

# Health Data Exploration

## Survey Questions - Individuals

[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

[ST\_Desc]

‘Tracking personal data’ and ‘self-tracking’ are not only about health in the medical sense.

We’re interested in how you track activities related to lifestyle, recreation enjoyment, exploration and curiosity, as well as living long and well.

[ST1]

Do you record or otherwise keep track of your personal health and activity data?

Please choose only one of the following:

- Yes
- Yes, but I don’t write it down – I keep it in my head.
- No

[ST2]

Do you associate yourself with the ‘Quantified Self’ trend?

The Quantified Self is a movement to incorporate technology into data acquisition on aspects of a person's daily life in terms of inputs (e.g. food consumed, quality of surrounding air), states (e.g. mood, arousal, blood oxygen levels), and performance (mental and physical). Such self-monitoring and self-sensing, which combines wearable sensors (EEG, ECG, video, etc.) and wearable computing, is also known as lifelogging.

Please choose only one of the following:

- Yes
- No

[ST3]

How long have you been keeping track of your personal health and activity data?

Please choose only one of the following:

- Less than 6 months
- 6 months to less than a year
- One year to less than 2 years
- 2 years to less than 3 years
- 3 years to less than 5 years
- 5 years or more

[ST5]

Would you say that you keep track of your personal health and activity data mainly for the betterment of your life -- not primarily for a medical reason?

Please choose only one of the following:

- Yes
- No

[ST\_Pew24]

Now thinking about your health overall... Do you currently keep track of your own weight, diet, or exercise routine, or is this not something you currently do?

Please choose only one of the following:

- Yes, I keep track
- No, not something I currently do

[ST6]

Do you currently track your personal health and activities because of medical advice you've been given?

Please choose only one of the following:

- Yes
- No

[ST7]

Do you live with a chronic illness?

Please choose only one of the following:

- Yes
- No

[ST8]

Do you take care of someone who lives with a chronic illness?

Please choose only one of the following:

- Yes
- No

[HT\_Pew26]

Thinking about the health indicator you pay the MOST attention to, either for yourself or someone else, how do you keep track of changes?

Please choose all that apply:

- Paper, like a notebook or journal
- A computer program, like a spreadsheet
- A website or other online tool
- An app or other tool on your phone or mobile device
- A medical device, like a glucose meter
- Or do you keep track just in your head?
- Other:

[HT\_Pew22]

On your cell phone, do you happen to have any software applications or “apps” that help you track or manage your health, or not?

Please choose only one of the following:

- Yes
- No
- Don't know

[HT\_Pew23]

What kind of health apps do you currently have on your phone? What health issue or topic do your apps deal with?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '17 [HT\_Pew22]' ( On your cell phone, do you happen to have any software applications or “apps” that help you track or manage your health, or not? )

Please choose all that apply:

- Exercise, fitness, pedometer or heart rate monitoring (includes specific types of exercise like running, ab workouts, yoga, etc.)

- Diet, food, calorie counter
- Weight
- Period or menstrual cycle
- Blood pressure
- WebMD
- Pregnancy
- Blood sugar or diabetes
- Medication management (tracking, alerts, etc.)
- Mood
- Sleep
- Fertility, ovulation, or basal body temperature
- Athletic activity or sport
- Blood levels (other than blood sugar or diabetes), e.g. hormone
- Alcohol
- Smoking
- Meditation or relaxation techniques
- Other:

[HT3]

What kind of health websites or other online tools do you currently use? What health issue or topic do they deal with?

Only answer this question if the following conditions are met:

Answer was at question '16 [HT\_Pew26]' ( Thinking about the health indicator you pay the MOST attention to, either for yourself or someone else, how do you keep track of changes? )

Please choose all that apply:

- Exercise, fitness, pedometer or heart rate monitoring (includes specific types of exercise like running, ab workouts, yoga, etc.)
- Diet, food, calorie counter
- Weight
- Period or menstrual cycle
- Blood pressure
- WebMD
- Pregnancy
- Blood sugar or diabetes
- Medication management (tracking, alerts, etc.)
- Mood
- Sleep
- Fertility, ovulation, or basal body temperature
- Athletic activity or sport
- Blood levels (other than blood sugar or diabetes), e.g. hormone
- Alcohol
- Smoking
- Meditation, relaxation techniques
- Other:

[HT4]

Which of the following apps or devices have you used in the past year?

These are listed in alphabetical order.

Please choose all that apply:

- 60Beat
- Avera
- Azumio
- Basis
- Bayer Diabetes
- Beddit
- BestLifeReward
- BodyMedia
- Bplog
- CalorieCount
- CareLogger
- Cessation Nation
- Digifit
- Dreamboard
- Everyday Health
- FatSecret
- FitBit
- Fitday
- Get Rich or Die Smoking
- Glucose Buddy
- GoMeals
- HealtheHuman
- HealthMate
- Heart & Stroke
- iHealth Ventures
- Ithlete
- Jawbone
- Leading Edge App
- Lose It
- MapMyRun
- MedHelp
- merckEngage
- MIO
- MyFitnessPal
- MyFoodDiary
- MyNetDiary
- MyRefillRx
- My Sugar Level
- Omron
- Ozeri Pedometer
- Period Tracker (P Tracker)

- Pulse Activity Tracker
- Quit Smoking
- Runastic
- RunKeeper
- SparkPeople
- Sleep Cycle
- SleepTracker
- SoundTells
- Stava
- Tactio
- The Daily Plate
- WakeMate
- WebMd
- WeightWatchers
- Zeo
- Other:

[HT5]

Do you use social media-oriented web sites to track your data?

