



Special Communication

An International and Multidisciplinary Consensus on the Labeling of Spatial Neglect Using a Modified Delphi Method



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Timothy J. Rich received financial support from the Wallerstein Foundation for Geriatric Life Improvement (no grant number) and National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development (grant no. 1K01HD109446-01A1). Lindy J. Williams received financial support through an Australian Government Research Training Program Scholarship. These funding sources had no involvement in the study design, data collection process, analysis or interpretation of the data, writing of the report, or decision to submit the article for publication.

Disclosure: Audrey Bowen reports awards (paid to institution) from National Institute for Health and Care Research (United Kingdom) and Stroke Association United Kingdom and expenses reimbursed for invited presentations and conference registration fees waived by United Kingdom Stroke Forum, Organisation for Psychological Research into Stroke, and Amazing Brains Stroke Association and is cofounder and chair of the International group on Spatial Attention and Neglect Disorders (I-SAND). Gail A. Eskes reports 2 operating grants for spatial neglect research from Nova Scotia Health Research Fund, honorarium for presentation from Mount Allison University, and patent pending for a process for improving cognitive function. Helena Fordell reports support from the Department of Clinical Science, Neurosciences, Umeå University, and stock in Brain Stimulation. Peii Chen reports employment at Kessler Foundation and honoraria for lectures from Shirley Ryan Ability Lab and MC CogRehab Resources, LLC, and is chair of a clinical trial titled “Evaluation of a Theory-Driven Manualized Approach to Improving New Learning and Memory in MS” National Institute of Health R01HD095915-01A1 (PI: Chiaravalloti), member of a sitespecific project titled “Randomized Controlled Trial of Combined Cognitive Rehabilitation and Aerobic Exercise for New Learning and Memory in Persons with Moderate-to-Severe TBI” within the National Institute on Disability, Independent Living, and Rehabilitation Research-funded Northern New Jersey Traumatic Brain Injury System, and chair of a clinical trial titled “Use of the KF Modified Story Memory Technique to Improve New Learning and Memory in Individuals with Mild Cognitive Impairment” National Institute of Health 1R01AG073235-01A1 (PI: Chiaravalloti). The other authors have nothing to disclose.

Cite this article as: Arch Rehabil Res Clin Transl. 2024;6:100343

<https://doi.org/10.1016/j.arrct.2024.100343>

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KEYWORDS

Consensus;
Delphi technique;
Neurologic
rehabilitation;
Perceptual disorders;
Rehabilitation

Abstract Survivors of neurologic injury (most commonly stroke or traumatic brain injury) frequently experience a disorder in which contralesionally positioned objects or the contralesional features of individual objects are often left unattended or underappreciated. The disorder is known by >200 unique labels in the literature, which potentially causes confusion for patients and their families, complicates literature searches for researchers and clinicians, and promotes a fractionated conceptualization of the disorder. The objective of this Delphi was to determine if consensus ($\geq 75\%$ agreement) could be reached by an international and multidisciplinary panel of researchers and clinicians with expertise on the topic.

To accomplish this aim, we used a modified Delphi method in which 66 researchers and/or clinicians with expertise on the topic completed at least 1 of 4 iterative rounds of surveys. Per the Delphi method, panelists were provided with results from each round prior to responding to the survey in the subsequent round with the explicit intention of achieving consensus. The panel ultimately reached consensus that the disorder should be consistently labeled *spatial neglect*. Based on the consensus reached by our expert panel, we recommend that researchers and clinicians use the label *spatial neglect* when describing the disorder in general and more specific labels pertaining to subtypes of the disorder when appropriate.

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In the late 19th and early 20th centuries, a collection of striking spatial deficits after unilateral brain damage was first described in the literature. For instance, one case study described a patient who made reading errors primarily on the contralesional side of words,¹ another described a patient who rarely used their contralesional arm despite intact motor function,²⁻⁴ and another described a patient who collided with stationary objects on her contralesional side while walking.⁵ Then labeled as *imperception*,^{1,6} *discharia*,²⁻⁴ or *visual disorientation*,^{5,7} the disorder has since been ascribed to >200 unique labels in the literature.⁸ Today, it is most commonly labeled as *unilateral neglect*, *spatial neglect*, *unilateral spatial neglect*, *hemispacial neglect*, or the *neglect syndrome*.⁸ The disorder is most often defined as a failure “to report, or to respond or orient to, novel or meaningful stimuli presented to the side opposite a brain lesion.”^{9(p209)}

