



HAND-Q©

A User's Guide for Researchers and Clinicians

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1. What is the HAND-Q?

Hand conditions are extremely common and have a major impact on a person's life. Since patients are the best source of information on how they *function* and *feel*, it is vital to include the patient perspective in the assessment of outcomes. The HAND-Q is a rigorously developed patient-reported outcome measure (PROM) that measures outcomes important to patients with any type of congenital or acquired condition affecting the hands. The HAND-Q can be used to measure outcomes in research and clinical practice from the perspective of patients.

2. How was the HAND-Q Developed and Validated?

The HAND-Q represents a new generation of PROMs developed using a modern psychometric approach called Rasch Measurement Theory (RMT). In RMT, scales that compose a PROM are each designed to measure and score a unidimensional construct. In scale development, data that meet the requirement of the Rasch model provide interval-level measurement. When a scale has high content validity and is targeted to measure a concept as experienced by a sample, accurate tracking of clinical change can be achieved. In addition to their use in research studies, HAND-Q scales can be used with individual patients to inform clinical care.

Figure 1 shows the multiphase mixed-methods approach we use to develop Q-Portfolio instruments. We followed internationally recommended guidelines for PROM development to ensure that the HAND-Q meets requirements of regulatory bodies. A detailed description of the protocol we followed to develop the HAND-Q has been published [1].

The qualitative phase took place between June and November 2017 [2]. We conducted 62 concept elicitation interviews with 40 participants in Australia and 22 in Canada. The sample included more females (n=34, 55%) than males. The mean age of participants was 65 ± 11 years (range, 28 to 86). The participants' diagnoses included carpal tunnel (n=20), Dupuytren's contracture (n=14), trigger finger (n=8), osteoarthritis (n=8), trauma (n=7), and other less common hand conditions (n=4).

Analysis led to the development of a conceptual framework and a set of scales that measure concepts important to patients. The qualitative dataset included 3008 unique codes, which were organized into top-level domains of hand appearance, health-related quality of life (HRQOL), experience of care, and treatment. Figure 2 shows the HAND-Q conceptual framework. A set of independently functioning scales was developed from the coded material.

Content validity for HAND-Q scales was established through 20 cognitive debriefing interviews conducted in 3 rounds between January and February 2018. Most participants were female (n=13, 65%), and the mean age of the sample was 60 ± 12 years (range, 32

to 76). Participants were seeking or had received treatments for a range of hand conditions, including carpal tunnel (n=9), Dupuytren's contracture (n=3), trigger finger (n=3), osteoarthritis (n=7), trauma (n=5), and other less common conditions (n=3). In addition, a total of 25 experts provided input on the content of the HAND-Q scales. Based on patient and expert input, the scales were further refined.

Teams in Finland and France performed translation and cultural adaptations of the HAND-Q in preparation for data collection. The field-test study took place in Australia, Canada, the United Kingdom, the USA, France, and Finland between August 2018 and January 2021. Data were collected from 1277 patients with a broad range of hand conditions. Research Electronic Data Capture System (REDCap) was used for data entry. Some data were collected using paper booklets. Table 1 shows characteristics for the field-test sample. The mean age of the sample was 50 (SD=17) and ranged from 16 to 89 years. Most data were collected using the English version of the HAND-Q, with other contributions in Finnish and French.

The final version of the HAND-Q measures 4 domains: appearance; HRQOL; experience of healthcare; and treatment. Each domain has multiple independently functioning scales (see Table 2). RMT analysis provided evidence of reliability and validity for 14 independently functioning HAND-Q scales. Each scale evidenced reliability and validity. Examination for Differential Item Functioning by age, gender, language, and type of hand condition (i.e., non-traumatic versus traumatic) confirmed that a common scoring algorithm for each scale could be implemented. Further details about the development and validation of the HAND-Q are available in our publications [1-3].

