

## Núcleo de Avaliação de Tecnologias em Saúde da FMB

Afonso Nogueira Simões Correa Neto, MD<sup>1</sup>, Mariana Andrade Fiorino Monteiro Novo, M.Sc<sup>2</sup>, Muriel Barros, M.Sc<sup>3</sup>, Suena Parahiba, M.Sc<sup>3</sup>, Bruna Marmett, M.Sc<sup>3</sup>, Gilson Dorneles, M.Sc<sup>3</sup>, Vania Santos Nunes-Nogueira, PhD, MD<sup>2</sup>, Julia Simoes Correa Galendi, PhD, MD<sup>2</sup>.

<sup>1</sup>Universidade do Estado do Rio de Janeiro (UERJ), Rio de Janeiro, Brazil; <sup>2</sup>Botucatu Medical School, University of the State of São Paulo (UNESP), Botucatu, Brazil; <sup>3</sup>Escritório de Projetos, Hospital Moinhos de Vento, Porto Alegre RS, Brazil, Porto Alegre, Brazil

## CONTEXT

Organic hypogonadotropic hypogonadism (OHH) is a rare endocrine disorder characterized by deficient gonadotropin secretion, resulting in impaired gonadal function.

Clinical presentation vary with onset: Congenital cases present with absent pubertal development, infertility, and high psychological distress. In adults, symptoms include reduced muscle mass, fatigue, testicular atrophy, gynecomastia, infertility, and increased risk of osteoporosis and cardiovascular disease.

A study was carried out with the objective of obtaining utility values by the time trade off (TTO) method for different health states of OHH

## METHODS

A cross-sectional pilot study was conducted with participants from São Paulo (SP), Rio de Janeiro (RJ), Minas Gerais (MG) and Porto Alegre (RS), Brazil.

Convenience sample composed of students or health professionals, without in-depth knowledge about the condition or experience in the treatment of this population.

A minimum sample of 15 men and 15 women was defined in the registered protocol (<https://doi.org/10.17605/OSF.IO/WTBRX>).

## DATA COLLECTION AND ANALYSIS

- Data collection was carried out by videoconference, using the Zoom platform. If the participant allowed it, the conference was recorded for internal use only. During the online video conference, participants received basic information about the disease and the TTO method.
- Five different vignettes of health statuses were developed through literature review and consultation with clinical experts.
- The data were analyzed using descriptive statistics, with mean and standard deviation for profitability in each health state. Furthermore, Brazilian population norms (baseline utility of 0.824 from Santos et al. 2021) were considered to calculate utility values for this population.

Participants assigned TTO utility values to five vignettes, weighting how long they would choose to live in perfect health versus living ten years in each health state presented:



## RESULTS

- Thirty-nine interviews were conducted with health professionals and medical students between April 11 and May 2, 2025.
- The study included 39 participants, 20 men (51%) and 19 women (49%), with a mean age of 27.9 years (SD 7.0).
- Regarding residence, 4 participants (10%) lived in Minas Gerais (MG), 26 (63%) in São Paulo (SP), and 9 (22%) in Rio de Janeiro (RJ).

Table 1. Utility values for HHO health states

Health State	Mean Utility	SD	n
Boys with untreated OHH	0.24	0.19	20
Boys with OHH treated with intramuscular testosterone	0.69	0.20	20
Men with untreated OHH	0.37	0.24	20
Men with OHH treated with intramuscular testosterone	0.70	0.13	20
Girls with untreated OHH	0.23	0.21	19

This work was supported by the São Paulo State University Development Foundation (FundUNESP) through the Agreement SCON2022-00285, in partnership with the Pan American Health Organization (PAHO)/World Health Organization (WHO)

Research Ethics Committee: This study is exempt from the usual ethical and regulatory review by the Research Ethics Committee (CNS Resolution No. 510, of 2016, article 1, Sole Paragraph, item I)

## MAIN FINDINGS

1. Treatment with intramuscular testosterone was perceived to significantly improve quality of life in OHH, with utility values rising from 0.24 to 0.69 for boys and from 0.37 to 0.70 for men compared to untreated states.
2. Untreated OHH health states were rated far below the Brazilian population's baseline utility norm (0.824), indicating a substantial perceived burden of the condition without therapy.
3. The main limitation was the use of a convenience sample of health professionals and medical students without direct experience with OHH, which may limit the representativeness and generalizability of the results.

## References:

Santos M, Monteiro AL, Santos B. EQ-5D Brazilian population norms. Health Qual Life Outcomes. 2021 Jun 10;19(1):162. doi: 10.1186/s12955-021-01671-6. PMID: 34112207; PMCID: PMC8190837.