This variability in labeling the disorder reflects its complexity. There is debate as to whether it is a unitary phenomenon because many instances of behavioral double dissociations have been reported.¹⁰⁻¹² Numerous subtypes of the disorder have been proposed based on these dissociations, such as by spatial frames of reference (eg, *egocentric neglect*, *allocentric neglect*^{13,14}), delineations of proximal space (eg, *peripersonal neglect*, *extrapersonal neglect*^{15,16}), sensorimotor modality (eg, *visual neglect*, *auditory neglect*, *motor neglect*), task specificity (eg, *neglect dyslexia*^{17,18}), and others.

The inconsistent labeling of the disorder is problematic for several reasons. In clinical settings, it can cause

confusion for patients and families, health care professionals, and other stakeholders such as hospital administration, government health care agencies, or insurance providers. In the research setting, a comprehensive literature review requires multiple searches and is at risk of unintentional exclusion of studies that have used an unsearched label. Furthermore, many labels reflect (or do not reflect) psychological or neurobiological processes theorized to underlie its behavioral symptoms (eg, *inattention*), which are not yet fully understood.¹⁹ This can hamper progress in developing a better understanding of its mechanisms and make it more difficult to develop and test theory-driven interventions.

Here we sought consensus on the appropriate label of the disorder using a modified Delphi method in order to promote international and interdisciplinary consistency in the label used by researchers, clinicians, and other stakeholders. The Delphi method uses a series of surveys with interspersed feedback to obtain expert consensus on a topic that otherwise would be impossible or impractical to obtain through traditional empirical designs.^{20,21} In the Delphi method, the research team defines criteria for panel inclusion, systematically identifies eligible researchers based on those criteria, and invites them to serve as panelists. Panelists typically respond to 2-4 rounds of surveys. After each round, the results are analyzed and collated by the research team and are used to develop the subsequent round's survey. Items for which responses meet or exceed a threshold level of agreement, specified a priori, are considered to have obtained consensus. The results of each round are provided to panelists prior to completing the subsequent survey.

Panelists are encouraged to consider the results from the prior round with the goal of consensus.

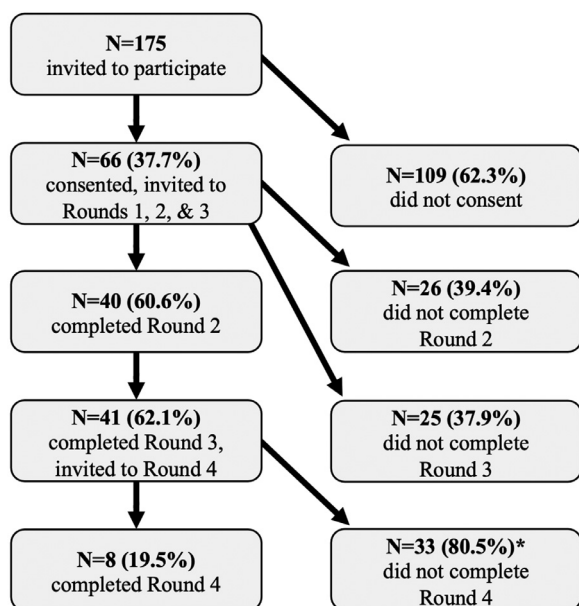
Methods

Participants

This protocol was approved by the institutional review boards of the Kessler Foundation (1-1136-21) and the University of South Australia (203806) and conforms with the Declaration of Helsinki. The protocol was not prospectively registered. Two hundred twenty-five experts were identified through a Scopus search restricted to the criterion of having published ≥ 5 peer-reviewed articles on the definition or assessment of spatial neglect. After those who were deceased, inactive, or without publicly available or current contact information were excluded, 175 experts remained. Experts received an invitation to participate via email, which included a brief description of the protocol, a link to provide informed consent electronically, and a link to the round 1 survey. Only those who had completed the round 1 survey were invited to participate in rounds 2 and 3. Because round 4 was an online meeting, participation was restricted to 8 panelists in order to facilitate a “round table” discussion. A flowchart of the number of participants who were invited to and participated in each round is presented in figure 1.

