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ORIGINAL ARTICLE

The upper extremity postthrombotic syndrome score: an international Delphi consensus study to determine the score's functional disability component

Ludo Schropp MD[1] | Roos B. Cats BSc[1] | Robert J. C. M. F. de Kleijn MD[1] | Eline S. van Hattum MD, PhD[1] | Saskia Middeldorp MD, PhD[2] | Mathilde Nijkeuter MD, PhD[3] | Jan Westerink MD, PhD[4] | Bart-Jeroen Petri MD, PhD[1] | Gert J. de Borst MD, PhD[1] | in collaboration with the Upper Extremity PTS group[††]

[1]Department of Vascular Surgery, University Medical Center Utrecht, The Netherlands

[2]Department of Internal Medicine & Radboud Institute of Health Sciences, Radboud University Medical Center, Nijmegen, The Netherlands

[3]Department of Internal Medicine, University Medical Center Utrecht, The Netherlands

[4]Department of Internal Medicine, Isala Hospital, Zwolle, The Netherlands

Correspondence
Gert J. de Borst, Department of Vascular Surgery G04.129, UMC Utrecht, Heidelberglaan 100, 3584 CXUtrecht, The Netherlands.
Email: G.J.deBorst-2@umcutrecht.nl

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Abstract

Background: In upper extremity thrombosis research, the occurrence of upper extremity postthrombotic syndrome (UE-PTS) is commonly used as the main outcome parameter. However, there is currently no reporting standard or a validated method to assess UE-PTS presence and severity. In a recent Delphi study, consensus was reached on a preliminary UE-PTS score, combining 5 symptoms, 3 signs, and the inclusion of a functional disability score. However, no consensus was reached on which functional disability score to be included.

Objectives: The aim of the current Delphi consensus study was to determine the specific type of functional disability score to finalize UE-PTS score.

Methods: This Delphi project was designed as a three-round study using open text questions, statements with 7-point Likert scales, and multiple-choice questions. The CREDES recommendations for Delphi studies were applied. In this context, a systematic review was conducted before the start of the Delphi rounds to identify the available functional disability scores as available in the literature and present these to the expert panel.

Results: Thirty-five of 47 initially invited international experts from multiple disciplines completed all the Delphi rounds. In the second round, consensus was reached on the incorporation of the quick disabilities of the arm, shoulder, and hand (QuickDASH) in the UE-PTS score, rendering the third round obsolete.

Conclusion: Consensus was reached that the QuickDASH should be incorporated in the UE-PTS score. The UE-PTS score will need to be validated in a large cohort of patients

In collaboration with the Upper Extremity PTS group (Supplementary Appendix 1)

[††] The authors from the Upper Extremity PTS group are mentioned in Appendix S1.

with upper extremity thrombosis before it can be used in clinical practice and future research.

KEYWORDS
Delphi technique, diagnosis, functional status, postthrombotic syndrome, surveys and questionnaires, thoracic outlet syndrome, upper extremity deep vein thrombosis

Essentials

- A Delphi study was performed to complete the upper extremity postthrombotic syndrome score.
- Consensus was reached on which functional disability score should be incorporated in the score.
- The quick disabilities of the arm, shoulder, and hand were incorporated in the final score.
- Future clinical evaluation and validation of the final upper extremity postthrombotic syndrome score is mandatory.

1 | INTRODUCTION

Most cases of upper extremity deep venous thrombosis (UEDVT) are provoked by a clear cause such as intravenous devices (ie, pacemaker lead or venous catheter) or malignancy-induced hypercoagulability, referred to as secondary UEDVT (sUEDVT) [1,2]. The treatment of sUEDVT is well described in the current guidelines [3–5]. By contrast, primary UEDVT (pUEDVT) can be caused by positional compression of the vein, ie, venous thoracic outlet syndrome (TROTS) or it can arise without an apparent reason, ie, idiopathic UEDVT [1,6,7]. pUEDVT is a rare disease, and estimates of the incidence range from 1 to 3 per 100,000 people/year [8,9]. Treatment strategies range from conservative to invasive regimens; high-quality evidence is however lacking [6,10,11]. Patient's clinical outcome is usually expressed as the incidence of the postthrombotic syndrome (PTS) [6,10,12–14]. In pUEDVT, an incidence of PTS in the upper extremity (UE) has been reported up to 60%, which potentially has a high negative impact on the quality of life of these patients [6,15,16]. Although most UEDVT studies use upper extremity postthrombotic syndrome (UE-PTS) as the main outcome parameter, currently, there is no reporting standard nor a validated method to assess a patient for UE-PTS and determine its severity [17]. As a consequence, the current literature comprises incomparable studies reporting a wide array of subjective outcome parameters. This is reflected in the recommendations of the current pUEDVT guidelines, all based on low-quality evidence or expert opinion and, sometimes, even conflicting between different guidelines [3–5,18]. Hence, a uniform and validated reporting standard of UE-PTS to be used as a primary outcome in future (randomized) guideline informing pUEDVT studies is needed [17].

