

Health Data Exploration

Survey Questions - Researchers

[age]

What is your age?

Please choose only one of the following:

- 18-25 years old
- 26-35 years old
- 36-45 years old
- 46-55 years old
- 56-65 years old
- 66 years or older

[uslive]

Do you live in the United States?

Please choose only one of the following:

- Yes
- No

[uswork]

Do you work or study primarily in the United States?

Please choose only one of the following:

- Yes
- No
- I am not currently working or studying

[role]

What is your current role? Please choose the category that is closest to your role.

Please choose only one of the following:

- Senior institutional leadership (e.g. CEO, President, VP, director, department head)
- Academic staff (e.g. professor, senior lecturer, lecturer)
- Research staff (staff who primarily conduct research, e.g. research scientists, postdoctoral researchers, and contract researchers)
- Management and administrative staff (staff whose responsibility focuses on a functional area or services)
- Graduate or post-graduate student
- Other position at an institution
- Not currently working at an institution

[sector]

What sector are you currently in? (Please choose the category that best matches your primary affiliation.)

Please choose only one of the following:

- Academia
- Industry
- Government
- Non-Profit
- Self-employed
- Not currently employed
- Other

[resengag]

Please choose the statement below that best matches your current research engagement.

Please choose only one of the following:

- I have never conducted research.
- I used to conduct research, but I am not currently conducting research.
- I currently conduct research but I am not responsible for establishing research goals.
- I currently lead or co-lead research project(s) or program(s).

[resfocus]

Please specify the primary domain areas that best characterize your research focus.

Please choose all that apply:

- Arts & Humanities
- Health Sciences, including Medicine, Pharmacology, Public Health, Epidemiology, and so forth
- Life Sciences
- Physical Sciences
- Engineering & Technology
- Social Sciences
- Other:

[resdesc]

Please describe your research in 1 or 2 sentences.

Please write your answer here:

[consult]

Are you currently or have you ever served as a consulting scientist for a company, research institute, foundation, or governmental body (e.g., NIH, NSF)?

Please choose only one of the following:

- Yes
- No

[resfund]

What are your sources of research support at present and during the past 5 years?

Please choose all that apply:

- National Science Foundation
- National Institutes of Health
- Other federal government
- State or local government
- Community organizations
- Private or not-for-profit foundations or philanthropies
- Corporations
- Venture capital
- Internal organization funding (for example, individual research budget, internal grant competitions, corporate project or product funding)
- Other:

[datasrc]

From what sources have you acquired the data necessary for your research?

Please choose all that apply:

- Collected or generated by me or my close colleagues (e.g. within the same lab or research group)
- From the institutions with which I am affiliated
- Directly from colleagues at other institutions
- From publicly available datasets
- From purchased datasets
- From private companies with whom I have a personal or professional relationship
- From research sponsors
- Directly from private individuals who collected the data
- Other:

[fndpurch]

Do any of your funding sponsors allow you to write into a budget the costs for purchasing data from a third-party vendor to conduct your research?

Please choose only one of the following:

- Yes
- No
- I don't know
- I don't have a current funding sponsor

[acptpub]

Would your organization allow you to accept a dataset collected by a private citizen?

Please choose only one of the following:

- Yes
- No
- I don't know
- Not currently affiliated with an organization

[acptcorp]

Would your organization allow you to accept a dataset donated by a corporation?

Please choose only one of the following:

- Yes
- No
- I don't know
- Not currently affiliated with an organization

[acptrest]

Sometimes proprietary or intellectual property concerns prohibit publishing data or otherwise sharing research data freely. Which of the following statements comes closest to your view about using proprietary data in your research?

Please choose only one of the following:

- In my research, I would only use data that could be published or shared.
- While I prefer not to, I would consider using data that could not be published or shared.
- In my research, it would not matter if data could be published or shared.

[humsubj]

Does your research involve human subjects?

