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ORIGINAL ARTICLE

Colorectal cancer guidelines seldom include the patient perspective

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Abstract

Objectives: This study aimed to describe how colorectal practice guidelines (PGs) incorporate the patient perspective.

Study Design and Setting: We searched in the Guidelines International Network library, MEDLINE, National Guideline Clearinghouse, NHS Evidence database, and TRIP database. Two authors independently selected the PGs. We considered recommendations rated or worded as weak or conditional or suggesting multiple options, as potentially preference sensitive. Two authors independently evaluated if, in potentially sensitive recommendations, the patient perspective was incorporated.

Results: We included 28 PGs that contained 588 recommendations, being 256 potentially preference sensitive. Ten PGs (36%) included patients in the development process, and 12 (43%) provided information about patients' perspectives. Nine PGs (32%) included recommendations in which the patient perspective was explicitly considered, and 13 (46.4%) that recommended a discussion with the patient. From a total of 588 recommendations, 9.7% (25/256) of potentially preference-sensitive recommendations considered the patient perspective. The inclusion of patients in the development process was associated with a more frequent incorporation of the patient perspective in potentially preference sensitive recommendations (70% vs. 0%; $P < 0.001$).

Conclusions: Guideline users should be aware that the incorporation of the patient perspective in colorectal cancer PGs is suboptimal. Guideline developers should make efforts to incorporate the patient perspective, especially in preference-sensitive recommendations.

Keywords: Colorectal neoplasms; Patient preference; Patient participation; Guidelines as topic; Clinical Practice Guideines; Patient perspective

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1. Introduction

Practice guidelines (PGs) are "statements that include recommendations intended to optimize patient care that are informed by systematic reviews (SRs) of evidence and an assessment of the benefits and harms of alternative care options" [1]. PGs have the potential to facilitate decision-making, improve patient care, and optimize the use of resources [1,2].

During PG development, the clinicians and professionals involved provide the knowledge on technical aspects such as the epidemiology of the health problem, prognosis, preventive strategies, and diagnostic and therapeutic procedures. However, patients are best suited to assessing the impact of the disease on their lives, social circumstances, habits, behavior, attitudes to risk, as well as their perceptions of the relative importance of the outcomes at play—

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What is new?

Key findings

- Incorporation of patients or patient-related research is still suboptimal in contemporary colorectal cancer practice guidelines.
- Question formulation and guideline revision are the most common tasks in which patients are involved.
- Only a minority of potentially preference sensitive recommendations incorporate the patient perspective.
- The inclusion of patients in the guideline development process facilitates the incorporation of their perspective in recommendations.

What this adds to what was known?

- This survey is the first to critically review the available guidance, provided by colorectal cancer practice guidelines for how to incorporate patients and their views.

What is the implication and what shold change now?

- Clinicians should know that the patient perspective is not considered in many practice guidelines and take this into consideration in their encounters with patients.

whether desirable or undesirable [3−5]. Furthermore, there is evidence that the importance that patients place on health care outcomes often varies and often differs from that of clinicians [6,7]. It is therefore crucial to consider the perspective of those affected by the decisions, typically patients, when formulating recommendations [1,5,8,9]. Patient perspective can be understood as patient views, wants or, as the GRADE group coined, “patient values and preferences” [8,10]. The GRADE working group uses the term “values and preferences” as an overarching term that includes patients’ perspectives, priorities, beliefs, expectations, values, and goals for health and life. In addition, to mean the processes that individuals use in considering the potential benefits, harms, costs, and inconveniences of the management options in relation to one another [5,8,11,12]. In the present paper, “patient perspective” and “patient preferences” are used indistinctively. However, consideration of the patient perspective is an important aspect often ignored by organizations, both in guidance documents [13] and PGs [14,15].

Incorporating the perspective of patients into recommendations is even more relevant in fields such as oncology, where it is common to find scenarios in which benefits and risks are closely balanced. In this type of scenario, the best course of action is very dependent on a patient’s context and associated values and preferences. For example, in patients with advanced cancer, it is necessary to weigh up an improvement in survival against the risk of significant associated toxicity of adjuvant treatment [16]. In the context of colorectal cancer (CRC), in general, patients are willing to accept a shorter survival to avoid a stoma, a frequent serious surgical complication. However, other patients are willing to accept significant treatment side effects with neoadjuvant treatment for relatively small potential increases in life expectancy [17]. Patient involvement in screening decisions is also important because it entails a close balance between the expected benefits from a preventive intervention and the risk associated with the test involved [18].

CRC is one of the most common cancers and has a significant impact on the health of the population. CRC is the third most common cancer in men (after lung and prostate) and the second in women (after breast) and is the second cause of cancer death (after lung in men and after breast in women) in Europe [19]. In terms of trading-off closely balanced benefits and harms present in multiple management decisions of CRC patients [16,20], most of the scenarios are sensitive to patients’ preferences. For example, some of these decisions are whether to participate or not in screening programs, the choice of different treatment options with significant differences in survival and quality of life, or the option of palliative care over further treatment. To the best of our knowledge, a systematic survey of how colorectal PGs incorporate the patient perspective, either in the development process or in the content of recommendations, does not exist. Therefore, we conducted a systematic evaluation on this topic.

2. Methods

2.1. Study design

2.1.1. Systematic survey of PGs

The study protocol was registered in PROSPERO (CRD42018095606). We report the results according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA) statement [21] (Appendix 1).

2.2. Search strategy

We conducted a comprehensive search in June 2014 on MEDLINE (via Ovid), the National Guideline Clearinghouse, the NHS evidence database, Guidelines International Network (GIN) library, Trip database, and Web sites of relevant institutions. We also conducted a hand-search of references of the relevant PGs retrieved and consulted the Web sites of the development organizations identified.

