

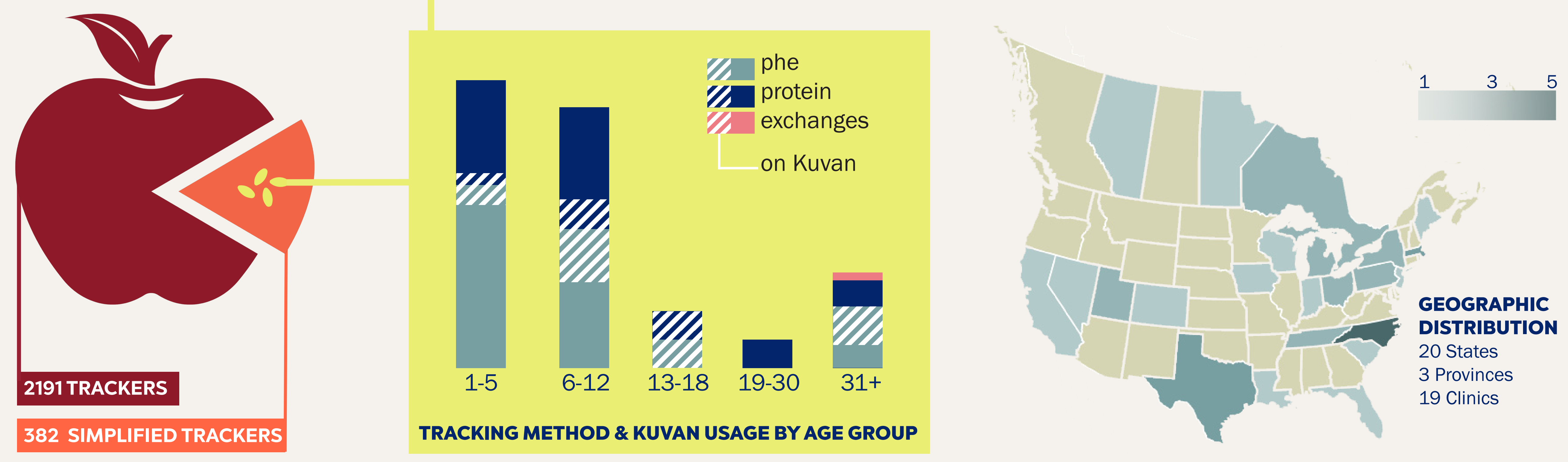
THE SIMPLIFIED DIET FOR PKU ON HOW MUCH PHE

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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.

