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Research Article

Development of a Core Set of Self-Management Support Needs of Esophageal Cancer Patients: Results from a Delphi Study among Healthcare Professionals

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Objective. We aimed to gain consensus on HCPs' perspectives on self-management support information needs of patients with esophageal cancer during the preoperative phase. **Methods.** Based on the literature, observations of clinical consultations, and hospital patient information leaflets, a survey was created. HCPs were surveyed twice about their opinion on importance of information, from "not essential" to "absolutely essential," using Delphi methods. Topics were included in the second round if predetermined criteria were met. To be included in the final list, topics had to meet criteria for consensus and stability. **Results.** 64 information items and 6 sources of support were identified. Survey response rates were 59% (68 out of 116, first round) and 75% thereafter. The final list included 33 topics, including logistical information, expectations for future health condition, complications, follow-up care, nutrition during treatment, and nutrition during recovery as topics with 100% agreement. Consensus on the source of support was reached for face-to-face contact, written information, information video, and a case manager. **Conclusion.** This study provides a list of important topics, from the perspectives of HCPs, to guide the systematic provision of education to support EC patients' self-management during the preoperative phase. Additionally, the most preferred sources of support were face-to-face contact and a case manager.

1. Introduction

The incidence of esophageal cancer (EC) is increasing, particularly due to the growing number of adenocarcinomas diagnosed in the Western world [1]. EC is the sixth leading cause of cancer-related mortality and esophagectomy with or without neoadjuvant chemo(-radio)therapy (CRT) is the mainstay of curative treatment for EC. Newly diagnosed patients with EC often suffer considerably from physical symptoms [2–4] and psychosocial problems. A major challenge for patients is dealing with the impact of the disease and its treatment on physical and nutritional status, its self-management, and ultimately quality of life [5]. Self-management is considered an important part of the preoperative clinical pathway and prehabilitation [6] and refers to the individuals' ability to manage symptoms, treatment, and physical and psychosocial consequences of disease [7].

Self-management may be challenging for patients with EC. Self-management support by healthcare professionals (HCPs) appears to be crucial and is defined as the systematic provision of education and supportive interventions by HCPs to increase patients' skills and confidence in managing their specific health problems, including the regular assessment of progress and problems, goal setting, and problem-solving support [8]. Self-management programs may be associated with reduction in anxiety and unscheduled hospital visits and an increase in self-efficacy [8, 9]. Self-management support can be offered by variable methods, ranging from face-to-face contacts and group meetings, with or without expert patients, to digital applications.

A core element of patient self-management is having knowledge about EC, to be able to deal with the disease, to make important day-to-day decisions, and to live a satisfactory life despite the consequences of having the disease. This knowledge is based on general information about the disease and increases as the patients gain their own experience of the disease. Previous studies have considered general information preferences for patients with esophageal cancer [10–13], showing patients want to be informed about prognosis, perioperative care, and quality of life, but none of these studies focused on information needs to support self-management specifically.

By using a collaborative approach during the preoperative pathway of patients with esophageal cancer, HCPs and patients work together to increase the patients' knowledge in order to ensure the patient is in the best optimal condition (for treatment) [14]. To define optimal support for patients with EC, both the patient perspective and the healthcare professionals' perspective is needed [15]. While HCPs know what is best for the patient from a "medical point of view," patients know what is best from a "personal point of view"[16]. However, no formal consensus exists among patients with esophageal cancer and

HCPs on the information topics to support patients' self-management that needs to be addressed in the preoperative phase of curative treatment and on the source to deliver this support. Therefore, the aims of this study are to develop a core set of self-management support information needs of patients with EC during the preoperative phase from the perspective of HCPs and to explore the sources of this support. This study is part of a larger study in which the perspectives of patients and HCPs have been combined.

2. Methods

2.1. Study Design. In this study, the Delphi methodology was used to gather information from a large group of experts. In a Delphi survey, a panel is asked for their opinion on a question and subsequently repolled with controlled feedback regarding the polled opinions to encourage consensus between the (groups of) experts [17]. For this Delphi study, we generated an extensive list of all the topics that could be of interest for the patient with EC in the preoperative phase. Thereafter, the list was reduced by merging overlapping domains. Finally, this reduced list was used to create questionnaire items (phase 1). In phase two, the questionnaire was sent by e-mail to survey HCPs' views on the importance of each item. Although there is no formal sample size requirement for Delphi consensus methods, we aimed to obtain responses of at least 50 HCPs in the first round [18].

