

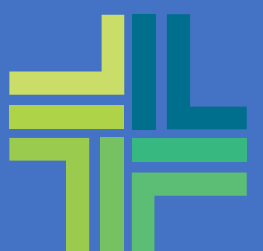
How Can We Improve and Standardize Outcome Assessment Following Gender-Affirming Genital Reconstruction?

Development of a Questionnaire with Urinary, Sexual, and Quality of Life Domains

American Urological Association 2020 Annual Meeting, May 15th-18th, Washington DC. Abstract ID: 20-8660

Luca Morgantini, S. Essie Ghafoor, Omer Acar, Ervin Kocjancic

University of Illinois at Chicago, College of Medicine, Department of Urology



UROLOGY
COLLEGE
OF MEDICINE



INTRODUCTION and OBJECTIVE

Gender-Affirming Genital Reconstruction (GAGR) involves surgical procedures that are designed to give a sense of congruence between the outer body and the inner self in transgender and gender non-conforming (TGNC) individuals.¹

Often referred to as “bottom surgery”, GAGR is usually the last step of a multi-year journey for individuals who desire functional and aesthetically pleasing external genitalia that matches the gender with which they identify.

- There is no standardized tool that investigates the unique outcomes of GAGR.
- We propose a questionnaire that has been specifically designed for cross-sectional and longitudinal evaluation of TGNC individuals post-GAGR.

METHODS

The questionnaire has been designed, since its inception, with the active participation of TGNC community members and organizations. Their contribution was essential for the relevance of this instrument.

We identified three domains that influence the outcomes of GAGR: urinary function, sexual function, and quality of life.

We adapted validated surveys, such as IPSS² and FSFI³ to better understand how the expectations of TGNC individuals meet with the outcomes of GAGR.

We tried to be as inclusive as possible of people that identify outside the binary. Considering how novel many of these surgical techniques are and how little is known about the long-term results, we included open-ended questions to cover and identify all the possible outcomes.

PILOT-TESTING AND VALIDATION

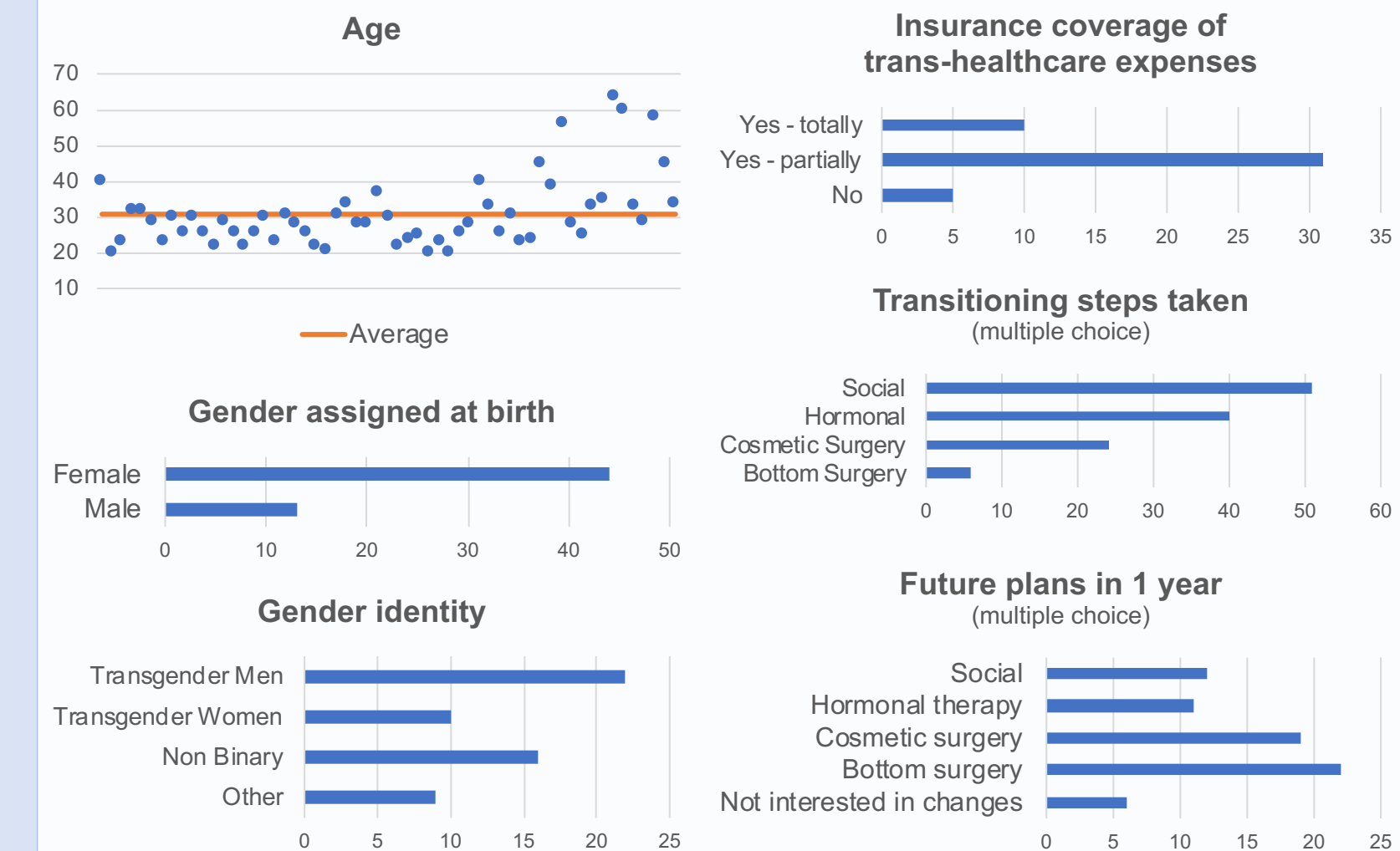
The questionnaire was evaluated by 11 experts from different disciplines: Urology, Public Health, Epidemiology, Psychiatry, Plastic Surgery, and Gynecology.