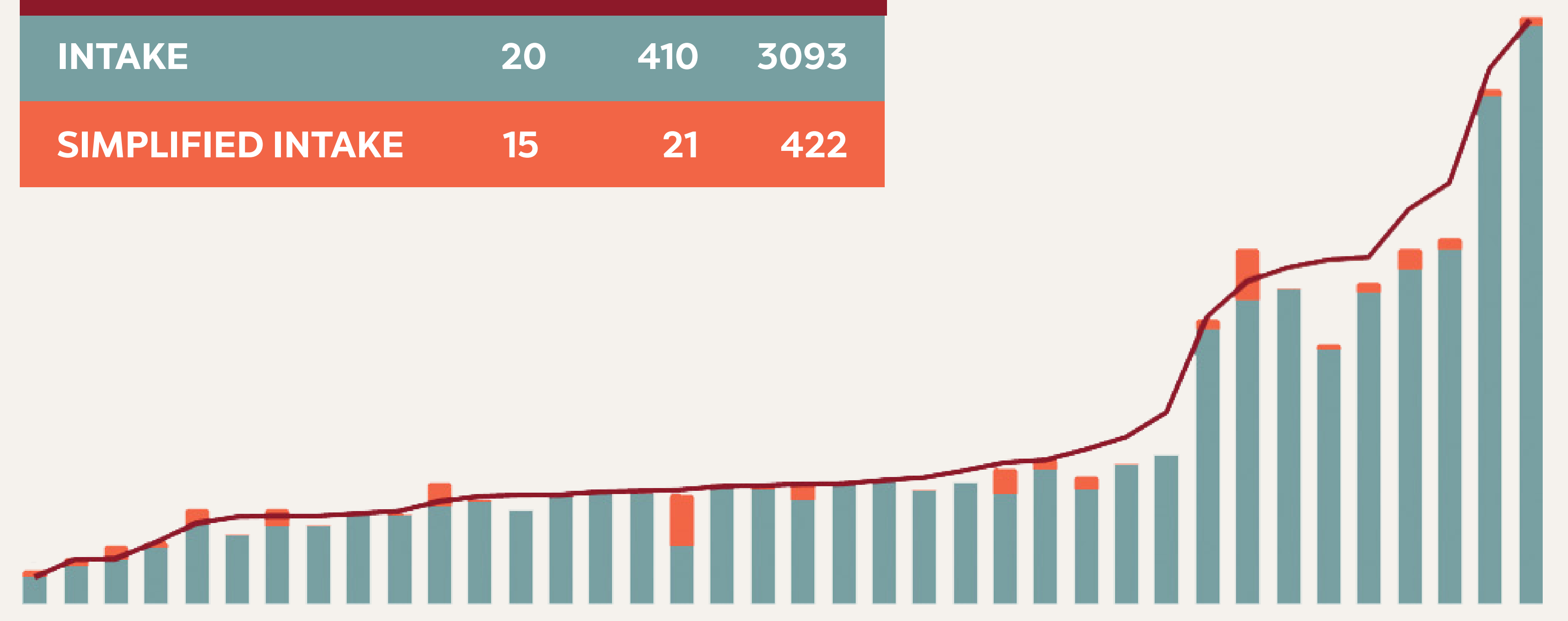
WHO ARE THE SIMPLIFIED TRACKERS ON HowMuchPhe.org?

Data represents a cohort of 38 individuals who consistently used simplified tracking & tracked on at least 50% of the days during their 2019 HMP subscription.



HOW MUCH OF THEIR TRACKED INTAKE IS SIMPLIFIED FOODS?

