SCAR-Q©

A User's Guide for Researchers and Clinicians

Printing History: July 2018
                              November 2022

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1. What is the SCAR-Q?

In clinical trials of treatments for scars, symptoms, and psychosocial distress are recognized as important outcomes. However, scar appearance is an aspect important to patients that is often unaddressed. Measuring appearance as a concept separate from symptoms and psychosocial distress has been largely overlooked in existing scar-specific patient-reported outcome measures (PROMs). Therefore, the SCAR-Q represents the first rigorously developed comprehensive PROM designed for children and adults to report how their scar looks. The SCAR-Q also has scales that measure symptoms and psychosocial impact. The SCAR-Q can be used with children and adults aged 8 years and older with any kind of surgical, traumatic, or burns scar.

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

The SCAR-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, SCAR-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 SCAR-Q meets requirements of regulatory bodies.

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 PROMs: BREAST-Q®, with modules for different types of breast surgery, FACE-Q®, with modules for aesthetic treatments, head and neck cancer, skin cancer, and 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. Pediatric patients were well represented by inclusion of qualitative data from the CLEFT-Q and the FACE-Q Craniofacial module, which included interviews with children and young adults aged 8 to 29 years.

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) [1].

Codes were used to create a comprehensive item pool for use in scale development. 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 represented [2-3]. Table 1 shows the field-test sample characteristics. In the RMT, the 3 SCAR-Q scales evidenced strong psychometric properties. Reliability was high for the Appearance, Symptoms, and Psychosocial Impact scales, with Person Separation Index values of 0.91, 0.81, and 0.79; Cronbach's alpha values of 0.96, 0.91, and 0.95; and intraclass correlation coefficient values of 0.92, 0.94, and 0.88, respectively.

The SCAR-Q represents a rigorously developed, internationally applicable PROM that can be used to evaluate scars in research, clinical care, and quality improvement initiatives.

Figure 1: The multiphase mixed methods approach for developing the CLEFT-Q (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.)
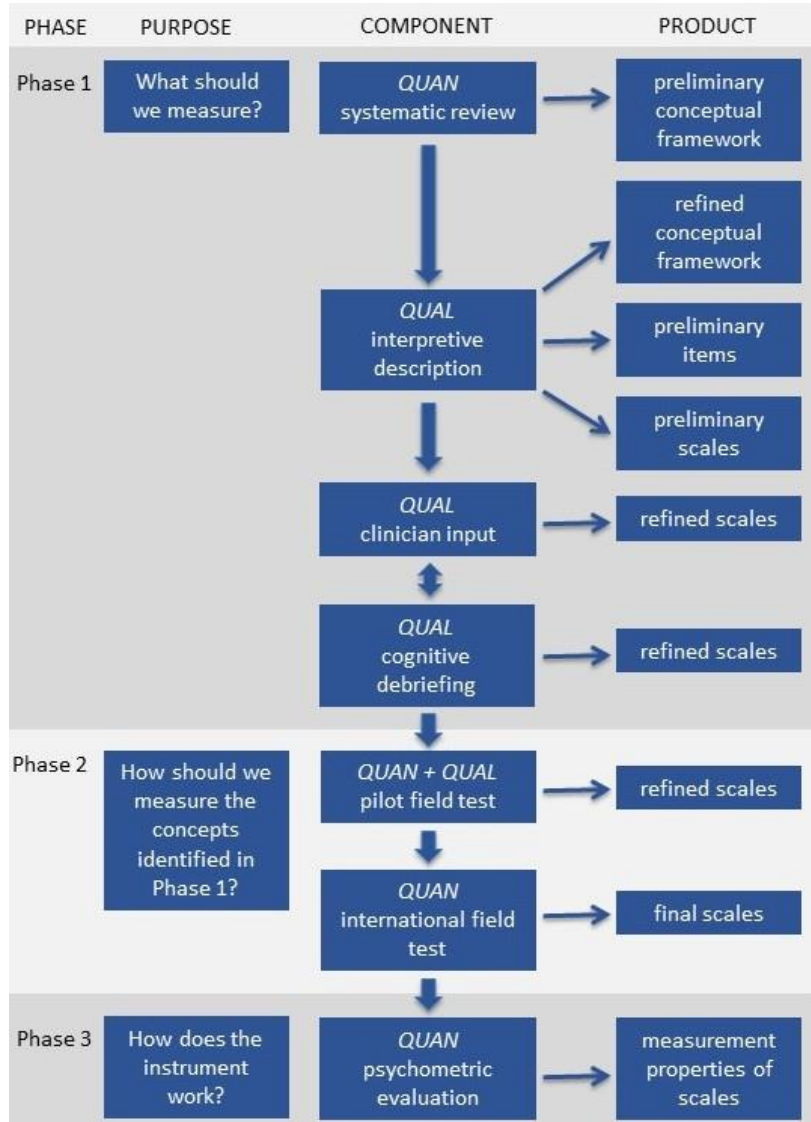
Table 1: Characteristics (Number, %) of field-test participants

		N	%
Country, N=731	Canada	293	40.1
	Chile	45	6.2
	New Zealand	270	36.9
	United States	123	16.8
Age in years, N=722	8-21	218	29.8
	22-49	278	38.0
	50-88	226	30.9
Gender, N=726	Female	371	50.8
	Male	350	47.9
	Other	5	0.6
Fitzpatrick skin type, N=654	I	12	1.6
	II	138	18.9
	III	318	43.5
	IV	153	20.9
	V or VI	33	4.5
Scar cause, N=727	Burn	184	25.2
	Surgical	354	48.4
	Traumatic	199	25.9
Scar location, N=722	Facial	191	26.5
	Other	531	73.5
Scar age, N=682	<3 months	123	16.8
	3-12 months	159	21.8
	1-5 years	140	19.2
	>5 years	260	35.6