Approach

The labeling of the disorder was one of several topics addressed in the Delphi and is the sole focus of this article. Surveys in each round were created by authors L.J.W. and T. J.R., both of whom are early career researchers with clinical



*8 other panelists were included in Round 4 for second study arm

Fig 1 Flow diagram of participants through the 4 rounds of the Delphi.

backgrounds in occupational therapy. Feedback and suggestions were provided by a steering committee composed of authors A.B., G.A.E., and P.C., all of whom are senior-level researchers with backgrounds in cognitive psychology and neuropsychology and with expertise in spatial neglect. Those on the steering committee met the expert criterion but did not participate in any round.

Responses for each round were analyzed by L.J.W. and T. J.R., with input provided by authors A.B., G.A.E., and P.C. when discrepancies arose in the analyses or to provide alternate interpretations of the analyses. Consensus was defined a priori as $\geq 75\%$ agreement on an item or concept.^{21,22} Before rounds 2-4, collated, anonymized results from the prior round(s) were provided to panelists. They were encouraged to review the results prior to responding to the next survey and to take them in consideration with the goal of achieving consensus.

Consent and rounds 1-3 were completed using REDCap (Research Electronic Data Capture),^{23,24,a} an online data collection platform with encrypted data storage, hosted at the University of South Australia. Demographic information was collected immediately after receiving consent in round 1. Round 4 was an online discussion to facilitate consensus completed via the Zoom platform. Probes and response choices for each round pertaining to the label are detailed in the [Supplemental Appendix S1](#) (available online only at <http://www.archives-pmr.org/>).

Results

Round 1

There were a total of 66 respondents to the round 1 survey. Demographic characteristics are presented in table 1. Fifteen nationalities across 5 continents were represented in our panel. Fifty-eight of the 66 panelists provided their discipline, and 3 included a second discipline. Thus, we used $N=61$ to determine the proportion of the panel represented by each of the 7 disciplines reported. Neuropsychologists, physicians, and psychologists made up 78.7% of the panelists, and 77.8% of panelists claimed to have >15 years of research experience on the topic ($N=63$). Nearly half of the panelists were clinicians who had frequently worked with patients with the disorder.

For question 1, “Do you agree with using any of the following terms and/or prefixes as part of the neglect label?,” consensus was reached for the inclusion of the terms *neglect* (endorsed by 90.9% of respondents) and *spatial* (endorsed by 89.1%) as part of the label. *Contralesional* (endorsed by 63.6%) and *unilateral* (endorsed by 59.1%) received majority support but fell short of our threshold of 75% agreement for consensus.

Results of question 2, “What is your preferred label for ‘neglect?’,” are presented in the leftmost panel of figure 2. We received 18 unique labels from 64 respondents. We tallied the frequency of each of the 18 labels and arranged them in a ranked list. Responses of *spatial neglect*, *unilateral spatial neglect*, and *unilateral neglect* were most frequent, with 15, 12, and 10 responses, respectively. *Hemispatial neglect*, *neglect*, and *the neglect syndrome*

Table 1 Demographics of the expert panel in round 1.

Demographic	No. of Panelists	Proportion of Panel (%)
Country represented (N=66)		
Italy	16	24.2
United States	11	16.7
United Kingdom	9	13.6
Canada	6	9.1
France	6	9.1
Germany	5	7.6
Switzerland	4	6.1
The Netherlands	2	3.0
Australia	1	1.5
Belgium	1	1.5
Brazil	1	1.5
Finland	1	1.5
Hong Kong	1	1.5
Israel	1	1.5
Japan	1	1.5
Years of research experience (N=63)		
15+	49	77.8
11-15	5	7.9
7-10	4	6.4
4-6	5	7.9
0-3	0	0.0
Years of clinical experience (N=28)		
15+	24	85.7
11-15	3	10.7
7-10	0	0.0
4-6	1	3.8
0-3	0	0.0
Discipline (N=61)*		
Neuropsychologist	21	34.4
Physician	18	29.5
Psychologist	9	14.8
Cognitive neuroscientist	4	6.6
Physiotherapist	4	6.6
Occupational therapist	3	4.9
Orthoptist	2	3.3

* Panelists were permitted to select >1 discipline.

each received 3-5 responses; *contralateral spatial neglect*, *contralesional neglect*, *hemineglect*, and *unilateral inattention* each received 2 responses; and 9 additional labels received 1 response.