2.2. Phase 1: Questionnaire Generation. To identify all possible topics of self-management support, three different sources were used. First, the PubMed database was searched for the eligible international literature using the following search terms: esophageal cancer, esophageal neoplasm, and needs and patient attitudes combined in a Boolean search. Searches were limited to studies published in English language and studies investigating the unmet/supportive care needs of patients with (esophageal) cancer. DA screened the titles, abstracts, and full texts [10, 12, 13, 19–26]. Second, all Dutch specialized expert centers treating esophageal cancer patients were asked to send their written patient information leaflets. DA and FH screened the information leaflets independently. Third, consultations were observed between patients and the different healthcare professionals (i.e., dietitians, nurse specialists, physical therapists, surgeons, radiotherapists, and oncologists) that are involved in the preoperative phase in one Dutch expert center by DA and fieldnotes were made. Clinical items from the different sources were transferred to an Excel spreadsheet database to systematize them and were categorized by two members of the study team into domains (DA and FH). Discrepancies were resolved by discussion with the study group and a final list of topics was produced. Questionnaire items were created from the final domains (in lay language) using a Likert scale to rate items from 1 to 9, for which 1 was considered

“not essential” and 9 “absolutely essential.” The questionnaire was piloted by two independent persons and four members of a patient support group for face validity, understanding, and acceptability. Following this, modifications were made. The questionnaire reported the following Cronbach’s alpha coefficients: 0.816 on the domain “esophageal cancer,” 0.924 on the domain “treatment,” 0.884 on the domain “prognosis,” 0.900 on the domain “pre- and rehabilitation,” 0.772 on the domain “follow-up,” 0.847 on the domain “coping,” 0.677 on the domain “interpersonal relations,” 0.877 on the domain “finance,” and 0.816 on the domain “source of support,” which indicates an acceptable level of the questionnaire’s reliability [27].

2.3. Phase 2: Delphi Methods. A two-round Delphi survey was used to gather information from a large group of experts to produce consensus on the core set.

There are 14 specialized EC surgery centers in the Netherlands. HCPs (dietitians, gastroenterologists, nurse specialists, oncologists, oncological nurses, physical therapists, radiotherapists, and surgeons) who were currently active in the preoperative treatment of patients with EC in these specialized EC surgery centers were identified through the Dutch Upper GI Cancer Group (DUCG) and were invited to participate in this study ($n = 116$). All HCPs were contacted by e-mail, with the questionnaire developed in phase 1 attached and the instruction to return the questionnaire within 1 week. Nonresponders received up to three reminders. The first round questionnaire consisted of four parts. The first part included some questions on socio-demographic and clinical background information (age, sex, profession, and years of work experience as an HCP). In the second part, HCPs were asked to rate the items, derived from phase 1, from 1 to 9, for which 1 was considered “not essential” and 9 “absolutely essential” according to the stem question, “What is the patients’ level of need for information about. . . .” When an item was scored ≥ 4 , a next question popped up: “What is the patients’ level of need for support to gather information about. . . .” In the third part, HCPs were asked to rate the source to receive the support, derived from phase 1, from 1 to 9, for which 1 was considered “not essential” and 9 “absolutely essential” according to the stem question “What source of support does the patient want in obtaining this information?” In the fourth part, HCPs were able to add important topics and other sources to support patients that were not already mentioned in the first-round questionnaire.

After the first round, the questionnaires were analyzed. HCPs who did not provide all importance ratings, but provided background information in the first part of the questionnaire and importance ratings for at least the first domain (*esophageal cancer*) of the second part of the questionnaire, were included in the first-round analyses and were invited for the second round. The second round questionnaire (round 2) contained a reduced number of items (for the method of reduction, see below) and the feedback of round 1. The feedback consisted of the individuals’ scores and the group feedback on both questions

(level of need and level of need for support) (summarized as a median score in order to be understood by participants). In round 2, HCPs were asked to rescore each item between 1 and 9.

2.3.1. Data Analysis. In the absence of a formal guideline, data analysis (including statistical analysis) was based on a previous Delphi study among EC patients and HCPs treating EC, in which a list of topics selected by patients and HCPs was provided that may be addressed systematically at the initial follow-up consultation after esophageal cancer surgery [11].

