

Assessing Growth and Energy Requirements of Children with Prader-Willi Syndrome

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Introduction

Prader-Willi syndrome (PWS) is a rare and complex genetic disorder that affects 1 in every 20,000 to 30,000 births¹. The metabolic, endocrine, and neurological body systems are affected and it presents with several behavioural, developmental, and intellectual challenges¹. Other physical characteristics include hypotonia, atypical body composition, short stature¹.

Children with PWS also experience distinct nutritional phases, including hyperphagia, an extreme, insatiable hunger². If left uncontrolled, this often leads to the development of obesity during childhood, which has been identified as the most important health problem in this population².

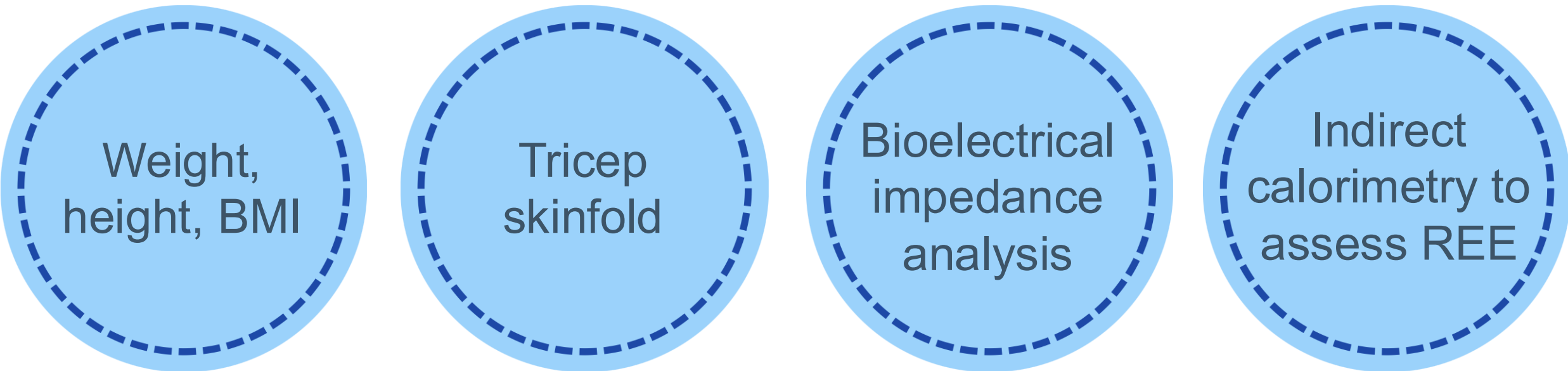
Dietetic intervention is based on energy (calorie) restrictions, however recommended energy intakes across the literature vary considerably². Predictive equations that are used across standard dietetic practice to predict energy requirements are not specific to a paediatric PWS population and therefore do not account for the differences in growth and body composition².

Aim

Given the differences in recommended energy intake, along with the atypical body composition and an identified gap of there being no PWS-specific predictive equations for a paediatric population, this study aimed to explore the growth and energy requirements of children with PWS, and understand how measured resting energy expenditure (REE) compared to predicted values using existing equations.

Methods

This cross-sectional observational study was conducted at The Royal Children's Hospital in Melbourne, Australia and included participants with PWS aged between 2 and 17 years. Eligible participants attended an outpatient clinic appointment where the following measurements were taken:



Alongside this, further data was collected via:

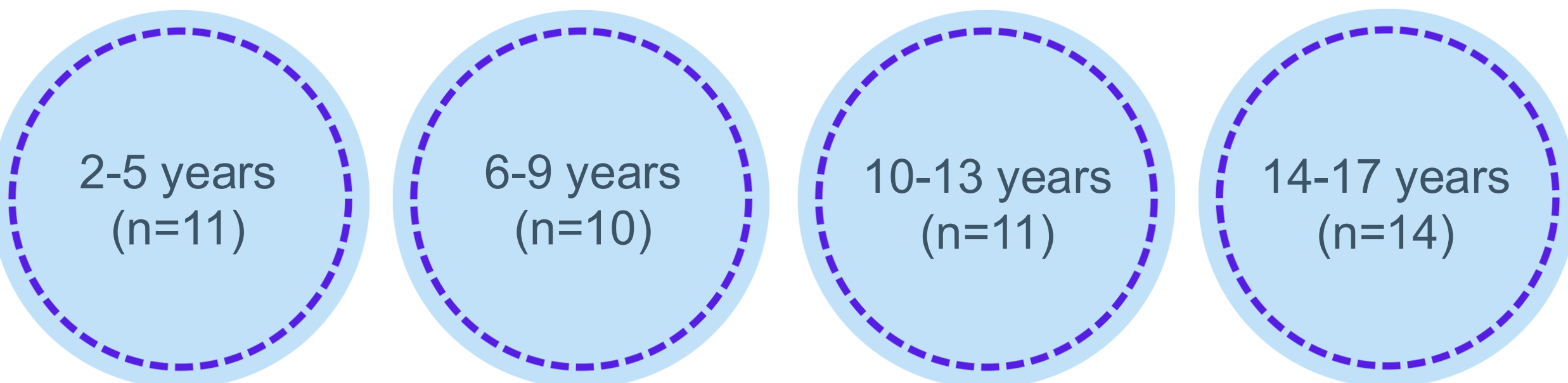
1. Self-developed parental questionnaire
2. Hyperphagia Questionnaire for Clinical Trials (HQ-CT)
3. Children's Leisure Activities Study Survey (CLASS)
4. Pedometer
5. 3-day food diary

Descriptive statistical analyses were conducted using IBM SPSS Statistics (Version 30.0 (172)) with significance set as $P < 0.05$.

Results

Descriptive summary:

- Total of 46 participants were enrolled and completed data collection
- 57% male (26 male, 20 female)
- Distribution of age as below:



Approximately 75% (n=33) of the participants were on growth hormone therapy. Body fat percentage ranged from 19.5% to 65.1%, with z-score values trending downwards as age increases. The average REE as kcal/kg was 31.4 kcal, with the average REE as a percentage when compared to predicted values was 96% (figure 1). Figure 1 presents data from 42 participants who completed indirect calorimetry. Measured REE results were adjusted by 10% for those who were not in a fasting state to account for diet induced thermogenesis.