3. SCAR-Q Scales

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

Table 2: Description of SCAR-Q scales

Name of scale	Items	Response options	Recall	Flesch-Kincaid
Appearance	12	bothered very much → not at all	now	0-5.8
Symptoms	12	feel very much → not at all	past week	0-4.9
Psychosocial impact	5	always → never	past week	0-4.4

Appearance of scars: This 12-item scale measures how bothered (not at all, a little, quite a bit, very much) someone is by the appearance of their scar(s). If the person has more than one scar, they are asked to answer thinking of the scar that bothers them the most. Items ask about the length, width, color, shape, and size of the scar, as well as how it looks up close and from different angles.

Symptoms: This 12-item scale measures how bothered (not at all, a little, quite a bit, very much) someone is by how their scar has felt in the past week. As with appearance, if the person has more than one scar, they are asked to answer thinking of the scar that bothers them the most. Items ask if the scar is painful, numb, itchy, hard or firm, tight, and sensitive when touched, as well as whether the scar makes it hard to move parts of the face or body or do some activities.

Psychosocial impact: This 5-item scale measures how someone feels about their scar in terms of frequency (never, sometimes, often, always) and in the past week. Items ask about feeling upset, embarrassed, or unhappy about the scar, as well as how they feel when someone sees their scar.

4. Administration of the SCAR-Q

The SCAR-Q is designed to be completed by patients aged 8 years and older 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 SCAR-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 SCAR-Q data collection, the ePRO company may need a license. If you have had SCAR-Q scales converted into an electronic format and require an e-conversion review and certificate, please email [qportfolioteam@gmail.com.](mailto:qportfolioteam@gmail.com)

5. Scoring the SCAR-Q

There is no overall or total SCAR-Q score. Instead, the SCAR-Q is composed of 3 independently functioning scales that are each scored separately.

Scores for SCAR-Q scales range from 0 to 100, with higher scores representing a better outcome. To ensure that higher scores represent a better outcome, the raw data for the appearance and symptom scales need to be scored as follows: "Not at all" = 4; "A little" = 3; "Quite a bit" = 2; "Very much" = 1. Similarly, the raw data for the psychosocial impact scale needs to be scored as follows: "Never" = 4; "Sometimes" = 3; "Often" = 2; "Always" = 1. Once you have ensured that the data are scored this way, to obtain a score for a scale, add together the raw scores for the set of items 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. For example, if there is a 10-item scale and someone has not responded to all the items, but has responded to ≥5 items, all other items for that person can be imputed with a within-person mean (rounded to the nearest integer), and a summed score can be calculated. Alternatively, for a 10-item scale, if someone has responded to ≤4 items, the summed score for this person cannot be computed and is classified as missing data. Importantly, the Conversion Tables are only valid with complete data (i.e., when a person has ≥50% completed responses). 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. 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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Q by "for-profit" organizations (e.g., pharmaceutical companies, contract research organizations, ePRO companies) is subject to a licensing fee.

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https://research.mcmaster.ca/industry-investors/technologies-available-for-licensing/request-for-license/

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- **You will not sell, sublicense, rent, loan, or transfer the SCAR-Q to anyone**
- **You will not reproduce any SCAR-Q scales in publications or other materials**
- **You will not translate the SCAR-Q without permission from our team**

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

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7. Frequently Asked Questions

Do I have to use all of the SCAR-Q scales?

Each scale functions independently, therefore patients can be asked to complete one or all SCAR-Q scales. It is not necessary for a patient to complete all 3 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 or add or change any items or response options of the SCAR-Q?

You cannot delete or 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 prohibited under copyright laws. Making changes to the SCAR-Q would invalidate its psychometric properties.

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

According to the licensing agreement, you cannot reproduce the content of SCAR-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 SCAR-Q field-test study [2].

Can I translate SCAR-Q scales into a new language?

Yes, with permission, you can translate the SCAR-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 methods you need to follow. Email us at qportfolioteam@gmail.com for more information. Please note that the developers of the SCAR-Q own the copyright of all translations 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 for information about fees (milo@mcmaster.ca).

8. Publications Related to SCAR-Q Development and Validation

1. 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 Glob Open. 2018 Apr 24;6(4):e1672. doi: 10.1097/GOX.0000000000001672.

2. 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. Plast Reconstr Surg. 2020 Sep;146(3):331e-338e. doi: 10.1097/PRS.0000000000007078.

3. Ziolkowski N, Behman R, Klassen AF, Fish JS, Mundy LR, She RW, Forrest CR, Hollenbeck S, Arriagada C, Greenhalgh D, Pusic AL. Determining the independent risk factors for worse SCAR-Q scores and future scar revision surgery. Plast Reconstr Surg. 2021 Jul 1; 148(1):203-212. doi: 10.1097/PRS.0000000000008095.

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

APPEARANCE	SYMPTOMS	PSYCHOSOCIAL IMPACT
far away	dry	people see
width	hard to move	embarrassed
different angles	painful	upset
thick	puffy	dislike
length	tingly	unhappy
bumpy	numb	
color	pulling	
different from skin	do activities	
contour	itchy	
overall size	sensitive	
up close	hard or firm	
noticeable	tight	