Our research group recently performed a first Delphi study with the aim to reach consensus on a clinical bedside tool to assess the presence and severity of UE-PTS. This Delphi study concluded that the UE-PTS score, consisting of 5 symptoms and 3 clinical signs scored as absent/mild/moderate/severe, should be combined with a functional disability score to assess the impact of these PTS symptoms on a patients' arm functionality [17].

The aim of the current study was to gain expert consensus on the specific type of functional disability score to complete the UE-PTS score.

2 | MATERIAL AND METHODS

The Delphi method is commonly used in medical research to reach consensus on a topic with the aid of an expert panel [19,20]. According to the "conducting and reporting Delphi studies (CREDES)" criteria, the study was designed and conducted as follows: (I) identification and invitation of the expert panel, (II) informing the expert panel on the research question and subject, and (III) conducting 3 Delphi rounds to reach consensus on the research question [21]. The Delphi steering committee consisted of 3 vascular surgeons experienced in UEDVT (E.v.H., B.P., and G.d.B.), 1 PhD researcher (L.S.), and 1 researcher (R.C.).

The aim was to form an international, heterogeneous, and multidisciplinary expert panel of specialists experienced in the management of UEDVT and UE-PTS. The 25 experts involved in the initial UE-PTS Delphi study were all invited for this current Delphi project. Additional experts were selected on the basis of involvement in upper extremity (UE) thrombosis guidelines and UEDVT research. Finally, 47 experts were invited to participate in this Delphi study.

To inform the expert panel on which validated functional disability scores are available in the current literature, a systematic review was conducted. For this systematic review, a PUBMED search was performed in February 2022 combining the following MeSH terms and their synonyms: "Functional Status," "Surveys and Questionnaires," and "Upper Extremity." See Supplementary Appendix 2 for the complete search string. Original articles in English reporting on the development, validation, or the use of 1 or multiple UE functional disability scores were included. Through cross-referencing, additional functional disability scores were identified. For each functional disability outcome measures, it was tallied how often it was used in the literature. An overview of the systematic review was presented to the expert panel before the start of the Delphi including the original

article describing the development of the score and the corresponding validity studies. In addition, the results of the previous UE-PTS Delphi study and the aim of the current study were communicated with the experts. It was underlined that the aim of this Delphi study was to establish which type of existing functional disability score should be incorporated in the final UE-PTS score.

The study was designed with 3 Delphi rounds. In round 1, experts were inquired on which functional disability score(s) they considered to be potentially appropriate for incorporation in the UE-PTS score and why, by using open text answers. The experts were encouraged to suggest any scores not found with the systematic review. Only the suggested scores that actually assess the functional status of the UE were taken to the subsequent round; other suggested scores (eg, quality of life) were discarded. In addition, the experts were asked whether they used a UE functional disability score in their day-to-day practice. In the second round, the results of the first round were presented to the expert panel. Each suggested score from the first round was then placed in a statement and offered to the expert panel as follows: "The [functional disability score X] should be incorporated in the UE-PTS score." By using a 7-point Likert scale (1 = completely disagree, 4 = neutral, and 7 = completely agree), experts were asked to assess each score. To reach consensus, at least 70% of the experts had to give a score of 6 or 7. The threshold value for consensus is much debated and highly variable among Delphi studies, and the CREDES criteria do not give precise recommendations [21]. The 70% threshold was chosen based on the previous by using a 7-point Likert scale [21–23]. The third round was reserved as a backup round in case there was no consensus on a score or multiple scores were scored equally. In case a third round was needed, first, the results of the second round would be presented. Subsequently, the experts would be asked to assess the remaining scores from round 2 in a multiple-choice question as follows: "Which functional disability score should be incorporated in the UE-PTS score?" For this multiple-choice question, agreement for consensus was set at 70%. The study was performed with the aid of an online survey program. Participants who failed to complete ≥1 round(s) were excluded from the subsequent round.

3 | RESULTS

3.1 | Expert panel

A total of 47 experts worldwide were invited to participate in this Delphi study. In total, 36 experts (77% from invited experts) agreed to participate and completed the first round. Of these 36, 16 experts also participated in the previous Delphi. Most experts were either vascular surgeons (31%) or vascular medicine specialists (31%). All experts had more than 5 years of experience in the field of thrombosis, and most (80%) treat up to 25 patients with UEDVT per year. Most experts were registered as medical specialist in the Netherlands, United States of America, and Canada. See Table 1 for a full description of the expert panel.

