Add Health Consumer Wearable Ancillary Study

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delivering **the promise of science**
for global good

RTI International is an independent, nonprofit research institute dedicated to improving the human condition. We combine scientific rigor and technical expertise in social and laboratory sciences, engineering, and international development to deliver solutions to the critical needs of clients worldwide.

Wearable device data elements

Self-report

- Height
- Weight
- Age
- Gender

Basic Dataset

- Steps
- Distance traveled
- Floors climbed
- Calories burned
- Active minutes
- Sedentary minutes
- Specific exercises / activities
- Sleep time
- Sleep quality

Expanded Dataset

- Heart rate
- Fitness score
- Workout routes and pace
- NN interval
- RR interval
- Respiratory rate
- Tidal volume
- Minute ventilation
- Abdominal / thoracic respirations

Wearable devices enable low-cost, distributed, passive, longitudinal measures of human behavior and physiology.

ClinicalTrials.gov

Fitbit Research Library
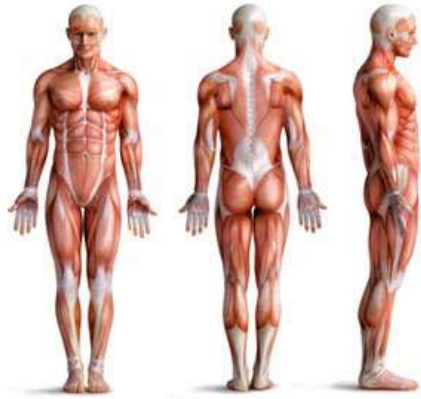
431 devices are available from 266 different vendors.

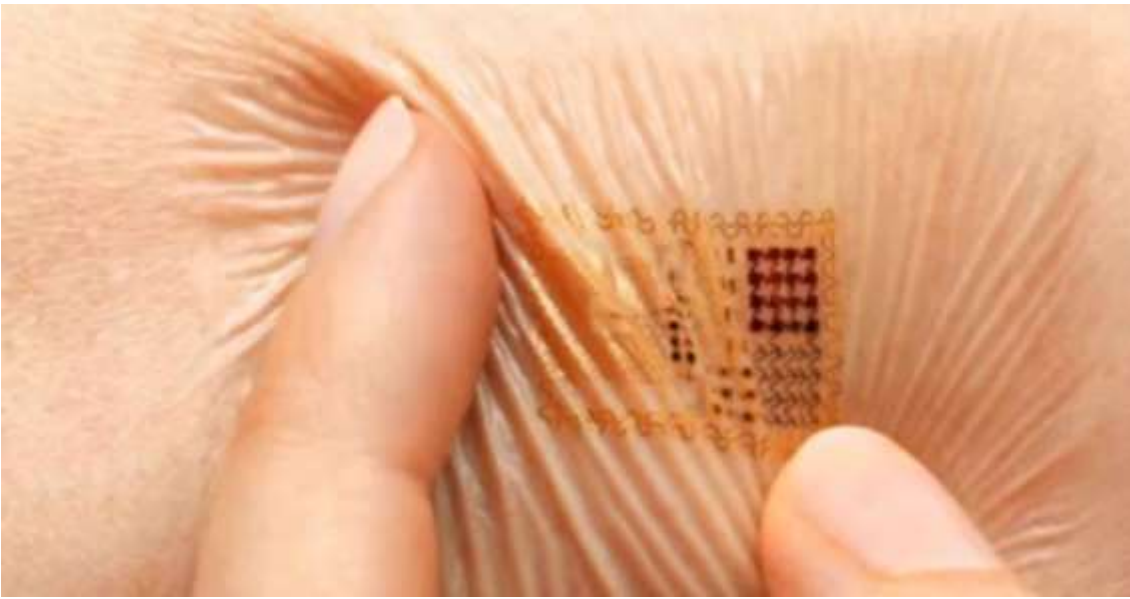335 registered clinical trials are using Fitbit devices for data collection.

Over 682 papers have been published on Fitbit devices since 2012.

