would work together." (Project lead, panel 2).*

How the themes interact and shape learning needs

Although presented separately, the three themes influenced each other (Figure 1). The guideline topic shaped which perspectives and expertise needed to be represented. Which panel members then participated in the panel influenced which key questions were prioritised (Theme 1). How these key questions were selected was influenced by participation dynamics (Theme 2). These participation dynamics were shaped by personal characteristics (e.g., experience in guideline development or scientific research, assertiveness, group dynamics, pre-existing relationships and perceived hierarchies and chairs). This affected who contributed the most and how inclusive the discussions felt. Panels also adapted task allocation (Theme 3) to the available expertise and resources. At the same time, task allocation depended on the methodological approach required by the key questions, meaning that the topic indirectly shaped which tasks and competencies were needed and how responsibilities were distributed. Together, these interacting themes show that learning needs are not determined by a single factor, but emerge from the combination of topic-related demands, participation dynamics, and task division. Consequently, participants described training needs that go beyond methodological instruction, including support in clarifying roles and expectations, fostering psychologically safe and inclusive collaboration, and how to approach guideline development when evidence is limited or addresses key questions other than therapeutic intervention questions.

Discussion

Research on learning needs for guideline development has been limited. This study showed that methodological competence training alone is insufficient for effective and confident participation in guideline development, expanding on previous research on the needs of guideline panel members [60, 159]. Where the competency-based model by Sultan et al. primarily emphasises methodological competencies (e.g., question formulation, critical appraisal) [60], this study demonstrated that learning needs arise from the interaction between guideline topic, participation dynamics and task allocation. Their interactions created different learning needs for panel members in each project.

The nature of the guideline topic strongly shaped both panel composition and the methodological demands placed on panel members, thereby influencing their learning needs. In the Netherlands, panels typically comprise of ten to fifteen members with heterogeneous healthcare professional backgrounds and try to include a patient representative [22, 79, 159]. Members with research experience or prior familiarity with

guideline development felt capable of contributing to the process. In contrast, those with practice-based or lived experience struggled to follow methodological discussions and doubted the value of their contributions even when their contextual knowledge was essential. This confirms earlier findings that methodological literacy supports confidence [60, 159, 185]. However, our data also indicate that conventional training does not always match the actual methodological diversity required in panels [60]. Conventionally, guideline development methodology focuses heavily on intervention questions and quantitative evidence [50, 186]. However, guideline panels also work with questions related to organisation of care, diagnosis or prognosis, each requiring different competencies and tools (e.g., diagnostic GRADE tool, GRADE-Cerqual) [187-189]. Furthermore, the amount and type of available evidence further shaped learning needs. Although GRADE's Evidence to Decision framework allows panels to formulate recommendations when evidence is limited or of low certainty [50], many members felt insecure doing so. Because training and project leads tend to focus on interpreting evidence rather than on decision-making when scientific evidence is scarce [60]. As a result, members were unsure how to contribute when experiential or contextual knowledge became more relevant. As Dutch guidelines are developed from practice-identified problem areas, limited evidence is common [22, 50]. Together, these findings highlight the value of contextual learning, in which training is aligned with the specific methodological and learning demands of different guideline projects, enhancing panel members' learning [65, 169].

A second key finding is that participation was not solely determined by methodological knowledge. Individual characteristics (e.g., assertiveness, motivation), prior professional relationships, hierarchy, and group dynamics influenced whose voices were heard [185]. Psychological safety proved essential: members felt motivated to contribute when they felt listened to and taken seriously, while dominance by certain members led to withdrawal. These findings resonate with earlier work that showed that social dynamics influenced guideline recommendations [170]. Similar to the current study, Li et al. (2024) found that chairs played an influential role in facilitating safe learning and working environments [170]. Chairs could legitimise divergent viewpoints, but when taking a directive role, could reinforce hierarchy [170]. Our findings indicate that dedicated chair training could be beneficial to ensure inclusive and constructive guideline development processes due to their influential role. Additionally, offering multiple routes to contribute (e.g., via e-mail, small groups, one-on-one with project leads) helped panel members voice their input. Digital collaboration introduced new opportunities and challenges. Online meetings improved feasibility and accessibility to participate by reducing travel time. However, several participants described uncertainty or stress when using digital tools, highlighting digital literacy as an emerging learning

need. At the same time, members valued the trust and cohesion generated during in-person interactions, noting that informal conversations during breaks were important for relationship building. These findings reinforce that guideline development is inherently a collaborative process in which panel members learn with and from one another rather than individually, whilst they are jointly responsible for the final guideline. Training programs should therefore embed elements of collaborative learning in their design to support inclusive communication, integration of different forms of expertise, and constructive group deliberation.

The third mechanism shaping learning needs was how tasks were allocated within panels. Some guideline projects involved panel members more actively in literature reviewing, evidence appraisal, and drafting recommendations than others. This influenced the depth of methodological understanding required from panel members, and project leads believed this affected their sense of ownership. Indeed, educational research has shown that co-creation can enhance feelings of ownership [190]. A modular training program may be suitable, with shared core and optional (in-depth) modules. Panels can then select content and depth based on their task allocation, as well as their experience. Project leads supported panel members throughout the guideline project by creating clear expectations, enabling different forms of participation (e.g. one-on-one or (asynchronous) digital input), and collaborating closely with the chair. The importance of clear expectations and the coordinating role of project leads was reported as a facilitator of collaboration by Prematunge, et al. (2025) [185]. Notably, four of the five guideline projects experienced changes in project leadership. Although participants in our study did not explicitly state that leadership changes affected their participation or learning, previous research suggests that leadership turnover can affect learning and collaboration [191]. Given the role of project lead in shaping participation dynamics, it is relevant to examine how leadership transitions influence these dynamics. Furthermore, it would be valuable to investigate whether training project leads in these dynamics might foster inclusive participation. Finally, organisational transitions to different methodologies or process approaches could create new learning needs that require adjustments in training programs.

Implications for training and educational design

These findings indicate that training for guideline development should not follow a one-size-fits-all approach. A shared foundation remains important, including basic knowledge on core methodological principles (e.g., the GRADE EtD approach) [60, 185] and guidance on participation dynamics, given their influence on how panel members collaborate, contribute and make decisions [170, 185]. Training can support collaboration by explicitly valuing diverse perspectives, helping set collaboration agreements and

clarify expectations at the start of a project, and encouraging panels to revisit these agreements throughout. At the same time, training needs to be responsive to project-specific demands, for example, via selectable modules aligned to the guidelines' topic/key questions (e.g., intervention, organisation of care, etc.), the nature of the evidence base (e.g., limited (scientific) evidence, qualitative evidence, clinical practice expertise), and role- and task-specific responsibilities (e.g., chairing, appraising evidence). A modular design can support this flexibility and context sensitivity. Table 4 provides an overview of key design considerations for future guideline development training programs.

Table 4. Overview of factors to take into consideration when developing guideline development training.

	Lessons for educational design of guideline development training
1	**Training should move beyond methodological focus and address participation dynamics** Panel members require more than only technical guideline development competencies, they need support in navigating the diverse roles, expectations and interactions with others.
2	**Training should address psychological safety and interpersonal competencies** Psychological safety strongly influenced participation. Dominant behaviour reduced engagement, while inclusive facilitation enhanced participation. Panel members, and specifically chairs, could benefit from training that addresses group dynamics and collaboration. Educational initiatives should consider learning strategies that support collaboration and trust in digital and in-person settings.
3	**Training should be modular and adaptable, with tailored methodological modules aligned to the type of key questions and the amount of available scientific evidence** Different guideline topics ask for different methodological approaches. A modular training, with methodological modules tailored to the guideline's key questions and the available scientific evidence, would be appropriate. Allowing panels to select the most relevant methodological content for their guideline topic, rather than overwhelming panel members with information they will not apply.
4	**Training should explicitly legitimise experiential, contextual, and lived knowledge and clarify how these inputs can inform decision making** The heterogeneous composition of panels creates different forms of expertise contributing to the guideline. It is important for panel members to understand their own added values and those of others. Additionally, they need to be aware of what (inter)national policies could affect the guideline.
5	**Training should address guideline development when scientific evidence is limited** Across all panels we saw that scientific evidence was limited, therefore a need to arises to address reasoning and decision-making when evidence is scarce.
6	**Training should contain role-specific modules** Differences in responsibilities require different competencies and thus learning needs. For example, chairs could benefit from separate training of how to shape discussion, manage hierarchy and create an inclusive environment.

Strengths and limitations

A key strength of this study is its longitudinal design, where we followed panels and conducted interviews to capture how panel members' learning needs evolved throughout guideline development. Including perspectives from panel members (healthcare professionals, researchers, and patient representatives), chairs, and project leads enabled insights into learning needs for different roles. Additionally, following diverse guideline projects enabled a nuanced understanding of how these learning needs can vary per project. The use of sensitising concepts supported initial data organisation while preserving inductive theme development, a process strengthened by the interdisciplinary research team.

Social desirability bias may have influenced interview data, as the interviewer also served as a guideline trainer. However, this dual role also facilitated trust, enabled longitudinal engagement, and supported informed probing grounded in participants' experiences. Finally, the limited number of interviewed chairs and patient representatives may have restricted the breadth of perspectives on leadership and patient involvement, indicating directions for future research.

Declarations

Acknowledgements

We want to express our gratitude to all the organisations that participated in the pilot of this training. Specifically, the project leads and members of the participating guideline panels.

Authors' contributions

All authors, except MKH, contributed to the study's conceptualisation and design. All authors contributed to methodology and investigation. CdM and MKH performed formal analyses. CdM visualised data, administered the project and prepared the original draft. All authors reviewed, edited, and approved the final manuscript. MM acquired the funding.

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Ethics approval and consent to participate

This study was reviewed and approved by the Maastricht University Faculty Health, Medicine and Life Sciences Ethics Review Committee (ID: FHML-REC/2023/120). All participants were informed of the purpose of the study at the start of the survey and gave their consent.

Disclosure statement

The authors report there are no competing interests to declare.

Appendix 1: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3	Occupation	What was their occupation at the time of the study?
4	Gender	Was the researcher male or female?
5	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6	Relationship established	Was a relationship established prior to study commencement?
7	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *e.g. Bias, assumptions, reasons and interests in the research topic*

	Remarks	Section, subsection
	CdM	Data-collection
	CdM (MSc), MKH (MSc), DD (PhD), AP (Prof.), MM (Prof), DV (Assoc. Prof.)	
	CdM: PhD candidate in the field of clinical practice guideline development, education, and health service research; MSc, Health Biology MkH: PhD candidate in the field of clinical practice guideline development and patient participation; MSc, Medicine & Clinical Research; MA Care Ethics and Policy DD: Team lead & senior advisor knowledge tools, quality management/ improvement, knowledge translation/implementation, and patient participation/SDM AP: Full professor in Economics of Education and Healthcare MM: Full professor epilepsy and education; neurologist DV: Assoc. Prof. instructional design and educational research	Reflexivity
	All researchers were female	
	All researchers had experience conducting different types (interviews, focus groups) of qualitative research and analyses.	
	Researcher CdM followed the guideline panels included in this study for various time periods. She provided training elements to these panels, as did researcher DD and DV.	Reflexivity
	The participants got to know the main researcher (CdM) in a professional capacity throughout the period she followed the panel and gave training. From the first meeting she specified how they developed the training and why this was part of a research project, as well as the goal of the research. This was repeated when participants were invited to participate in the interviews.	Participants, reflexivity
	Researcher CdM is a PhD candidate working in the field of clinical practice guidelines, educational science and health services research. She had experience in qualitative research.	Reflexivity

Appendix 1: Continued

No	Item	Guide questions/description
Domain 2: study design		
Theoretical framework		
9	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis.*
Participant selection		
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12	Sample size	How many participants were in the study?
13	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15	Presence of non-participants	Was anyone else present besides the participants and researchers?
16	Description of sample	What are the important characteristics of the sample? e.g. *demographic data, date*

	Remarks	Section, subsection
	This study reports a case-study following the approach of Merriam (2016). This employs a constructivism epistemology. The data were thematically analysed using an iterative inductive-deductive approach guided by the principles of Braun and Clarke (2022). The Bronfenbrenner's social-ecological model was utilised as a sensitising concept.	Design, data-analysis
	Panel members form participating guideline panels in the training were invited. Project leads registered the panels for the training and panel members were informed on the training before the start of the guideline project. These panel had to be multidisciplinary. Participation to the training and interviews was voluntarily. Therefore, one can speak of purposive sampling.	Participants
	Participants were approached to participate in the interviews face-to-face during (digital) panel meetings and via e-mail.	Participants
	In total, 28 interviews with 18 panel members and 10 project leads participated	Results
	Based on the participating panel members and project leads present the moment the interviews were conducted. The percentage of panel members participating was 32% (18/56) and 90% (10/11) of the project leads. As participation was voluntarily panel members were free not to participate. Possible explanations might be the busy schedules of the healthcare professionals and no financial reimbursement for the interviews.	Table 2 and Table 3
	The participants were given the choice to do this via online setting or in-person. The interviews were conducted via videoconference (Microsoft Teams). The participants conducted the interviews from their home-setting or work-setting.	Data collection
	No. The researchers were also not present when the respondent filled in the survey.	N/A
	Their role in the guideline project, if they followed the training, experience with guideline development or scientific research.	Table 3

Appendix 1: Continued

No	Item	Guide questions/description
Data collection		
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20	Field notes	Were field notes made during and/or after the interview or focus group?
21	Duration	What was the duration of the interviews or focus group?
22	Data saturation	Was data saturation discussed?
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24	Number of data coders	How many data coders coded the data?
25	Description of the coding tree	Did authors provide a description of the coding tree?
26	Derivation of themes	Were themes identified in advance or derived from the data?
27	Software	What software, if applicable, was used to manage the data?
28	Participant checking	Did participants provide feedback on the findings?
Reporting		
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g., participant number*
30	Data and findings consistent	Was there consistency between the data presented and the findings?