Figure 1: The multiphase, mixed-methods approach our team follows to develop PRO measures (Reprinted from Wong Riff *et al.*). *BMJ Open*. 2017;7:e015467. doi:10.1136/bmjopen-2016-015467)

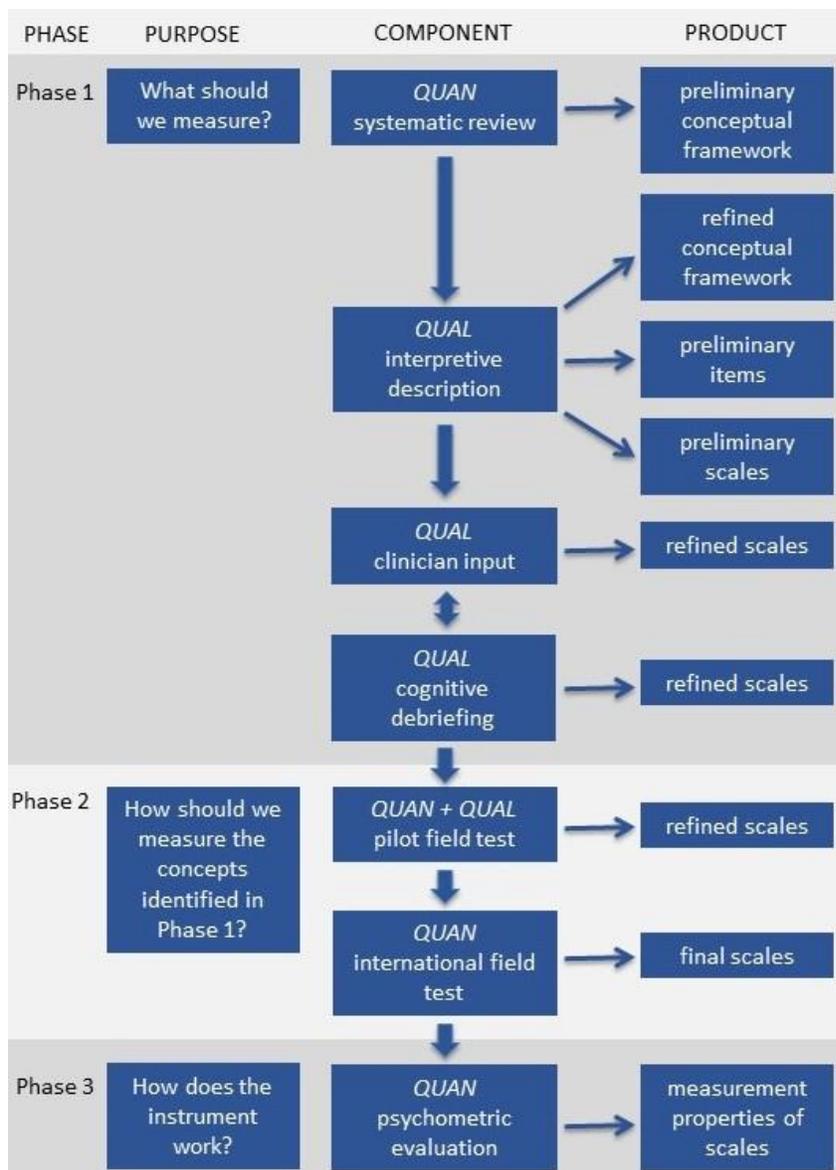


Figure 2: HAND-Q conceptual framework

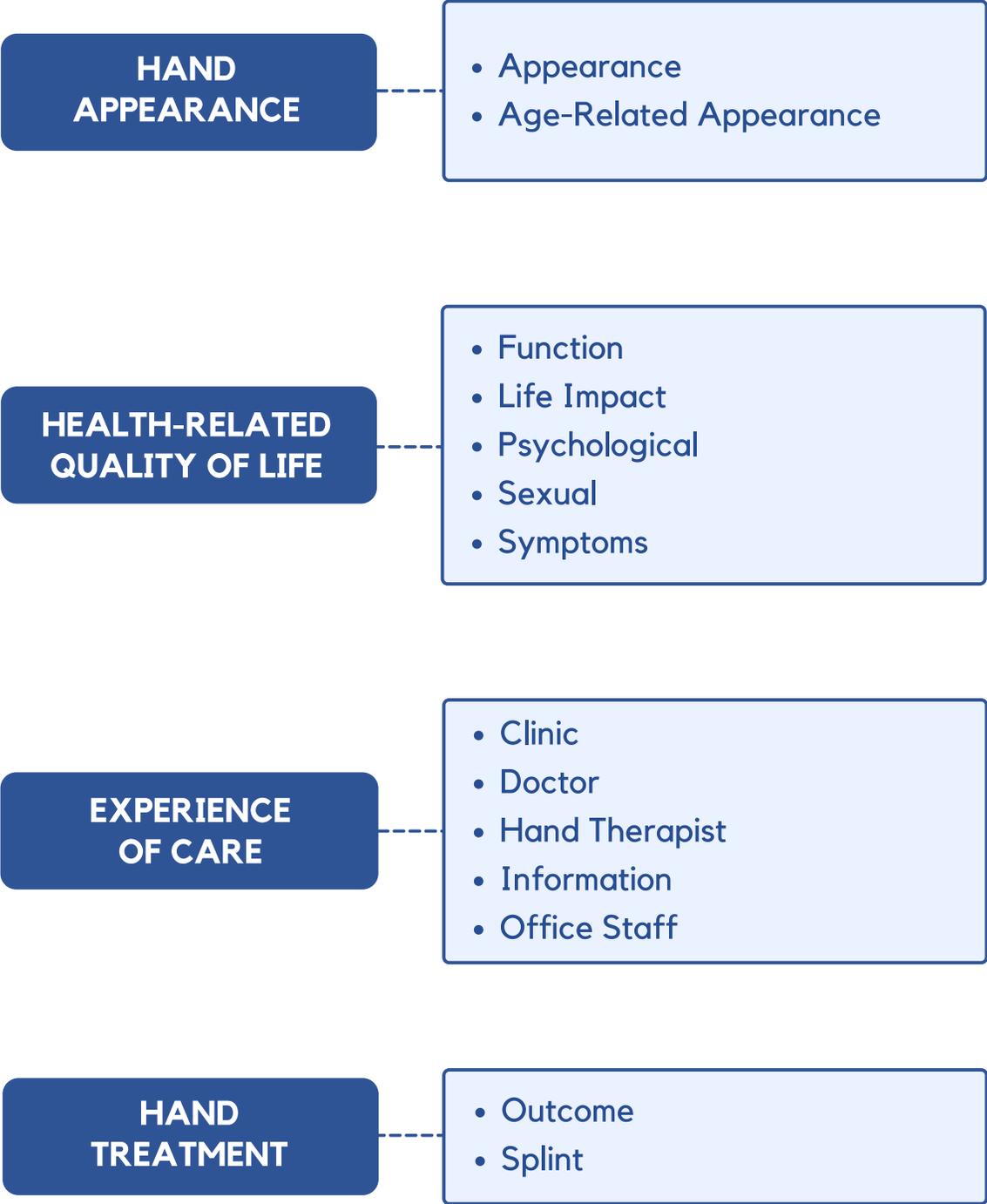


Table 1: Characteristics of 1277 HAND-Q field-test study participants

		N	%
COUNTRY	Australia	446	35
	Canada	85	7
	Finland	184	14
	France	82	6
	UK	98	8
	USA	382	30
LANGUAGE	English	1011	79
	Other	266	21
GENDER	Male	574	45
	Female	680	53
	Other	6	1
	Missing	17	1
AGE	16-39	360	28
	40-59	507	40
	60 +	392	31
	Missing	18	1
EDUCATION	Primary school	65	5
	High School	564	44
	Further education (college, university or similar)	572	45
	Other	54	4
	Missing	22	2
HAND CONDITION	Carpal tunnel syndrome	183	14
	Dupuytren's Disease	36	3
	Trigger finger	70	5
	Osteoarthritis	62	5
	Rheumatoid arthritis	13	1
	Other nerve compression	23	2
	Ganglion	18	1
	Trauma (injury, fracture)	519	38
	Multiple non-traumatic conditions	117	9
	Mixed non-traumatic and traumatic conditions	65	5
	Other	171	13
SEVERITY OF HAND CONDITION	Mild	202	16
	Moderate	521	41
	Severe	521	41
	Missing	33	3

3. HAND-Q Scales

Table 2 shows the HAND-Q scales, including number of items, response options, recall period, and Flesch-Kincaid (FK) grade reading level. Below the Table 2 is a brief description of the content of each scale.