The search was updated in November 2016 and tracked for updates of the included guidelines in January 2018. The search strategies are available in Appendix 2.

2.3. Eligibility criteria

We included CRC PGs published in English from 2011. To consider a document as a PG, we adopted the definition provided by the Institute of Medicine: "*statements that include recommendations intended to optimize patient care that are informed by systematic reviews (SRs) of evidence and an assessment of the benefits and harms of alternative care options*" [1]. We included PGs if they provided recommendations, literature searches in at least two databases and reported a procedure to assess the quality of the evidence and strength of recommendations.

We excluded health technology assessment reports, documents derived from original PGs (e.g., clinical pathways) except patient materials, documents endorsed by other institutions that were not the primary developers, and updates of previously published PGs whose literature searches had not been updated. Two reviewers independently assessed documents for eligibility, initially reviewing titles and abstracts, and then the full text of those deemed eligible. Disagreements were solved by consensus.

2.4. Data extraction

We developed and pilot tested a case report form, which is available on request. One reviewer (A.S.) extracted the data, whereas other reviewers (E.N.d.G., C.S., M.B., and C.V.) checked the data for accuracy. Disagreements were solved by consensus.

We extracted the following data from the eligible guidelines: the guideline's general information (e.g., institution, country, and year of publication), topic assessed (e.g., prevention, screening, or treatment), method used to assess the quality of the evidence, method used to formulate and grade recommendations, inclusion of patients or patient representatives in the guideline development process, inclusion of information about patients' perspective and source (e.g., systematic review of the literature, de novo research [e.g., surveys, focus groups, or interviews], and/or panel judgment), and methods used to incorporate the patient perspective into recommendations. We extracted data at recommendation level collecting whether (1) patients' values and preferences were explicitly considered when making the trade-offs between benefits and harms and (2) the recommendation explicitly suggested the need for a discussion with the patient.

We also collected all the recommendations that could be potentially sensitive to patients' preferences. We considered potentially preference-sensitive recommendations as those that (1) were rated as weak or conditional, (2) were worded as conditional, and (c) suggested alternative courses of action. To classify recommendations as weak or conditional—irrespective of the rating system used—we applied the GRADE definitions. According to GRADE, weak recommendations are those in which "the majority of individuals in this situation would want the suggested course of action, but many would not." Appendix 3 provides a table with the conversion of the different rating systems to what we considered weak or conditional ratings. We considered the level of obligation in the recommendation wording, with the conditional recommendations being those that used language conveying an intermediate or low level of obligation (e.g., "suggests," "consider," "is appropriate," "may," and "might") [22,23]. Pairs of reviewers independently evaluated all potentially preference-sensitive recommendations and determined if they explicitly included the patient perspective. Disagreements were solved by consensus.

2.5. Analysis

We conducted a descriptive analysis of the data providing absolute frequencies and proportions or medians and ranges as appropriate. We analyzed the association between including patients in the PG development process geographical region and type of organization with the proportion of recommendations that included the patient perspective (as a categorical variable) using the chi-squared and the Fisher F-test when appropriate. Statistical analyses were performed using SPSS, version 23.0 (SPSS Inc., Chicago, IL, USA).

3. Results

We retrieved a total of 2,447 references from the search, selected 311 for full-text review and excluded 283 (the reasons are described in the PRISMA flowchart; Fig. 1). Finally, we included a total of 28 colorectal PGs (Appendix 4).

3.1. Characteristics of the included PGs

Most included PGs were developed by organizations located in North America (11, 39.3%), and Europe (10, 35.7%). The majority were developed by scientific societies (16, 57.1%) or public institutions (11, 39.3%). Thirteen PGs (46.4%) were de novo PGs, whereas 15 (53.6%) were updated PGs. The topics about CRC management most frequently included were treatment (13, 46.4%), diagnosis (11, 39.3%), and screening (9, 32.1%). Most PGs discussed only one (13, 46.4%) or two aspects (11, 39.3%), whereas four PGs treated three or more of them (4, 14.3%). The GRADE system or adaptations were the most frequent system used to assess the quality of the evidence (12/28, 42.9%) and to grade recommendations (11/28, 39.3%; Table 1).

3.2. Incorporation of patients in the development process

Ten PGs (35.7%) included patients or patients' representatives (hereinafter "patients") in their development process,