For question 3, "Do you think your preferred label for 'neglect' should be used for all research and clinical purposes?" 42 respondents (63.6%) indicated that their preferred term should be used for all research and clinical purposes. Four respondents (6.1%) answered "no" to the same question, and 20 respondents (30.3%) reported "no preference."

Round 2

We received 40 responses to the round 2 survey. Four panelists had incomplete responses and were not included. Thus,

36 responses were included. The overall rank of preference for the 9 labels is detailed in the second panel of [figure 2](#). Because we asked panelists to rank their preferences, we calculated the mean rank for each label. In this ranking scheme, lower values indicated a higher rank (ie, 1 indicated highest rank). The most highly ranked labels, reported in mean (SD), were *unilateral spatial neglect*, rank 3.6 (2.4); *spatial neglect*, rank 3.7 (2.5); *unilateral neglect*, rank 4.1 (1.9); *hemispatial neglect*, rank 5.0 (2.1); and *visuospatial neglect*, rank 5.4 (2.7).

Round 3

We received 41 responses to the round 3 survey. For question 1, there was consensus that it is important for the field to adopt a consistent label, with 80.1% of respondents endorsing its importance and 19.5% denying its importance. For question 2, "Why do you or why do you not think it is important for the field to adopt a consistent label for neglect?," respondents who endorsed the importance of a consistent label made comments centered around 3 main themes: (1) that a consistent label would reduce confusion among clinicians, researchers, and patients; (2) that it would help bring convergence to the field as to what behavioral symptoms constitute the disorder; and (3) that it would reduce the effort required when conducting literature searches. Comments from respondents who denied the importance of a consistent label cited that multiple labels are needed to adequately describe the many subtypes of the disorder and that preference likely varies in different parts of the world.

Results for question 3, "My overall preferred label for neglect is: (multiple choice response)," are presented in the third panel of [figure 2](#). *Unilateral spatial neglect* and *spatial neglect* were clearly the most preferred labels, with 48.8% and 34.2% of votes, respectively. *Unilateral neglect* and *hemispatial neglect* each received 4.9% of votes, and 7.3% of respondents selected *other* and entered their preferred label via free text.

For question 4, "Did your response above change from round 1 and/or round 2 based on their results?," 7.3% of respondents reported changing their response to their overall preferred label from round 1 or 2.

In response to question 5, "For each of the following labels, would you use it in the future if consensus was reached within this panel of experts?," among the 27 panelists who did not choose *spatial neglect* as their preferred label, 77.8% reported that they would use it if there was consensus established through this Delphi process. For the same question, 71.4% of the 21 panelists who did not choose *unilateral spatial neglect* and 59.0% of the 39 panelists who did not choose *unilateral neglect* reported that they would use the label if consensus was reached.

Most comments left by panelists pertained to the inclusion or exclusion of specific terms in the label. Several respondents expressed the inaccuracy of the terms: *contralesional*, because of the infrequent but noteworthy occurrence of ipsilesional deficits; *hemispatial*, because it implies that deficits only present in one half of space while they have been shown to follow a horizontal gradient; and *visuospatial*, because it ignores the other sensory modalities often affected. One comment questioned the necessity of

