# **GENDER-Q©**

### A User's Guide for Researchers and Clinicians

Information in this document is subject to change without notice. Complying with all applicable copyright laws is the responsibility of the user. No part of this document may be reproduced or transmitted on any form or by any means, electronic or mechanical, for any purpose, without the express written permission of McMaster University. Copyright©2025 McMaster University, and Brigham and Women's Hospital. All Rights Reserved.

Printing History: July 2025

While every precaution has been taken in the preparation of this User's Guide, the publisher assumes no responsibility for errors or omissions, or for damages resulting from the use of information contained herein.

Licensing: The GENDER-Q patient-reported outcome measure was authored by Drs. Anne Klassen, Andrea Pusic and Manraj Kaur. The copyright of this work is owned by McMaster University (Hamilton, Canada), and Brigham and Women's Hospital (Boston, USA). Users must sign a Licensing Agreement. The GENDER-Q can be used free of charge for non-profit purposes (e.g., clinicians, researchers, and students). For-profit users (e.g., pharmaceutical companies and organizations carrying out studies sponsored by for-profits) are required to pay a licensing fee. For more information, contact the McMaster Industry Liaison Office at McMaster University, email: <a href="mailto:milo@mcmaster.ca">milo@mcmaster.ca</a>

### **Table of Contents**

1. What is the GENDER-Q?	2
2. How was the GENDER-Q Developed and Validated?	2
3. GENDER-Q Scales	7
4. Administration of the GENDER-Q	17
5. Scoring the GENDER-Q	17
6. How to Deal with Missing Data	18
7. Conditions of Use	20
8. Frequently Asked Questions	21
9. Acknowledgements	22
10. Publications Related to GENDER-Q Development and Validation	25

### 1. What is the GENDER-Q?

The GENDER-Q is a rigorously developed patient-reported outcome measure (PROM) for adults aged 18 years of age and older. The GENDER-Q can be used in research and clinical care to precisely measure how people function and feel from the patient perspective [1-4]. The GENDER-Q can be used to evaluate outcomes for gender-affirming treatments that aim to change the appearance of the face, body, hair, chest/breasts, and genitals. The GENDER-Q can also be used to measure patients' experience of gender-affirming care (e.g., healthcare professionals, clinic, information about surgery) and gender practices (i.e., binding and tucking). The GENDER-Q is comprised of 54 independently functioning scales and 2 checklists covering 13 domains [4]. Due to the modular approach taken to develop the GENDER-Q, only the subset of scales most relevant to a specific research objective or clinical population needs to be administered.

### 2. How was the GENDER-Q Developed and Validated?

The GENDER-Q represents a new generation of PROMs developed using a modern psychometric approach called Rasch Measurement Theory (RMT) [5]. In this approach, scales that compose a PROM are designed to measure and score a unidimensional construct. In scale development, data that meet the requirements 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, GENDER-Q scales can be used with individual patients to inform clinical care.

We followed internationally recommended guidelines for PROM development to create the GENDER-Q. A detailed description of the protocol has been published [1]. The qualitative step involved two parts. In part 1, cognitive debriefing interviews with 21 people who identified as transgender and gender diverse (TGD) from Canada and the United States (US) reviewed existing BREAST-Q, FACE-Q and BODY-Q scales that we hypothesized would have content relevant to gender-affirming care. In part 2, concept elicitation interviews were conducted with 84 TGD individuals seeking or receiving gender-affirming care from Canada, the US, Denmark, and the Netherlands [2, 3]. The findings from both parts were used to develop a conceptual framework comprised of the following 13 domains: health-related quality of life, sexual, urination, gender practices, voice, hair, face & neck, body, breasts, genital feminization, chest, genital masculinization, and experience of care. A GENDER-Q scale was developed for each aspect of the conceptual framework. Cognitive debriefing interviews with 14 TGD individuals from Canada and the US, along with feedback from 50 international gender-affirming care experts provided input used to refine the scales and to demonstrate their content validity [2]. Table 1 shows the sample characteristics for the qualitative step. The experts were from the US (n = 28), Denmark (n = 6), Canada (n = 5), The Netherlands (n = 4), Belgium (n = 6)

= 3), Spain (n = 3), and Switzerland (n = 1). Experts' specialties included plastic surgery (n = 30), psychology (n = 4), urology (n = 3), endocrinology (n = 3), speech therapy (n = 3), research (n = 3), gynecology (n = 2), and other (n = 2). Depending on the scale, feedback was obtained from 4 to 37 experts and 7 to 14 patient participants. The scales were pilot tested in an online crowdsourcing research platform (i.e., Prolific). In 2 rounds of pilot testing, 601 people from 30 countries completed the GENDER-Q. An exploratory RMT analysis was performed, and the field test version was finalized [2].

In preparation for the international field test study, the GENDER-Q was translated and culturally adapted into Dutch, Danish [6], and Canadian French following the Professional Society for Health Economics and Outcomes Research (formerly ISPOR) international guidelines [7]. The field test study recruited a cross-sectional sample of TGD individuals aged 18 years and older who were either seeking or had received gender-affirming care within the last 5 years [4]. Recruitment took place at 21 clinical sites in Canada, the US, the Netherlands, and Spain. Additionally, data were collected using community-based methods that included outreach to TRANSPULSE Canada project participants and through closed TGD-specific social media groups (primarily in the UK, Spain, Denmark, and Australia), Trans Pride Australia, Copenhagen Pride, and the qportfolio.org website. A total of 5,497 patients participated in the international field test with most participants residing in the US, Canada, the Netherlands, Australia, Denmark, and the United Kingdom [4]. Table 1 shows the sample characteristics. Please see Kaur et al [4] for more detailed demographic and clinical information. The final GENDER-Q conceptual framework with the set of scales is shown in Figure 1.