	Remarks	Section, subsection
	The interview guides can be found in appendix 2. Three pilot interviews were conducted to test the interview guide with project leads unrelated to the participating guideline panels. Project leads assumed their usual role or were asked to imagine themselves as a panel member.	Appendix 2, Data collection
	N/A	N/A
	Microsoft Teams was used to record the interviews.	Data collection
	CdM made some small notes during the interviews to prompt asking further questions. Additionally, CdM wrote reflexive diary entries on how the interviews went and what stood out to her.	N/A
	Between 30-60 minutes. With panel members conducting interview of 30 minutes and project lead of 60 minutes.	Data collection
	Yes.	N/A
	Yes. Participants were allowed to review and correct their interview transcripts. One participant asked for a part of the interview to be excluded, due to the sensitive nature of what was discussed.	Data collection
	Two authors (CdM and MKH). Any disagreements were resolved through discussion and/or consulting researchers DV and DD.	Data analysis
	No	N/A
	Themes were derived from the data, but the Bronfenbrenner's social-ecological model was utilised as a sensitising concept. The analysis entailed an iterative inductive-deductive thematic analysis approach.	Data analysis
	Atlas.ti, version 25.	Data analysis
	No	N/A
	Yes.	Results: Theme 1, Theme 2 and Theme 3
	Yes	Results

Appendix 1: Continued

No	Item	Guide questions/description
31	Clarity of major themes	Were major themes clearly presented in the findings?
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

	Remarks	Section, subsection
	Yes	Results: Themes, Figure 1
	Yes	Results: within Theme 1,2 and 3

Appendix 2: Interview guides

Interview guide – Panel members

Introductory questions

1. Could you please briefly introduce yourself?
    a. What is your day-to-day role/occupation, and what was/is your role in this guideline development process?
    2. How have you experienced the guideline development process so far?

Questions

Defining the scope of the guideline topic

The first step in the process was to determine the topic of the guideline, [insert guideline topic]. This had broadly been established before you joined the panel, but during the meetings, you further refined the scope.

3. Could you tell me how you defined the scope of the guideline topic, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

Problem areas

Defining the scope of the topic also went hand in hand with identifying the problem areas that you aimed to address in the guideline.

4. Could you tell me how the process of identifying and prioritising key problem areas worked in your panel, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

Composition of the panel

5. How was the panel formed, and did the identifying interests/conflicts of interest proceed?
    a. Did you feel that all the necessary expertise was represented in the panel?
    b. Do you feel that the expertise of all panel members, including your own, was sufficiently heard/used?
        i. Could you give an example?
    c. How could the training help to ensure that everyone's perspective is heard?

Key questions

Based on the selected key problem, key questions were formulated.

6. Could you tell me how the key questions were formulated in your panel, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

Considerations

Next, you started working on answering the key questions. For this, you are drafting or have drafted considerations.

7. Could you tell me what this process looked like in your panel, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

Literature review and expert opinion

For some of these considerations, a literature review was conducted, while others were informed more by expert opinion.

8. Could you tell me what the literature review process looked like in your panel, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

9. Could you tell me what the expert opinion process looked like in your panel, and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

Cost considerations

In the training, we also paid attention to cost considerations in guidelines.

10. Has this module changed the way you think about incorporating cost considerations in your guideline?
    a. Do you feel better able to include cost considerations in your guideline as a result of the training?

b. *(If the module was not completed)* Why did you not complete the module? Do you think cost considerations should be included in guidelines?

Recommendations

Finally, I would like to ask you about the formulation of the recommendations.

11. Could you tell me what this process looked like in your panel and what your role was?
    a. To what extent did you feel able to fulfil this role?
    b. Did the training help with this in any way?

We have reached the end of the questions I wanted to ask.

12. Is there anything else you would like to share that we have not yet covered?

Interview guide – Project leads

Introductory questions

1. Could you please briefly introduce yourself?
    a. What is your day-to-day role/occupation, and what was/is your role in this guideline development process?

2. How have you experienced the guideline development process so far?

Questions

Defining the scope of the guideline topic

The first step in the process was to determine the topic of the guideline, [insert guideline topic]. This had broadly been established before you joined the panel, but during the meetings, you further refined the scope.

3. Could you tell me how the scope of the guideline topic was defined, and what the role of the panel members was?
    a. To what extent do you think the panel members were able to fulfil this role?
    b. How could training support panel members in this?

Problem areas

Defining the scope of the topic also went hand in hand with identifying the problem areas that you aimed to address in the guideline.

4. Could you tell me how the process of identifying and prioritising problem areas worked in your panel, and what the role of the panel members was?

a. To what extent do you think the panel members were able to fulfil this role?
b. How could training support panel members in this?

Composition of the panel

5. How was the panel formed, and did the identifying interests/conflicts of interest proceed?
   a. Did you feel that all the necessary expertise was represented in the panel?
   b. Do you feel that the expertise of all panel members was sufficiently heard/used?
      i. Could you give an example?
   c. How could the training help to ensure that everyone's perspective is heard?

Key questions

Based on the selected key problem, key questions were formulated.

6. Could you tell me how the key questions were formulated and what the role of the panel members was?
   a. To what extent do you think the panel members were able to fulfil this role?
   b. How could training support panel members in this?

Considerations

Next, you started working on answering the key questions. For this, you are drafting or have drafted considerations.

7. Could you tell me what this process looked like in your panel, and what the role of the panel members was?
   a. To what extent do you think the panel members were able to fulfil this role?
   b. How could training support panel members in this?

Literature review and expert opinion

For some of these considerations, a literature review was conducted, while others were informed more by expert opinion.

8. Could you tell me what the literature review process looked like in your panel, and what the role of the panel members was?
   a. To what extent do you think the panel members were able to fulfil this role?
   b. How could training support panel members in this?

9. Could you tell me what the expert opinion process looked like in your panel, and what the role of the panel members was?
    a. To what extent do you think the panel members were able to fulfil this role?
    b. How could training support panel members in this?

Cost considerations

In the training, we also paid attention to cost considerations in guidelines.

10. Has this module changed the way you think about incorporating cost considerations in your guidelines?
    a. Do you feel better able to include cost considerations in your guidelines as a result of the training?
    b. *To what extent were panel members able to include cost considerations?*
    c. How could training support panel members in this?

Recommendations

Finally, I would like to ask you about the formulation of the recommendations.

11. Could you tell me what this process looked like in your panel and what the role of the panel members was?
    a. To what extent do you think the panel members were able to fulfil this role?
    b. How could training support panel members in this?

We have reached the end of the questions I wanted to ask.

12. Is there anything else you would like to share that we have not yet covered?



Chapter 7

General Discussion



Research aim

Health care is inseparable from the use of guidelines. They support healthcare professionals and patients in making decisions about appropriate care, help reduce unwarranted practice variation and promote cost-conscious practice [9]. As guidelines play a central role in health care, their development must be transparent and follow a clearly defined process. The Appraisal of Guidelines for REsearch and Evaluation (AGREE)-II instrument and the GRADE Evidence to Decision (EtD) framework have strengthened the methodological foundation of guideline development [18, 20, 28]. They encourage guideline panels to consider not only the certainty of the evidence, but also the balance of benefits and harms, patient values and preferences, and broader contextual factors such as equity, feasibility, acceptability, and resource implications. This supports the development of recommendations that are better suited to the context in which the guidelines are implemented [28-31].

Fully considering all EtD factors remains challenging. In this dissertation, we focus on two of these factors. First, studies have shown that patient preferences are insufficiently integrated or not explicitly reported in guidelines [36, 37, 50]. However, shared decision-making and patient-informed guideline development are crucial. When guidelines align with patient values and preferences, their relevance, implementation and adherence could be enhanced [37, 40]. Second, the incorporation of economic considerations in guidelines is limited. Even though healthcare systems are facing increasing pressure due to limited (financial) resources [2, 4, 50], structurally integrating economic considerations into guidelines could support efficient resource allocation and strengthen cost-conscious decision-making [47]. Currently, knowledge on which factors could stimulate or hinder the broader inclusion of economic considerations is limited [46].

Guideline development is complex and requires a variety of competencies from those involved [60]. Panel members (i.e. healthcare professionals, patient representatives, and researchers), supported by guideline methodologists and project leads, develop guidelines [9, 53]. Yet many panel members receive limited or no formal education in guideline development. Evidence from healthcare settings suggests that education can improve complex decision-making, including cost-conscious care and shared decision-making, indicating that education holds promise for supporting guideline development [42, 55-58]. However, little is known about the learning needs of panel members or how education could meaningfully support them in guideline development. This led to this dissertation's main research question: How can an educational programme based on practical needs and educational theory support panel members in guideline development?

Main findings

Part 1 – Analysis of needs

To develop a meaningful educational programme, it was important to identify explicit learning needs but also to understand the broader challenges that panel members face during guideline development. **Chapters 2-4** describe the learning needs regarding guideline development, but also a broader view on challenges in incorporating economic considerations and the patient perspective in guidelines.

In **Chapter 2**, we reported results of a questionnaire study and found that guideline development involved role-specific tasks as well as responsibilities shared across roles. Panel members noted that prior experience, adequate guidance, and education shaped their sense of preparedness. Additionally, respondents (i.e. panel members, methodologists, and project leads) stated that the incorporation of economic considerations and patient perspectives is important. These aspects were addressed in varying ways. The survey revealed four priority areas for education: (1) explanation of the guideline methodology, (2) inclusion of different perspectives, (3) clarity about roles and responsibilities, and (4) economic considerations. Importantly, panel members emphasised that not only content-related but also process-related aspects must be addressed in education.

In **Chapter 3**, we conducted a literature review to examine the complexities that hinder the incorporation of economic considerations in guidelines. These challenges include methodological ambiguities, limited or poor-quality economic evidence, and difficulties applying evidence across different healthcare contexts. In **Chapter 2,** most guideline developers indicated they found the incorporation of economic considerations important. At the same time, literature in this review hinted at an ongoing discourse on the place of economic considerations in guidelines. Potentially echoing this discourse, the review also showed a need for guidance and practical tools on how to appraise and include economic considerations. Education could be a crucial first step to help panel members navigate these complexities by equipping them with basic economic literacy and showing them how they can make informed, cost-conscious decisions during guideline development.

The experiences of patient representatives, further explored in an interview study reported in **Chapter 4**, showed that guidelines are seen as valuable tools for navigating health care. However, meaningful participation in development processes is often hindered by medical jargon, unclear expectations, and unfamiliar methodological terminology. Such themes were found to be important in guideline development

education in **Chapter 2**. Patient representatives advocated for guidelines that are holistic and acknowledge areas beyond clinical health, such as education, work and social relationships. They also stressed that guidelines should be accessible and sensitive to the heterogeneity of patients' disease expression and lived experiences. In addition, they emphasised that effective partnership in guideline panels requires attention to interpersonal and relational dynamics. While educating patient representatives in guideline methods can offer support, strengthening partnerships ultimately requires educating all panel members in interprofessional collaboration and inclusive dialogue, as echoed in **Chapter 2**.

Taken together, **Chapters 2-4** showed that guideline development is complex and demanding. Panel members must navigate methodological requirements and interpersonal dynamics. Whilst the importance of economic considerations and patient perspectives was acknowledged, further education may be needed to support their effective incorporation into practice.

Part 2 – Designing and evaluating an educational programme

Building on the identified learning needs, we designed and evaluated a training for panel members. This training aimed to support panel members during guideline development by providing methodological knowledge in alignment with the responsibilities of panel members. Additionally, we explicitly addressed the incorporation of economic considerations, as well as meaningful collaboration in multidisciplinary panels. In **Chapters 5** and **6**, we explored how education could strengthen panel members' competencies and preparedness for their roles in guideline development.

Chapter 5 described the development and evaluation of the training. The training was co-developed with guideline methodologists from various Dutch guideline development organisations, health economists and educationalists. The intended learning outcomes were defined using the Responsible, Accountable, Consulted and Informed (RACI) matrix to clarify role-specific responsibilities and associated competencies during guideline development. Five design principles were used to shape the training to support learning in real-world settings, namely constructive, collaborative, contextual, blended, and just-in-time learning. The training was integrated into the timeline of actual guideline projects and consisted of five modules. Each module combined an asynchronous preparatory e-learning with a synchronous session delivered either in-person or via videoconference. Panel members completed the preparatory e-learning when the knowledge was relevant, and the synchronous sessions were mostly embedded within panel meetings. Figure 1 provides an overview of the training structure and the topics covered in each module. A more extensive description of the training can be found in **Chapter 5**.