TABLE 1 Characteristics of the expert panel.

Expert characteristics	Distribution
Medical specialty	Vascular surgery (31%)
	Vascular medicine (31%)
	Hematology (22%)
	Internal medicine (11%)
	Pediatrics (6%)
Years' experience in thrombosis	0-5 (0%)
	6-10 (8%)
	11-20 (39%)
	>20 (53%)
No. of patients with UEDVT per year	0-10 (44%)
	10-25 (36%)
	25-50 (14%)
	>50 (5%)
Country registered as medical specialist	The Netherlands (56%)
	USA (14%)
	Canada (14%)
	Greece (6%)
	UK (6%)
	India (3%)
	Italy (3%)

UEDVT, upper extremity deep venous thrombosis; UK, United Kingdom; USA, United States of America.

3.2 | Systematic review functional disability scores

The search yielded a total of 747 articles. After title and abstract screening, 269 original articles remained describing 4functional disability scores for the UE, 6 scores specific for the hand and wrist, 1 specific for the elbow, and 4 specific for the shoulder. 6 review articles were found and used for cross-referencing, in which 2 additional UE functional disability scores were identified: the upper extremity function scale (UEFS) and neck and upper limb index (NULI). The NULI is mentioned in 1 review, and the UEFS in 3 of the 6. When specifically searching PubMed for original articles describing or using these scores, zero NULI and 4 UEFS studies were found. The limited yield in cross-referencing the 6 review articles suggests that the performed search identified all available functional disability scores. From the scores assessing the complete UE most notably where the disabilities of the arm shoulder and hand (DASH), the QuickDASH, Patient-Reported Outcomes Measurement Information System upper extremity computer adaptive testing (PROMIS UE CAT), and the upper extremity functional index [24–27]. These scores where used in 205, 75, 19, and 11 original articles, respectively. See Supplementary Appendix 3 for all functional disability scores because they were presented to the expert panel.

TABLE 2 Round 1: Potentially appropriate functional disability scores suggested by the expert panel.

Suggested functional disability score	Times mentioned by the expert panel
QuickDASH	23
DASH	13
PROMIS UE CAT	3
UE functional index (20)	2
UE functional index (15)	1
UE functional scale	1

DASH, disabilities of the arm shoulder and hand; PROMIS UE CAT, Patient-Reported Outcomes Measurement Information System upper extremity computer adaptive testing; UE, upper extremity.

3.3 | Delphi round 1

In round 1, 6 functional disability scores for the UE were suggested by the experts (Table 2); the average number of suggested scores per expert was 1, 5. Most notable were the QuickDASH (suggested 23 times) and the DASH (suggested 13 times). Three experts (8%) were unsure which functional disability score could be potentially appropriate. All scores that were suggested by the experts were also identified in the systematic review. The experts gave various arguments on why they considered the scores as potentially appropriate. The eminent difference between the QuickDASH and DASH was that the QuickDASH was considered short but still complete (Table 3). Eighty-six percentage of the experts did not use a validated functional disability score to assess patients with UEDVT in their day-to-day practice.

3.4 | Delphi round 2

Thirty-five of the 36 experts completed the second round. In round 2, 26 of the 35 experts (74%) scored the QuickDASH a 6 or 7; therefore, consensus was reached on the statement: "The QuickDASH should be incorporated in the UE-PTS score." None of the other scores reached the threshold for consensus (Table 4). Following the QuickDASH, the DASH was scored a 6 or 7 by solely 5 of the 35 experts (14%). Because consensus was reached, there was no need for a third round. See Supplementary Appendix 4 for an overview of the scores given by each expert per functional disability score in round 2. In Supplementary Appendix 5, the complete UE-PTS score including the QuickDASH is presented.

4 | DISCUSSION

The UE-PTS score was finalized by the addition of a functional disability score. Within 2 Delphi rounds only, our international multidisciplinary expert panel reached consensus that the QuickDASH should be part of the final UE-PTS score. None of the other functional disability scores reached the threshold for consensus. With the addition of the QuickDASH, the final UE-PTS score is as follows: 5 symptoms and 3 clinical signs (scored absent/mild/moderate/severe) resulting in no/mild/moderate/severe PTS combined with the QuickDASH.