Pilot testing was achieved by the participation of Transfeminine Alliance of Chicago (T-FEM), Transmasculine Alliance of Chicago (T-MAC), and other TGNC individuals.

A total of 57 unique records were obtained. Forty-four respondents were assigned female at birth and only this subset of the population was used for validation.

Cronbach’s alpha of this questionnaire was 0.82, which translates into good internal consistency reliability.

RESULTS - DEMOGRAPHICS



Gender-Affirming Genital Reconstruction: Follow-up Questionnaire

Urinary Domain:

All the following questions are related to the past two weeks

- On average, how often did you pee during the daytime?
 Cannot urinate 1-2 3-8 9-10 11+
- On average, how many times do you wake up at night to pee?
 0 1 2 3 4+
- In which position did you feel most comfortable peeing? (Select all answers that apply)
 Sitting Standing Other, which one? _____

During the past two weeks:	Not Applicable	Almost Never / Never	A Few Times	Sometimes	Most of the Time	Almost Always / Always
How often do you feel like pee gets stuck in your vagina while peeing?						
How often do you feel like you didn't completely empty your bladder?						
While peeing, how often do you feel you have to start and stop?						
How often do you find it difficult to hold in your pee and go to the bathroom later?						
How often did your pee come out slowly?						
After you're done peeing, how often do drops of pee come out?						
How often did you have to push to start peeing?						
How often did your pee not come out straight?						
How often did pee come out when you coughed, sneezed, ran, walked, jumped?						
How often did pee come out during sex?						
How often did you pee on yourself?						

- How do you feel about your peeing?
 Extremely dissatisfied
 Mostly dissatisfied
 Neither satisfied or dissatisfied
 Mostly satisfied
 Extremely satisfied
- Do you have any comments regarding your peeing?

Sexual Domain:

All the following questions are related to the past two weeks

PENILE INTERCOURSE SECTION

Complete this section if you use your phallus sexually

- How do you achieve erections? (check all the answers that apply to you and write in if other)
 Natural erection Cock ring / Tension band Layered condoms
 Penile sleeve / Rx Sleeve Penile support device / The Elator Vacuum device
 Inflatable penile prosthesis Malleable penile prosthesis Pills (e.g. Viagra, Sildenafil, etc.)
 Other: _____

During the past two weeks:	Very Low	Low	Moderate	High	Very High
How would you rate the degree of the sexual sensation of the penis?					
The overall quality of your erections was?					
How often did you have penetrative sex (with or without a partner)?					
How often were you able to get an erection hard enough for penetration during sex?					
During sex, how often were you able to maintain your erection after you had penetrated your partner?					
When you had sexual stimulation or intercourse, how often did you orgasm?					
How often did you experience pain or discomfort in your penis during sex?					