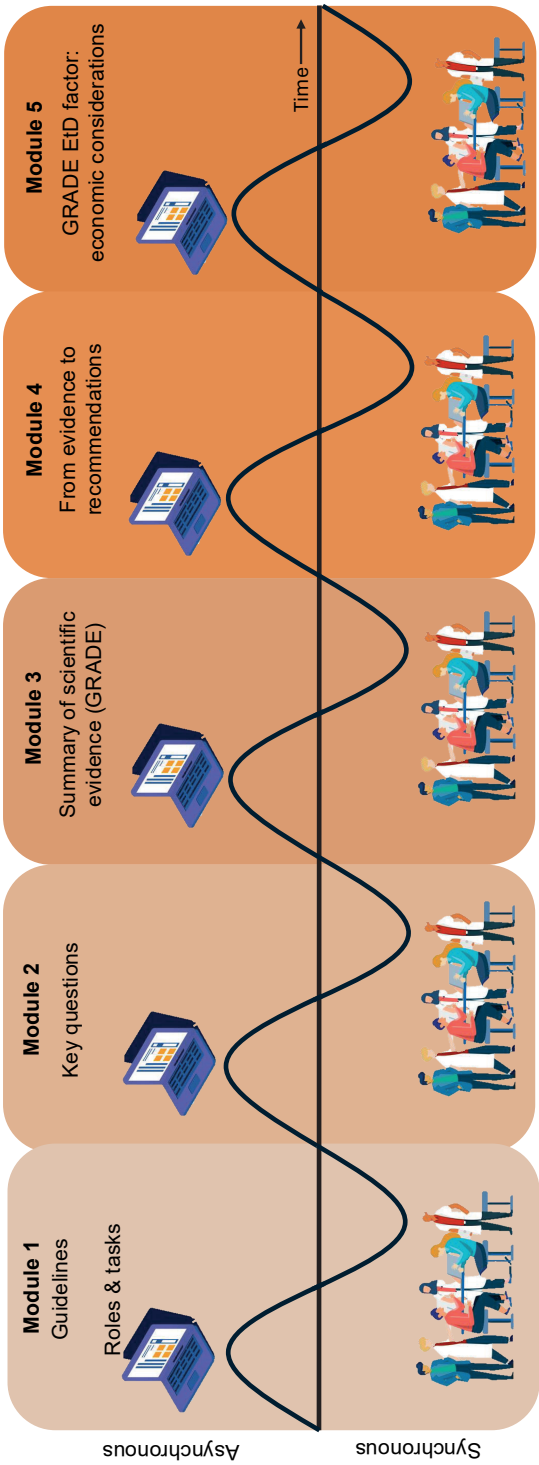

Figure 1. Overview of the designed guideline development training for panel members.

Chapter 5 emphasised that in-person training sessions were essential for building shared understanding and collaboration (collaborative learning), noting that online modules alone would be insufficient. The training increased panel members' understanding of the guideline process, helped clarify their roles, improved their confidence, and stimulated awareness and consideration of economic aspects. Constructive and collaborative elements encouraged active engagement, while the just-in-time principle enabled panel members to apply knowledge directly to ongoing tasks. We concluded that education grounded in constructive, collaborative, contextual, blended, and just-in-time design principles can meaningfully support guideline panel members during guideline development. However, it also became clear that no guideline project was the same. Whilst the just-in-time principle was appreciated, alignment with the guideline projects was not always perfect. Variations in (subgroup) timelines, task allocation, and scheduling conflicts challenged alignment. Panel members also indicated that links between the training's content and current guideline tasks could have been made more explicit during in-person sessions. Additionally, **Chapter 5** implied that contextual factors affected the effectiveness of the training.

Building on this, **Chapter 6** explored how contextual factors shaped panel members' learning needs. We found that learning needs emerged from the interaction of three interrelated themes: guideline topics, participation dynamics, and task allocation within the panel. First, the guideline topic influenced panel composition, needed methodological approaches, and the extent to which the panel could rely on scientific evidence or (clinical practice) expertise. For example, panels addressing diagnostic key questions required different methodological competencies than those focusing on interventions. Likewise, when scientific evidence is limited, panels will rely more on (clinical practice) expertise and will require more training on justifying recommendations in the absence of scientific evidence. Second, participation dynamics shaped which voices were heard, valued, and integrated into the guideline. Engagement was influenced by interpersonal dynamics, experience (in research and guideline development), confidence, perceived hierarchy, and psychological safety. Chairs played an important role in facilitating inclusive collaboration. Third, task allocation varied across guideline projects. Similar roles could entail responsibility for different tasks and therefore affect competency requirements. For example, responsibilities for evidence searching, appraisal, and drafting recommendations were distributed differently between panels. Similar to the findings in **Chapters 2 and 4**, this study showed that methodological competence in guideline development alone is insufficient for effective and equal participation. Panel members also need support in clarifying their roles, responsibilities, and how they can contribute and collaborate within the panel.

Drawing on the findings from **Chapters 5** and **6**, we conclude that educational programmes for guideline development cannot take a one-size-fits-all approach. They must be adaptable and context-sensitive, combining a shared methodological foundation with flexible modules that can respond to project-specific demands. Importantly, education should also address the participation dynamics of guideline development, including interpersonal and group dynamics, as this influences whose voices are heard during the development process. Constructive, collaborative, contextual, blended, and just-in-time design principles were shown to support strengthening panel members' guideline development competencies. This increased panel members' confidence, preparedness, and capacity to contribute meaningfully to guideline development.

Reflections

1. Education supports the incorporation of economic considerations, but it is not enough on its own

Across this dissertation, we highlighted the importance of incorporating economic considerations into guidelines. Education is one promising strategy to support this endeavour, but not sufficient on its own [34]. Chapter 2 showed that panel members generally accepted the relevance of economic considerations and were willing to address them. Chapter 5 further demonstrated that our training helped panel members better understand the importance of economic considerations. Additionally, the training supported panel members in discussing the incorporation of economic aspects. However, Chapter 3 noted challenges outside of education affecting the incorporation success. In the literature, we found that suitable economic evidence was scarce, that there were limited resources to develop guidelines, and doubts about which methodological approach to take. The latter was also reflected in our experience developing the educational module concerning economic considerations. Here, uncertainty about how economic considerations should be embedded, both within guidelines and within the training, was apparent. Although our co-developers (e.g., guideline methodologists) endorsed incorporation, they struggled to concretise what was expected of panel members in this regard. This reflected a broader lack of clarity on who holds responsibility for addressing economic aspects in guideline development.

These findings suggest that structural incorporation of economic considerations requires more than education alone. The evidence base of economic evidence should be strengthened, for example, by encouraging economic evaluations alongside clinical trials. In the Netherlands, ZonMw has supported such efforts

over the past decades to support efficient and sustainable care [192]. In addition, explicit decisions are needed about which responsibilities should fall to guideline developers, specifically panel members, regarding economic considerations. Once these roles and expectations are clear, one can develop education that better matches the required competencies.

2. Guideline development education should balance methodological foundations with adaptability to context

Designing education for panel members involved balancing the need for a shared methodological foundation with the contextual needs of guideline projects. In the Netherlands, guideline development is grounded in the transparent and systematic methodology of the GRADE EtD framework [28, 29]. Educating panel members in the basic principles of this framework offers them an important foundation to help them develop guidelines [60, 159]. At the same time, this dissertation showed that no guideline project was the same. We found that the learning needs of panel members were affected by the guideline topic, task allocation, and participation dynamics. For example, the level and nature of the methodological expertise required of panel members differed depending on the type of key questions they wanted to address, as well as their responsibility in the development process (understand or execute) and their own level of experience or interest.

These differences result in diverse learning needs among panel members. Thus, whilst a shared methodological foundation is valuable, a single rigid educational programme is unlikely to meet the learning needs of all panel members. While core design principles (constructive, collaborative, contextual, blended, and just-in-time learning) remain valuable anchors, strict adherence to a fixed programme may hinder learning when educational elements do not align with the guidelines' setting [178]. In designing our training, we combined a core educational programme with context-sensitive educational elements. By embedding the training in panel members' ongoing guideline projects, we aimed to enhance context-sensitivity and align with contextual learning. In doing so, we emphasised engagement with authentic, real-world learning [65, 66]. The just-in-time principle helped to make this approach practical, providing educational input at moments when specific knowledge was required [69]. However, we learned that just providing the core educational programme elements alone at the right moments required was not always sufficient. The training also had to be adapted to the context of the guideline project; for example, all panels received education on the basic principles of scientific evidence selection and evidence appraisal. In some projects, this level of education was sufficient. In others, (some) panel members were expected to

actively contribute to evidence selection and appraisal, requiring a different level of education. Conversely, in projects with limited scientific evidence, greater emphasis may be needed on how to deliberate and justify recommendations in the absence of evidence. These findings suggested that a core educational programme should be complemented by adaptable or modular components that can be tailored to the specific characteristics of guideline projects to support learning [178].

3. Harmonising just-in-time and collaborative learning can be challenging

When implementing the training, we found some tension between the just-in-time and collaborative learning design principles. Just-in-time learning aims to support learners by providing knowledge at moments when it is immediately relevant and can be applied [69]. Collaborative learning relies on a shared process in which learners together develop knowledge [64, 65]. The blended principle helped bridge these two principles [67, 68]. The online learning modules enabled panel members to asynchronously follow certain topics, depending on what they needed or wished to learn. At the same time, the in-person sessions supported collaborative learning as panels together followed training sessions.

However, we saw that variation in task allocation within panels could affect whether knowledge was timely. A subgroup of panel members could work on formulating considerations for one key question earlier than others. Additionally, we saw changes in panel composition in various guideline projects where we implemented the training. For example, we saw panel members who joined panels later in the process. Such additions could cause individual learning needs to become asynchronous in relation to the timing and progression of the development process. Furthermore, we saw that differences in experience with guideline development or research also created differences in learning needs within panels. As we aimed to create a shared (methodological) understanding across a panel, individual panel members differed in what they needed to learn. Thus, what would be timely and relevant for one panel member might not necessarily be so for others. As a result, efforts to provide just-in-time support for individuals could conflict with collaborative learning [63, 64, 69].

4. Education must extend beyond the guideline development methodology

Guideline development is not merely a methodological exercise; it is also a social process. Guideline panels bring together healthcare professionals from various disciplines and patient representatives who must jointly develop recommendations. While the methodological rigour and transparency of guideline development have increased (e.g., GRADE EtD) [77, 174], less explicit attention has been paid to the social dimension in guideline development. Chapter 6 showed that social dynamics

shaped how panel members participated in the development process. Feelings of hierarchy, unequal partnership, and uncertainty about one's role sometimes seemed to inhibit open dialogue. This could be particularly true for patient-representatives, whose experiential contributions may be difficult to express when panels have a classical healthcare professional-patient dynamics [56]. Moving towards equal partnership may initially create uncertainty for both patient representatives and professionals, as this may be uncommon to them [193]. Thus, the social dynamics at play in panels may affect whose input is heard and that, in turn, will affect the final recommendations [170]. Therefore, it is beneficial to address the collaboration and social aspect of guideline development in education.

Learning needs related to the social aspects of guideline development were also found in the analysis phase of this dissertation, specifically Chapters 2 and 4. A need to address collaboration, equal partnership, and group dynamics in guideline development education was expressed by panel members. A panel needs time to become a team and effectively collaborate. Similar to our findings, the literature on team development shows that panel members must build a safe environment, clarify roles, and establish collaboration agreements. Chairs could play a broker role in these efforts [194]. Our training was unique as we delivered it to entire panels, enabling us to address such topics more easily. At the same time, we encountered tension in practice. In informal discussions during the training's implementation, project leads often emphasised efficiency. They noted that panels had limited time and should quickly move toward guideline content. Yet, Chapter 6 showed that project leads and panel members valued taking time for introductory activities, clarifying roles and establishing collaboration agreements. They felt this supported the teamwork throughout the development process. Thus, guideline development education must move beyond the methodological components alone.

Reflections upon the research design

Author reflexivity

Before reflecting upon the design-based research approach taken in this dissertation, it is important to acknowledge my own position within the research process. When I began my PhD, the fields of guideline development, health care and health economics were new to me. Although I was trained as a high school teacher, I had limited experience with educational research. However, my curiosity about health care and education was shaped early on, as I grew up with parents working in both fields. In that sense, the apple has not fallen that far from the tree.

My academic background was largely shaped by a post-positivist perspective, rooted in experimental thinking and the idea that research is neutral and detached from the researcher. Throughout my PhD, I came to understand that research is never entirely impartial. The questions asked, the methods chosen, and the interpretations made are shaped by the researchers. Over time, my perspective shifted towards a more pragmatic and constructivist understanding of research.

The PhD process is not solitary, and collaborations shaped my work. My supervisors guided me with their different expertise in education, guidelines, and health economics. The interplay between these perspectives stimulated critical discussions and refined the choices made in this dissertation. At the same time, stakeholders provided valuable insights and challenged our assumptions. I feel the proverb 'If you want to go fast, go alone. If you want to go far, go together' resonates with me personally, as well as with this dissertation. Although collaborations brought challenges, they ultimately enriched this dissertation and strengthened the development of the guideline development training.

In this dissertation, I acted simultaneously as researcher, educator, and project lead. My close involvement with guideline panels and project leads strengthened the connection between research and practice. At the same time, this triple role has shaped both the training's development and evaluation. To remain critical of my assumptions and interpretations, I engaged in continuous reflection with my supervisors throughout the research process.

The research design

The overarching research approach in this dissertation was design-based research (DBR). This approach is well-suited to developing education in complex real-world settings, as it combines educational theory and practical insights to shape education [72]. It consists of three iterative phases: (1) analysis and exploration, (2) design and construction, and (3) evaluation and reflection.