Historically, mortality, and morbidity were the main outcome parameters in medical research. However, because the introduction of the World Health Organization's International Classification of Impairment, Disability, and Handicap (ICIDH) in the 1980s, the impact of disease on a person's functioning has become another important outcome parameter [28]. Nowadays, there are many tools available to assess a patient's functional (dis)ability, ranging from generic (eg, the ICIDH-2) to disease specific (eg, the foot function index or the Barthel Index for stroke research). In addition, functional disability has been found to correlate with a patient's quality of life (QOL) [29–31].

In the previous Delphi study, the expert panel reached strong consensus (91% agreement) that a functional disability score should be a fixed part of the UE-PTS score, but at the time, no consensus was reached on the specific type of functional disability score. This might be partially explained by the relative unfamiliarity of physicians with UE functional disability scores. In the panel of the current study, only 5 experts reported to use a functional disability score in their day-to-day

TABLE 3 Round 1: Argumentation used by the experts for the potential appropriateness of each functional disability scores, including times mentioned.

Argument	QuickDASH (*N* = 23)	DASH (*N* = 13)	PROMIS UE CAT (*N* = 3)	UE functional index (20) (*N* = 2)	UE functional index (15) (*N* = 1)	UE functional scale (*N* = 1)
Validated	8	5	1	1	1	1
Short	12	0	0	1	1	1
Easy to use	6	3	1	0	0	0
Complete	7	2	0	0	0	0
Used in literature	4	3	0	0	0	0
Focuses on the whole arm	5	1	1	1	1	1
No payment	1	0	0	1	1	1

DASH, disabilities of the arm shoulder and hand; *N*, number of times mentioned as potentially appropriate in round 1 by the experts; PROMIS UE CAT, Patient-Reported Outcomes Measurement Information System upper extremity computer adaptive testing; UE, upper extremity.

TABLE 4 Round 2: Functional disability scores rated 6 or 7 on the Likert scale (1-7) by the expert panel (n = 35). Threshold for consensus >70%.

Functional disability score	Rated 6 or 7
QuickDASH	26 (74%)
DASH	5 (14%)
PROMIS UE CAT	0
UE functional index (20)	0
UE functional index (15)	0
UE functional scale	1 (3%)

DASH, disabilities of the arm shoulder and hand; PROMIS UE CAT, Patient-Reported Outcomes Measurement Information System upper extremity computer adaptive testing; UE, upper extremity.

practice. To overcome this issue and avoid a similar outcome as in the first Delphi, efforts were made with the systematic review to improve the experts' familiarity with the validated UE functional disability scores used in the current literature. The DASH score was found to be the most utilized score in the literature, followed by the QuickDASH.

The DASH was developed in 1996 by the Council of Musculoskeletal Specialty Societies, the American Academy of Orthopaedic Surgeons, and the Institute for Work and Health Canada and has since found widespread acceptance and use [24]. It was designed to be a standardized measurement of the impact on function of a variety of UE disorders. The DASH consists of 30 questions: 21 questions test the extent to which the subject has had problems performing specific activities within the last week, 6 questions assess certain symptoms (eg, difficulty sleeping and pain), and 3 assess occupational and social limitations. The score has been widely used as an reliable outcome measure in numerous research fields [32]. In addition, the DASH has been found to correlate with the QOL [33]. In 2005, the DASH was shortened to the 11 questions QuickDASH, aiming to create a shortened, although still reliable, questionnaire [25]. In literature comparing both scores, even directly, a similar strong validity, reliability, and discriminating ability has been found, indicating that the shorter QuickDASH can be used as an reliable outcome measure just like the DASH score [34–36]. The QuickDASH results in a score of 0 (no disability) to 100 (most severe disability) and is available and validated in more than 50 languages.

Before the UE-PTS score can be used in UEDVT research, the following elements need to be determined: (I) threshold values for the difference in arm circumference, (II) threshold values for no/mild/moderate/severe PTS, (III) the inter and intraobserver reliability of the score, and (IV) the validity of the score as a whole in assessing UE-PTS. To investigate these components and evaluate the clinical value of the UE-PTS score, a multicenter clinical study with a large cohort of patients with UEDVT is mandatory. However, the main challenge will be the validation of the UE-PTS score because there is no gold standard to determine the presence and severity of PTS to compare the UE-PTS score with.