	MIN	MEAN	MAX
TOLERANCE	25	432	2650
INTAKE	20	410	3093
SIMPLIFIED INTAKE	15	21	422



6.5%
of average tracked daily intake was Simplified Foods

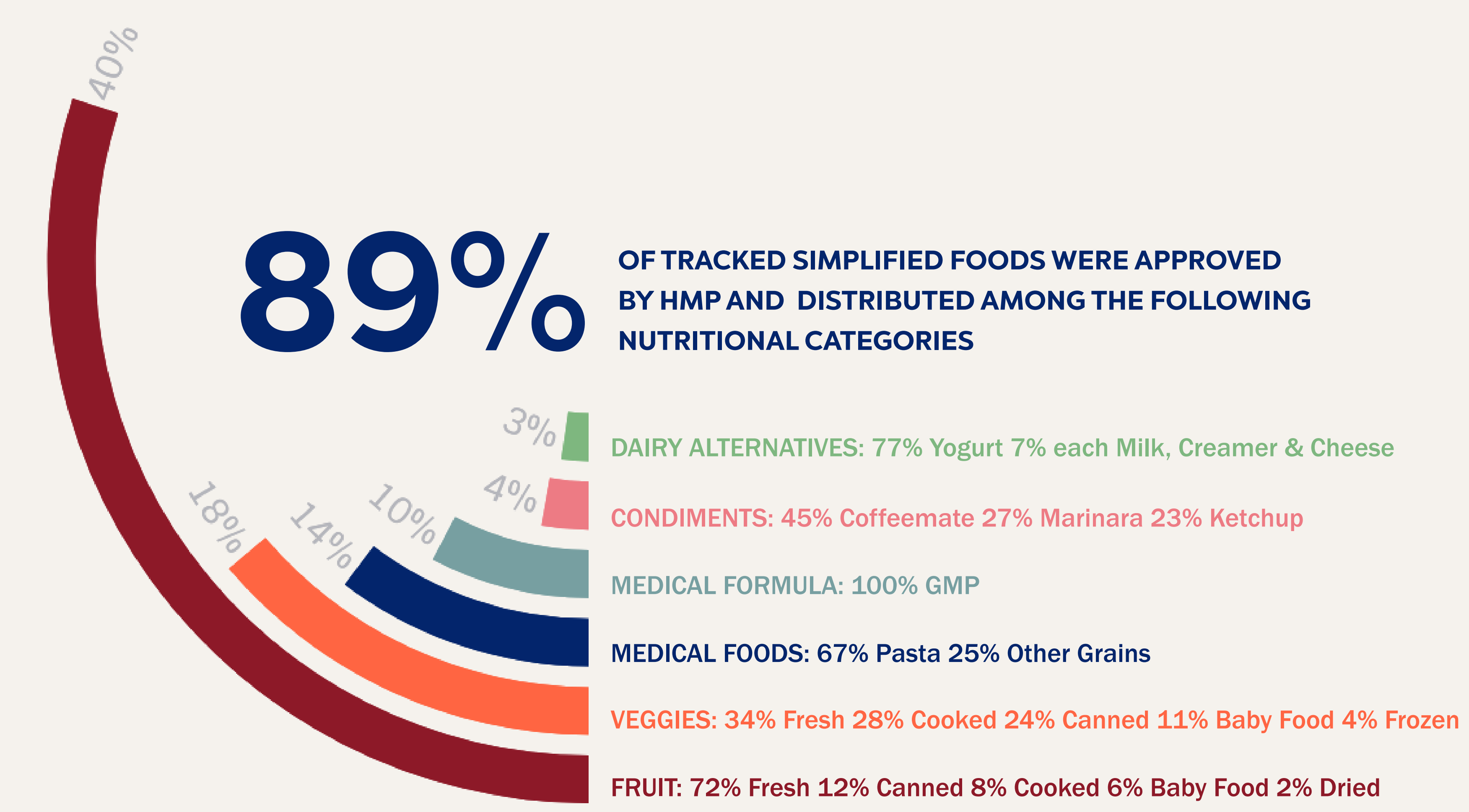
21 FREE **410 COUNTED**
Mean phe per day in mg

