

Understanding Why Research Participants Refuse to Donate Data from Personal Wearable Devices

2020 Internship Showcase

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Personal Wearables and Public Health: Background

- Personal wearables (e.g., Apple Watch, FitBit) are becoming commonplace among the public.
 - These devices track daily physical activity (PA) through several metrics and help users maintain healthy lifestyles.
- Public health researchers also benefit from accessing PA data on research subject devices.
 - Wearable PA data avoid certain forms of measurement error (e.g., social desirability bias) and are more detailed than self-report data.

Personal Wearables and Public Health: Problem

- However, research subjects often do not want to donate the data on their personal wearable devices.
- This creates two problems for public health researchers:
 1. Reduced sample size: Researchers have less data to draw inference from.
 2. Selection bias: Those who refuse to donate are systematically different from donators.

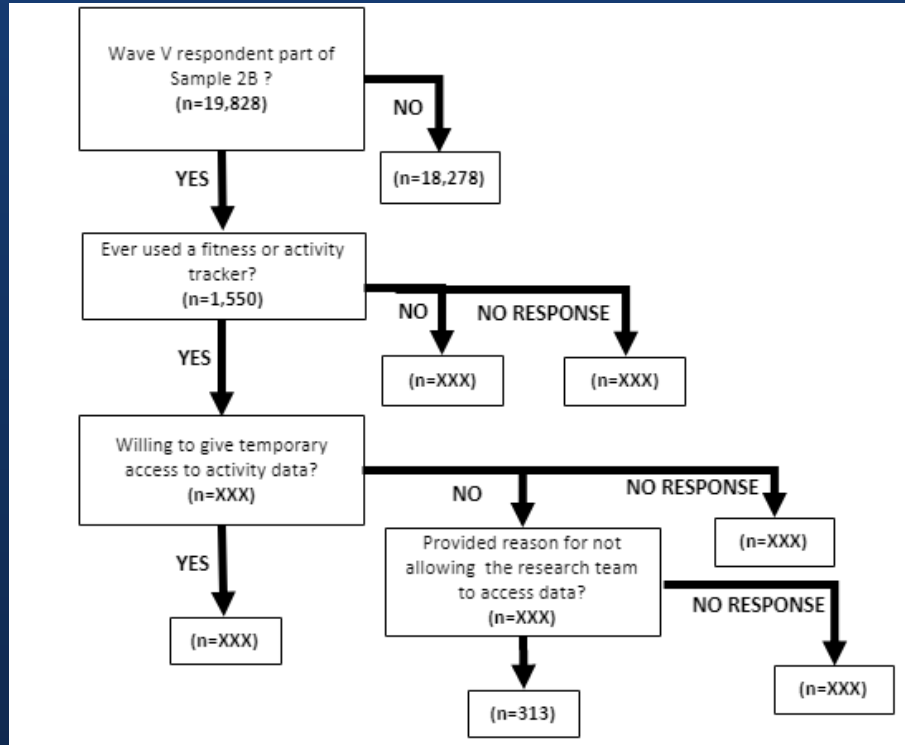
Personal Wearables and Public Health: Our Contribution

- What common refusal reasonings do respondents with personal wearable devices give?
- We qualitatively analyze a large cohort study and offer recommendations based on the results for researchers relying on PA data from personal wearable devices.
 - These recommendations are aimed toward alleviating research subject concerns and increasing willingness to donate wearable data.

Describing the Add Health Data

- **Data Source:** Wave V of the National Longitudinal Study of Adolescent to Adult Health (Add Health) was the source.
- **Sample:** Sample 2B from Wave V (N = 1550) included a Fitness Tracking module that asked respondents to donate historical PA data from their devices.
- **Key Variable:** Those who refused donation were asked to explain in an open-ended format why they refused to donate.

Add Health Wave V Fitness Tracking Data Flow



Note: We are currently waiting on numbers for some branches from Add Health.

These branches are denoted by n = XXX.



Our Analysis Strategy

We are still waiting for access to data

- Add Health Wave V data
- Raw open-ended responses from Sample 2B

Our plan is to look at the open-ended refusal responses and categorize them based on common barriers

- We will also look at which types of individuals tend to express certain types of concerns

Reasons for Refusal Categories Example

Category	Frequency	% of Total	% of Valid
Privacy	107	0.9	30.2
No Reason	76	0.6	21.5
Technical Difficulties	59	0.5	16.7
Stopped Using	44	0.4	12.4
Data Security	27	0.2	7.6
Hassle	16	0.1	4.5
Survey Fatigue	13	0.1	3.7
Lack of Incentive	6	0.0	1.7
Do not Understand	3	0.0	0.8
Physical Inactivity	3	0.0	0.8
TOTAL	354	2.9	100

Categories
provided by Add
Health
codebook

General Takeaways on Donation Refusal

- Personal privacy is most common reason for refusal
- Are respondent concerns founded?
 - Researchers can take action to alleviate misperceptions (e.g., concern over data that will not be collected)
- Who has what concerns?
 - Certain individuals may be systematically more likely to express certain reasons for refusal

Our Recommendations for Increasing Donation Rates

1. Improved Consent Forms: What specific data is being collected, how is it being analyzed, and for how long?
2. Incentive: Give respondents a reason to donate data. This is shown to alleviate concerns from some of the categories.
3. Strategic Intervention: Customize consent forms and time donation asks based on individualized respondents.



Thank you

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