

SCAR-Q[©]

A Guide for Researchers and Clinicians

USER'S GUIDE

VERSION 1.0

JULY 2018

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1. What is the SCAR-Q©?

The SCAR-Q© is a rigorously developed patient-reported outcome (PRO) instrument that can be used to collect and compare evidence-based outcomes data from children and adults aged 8 years and older with a surgical, traumatic or burns scar.

2. How was the SCAR-Q© Developed?

Figure 1 shows the multiphase mixed methods approach used by our team to develop PRO instruments. To identify concepts of interest to patients with scars, our team performed a secondary analysis of qualitative datasets used by our team to design the following PRO instruments: BREAST-Q, with modules for different types of breast surgery, FACE-Q, with modules for aesthetic treatments, head and neck cancer, skin cancer, and children and young adults with craniofacial conditions (i.e., ear anomalies, facial paralysis, skeletal conditions and soft tissue conditions), BODY-Q for weight loss and body contouring and CLEFT-Q for cleft lip and/or palate.

Within each qualitative dataset, the key word “scar*” was used as a search term to identify and extract all quotations where a scar was mentioned. A total of 52 children and 192 adults from the qualitative datasets provided between 1 and 34 scar-specific codes (n=1227). The analysis led to the identification of 3 key domains for which scales were developed: scar appearance, scar symptoms and psychosocial impact (e.g., feeling self-conscious or bothered by scar). Codes were used to create a comprehensive item pool for use in scale development. The aim was to develop independently functioning scales using a modern psychometric approach called Rasch Measurement Theory whereby scales are designed to work like “rulers” with the items mapping out a clinical hierarchy. In creating the wording for items in scales, we retained the words of patients as much as possible and used the lowest possible grade reading level to maximize comprehension by children as young as 8 years of age. The scales were then refined through cognitive interviews with 25 adults and 20 children with scars. We also obtained feedback from 27 experts from 8 countries, including the entire pediatric burns team at the Hospital for Sick Children (Toronto). The SCAR-Q© was field-tested in 4 countries. Participants (n=731) were aged 8 to 88 years with 354 surgical, 184 burn, and 199 traumatic scars.

3. SCAR-Q© scales

Table 1: SCAR-Q© scales, including the number of items and grade reading level. Below the table is a brief description of each scale.