A strength of DBR is that it allows integration of different study designs to inform educational design. In this dissertation, we combined a mixed-methods survey, scoping review and focus groups to explore the learning needs of panel members broadly and in depth. The bottom-up approach in Chapters 2 and 4 to capture panel members' perspectives, combined with the training's co-design process, reflects the close entwinement of research and practice central to DBR.

Through this collaborative development process, we aimed to align the training as closely as possible with the realities of guideline development. However, meaningful co-creation takes time, and the limited development time constrained the depth of participatory engagement. Future iterations could explore more participatory approaches. For example, by involving panel members directly in the development of modules. Patient perspectives were limited in Chapters 5 and 6, as only two panels included a patient representative continuously. Discussions with project leads showed practical challenges to sustained patient involvement, including the absence of available patient representatives. These challenges suggest that additional or alternative approaches might be needed to strengthen the patient perspective beyond panel-based participation.

Conducting this research within ongoing guideline projects provided rich insights into how the training worked in a real-world setting, but it reduced our control as researchers. Shifting timelines and changes in panel composition required continuous adaptation by us. Following six guideline panels longitudinally allowed us to understand how learning needs are shaped during guideline development. However, this approach also limited the opportunity for a full redesign as intended in DBR. Nevertheless, we implemented small adaptations throughout the training's implementation to match guideline-specific needs. For example, when discipline-specific examples confused panel members from other fields, we revised the e-learning material to more neutral examples. This underscored the importance of contextual learning and adaptable educational materials.

We did not evaluate the long-term impact of the training on guideline recommendations, implementation, or clinical outcomes. Such an evaluation would require a larger-scale quantitative design, particularly if one aims to examine causal effects. As this dissertation has shown, education alone does not determine the final guideline recommendations. Contextual factors, such as social dynamics, also shape guideline development. Ethnographic research could help to create insights into how decision-making unfolds within guideline panels.

Future directions

Guideline development has evolved over the past decades, moving toward evidence-based guidelines [9]. In addition to the scientific evidence, guideline panels are now also asked to consider various other factors, such as patient values and preferences, economic considerations, equity, feasibility and acceptability [28-31]. Our findings

showed that meaningful integration of patient perspectives and economic considerations remains challenging in practice. At the same time, we saw new demands emerge, such as considering planetary health [195] and healthcare system capacity [35]. This further intensifies the demands placed on guideline panels. These developments and the findings of this dissertation underscore the need for (new) strategies to support panels in guideline development and have resulted in the following recommendations.

Recommendations for the guideline development field

Greater clarity on who (e.g., panel members, project leads, health economists) is responsible for incorporating economic aspects and how this should be operationalised. These choices shape the required competencies of those involved in guideline development and determine the resources needed to realise this endeavour (e.g., education, hiring of an external expert). Additionally, the structural integration of economic considerations in guideline development can be supported by investing in the development of economic evidence. Stimulating economic evaluations alongside clinical trials can expand the evidence base needed for cost-conscious recommendations. In the Netherlands, ZonMw has stimulated such research over the last few decades [192, 196]. Additionally, initiatives such as 'Passende zorg' and 'Zorgevaluatie & Gepast Gebruik (ZE&GG)' further raise attention and effort to enhance cost-effective health care by stimulating cost-effectiveness research or de-implementing non-effective care [3, 197, 198].

Guideline development organisations should tailor support structures to each project's specific needs. Because guideline topics, participation dynamics, and task distribution vary, the required support may differ in timing, format, and depth. Clarifying roles and tasks early in the process helps determine the type of methodological or educational support that is appropriate. Moreover, it should be recognised that guideline development is a collaborative and social process. Organisations should invest time and resources to foster psychological safety, build trust, and equal partnerships within panels. So that all panel members' perspectives can be meaningfully integrated into recommendations. Chairs have a particularly influential role in promoting inclusive dialogue and safe collaboration. Education should be a core support structure. Organisations should provide education on leadership for chairs and education that addresses the social aspects, in addition to the methodological components of guideline development. Structural investment in education is essential to prepare panel members for their roles, as guideline development will continue to evolve and become more complex.

Lastly, collaboration across healthcare professional and patient organisations should be actively promoted. Shared educational initiatives, joint methodological approaches, and the exchange of tools can reduce duplication of effort and enhance consistency across the guideline landscape.

Recommendations for education

It should be recognised that there is no one-size-fits-all approach when educating guideline panel members. Modular designs and context-sensitive adaptation (e.g., in examples) allow educational content to align with guideline-specific demands and panel members' needs. Thereby, creating a more relatable educational programme with educational pathways tailored to the responsibilities and required competencies of panel members, chairs and project leads. Additionally, education should explicitly address collaboration, equal partnership and shared understanding of roles, as guideline development is a socially shaped collective decision-making process. Educating entire guidelines panels rather than individuals in isolation may help foster these collaborative competencies.

Education should be grounded in effective learning principles. Constructive, collaborative, and contextual learning principles, supported by blended and just-in-time formats, can effectively support panel members during guideline development. These principles allow education to be tailored in timing and depth to the panel's learning needs, create opportunities for direct application in practice, and strengthen collaboration. In this dissertation, we focused on the competencies required by panel members to contribute to guideline development. However, facilitating education on guideline development also requires a specific skill set for the trainers. Trainers should not only possess thorough knowledge of the guideline development process but also understand educational theory and instructional design.

The training designed in this dissertation addresses key competencies for guideline development, but it does not cover the full scope of guideline development. Therefore, further expansion of the programme with additional modules (e.g., implementation and sustainability) may be beneficial. In future educational initiatives, educators in guideline development should actively involve key stakeholders in the co-design of educational programmes. Co-creation with guideline methodologists, project leads, panel members, and experts on specialised topics helps ensure that educational programmes remain grounded in real-world guideline practice. Thereby, creating educational programmes that are both feasible and meaningful within ongoing guideline projects. Based on the findings

across the chapters of this dissertation, several recurring educational needs of guideline panel members were identified. Table 1 summarises these needs and translates them to concrete recommendations for educational design for guideline development.

Table 1. Educational needs of guideline panel members and implications for education.

Educational need		**Implications for education**	**Chapter**
Shared methodological foundation	Panel members need a shared foundation in the basics of guideline development methodology (e.g., GRADE, GRADE EtD) to participate meaningfully.	A core educational programme should be provided, focused on guideline methodology to establish a common baseline.	2 & 5
Clarification of roles and expectations	Panel members require clarity about their role and associated responsibilities within the development process. This can differ per guideline project.	Education should address the different roles within the guideline development process and the associated responsibilities. This needs to be specified for the specific guideline project. Tools such as the RACI matrix can help clarify the responsibilities, thereby identifying which competencies and learning needs should be address in education.	2, 5 & 6
Social and collaborative competencies	Guideline development is a social process. Hierarchy, psychological safety, and unequal participation affect the dialogues and can affect final recommendations.	Education must address group dynamics, psychological safety and collaboration forms. Providing education to entire panels can provide a facilitative role by taking the time to acknowledge participation dynamics during the panel meetings. For example, getting to know each other, learning each other's motivations for participation and the valuable perspectives each panel member bring. Additionally, setting clear collaboration agreements can be beneficial.	2, 4 & 6

Table 1. Continued

Educational need		Implications for education	Chapter
Incorporation of economic considerations	Panel members value cost-conscious recommendations but lack basic economic literacy, guidance, and clarity on responsibility for economic aspects.	Education must address basic economic concepts and the practical application in recommendations, preferably to the specific guideline project. For example, by discussing the economic considerations for a specific key question of the guideline.	2, 3 & 5
Context sensitive and timely education	Panel members learning needs will vary based on the guideline topic, participation dynamics and task allocation.	Education should consist of diverse, modular components that together cover the full guideline development process. As the content and focus of guideline projects vary, modules should be selectable and adaptable to align with project-specific and panel members' learning needs. Additionally, what might be relevant at the start of some projects might be later relevant in others. Coordination with project leads is crucial and blended education with online learning modules can play a facilitative role. Where live formats lend themselves towards context-sensitive adjustments.	5 & 6

Recommendations for research

Future research should examine why the incorporation of economic considerations remains difficult despite the existence of tools and frameworks [6, 135, 137, 138]. Identifying which additional guidance, resources, or implementation strategies are needed is important to making the integration feasible within real-world settings. To realise this, collaborations between the health economics, guideline and potentially the education field could be beneficial.

Research should also explore how panels can better navigate guideline development under scientific uncertainty. This includes learning how to balance experiential knowledge, contextual considerations, and research evidence. Additionally, research should also investigate how diverse forms of research evidence (e.g. qualitative or real-world data) can be more systematically incorporated into guideline development [199], particularly when RCTs or observational studies are unavailable or not feasible. Whilst initiatives exist, such as the GRADE CERQual, hurdles still seem to exist to this endeavour [188].

Future studies should investigate how social dynamics shape decision-making in guideline development. Longitudinal qualitative and ethnographic approaches may be valuable to capture evolving panel dynamics, as well as the role of chairs and project leads as brokers in this collaborative process. Finally, research should continue to evaluate how educational initiatives can best support guideline panels in their endeavours.



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Impact



Impact



Introduction

When surgeon Jane received an email inviting her to join a national guideline development panel, she felt both honoured and nervous. She was proud that her clinical experience was recognised as valuable, but she hesitated when she read about making evidence-based decisions and weighing scientific evidence. Jane used guidelines every day in her work, but she had never helped to create one herself. Still, she felt motivated to contribute because she wanted her patients to receive the best possible care.



Max, a physical therapist nearing retirement, with many years of clinical experience, has seen treatments evolve and practice change. When he was invited to join the panel, he felt confident in his clinical expertise. However, he realised that guideline development had changed since the last time he helped develop a guideline fifteen years ago.

During the first panel meeting, Jane and Max quickly realised that guideline development involved much more than describing what works clinically. The panel also had to consider patient values, feasibility, and even costs. These were topics Jane and Max had little experience with. In addition, collaborating with professionals from different backgrounds and with patient representatives felt intimidating. When the project lead explained that the panel members would receive training alongside the guideline development process, both felt reassured. With this additional support, they felt more confident about contributing meaningfully to the panel's work.

Why did we do this research?

Situations like those of Jane and Max are not unique. Guideline development is a complex methodological and social process. Guidelines are expected to not only focus on clinical effectiveness, but also on factors such as patient values and preferences, and the incorporation of economic considerations. To help with patient-centred and cost-conscious decision-making. The latter is particularly relevant in the context of rising healthcare costs and increasing pressure on healthcare systems. Developing guidelines is challenging, and people participating in panels often do not receive formal education to prepare them.

With this dissertation, we explored the challenges and related educational needs of panel members and developed a training tailored to those needs. The training paid attention to economic considerations, the diverse perspectives in guideline panels and guideline methodology. We implemented and evaluated the training in real guideline development projects. Throughout the dissertation, we combined insights from guideline development practice, educational theory, and empirical research. We also closely collaborated with stakeholders in the guideline domain to develop a training fitting to real-world practice.

How did our research impact science?

This dissertation advanced the scientific understanding of the learning needs of guideline panel members and demonstrated that education theory can be applied to support learning in guideline development. While guidelines have a central role in health care, limited research has examined what those involved in their development need education-wise to fulfil their roles effectively. By making these learning needs experienced by panel members explicit, we addressed a gap in the literature.

We found that panel members wanted to learn about the guideline methodology, how to address economic considerations, and how to work together during the development process. Our literature review supported this, showing that education could potentially help panel members include economic information in guidelines. In addition, the focus groups with patient representatives showed that equal partnership within panels is important. These findings, together with educational design principles (constructive, collaborative, contextual, blended, and just-in-time learning), guided the design of a training for guideline development. To ensure that the training was also grounded in practice, we co-developed it with guideline methodologists, health economists, and educationalists. This co-creation process strengthened the relevance of the training and applicability but required sufficient time investment from all involved.



Given that guideline development often takes one to two years to complete, we designed a modular training where we aligned learning moments with the actual stages of the guideline development process. This provided panel members the possibility to directly implement their newly learned knowledge. The blended format of preparatory e-learning and collective in-person learning moments during panel meetings supported these efforts. The in-person sessions allowed us to adapt the training to the specific setting of the guideline projects. Overall, panel members felt better prepared and more confident in their contributions. These findings illustrated how education theory can support learning in the complex and long-running process of guideline development.

At the same time, we found that no guideline development project or panel member is the same and different learning needs arise. We saw that panel members' learning needs were shaped by the guideline topic, task allocation and participation dynamics. Panel members with different backgrounds and perspectives must work together towards a shared goal. However, participation dynamics (i.e. how panel members could contribute, hierarchy and feelings of social safety) affected whether panel members felt able to contribute. These findings suggest that education could play an even stronger role in supporting inclusive dialogue and social safety throughout the guideline development process. It was also highlighted that chairs and project leads could play broker roles in group dynamics. These insights contribute to a broader understanding of guideline development as a social and collaborative process, rather than a purely methodological one. Addressing these social dimensions in guideline development education may help ensure that a wider range of perspectives is meaningfully integrated into guideline recommendations.