Table 1. Characteristics of participants in the qualitative and quantitative steps, n (%)

		(	Quantitative		
		Cognitive debriefing of existing scales (N=21)	Concept elicitation (N=84)	Cognitive debriefing (N=14)	Field test sample (N=5,497)
Country	Canada	5	20	1	1751 (32)
-	Denmark	0	12	0	2440 (44)
	The Netherlands	0	21	0	136 (2)
	United States	16	31	13	172 (3)
	United Kingdom				314 (6)
	Australia				275 (5)
	Other <sup>+</sup>				402 (7)
	Not answered				7 (1)
Gender	Trans masculine/Man	3	42	7	1837 (33)
Identity	Trans feminine/Woman	18	37	7	2036 (37)
	Nonbinary/Gender queer/ Gender non-conforming	0	5	0	1307 (24)
	Indigenous or other cultural gender minority				49 (1)
	Another gender				268 (5)
Age (years)	16-17	0	5	0	
	18-24	1	19	0	1565 (28)
	25-29	3	13	0	1230 (22)
	30-39	9	20	8	1465 (27)
	40-49	5	11	2	597 (11)
	50 years or older	3	16	4	640 (12)
Race	White	16	53	12	4236 (77)
	Other	4	9	2	1163 (21)
	Not answered	1	22	0	98 (2)
Marital	Single, never married	5	35	3	3209 (58)
status	Married / Living common law	5	20	7	1403 (26)
	Divorced/Separated/Not in relationship	3	10	1	605 (11)
	Currently in relationship	8	19	3	
	Widowed				32 (1)
	Other				187 (3)
	Not answered				48 (1)
Education	Some high school/Completed high school	2	32	0	907 (16)
	Some college, trade, or university	4	8	3	1469 (27)

	Completed college, trade, or university	12	36	8	2014 (37)
	Some Masters or Doctoral degree				315 (6)
	Completed Masters/Doctoral degree	3	8	3	742 (13)
	Not answered				50 (1)
Goal of gender-	To look, function, or feel more masculine	3	47	7	2673 (49)
affirming care	To look, function, or feel more Feminine	18	37	7	2271 (41)
	To look, function, or feel more Gender Fluid				481 (9)
	None of the above/missing				72 (1)
Surgery/or	Body contouring	1	1	1	261 (5)
Procedures	Scalp advancement	0		1	139 (3)
participants	Facial surgery/procedure	3	6	1	2026 (37)
had*	Nose			1	415 (8)
	Lips			1	271 (5)
	Cheeks			1	172 (4)
	Chin			1	364 (7)
	Jawline			1	325 (6)
	Adam's Apple	1	3	0	331 (16) <sup>a</sup>
	Chest augmentation	8	10	2	574 (25) b
	Vaginoplasty	16	22	6	1334 (59) <sup>c</sup>
	Chest contouring	3	31	7	2295 (76) <sup>d</sup>
	Phalloplasty	0	10	5	293 (70) <sup>e</sup>
	Erectile device	0	3	1	84 (29) <sup>f</sup>
	Metoidioplasty	0	6	1	108 (25) <sup>e</sup>
	Scrotoplasty	0	5	2	341 (11)
	Testicular implants	0	3	0	163 (50) <sup>g</sup>
	Glansplasty	0	5	2	242 (8)
	Perineum				201 (7)
Voice	Surgery and/or therapy	6	15	3	1297 (24)
Hormones	Currently taking	21	73	14	4484 (83)

Note: Table 1 is adapted from Kaur MN, Morrison SD, Kennedy SL et al. International study to develop a patient-reported outcome measure to evaluate outcomes of gender-affirming care – the GENDER-Q. JPRO 2024; 8:143, and Kaur MN, Rae C, Morrison SD et al. Development and assessment of a patient-reported outcome instrument for gender-affirming care. JAMA Network Open 2025; 8(4): e254708.

<sup>+</sup> Includes participants recruited through the Prolific platform and social media (e.g., Poland n=46, Germany n=39, Mexico n=35, South Africa n=27, Portugal n=27, France n=26, Spain n=24, Italy n=23, Sweden n=18, Austria n=16, Norway n=13)

<sup>\*</sup>Denominator for procedures vary based on applicability of surgery by sex assigned at birth and missing data

<sup>&</sup>lt;sup>a</sup> only participants seeking feminization procedures – tracheal shave

<sup>&</sup>lt;sup>b</sup> only participants seeking feminization procedures – top surgery

 $<sup>^{\</sup>rm c}$  only participants seeking feminization procedures – bottom surgery

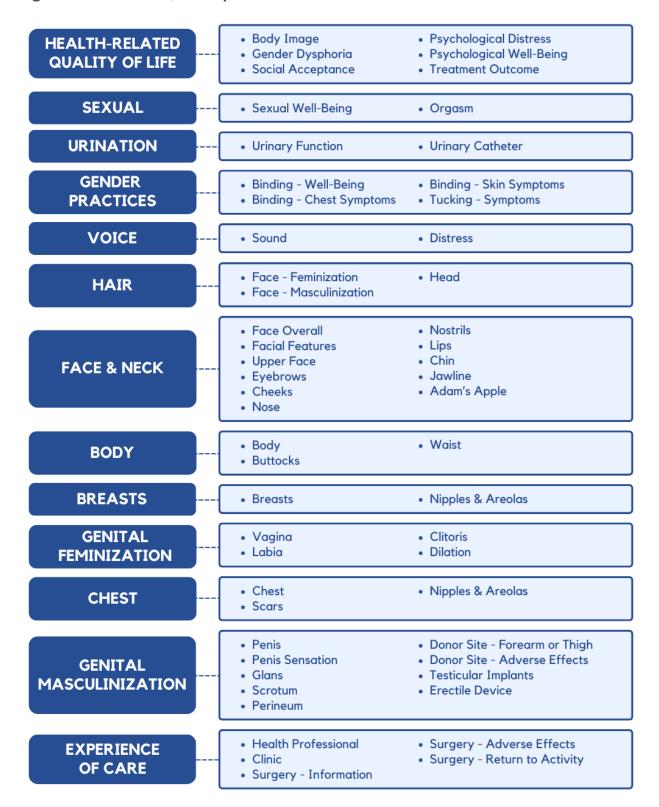
<sup>&</sup>lt;sup>d</sup> only participants seeking masculinization procedures – top surgery

<sup>&</sup>lt;sup>e</sup> only participants seeking masculinizing procedures – bottom surgery

<sup>&</sup>lt;sup>f</sup> subset of participants who had phalloplasty

g subset of participants who had scrotoplasty

Figure 1: GENDER-Q conceptual framework



### 3. GENDER-Q Scales

Table 2 shows the GENDER-Q scales, including the number of items, the context of use (i.e., the population included in the RMT analysis), response options, and recall period. Below the table is a brief description of the content of each scale.