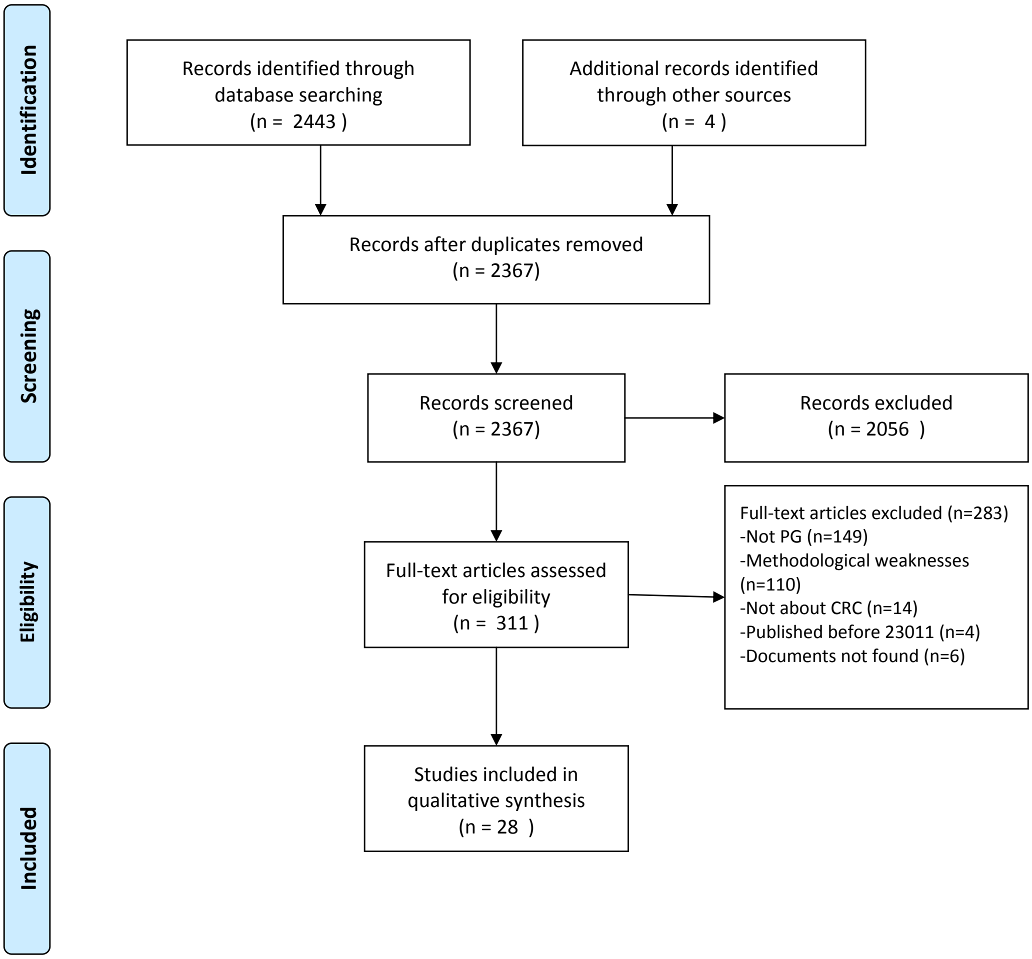

Fig. 1. PRISMA 2009 flow diagram.

and they were part of the guideline panel in 90% of the cases. The majority of PGs included only one patient (4/10, 40%). Six (6/10, 60%) provided information that allowed the identification of the patients included (names and surnames), and five (5/10, 50%) provided their declaration of conflicts of interest. The proportion represented by patients in the guideline panels ranged from 3% to 20%. The type of participants most frequently included were members of patient associations (5/10, 50%) and patients (4/10, 40%).

Of the 10 PGs that included patients, two (20%) [PGs 1, 17] reported some details about the methodology used to include them: both PGs described the participant identification and recruitment process (Appendix 5, Box 1), and one also described the selection process [PG 1]. No PGs reported the resources used or training provided, if any (Table 2).

Most of the PGs that included patients in the development process also indicated the tasks in which they participated (8/10, 80%), the most common being the review of the guideline (7/10, 70%), followed by the formulation of the included questions (4/10, 40%). Other steps involving patients were defining the scope and objectives, identifying and reviewing the scientific evidence, developing recommendations, and producing information for patients. None of the included PGs considered their participation in identifying panel members, writing the PG, or conducting dissemination and implementation activities.

3.3. Incorporation of information about the patient perspective

Twelve PGs (12/28, 42.9%) provided information about the patient perspective (Table 3). The most frequent sources were (1) explicit judgment of the guideline panel (7/12, 58.3%), (2) conducting a systematic review (6/12, 50%), and (3) conducting a narrative review (5/12, 41.7%). None of the included PGs conducted primary research (e.g., a de novo qualitative study or survey) as a source of evidence. None of the PGs that used panel judgment provided the methods used. Three (50%) of the six PGs that conducted a systematic review provided the search strategy used [PG 2, 3, 24], and five (83.3%) provided the databases searched [PG 2, 3, 16, 17, 24]. The most frequent study design was a cross-sectional survey (3/6, 50%). None of the PGs assessed the risk of bias of included studies, nor the certainty of evidence about this type of evidence.

Table 1. Characteristics of included clinical guidelines

Clinical guidelines characteristics	***n* (%)**	**References**
Region		
North America	11 (39.3)	[6–8,10,11,15,16,19,22,23,27]
Europe	10 (35.7)	[1–4,12,17,20,21,25,28]
Asia	5 (17.9)	[13,14,18,24,26]
Oceania	2 (7.1)	[5,9]
Type of organization		
Scientific society	16 (57.1)	[4,7,8,12–16,20–22,24–28]
Public institution	11 (39.3)	[1–3,5,6,9–11,17,19,23]
Other (NGO)	1 (3.6)	[18]
Year of publication		
2011–2014	16 (57.1)	[1,3–14,18,23,28]
2015–2017	12 (42.9)	[2,15–17,19–22,24–27]
Type of document		
Journal article	15 (53.6)	[4,7,8,13–16,18–22,25,26,28]
Full guideline not published in a journal	9 (32.1)	[1–3,5,9–11,17,27]
Both	4 (14.3)	[6,12,23,24]
Condition assessed		
Colorectal cancer	20 (71.4)	[1–6,9,10,12–16,18,19,22,24,26–28]
Colon cancer	2 (7.1)	[7,21]
Rectal cancer	6 (21.4)	[8,11,17,20,23,25]
Topic discussed[a]		
Prognosis/risk factors	6 (21.4)	[1–3,5,21,27]
Screening	9 (32.1)	[2,6,12,14,16,18,19,24,28]
Diagnosis	11 (39.3)	[1,2,4,7–9,13,17,20,23,27]
Treatment	13 (46.4)	[1,2,7–11,13,17,20,21,25,26]
Follow-up	7 (25.0)	[1,2,5,9,15,22,26]
Other[b]	4 (14.3)	[2,12,26,27]
New guideline/update		
New	13 (46.4)	[3,4,6,9,10,12–14,20,21,23,24,28]
Update	15 (53.6)	[1,2,5,7,8,11,15–19,22,25–27]
Method to assess quality of the evidence		
GRADE system or adaptation	12 (42.9)	[1,3,4,7,8,13,15–17,22,24,26]
OXFORD levels of evidence	3 (10.7)	[12,20,21]
SIGN system or adaptation	2 (7.1)	[2,28]
Levels of evidence from NHMRC	2 (7.1)	[5,9]
USPSTF levels of evidence	1 (3.6)	[19]
No formal system. Assessment of the quality of included studies	8 (28.6)	[6,10,11,14,18,23,25,27]
Method to grade recommendations		
GRADE system or adaptation	11 (39.3)	[4,7,8,13–17,22,24,26]
CEBM Oxford System	3 (10.7)	[12,20,21]
SIGN system	2 (7.1)	[2,28]
Other	2 (7.1)	[19,25]
Own system	2 (7.1)	[5,18]
No rating	7 (25.0)	[1,3,6,10,11,23,27]
Number of recommendations		
<10	12 (42.9)	[6,10,11,13–17,19,22–24]
10–19	6 (21.4)	[3,4,18,20,21,27]