Table 2: Description of HAND-Q scales

Name of scale	Items	Response options	Recall period	FK
Appearance				
Appearance	10	dissatisfied → satisfied	now	1.6
Appearance: Age-related	10	dissatisfied → satisfied	now	1.0
Health-Related Quality of Life				
Function	15	extremely → not difficult	past week	4.0
Life Impact	8	very much → not at all	past week	7.7
Psychological	10	always → never	past week	10.3
Sexual	7	extremely → not at all	n/a	8.2
Symptoms	10	severe → none	past week	2.3
Experience of Care				
Clinic	10	disagree → agree	n/a	5.0
Doctor	10	disagree → agree	recent	4.3
Hand Therapist	10	disagree → agree	recent	4.8
Information	10	dissatisfied → satisfied	n/a	6.4
Office Staff	8	disagree → agree	recent	4.9
Treatment				
Outcome	7	disagree → agree	recent	4.9
Splint	8	dissatisfied → satisfied	recent	4.5

APPEARANCE

Appearance: This 10-item scale measures how satisfied someone is with the appearance of their hands. Content in this scale is relevant to all hand conditions. Items ask about parts of the hand such as the knuckles and shape and size of the fingers and thumbs, as well as how straight they look. Items also cover how the hand looks when holding a glass and waving at someone.

Appearance: Age-Related: This 10-item scale measures how satisfied someone is with the appearance of their hands. Unlike the previous scale, this scale focuses on age-related concerns, such as the age the hands look, and how the skin, veins, and tendons look. Items also cover how the hands look when the palms rest on the table, how they look up close, and how they look compared with other people’s hands.

HEALTH-RELATED QUALITY OF LIFE

Function: This 15-item scale measures how difficult (extremely, moderately, a little, not at all) it is for someone to use their hands for various tasks that range in difficulty. Easier items to endorse include using the hands to eat, brush the teeth, and get dressed. Harder items to endorse include using the hands to write with a pen or pencil, turn a key in a lock, and open a jar.

Life Impact: This 8-item scale measures how much (very much, quite a bit, a little bit, not at all) someone's hand problem has interfered with their quality of life. Items ask about the impact on one's social life, emotional well-being, physical activity, and sleep at night, etc.

Psychological: This 10-item scale measures how often (always, often, sometimes, never) in the past week someone's hand condition has affected their psychological function. Items ask about feeling hopeless, depressed, anxious, fed up, frustrated, etc.

Sexual: This 7-item scale measures how bothered (extremely, moderately, a little, not at all) someone is by how much their hand problem has affected their sexual life. Items ask about symptoms (e.g., pain, numbness) and function (e.g., grip, strength) interfering with sexual activity, and the hand problem being a distraction during sexual activity.

Symptoms: This 10-item scale measures the severity (severe, moderate, mild, none) of hand symptoms. Items cover cramping, pain, tingling, numbness, swelling, and weakness in the hands.

EXPERIENCE OF CARE

Clinic: This 10-item scale measures how much someone disagrees or agrees with statements about the hand clinic a patient has attended. Answers are based on recent visits. Items ask about the clinic's atmosphere (e.g., welcoming, calm), and whether it was well organized, and had enough healthcare staff.

Doctor: This 10-item scale measures how much someone disagrees or agrees with statements about the hand surgeon or doctor a patient has seen. Answers are based on recent appointments. Items ask whether the doctor was friendly and kind, knew what they were doing, were easy to talk to, and involved the patient in decisions about their treatment.

Hand Therapist: This 10-item scale measures how much someone disagrees or agrees with statements about the hand therapists a patient has seen. Answers are based on recent appointments. Items ask whether the therapists treated the patient with respect, were knowledgeable about hand conditions, looked after the patient's hands carefully, and spent enough time with them.

Information: This 10-item scale measures how satisfied someone is with the information they were given about their hand surgery and recovery, as well as how the information

was given. Items cover how the surgery would be done, possible complications and what to do if one occurred, as well as who would be involved in their care.

Office Staff: This 8-item scale measures how much someone disagrees or agrees with statements about the office staff (e.g., secretaries, receptionists) at the location where the patient saw a surgeon about their hand problem. Answers are based on recent visits. Items include whether they acted in a professional manner, made the patient feel comfortable, were thorough, and were attentive to the patient's needs.

TREATMENT

Outcome: This 7-item scale measures how much someone disagrees or agrees with statements about the outcome of their recent hand treatment. Example statements include whether the person would recommend the treatment to others, was glad they had it, and was satisfied with the results.

Splint: This 8-item scale measures satisfaction with a hand splint or brace that was recently used to treat their hand problem. Items ask about how easy the splint was to remove, how it looked, and a person's ability to socialize, sleep, and be physical active with the splint on.