**Table 2. Description of GENDER-Q Scales** 

Scale	# items	Context of use	Response options	Recall period		
Health-related Quality of Life						
Body Image	8	Any	Frequency	Past Week		
Gender Dysphoria	14	Any	Frequency	Past Week		
Social Acceptance	9	Any	Frequency	Past Week		
Psychological Distress	10	Any	Frequency	Past Week		
Psychological Well-being	10	Any	Frequency	Past Week		
Treatment Outcome	10	Any GAS	Agreement	Most Recent		
Sexual						
Sexual Well-being	12	Any	Frequency	None		
Orgasm	8	Any	Frequency	Last few times		
Urination						
Urinary Function*	15	Genital Surgery	Frequency	Past Week		
Urinary Catheter	10	Genital Surgery	Time	Post-op		
Gender Practices						
Binding – Well-being	8	Currently Binding	Frequency	Past Week		
Binding – Chest Symptoms	10	Currently Binding	Frequency	Past Week		
Binding – Skin Symptoms	5	Currently Binding	Frequency	Past Week		
Tucking – Symptoms	10	Currently Tucking	Frequency	Past Week		
Voice						
Voice Sound	15	Any	Satisfaction	Past Week		
Voice Distress	10	Any	Frequency	Past Week		
Hair						
Face Hair – Feminization	7	Feminization	Satisfaction	Past Week		
Face Hair – Masculinization	12	Masculinization	Satisfaction	Past Week		
Hair – Head	12	Any	Satisfaction	Now		
Face & Neck						
Face Overall	15	Any	Satisfaction	Now		
Facial Features	9	Any	Satisfaction	Now		
Upper Face	9	Any	Satisfaction	Now		
Eyebrows	5	Any	Satisfaction	Now		
Cheeks	9	Any	Satisfaction	Now		
Nose	10	Any	Satisfaction	Now		
Nostrils	7	Any	Satisfaction	Now		
Lips	12	Any	Satisfaction	Now		

Chin	10	Any	Satisfaction	Now
Jawline	10	Any	Satisfaction	Now
Adam's Apple	10	Feminization	Bother	Now
Body	0		200	
Body	10	Any	Satisfaction	Now
Buttocks	10	Any	Satisfaction	Now
Waist	7	Any	Satisfaction	Now
Breasts		,		
Breasts	12	Feminization	Satisfaction	Now
Breasts – Nipples & Areolas	8	Feminization	Satisfaction	Now
Genital Feminization				
Vagina	10	Genital Surgery	Satisfaction	Now
Labia	12	Genital Surgery	Satisfaction	Now
Clitoris	6	Genital Surgery	Satisfaction	Now
Dilation	5	Genital Surgery	Satisfaction	Past Week
Chest				
Chest	10	Masculinization	Satisfaction	Now
Chest Scars	12	Chest Surgery	Bother	Now
Chest – Nipples & Areolas	8	Masculinization	Satisfaction	Now
Genital Masculinization				
Penis	12	Genital Surgery	Satisfaction	Now
Penis Sensation	11	Genital Surgery	Amount	Past Week
Glans	9	Genital Surgery	Satisfaction	Now
Scrotum	10	Genital Surgery	Satisfaction	Now
Perineum	8	Genital Surgery	Satisfaction	Now
Donor Site – Forearm or Thigh	8	Genital Surgery	Bother	Now
Donor Site – Adverse Effects	12	Genital Surgery	Concern	Past Week
Testicular Implants	10	Genital Surgery	Satisfaction	Now
Erectile Device	12	Genital Surgery	Satisfaction	None
<b>Experience of Care</b>				
Health Professional	15	Any	Agreement	Most Recent
Clinic	10	Any GA care	Agreement	Most Recent
Surgery – Information	10	Any GAS	Satisfaction	Pre-op
Surgery – Return to Activity	12	Chest, Breast or Genital	Difficulty	Past Week
Surgery – Adverse Effects*	30	Any GAS	Concern	Past Week

<sup>\*</sup>Represents a checklist of problems that patients might experience post-operatively GA – Gender-affirming, GAS – Gender-affirming surgery

### **HEALTH-RELATED QUALITY OF LIFE**

**Body Image:** This 8-item scale measures body image using *frequency* for the response options (never, rarely, sometimes, often, always) and *past week* as the recall period. Items ask about self-confidence, perceived attractiveness, and appearance in everyday contexts (e.g., when looking in the mirror, when clothed).

**Gender Dysphoria:** This 14-item scale measures the interference of gender dysphoria on daily life using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about work/school, close relationships, physical activity, social life, and mental health.

**Social Acceptance**: This 9-item scale measures social well-being using *frequency* for the response options (never, rarely, sometimes, often, always) and *past week* as the recall period. Items ask about feeling respected, having people to talk to, and feeling accepted by others.

**Psychological Distress**: This 10-item scale measures negative emotions using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about feeling worried, depressed, lonely, afraid, frustrated, and overwhelmed.

**Psychological Well-being**: This 10-item scale measures psychological well-being using frequency for the response options (never, rarely, sometimes, often, always) and past week as the recall period. Items ask about feelings of acceptance, hope, happiness, confidence, and empowerment.

**Treatment Outcome**: This 10-item scale measures the outcome of the gender-affirming surgery using *agreement* for the response options (disagree, slightly agree, mostly agree, strongly agree) and *most recent* gender-affirming surgery as the recall period. Items ask whether the treatment improved their life, was better than expected, and made them feel affirmed in their gender.

#### **SEXUAL**

**Sexual Well-being:** This 12-item scale measures sexual activity (e.g., masturbation, partnered sex) using *frequency* for the response options (never, rarely, sometimes, often, always) and has no specific recall period. Items ask about feeling relaxed during sexual activity, feeling comfortable being touched, and being confident in the appearance of their body and genitals during sexual activity.

**Orgasm**: This 8-item scale measure orgasms using *frequency* for the response options (never, rarely, sometimes, often, always) and *last few times* the person engaged in sexual activity as the recall period. Items ask about their ability to reach orgasm, the intensity and duration of orgasm, and how easy it was to orgasm.

#### **URINATION**

**Urinary Function:** This 15-item checklist measures urinary function using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about pain during urination, urinary leakage in specific situations (e.g.,

coughing/sneezing, sleeping, when physically active), increased frequency, and difficulty with bladder emptying.

**Urinary Catheter:** This 10-item scale measures catheter use following genital surgery using *how much time* for the response options (most of the time, some of the time, none of the time) and has no specific recall period. Items ask about feeling pain, itchiness, anxiety, as well as interference with sleep, leaving the house, and bathing or showering.

#### **GENDER PRACTICES**

**Binding** – **Well-being**: This 8-item scale measures the impact of binding on body image and psychological well-being using *frequency* for the response options (never, rarely, sometimes, often, always) and *past week* as the recall period. Items ask about feeling affirmed in their gender, confident, happy, comfortable in clothing, and safe/relaxed around others.

**Binding** – **Chest Symptoms**: This 10-item scale measures chest-related symptoms experienced while wearing a binder using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about pain, ribs feeling bruised or crushed, as well as having difficulty eating, drinking, and breathing (e.g., when breathing deeply or walking briskly).