(*Continued*)

Table 1. Continued

Clinical guidelines characteristics	*n* (%)	References
20–29	4 (14.3)	[7,8,26,28]
>30	6 (21.4)	[1,2,5,9,12,25]

Abbreviations: CEBM, Centre for Evidence-Based Medicine; GRADE, Grading of Recommendations Assessment, Development and Evaluation; NGO, nongovernmental organization; NHMRC, National Health and Medical Research Council, Australia; SIGN, Scottish Intercollegiate Guidelines Network; USPTF, US Preventive Services Task Force.

[a] More than one option could be selected.

[b] Other aspects were palliative care, referral, and quality of procedures.

3.4. The patient perspective at recommendation level

Overall, the 28 included PGs provided 588 recommendations (range 1 to 74, median 14; Table 4), with the majority (42.9%) providing less than 10 recommendations (Table 1).

3.4.1. Explicit consideration

Nine PGs (9/28, 32.1%) included at least one recommendation in which the patient perspective was explicitly considered in their formulation. Within these guidelines, the proportion of recommendations that explicitly consider the patient perspective ranged from 4.2% to 100%. Thirteen PGs (13/28, 46.4%) included recommendations that explicitly indicated in their wording the need to have a discussion with the patient. The proportion of recommendations that explicitly considered discussion with the patient ranged from 1.7% to 100% across the PGs. Of the 588 recommendations provided by the 28 included PGs, 34 (5.8%) explicitly considered the patient perspective in their formulation, and 40 (6.8%) explicitly indicated the need to have a conversation with the patient or indicated the need to consider the patient perspective in the clinical encounter (Table 4).

PGs that included patients in their development process contained a higher proportion of recommendations that explicitly considered the patient perspective in their formulation or explicitly indicated the need to have a discussion with the patient (70% of PGs that include patients in their development process included the patient perspective in more than one-fourth of their recommendations compared with 0% of guidelines that did not include patients in their development; $P < 0.001$). Two guidelines made research recommendations related to patient preferences [PG1, 24] (Appendix 4, Box 2).

European guidelines, compared with those produced in other regions, provided a higher number of recommendations explicitly including the patient perspective (50% of European guidelines included the patient perspective in more than one-fourth of their recommendations compared with 18% of guidelines from North America) ($P = 0.173$). We did not observe important differences between PGs developed by scientific societies or public institutions (62.5% vs. 54; $P = 0.679$; Appendix 6, Complementary Analysis).

From the 11 PGs that used the GRADE system to rate recommendations, five (45.5%) explicitly considered either the patient perspective in the formulation of recommendations or indicated the need to consider this aspect in the clinical encounter [PG 16, 17, 22, 24, 26]. The other six PGs that used GRADE did not consider explicitly the patient perspective despite formulating weak recommendations. The proportion of PGs that did not use GRADE and explicitly considered patient preferences was 64% (11/17; $P = 0.441$; Appendix 6, Complementary Analysis).

3.4.2. Considerations in preference-sensitive recommendations

3.4.2.1. Recommendations rated as weak or conditional. Seventy-five percent of PGs rated the strength of the recommendations (Table 5). Appendix 3 provides the conversion of the original rating systems to what we considered weak or conditional ratings. Eighteen PGs (18/28, 64.3%) provided recommendations rated as conditional. Eight of these PGs (8/18, 44.4%) considered the patient perspective to some extent. Overall, all the included PGs provided a total of 173 recommendations rated as weak/conditional (173/588 29.4%). Fifteen of these recommendations (15/173, 8.7%) considered the patient perspective to some extent.

3.4.2.2. Recommendations worded as conditional. Recommendations included in this section were those using a conditional wording but were not rated as weak or conditional (considered in the section above) or were not rated at all. Eleven PGs (11/28, 39.3%) provided conditionally worded recommendations, and four of them (4/11, 36.4%) considered the patient perspective to some extent. Overall, the 28 PGs provided a total of 54 recommendations that were worded as conditional (54/588, 9.2%), and of those, six (6/54, 11.1%) considered the patient perspective to some extent.

3.4.2.3. Recommendations suggesting multiple options. Twelve PGs (12/28, 42.8%) provided recommendations that suggested more than one option, and two of these (2/12, 16.7%) considered patient preferences in some way. Overall, the 28 PGs provided 29 recommendations that suggested more than one option (29/588, 4.9%), and four (4/29, 13.8%) of these considered patients preferences in some way.