From research to practice: relevance and dissemination of findings

The results of this dissertation are relevant to several groups. First, the findings and the training are valuable to guideline panel members. The dissertation addresses the challenges they face during guideline development, and the training offers concrete support. This training prepares them for their roles in the development process, supports collaboration and improves their confidence to contribute. The results are also relevant for the guideline project leads and chairs. They play a key role in organising guideline development and supporting panel members throughout the process. The insights from this dissertation can help them recognise learning needs, address group dynamics, and create conditions that support inclusive collaboration. Additionally, they can offer the training to their panels to help them be better prepared. Due to the positive response to the training, it is currently being transferred to Richtlijnen Netwerk Nederland (RNN). This organisation will continue the training for Dutch guideline panels. To support implementation, we provided RNN with an overview of the time and financial investment we made to develop the training. This transparency supports realistic planning and budgeting for future continuation. In this way, the results of the research directly support ongoing guideline development in practice. Additionally, we developed a train-the-trainer guide to support new trainers for the training. This guide can be found in the Addenda of this dissertation.

Furthermore, educators and researchers in the fields of guideline development, evidence-based medicine, and professional education can build on the scientific insights of this dissertation. They can use these findings to design future support

structures and educational initiatives that fit the diversity of guideline projects. Patient organisations could use these findings to argue that for equal partnership and inclusive guideline development, whole panels should be educated on the social aspects as a team.

The knowledge developed in this dissertation has been actively shared with these target groups. For example, through the project, we held stakeholder meetings and gave presentations at national and international conferences. An overview can be found in the Addenda. Additionally, the scientific findings have been shared through peer-reviewed publications. To further support access to learning opportunities, we contributed to the development of an online repository on the RNN website that provides an overview of national and international educational initiatives related to guideline development. This repository helps panel members and project leads identify education initiatives and tools fitting their needs. Additionally, it highlights areas where additional educational initiatives may be needed.



Summaries



English summary

Guidelines are an essential part of health care. They support healthcare professionals and patients in making decisions about appropriate care. They can also help reduce needless practice variation and promote cost-conscious practice. The latter is increasingly important with limited resources and rising healthcare costs. Developing guidelines is complex and done by guideline panels. These panels may include healthcare professionals from various disciplines, patient representatives, and researchers; they are called panel members. These panel members are supported by project leads and guideline methodologists.

Over the past decades, guideline development has become more transparent and methodologically underpinned by approaches such as the GRADE methodology and the GRADE Evidence to Decision framework. This framework encourages guideline panels to consider not only scientific evidence but also patient values and preferences, acceptability, feasibility, equity, and cost considerations when developing recommendations. While such developments have strengthened the methodological foundation of guidelines, they have also increased the complexity of guideline development. Additionally, studies have shown that in practice it remains challenging to the meaningful integrate of patient perspectives and economic considerations into guidelines. Despite the increasing complexity of guideline development, many panel members have not had formal education to prepare them for their role, even though they are expected to make difficult decisions together. Research on how to support panel members in guideline development through education remains scarce (**chapter 1**).

This PhD dissertation aimed to investigate how education can support panel members in guideline development. To do this, we studied the experienced challenges and learning needs of panel members and designed, implemented, and evaluated a training that was used during real guideline development projects.

In the first part of this dissertation, we examined the challenges panel members experience and what learning needs they have. In **Chapter 2** we explored the learning needs of panel members with a survey amongst people involved in Dutch guideline development. We developed this survey in collaboration with Dutch patient and healthcare professional organisations involved in guideline development. This survey showed that panel members often feel insufficiently prepared for their role. Prior experience with guideline development, guidance during the process and education were indicated to help panel members in their role. Panel members

said that educational programmes should explain what guideline development entails, what is expected of them, and how different perspectives, such as those of patients, can be included. Many respondents also indicated that considering costs in guidelines is important, but that they lacked knowledge and guidance on how to do this in practice. Moreover, panel members said educational programmes should not only focus on content-related knowledge but also on process-related aspects, such as collaboration.

In **Chapter 3,** we conducted a literature review to better understand the challenges and stimulating factors to include economic considerations in guidelines. This showed several challenges: limited available economic evidence, translating available evidence from one healthcare setting to another, discussion on the role of economic considerations in guidelines, uncertainty about how to include economic considerations (methods), and a lack of resources (e.g. time). At the same time, we found factors that could help improve the inclusion of economic considerations: greater acceptance of discussing economic considerations in guidelines, better methodological guidance and basic education concerning economic concepts.

Chapter 4 explores the experiences of patient representatives who participate in guideline development, specifically patient representatives for rare conditions. They considered guidelines to be valuable tools to help them navigate health care and support patient advocacy. However, they often found it difficult to participate fully in deliberations. Medical language, unclear expectations, and unfamiliarity with guideline development made it difficult to contribute. They emphasised that guidelines should reflect the diversity of patients' experiences and address daily life issues, not only medical outcomes. Additionally, they argued that good collaboration and equal partnership in panels requires explicit attention.

In the second part of the dissertation, we developed and evaluated a training for panel members based on the found learning needs. **Chapter 5** describes how we determined the training format based on the identified learning needs. We did this together with guideline methodologists, educators, and health economists. Educational theory (principles of active, collaborative, contextual, blended and just-in-time learning) guided the development of the training. We implemented and evaluated the training with six ongoing guideline projects. The training combined e-learning modules with joint in-person sessions during panel meetings. Panels followed training modules just-in-time, meaning they received the content when required during the development process so that they could directly apply the learned knowledge in their own guideline project. Panel members said the training

helped them better understand the guideline development process, made them feel better prepared and encouraged the incorporation of economic considerations. The in-person sessions were important to create a shared understanding and support collaboration within the panel, indicating that online learning alone would not be enough.

During the implementation of the training, it became clear that no guideline development project was the same. **Chapter 6,** therefore, explored how the learning needs of panel members were shaped across and within these different projects. We interviewed the panel members and project leads of the guideline projects which followed the training. We found that learning needs were shaped by three closely connected factors: the topic of the guideline, how tasks were divided, and how panel members interacted and were able to participate. First, the topic of the guideline influenced which knowledge was important. For example, a guideline that does not include diagnostic questions would not benefit from education focused on diagnostics. Additionally, the topic affected whether scientific evidence was available, as some topics are less (scientifically) researched than others. Second, the way tasks were divided influenced what panel members needed to learn. For example, when panel members were not expected to assess scientific literature themselves, specific education on these activities was less useful for them. Finally, how panel members interacted played an important role. Factors such as experience in research or guideline development, hierarchy, confidence, and feeling safe to speak up influenced whose perspectives were heard and integrated into the guideline. Chairs were seen as having an important role in supporting inclusive dialogues and collaboration within the panel. This showed that methodological knowledge on guideline development alone is not enough to participate meaningfully. Overall, these findings indicate that educational programmes cannot be the same for every panel. Instead, they should be flexible and adaptable to the specific needs of guideline projects.

Overall, **Chapter 7** reflects upon the findings in the dissertation and the research approach we took. First, a shared understanding of how guideline development works is important, but education cannot have a one-size-fits-all approach. Because guideline projects differ in topic, task division, and how people participate, education needs to be flexible and adaptable to project-specific needs. Second, education can help panel members better understand and discuss economic considerations in guidelines. This is important to support future-proof health care in times of rising healthcare costs and limited resources. However, education alone is not enough. Clear agreements are needed about who is responsible for addressing economic aspects,

what information should be included in guidelines, which methods should be used, and better availability of economic evidence is needed to support this effort further. Third, we learned that providing knowledge at the right moment for everyone is challenging. Panel members often work on different tasks at different times, making it difficult to fully align individual learning needs with learning together as a group. Additionally, differences in experience and knowledge, as well as changes in panel composition, could influence the educational timing needs of panel members. Fourth, guideline development is not only a methodological process, but also a social one. Supporting collaboration, clear communication, and equal participation is just as important as teaching the guideline development methodology. Overall, this dissertation showed that education grounded in educational theory, using active, collaborative, contextual, blended, and just-in-time learning, can support guideline panel members during guideline development. This made the complex process of guideline development, including the discussion of topics such as economic considerations and patient values, more feasible in practice.

Nederlandse samenvatting

Richtlijnen zijn een belangrijk onderdeel van de gezondheidszorg. Ze helpen zorgverleners en patiënten bij het nemen van beslissingen voor passende zorg. Ook kunnen ze onnodige en ongewenste verschillen in de praktijk verminderen en bijdragen aan doelmatig gebruik van zorg. Dat laatste wordt steeds belangrijker, omdat middelen beperkt zijn en de kosten van de zorg blijven stijgen. Het ontwikkelen van richtlijnen is een complex proces en gebeurt door speciale werkgroepen. In deze werkgroepen nemen zorgprofessionals van verschillende disciplines, patiëntvertegenwoordigers en onderzoekers deel. Deze werkgroepleden worden ondersteund door projectleiders en methodologen die gespecialiseerd zijn in richtlijnontwikkeling.

In de afgelopen decennia is de ontwikkeling van richtlijnen transparanter geworden en methodologisch beter onderbouwd met behulp van de GRADE-methodologie en het GRADE Evidence to Decision raamwerk. Dit raamwerk stimuleert werkgroepen om bij het opstellen van aanbevelingen niet alleen naar de effectiviteit van een behandeling te kijken, maar ook naar de waarden en voorkeuren van patiënten, de gevolgen voor kosten en middelen en de aanvaardbaarheid, haalbaarheid en gelijkheid van een aanbeveling. Hoewel deze ontwikkelingen de kwaliteit van richtlijnen hebben versterkt, hebben ze het richtlijnontwikkelproces ook complexer gemaakt. Los daarvan hebben studies laten zien dat het in de praktijk nog steeds lastig is om patiëntperspectief en economische overwegingen mee te nemen in richtlijnen. Ondanks de toenemende complexiteit van richtlijnontwikkeling hebben veel werkgroepleden geen formele opleiding gehad om hen voor te bereiden op hun rol. Terwijl er wel verwacht wordt dat zij samen moeilijke beslissingen met betrekking tot de aanbevelingen moeten nemen. Momenteel is er nog weinig onderzoek gedaan naar hoe werkgroepleden hierin ondersteund kunnen worden door educatie (**hoofdstuk 1**).

Met dit proefschrift wilden we onderzoeken hoe educatie werkgroepleden kan ondersteunen bij het ontwikkelen van richtlijnen. Hiervoor onderzochten we de uitdagingen en leerbehoeften van werkgroepleden en ontwikkelden een training. Deze training hebben wij toegepast bij zes werkgroepen tijdens hun richtlijnproject en na afloop geëvalueerd.

In het eerste deel van dit proefschrift hebben we onderzocht welke uitdagingen werkgroepleden ondervinden en welke leerbehoeften zij hebben. In **hoofdstuk 2** hebben we de leerbehoeften van werkgroepleden in kaart gebracht aan de hand van een vragenlijst onder mensen die betrokken zijn bij de ontwikkeling van Nederlandse richtlijnen. Deze vragenlijst hebben wij samen ontwikkeld met Nederlandse

patiëntenorganisaties en de beroepsverenigingen van zorgprofessionals. Uit het onderzoek bleek dat werkgroepleden zich regelmatig onvoldoende voorbereid voelen op hun rol bij richtlijnontwikkeling. Eerdere ervaring met richtlijnontwikkeling, goede begeleiding tijdens het proces en training bleken werkgroepleden te helpen bij hun rol tijdens richtlijnontwikkeling. Volgens de deelnemers zouden onderwijsprogramma's moeten uitleggen wat richtlijnontwikkeling inhoudt, wat er van werkgroepleden wordt verwacht en hoe verschillende perspectieven, zoals die van patiënten, kunnen worden meegenomen. Het merendeel van de deelnemers gaf ook aan dat het belangrijk is om in richtlijnen rekening te houden met kosten, maar dat zij kennis en begeleiding misten over hoe ze dit in de praktijk moesten doen. Daarnaast gaven zij aan dat training zich niet alleen op inhoudelijke kennis (bijvoorbeeld richtlijnmethodologie) moet richten, maar ook op de proces gerelateerde aspecten van richtlijnontwikkeling, zoals samenwerking.

In **hoofdstuk 3** hebben we een literatuuronderzoek uitgevoerd om beter te begrijpen welke uitdagingen en stimulerende factoren er zijn voor het opnemen van economische overwegingen ('kosten') in richtlijnen. Hieruit bleek dat richtlijnontwikkelaars met verschillende uitdagingen te maken hadden. Zo is er vaak weinig economisch bewijs beschikbaar, is het lastig om onderzoeksresultaten uit het ene zorgsysteem te vertalen naar een ander systeem en bestaat er discussie over de rol van kosten in richtlijnen. Ook is er onzekerheid over hoe economische overwegingen meegenomen moeten worden en is er soms een gebrek aan middelen (bijvoorbeeld tijd). Tegelijkertijd vonden we factoren die kunnen helpen om economische overwegingen mee te nemen in richtlijnen: een grotere acceptatie om kosten te bespreken, betere methodologische begeleiding en basiskennis over economische concepten.