4. Administration of the HAND-Q

The HAND-Q was designed for patients to complete on their own (self-report). Each scale is independently functioning, which means that only scales relevant to the clinical situation or research question need to be completed. Patients can thus be asked to complete a subset of scales relevant to their situation. Brief instructions are provided at the start of each scale. The HAND-Q was field-tested using two modes of data collection, i.e., online data collection using Research Electronic Data Capture System (REDCap) and paper-and-pencil. You may use the paper and pencil format or create an online version for ease of administration in non-profit academic research (e.g., REDCap) and in clinical care (e.g., hospital EMR such as Epic). If you plan to have an ePRO company capture and manage HAND-Q data collection, the ePRO company may need a license. If you have had HAND-Q scales converted into an electronic format and require an e-conversion review and certificate, please email qportfolioteam@gmail.com.

5. Scoring the HAND-Q

There is no overall or total HAND-Q score. The HAND-Q is composed of independently functioning scales that are scored separately. To score a scale, the raw scores for the set of items in a scale are added together to produce a total raw score. If missing data is less than 50% of the scale's items, the within person mean for the completed items can be imputed for the missing items prior to computing a total raw score. As necessary, the imputed raw score for each item should be rounded to an integer. Then the items can

be summed to produce a total scale raw score. Once a total raw score for the scale is computed, the Conversion Table can be used to convert the raw score into a score that ranges from 0 (worst) to 100 (best). The conversion, which linearizes the scores, is based on the findings from the Rasch analysis. Higher scores for HAND-Q scales reflect a better outcome. The Conversion Tables for changing raw scores into 0 to 100 scores are available after a license agreement is signed.

6. Conditions of Use

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Use of the HAND-Q questionnaire requires completion of a licensing agreement. The use of the HAND-Q and its modules in non-profit academic research and in clinical care is free of charge. The use of the HAND-Q by ‘for-profit’ organizations (e.g., pharmaceutical companies, contract research organizations, ePRO companies) is subject to a licensing fee.

Non-profit users can access the HAND-Q using the following link:

<https://fhspeds.mcmaster.ca/pedsCapOne/surveys/?s=WTNMDPJRC7>

For questions regarding fees to be paid by ‘for-profit’ organizations, please contact:

Licensing Manager

Office of Technology Development

Memorial Sloan Kettering Cancer Center

633 3rd Ave, 4th Floor, New York, NY 10016

gotdtrm@mskcc.org

PLEASE NOTE

When you sign a HAND-Q license, you agree to the following terms:

- You will not modify, adapt, or create another derivative work from the HAND-Q
- You will not sell, sublicense, rent, loan, or transfer the HAND-Q to anyone
- You will not reproduce any HAND-Q scales in publications or other materials
- You will not translate the HAND-Q without permission from our team

For questions regarding study design and optimal use of HAND-Q scales, contact:

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7. Frequently Asked Questions

Do I have to use all the scales?

Each scale functions independently; therefore, patients can be asked to complete some or all of the HAND-Q scales. It is not necessary for a patient to complete all of the scales as there is no overall or total HAND-Q score. A researcher or clinician may therefore select a subset of scales depending on the particular purpose of the study or use.

Can I delete or add or change any items or response options of the HAND-Q?

You cannot delete or add or change the wording of any items or response options of the HAND-Q. Any modification to the content of the HAND-Q is prohibited under copyright laws. Making changes to the HAND-Q would invalidate its psychometric properties.

Can I reproduce HAND-Q scales in a publication or other public document (e.g., PhD thesis)?

According to the licensing agreement, you cannot reproduce the content of HAND-Q scales verbatim in a publication. However, it is possible to show shortened versions of items. The short forms of items that can be used in a publication are shown in Table 3 below. These short forms are from the publication that described the international HAND-Q field-test study [3].

Can I translate the HAND-Q into a new language?

Yes, with permission, you can translate the HAND-Q into different languages. Before starting a translation, check our translations list on www.qportfolio.org to see if there is

a translation in the language you need. If there is not a translation in the language you need, you will need to obtain permission from our team, sign a translation licensing agreement, and receive information on the method you need to follow. Email us at qportfolioteam@gmail.com for more information. Please note that the developers of the HAND-Q own the copyright of all translations of the HAND-Q.