**Binding – Skin Symptoms:** This 5-item scale measures chest skin-related symptoms experienced while wearing a binder using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about skin under the binder feeling numb, irritated, and itchy, as well as skin and nipple soreness.

**Tucking – Symptoms:** This 10-item scale measures symptoms experienced while tucking using *frequency* for the response options (always, often, sometimes, never) and *past week* as the recall period. Items ask about genital numbness, pain during urination, walking, and sitting, as well as skin-related symptoms (e.g., sores, feeling hot, irritation).

#### **VOICE**

**Voice Sound:** This 15-item scale measures how the voice sounds using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *past week* as the recall period. Items ask about voice (clarity, expressiveness, and pitch), how their voice sounds in different situations (e.g., when laughing, speaking naturally, talking on the phone, when upset or excited), and how much their voice makes them feel affirmed in their gender.

**Voice Distress:** This 10-item scale measures voice-related distress using *frequency* for the response options (always, often, sometimes, rarely, never) and *past week* as the recall period. Items ask about avoiding certain activities (e.g., going out or speaking in different

social situations), feeling self-conscious, feeling unsafe in public, and wishing their voice sounded different.

#### **HAIR**

**Face Hair – Feminization:** This 7-item scale measures appearance of facial hair using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *past week* as the recall period. Items ask about the time required to remove facial hair, its amount and texture, how noticeable it is, and the speed and location of its growth.

**Face Hair – Masculinization:** This 12-item scale measures appearance of facial hair using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *past week* as the recall period. Items ask about feeling affirmed in their gender, the amount and density of facial hair, how it looks up close and in profile, how fast it grows, and the ability to grow sideburns, a moustache, and a beard.

**Hair** – **Head**: This 12-item scale measures how the hair on the head looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about feeling affirmed in their gender, amount of hair, hair fullness (e.g., on the sides, back, and top of the head), and how the hairline looks (e.g., location, shape, and appearance when hair is wet).

#### **FACE & NECK**

**Face Overall:** This 15-item scale measures how the face looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about the extent to which their face makes them feel affirmed in their gender, facial shape and attractiveness, and how the face looks far away, in the mirror, from different angles, up close, and in photos.

**Facial Features:** This 9-item scale measures how different facial features look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about the appearance of the eyes, lips, cheekbones, nose, cheeks, brow bone, forehead, chin and jawline.

**Upper Face:** This 9-item scale measures how the upper face (i.e., forehead, brow bone, and eyes) looks using *satisfaction* as the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* for the recall period. Items ask about the shape of the brow bone and

forehead, how much the upper face makes them feel affirmed in their gender, as well as how the upper face looks in the mirror, from different angles, and in photos.

**Eyebrows:** This 5-item scale measures how the eyebrows look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about how close together and well-matched the eyebrows are, as well as eyebrow shape and fullness.

**Cheeks:** This 9-item scale measures how the cheeks look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about cheek contour, size, attractiveness, how the cheeks look from different angles, and how much their cheeks make them feel affirmed in their gender.

**Nose**: This 10-item scale measures how the nose looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the nose (e.g., length, overall size, shape in profile view), how attractive the nose looks, and how much their nose makes them feel affirmed in their gender.

**Nostrils:** This 7-item scale how the nostrils look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the nostrils (e.g., shape, width, and size), as well as how the nostrils look in the mirror and in photos.

**Lips**: This 12-item scale measures how the lips look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the lips (shape, style, size, fullness), how the lips look when smiling, attractiveness of the lips, and how much their lips make them feel affirmed in their gender.

**Chin:** This 10-item scale measures how the chin looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the chin (width, size, and shape), how much their chin makes them feel affirmed in their gender, as well as how the chin looks in the mirror, in photos, and from different angles.

**Jawline:** This 10-item scale measures how the jawline looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the jawline (width, shape, definition), attractiveness of the jawline, how much their jawline makes them feel affirmed in their gender, and how the jawline looks in the mirror, from the side, and in photos.

Adam's Apple: This 10-item scale measures how the Adam's apple looks using bothered for the response options (extremely bothered, very bothered, somewhat bothered, a little bothered, not at all bothered) and now as the recall period. Items ask about the shape and size of the Adam's apple, as well as how it looks in the mirror, while talking and swallowing, in photos, and from different angles.

#### **BODY**

**Body:** This 10-item scale measures how the body looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about how their body looks when dressed and when unclothed, in different situations (e.g., summer clothes, photos, swimsuit), and how much their body makes them feel affirmed in their gender.

**Buttocks:** This 10-item scale measures how the buttocks look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the buttocks (e.g., size, shape, firmness), attractiveness of the buttocks, how much their buttocks make them feel affirmed in their gender, and how the buttocks look in different situations (e.g., in snug clothing, when naked).

**Waist:** This 7-item scale measures how the waist looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the waist (e.g., size, shape), how much their waist makes them feel affirmed in their gender, and how the waist looks when dressed and when naked.

#### **BREASTS**

**Breasts:** This 12-item scale measures how the breasts look and feel using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the breasts (e.g., size, shape, how natural they look

and hang, how closely matched they are to each other), as well as how much the breasts feel like a part of their body.

**Breasts – Nipples & Areolas:** This 8-item scale measures how the nipples and areolas look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about nipple and areola color, size, position on the breasts, direction the nipples point, and nipple projection.

#### **GENITAL FEMINIZATION**

**Vagina:** This 10-item scale measures the vagina using *satisfaction* for the response options (dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the vagina (e.g., width, depth, color, size and location of vaginal opening), as well as how much the vagina feels like a part of their body and makes them feel affirmed in their gender.

**Labia:** This 12-item scale measures how the labia look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about the length, shape, size, fullness, and natural appearance of the inner and outer labia.

**Clitoris:** This 6-item scale measures how the clitoris looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about the shape, size, and prominence of the clitoris, as well as the appearance and size of the clitoral hood.

**Dilation:** This 5-item scale measures the experiences of vaginal dilation using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *past week* as the recall period. Items ask about the size of the dilator, comfort, amount of time spent, and how often they needed to dilate.

#### **CHEST**

**Chest:** This 10-item scale measures how the chest looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about how the chest looks when wearing a loose or snug T-shirt, without a shirt, how much their chest makes them feel affirmed in their gender, and how it in various situations (e.g., when lying on back, standing up straight, being active, bent over).

**Chest Scars:** This 12-item scale measures how the chest scars look using *bothered* for the response options (very much, quite a bit, a little, not at all) and *now* as the recall period.

Items ask about the width, thickness, length, color, contour, and size of the scars, as well as how the scars look in different situations (e.g., far away, different angles, up close).