Hoofdstuk 4 beschrijft de ervaringen van patiëntvertegenwoordigers die deelnemen aan richtlijnontwikkeling, specifiek voor zeldzame aandoeningen. Patiëntvertegenwoordigers zien richtlijnen als een waardevol hulpmiddel om hun weg te vinden in de zorg en om belangenbehartigers van patiënten te ondersteunen. Tegelijkertijd vonden de patiëntvertegenwoordigers het vaak moeilijk om volledig mee te doen aan de discussies tijdens werkgroepbijeenkomsten. Zij gaven aan dat medisch jargon, onduidelijke verwachtingen en onbekend zijn met de ontwikkeling van richtlijnen het moeilijk maakten om een bijdrage te leveren. De patiëntvertegenwoordigers benadrukten dat richtlijnen niet alleen medische uitkomsten moeten beschrijven, maar ook aandacht moeten besteden aan het dagelijks leven van patiënten en aan de diversiteit van patiëntervaringen. Daarnaast gaven zij aan dat goede samenwerking en een gelijkwaardig partnerschap in werkgroepen specifieke aandacht vereisen.

In het tweede deel van het proefschrift hebben we op basis van de gevonden leerbehoeften een training voor werkgroepleden ontwikkeld en geëvalueerd. In **hoofdstuk 5** beschrijven we de vorm van de training en hoe wij dit hebben bepaald samen met richtlijnmethodologen, onderwijskundigen en gezondheidseconomen. De ontwikkeling van de training werd gestuurd door onderwijskundige principes: actief, samen, contextueel, blended en just-in-time leren. Wij hebben de training geïmplementeerd en geëvalueerd bij zes richtlijnprojecten. De training bestond uit e-learning modules gecombineerd met gezamenlijke sessies tijdens de werkgroepbijeenkomsten. De werkgroepen volgden de training just-in-time, wat betekent dat ze de inhoud aangeboden kregen op het moment dat het nodig was tijdens hun richtlijnproces. Hierdoor kon de opgedane kennis direct toegepast worden in hun eigen project. Werkgroepleden gaven aan dat de training hen hielp het proces van richtlijnontwikkeling beter te begrijpen, zich beter voorbereid te voelen en het meenemen van economische overwegingen te stimuleren. De gezamenlijke sessies waren belangrijk om gedeeld begrip te creëren en de samenwerking binnen de werkgroep te ondersteunen. Dit geeft aan dat alleen zelfstandig online leren niet voldoende zou zijn.

Tijdens de uitvoering van de training werd duidelijk dat geen enkel richtlijnproject hetzelfde is. In **hoofdstuk 6** is daarom onderzocht hoe de leerbehoeften van werkgroepleden gevormd worden en hoe er verschillen zijn tussen en binnen projecten. We interviewden werkgroepleden en projectleiders van de zes richtlijnprojecten die de training hadden gevolgd. We ontdekten dat leerbehoeften vooral worden beïnvloed door drie met elkaar verbonden factoren: het onderwerp van de richtlijn, de taakverdeling en participatiedynamiek. Ten eerste beïnvloedde het onderwerp van de richtlijn welke kennis belangrijk was. Zo heeft een richtlijn zonder diagnostische vragen geen baat bij training gefocust op diagnostiek. Ook verschilt de hoeveelheid beschikbaar (wetenschappelijk) bewijs per onderwerp. Ten tweede bepaalde de taakverdeling wat werkgroepleden moesten kunnen en daardoor leren. Wanneer werkgroepleden bijvoorbeeld niet werden verwacht zelf wetenschappelijke literatuur te beoordelen, was gedetailleerd training over deze activiteit minder nuttig voor hen. Als laatste speelde de manier waarop werkgroepleden met elkaar omgingen een belangrijke rol. Factoren zoals ervaring met onderzoek of richtlijnontwikkeling, hiërarchie, zelfvertrouwen en een veilige sfeer waren bepalend voor welke perspectieven werden gehoord tijdens werkgroepbijeenkomsten. Voorzitters werden gezien als belangrijke schakels bij het ondersteunen van inclusieve gesprekken en samenwerking binnen de werkgroep. Deze bevindingen laten zien dat alleen methodologische kennis over richtlijnontwikkeling niet voldoende is om goed te kunnen deelnemen aan het proces. Daarnaast laten ze zien dat training niet voor elke werkgroep hetzelfde kan zijn. Training moet flexibel zijn en aangepast kunnen worden aan de behoeften van een specifiek richtlijnproject.

In **hoofdstuk 7** reflecteren we op de belangrijkste bevindingen van het proefschrift en onze onderzoeksaanpak. Ten eerste is een gedeeld begrip van richtlijnontwikkeling belangrijk, maar een one-size-fits-all trainingsaanpak is niet passend. Gezien de verschillen in onderwerpen, taakverdeling en samenwerking tussen richtlijnprojecten, moet training aanpasbaar zijn. Ten tweede kan training helpen om economische overwegingen beter te begrijpen en te bespreken tijdens richtlijnontwikkeling. Dit is belangrijk voor de ontwikkeling van toekomstbestendige gezondheidszorg in tijden van stijgende kosten en beperktere middelen. Tegelijkertijd is training alleen niet voldoende. Er zijn duidelijke afspraken nodig over wie verantwoordelijk is voor het adresseren van economische aspecten, welke bewijs in richtlijnen moet worden opgenomen, welke methoden gebruikt kunnen/moeten worden en is er meer economisch bewijs nodig. Ten derde hebben we geleerd dat het een uitdaging is om iedereen op het juiste moment van kennis te voorzien. Werkgroepleden werken soms op verschillende momenten aan verschillende taken. Ook verschillen in ervaring en kennis, evenals veranderingen in de samenstelling van de werkgroep, hebben invloed op de timingbehoeften van educatie. Als laatste is richtlijnontwikkeling niet alleen een methodologisch proces, maar ook een sociaal proces. Aandacht voor goede samenwerking, duidelijke communicatie en gelijkwaardige deelname is net zo belangrijk als methodologische kennis over richtlijnontwikkeling.

Dit proefschrift laat zien dat training gebaseerd op onderwijskundige principes, zoals actief, samen, contextueel, blended en just-in-time leren, werkgroepleden kan ondersteunen bij het ontwikkelen van richtlijnen. Dit maakt het complexe proces van richtlijnontwikkeling, inclusief het bespreken van onderwerpen zoals kosten en patiëntwaarden, beter uitvoerbaar in de praktijk.



Addenda

Train the trainer guide:
Just-in-time guideline
development for panel members



Introduction

Welcome to this train-the-trainer guide for the just-in-time training for panel members of guideline development panels.

This training was developed as part of the ZonMw project *'Learning Platform for Guideline Development: Future-Proof and Sustainable'* with project number 859002001. The training's purpose is to help panel members contribute to guideline development in a way that fits the needs and context of their own guideline.

The design is informed by a Dutch survey amongst people involved in guideline development. The study highlighted what was important for panel members to meaningfully contribute to guideline development. Participants indicated that training should address both content-related themes (such as the methodology of guideline development) and process-related themes (such as collaboration within the panel, incorporating different perspectives, and distributing responsibilities) [159].

The training is aimed specifically at panel members. The RACI matrix (Responsible, Accountable, Consulted, Informed) was used to clarify roles and responsibilities in guideline development [162]. Thereby, helping formulate the learning objectives of this training. These can be found at the end of this guide.

Learning needs of panel members can differ, as no guideline project or panel is the same. Therefore, it may be necessary to adapt elements of the training to your specific guideline project. The learning objectives can help determine which elements are relevant for your guideline project.

Learning modules were developed based on the learning objectives and educational design principles, together with several guideline development organisations. Five educational design principles underpin the training:

1. Encouraging active learning – Active learning means that participants do not simply receive information passively but actively process it by doing something with the knowledge. For example, through practice-based tasks or discussions. By actively linking newly learnt knowledge to existing knowledge and experience, it is better retained and applied in new situations. Active learning approaches also help motivate participants, particularly when they relate closely to their own context.

2. Encouraging contextual learning – Complex tasks are best learned in a realistic setting. Applying knowledge in situations that resemble the actual work environment contributes to meaningful learning. Allowing participants to practise with tasks, cases, and dilemmas that are comparable to or directly related to their own practice ensures that knowledge is immediately applicable. Contextual learning can be enhanced by using realistic examples from similar guidelines or issues drawn from your own guideline project.

3. Encouraging collaborative learning – Learning is a social process in which panel members learn from and with each other. Participants learn by discussing ideas, asking questions, giving and receiving feedback, and working together on tasks. Collaborative learning encourages participants to actively share knowledge and build on each other's contributions, fostering deeper understanding. A crucial condition for collaborative learning is a safe learning environment and trust between participants. Deliberately allowing time for introductions and agreeing on ways of working contributes to creating such an environment. It is the trainers' responsibility to ensure this happens and to address any issues that arise.

4. A blended learning approach – A blended learning approach combines online learning with in-person learning moments. This approach can be particularly helpful when contact time is limited. The e-learning modules primarily provide foundational knowledge and introduce participants to key concepts. These are then explored in greater depth during in-person group sessions through activating learning methods and are linked directly to the participants' own context. In this case, their guideline. It is important that the trainer regularly refers back to the e-learning modules to ensure coherence between the online modules and the group sessions.

5. Delivering training components just-in-time – The principle of just-in-time learning means that knowledge is provided in small, relevant segments when participants need it. For example, during a specific phase of the guideline development process. This ensures that the knowledge can be applied immediately and supports contextual learning.

Together, these principles promote active knowledge transfer, collaboration, and direct application in practice.

The training consists of five modules. Each module includes:

- An e-learning module that participants complete independently (approximately 30 minutes)
- A group session (face-to-face or online) in which the modules content is explored further and applied to the panel's practice.

Most group sessions take place during regular panel meetings. This ensures that the training aligns directly with the moment the knowledge is needed, allowing participants to apply what they learn immediately to their own guidelines.

General tips and tricks

- Ensure you are familiar with the content of the e-learning modules. This will help you refer back to them during group sessions/panel meetings.
- Contact the guideline project lead to discuss the guideline, the composition of the panel, and agree on how the training will be integrated into the panel meetings.
- Ensure that panel members receive a reminder to complete the e-learning modules. You can do this, as the trainer, or the project lead. Agree on this in advance.
- You can use various digital tools to activate panel members. The training uses digital programmes. Possible tools include Kahoot, Mentimeter, Wooclap or Miro to create quizzes, word clouds, or ranking activities.

Below are module-specific tips and tricks for organising the in-person sessions.

Tips and tricks for the in-person sessions

Below are practical suggestions for shaping the in-person sessions (face-to-face or online). Where relevant, these tips are linked to the learning principles (shown in *italics* in brackets).

Module 1: Guidelines

Aim: Panel members gain insight into what a guideline is, the steps in the guideline development process, their own role within the process, and potential conflicts of interest. The foundation for collaboration during the guideline development process is also established.

Group session (during the first panel meeting)

Preparation

- Inform panel members that they must complete the first e-learning module before the first panel meeting.
- Prepare a short introduction explaining the structure of the training and how it pairs with the guideline development process.
- Ensure there is a way to visibly record collaboration agreements during the session. For example, using a flipchart, or (if online) the chat function or a shared document (e.g. Wooclap) where agreements can be recorded visibly during the session.

The training session

Moment 1: Introductions [± 25 minutes]

- Allocate time for participants to get to know one another *(collaborative learning)*. An activating method could be to ask panel members to introduce themselves to one another in pairs using the following three questions:
  - 1. What is your professional background?
  - 2. What expertise do you bring to the panel?
  - 3. Why are you participating in this guideline project?
- Then ask each participant to introduce their partner to the group.
- In an online setting, pairs can be formed in breakout rooms, or members can introduce themselves using the same three questions.

This approach stimulates engagement and group cohesion. It is important to allow sufficient time for this introduction, as it contributes to mutual trust and a safe working atmosphere *(active learning)*.

Moment 2: Roles and collaboration agreements [± 25 min]

- Ideally, this moment follows a short explanation by the project lead about how the specific guideline process will unfold. Ask the project lead to specify the roles and tasks of panel members.
- Ask whether members feel their role and tasks are clear. Here, you can refer to the final assignment in the e-learning module. Panel members were asked to describe what they expected their role to be. This encourages reflection by the panel members on their role and potential expectations by the project lead. This will help create clear expectations about the guideline development process *(active and contextual learning)*.

- You may ask activating questions such as:
  - How do you see your role in this development process?
    - Is this different from what you expected? Why?
  - What do you think of your role and tasks in this process?
  - What would you like to learn or know more about regarding your role?

[Transition to making agreements]

- Acknowledge that you heard different backgrounds and motivations for participation within the group. Emphasise the importance of good collaboration during guideline development. Encourage panel members to reflect on what they need for successful collaboration. For example, by asking them the following questions *(collaborative learning)*:
  - What is needed for good collaboration?
    - What role do you see for yourself in the collaboration with the other panel members?
    - What do you need from others to fulfil your role effectively?
  - You can add topics/agreements if needed. You can address that you saw that other panels made agreements, for example, on how to collaborate online. The project lead and chair may also contribute to the agreements *(collaborative learning)*.
- Ask how the suggested points can be translated into concrete agreements. These agreements will form the foundation for collaboration during the development process *(contextual and collaborative learning)*. Let the group formulate these themselves to foster ownership and shared responsibility. This could help create a safe work environment.
- Ensure the agreements are recorded.
- Provide a brief overview of how the training will continue throughout the project. Clarify what is covered in the e-learning modules and what will be addressed in group sessions *(blended learning)*.
  - For example: 'In the e-learning, you will… and in the group session, we will link this to your guideline…'. This ensures panel members know what to expect.
- Ask if there are any final questions regarding the training and/or the steps of the guideline development process. Then hand back the meeting to the chair or project lead to continue with the guideline agenda. For example, discussing conflicts of interest.

