Validating MyRareDiet®: A Diet Tracking and Monitoring mHealth Tool for Patients with Inborn Errors of Metabolism

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Background

Inborn errors of metabolism (IEM) are a group of rare genetic disorders that are often managed by diet. Current diet applications are not able to measure specific and multiple amino acids, fats and carbohydrates in the diet. In IEM, paper diet diaries are used to track food intake and influence therapy recommendations, however these diaries are often not adequate to capture what is actually being consumed.

The National Urea Cycle Disorders Foundation (NUCDF) is developing an application called MyRareDiet to be used to improve dietary tracking in patients with IEM.

Objective

The purpose of this study is to evaluate the food diary app MyRareDiet® for people who have or take care of those who have IEM.

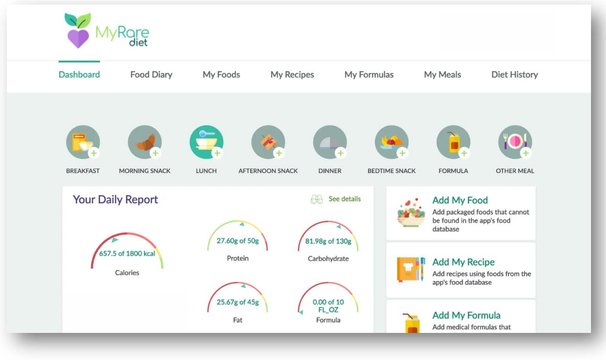
MyRareDiet® is a nutrition software application and mobile application that can be used by patients to track their dietary intake.

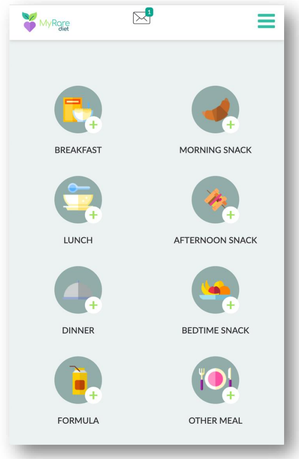
It was developed by BrightOutcome in collaboration with NUCDF. The app uses the nutrient databases of Metabolic Pro (Genetic Metabolic Dietitians International) and the Nutrient Data Systems for Research (NDSR, University of Minnesota). Patients enter the foods and amounts they eat for each meal and the app to convert foods entered into nutrients consumed. Patients with inborn errors of metabolism can use the app to track their protein or specific amino acid intake.

Our Solution: MyRareDiet®

MyRareDiet® is a nutrition software application and mobile application that can be used by people with inborn errors of metabolism to track their dietary intake.

- Designed to serve the dual purposes of diet and research management for individuals with inborn errors of metabolism.
- Participants enter amount and types of foods consumed
- Customizable and includes information on nutritional products specific to this patient population
- Participants can set up formulas or common foods to use repeatedly
- Dashboard tracks total protein intake throughout the day





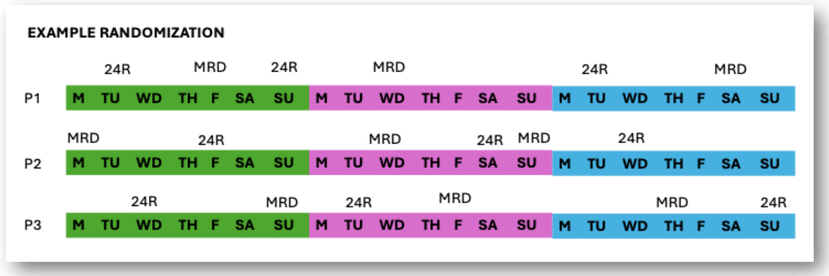
MyRARE DIET

Methods

We are conducting a validation study of MyRareDiet®. Validation of a novel nutrition tool often compares the new tool to an accepted method. We are comparing MyRareDiet® to a dietitian-administered 24-hour diet recall.

- Participants with a Urea Cycle Disorder (UCD), Maple Syrup Urine Disease (MSUD), Propionic Acidemia (PA), and Methylmalonic Acidemia (MMA) were recruited to complete a randomized study.
- They were randomly assigned to complete three days of MyRareDiet® entries and three days of a telephone 24-hour recall with a research dietitian over the course of three weeks including two weekdays and one weekend day.
- Participants were trained how to use MyRareDiet®.
- After training, participants randomly completed the diet entries as illustrated below.
- At the end of the study, participants completed a survey about the use of MyRareDiet®

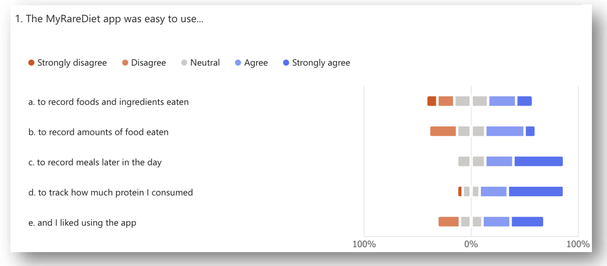
A 24-hour recall is a standard nutrition assessment tool. Participants are interviewed by a trained dietitian about what they ate the previous day. Interviewers use a standard multi-pass method: Quick list of all foods; Review list for forgotten foods; Designate time and meal; Provide details; Final review.



P1,P2,P3, participants 1,2 and 3. M=Monday, TU=Tuesday, WD=Wednesday, TH=Thursday, F=Friday, SA=Saturday, SU=Sunday. Colors indicate weeks 1, 2 and 3. 24R=24-hour recall; MRD = MyRareDiet® diet entry day

Discussion

Thirty-one participants are currently completing the MyRareDiet® validation study. We will compare dietary intake, particularly total protein and total calories, between the 24-hour recall and MyRareDiet® to validate our nutrition app. Follow-up surveys completed by participants to date show overall satisfaction with the experience of using the app. Participants liked the visuals, the easy availability of food databases, and the ability to track daily protein intake. Some found the food entry process frustrating. Of 19 respondents, 11 (58%) would like to continue using the app to track food intake.



Learn More

To learn more about MyRareDiet®, visit this informational article:

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This project is funded through a NICHD-funded **Small Business Innovation Research (SBIR) NICHD grant.**
Contract Number: 1R44HD107766-01A1
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