99.25%
Percent of tolerance per day was tracked on average

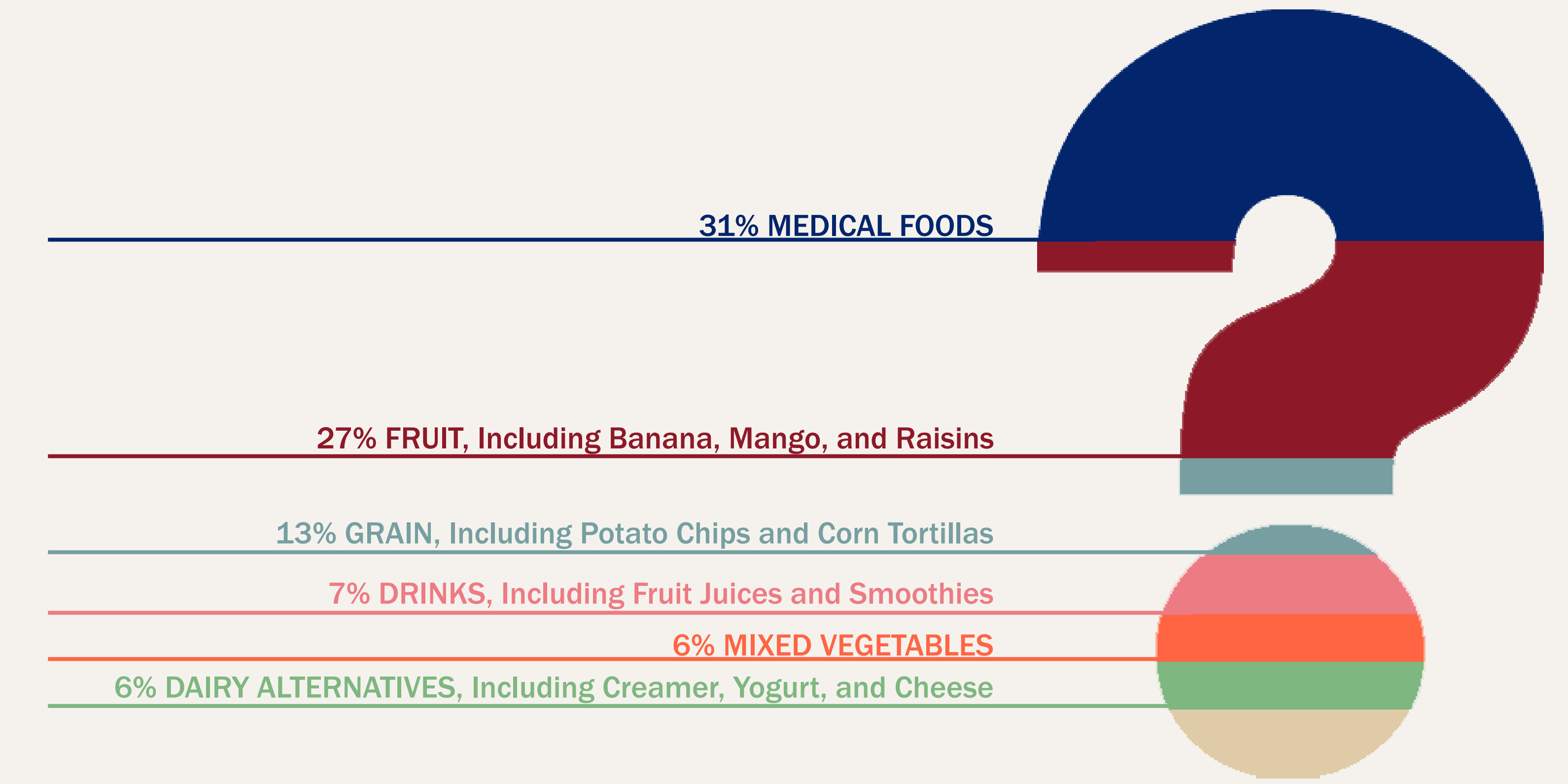
432
Mean tolerance (in mg per day)
Cohort members averaged 10 (min 1/max 43) dietary Rx adjustments throughout their 2019 tracking period

Whether users choose to track in mg of phe, grams of pro, or exchanges, all these values are recorded for each record. For ease of comparison, we've used the mg of phe data for all users in the cohort. Within the cohort's tracking records in 2019, only days on which the user tracked at least 50% of their tolerance were included in quantitative intake analysis.

WHAT ARE THESE SIMPLIFIED FOODS?



11% OF TRACKED SIMPLIFIED FOODS WERE CREATED BY USERS. THEIR TRUE PHE/PRO CONTENT IS UNKNOWN. 1/3 OF THOSE FOODS WERE LABELED AS RECIPES. THE REST ARE DISTRIBUTED AS FOLLOWS



IS IT THAT SIMPLE?

- **THESE DATA ONLY SHOW WHAT PEOPLE TRACK** 382 people have turned on Simplified Tracking, but only 235 have ever tracked anything as Simplified (60%). We don't know if this means they are eating additional untracked Simplified Foods.
- **WE'RE ON THE RIGHT TRACK** 89% of the foods tracked as Simplified are approved by HMP as Simplified Foods, which suggests the parameters for allowing foods to be tracked as Simplified are reasonable.
- **SIMPLIFIED FRUITS ARE VERY POPULAR** The most popular simplified fruit is the banana (consumed an average of 16 times year/user in the cohort). The most popular Simplified veggie is carrots (12 times user/year on average).
- **ROOM FOR MORE?** The diet records of this cohort of conscientious trackers indicate that they are consuming far less than the 30% of the prescription many clinics allow for in Simplified Foods. More research is necessary to confirm.

WANT MORE THAN PRETTY PICTURES?
The full data set & detailed notes for this study can be found at pheed.me/simplified2019 or by scanning this QR Code.

ACKNOWLEDGMENTS

We owe a debt of gratitude and expertise to the group of RDs who worked with PKU News & How Much Phe to help develop our guidelines for Simplified Diet Tracking, to Anne O'Neill, RD, for suggesting we record for analysis the "hidden" phe/pro that users track as Simplified, and to our dedicated user community.