After the session

- Share an overview of the agreed collaboration points or agree in advance that the project lead will do so. These agreements can be revisited at the start of future group sessions to help remind panel members of the agreements that were made.

Module 2: Key questions

Aim: Panel members learn how problem areas are identified and how these are translated into key questions.

Group session (during the appropriate panel meeting)

Preparation

- Check whether any new panel members will be present.
- Prepare a slide with the collaboration agreements.
- Prepare a short quiz about problem areas and key questions (e.g. using Kahoot or Mentimeter).
- Inform panel members that they must complete the second e-learning module before the next panel meeting.

The training session

Moment 1: Introductions of new members and review previous session [± 10 minutes]

- Invite new members to introduce themselves using the same three questions as in the first group session. This may also be facilitated by the chair.
- Briefly reflect (possibly together with the project lead or chair) on the previous group session and the agreements made. Then look ahead to where the panel is in the process and what will be addressed today. This clarifies expectations and enables panel members to contribute more effectively *(active learning)*.

Moment 2: Reflection [± 10 min]

- Ask whether there are any questions following the e-learning module. An open question may generate little response. If so, you can activate the group with a short quiz.
- Examples of activating quiz formats *(active learning)*:
  - Word cloud: Ask panel members to indicate what they believe are important criteria for prioritising problem areas in their own guideline. Then invite them to explain why they consider these criteria important *(active and contextual learning)*.

- Multiple-choice questions: Ask members to select improvement options for examples of 'bad' PICO questions. Invite the panel members to explain why a particular answer is correct and how this might apply to their own guideline. This encourages participants to actively reflect on what they have learned and link it to their own context *(active learning)*.
    - Use an example from a similar guideline or a fictional guideline that resonates with the group's professional context *(contextual learning)*.

After the session

The project lead and/or chair takes over, and the panel proceeds with identifying problem areas and/or formulating their own key questions.

Module 3: Summarising evidence (GRADE)

Aim: Panel members. Learn how scientific evidence is collected, assessed and summarised according to the GRADE methodology.

Group session (a separate face-to-face or online session)

Preparation

- Agree with the project lead on which key question and/or evidence table can be used as an example in this session.
- Prepare two example evidence tables and slides on critical outcomes and clinical relevance. Include an interactive ranking system (e.g. Mentimeter).
    - Agree with the project lead on the appropriate level of detail for the group session.
- Ensure that the session can be recorded for those unable to attend.
- Inform panel members that they must complete the third e-learning module before the next panel meeting.

The training session

Moment 1: Welcome [± 10 minutes]

- Provide an overview of the session and explain where this step fits into the guideline development process. Refer to what has already been covered in the training and the guideline project. This helps set expectations and clarifies the panel members' role at this stage *(contextual learning)*.
- Ask what questions the panel members have after following the e-learning module. This increases engagement and demonstrates that their prior knowledge is valued *(blended learning)*.

    - Indicate that you will address as many questions as possible during the session and that you will respond to any remaining questions afterwards or by email.

Moment 2: GRADE evidence table [± 20 min]

- Briefly explain how the certainty of scientific evidence is determined (the five GRADE criteria for downgrading). Ask the panel whether they can identify examples of how these criteria might apply to their own literature review/ guideline *(contextual learning)*.
- Using a completed evidence table (in the organisation's standard format), ask members to determine the certainty of the evidence and explain their reasoning *(active learning)*.

Moment 3: Critical outcomes [± 10 min]

- Explain the difference between critical and important outcomes.
- Ask panel members (e.g. via Mentimeter) to rank outcomes from most to least important for one of their key questions *(active learning)*.
- Invite panel members to explain their ranking.
- Mention alternative ranking approaches, such as allocating points to different outcomes.

Moment 4: Clinical relevance [± 10 min]

- Provide a brief explanation of clinical relevance using a practical example aligned with the panel's guideline. This helps to link abstract knowledge to a realistic and applicable example, which supports learning *(contextual learning)*.
    - If possible, connect this to an existing key question within the guideline. This depends on where the panel is in the guideline development process and the remaining time of this group session.

<u>After the session</u>

- Send a summary of the topics discussed, a PDF of the slides, and, if needed, a written response to any outstanding questions. The panel members can use this as reference material throughout the rest of the project.

Module 4: From evidence to recommendations (GRADE EtD)

Aim: Panel members learn how recommendations are developed using the GRADE Evidence to Decision (EtD) framework.

Group session (during the appropriate panel meeting)

Preparation

- Inform panel members that they must complete the fourth e-learning module before the next panel meeting.
- Prepare an overview of where the panel currently is in the guideline development process, what has been completed, and what lies ahead.
- Prepare a short quiz about the EtD framework and the strength of recommendations.
    - Consult with the project lead whether you can use one of the panel's key questions or a related example should be used *(contextual learning)*.

The training session

Moment 1: Introductions of new members and review [± 10 min]

- Allow the chair to invite new panel members to introduce themselves using the same three questions as in the first session.
- Briefly review the steps completed so far in the development process. Clarify the current stage and what will be covered in this panel meeting and briefly outline what will follow afterwards *(active learning)*. This could also be done by the project lead.

Moment 2: Questions related to the training [± 10 min]

- Ask whether there are any questions following the e-learning module. An open question may generate little response. If so, you can activate the group with a short quiz.

Examples of activating quiz formats *(active learning)*:

- A multiple-choice question about which factor is (or is not) part of the EtD framework.
- A word cloud exploring one specific EtD factor in relation to one of their own key questions (e.g. "What might play a role within EtD factor X for key question Y?").
- A multiple-choice question about which recommendation is more strongly formulated.
    - Afterwards, it is important to briefly emphasise that the strength of a recommendation is not based solely on the certainty of the evidence.
- A word cloud or open question exploring what they believe would make a that a recommendation could be formulated stronger.

After the session

- The project lead may incorporate the outcomes of the word clouds into the subsequent meetings or subgroup meetings.

Module 5: GRADE EtD factor – cost considerations

Aim: Panel members understand the importance of incorporating cost considerations into guidelines. They learn where to find cost information and how to discuss it in relation to their guideline.

Group session (during the appropriate panel meeting)

Preparation

- Inform panel members that they must complete the fifth e-learning module before the next panel meeting.
- Prepare an overview of where the panel currently is in the guideline development process.
- Provide Post-it notes and a flipchart, or a digital alternative (e.g. Miro or Wooclap).
- Prepare slides explaining perspectives, the EtD framework, cost categories, and sources of cost information.
- Consult with the project lead whether a specific key question can be used as an example in this session.

The training session

Moment 1: Introduction [± 5 minutes]

- Briefly discuss what has been completed and what lies ahead. The project lead could also do this.
- Provide a disclaimer that you are not a health economist (if applicable), and that the purpose of today's session is to explore how cost considerations can be incorporated in guidelines. The aim of the session is not to reach concrete solutions.
- Explain that the focus of the session is not on precise calculations, but on understanding why costs and benefits are important and what the panel could consider within this EtD factor.
- You could provide a simple example illustrating costs and benefits. For example: "An adapted bicycle may cost more per individual, but it enables someone to keep travelling to work independently and be able to contribute to society."

Moment 2: Activating prior knowledge [± 5 min]

- Ask the panel, "Why do you think it is important to consider costs?". When this feels too abstract, you could also ask: "How do costs play a role in your daily professional practice, and what are your views on this?". This encourages the panel members to reflect on their personal experience with this topic and how important they find it *(active learning)*.

Facilitate time for potential discussion between panel members. You can also stimulate discussion by asking questions, for example:

- "Does anyone see this differently?"
- "Does anyone have other experiences?"

By discussing this, the panel members activate each other, and they learn how they each consider this topic. This provides more insight into the different perspectives panel members will bring in thel 'real' discussion when formulating the recommendations *(collaborative learning)*.

Moment 3: Post-it exercise [±25 min]

- Ask panel members to write three Post-it notes with potential costs relevant to a specific key question in their guideline. Give them three minutes to complete this exercise. By not specifying the type of costs in advance, panel members are challenged to think broadly on this subject. The experience is that diverse answers are shared. *(active and contextual learning)*.
- Discuss some of the Post-it notes by asking the author of the note to explain what they wrote and their reasoning.
  - Then ask the group to categorise the cost (patient level, healthcare sector, or other sectors). This stimulates the panel members to be actively engaged *(active learning)*.
- Provide room for possible benefits that are mentioned or actively ask for them.

Moment 4: Short presentation [±5 min]

- Provide a brief presentation on where cost information can be searched, the different perspectives that can be adopted, and the three cost categories.

<u>After the session</u>

- The identified costs and benefits are summarised by the trainer or project lead and incorporated into the subsequent panel meeting of the relevant key question.

The learning objectives

Module 1: Guidelines

<u>*Topic 1: What Are Guidelines and Their Purpose*</u>

- Participant understands what a guideline entails and what the intended purpose of a guideline is.

Topic 2: Guideline Development Process

- Participant is able to describe their task(s) in the guideline development process.
    - Participant understands how the guideline development process takes place.

Topic 3: Guideline Quality Criteria Based on AGREE-II/AQUA Criteria

- Participant is able to state that a guideline must adhere to AGREE-II criteria or the AQUA guideline.

Topic 4: Conflicts of Interest

- Participant is able to declare their interests and to identify potential conflicts of interest.
    - Participant understands the importance of declaring interests and the consequences of not declaring them (regarding the guideline development process).

Topic 5: Division of Tasks in Guideline Development

- Participant is able to describe their role and responsibilities as guideline panel members, as well as those of the other members.

Topic 6: Good Communication and Bringing Perspectives Together

- Participant is capable of expressing their own perspective while taking into account the perspective and input of their stakeholders (e.g., patient and/or healthcare professional societies).
- Participant remains open to perspectives of other panel members and can engage in constructive and respectful dialogues.
- Participant understands how active listening and constructive dialogue between panel members enhances guideline quality.

Module 2: Key Questions

Topic 1: Identifying and Prioritising Problem Areas

- Participant is able to make a prioritisation of the collected problem areas for the guideline.

In some panels this will only require understanding:

- Participant understands how the problem areas are identified and collected.
- Participant can indicate considerations to contemplate when prioritising problem areas.

Topic 2: From Topic Selection to Key Questions

- Participant is able to share their perspective regarding the key question to be formulated.
- Participant is able to provide feedback on formulated key questions based on their content knowledge and expertise.
    - Participant is able to explain how a problem area is formulated into a key question and the corresponding PICO.

Module 3: Summary of Scientific Evidence (for Interventions using GRADE)

Topic 1: Summary of Scientific Evidence

Topic 1.1: Summary of Scientific Evidence – Literature Search

- Participant can provide input to help shape the systematic literature search strategy.
    - Participant understands the purpose and process of a systematic literature search.

Topic 1.2: Summary of Scientific Evidence – Literature Selection

- Participant understands why certain studies are included based on the PICO.

In some panels:

- Participant is able to select appropriate literature for the guideline using the established in- and exclusion criteria based on the PICO.

Topic 1.3: Summary of Scientific Evidence – Data Extraction/Summarising Study Characteristics

- Participant is able to describe how and why relevant information/study characteristics were extracted.

Topic 1.4: Summary of Scientific Evidence – Meta-Analysis

- Participant is able to explain what a meta-analysis and why it is used.
- Participant is able to interpret the results of a meta-analysis.

Topic 2: Appraising and Grading the Evidence with GRADE

Topic 2.1: Determining the Quality of Evidence

- Participant understands how studies quality is collectively assessed using the GRADE methodology.
- Participant can name the five GRADE criteria for downgrading evidence (risk of bias, imprecision, inconsistency, indirectness, and publication bias).

Topic 2.2: GRADE Evidence Table

- Participant is able to discuss the literature conclusions, e.g. in the GRADE evidence table, from the perspective of their expertise.

Module 4: Evidence to Recommendations (GRADE EtD)

Topic 1: GRADE Evidence to Decision (EtD) Framework

- Participant is able to formulate considerations/judgements for each factor of the EtD framework together with the other panel members.
- Participant can listen to and discuss considerations/judgements brought forward from other perspectives.

Topic 2: Formulating Recommendations

- Participant is capable of drafting recommendations using the EtD framework and the panel members' (subject-matter) expertise.
  - Participant is able to describe the appropriate strength of a recommendation based on the EtD framework.
  - Participant is able to explain how the EtD framework is used to formulate recommendations.
- Participant can weigh the perspectives of the panel members and integrate them into a recommendation.
- Participant can discuss the recommendations with the panel members, using their relevant expertise and the EtD framework.

Module 5: GRADE EtD Factor: Cost Considerations

Topic 1: What are Cost Considerations

- Participant knows the basic principles of how cost information is reported in studies (study design, outcome measures, reporting of results) relevant for decision-making in guidelines.
- Participant is able to share ideas about potential cost aspects relevant for the guideline.

Topic 2: Why Include Cost Considerations in Guidelines

- Participant understands the importance of considering costs in guidelines.
- Participant understands how cost considerations help the justification and formulation of guideline recommendations.



Topic 3: How to Include Cost Considerations in Guidelines

Topic 3.1: Conducting Economic Evaluations

- Participant is familiar with the different perspectives (e.g., societal, patient) that can be applied to cost considerations.
- Participant knows when and how cost considerations can be included during the guideline development process.