The majority of PGs (24/28, 85.7%) provided some preference-sensitive recommendations, and a half of them (12/24, 50%) considered the patient perspective to some extent. PGs that included patients in their development process had a higher proportion of preference-sensitive recommendations, considering the patient perspective to some

Table 2. Inclusion of patients or patients' representatives in the PG development process

Inclusion of patients or representatives	n (%)	References
Inclusion of patients or patients' representatives		
Yes	10 (35.7)	[1–3,5,9–11,16,17,24]
No	15 (53.6)	[6–8,12–15,18–21,23,25–27]
Not reported	3 (10.7)	[4,22,28]
Type of patient or patient representative[a,b]		
Patient	4 (40.0)	[1–3,24]
Member of a patient association	5 (50.0)	[5,9–11,17]
Carer or family	1 (10.0)	[1]
Not reported	1 (10.0)	[16]
Methods described to incorporate patients or representatives[a]	2 (20.0)	[1,17]
Number of patients or representatives included[a]		
1	4 (40.0)	[2,5,10,24]
2	2 (20.0)	[3,9]
3	1 (10.0)	[1]
Not reported	3 (30.0)	[11,16,17]
Proportion of patients in the guideline working group[a]		
<10%	3 (30.0)	[2,5,10]
10–20%	3 (30.0)	[1,3,9]
Not reported	4 (40.0)	[11,16,17,24][c]
Steps of the guideline development process in which patients or representatives were included[a,b]		
Identification of panel members	0	
Defining scope and objectives	2 (20.0)	[5,24]
Formulating review questions	4 (40.0)	[1,9,24,27]
Identifying/reviewing scientific evidence	2 (20.0)	[1,9]
Developing recommendations	2 (20.0)	[9,24]
Writing the guideline or a part of it	0	
Guideline review	7 (70.0)	[1–3,5,9,17]
Developing information for patients	1 (10.0)	[16]
Diffusion and implementation	0	
Other[d]	1 (10.0)	[1]
Not reported	2 (20.0)	[10,11]
Patients included could be identified (name, surname)	6 (60.0)	[1–3,5,9,10]
Declaration of conflicts of interest of included patients	5 (50.0)	[2,5,9,10,24]

Abbreviation: PG, practice guideline.

[a] Only for guidelines that recommend the inclusion of patients or patients' representatives ($n = 10$).

[b] More than one option could be selected.

[c] Guideline 24 did not report the number of participants of the guideline working group.

[d] To ensure that the evidence addressed patients' views and preferences.

extent (median of 32.5% vs. 0%, $P = 0.001$). Overall, of the 588 recommendations included in the 28 PGs sample, 256 (43.5%) could be considered preference sensitive, and 25 (9.8%) of these considered patients' preferences (Fig. 2).

3.5. *Terminology used*

Twenty-one PGs (75.0%) included patient perspective–related terminology. The term most frequently used was “patients' preferences” (13/21,

Table 3. Incorporation of patient perspective evidence

	n (%)	References
Reporting information about patient perspective or preferences	12 (42.9)	[1–3,5,9,11,12,16,17,22,24,28]
Source for obtaining evidence on patients' preferences[a]		
Systematic review	6 (50.0)	[2,3,5,16,17,24]
Nonsystematic review of the literature	5 (41.7)	[1,9,11,12,22]
Panel judgment	7 (58.3)	[1–3,5,22,24,28]
De novo research	0 (0.0)	
Development of a systematic review[b]	6	[2,3,5,16,17,24]
Provision of search strategy	3 (50.0)	[2,3,24]
Provision of databases to search[c]	5 (83.3)	[2,3,16,17,24]
Type of studies included		
Qualitative studies	1 (16.7)	[2]
Surveys	3 (50.0)	[3,5,24]
Other[d]	2 (33.3)	[2,17]
Assessment of risk of bias	0 (0.0)	
Terminology	21 (75.0)	[1–3,5,7–19,22,24,26,28]
Terms used[e]		
Patients' preferences[f]	13 (61.9)	[1–3,5,7–10,12–17,19,22,24,26,28]
Patients' values[f]	9 (42.9)	[7–9,13–17,22,24]
Patients' views	2 (9.5)	[10,26]
Patients' satisfaction	2 (9.5)	[12,20]
Individual environment/ circumstances	2 (9.5)	[13,14]
Discussion with the patient	4 (19.0)	[7,11,12,18]
Other terms[g]	9 (42.9)	[2,3,5,7,9,24,26,28]
Section of the guideline in which these terms are located[e]		
Introduction	9 (42.9)	[1–3,5,9,12,17,19,22]
Methods	13 (61.9)	[1,2,7,8,10,13–17,22,24,26]
Recommendations section	14 (66.7)	[1–3,5,7,10,11,16–18,22,24,26,28]
General statement in the guideline	4 (19.0)	[7,16,17,22]
Specific chapter	6 (28.6)	[1,3,5,9,16,19]

[a] Only for guidelines that report evidence about patient perspective ($n = 12$).

[b] Only for guidelines that developed a systematic review to obtain VPP ($n = 6$).

[c] Databases: Medline (5/5), EMBASE (4/5), CINAHL (2/5), PsycINFO (2/5) and the Cochrane database of systematic reviews (2/5), CENTRAL (1/5), DARE (1/5), HTA database (1/5), EBSCO (1/5), and NHS Evidence (1/5).

[d] Quantitative studies [2] and systematic reviews [17].

[e] Only for guidelines mentioned someway the concept of patients' views.

[f] Eight CGs used the combination ''patient's values and preferences'' [CGs 8, 13, 14, 15, 16, 17, 22, 24].

[g] Other terms used were patient counseling [7], patients' belief [9], patients' important outcomes [24], patients' wishes [26], patients' acceptability [28], patients' issues [2], patients' needs [3], patients' expectations [5], and community attitudes [5].

61.9%), followed by ''patients' values'' (9/21, 42.9%), and ''patient values and preferences'' (8/21, 38.0%). Other terms used are summarized in Table 3. Guidelines addressed the patient perspective most commonly in the recommendations section (14/21, 66.7%), followed by the methods section (13/21, 61.9%), and the introduction (9/21, 42.8). Box 3 in Appendix 5 provides examples from the included PGs.