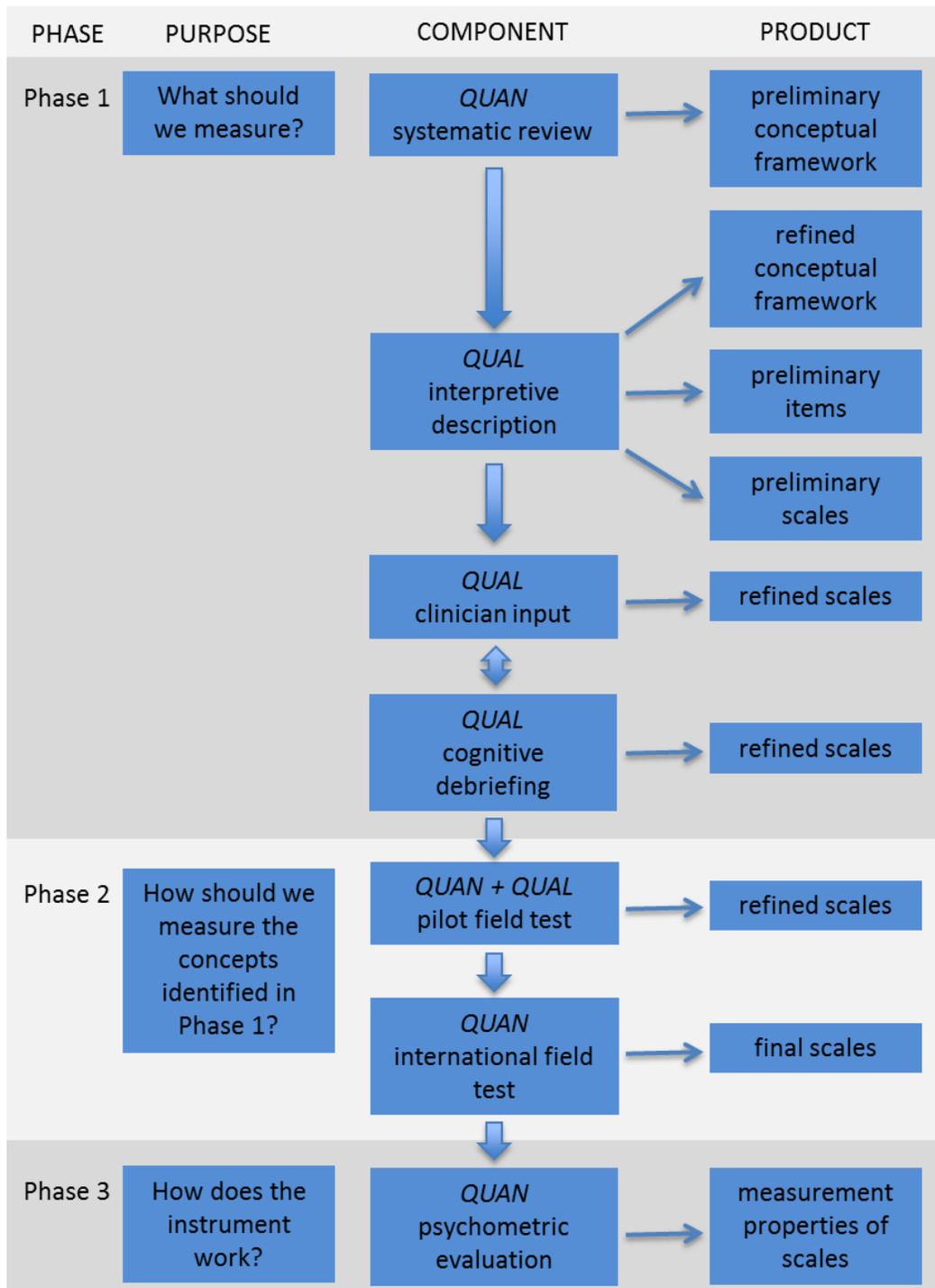
Name of scale	Items	Flesch-Kincaid grade level
Scar appearance	12	0-5.8
Scar symptoms	12	0-4.9
Psychosocial impact	5	0-4.4

Appearance of scars: This scale measures appearance of scars in terms of their length, width, color (including how closely it matches skin colour), shape, size, etc.

Adverse symptoms: This scale measures how scars feel with items such as how sore, painful, tight, itchy or tingly scars feel, etc.

Psychosocial impact: This scale measures psychosocial distress caused by scars, with statements that ask about covering or hiding scars and feeling self-conscious, embarrassed or upset about scars.

Figure 1: The multiphase mixed methods approach our team follows to develop patient-reported outcome instruments (Reprinted from Riff KW, Tsangaris E, Goodacre T, et al. International multiphase mixed methods study protocol to develop a cross-cultural patient-reported outcome instrument for children and young adults with cleft lip and/or palate (CLEFT-Q). *BMJ Open*. 2017;7(1):015467.)



4. Administration of the SCAR-Q©

The SCAR-Q© is designed to be completed by patients aged 8 years and older. Each scale is independently functioning, which means that only relevant scales need be completed. Brief instructions are provided at the start of each scale. You may use the paper and pencil format or create your own online version of the SCAR-Q© for ease of administration.

5. Response Options for the SCAR-Q© scales

Each SCAR-Q© scale provides 4 response options that measure frequency. All scales use the following response options: 1 (Not at all), 2 (A little), 3 (Quite a bit), 4 (Very much).

6. Scoring the SCAR-Q©

There is no overall or total SCAR-Q© score, only scores for each independent scale. Each SCAR-Q© scale is transformed into scores that range from 0-100. The scores are computed from the responses to the items by adding them together and converting the raw score to a scale from 0 to 100. Higher scores reflect a better outcome. If missing data is less than 50% of the scale's items, insert the mean of the completed items. Use the Conversion Tables available from the authors to convert the raw summed scale score into a score from 0 (worst) to 100 (best).