Topic 3.2: Considering Costs in Formulating Recommendations

- Participant is able to interpret and appraise economic evidence (e.g., using the CHEC checklist) and relate it to clinical practice.
- Participant is able to incorporate the results from cost-effectiveness studies (e.g., ICER, QALY) into judgments on the strength and direction of the recommendation.



Addenda

About the Author



About the Author



Picture by Steven

Chloé (Aymée de Mortier) was born in Diemen on the 1st of July in 1997. She has had a curious mind from a young age. Always asking her parents how things work. Her parents shaped her interests for education and health care early on and supported her in every endeavour she undertook.

She completed her secondary education at the Open Schoolgemeenschap Bijlmer in Amsterdam. While completing her VWO, she worked at the HEMA Waterlooplein. In 2015, Chloé moved to Wageningen to study Biology at the Wageningen University. Here she discovered life beyond the Ring A10. She completed the minor Education, thereby qualifying as a high school biology teacher. During her bachelor she joined four committees of the study association B.V.W. Biologica in various roles.

As a child Chloé practised gymnastics, dancing, and ice-skating. Ice-skating was the starting point of a life shaped by teaching. At fourteen, she became an ice-skating instructor for young children. She continued this role until her second year at university. In recent years, she explored more creative hobbies such as sewing, ceramics and going to concerts and festivals.

Chloé continued her Master's studies in Wageningen, specialising in health biology and infectious diseases. During her internship at the GGD, she conducted epidemiological research on the impact of COVID measures in North-East Gelderland. For her master thesis, she worked at the WUR laboratory of Entomology and Virology, studying how viruses affect tick behaviour. She also taught in multiple courses as a student teacher.

In 2021, she 'broadened her horizon' to below the rivers and Utrecht. She started a PhD at the department of Health Services Research (HSR) and the School of Health Professions Education (SHE) at Maastricht University, in collaboration with the Knowledge Institute of the Federation of Medical Specialists. Her research focused on guidelines, health economics and education. She developed a training programme for guideline development emphasising the social aspects of guideline development and cost considerations in guidelines. She collaborated closely with many different healthcare societies and patient organisations to realise the training programme.

Never one to sit still, Chloé joined the junior board of the Dutch Association of Medical Education, two SHE SIG working groups (interprofessional education and co-creation) and the Guidelines International Network (GIN) working group Guidelines in Medical Education (GIME). These activities provided her with motivation and inspiration throughout her PhD. She also obtained her University Teaching Qualification certificate.

This book marks the end of her PhD journey. It has now become time for a new adventure.



Addenda

Dankwoord



Dankwoord

Welkom bij het meest gelezen stuk van een proefschrift.

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'Dag lieve vrienden, de vlaai is op'



Addenda

Publications and Presentations



Publications and Presentations

Publications related to this dissertation

de Mortier, C. A., Klein Haneveld, M. J., Verstegen, D. M. L., van Mastrigt, G. A. P. G., Paulus, A. T. G., Evers, S. M. A. A., Dreesens, D. H. H., & Majoie, M. H. J. M. (2025). Unravelling Education Needs for Clinical Practice Guideline Development: A Survey Performed in the Netherlands. *Journal of Evaluation in Clinical Practice*, *31*(1), e14274. DOI: https://doi.org/https://doi.org/10.1111/jep.14274

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Yaros, J., **de Mortier, C**., Oude Egbrink, M., Evers, S., & Paulus, A. (2023). Identifying costs in health professions education: a scoping review protocol. *British Medical Journal Open*, *13*(10), e074410. https://doi.org/10.1136/bmjopen-2023-074410

Selection of Presentations

Van onzekerheid naar zelfvertrouwen: zorgprofessionals voorbereiden op richtlijnontwikkeling. *Nominated for best practice paper presentation at the Nederlandse Vereniging voor Medisch Onderwijs (NVMO). 2025.*

Training voor het ontwikkelen van multidisciplinaire, doelmatige richtlijnen: een behoefteanalyse. *Poster presentation and plenary pitch presentation at the Clinical Scientific Symposium Kempenhaeghe. 2024.*

Unravelling Education Needs for Clinical Practice Guideline Development: A survey in the Netherlands. *Short oral presentation at the Global Evidence Summit. 2024.*

The Price is Right: Empowering Clinicians to make Economically-Informed Decisions. *Poster presentation at the Global Evidence Summit. 2024.*

Training voor het ontwikkelen van multidisciplinaire, doelmatige richtlijnen/ standaarden: een behoefteanalyse. *Poster presentation at the Nederlandse Vereniging voor Medisch Onderwijs (NVMO). 2023.*

Workshops and other contributions

Building Bridges. *Organiser of the Young Researchers Network from the NVMO Research Day. 2025.*

Online Co-Creation of Education: New Ways to Listen to Diverse Learners' Voices for Enhancing Future Learning. *Workshop, at the Association for Medical Education in Europe (AMEE). 2024.*

Get out of Your Bubble. *Organiser of the Young Researchers Network from the NVMO Research Day. 2024.*

Embracing Imperfections: Navigating Mistakes in Medical Education Research. *Workshop at the pre-conference of the NVMO. 2024.*


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Addenda

SHE Dissertation series



SHE Dissertation series

The SHE Dissertation Series publishes dissertations of PhD candidates from the School of Health Professions Education (SHE) who defended their PhD theses at Maastricht University. The most recent ones are listed below. For more information go to: https://she.mumc.maastrichtuniversity.nl

Yaros, J. (29.06.2026) *Cost Identification and Cost-Conscious Decision-Making in Health Professions Education: From Opacity to Opportunity*

David, L. (18.05.2026) The Effort of Change Understanding and Supporting Students' Sustainable Use of Effective Learning Strategies

Fuentes Cimma, J. (20.04.2026) Designing for Productive Feedback: A Sociocultural and Co-Created Approach to Clinical Education

Godschalx-Dekker, J. (08.04.2026) LEARNING FROM LAW CASES Exploring regulations on residents' (un)professional performance in postgraduate medical education

Hornstra, S. (30.03.2026) Fostering officer competence: A multi-faceted study of military training, academic education and design thinking-based innovation in officer development

Sultan, L. (04.02.2026) Palliative Care Education for Health Professions Students: An Interprofessional Shared Decision-Making Approach

Keulen, M.H.F. (30-10-2025) Outpatient hip and knee arthroplasty: Advancing the Optimization of Care Pathways

Gerretsen, E.C.F (06-10-2025) Learning to navigate the bronchial tree: considerations for simulation-based bronchoscopy training

Martinino, A. (03-10-2025) Predatory Publishing Impacts on Medicine and Educational Interventions for Scholarly Integrity

Steen van der, J. (26-09-2025) Formative assessment plans for better informed decision-making. Educational Design Research in Secondary Education

Anderson, H.K. (18-09-2025) Exploring Equity in Workplace-based Assessment: a justice-oriented approach

Yu, H. (11-09-2025) Mastering Medical Communication: A Journey Through Language, Motivation, and Feedback

Hari, R. (05-09-2025) Near-Peer-Teaching in Undergraduate Skills Training Exploring Teaching Strategies and Implementation

Leatemia, L.D. (26-06-2025) Strengthening student-centeredness in teachers in problem-based learning

Kinnear, B. (19-06-2025) From Evidence to Argument: Bringing Validity to Life in Health Professions Education Assessment

Janesarvatan, F. (13-06-2025) Rooted In Reality: Virtual Patient Simulations in Dental Education

Tan, E. (10-06-2025) Beyond Hogwarts and Sorting Hats: How a House System shapes medical student support

Zhu, Y. (28-05-2025) Driven to Learn: Understanding and Supporting Student Autonomous Motivation in Health Professions Education

Wijbenga, M. (19-05-2025) Challenges, Pitfalls and Opportunities: workplace learning during healthcare placement

Bock. L. (25-04-2025) Exploring value-based healthcare decision-making in postgraduate medical education: A focus on medical residents' perspectives

Kolm, A. (24-03-2025) TRANSCENDING TIME, SPACE, AND CULTURE: International Online Collaboration Competencies in Health Professions Education

Suliman, S. (27-01-2025) Learners' Mental Health and Challenging Transitions: The Added Value of Co-Creation

Onan, E. (20-12-2024) Promoting the self-regulated use of desirable difficulties: The case of Interleaved Practice

Shimizu, I. (18-12-2024) Social interdependence in collaborative learning

McDonald, J. (28-11-2024) Collections for reflection: the transformative potential of portfolios in medical education

Barry, E. (20-11-2024) Leadership and Followership within Healthcare Teams: Exploring the roles and collaborative dynamics in interprofessional teams

Linden van der, J. (14-10-2024) Learning Beyond Assessment Compliance. The conundrum of self-regulated learning in the context of summative assessment

Smeets, H. (04-10-2024) Beyond the silos: Design guidelines for interprofessional assessment in higher healthcare education

Wisener, K. (24-09-2024) From Incentive Schemes to Feedback Processes: On the challenges of recruiting, supporting, and retaining clinical educators

Maulina, F. (06-09-2024) Developing Physician Leadership in Indonesia's Rural and Remote Contexts: Culture Matters

Wu, J. (24-06-2024) Sitting Smartly in Tertiary Education Exploring Strategies to Tackle Sedentary Behavior for Student's Cognitive and Physical Well-being

Bossen, J. (16-05-2024) Shared Decision Making in Orthopaedic Surgery: Implementation of tools and training in clinical practice

Klasen, J. (02-05-2024) Allowing Failure as an Unspoken Pedagogy in Residency Training

Behrens, C. (31-01-2024) Medical students' emotions in complex simulation

Nicholson, J. (20-12-2023) Partnering for Success: Librarian Involvement in Assessment for Learning

Barber, C. (20-12-2023) Aligning education to societal needs: Evaluating social accountability in health professions education

Ilishkina, D. (19-12-2023) Self-Regulation of the Motivation to Learn

Loosveld, L. (07-12-2023) Finding the merit of mentoring Mentors' personal knowledge and beliefs about mentoring in health professions education

Puranitee, P. (02-11-2023) Alleviating burnout in medical school: increasing a sense of belonging and collegiality in the clinical workplace

Nobel, M. (28-09-2023) The radiological report: a compromise between structured reporting and natural language processing

Heijnens, L. (16-06-2023) Aspects of geometry, fixation and materials in total hip arthroplasty. What have we learned?

Gillespie, H. (06-06-2023) Helping students become doctors: analysing tensions and releasing opportunities in clinical workplaces

Khan, M. (16-05-2023) Overcoming barriers in the prevention of surgical site infections: a master plan employing task-based interprofessional training

Tremblay, M-L. (08-05-2023) Lights. Camera. Action. Debrief. Designing Immersive Simulation for Novices to Promote Learning

Bynum, W. (15-02-2023) Out of the Shadows: A qualitative exploration of shame in learners across the continuum of medical education

Mordang, S. (07-02-2023) Challenges in high-value cost-conscious care training of residents: Exploring the various stakeholders' roles and attitudes

Brouwer, E. (12-12-2022) Medical education without borders. The what, why and how of International Medical Programmes

Kellar, J. (26-10-2022) Becoming Pharmacists: Professional identity struggles of a profession in transition

Biwer, F. (08-07-2022) Supporting Students to Study Smart – a learning sciences perspective

Bransen, D. (22-06-2022) Beyond the self: A network perspective on regulation of workplace learning

Lee, J. (08-06-2022) The Medical Pause in Simulation Training

Kruepunga, N. (17-05-2022) Development of the caudal part of the human embryo

Cantillon, P. (28-04-2022) The Social construction of clinical education: being and becoming in clinical teams

Pieters, J. (01-04-2022) Let's talk about it:Palliative care education in undergraduate medical curricula

Jonge de, L. (28-03-2022) Is it all in the mind? Stakeholder conceptions on workplace based assessment

Beuken, J. (25-3-2022) Waves towards harmony: Learning to collaborate in healthcare across borders

Ilgen, J. (15-12-2021) Comfort with uncertainty in medical professionals. An exploration of how clinicians experience and manage dynamic problems in practice

Schut, S. (9-12-2021) The Burden of Proof - Agency and Accountability in Programmatic Assessment'

Hui, L. (6-12-2021) 'Fostering Self-Regulated Learning: the Role of Perceived Mental Effort'

Meeuwissen, S. (12-11-2021) 'Team learning at work. Getting the best out of interdisciplinary teacher teams and leaders'

Nguyen Thi, V.A. (02-11-2021) Motivating and educating health professionals to work in less attractive specialties: Findings from experiences of Vietnam

Martens, S. (15-10-2021) Building student-staff partnerships in higher education

Lestari, E. (05-10-2021) INTERPROFESSIONAL EDUCATION Lessons from Indonesia

Atherley, A. (27-09-2021) Beyond the struggles: Using social-developmental lenses on the transition to clinical training

Schillings, M. (06-07-2021) Talking about feedback: Face-to-face peer dialogue about written feedback

Wilbur, K. (05-07-2021) NO WHERE | NOW HERE: Context and Competency Expectations in Workplace-Based Training

Bendermacher, G. (02-07-2021) Navigating from Quality Management to Quality Culture

Ahmed Khan, R. (29-06-2021) Assessing curriculum viability in Undergraduate Medical Education

Chim, H.Q. (30-03-2021) Physical Activity Behavior and Learning in Higher Education

Dominguez, L.C. (23-02-2021) Persistence in surgical training: The role of job crafting and leadership

Bindels, E. (22-02-2021) DOING WELL, GETTING BETTER; Facilitating physicians' reflection on their professional performance