Figure 1

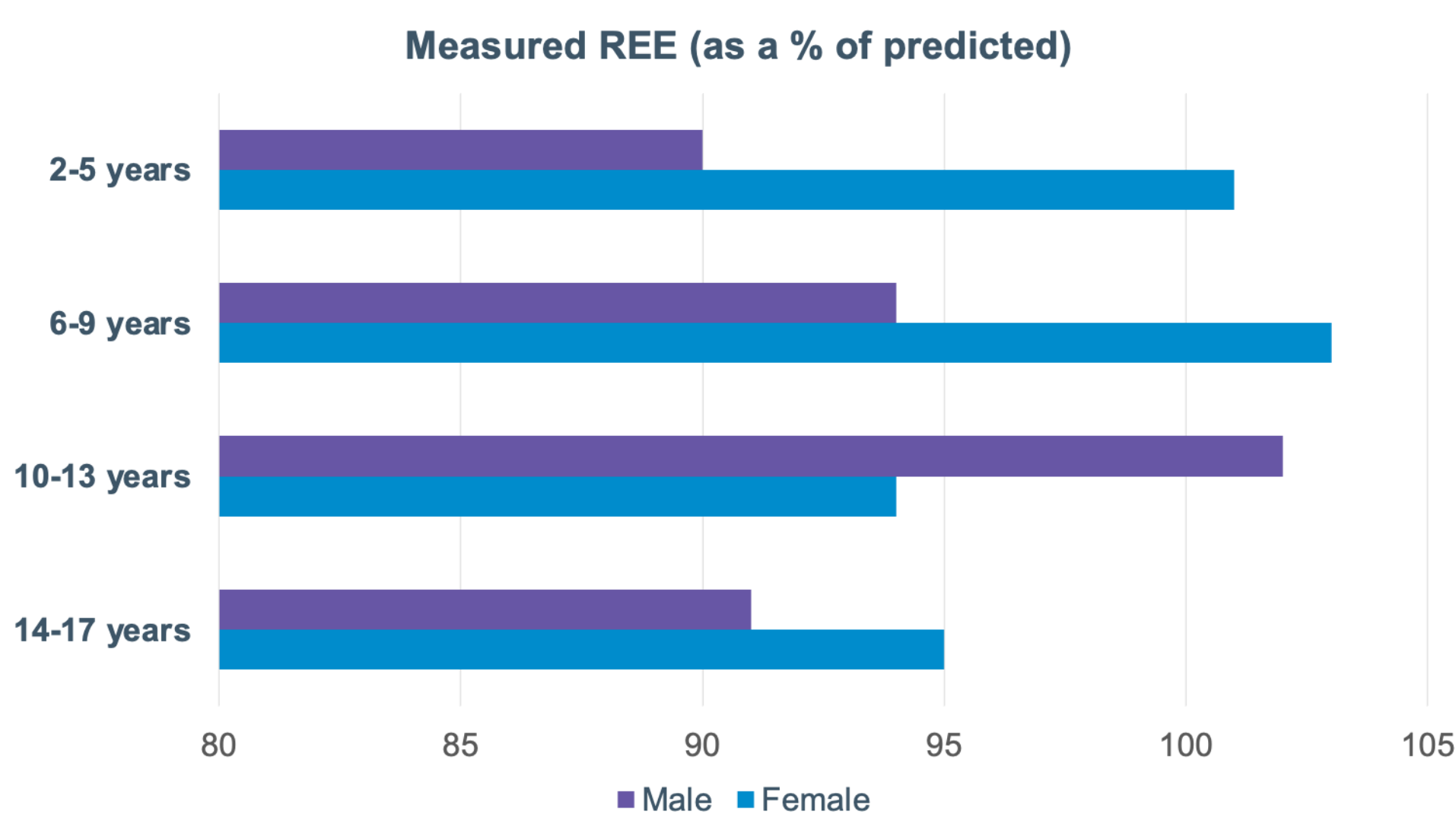
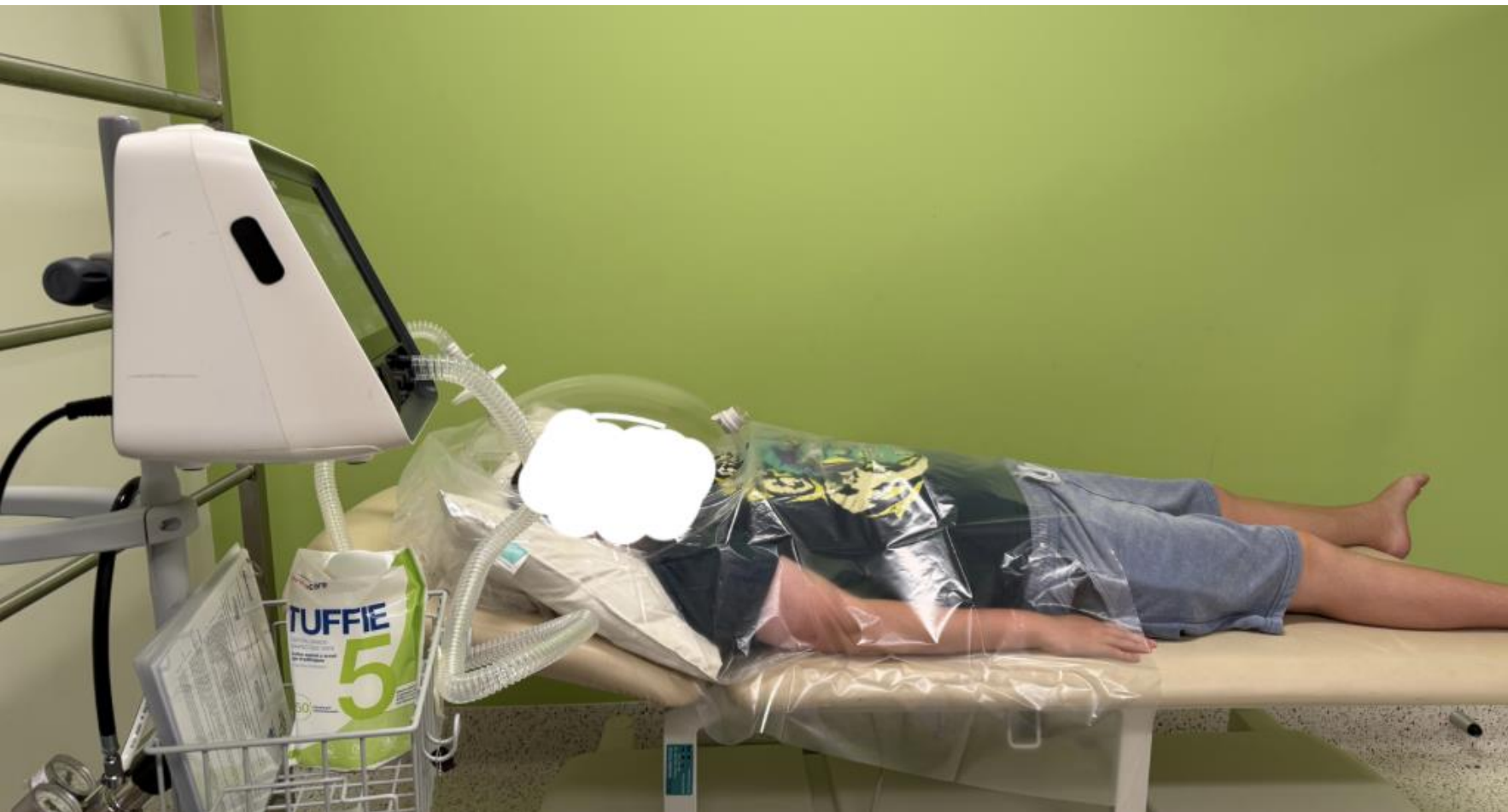