7. Conditions of Use of the SCAR-Q©

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Use of the SCAR-Q© questionnaire requires the completion of a user's agreement. The use of the SCAR-Q© scales in non-profit academic research and in clinical care is free of charge. The use of the SCAR-Q© by 'for-profit' organizations is subject to a license fee.

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

<https://research.mcmaster.ca/industry-and-investors/technologies-available-for-licensing/questionnaire-request-form/>

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

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8. Frequently Asked Questions

Do I need to sign a license to use the SCAR-Q©?

Yes, you must sign a licensing agreement for any use of the questionnaires, whether it is commercial or academic. The questionnaires are protected by copyright and are the exclusive property of Memorial Sloan Kettering Cancer Center.

Do I have to use all of the scales?

Patients can be asked to complete some or all of the SCAR-Q© scales. It is not necessary for a patient to complete all of the scales as there is no overall or total SCAR-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, add or change any items or response options of the SCAR-Q©?

You cannot delete, add or change the wording of any items or response options of the SCAR-Q©. Any modification to the content of the SCAR-Q© is not acceptable. There are three main reasons why deleting or adding items is not allowed. The first is that deleting or adding items would nullify the psychometric properties of SCAR-Q© scales. The second reason is that by deleting or adding items, it would then not be possible to score the SCAR-Q© and you would not be able to compare findings with those of other SCAR-Q© studies. Finally, adding or deleting items is prohibited under copyright laws.

Can I translate the SCAR-Q© into a new language?

Yes, you can translate the SCAR-Q© into different languages. Check with the licensing assistant at McMaster (milo@mcmaster.ca) 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 sign a licensing agreement. Please note that the developers of the SCAR-Q© own the copyright of all translation of the SCAR-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 SCAR-Q©?

Use of SCAR-Q© scales is free for non-profit users. For-profit users should contact McMaster University to sign a license (milo@mcmaster.ca).

9. SCAR-Q© Publications

1. Ziolkowski N, Pusic AL, Fish J, Mundy LR, Forrest CR, Binhammer P, Hollebeck S, Arriagada C, Greenhalgh D, Klassen AF. Psychometric Findings for the SCAR-Q Patient-Reported Outcome Measure Based on 731 Children and Adults with Surgical, Traumatic and Burn Scars from 4 Countries. Submitted for publication.
2. Klassen AF, Ziolkowski N, Mundy LR, Miller C, DiLaura A, Pusic A. Development of a New Patient-Reported Outcome Instrument to Evaluate Treatments for Scars: The SCAR-Q. *Plast Reconstr Surg Global Open*. 2018;6:e1672.
3. Ziolkowski N, Klassen A, Mundy L, Fish J, Pusic A. SCAR-Q Kids: Developing a patient-reported outcome instrument for the pediatric burn, traumatic, and surgical scar populations. *Canadian Society of Plastic Surgery*. Winnipeg, 23 June 2017. Oral Presentation.
4. Ziolkowski N, Fish J, Mundy L, Pusic A, Klassen A. SCAR-Q: Developing a patient-reported outcome instrument for a pediatric and adult burn, surgical and traumatic scar population. *American Burn Association 49th Annual Meeting*, March 21-24, 2017 Boston USA. Poster Presentation.
5. Ziolkowski N, Fish J, Mundy L, Pusic A, Wong K, Klassen A. Developing a patient-reported outcome instrument for adult and pediatric patients with scars: Scar-Q. *American Society Plastic Surgery*. Los Angeles, California. 24 Sept, 2016. Oral presentation.
6. Ziolkowski N, Fish F, Pusic A, Wong K, Klassen A. Developing a patient-reported outcome instrument for adult and pediatric patients with scars: SCAR-Q. *Canadian Plastic Surgery Meeting. Resident Poster Corner*. *Plast Surg* 2016;24(2):150-151. Poster Presentation.