**Chest – Nipples & Areolas:** This 8-item scale measures how the nipples and areolas look using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the nipples and areolas (e.g., position on the chest, size, and shape), as well as the direction the nipples point and how flat the nipples look.

#### **GENITAL MASCULINIZATION**

**Penis:** This 12-item scale measures how the penis looks and feels using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the penis (e.g., the amount of skin, location on body, shape, length, size, girth), how the penis looks and feels when it hangs, as well as how it looks when naked.

**Penis Sensation:** This 11-item scale measures penis sensation using *amount* for the response options (no feeling, a little feeling, some feeling, a lot of feeling, complete feeling) and *past week* as the recall period. Items ask about sensations felt in the penis in different situations, including when the penis is squeezed, touched sexually, touched lightly or through clothing, and during activities such as walking or sitting.

**Glans:** This 9-item scale measures how the glans looks using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about smoothness, size, shape, and color of the glans, as well as how realistic it looks and how distinct it is from the rest of the penis.

**Scrotum:** This 10-item scale measures how the scrotum looks and feels using *satisfaction* for the response options (extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about physical characteristics of the scrotum (e.g., location on body, size, shape, fullness), along with how the scrotum feels when it hangs, how freely it moves, and how natural it appears.

**Perineum:** This 8-item scale measures how the perineum looks and feels using satisfaction for the response options (dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and now as the recall period. Items ask about physical characteristics of the perineum (e.g., length, color, smoothness, flatness, scars), as well as the amount of sensation and how the scars feel.

**Donor Site – Forearm or Thigh:** This 8-item scale measures how their donor area used to create the penis looks using *bothered* for the response options (extremely bothered, very bothered, somewhat bothered, a little bothered, not at all bothered) and *now* as the recall period. Items ask about the shape, color, and size of the donor area, how the skin surface looks, how noticeable the donor area is, and how it looks up close.

**Donor Site – Adverse Effects:** This 12-item scale measures symptoms related to the donor area used to create the penis using *concern* for the response options (very concerned, somewhat concerned, not at all concerned) and *past week* as the recall period. Items ask about symptoms such as tingling, pain, itchiness, sensitivity to temperature and touch, swelling, dryness, numbness, and tightness.

**Testicular Implants:** This 10-item scale measures how the testicular implants look and feel using *satisfaction* for the response options (dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and *now* as the recall period. Items ask about the implants feeling like a part of the body, how well-matched the testicles are, how they look and feel as they hang, how freely they move, and the size of the implants.

**Erectile Device:** This 12-item scale measures the use of an erectile device for sexual activity (e.g., masturbation, penetrative sex) using *satisfaction* for the response options (dissatisfied, somewhat satisfied, very satisfied, extremely satisfied) and has no specific recall period. Items ask about how much the device makes them feel affirmed in their gender, how noticeable the device is when dressed, ease of achieving an erection, how the device affects the look and feel of the penis, and firmness.

#### **EXPERIENCE OF CARE**

**Health Professional:** This 15-item scale measures gender-affirming care received from a health professional using *agreement* for the response options (strongly disagree, mostly disagree, slightly disagree, slightly agree, mostly agree, strongly agree) and the *most recent interactions* as the recall period. Items ask about respect, trustworthiness, answering questions, listening, shared decision-making, and level of care.

**Clinic:** This 10-item scale measures gender-affirming care received at a clinic using agreement for the response options (strongly disagree, mostly disagree, slightly agree, mostly agree, strongly agree) and the most recent appointments for the recall period. Items ask about showing respect, professionalism, friendliness, responsiveness, and being knowledgeable.

**Surgery - Information:** This 10-item scale measures the oral and written information received in advance of their gender-affirming surgery using *satisfaction* for the response options (not at all satisfied, a little satisfied, somewhat satisfied, very satisfied, extremely satisfied) and has no specific recall period. Items ask about the information provided on

the treatment procedure, complications, change in appearance, managing symptoms, and recovery.

**Surgery – Return to Activity:** This 12-item scale measures return to activity following the most recent chest, breast, or genital gender-affirming surgery using *difficulty* for the response options (extremely difficult, very difficult, somewhat difficult, a little difficult, not difficult) and *past week* as the recall period. Items ask about activities such as personal grooming, walking, getting in or out of bed, getting dressed, doing chores, bathing or showering, and bending over.

**Surgery** — **Adverse Effects:** This 30-item checklist inventories adverse effects following gender-affirming surgery using *concern* for the response options (extremely concerned, very concerned, somewhat concerned, a little concerned, not at all concerned) and *past week* as the recall period. Items ask about pain, stiffness, burning sensation, itchiness, bleeding, numbness, odor, bruising, feeling depressed or anxious, as well as problems with sleep, urination, breathing, and eating/drinking.

### 4. Administration of the GENDER-Q

The GENDER-Q is designed to be completed by patients 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. Brief instructions and the timeframe for reporting are provided at the start of each scale. The GENDER-Q was field tested using online data collection, i.e., Research Electronic Data Capture System (REDCap). 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., a hospital electronic medical record). If you plan to have an electronic PRO (ePRO) company develop and/or manage GENDER-Q data collection for you, the ePRO company may need a license. If you have or plan to have an ePRO company convert GENDER-Q scales into an electronic format, an e-conversion review and certification is required. Please email <a href="mailto:qportfolioteam@gmail.com">qportfolioteam@gmail.com</a> for more information.

### 5. Scoring the GENDER-Q

There is no overall or total GENDER-Q score. Instead, the GENDER-Q is composed of independently functioning scales and checklists (see Table 2 above).

### To score a scale:

The raw scores for the set of items in a scale are added together to produce a total raw score. Once a total raw score for the scale is computed, the Conversion Table can be used to convert the total raw score into a score that ranges from 0 (worst) to 100 (best). The conversion, which linearizes the score, is based on the findings from the Rasch analysis. Higher scores for GENDER-Q scales reflect a better outcome. The Conversion Tables for

changing raw scores into 0 to 100 scores are available after a Licensing Agreement is signed.

On page 19 is an example of how to compute a scale score using the GENDER-Q Body Image scale. First, you compute the <u>sum score</u> (total raw score) by adding the raw scores for items 1-8. In the example, the sum score = 24. Second, you will find the sum score in the Body Image Conversion Table. The sum score of 24 is then converted to a Rasch score (linearized score) of 48.

### To score a checklist:

The 2 checklists (Urinary Function and Return to Activity) are sets of items that represent a list of problems that patients might experience. These checklists provide descriptive data. Therefore, the choice of how to score the checklists is up to the end user. For example, the raw scores can be added to obtain a total score, or you can simply count the number of problems that the respondents experienced.