Please choose only one of the following:

- Yes
- No

[hsreview]

What ethics or human subjects review procedures are required by your organization?

Please choose all that apply:

- Federally-mandated Institutional Review Board
- Other formal internal review procedure
- Informal peer review
- No review required

- I don't know
- Other:

[resoutput]

What are the primary outputs and results of your research?

Please choose all that apply:

- Published articles, papers, or books
- Published reports
- Internal or confidential (unpublished) reports
- Patents
- New products or procedures
- Software, algorithms, or code
- Other:

[reqshare]

Are you required by your organization, funding sponsors, journals, or norms in your field to publish or otherwise share the data you use in your research?

Please choose only one of the following:

- Always
- In most cases
- In some cases
- Not required to share data
- I don't know

[reqimp]

How are requirements on publishing data imposed?

Only answer this question if the following conditions are met:

Answer was 'In some cases ' or 'In most cases ' or 'Always ' at question '22 [reqshare]' (Are you required by your organization, funding sponsors, journals, or norms in your field to publish or otherwise share the data you use in your research?) and Answer was 'In some cases ' or 'In most cases ' or 'Always ' at question '22 [reqshare]' (Are you required by your organization, funding sponsors, journals, or norms in your field to publish or otherwise share the data you use in your research?) and Answer was 'In some cases ' or 'In most cases ' or 'Always ' at question '22 [reqshare]' (Are you required by your organization, funding sponsors, journals, or norms in your field to publish or otherwise share the data you use in your research?)

Please choose all that apply:

- By my organization
- By funding sponsors
- By journals
- By norms in my field

- Other:

[stdintro]

Recently, a number of devices, software applications, online social media and web sites have become available that help individuals to measure, quantify and otherwise track various aspects of their daily lives. The Health Data Exploration Project is exploring the potential for leveraging these new sources of data for research in health, medicine, psychology, sociology, and other fields. The following questions ask about how these new kinds of “self-tracking” data – individuals’ personal health and activity data -- might fit into your research.

[stduse]

Have you used or are you currently using any kinds of personal self-tracking data in your research?

Please choose only one of the following:

- Yes
- No

[stdusewhat]

What kind of self-tracking data have you used?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '25 [stduse]' (Have you used or are you currently using any kinds of personal self-tracking data in your research?)

Please write your answer here:

[stdtypes]

How useful could the following types of self-tracking data be for your research?

Please choose the appropriate response for each item:

Not At All Useful | Not Too Useful | Somewhat Useful | Very Useful

- Physical activity, exercise, fitness, e.g. pedometer, gym logs
- Weight, Body Mass Index (BMI), or body fat
- Vital signs, e.g. blood pressure, temperature, heart rate
- Mood, state of mind
- Sleep patterns
- Diet, food, e.g. calories, water consumption
- Menstrual cycles, basal body temperature, ovulation
- Medication
- Smoking
- Alcohol consumption
- Environmental exposure data, e.g. air quality, noise
- Blood levels, e.g. insulin, hormones, enzymes
- Meditation, yoga, relaxation techniques
- Stress levels - personal, environmental
- Personal genetic test data (e.g. 23andMe)

[comment_help]

Please tell us what you think would be most helpful to you as a researcher to either continue to conduct research in this area or to begin such research.

Please write your answer here:

[stdsrce]

If you could get the self-tracking data that you need for your research, how likely would you be to use data from the following sources?