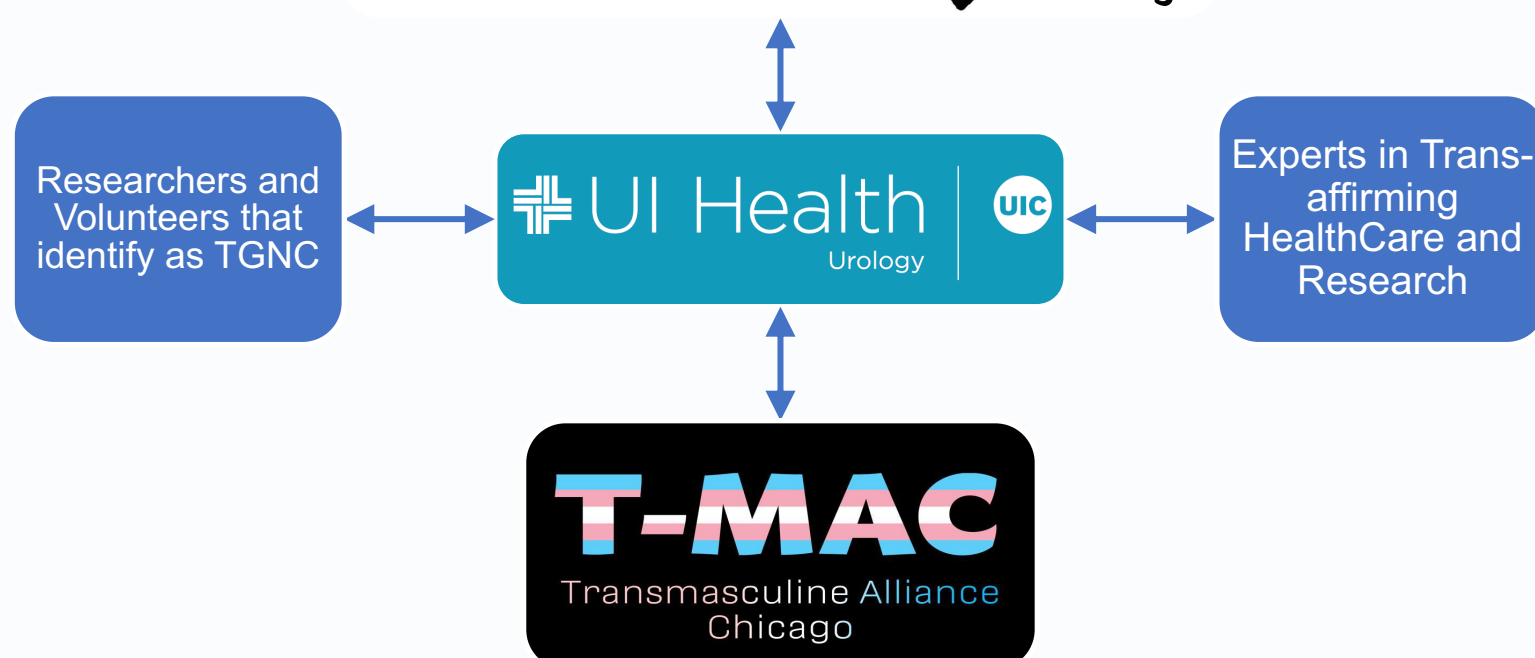
VAGINAL INTERCOURSE SECTION

Complete this section if you use your vagina sexually

During the past two weeks:	Almost Never / Never	A Few Times	Sometimes	Most of the Time	Almost Always / Always
How often did you have penetrative vaginal sex?					
When you had sex (with or without a partner), how often did you reach orgasm?					
How often did you feel vaginal dryness during penetrative vaginal sex?					
How often did you experience discomfort or pain during penetrative vaginal sex?					

For **EVERYONE**, please complete the following questions related to the past two weeks

- How do you feel about your Sexual functioning?
 Extremely dissatisfied
 Mostly dissatisfied
 Neither satisfied or dissatisfied
 Mostly satisfied
 Extremely satisfied
- Do you have any comments regarding your sexual functioning?



Quality of Life:

All the following questions are related to your experiences since the Gender-Affirming Genital Surgery

- How satisfied are you with the cosmetic appearance of your external genitalia?
 Extremely dissatisfied
 Mostly dissatisfied
 Neither satisfied or dissatisfied
 Mostly satisfied
 Extremely satisfied
- Has the gender-affirming genital surgery met your expectations?
 Not at all
 Not so much
 Somewhat
 Very much
 Completely
- How confident has this surgery made you feel about your ability to engage in sexual activity?
 Not at all confident
 Not so confident
 Somewhat confident
 Very confident
 Extremely confident
- Would you recommend this surgery to a person that wants gender-affirming genital surgery?
 Yes
 No

CONCLUSIONS

This questionnaire, which has been endorsed by TGNC individuals and communities, is the first validated instrument that allows for cross-sectional and longitudinal assessment of GAGR outcomes, focusing on urinary, sexual, and QoL issues.

The questionnaire has been validated in TGNC individuals who were assigned female at birth.

FUTURE DIRECTIONS

- Validation in TGNC individuals who were assigned male at birth
- Development of a scoring system to evaluate how urinary function, sexual function, and quality of life evolve over time.

CONTACTS

lmorga5@uic.edu | sghafo3@uic.edu | oacar2@uic.edu | ekocjanc@uic.edu
 @omer_acar_ | @ervkoc | @UICUrol
 tfemchicago@gmail.com | transmaschi@gmail.com

DOWNLOAD THE QUESTIONNAIRE:



ACKNOWLEDGEMENTS

The authors would like to thank all the individuals that have participated in the design, development, and testing of this questionnaire, Heng Wang for statistical evaluation, and Kathleen Diviak for REDCap setup.

REFERENCES

- Coleman E, et al. (2012). Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7. Int. J of Transgenderism. 13.
- Barry MJ, et al. (1992) The American Urological Association symptom index for benign prostatic hyperplasia. The Measurement Committee of the American Urological Association. J Uro 148.
- R. Rosen, et al. (2000) The Female Sexual Function Index (FSFI): A Multidimensional Self-Report Instrument for the Assessment of Female Sexual Function, Journal of Sex & Marital Therapy, 26:2.