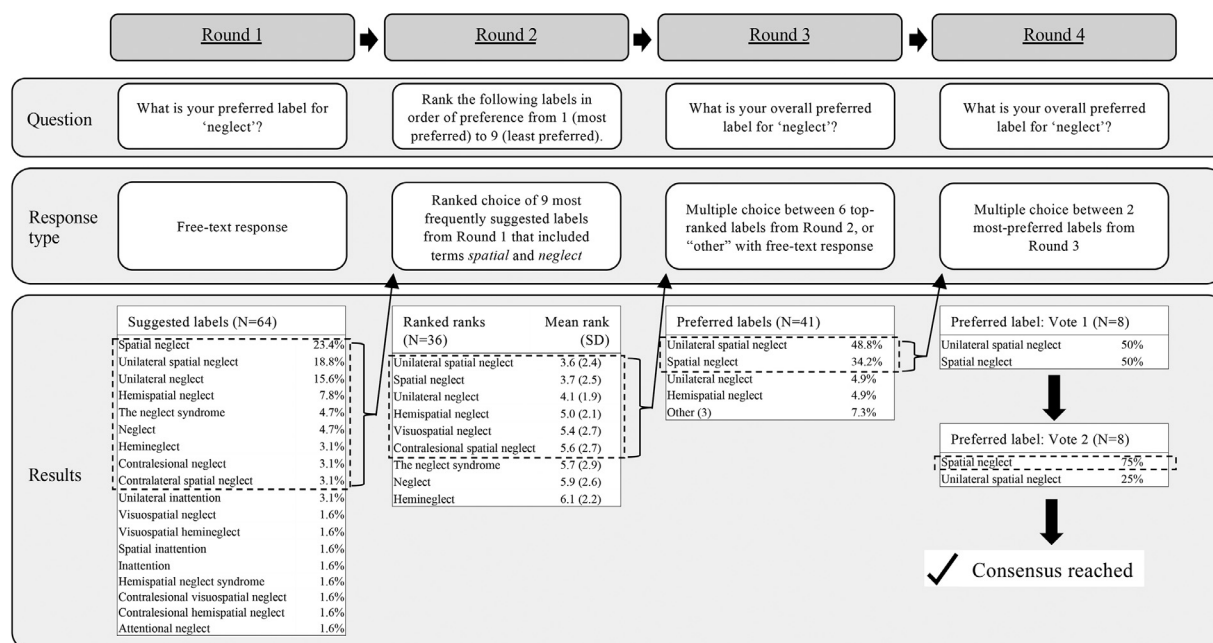


Fig 2 Specific questions, response types, and results for each of the 4 rounds of the Delphi. Dotted boxes indicate labels that received the most votes or highest ranks and were carried on for consideration in the subsequent round.

using the Delphi technique, stating that the loose collection of labels used in the literature to date causes no controversy and no confusion to researchers or clinicians.

Round 4

Results of round 4 are presented in the rightmost panel of [figure 2](#). Panelists voted twice on their preferred label. The first vote was split evenly (4-4) between the 2 choices of *unilateral spatial neglect* and *spatial neglect*. During the round robin discussion that followed, panelists described the reasons for their choice, which were generally consistent with many of the comments provided regarding the inclusion or exclusion of specific terms in round 3. Those who argued for the label *unilateral spatial neglect* attributed their choice to (1) their professional training, clinical experience, and discipline's tradition; and (2) its emphasis on the asymmetric behavioral characteristics of the disorder. Panelists who argued for the label *spatial neglect* attributed their choice to (1) the inaccuracy of the term “unilateral,” given that it implies impaired performance on one side of the midline and normal performance on the other, when, in fact, the impairment follows a gradient that is defined by dynamic spatial coordinates; and (2) its succinctness relative to other labels. After the discussion, 2 panelists changed their choice for the second vote, resulting in consensus (ie, 75% agreement) for the use of the label *spatial neglect*.

Discussion

We used a modified Delphi process to establish consensus on the label used for the neurologic disorder known by >200 unique labels⁸ such as *spatial neglect*, *unilateral neglect*,

and *hemispatial neglect*. Sixty-six experts in the field, all with ≥ 5 peer-reviewed publications on the topic, participated in ≥ 1 rounds of the Delphi process. Panelists initially reported 18 different preferred labels in round 1. In subsequent rounds, multiple choice selection was used with increasingly narrowed options through the systematic elimination of less-favored labels. After 2 votes in round 4, consensus was reached, supporting the use of the label *spatial neglect*.

Consensus was also reached that it is important for the field to adopt a unified label for the disorder. Reasons provided by panelists fell under 3 main themes: (1) for consistency in communication among clinicians, patients, and families²⁵; (2) for clarity and convergence on what symptoms constitute the disorder; and (3) to streamline literature searches. However, because many dissociable subtypes of spatial neglect have been identified, the use of more deficit-specific labels (eg, peripersonal neglect, auditory neglect, allocentric neglect, neglect dyslexia) is warranted. Thus, we recommend that stakeholders use *spatial neglect* as an “umbrella” label when describing the disorder in general, and, if and when applicable, use a more specific label when describing deficits related to specific tasks, spatial frames of reference, or sensorimotor modality.