### 6. How to Deal with Missing Data

The choice of how to handle missing data, such as whether or not to impute the mean when there is missing data, is ultimately up to the end user of GENDER-Q. Our suggestion follows the most common method for scoring when there is missing data, which is to impute a missing value using the mean value of responses to completed items if more than 50% of items are answered. This method is recommended in the scoring manuals of numerous widely used PROMs, such as the Short Form (SF)-36 generic questionnaire used extensively in research for decades [7-8]. As such, GENDER-Q scores can be computed if missing data is less than 50% of the scale's items. In this approach, the within person mean for the completed items can be imputed for the missing items prior to computing a summed score (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.

These questions ask how you feel about your APPEARANCE.

Please answer thinking of the PAST WEEK. With your GENDER IDENTITY in mind, how often does each statement apply to you?

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
I like how I look when I am clothed.	1	2	3	4	5
I feel comfortable with how I look.	1	2	3	4	5
3. I like the way I look.	1	2	3	4	5
4. I feel happy about how I look.	1	2	3	4	5
5. I feel confident about how I look.	1	2	3	4	5
6. I like seeing myself in a mirror.	1	2	3	4	5
7. I feel attractive.	1	2	(3)	4	5
8. I feel great about how I look.	1	2	3	4	5

<sup>© 2024,</sup> McMaster University and Brigham and Women's Hospital. All rights reserved. Contact the McMaster Industry Liaison Office at McMaster University, email: milo@mcmaster.ca for licensing details.

**GENDER-Q – BODY IMAGE CONVERSION TABLE** 

SUM SCORE	RASCH SCORE (0-100)	SUM SCORE	RASCH SCORE (0-100)
8	0	25	51
9	7	26	54
10	12	27	57
11	15	28	60
12	18	29	63
13	21	30	66
14	24	31	69
15	26	32	72
16	28	33	76
17	31	34	79
18	33	35	82
19	36	36	84
20	38	37	87
21	40	38	90
22	43	39	95
23	46	40	100
24	48		

### 7. Conditions of Use

McMaster University and Brigham and Women's Hospital hold the copyright of the GENDER-Q and all of its translations (past, on-going, and future). To avoid any copyright infringement, please ensure that the copyright notice of the GENDER-Q is included in the questionnaire. If you're unsure of the copyright notice for the GENDER-Q, our website lists the copyright and trademark notice: <a href="https://aportfolio.org/copyright-information/">https://aportfolio.org/copyright-information/</a>.

Use of the GENDER-Q requires completion of a Licensing Agreement. The use of the GENDER-Q in non-profit academic research and in clinical care is <u>free of charge</u>. The use of the GENDER-Q by "for-profit" organizations (e.g., pharmaceutical companies or investigator-initiated studies sponsored by pharmaceutical companies, contract research organizations, ePRO companies) is subject to a licensing fee.

To obtain a license to use the GENDER-Q, please use the following link:

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

For questions regarding a GENDER-Q license, please contact: Licensing Assistant
McMaster Industry Liaison Office (MILO)
McMaster Innovation Park, Suite 305
175 Longwood Rd S, Hamilton ON L8P 0A1
milo@mcmaster.ca

### **PLEASE NOTE**

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

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

For questions regarding study design and optimal use of GENDER-Q scales, please contact either:

Manraj Kaur, PhD
Brigham and Women's Hospital
Harvard Medical School
Boston, Massachusetts
United States
mkaur17@bwh.harvard.edu

Anne Klassen, DPhil (Oxon)
McMaster University
Hamilton, Ontario
Canada
aklass@mcmaster.ca

### 8. Frequently Asked Questions

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

Since each scale functions independently, patients or research participants can be asked to complete one or more GENDER-Q scales. Researchers and clinicians should select the subset of scales that corresponds to the particular purpose of the study or use.

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

You <u>cannot</u> delete or add or change the wording of any items or response options of the GENDER-Q. Any modification to the content of the GENDER-Q is prohibited under copyright laws. Importantly, making changes to the GENDER-Q scales would invalidate their psychometric properties.

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

According to the Licensing Agreement, you <u>cannot</u> reproduce the content of any GENDER-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.

### Can I translate GENDER-Q scales into a new language?

Yes, you can translate the GENDER-Q into another language, but you must get permission first. Before starting a translation, check our website (qportfolio.org) to see if a translation already exists. If not, you will need to request permission from our team, sign a Translation Licensing Agreement, and follow our approved translation process. Email <a href="mailto:qportfolioteam@gmail.com">qportfolioteam@gmail.com</a> for more information. Please note that the developers of the GENDER-Q own the copyright of all translations of the GENDER-Q.

### Are there specific time-points when patients complete the scales?

A researcher or clinician should decide on the time points to administer the scales.

### Can I use the GENDER-Q with youth?

The GENDER-Q was designed to measure outcomes and experience of care for adults aged 18 years and older. Our team is currently developing a separate module of the GENDER-Q for youth aged 12 and older. For more information about GENDER-Q Youth, please visit our website qportfolio.org.

### Does it cost money to use the GENDER-Q?

Use of GENDER-Q scales is free for non-profit users. For-profit users should contact McMaster University for information about licensing fees (milo@mcmaster.ca).

### 9. Acknowledgements

Development and validation of the GENDER-Q has involved 1000s of people seeking or receiving gender-affirming care, along with many healthcare professionals and researchers around the world. We are truly grateful for their dedication and help with our research.

The GENDER-Q study has been generously funded by the following grants:

### **Phase I: Qualitative**

Canadian Institute for Health Research (CIHR) Foundation Grant (Award #FDN 167288), CIHR Strategy for Patient-Oriented Research (SPOR) Patient-Oriented Research Collaboration Grant (Award #157062).

The Plastic Surgery Foundation National Endowment for Plastic Surgery Grant (Award #568801) and ZonMw (Project number #636330001).

#### Phase II: Quantitative

The Canadian Institute for Health Research (CIHR) Foundation Grant (Award #FDN 167288).