Are there specific time points when patients complete the scales?

A researcher or clinician can decide the time points they would like to administer the scales.

Does it cost money to use the HAND-Q?

Use of HAND-Q scales is free for non-profit users, including the use by hospitals in patient care. For-profit users should contact Memorial Sloan Kettering Cancer Center for information about fees (gotdtrm@mskcc.org).

Table 3: Shortened items for HAND-Q scales to use in a publication

APPEARANCE	Open jar	Stiff	INFORMATION
Gender	LIFE IMPACT	Pain at use	Who is involved
Size fingers	Close relationships	Weak	Easy to understand
Wave	Social life	CLINIC	How surgery done
Proportion	Relax	Privacy	Easy to ask
Shape fingers	Emotional wellbeing	Sterile	Questions answered
Line up	Independence	Knowledgeable staff	Time to discuss
Knuckles	Sleep	Recommend	Complications
Normal	Physical activity	Front desk	Achieve goals
Hold glass	Activities you enjoy	Easy to book	Expectations
Straight	PSYCHOLOGICAL	Atmosphere	Consistent
APPEARANCE: AGE	Hopeless	Organized	OFFICE STAFF
Veins	Overwhelmed	Consistent staff	Professional
Tendons	Depressed	Enough staff	Comfortable
Wave	Sorry for yourself	DOCTOR/SURGEON	Friendly
Skin	Anxious	Friendly	Answered questions
Rest palms	Useless	Knowledgeable	Thorough
Hold glass	Upset	What to do	Teamwork
Age	Fed up	Right experience	Attentive
Compared	Worried	Easy to talk to	Knowledgeable
Youthful	Frustrated	Answered questions	OUTCOME
Close up	SEXUAL	High level care	Glad had it
FUNCTION	Enjoyment affected	Inspired hope	Recommend
Eat with hands	Symptoms interfere	Attentive	Have it again
Brush teeth	Hands distraction	Involved in decisions	Satisfied
Wash hands	Aware of hands	HAND THERAPIST	Changed life
Grooming	Giving pleasure	Respect	Met expectations
Get dressed	Tender ways	Easy to understand	Turned out great
Hold glass	Hand function	High level care	SPLINT/BRACE
Hold phone	SYMPTOMS	Knowledgeable	Remove
Clean after toilet	Cramping	Careful	Looked
Use cutlery	Pain at rest	Caring	Socialize
Turn tap	Tingling	Answered questions	Enjoy life
Write	Numb	Understood concerns	Comfortable
Turn key	Clumsiness	Spent time	Sleep
Grip handle	Swelling	Inspired hope	Active
Prepare food	Sleep disturbance		Get dressed

8. Acknowledgements

Development of the HAND-Q has involved hundreds of people with hand conditions and the collaboration of numerous healthcare professionals and researchers around the world. We are truly grateful for their dedication and help with our research. The HAND-Q study has been generously funded by the following grants:

1. Australasian Foundation for Plastic Surgery - Foundation Plastic Surgery and Reconstructive Surgical (PRS) Research Grant
2. Royal Australasian College Surgeons Small Project Grant

9. Publications Related to HAND-Q Development and Validation

1. Sierakowski KL, Dean NR, Pusic AL, Bain G, Cano S, Griffin PA, Klassen AF. International multiphase mixed methods study to develop a cross-cultural patient-reported outcome and experience measure for hand conditions (HAND-Q). *BMJ Open*. 2019 Mar 20;9(3):e025822. doi: 10.1136/bmjopen-2018-025822.
2. Sierakowski KL, Kaur MN, Evans Sanchez K, Bain GI, Cano S, Griffin PA, Klassen AF, Pusic AL, Lalonde D, Dean NR. Phase 1 development of a patient-reported outcome measure for hand conditions: The HAND-Q. *J Hand Surg*. (submitted)
3. Sierakowski KL, Dean NR, Evans Sanchez K, Griffin PA, Wormald JCR, Rodrigues JN, Mares O, Repo JP, Hulkkonen SM, Shah NV, Koehler S, Bain GI, Cano S, Pusic AL, Lalonde D, Klassen AF. The HAND-Q: Psychometrics of a new patient-reported outcome measure for clinical and research applications. *Plast Reconstr Surg Glob Open*. 2022 Jan 31;10(1):e3998. doi: 10.1097/GOX.0000000000003998.