National Longitudinal Study of Adolescent to Adult Health (Add Health)

Add Health

- Longitudinal study of a nationally representative sample

- Adolescents in grades 7-12 in the United States in 1994-95

- Have been followed through adolescence and the transition to adulthood with four in-home interviews

- Add Health is re-interviewing cohort members in a Wave V follow-up

- Collecting social, environmental, behavioral, and biological data

Add Health – Data access and use

- From its inception, Add Health has promoted use of its data across social science, public health, human development, biomedical sciences, and related fields

- Global data resource for over 10,000 users

- Pioneer in the secure release of confidential data

- Add Health has no proprietary period

- Access to new waves of data the same day as program investigators

Add Health - Publications

Add Health

The National Longitudinal Study of Adolescent to Adult Health

Search Site | Search

☐ only in current section

🐦 Follow @Add_Health

| About | Study Design | Data | Contracts | FAQ | Publications | Participants |

Publications

The Add Health bibliography includes **more than 6,000** journal articles, presentations, unpublished manuscripts, books, book chapters and dissertations by Add Health researchers. To obtain a copy of any item, please check the citation to see if a URL link to the article is available, or contact the author. New users may want to refer to the user guides and documentation written by Add Health staff for help with understanding and analyzing Add Health data.

Is one of your publications missing from our database? Please email addhealth@unc.edu with the full citation, and we'll add it to the database.

Search For: [   ]   **Sort By:** [Year (Reversed), Author, Title ↕]

Limit To:

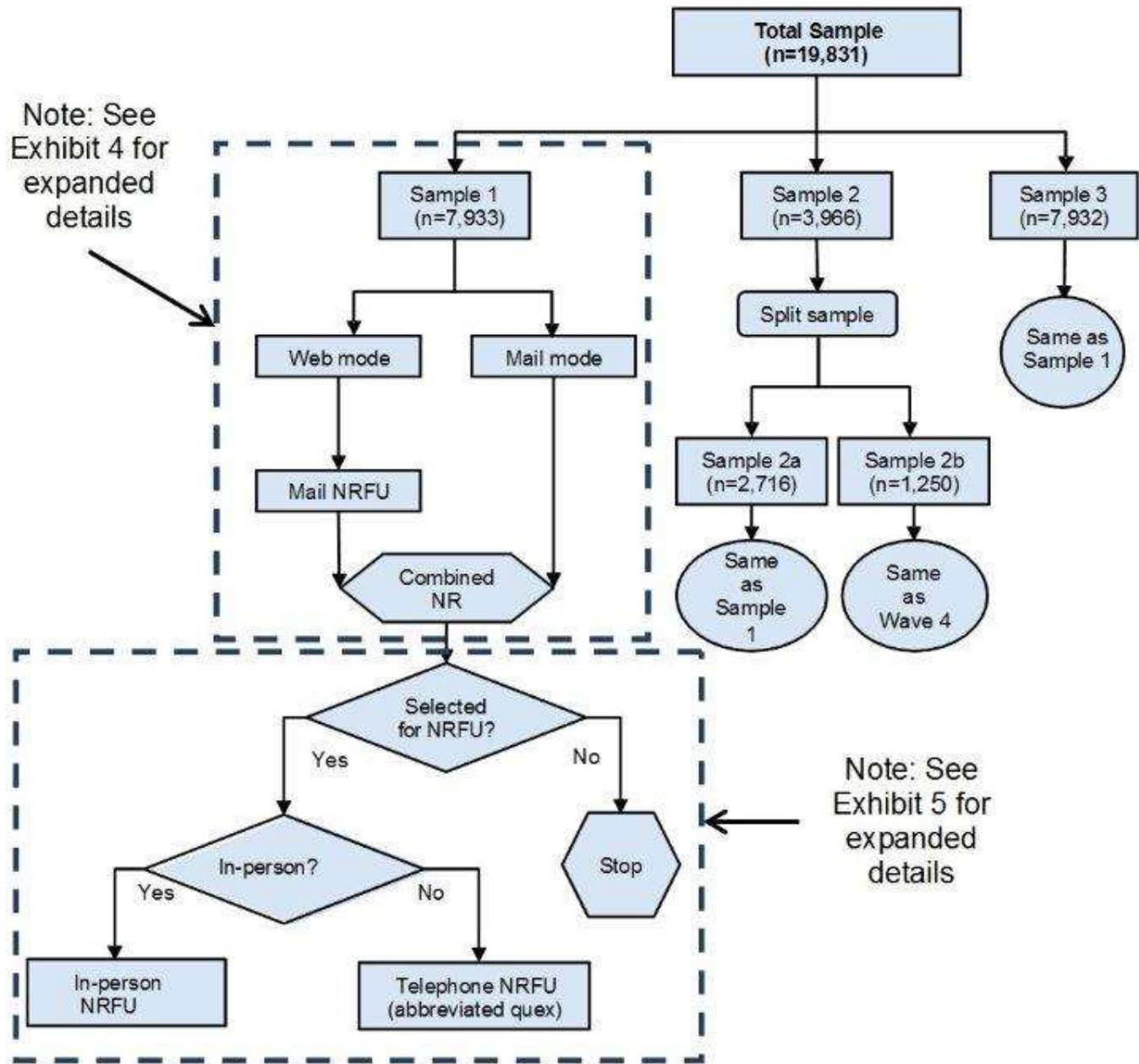☐ Book   ☐ Journal Article   ☐ Thesis / Dissertation
☐ Book Chapter   ☐ Magazine Article
☐ Conference Proceeding / Presentation   ☐ Report / Working Paper