Similarities can be found in the development of the clinical scores used in the lower extremities (LE). The Villalta scale is currently the most-used clinical score to assess a patient for LE-PTS and was proposed as the standard for use in LE thrombosis research by the International Society of Thrombosis and Haemostasis [37]. The validity of the Villalta scale has been assessed by determining whether the scale's scores and outcome categories correlate with relevant health outcomes and suggested anatomical or physiological correlates of LE-PTS [38]. In the original abstract from the 1990s, the Villalta scale correlated well with the degree in which venous symptoms and signs interfered with a patient's life [39]. In addition, other studies have demonstrated that the Villalta scale correlates well with the QOL reported by the patient (eg, VEINES-QOL and SF-36 physical component score) [14,15]. Finally, multiple anatomical and physiological abnormalities such as abnormalities on Duplex ultrasound, increased ambulatory venous pressure, and the Venous Filling Index seem to correlate well with the Villalta scale [40–42]. Despite all these validation studies producing circumstantial evidence, these probably are the most appropriate methods to validate a score with the lack of a "gold standard." Such a pragmatic approach is also, in our view, the best method to validate the UE-PTS score. The patient recruitment of such a validation study will be facilitated by the TROTS registry. The TROTS registry is a recently initiated international and multidisciplinary registry in which all patients with pUEDVT can be included [43]. Given the low incidence of pUEDVT, such a multicenter and multidisciplinary registry is vital to form a large enough patient cohort for qualitative research. Once validated, the UE-PTS score can also be incorporated in the TROTS registry as an additional outcome measure.

4.1 | Strengths and limitations

The current Delphi study is a consistent and scientifically sound subsequent to the first Delphi study. A transparent approach to the creation and eventually clinical evaluation of a novel score such as the UE-PTS score is vital to result in a score that will be widely accepted and used by all specialties involved. Owing to the large, heterogeneous expert panel of this study with experts from multiple disciplines and countries, the results are to be expected to reflect the overall view of the medical specialists involved in UEDVT and UE-PTS management. In addition, the outcome of the current study is unambiguous with solely the QuickDASH that reached the threshold for consensus.

The potential limitation of this study is the relative unfamiliarity with UE functional disability scores of the medical experts involved in pUEDVT management. The knowledge of the expert panel concerning the available functional disability scores was updated with the systematic review as presented to the experts before the start of the Delphi study. Despite these efforts, 3 experts were "unsure" in the first round when asked which functional disability score could be potentially appropriate to incorporate in the UE-PTS score. In addition, no paramedical specialists were included in the panel, which is to be expected with the rarity of UEDVT and UE-PTS and thereby relative unfamiliarity of paramedical specialists in this field. In addition, paramedical specialists are less involved in UEDVT and

UE-PTS management compared with medical specialists. They could have however provided input in the expert panel from another perspective.

5 | CONCLUSION

Within 2 Delphi rounds, consensus was reached that the QuickDASH should be incorporated in the UE-PTS score, finalizing this novel score for clinical evaluation. The UE-PTS score needs to be validated in a large cohort of patients with UEDVT before it can be used in future research and clinical practice.

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AUTHOR CONTRIBUTIONS

L.S.: Concept and design, analysis and interpretation of data, monitoring of the Delphi process, and writing of manuscript. R.B.C.: Concept and design, analysis and interpretation of data, monitoring of the Delphi process, and writing of manuscript. R.J.C.M.F.d.K.: Analysis, interpretation of data, and writing of manuscript. E.S.v.H.: Concept and design, interpretation of data between Delphi rounds, monitoring of the Delphi process, and revision of manuscript. S.M.: Expert in expert panel, interpretation of data, and revision of manuscript. M.N.: Expert in expert panel, interpretation of data, and revision of manuscript. J.W.: Expert in expert panel, interpretation of data, and revision of manuscript. B.-J.P.: Concept and design, interpretation of data between Delphi rounds, monitoring of the Delphi process, and revision of manuscript. G.J. d.B.: Concept and design, interpretation of data between Delphi rounds, monitoring of the Delphi process, revision of manuscript, and final approval of manuscript.

RELATIONSHIP DISCLOSURE

The main authors declare to have no conflicts of interest. From the Upper Extremity PTS group, the following conflits of interest exist: K. M. reports speaker fees from Alexion, Bayer and, CSL Behring, participation in trial steering committee for Bayer, consulting fees from Uniqure, and participation in data monitoring and endpoint adjudication committee for Octapharma. All fees are paid to her institution. M.J.H.A. K. reports an unrestricted research grant from Sobi and speakers fee from Sobi, Roche, and BMS. All fees are paid to her institution. M. C. reports research support and/or consultancy fees from Bayer, Daiichi Sankyo, and Viatris. M.V. H. reports research grant support from ZonMw, Dutch Heart Foundation, Boehringer Ingelheim, Bayer Health Care, Pfizer-BMS, and Leo Pharma.

TWITTER

Saskia Middeldorp @MiddeldorpS

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SUPPLEMENTARY MATERIAL

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