4. Discussion

4.1. Main findings

Our systematic evaluation of 28 international CRC PGs shows that only a minority of PGs incorporated patients or patient-related research evidence in their development. The included PGs provided very little detail about the role of participating patients or about the methodology used to

Table 4. Explicit incorporation of the patient perspective in recommendations

Clinical guideline	Number of PICOs	Number of recommendations	Consideration of patients' views and preferences in the trade-off decision process		Consideration of patients' views and preferences into clinical decision-making	
			n	%	*n*	%
1	16	67	7	10.4	16	23.9
2	NA	74	5	6.8	5	6.8
3	4	18	3	16.7	4	22.2
4	35	12	0	0.0	0	0.0
5	3	53	4	7.5	0	0.0
6	3	2	0	0.0	0	0.0
7	NA	24	0	0.0	0	0.0
8	NA	27	0	0.0	0	0.0
9	15	58	0	0.0	1	1.7
10	1	1	1	100.0	1	100.0
11	2	8	0	0.0	2	25.0
12	41	46	0	0.0	1	2.2
13	6	6	0	0.0	0	0.0
14	11	9	0	0.0	0	0.0
15	4	6	0	0.0	0	0.0
16	NA	4	1	25.0	2	50.0
17	3	5	5	100.0	0	0.0
18	4	16	0	0.0	1	6.2
19	NA	2	0	0.0	0	0.0
20	NA	19	0	0.0	0	0.0
21	NA	12	0	0.0	0	0.0
22	NA	9	0	0.0	1	11.1
23	7	9	0	0.0	0	0.0
24	7	7	7	100.0	0	0.0
25	7	36	0	0.0	3	8.3
26	22	21	0	0.0	2	9.5
27	4	16	0	0.0	0	0.0
28	3	21	1	4.8	1	4.8
Total of guidelines			9	32.1	13	46.4
Total recommendations		588	34	5.8	40	6.8

Abbreviations: NA, not applicable (i.e., no PICOs are formulated in the guideline); PICO question, clinical question containing: Population, Intervention, Comparison, Outcome.

obtain and/or summarize and appraise research evidence. Although the patient perspective may be important regardless the strength of a recommendation (e.g., to define the best way to communicate the burden of a highly effective treatment or the risk for false positives related to a screening test), we decided to focus our interest in recommendations in which desirable and undesirable effects are closely balanced.

Overall, a minority of potentially preference sensitive recommendations considered to some extent the perspective of patients. We observed that the inclusion of patients in the PG development process was associated with a greater incorporation of the patient perspective in recommendations. Finally, despite the fact that many included CRC practice guidelines used the GRADE system to rate recommendations, less than half explicitly considered the patient perspective when formulating their recommendations, despite being rated as weak.

4.2. Our results in the context of previous results

The proportion of patients' participation in guideline development is considerably lower (35.7% vs. 71.4%) than what we observed in a previous systematic evaluation of

Table 5. Incorporation of the patient perspective in potentially preference-sensitive recommendations

			Rated as weak/conditional				**Worded as conditional**				**Multiple option management**			
CG	**Number of recommendations**	**Rating system**	***n***	**%**	**Consider PP**	**%**	***n***	**%**	**Consider PP**	**%**	***n***	**%**	**Consider PP**	**%**
1	67	No rating	NA	NA	NA	NA	5	7.5	3	60.0	3	4.5	3	100.0
2	74	SIGN system[a]	29	39.2	4	13.8	3	4.0	0	0.0	4	5.4	0	0.0
3	18	No rating	NA	NA	NA	NA	4	22.2	1	25.0	0	0.0	NA	NA
4	12	GRADE[b]	4	33.3	0	0.0	4	33.3	0	0.0	4	33.3	0	0.0
5	53	NHMRC[c]	37	69.8	1	2.7	0	0.0	NA	NA	1	1.9	0	0.0
6	2	No rating	NA	NA	NA	NA	0	0.0	NA	NA	0	0.0	NA	NA
7	24	GRADE[b]	4	16.7	0	0.0	0	0.0	NA	NA	4	16.7	0	0.0
8	27	GRADE[b]	3	11.1	0	0.0	1	3.7	0	0.0	1	3.7	0	0.0
9	58	NHMRC adapt.[d], NZGG[e]	36	62.1	1	2.8	26	44.8	1	3.8	1	1.7	0	0.0
10	1	No rating	NA	NA	NA	NA	0	0.0	NA	NA	0	0.0	NA	NA
11	8	No rating	NA	NA	NA	NA	0	0.0	NA	NA	2	25.0	1	50.0
12	46	CEBM Oxford[f]	12	26.1	0	0.0	3	6.5	0	0.0	0	0.0	NA	NA
13	6	GRADE[b]	1	16.7	0	0.0	0	0.0	NA	NA	0	0.0	NA	NA
14	9	GRADE[b]	2	22.2	0	0.0	0	0.0	NA	NA	0	0.0	NA	NA
15	6	GRADE[b]	1	16.7	0	0.0	0	0.0	NA	NA	0	0.0	NA	NA
16	4	GRADE[b]	3	75.0	2	66.7	0	0.0	NA	NA	2	50.0	0	0.0
17	5	GRADE[b]	0	0.0	NA	NA	0	0.0	NA	NA	0	0.0	NA	NA
18	16	Own system[g]	9	56.2	1	11.1	0	0.0	NA	NA	0	0.0	NA	NA
19	2	USPSTF system[h]	1	50.0	0	0.0	0	0.0	NA	NA	0	0.0	NA	NA
20	19	CEBM Oxford[f]	1	5.3	0	0.0	1	5.3	0	0.0	0	0.0	NA	NA
21	12	CEBM Oxford[f]	0	0.0	NA	NA	0	0.0	NA	NA	0	0.0	NA	NA
22	9	GRADE[b]	2	22.2	1	50.0	0	0.0	NA	NA	0	0.0	NA	NA
23	9	No rating	NA	NA	NA	NA	1	11.1	0	NA	1	11.1	0	0.0
24	7	GRADE[b]	4	57.1	4	100.0	0	0.0	NA	NA	0	0.0	NA	NA
25	36	Shekelle et al.[i]	0	0.0	NA	NA	4	11.1	1	25.0	5	13.9	0	0.0
26	21	GRADE[b]	7	33.3	1	14.3	0	0.0	NA	NA	1	4.8	0	0.0
27	16	No rating	NA	NA	NA	NA	2	12.5	0	0.0	0	0.0	NA	NA
28	21	SIGN system[a]	17	80.9	0	0.0	0	0.0	NA	NA	0	0.0	NA	NA
Total CG	28		18	64.3	8	44.4	11	39.3	4	36.4	12	42.9	2	16.7
Total recommendations	588		173	29.4	15	8.7	54	9.2	6	11.1	29	4.9	4	13.8

Abbreviations: CEBM, Centre for Evidence-Based Medicine; GRADE, Grading of Recommendations Assessment, Development and Evaluation; NA, not available; NHMRC, National Health and Medical Research Council, Australia; NZGG, New Zealand Guideline Group; PP, patient perspective; SIGN, Scottish Intercollegiate Guidelines Network; USPTF, US Preventive Services Task Force.

[a] SIGN system: from levels, from A to D. Weak/conditional recommendations were those rated as D.

[b] GRADE rates recommendations as ‘‘strong’’ or ‘‘weak.’’

[c] NHRMC: recommendations are rated from A to D. Weak recommendations were those rated C or D.

[d] Adaptation of NHMRC: recommendations are rated as strongly recommended, recommended, equivocal, not recommended, strongly not recommended. Weak/conditional recommendations were those rated as: recommended, not recommended, and equivocal.

[e] NZGG system rates recommendations as A, B, or C. Weak/conditional recommendations are those rated as C.

[f] CEMB Oxford system rates recommendations as A, B, C, or D based on levels of evidence. Weak/conditional recommendations were those rated as C or D.

[g] Own system rating from A to E based on quality of the evidence (based on study design). Weak/conditional were those rated B (fair evidence to support), C (poor evidence to support the statement but recommendation made on other grounds), or D (fair evidence to refuse).

[h] USPTF systems: 5 levels, A, B, C, D, and I. Weak/conditional recommendations were those rated as C.

[i] System proposed in 1999 by Shekelle et al. Rating from A to D based on quality of the evidence (based on study design). Weak/conditional were those rated D.

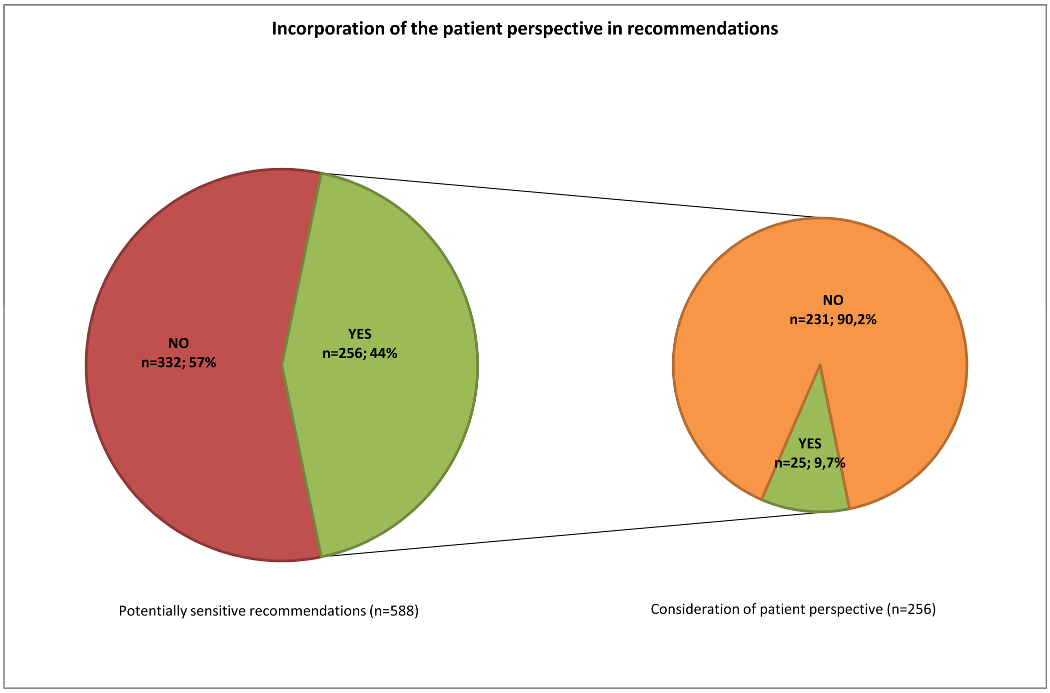

Fig. 2. Incorporation of the patient perspective in recommendations.

available PGs development guidance documents [13]. Fourteen PGs included in the present review were developed by eight institutions whose handbooks were included in that work. Just slightly more than half of the PGs developed by institutions that recommend the inclusion of patients did include them (4/7; 57.1%) [PG 1,2,3,5]. The comparison between handbooks and PGs regarding patient involvement is summarized in Appendix 7. These differences could indicate that PGs do not adhere to the guidance provided by the institutions. However, it is possible that the reporting of patient involvement in the guideline development process was suboptimal. Our results resonate with those observed in a survey of international guideline developers, in which 39% reported involving consumers through participation in the development group [24], and are more favorable than those reported in an older study assessing patient and public involvement strategies of guideline developers in the United States. In the latter, only 8% to 15% of PG developers required patient involvement [15].