[Search]   Advanced Search

Total Sample (n=19,831)

Note: See Exhibit 4 for expanded details

Sample 1 (n=7,933)
- Web mode → Mail NRFU
- Mail mode
- Combined NR

Sample 2 (n=3,966)
- Split sample
  - Sample 2a (n=2,716) → Same as Sample 1
  - Sample 2b (n=1,250) → Same as Wave 4

Sample 3 (n=7,932) → Same as Sample 1

Selected for NRFU?
- Yes → In-person?
  - Yes → In-person NRFU
  - No → Telephone NRFU (abbreviated quex)
- No → Stop

Note: See Exhibit 5 for expanded details

Add Health Consumer Wearable Ancillary Study

Add Health Consumer Wearable Ancillary Study - Aims

- Aim 1: Determine rates of smartphone and consumer wearable device adoption within the Add Health cohort.

- Aim 2: Invite cohort members identified in Aim 1 to make a one-time donation of historical data collected using personally owned wearable devices.

- Aim 3: Prepare a harmonized dataset.

- Aim 4: Conduct preliminary analysis of wearables data, including device types, duration and consistency of tracking, and physical activity outcomes.

Add Health Consumer Wearable Ancillary Study - Survey

1. Do you own a smartphone?

2. If yes, what kind?

3. Do you use smartphone apps to track or manage your health?

4. If yes, what category of wellness do you track or manage?

5. Do you own a wearable device?

6. If yes, what kind?

7. Would you be willing to donate your personal data to Add Health?

8. If no, please specify reason why.

Add Health
The National Longitudinal Study of Adolescent to Adult Health

Dear [NAME_FILL],

When you were interviewed for the Add Health Study, you indicated that you own a [DEVICE_FILL], and that you are willing to share some of your [DEVICE_FILL] data with Add Health researchers. The only data our researchers are collecting are height, weight, daily number of steps, floors climbed, distance walked or run, stride length, intensity of physical activity, and calories burned if this information is logged with your [DEVICE FILL] app or dashboard.

If you are still willing to share this information with us, please follow the link below to complete this process. It should take less than five minutes to complete.

<insert pghd url>

If you have any questions about this part of the Add Health Study, please contact Robert Furberg at rfurberg@rti.org or 919-316-3726. For questions about the study in general, you may contact addhealth@rti.org or 1-866-382-6814.

Thank you again for your participation in the study.

Sincerely,

Kathleen Mullan Harris

Kathleen Mullan Harris, PhD.
Principal Investigator, Add Health
University of North Carolina at Chapel Hill

Robert Furberg, PhD
Principal Investigator,
Add Health Consumer Wearable Ancillary Study
RTI International

Patient-Generated Health Data

Empowering the patient and harnessing the proliferation of smart phones and remote monitoring devices for sharing health data.

What is PGHD?

Patient-Generated Health Data, or **PGHD**, are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern.