Please choose the appropriate response for each item:

Not At All Likely | Not Too Likely | Somewhat Likely | Very Likely

- Directly from self-tracking individuals
- From a publicly available open data repository to which anyone could upload self-tracking data (individuals can upload, researchers can upload)
- From a publicly available curated data repository of donated self-tracking data
- A validated data set that requires paying a fee to access
- A validated data set that limits access to peer-reviewed research projects
- From a company that could provide data from its users
- From a health, clinical or medical institution that could provide data from patients

[stdstmnt]

Rate your agreement with the following statements:

Please choose the appropriate response for each item:

Strongly Disagree | Somewhat Disagree | Somewhat Agree | Strongly Agree

- Data collected in clinical settings will be of higher quality than self-tracking data.
- Self-tracking data will be useful for my research.
- Self-tracking data can help answer questions that other data can not.
- Self-tracking data cannot be trusted.
- There are insurmountable barriers to using self-tracking data in my research.
- Self-tracking data present greater privacy concerns than other types of data.
- Self-tracking data could be valuable in my research if privacy concerns could be addressed.

[vignette]

As with self-tracking data, there are many forms of information – many ‘digital traces’ -- collected about individuals by commercial entities with which they interact and ambient spaces through which they move. For example, when someone shops at the grocery store and uses a loyalty card, data are collected about the foods and purchases. Similarly, when someone uses Facebook or Twitter, information becomes available about his or her social network.

Environmental sensors that gather data on air quality may indicate what individuals have been exposed to by place-based information. Some of these data may also be useful for medical, public health and other research.

[dtdusefl]

If you could authorize it, which of the following kinds of data, if any, would be useful in your

research?

Please choose all that apply:

- How people interact in social networks, social network analysis
- Where people go, where they spend time, hang out
- Shopping practices, consumer behaviors relevant to health and activity
- Frequency of calls made or text messages sent on mobile phones (not the content)
- Places people go as tracked passively by GPS on their phones
- 'Digital traces' of individual activities via passive tracking by an app on a phone, e.g. the person using the phone does not interact with the app but the phone registers its user's movements
- Other:

[stdother]

Are there other kinds of individual self-tracking data that we haven't mentioned that would be useful in your research?

Please write your answer here:

[appcollab]

Have you collaborated or partnered with any companies that make or provide self-tracking apps, devices, or services?

Collaboration and partnership could include setting up data sharing agreements, working together on R&D, etc.

Please choose only one of the following:

- Yes
- No

[smcollabo]

Have you collaborated or partnered with any social media companies or web sites?

Please choose only one of the following:

- Yes
- No

[appwhich]

Which companies have you collaborated or partnered with?

Only answer this question if the following conditions are met:

----- Scenario 1 -----

Answer was 'Yes' at question '34 [appcollab]' (Have you collaborated or partnered with any companies that make or provide self-tracking apps, devices, or services?)

----- or Scenario 2 -----

Answer was 'Yes' at question '35 [smcollabo]' (Have you collaborated or partnered with any social media companies or web sites?)

Please write your answer here:

[stdthghts]

Do you have other thoughts about using individuals self-tracked data in research that we did not ask about?

Please write your answer here:

[educ]

What is the highest level of school you have completed or the highest degree you have received?

Please choose only one of the following:

- High school graduate (Grade 12 with diploma or GED certificate)
- Two year associate degree from a college or university
- Four year college or university degree/Bachelor's degree (e.g., BS, BA, AB)
- Master's or professional degree (e.g., MS, MA, MFA, MLS, MBA)
- Doctorate, medical or law degree (e.g., PhD, MD, JD)

[employ]

What is your current employment situation?

Please choose all that apply:

- Employed full-time
- Employed part-time
- Retired
- Not employed for pay
- Have own business/self-employed
- Disabled
- Full-time Student
- Part-time Student
- Other:

[hisp]

Are you, yourself, of Hispanic or Latino origin or descent, such as Mexican, Puerto Rican, Cuban, or some other Latin American background?

Please choose only one of the following:

- Yes
- No

[race]

What is your race?

Please choose all that apply:

- White
- Black or African-American
- Asian or Pacific Islander
- Mixed race
- Native American/American Indian

- Other:

[gender]

What is your gender?

Please choose only one of the following:

- Male
- Female
- I describe myself a different way (please specify in the box on the right)

Make a comment on your choice here: