

THE SIMPLIFIED DIET FOR PKU ON HOW MUCH PHE

Detailed Appendix Data Sheet for *The Simplified Diet for PKU on How Much Phe*,
presented at the NORD Summit, October 2020

Poster can be found at: <http://pheed.me/simplifiednordposter2020>

Overview

The Simplified Diet for PKU is designed to provide additional freedom in tracking intake, and to encourage consumption of more fruits and vegetables. Implementation varies, but most clinics in the US & Canada reduce the phe or protein Rx from “counted” foods and provide the patient with a list of, or criteria for, foods that do not need to be counted and can be considered Simplified. HowMuchPhe.org, an online low-protein diet-management platform, allows users to activate Simplified Diet Tracking, and has identified, in consultation with 12 RDs, ~1600 foods that can be tracked as Simplified. These foods are recorded in the food record with their calories, but the phe/pro/exchanges are not counted toward the user’s daily allowance.

Population Breakdown

- Current accounts (an account may have more than one profile/patient): 2,351
- Profiles that have activated tracking (represents an individual with PKU or other IEM): 2194
- Profiles with PKU that have activated the Simplified Diet option: 382 (17.4%)
- An average of 350 profiles track on any given day
- Of the 382 Simplified Trackers, our cohort of 38 users (10%) tracked at least 50% of the days during their 2019 tracking period, and consistently tracked using the Simplified Diet features. The data below concerns those 38 trackers.

Tracking Method

- Phe: 20 (53%)
- Pro: 17 (45%)
- Exchanges: 1 (<1%)

Age Group

- 1-5: 14 (37%)
- 6-12: 13 (34%)
- 13-18: 2 (<1%)
- 19-30: 1 (<1%)
- 31+: 8 (21%)

Kuvan usage (current)

- No: 24 (63%)
- Yes: 14 (37%)

Geographical Distribution (US State or Canadian Province)

AB, Canada	1		NJ	1
CA	1		NY	2
CO	1		OH	2
DC	1		ON, Canada	2
FL	1		PA	2
IA	1		SC	1
IN	1		TN	2
LA	1		TX	3
MA	3		UT	2
MB, Canada	1		WI	1
ME	1			
MI	2			
NC	5			

Intake Breakdown by total phe

	Mean	Median	Min - Max	SD
Sum of counted phe	389.5	292.7	0-3093	329.89
Sum Untracked (Simplified) phe	20.97	0	0-422.26	39.9
Total daily intake	410	307	20-3093	334.7
Tolerance	432	305	25-2650	357
Daily intake as percent of tol	99.26	99.85	50-327.84	23.54
Percent daily simplified	6.5	0	0-100	11.74

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Simplified Intake Breakdown - phe by category

- a. Fruit 39.8%
 - i. Bananas are most common of the fruits
- b. Veg 18.3%
 - i. Fresh, Cooked, Canned nearly perfectly split in thirds
- c. Medical food 13.8%
 - i. Pasta 66.6%
 - ii. Medical Formula 10.2%
- d. Condiments 3.77%
 - i. Pickles 16.5%
 - ii. Spreads 16.5%
 - iii. Syrup 13.8%
 - iv. Catsup/Ketchup 9.17%. Accounts for 1612 mg phe
 - v. Dairy Alternatives 2.92%
 - vi. Cheese, yogurt, milk
- e. Fat 5.19%
- f. Drinks 2.47%
 - i. Juice 67.6%
 - ii. Dairy Alt 8.82%
 - iii. Alcohol 5.88%
 - iv. Soda 8%** we filtered out
 - v. Coffee 5.88%
- g. Grain Gluten Free 2.27%
 - i. Pasta 41.4%