After the first round, the percentage of HCPs that rated a topic 1–3 (low importance), 4–6 (moderate importance), and 7–9 (high importance) was calculated and those topics that met the predefined criteria of consensus were included in the second round questionnaire (Table 1). Analyses are based on the ratings of a topic received with the stem question, “What is the patients’ level of need for information about. . . .” and “What source of support does the patient want in obtaining this information?” HCPs who did not provide any importance ratings in round 2 were excluded from the second-round analyses. Responses of round 2 were analyzed with the same cut-off criteria as round 1.

2.3.2. Statistical Analysis. All statistical analyses were conducted using the SPSS® version 25.0 (IBM, Armonk, New York, USA).

To be able to establish whether consensus had been achieved for a topic and whether a hypothetical third round might have changed the results, the stability of importance ratings across rounds was also determined, in accordance with the study of Jacobs et al. [11]: Stability was defined as the consistency of responses between successive rounds [11, 28] and ratings were considered stable across rounds if the stable category of consensus was reached, and at least three of the other four criteria were met (Table 1). To create a final list of topics, each topic was assigned to one of three defined categories: most important (at least 90% 7–9 and no more than 10% 1–3), very important (at least 80% 7–9 and no more than 15% 1–3), and important (at least 70% 7–9 and no more than 15% 1–3). Furthermore, for each of the topics included in this “final list,” consensus was determined for the need for support to gather the information on a specific topic.

3. Results

3.1. Phase 1. Review of all data sources generated a long list of potentially relevant topics for self-management of EC patients. 64 topics (Figure 1) were identified and grouped in eight domains, information on esophageal cancer (9 topics), treatment (21 topics), prognosis (9 topics), pre- and rehabilitation (10 topics), follow-up (5 topics), coping (4 topics), interpersonal relations (3 topics), and finance (3 topics). Each topic was formulated as an item for the Delphi survey questionnaire with examples in parentheses for some topics. To prevent the suggestion of ranking of importance,

TABLE 1: Criteria for consensus and stability of results.

	Criteria
Delphi process	Consensus was reached if $\geq 70\%$ of HCPs rated a topic as 7–9 on the Likert scale and $\leq 15\%$ rated 1–3 AND an i.q.r. of ≤ 2
Stability of results	(1) Stable category of consensus (mandatory) (2) Stable or decreased i.q.r. (3) Stable median (4) Nonsignificant Wilcoxon signed-rank test result (5) Significant Spearman's rank correlation result

topics in each domain were listed in alphabetical order. In the third part, the questionnaire contained the following question: What source of support does the patient want in obtaining this information? Six sources of support were identified (apps, face to face, Internet, peers, written, and telephone).

3.2. Phase 2

3.2.1. Participants. Rounds 1 and 2 were conducted in August and December 2020. Of the 116 identified potential HCPs, 68 (59%) responded to round 1, yielding 60 completed questionnaires (a completion rate of 88%). Most HCPs were female (55.9%). Of all HCPs, 20 were surgeons, 7 dieticians, 6 physical therapists, 6 oncologists, 7 oncological nurses/case managers, 10 nurse practitioners/physician assistants, 4 gastroenterologists, 7 radiotherapists, and 1 pathologist. The median age was 43.6 years. 54 HCPs (79.4%) had more than 5 years of working experience. Of the 68 potential round 2 participants, 51 (75%) responded, yielding 45 completed questionnaires (a completion rate of 88%). Characteristics of the participants are shown in Table 2.

3.3. Delphi Results

3.3.1. Round 1. HCPs considered 33 of the 64 topics on the long list to be important, reflecting five of the eight domains (Figure 1). No additional items were identified. Hence, panelists had to rate 33 topics in round 2. When considering the source of support to obtain the information, consensus was reached for face-to-face contact (96.7% high importance; median 8) and written information (83.3% high importance; median 8). Three additional items were identified: information video, case manager, and video call (Figure 2).

3.3.2. Round 2. All 33 topics in round 2 were considered important by HCPs (Figure 1 and Table S1). Moreover, support was considered important for all 33 topics (Figure 1).

When considering the source of support to obtain the information, consensus was reached for face-to-face contact (95.6% high importance; median 8), written information (88.9% medium importance; median 8), the information video (82.2% medium importance; median 7), and a case manager (100.0% high importance; median 8).