AddHealth Data Flow
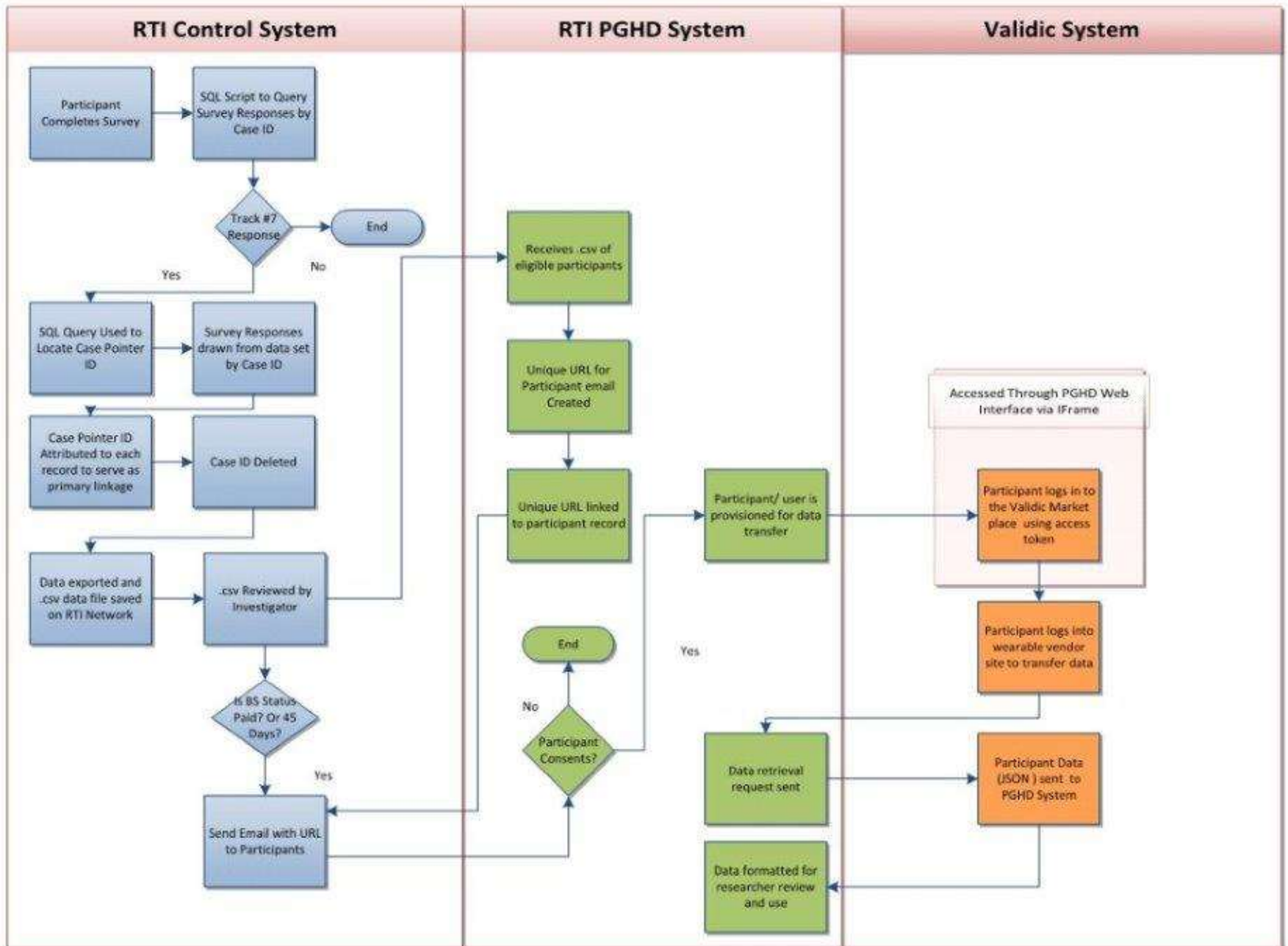
Current metrics

- 11,725 cases completed

- 955 wearable device owners
  - 485 agreed to donate their personal data
  - 470 declined

- Some of our most immediate questions include
  - How many participants are lost to eIC or on-boarding?
  - What are the characteristics of the wearables datasets we receive?
  - Prevalence of devices by model + features

Unexpected findings

- Device ownership rate is lower than expected
  - 8.14% adoption

- Data donation rate is higher than expected
  - Over 50% agreed

Next steps

- Add Health Wave V data collection will be complete by 31OCT

- Statisticians will begin weighting all Wave V items collected

- An effort will be made to harmonize the wearables data

- Documentation will be drafted to summarize validation literature

- Wearables dataset will be submitted for review by Add Health

- If approved…

…will be the first study to generate a public-use consumer wearable device dataset, linked to individual survey responses, biospecimens, and clinical measured collected from members of an NIH cohort.

More Information

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