Table 3: Shortened items for GENDER-Q scales that can be used in publications

HRQOL	TREATMENT OUTCOME	anxious	talk on phone	smile
BODY IMAGE	glad	pulling sensation	upset	facial features
clothed	affirmed in gender	interfere bath/shower	nervous	attractive
comfortable	best thing	uncomfortable	VOICE DISTRESS	end of day
like how look	improved life	get in way	avoid going out	bright light
happy how look	worth it	GENDER PRACTICES	avoid speaking social	different angles
confident	satisfied	BINDING WELL-BEING	unsafe in public	from the side
in mirror	outcome I wanted	affirmed in gender	avoid activities	up close
feel attractive	ecstatic	look in clothes	avoid activities avoid speaking groups	photos
		confident		FACIAL FEATURES
feel great	way I thought		speak less self-conscious	
GENDER DYSPHORIA	better than expected	comfortable in clothing		eyes
leave house	SEXUAL MELL BEING	safe	dislike	lips
daily activities	SEXUAL WELL-BEING	happy	worry	cheekbones
healthy lifestyle	enjoy	relaxed	wish sounded different	nose
activities enjoy	pleasurable	feel good	HAIR	cheeks
close relationships	physically excited	BINDING CHEST SYMPTOMS	FACE - FEMINIZATION	brow bone
handle stress	body feels	hard eat/drink	time to remove	forehead
active	body touched	nauseated	noticeable	chin
social life	genitals touched	unwell	how often remove	jawline
be yourself	relax	ribs feel bruised	amount	UPPER FACE
accept yourself	feel good	ribcage feels crushed	how fast grows	in mirror
happy	affirmed in gender	pain	where grows	shape brow bone
comfortable around others	attractive	breathe normally	texture	shape forehead
look at yourself	confident how genitals look	chest hurts	FACE - MASCULINIZATION	size brow bone
mental health	confident how body looks	breathe when walk	affirmed in gender	affirmed in gender
SOCIAL ACCEPTANCE	ORGASMS	breathe deeply	natural	forehead hair wet
care about me	satisfying	BINDING SKIN SYMPTOMS	from the side	from the side
accept me	able to	skin numb	up close	different angles
respect me	right time	nipples sore	photos	photos
understand me	intense	skin sore	sideburns	EYEBROWS
listen to me	satisfying length	skin irritated	where grows	close together
people I can talk to	feeling after	skin itchy	how fast grows	match
correct pronouns	how much sexual activity	TUCKING SYMPTOMS	amount	position
comfortable with gender	·	skin sores	density	
be myself	easy URINATION		mustache	shape full
PSYCH DISTRESS	URINARY FUNCTION	hurts to pee hurts to walk	beard	CHEEKS
afraid	leave house	in pain	HAIR - HEAD	contour
hurt	hurts to pee	numb	full on sides	shape
giving up	leak when active	hurts when active	full from back	from the side
nervous	leak when cough/sneeze	feels sore	affirmed in gender	size
depressed	leak when sleep	feels hot	amount	attractive
worried	hard to start pee	hurts to sit	density	different angles
overwhelmed				affirmed in gonder
	cannot hold pee	skin irritated	full at top	affirmed in gender
lonely	cannot hold pee long time pee	skin irritated VOICE	full at top from the side	full
lonely frustrated				
•	long time pee	VOICE	from the side	full
frustrated	long time pee need to push	VOICE VOICE SOUND	from the side style	full photos
frustrated anxious	long time pee need to push emptying bladder	VOICE VOICE SOUND clear	from the side style hairline location	full photos NOSE
frustrated anxious PSYCH WELL-BEING	long time pee need to push emptying bladder leak pee urgently	VOICE VOICE SOUND clear expressiveness	from the side style hairline location hairline in mirror	full photos NOSE length
frustrated anxious PSYCH WELL-BEING accept yourself	long time pee need to push emptying bladder leak pee urgently interfere sleep	VOICE VOICE SOUND clear expressiveness quality	from the side style hairline location hairline in mirror hairline shape	full photos NOSE length smile
frustrated anxious PSYCH WELL-BEING accept yourself hopeful	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often	VOICE VOICE SOUND clear expressiveness quality read out loud	from the side style hairline location hairline in mirror hairline shape hairline hair wet	full photos NOSE length smile in mirror
frustrated anxious PSYCH WELL-BEING accept yourself hopeful at peace	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often spray	VOICE VOICE SOUND clear expressiveness quality read out loud laugh	from the side style hairline location hairline in mirror hairline shape hairline hair wet FACE & NECK	full photos NOSE length smile in mirror tip
frustrated anxious  PSYCH WELL-BEING accept yourself hopeful at peace happy empowered	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often spray pee dribbles out URINARY CATHETER	VOICE VOICE SOUND  clear expressiveness quality read out loud laugh talked long time talk quickly	from the side style hairline location hairline in mirror hairline shape hairline hair wet FACE & NECK FACE OVERALL look your best	full photos NOSE length smile in mirror tip suits face affirmed in gender
frustrated anxious PSYCH WELL-BEING accept yourself hopeful at peace happy empowered feel good	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often spray pee dribbles out URINARY CATHETER itchiness	VOICE  VOICE SOUND  clear expressiveness quality read out loud laugh talked long time talk quickly affirmed in gender	from the side style hairline location hairline in mirror hairline shape hairline hair wet FACE & NECK FACE OVERALL look your best from far away	full photos NOSE length smile in mirror tip suits face affirmed in gender overall size
frustrated anxious  PSYCH WELL-BEING accept yourself hopeful at peace happy empowered feel good confident	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often spray pee dribbles out URINARY CATHETER itchiness pain	VOICE  VOICE SOUND  clear expressiveness quality read out loud laugh talked long time talk quickly affirmed in gender pitch	from the side style hairline location hairline in mirror hairline shape hairline hair wet FACE & NECK FACE OVERALL look your best from far away well-proportioned	full photos NOSE length smile in mirror tip suits face affirmed in gender overall size shape in profile
frustrated anxious  PSYCH WELL-BEING accept yourself hopeful at peace happy empowered feel good	long time pee need to push emptying bladder leak pee urgently interfere sleep pee more often spray pee dribbles out URINARY CATHETER itchiness	VOICE  VOICE SOUND  clear expressiveness quality read out loud laugh talked long time talk quickly affirmed in gender	from the side style hairline location hairline in mirror hairline shape hairline hair wet FACE & NECK FACE OVERALL look your best from far away	full photos NOSE length smile in mirror tip suits face affirmed in gender overall size