3.4. Stability of Results. No unstable ratings were identified across rounds across the 33 topics (Figure 1; Table S1, supporting information) or the source of support to obtain the information (Figure 2; Table S2, supporting information).

3.5. Final List of Topics. Thirty-three topics were included in the final list of important topics (Figure 1) (Table 3). Twenty topics were considered most important, reflecting 5 different domains, 12 very important, and one important (Table 3). Topics deemed most important were physical consequences of disease, prognosis of disease (*esophageal cancer information*), treatment success, available treatments/treatment options, side effects of treatment, purpose of treatment, physical effects of treatment, treatment plan/logistical information, reducing side effects of treatment, advantages of treatment (*treatment information*), life span or the survival rate, the chance of cure, expectations for the future health condition (*prognosis information*), recovery time, complications, side effects, follow-up care, nutrition during treatment, nutrition during recovery (*pre- and rehabilitation information*), and maintaining physical health or physical activity (*follow-up information*).

3.6. Final List of the Source of Support. Four topics were included in the final list of the source of support. Two sources were considered most important and two were very important. Sources of support deemed most important were face to face contact and a case manager.

4. Discussion and Conclusion

4.1. Discussion. In this study a core information set that includes the most relevant self-management information topics was developed to support self-management in the preoperative phase of patients with EC from the perspectives of HCPs. The consensus on the important topics and the source of support may guide the systematic provision of education to support patients' self-management during the preoperative phase. Based on two Delphi rounds, consensus was reached on a set of 33 topics and includes items on medical and behavioral topics to support the skills of patients. The most preferred sources of support were face-to-face contact and a case manager.

Previous studies have considered information preferences for patients with EC from the perspectives of HCPs [11,13], but none of these included information needs to

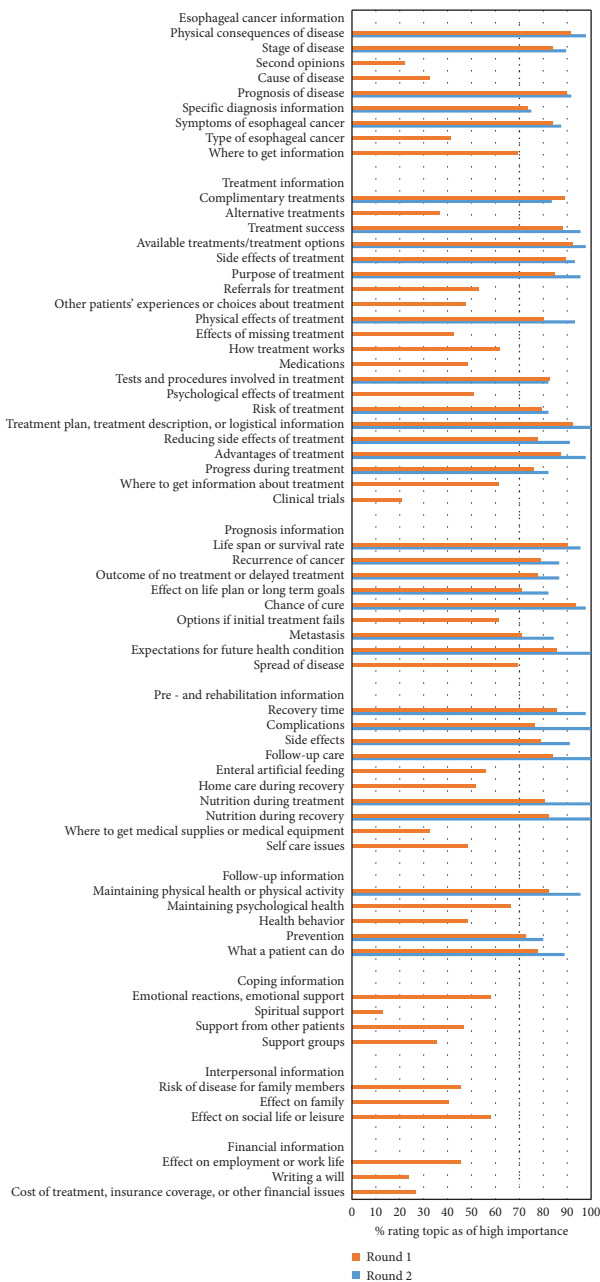


FIGURE 1: Results of the two-round Delphi survey: topics. The dashed line represents the level of agreement for consensus to be included. Orange bars indicate the results of the topics in round 1. Blue bars indicate the results of the topics in round 2. Topics with no bar in round 2 were those that were not carried forward from round 1.

support self-management. Furthermore, one of these studies [11] focused on postoperative information needs, while the most relevant information topics to support patients might not be the same in the pre- and postoperative pathway of patients with EC.

