Protein recommendations for adults with Phenylketonuria: One-size does not fit all

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BACKGROUND

For adults >18 years of age, the 2017 European dietary management guidelines for Phenylketonuria (PKU) recommend a protein intake of 0.83g/kg/day (FAO/WHO/UNU 2007) with an additional 40% from protein substitutes1. The evidence informing the protein requirements in adults with PKU is limited2. Furthermore, the optimal amount of protein substitute has caused extensive debate and remains undetermined3.

A survey conducted in 2013 amongst 63 European and Turkish Inherited Metabolic Diseases centres from 18 countries found no uniformity in the prescribing practices of total protein intake for people with PKU4.

METHODS

An online survey was sent to the British Inherited Metabolic Diseases subgroup of Dietitians working with adults with PKU to understand the clinical practice for protein recommendations for adults following a phenylalanine restricted diet, and circumstances where these recommendations vary.

RESULTS

Twelve Dietitians from nine UK-based centres completed the survey. 25% of respondents had changed their practice to align with the 2017 European guidelines. The remaining 75% of respondents utilised other protein recommendations (Fig 1).

![Figure 1: Protein requirements used for adults with PKU (>18 years of age)](image-url)

*Either 1-1.2g/kg/day or 0.83g/kg minus grams dietary protein x 1.2
RESULTS

25% of respondents reported they would alter protein requirements depending on patients’ ages, with majority considering an increase for patients >65 years of age. For patients undertaking high-intensity cardio-based exercise or high-intensity resistance-based exercise, 33% and 58% of respondents, respectively, would advise a different protein requirement with variable practices being used under these scenarios. Majority of respondents would recommend changing the timing of ingesting protein substitutes for individuals participating in exercise.

Respondents indicated that patients ‘often’ or ‘sometimes’ raise concerns about getting adequate protein for muscle growth (58% of respondents), for exercise and recovery (83% of respondents), and to keep healthy when on a PKU diet (58% of respondents) (Fig 2). Respondents themselves also expressed these concerns (Fig 3).

CONCLUSION

Protein recommendations used for adults with PKU vary across the UK. Further research is needed to establish evidence-based protein recommendations for adults across their lifespan.

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