NOSTRILS	from behind	LABIA	GENITAL MASCULINIZATION	surface of skin
in mirror	from the side	length outer labia	PENIS	overall size
shape	shape	shape outer labia	amount of skin	up close
show		size outer labia		noticeable
	photos		feels as hangs	
smile	unclothed	natural outer labia	location	people noticing
width	swimsuit	youthful	shape	DONOR SITE – AE
photos	BUTTOCKS	hang when stand	freely moves	tingling
size	firm	full	looks as hangs	pain
LIPS	clothes fit	inner outer labia distinct	realistic	sensitive to temperature
shape lower lip	affirmed in gender	natural inner labia	naked	itchiness
turned up upper lip	snug clothes	length inner labia	overall size	pressure
suit face	from the side	size inner labia	length	swelling
style	attractive	shape inner labia	size in relation to body	sensitive to touch
full lower lip	shape	CLITORIS	girth	dryness
affirmed in gender	size	shape	PENIS SENSATION	numbness
attractive	naked	size	accidentally bump	discomfort
corners of lips	size in relation to hips/waist	prominent	touched sexually	pulling
shape upper lip	WAIST	clitoral hood covers	squeeze	tightness
smile	dressed	clitoral hood looks	touch lightly	TESTICULAR IMPLANTS
size	clothes fit	clitoral hood size	lay on stomach	part of your body
full upper lip	affirmed in gender	DILATION	in shaft	feel as hang
CHIN	size in relation to hips/buttocks	size dilator	touch through clothing	match in size
		comfortable inside		
suits face	size		hold	underwear fit
in mirror	naked	comfortable to insert	sit hard surface	freely move
width	shape	amount of time	walk/move	sit on hard surface
size	BREASTS	how often	touches clothing	look as hang
shape	BREASTS	CHEST	GLANS	size
affirmed in gender	part of your body	CHEST	smooth skin	size – in relation to penis
photos	feel to touch	lie on back	size	match as they hang
from the side	closely matched	loose T-shirt	skin looks	ERECTILE DEVICE
different angles	position on chest	type of shirts	size – in relation to penis	affirmed in gender
attractive	affirmed in gender	affirmed in gender	shape	noticeable clothes on
JAWLINE	natural look	flat	distinct from penis	how quickly start sex
overall size	naturally sit/hang	active	color	how often use
width	shape without bra	snug T-shirt	ridge glans and penis	easy to get erection
in mirror	how bras fit	bend over	realistic	comfort
mouth closed	size	shape without shirt	SCROTUM	feels after sex
shape	cleavage	from side without shirt	feels as hangs	hard
affirmed in gender	close together	CHEST SCARS	location	penis look
from the side	BREASTS NIPPLES & AREOLAS	from far away	close to body	aware during sex
photos	color	width	size	comfort during sex
<u> </u>	1 1 1 1			
attractive	match	different angles	shape	firm near end
defined	natural	how thick	moves feely	EXPERIENCE OF CARE
ADAM'S APPLE	position on breasts	length	natural	HEALTH PROFESSIONAL
in mirror	direction nipples point	surface	both sides match	respect
when talk	size of nipples	color	size – in relation to penis	safe
photos	size of areolas	color different from skin	full	trustworthy
shape	nipples project	contour	PERINEUM	affirmed in gender
protrudes	GENITAL FEMINIZATION	overall size	length	asked relevant questions
swallow	VAGINA	up close	color	helped access treatment
different angles	affirmed in gender	noticeable	sensation	answered questions
noticeable	part of your body	CHEST NIPPLES & AREOLAS	scars feel	involved you in decisions
size	location of opening	direction point	scars look	listened
from the side	color match labia	position on chest	natural	easy to talk to
BODY	comfortable when aroused	size nipples	smooth	realistic expectations
BODY	natural	size areolas	flat	highest level care
dressed	size of opening	shape nipples	DONOR – FOREARM/ THIGH	thorough
clothes fit	size when aroused	natural	thick skin	explained treatments
affirmed in gender	width	shape areolas		best for you
		· ·	shape	best for you
summer clothes	depth	flat nipples	color of skin	

CLINIC	complications	in/out bed	stiffness	constipation
respect	realistic expectations	on/off clothes	tightness	light-headed
professional	take care of yourself	chores	throbbing	trouble sleeping
friendly	manage post-op symptoms	bathe	burning	perspiration
felt welcomed	how long to recover	on/off shoes and socks	pressure	tired
safe	what to do if complication	bend over	tingling	trouble concentrating
responsive to needs	surgical site looks healed	moderate exercise	pulling	depressed/anxious
recommend to others	sensation after surgery	SURGERY – ADVERSE EFFECTS	itchiness	trouble urinating
answer questions	RETURN TO ACTIVITY	pain at rest	numbness	trouble breathing
helpful with paperwork	on/off toilet	soreness	bleeding	trouble eating/drinking
knowledgeable	personal grooming	discomfort	discharge	
SURGERY - INFORMATION	walk/move	aching	odor	
how surgery done	up from chair	tenderness	bruising	
activities to modify	make something to eat	pain when move	swelling	

HRQL – Health-related quality of life; AE – Adverse effects

### 10. Publications Related to GENDER-Q Development and Validation

- Klassen AF, Kaur M, Johnson J, et al. International phase I study protocol to develop a patient-reported outcome measure for adolescents and adults receiving gender-affirming treatments (the GENDER-Q). BMJ Open 2018; 8:e025435. doi: 10.1136/bmjopen-2018-035435.
- 2. Kaur MN, Morrison SD, Kennedy SL, et al. International study to develop a patient-reported outcome measure to evaluate outcomes of gender-affirming care the GENDER-Q. JPRO 2024; 8:143. doi: 10.1186/s41687-024-00785-x.
- 3. Kaur MN, Morrison SD, Kennedy SL, et al. Core competencies for health practitioner and clinics providing gender-affirming care from the patient perspective: An international qualitative study. J Plast Reconstr Aesthet Surg 2024 103:384-388. doi: 10.1016/j.bjps.2024.10.014.
- 4. Kaur MN, Rae C, Morrison SD, et al. Development and assessment of a patient-reported outcome instrument for gender-affirming care. JAMA Network Open 2025; 8(4): e254708. doi:10.1001/jamanetworkopen.2025.4708.
- 5. Rasch G. Probabilistic Models for Some Intelligence and Attainment Tests. University of Chicago Press: Chicago, IL; 1980.
- Mistry Igbokwe M, Poulsen L, Kristensen TT, et al. Danish translation and linguistic validation of the GENDER-Q, a patient-reported outcome measure for use in genderaffirming care. European Journal of Plastic Surgery 2025; 48:11. doi: 10.1007/s00238-024-02255-5.
- 7. Wild D, Grove A, Martin ML, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. Value Health, 2005; 8(2):94–104.

- doi: 10.1111/j.1524-4733.2005.04054.x,
- 8. Ware JE, Kosinski MA, Keller SD. SF-36 physical and mental health summary scales: a user's manual. Boston, Massachusetts, Health Inst, New England Med. Center. 1995.
- 9. Ware JE, Snow KK, Kosinski M, Gandek B. SF-36 Health Survey manual and interpretation guide. Boston, Massachusetts, Nimrod Press. 1993.