The core set includes items about medical and behavioral topics to support the skills of patients. This is in line with a focus of self-management on medical and behavioral management in many European countries, and less on helping patients in dealing with emotional consequences

[29]. HCPs were therefore maybe less focused on these topics when ranking the different information topics. HCPs may perceive self-management support as merely handing out written information and telling patients what to do [16]. However, informing a patient about the disease and thereby solely addressing patients' "disease needs" is not sufficient; patients' coping skills and ability to activate resources should also be addressed [29–31]. This collaborative approach advocates incorporation of patients' needs and preferences for managing their condition into an individualized, biopsychosocial treatment plan [32]. Therefore, we are currently also undertaking an evaluation of the self-management support information needs from the perspectives of patients with EC in the preoperative phase.

When considering the source of support to obtain the information, highest consensus was reached for face-to-face contact and a case manager. In optimal self-management support, healthcare professionals, the patient, and their informal caregiver(s) work together as partners in managing the consequences of the disease on daily life adequately. In this partnership, they are all experts from their individual perspectives, in which the perceived problems and concerns of patients are the basis for care [15]. Although individual counseling is effective [33], it places a major burden on the available time of HCPs and healthcare budget [34]. Furthermore, according to a systematic review by Barlow et al. (2002), diversity in self-management interventions is advisable because "no approach will meet the needs of all participants at all points of time"[35]. Digital self-management support tools could be of an added value to support EC patients in their self-management. Interestingly, no consensus was reached for technological sources (e.g., apps, Internet, and video calls). Presently, many healthcare professionals do not consider technology routinely as an important solution for health problems [36], despite the rapid development of digital tools. One main factor is the fear that technology interferes with the relationship with the patient [37]. Care professionals worry about, e.g., the quality of the contact with patients through digital tools. In future research, it might be of interest to investigate whether EC patients consider technological sources as an added value in their self-management.

An important strength of this study is the selection of the final items by a consensus process involving the views of 68 HCPs reflecting 9 different disciplines, involved in the preoperative care plan of patients with EC. Furthermore, it is noteworthy that the majority of HCPs were experienced practitioners working within current models of best practice. Although this work has been conducted carefully, this study has also some methodological limitations. Consensus was obtained by surveys that may not have appealed to a full range of stakeholders. It is possible that nonparticipants (the response rate in the first round was 59 percent) may value information differently from participants. Furthermore, our study did not include a face-to-face meeting with experts between the Delphi rounds to discuss ratings, investigate areas of disagreement, and gain more in-depth insights. We did, however, include open questions at each phase to gain more understanding of the ratings.

TABLE 2: Characteristics of healthcare practitioners participating in the Delphi survey.

Characteristic	N = 68
Age (years) (mean (range))	43.6 (24–63)
Gender (number (%))	
Male	30 (44.1)
Female	38 (55.9)
Specialty (number (%))	
Surgeons	20 (29.4)
Dieticians	7 (10.3)
Physical therapists	6 (8.8)
Oncologists	6 (8.8)
Oncological nurses/case managers	7 (10.3)
Nurse practitioners/Physician assistants	10 (14.7)
Gastroenterologists	4 (5.9)
Radiotherapists	7 (10.3)
Pathologists	1 (1.5)
Working experience (number (%))	
<5 years	14 (20.6)
5–10 years	19 (27.9)
>10 years	35 (51.5)