Several efforts have been made to develop toolkits and strategies to help development organizations to involve patients and the public [25–28]. For example, the GIN-McMaster Guidelines 2.0 development checklist is a resource to support the development and implementation of PGs and contains specific items related to consumer involvement and to consider how those affected by decisions value outcomes and interventions [29]. One could argue that in the context of a condition such as cancer, the involvement of patients could be more problematic because patients could be older, more vulnerable, sicker, frail, and receive complex care. Results from a recent mixed methods study showed that the most common barriers to the involvement of cancer patients in PGs were the same that those reported in other contexts (time commitment, duration of the PG development process, financial costs, and reluctance to share personal experiences) [30]. Given that, and the fact that our results are aligned with those of others [15,24,31,32,33], we can safely conclude that patient involvement in CRC PGs is suboptimal, and that this is also likely for other cancer topics, and in general.

The main reason for incorporating patients perspective into recommendations is that it would be unethical not to consider the perspective of those affected by the recommendations. Also, recommendations considering patients' perspectives may be more easily accepted, implemented, and adhered to [32]. Our study shows that less than half of CRC-PGs provide evidence on patients' perspectives. Despite most PGs including at least one preference-sensitive recommendation, only a minority of these recommendations (less than 10%) explicitly considered patients' perspectives. Young et al. reviewed 13 Australian PGs on long-term conditions and found—as we did—that most of the PGs included at least one patient preference recommendation. However, when considering core recommendations, only 4.5% of recommendations were related to patient preferences [33]. Like Young, we also observed that the participation of patients in the PG development process was associated with a greater incorporation of the patients' perspective into recommendations.

Including patients in the guideline development process—either through their active involvement as members of panels or through consultation—is one of the proposed methods for integrating the patient perspective into PGs. Other proposed methods are the consideration of research evidence or conducting de novo research [26]. Zhang et al. described the methods used to incorporate patients' values and preferences to inform the importance of health outcomes in the development of 22 PGs following the GRADE approach. First, they conducted systematic reviews; second, they performed case studies on how to consider local values and preferences; and finally, they collected the input from the guideline panel [32]. This sequence is aligned with the current accepted definition of PGs, which assumes that recommendations should be informed by systematic reviews [1] and the claim for the need to systematically assess the existing evidence before conducting additional primary research [34]. Our results showed that, in fact, most included PGs that included evidence on patients' perspective (11/28) had conducted a review of the literature (either a systematic or not) to obtain them. Furthermore, PGs that involved patients were more likely to consider patient preferences although the overall proportion remained very small (9%).

4.3. Strengths and limitations

Despite having searched several guideline repositories (apart from searching MEDLINE), it is possible that we did not identify all the PGs available on the topic. However, it is unlikely that these PGs are of a higher quality than the ones we did identify. This assumption—if true—would strengthen our conclusions. Although the search was updated in 2016, it is possible that the PGs published thereafter may have greater consideration of the patient perspective. However, we believe that this is unlikely. As we did not find any association between the publication date of the included PGs and the inclusion of patients or the proportion of recommendations that included the patient's perspective (data not shown). We only included PGs published in English. However, it is also unlikely that those published in other languages are of higher quality. On the other hand, we did not contact original panels to gather omitted information from the assessed guidelines A potential final limitation is that our results might not be applicable to PGs on other topics, given that we focused our assessment on CRC PGs.

Our review has several strengths, including a rigorous and explicit methodology including the identification and assessment of preference-sensitive recommendations, which, to our knowledge, has not previously been assessed. The approach used to extract data was designed to comprehensively evaluate the incorporation of the patient perspective and contemplates the items that other standardized proposals include [26]. Our work builds on previous work from our group [13] and others [15] in the same area, providing new knowledge about the actual implementation of related methodological guidance in real PGs.

4.4. Implications for practice and research

Our results highlight the need to ensure that the patient perspective is optimally reflected in the guideline development process. Guideline development groups should elaborate detailed guidance but also implement strategies to facilitate this task for panels. Despite the difficulties faced by guideline panels—probably because of a mixture of lack of time, training, and resources—they should adhere further to published standards [13,26,29] and include the perspective of patients more explicitly. Groups that use the GRADE approach should adhere to its widely available guidance [8,11,35–39] and incorporate patient's values and preferences when developing recommendations [8]. Guideline users, in particular clinicians but also patients, should be aware that a minority of PGs consider the patient perspective and take this into consideration in their decision-making encounters.

A better understanding of the pros and cons of the different approaches to incorporating the patient perspective in the development of PGs is still required. Further research is needed to understand why panels do not consider this aspect optimally despite available guidance within their organizations. The GRADE working group and particularly its "Outcome importance project group" [8,11,32,35–39] as well as other authors [40,41] are actively working on strategies to facilitate this aspect of PG development.

CRediT authorship contribution statement

A. Selva: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Project administration. **A.J. Sanabria:** Conceptualization, Investigation, Writing - review & editing. **E. Niño de Guzman:** Investigation, Writing - review & editing. **M. Ballesteros:** Investigation, Writing - review & editing. **C. Selva:** Investigation, Writing - review & editing. **C. Valli:** Investigation, Writing - review & editing. **Y. Zhang:** Investigation, Writing - review & editing. **J.J. Yepes-Nuñez:** Investigation, Writing - review & editing. **I. Solà:** Investigation, Writing - review & editing. **H. Schünemann:** Conceptualization, Writing - review & editing. **P. Alonso-Coello:** Conceptualization, Writing - review & editing, Supervision, Project administration, Funding acquisition.

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Supplementary data

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