Figure 2



Description: Participant undergoing indirect calorimetry test

Discussion

This study demonstrates that the REE of children with PWS, assessed via indirect calorimetry, was comparable to predicted energy expenditure in this cohort, with a range of 90-103%. This is higher than values presented in past literature for individuals with PWS, which vary from 60-97%. However, there was substantial variability observed based on age and sex of participants. The observed changes in REE, BMI, and body composition over the ages and across sexes supports the need for individualised predictive equations that factor in age, sex, weight, height, and body composition.

Future work will include using the collected data to develop and validate new predictive equations. This would address a critical gap in the literature, as no predictive equations have yet been developed specifically for estimating energy requirements in a paediatric PWS population.

Additionally, the relationships between energy requirements and dietary intake, body composition, and infant growth rate will be explored.

Conclusion

New predictive equations specifically designed for children with PWS, which consider age, sex, weight, height, and body composition may enable more accurate estimations of energy requirements and assist in preventing excessive energy intake and thereby reduce the risk of obesity in children with PWS. Furthermore, findings may contribute to a more comprehensive understanding of metabolic regulation in this population and inform future clinical guidelines.

References

1. Daley, S.F., M.A. Fermin Gutierrez, and M.D. Mendez, *Prader-Willi Syndrome*, in *StatPearls*. 2026, StatPearls Publishing Copyright © 2026, StatPearls Publishing LLC.: Treasure Island (FL).
2. Halilagic, A., Longmore, D. K., Gilbertson, H., & Moschonis, G. (2024). Methods of Determining Energy Expenditure in Individuals with Prader-Willi Syndrome: A Systematic Literature Review. *Nutrients*, 16(13), 2161. <https://doi.org/10.3390/nu16132161>