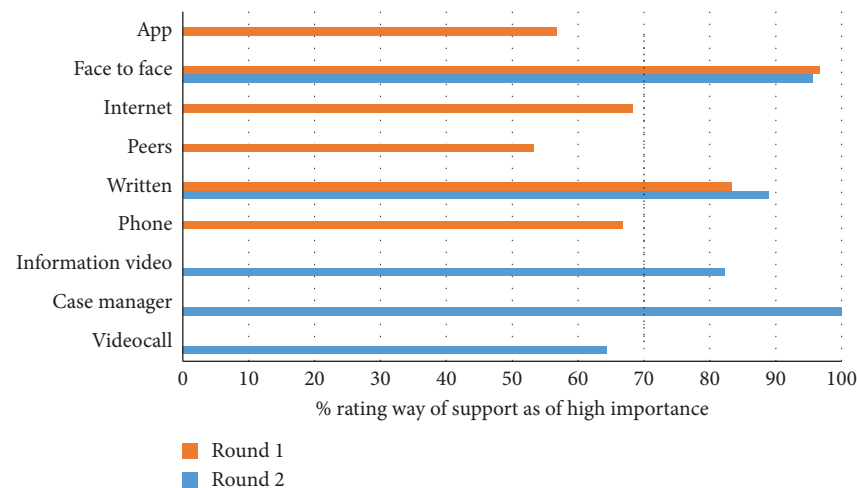


FIGURE 2: Results of the two-round Delphi survey: source of support. The dashed line represents the level of agreement for consensus to be included. Orange bars indicate the results of the topics in round 1. Blue bars indicate the results of the topics in round 2. Topics with no bar in round 2 were those that were not carried forward from round 1. Topics with no bar in round 1 were additional topics identified in round 1 by HCPs.

4.2. Conclusion. This study provides healthcare professionals with a list of important topics, from the perspectives of HCPs, to guide the systematic provision of education to support EC patients' self-management during the preoperative phase. Additionally, the most preferred sources of support were face-to-face contact and a case manager.

4.3. Practical Implications. The findings of this study are important to healthcare professionals providing self-management support to patients with esophageal cancer to direct the systematic provision of education to support the patients' self-management. Furthermore, our findings with

regard to the sources of this support are important to researchers focusing on the development of self-management interventions, because it is of interest to develop the best methods of delivering this information, all the more in view of the growing population of patients with cancer and health care budgets which are under increasing strain. However, to define optimal support for patients with EC, both the patient perspective and the healthcare professionals' perspective is needed. Therefore, future research should focus on the self-management support information needs from the perspectives of patients with EC in the preoperative phase and to combine these outcomes with the perspectives of HCPs to reach for consensus.

TABLE 3: Final list of important topics.

Domains	Most important [†]	Very important [‡]	Important [§]
Esophageal cancer information	Physical consequences of disease Prognosis of disease	Stage of disease Symptoms of esophageal cancer	Specific diagnosis information
Treatment information	Treatment success Available treatments/treatment options Side effects of treatment Purpose of treatment Physical effects of treatment Treatment plan/description or logistical information Reducing side effects of treatment Advantages of treatment	Complimentary treatments Tests and procedures involved in treatment Risk of treatment	
Prognosis information	Life span or the survival rate Chance of cure Expectations for the future health condition	Recurrence of cancer Effect on life plan or long term goals Metastasis Outcome of no treatment or delayed treatment	
Pre- and rehabilitation information	Recovery time Complications Side effects Follow-up care Nutrition during treatment Nutrition during recovery		
Follow-up information	Maintaining physical health or physical activity	Prevention What a patient can do	

[†] At least 90% rated a topic as 7–9 on the Likert scale and ≤10% rated 1–3. [‡] At least 80% rated a topic as 7–9 on the Likert scale and ≤15% rated 1–3. [§] At least 70% rated a topic as 7–9 on the Likert scale and ≤15% rated 1–3.

Data Availability

The data are available on request from the authors.

Ethical Approval

The study protocol was approved and is in accordance with the regulations of the Ethics Committee of Catharina Hospital Eindhoven.

Consent

All participants gave informed consent to participate and for publication.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

Study conception, design, material preparation, and data analysis were performed by Daniëlle JM Adriaans, Fanny Heesakkers, Hanneke WM van Laarhoven, Angelique TM Dierick-van Daele, and Grard AP Nieuwenhuijzen. All authors contributed to the data collection. The first draft of the manuscript was written by Daniëlle Adriaans and all authors commented on subsequent versions of the manuscript. All authors have read and approved the final manuscript.

Supplementary Materials

Table S1: criteria per round and across rounds to determine whether a topic is stable (stable category of consensus (mandatory), stable median and stable or decreased i.q.r., and the significant Spearman rank correlation and non-significant Wilcoxon signed-rank test). Table S2: kind of support; criteria per round and across rounds to determine whether a topic is stable (stable category of consensus (mandatory), stable median and stable or decreased i.q.r., and the significant Spearman rank correlation and non-significant Wilcoxon signed-rank test). (*Supplementary Materials*)

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