At the conclusion of round 3, there was convergence of opinion around 2 similar labels: *unilateral spatial neglect* and *spatial neglect*. In addition, approximately three-quarters of panelists who did not choose *unilateral spatial neglect* and/or *spatial neglect* as their most preferred label agreed that they would adopt either label if consensus was reached through this Delphi, whereas only approximately half agreed to the same question for the other 4 labels proposed at that stage. Ultimately, *spatial neglect* was selected by the round 4 panelists after a brief discussion in which some raised an issue with the accuracy of the term

“unilateral” as part of the label. This was consistent with the only known article confronting these labeling inconsistencies in which a panel of 9 prominent researchers in the field advocated for the use of *spatial neglect* (however, also included *neglect*, *unilateral spatial neglect*, and *hemispatial neglect* as acceptable alternatives).²⁶

Despite *unilateral spatial neglect* being a final contender for the consensus-based label, there were far fewer comments submitted in its support than those against it. Those in favor referred to its implication of asymmetric, spatially lateralized deficits, a core feature of the disorder. Nearly all comments from those against *unilateral spatial neglect* referred to the inaccuracy of the term “unilateral” because it implies that there are deficits to one side of the midline but not the other, when, in fact, it often occurs along a gradient, with a monotonic increase in errors or omissions from the ipsilesional to contralesional side.^{15,27,28}

We received comments against the inclusion of “contralesional/contralateral” in the label. These comments followed 2 themes. Similar to “unilateral,” most comments referenced the inaccuracy of the term because of cases of ipsilesional deficits.²⁹⁻³¹ A few panelists suggested that the use of “contralesional” requires assumptions about the neurobiological underpinnings of a disorder that can only be defined and diagnosed by behavioral symptoms.

Inattention versus neglect

Although only 7.9% of panelists in round 1 reported a preferred label including the term “inattention” (or “attentional”), comments regarding its inclusion were controversial because it implies a theoretical interpretation that is far from settled.³²⁻³⁴ One panelist commented that although attention does not encapsulate everything about the disorder, it does describe its behavioral characteristics; another commented that it appropriately emphasizes that the disorder is attentional and not perceptual in nature. Conversely, several panelists against its inclusion stated that it is too narrow because the disorder is not only attentional but may also involve perception and/or mental representation. Others stated that the use of the term “inattention” in the label is problematic because there is no consensus definition of the psychological construct of “attention.”

Study limitations

There are several limitations to this work. First, although we were fortunate to have such diverse global representation, we were unable to identify eligible researchers from African countries and very few were identified from Asian countries. Thus, the panel is biased toward the experiences and training of North American and European countries.

Second, approximately 40% of round 1 panelists did not participate in round 2 or round 3. This high rate of attrition is contextualized by prior reports that 20%-30% attrition is to be anticipated in Delphi studies.^{35,36} Nevertheless, many consented panelists who provided their initial opinions in round 1 did not contribute to the Delphi process of reviewing the panel results in order to build consensus. However, the penultimate consensus for the label *spatial neglect* was consistent with round 1, in which it was the most preferred label via

free-text response; and round 3, in which more than three-quarters of respondents who chose another label as their preferred choice reported that they would use *spatial neglect* if consensus was reached for it through this Delphi process.

Third, panelists were invited to participate based on the number of articles published on the topic. Although we used multiple labels in our initial Scopus search, there is a chance that researchers who would have otherwise been included were not identified because of the use of a less common label.

Conclusions

In summary, using a modified Delphi method, an international and multidisciplinary panel of researchers and clinicians with expertise on the topic reached consensus that the disorder should consistently be labeled *spatial neglect*. Thus, we advocate for researchers, clinicians, and other stakeholders to use this label going forward in order to reduce confusion, facilitate expedient literature searches, and promote awareness in the field of the diversity of symptoms that constitute the disorder.

Suppliers

- a. REDCap (Research Electronic Data Capture); Vanderbilt University.

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Acknowledgments

We would like to thank the graduate students who assisted with elements of this work and the researchers who participated as panelists in this Delphi study.

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