Please choose only one of the following:

- Yes
- No

[HT6]

Do you provide assistance to a family member in tracking his or her activity data?

Please choose only one of the following:

- Yes
- No

[HT7]

Do you promote self-tracking data for someone you help as part of health-coaching, e.g. for muscle strength for osteoporosis, or other life-coaching?

Please choose only one of the following:

- Yes
- No

[ShareText]

We're interested in finding out if you share your personal health and activity data with others and, if you do, how you share your personal data with others. For example, if you share data about your health and activities with a friend or group of friends, with someone in your family, with a doctor, nurse or other caregiver, in a patient group or on a social media-oriented web site. We're also interested in knowing if you would consider sharing your self-tracked data with researchers who hope to gain insight into social group behaviors related to health and well-being.

[priv1\_Pew28]

Do you share these health tracking records or notes with anyone, either online or offline?  
Please choose only one of the following:

- Yes
- No

[priv2\_Pew29]

Who do you share this information with?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '25 [priv1\_Pew28]' (Do you share these health tracking records or notes with anyone, either online or offline?)

Please choose all that apply:

- Health or medical professional (includes doctor, nurse, therapist, physician's assistant)
- Your spouse or partner
- Other family members, someone in your family relationships
- Friend
- A parent
- Your child, one or more of your children
- Your brother, sister, other sibling
- A member of social group: church, community association, volunteer group
- A personal trainer or health coach
- Other:

[priv3]

How do you share your self-tracked personal data?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '25 [priv1\_Pew28]' (Do you share these health tracking records or notes with anyone, either online or offline?)

Please choose all that apply:

- I don't share any of the personal data that I track
- I share my data in a research study
- I share my data with a doctor, nurse or other caregiver
- My employer requires blood pressure, weight loss, drug testing, other data
- I share my data in an on-line patient group
- Other:

[priv4]

What method do you use to share your self-tracked personal data?

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '25 [priv1\_Pew28]' (Do you share these health tracking records or notes with anyone, either online or offline?)

Please choose all that apply:

- I share my self-tracked data on paper
- I share my self-tracked data in person only (never online)
- I post my self-tracked data at a secure public online web site
- I share my self-tracked data at a private online site that I belong to
- Other:

[DVDescr]

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 'passively tracked' data may also be useful for medical, public health and other research.

[DV1]

How do you interact in online social networks, for example via apps on your mobile phone, health-related devices, wearable sensors, or any other ways?

Please choose all that apply:

- Apps on my mobile phone
- Health and activity-related devices
- Wearable sensors
- Apps linked to the social media-oriented web sites that I go to
- Purely social fun apps (not health related)
- I don't interact in any online social networks
- Other:

[DV2]

Does your concern for your health influence your shopping habits?

Please choose only one of the following:

- Definitely yes
- Somewhat yes
- Not too much
- Not at all

[DV3]

How often do you make calls from your mobile phone?

Please choose only one of the following:

- 5 times a day or fewer



- 6 up to 10 times a day
- 11 up to 20 times a day
- 20 or more times a day

[DV4]

By 'being tracked passively,' we mean when an app, device or sensor registers data about your movements, even though you're not directly interacting with the app, device or sensor.

What places do you go to regularly and/or hang out where you're likely to be tracked passively, e.g. by GPS on your phone or other sensors?

Please write your answer here:

[DV5]

Do you believe that you "own" -- or should own -- all of the data that are about you, even when these data are indirectly collected?

Please choose only one of the following:

- I believe that I do own and should own all of my data
- I should share ownership of my data with the company that collected my data
- The company that collected my data owns it
- This is not something I care about

[DV6]

Do you believe that the data collected about you belongs to the app, device or social media owner or company that collects it, e.g. Google, your phone carrier, and/or the app designer?

Please choose only one of the following:

- The company that collected the data owns it even though the data are about me
- The company should share its ownership of my data with me
- I should be the primary owner of my data
- This is not something I care about

[DV7]

Do you want to own this kind of data?

Please choose only one of the following:

- Yes
- No
- This is not something I care about

[DV9]

How do you think this kind of data could be useful to you?

Please write your answer here:

[DV8]

Would you be open to sharing these kinds of data that were collected about you, for medical and/or other research for better health?

Please choose only one of the following:

- Definitely yes
- Possibly yes
- Unsure / It depends
- Probably not
- Not at all

[SciShareDesc]

Some people are beginning to suggest that it would be valuable for individuals to share personal data on their health, activities and related information that they collect. Imagine, for example, that you have a set of data about your weight, your diet, and your exercise that could be helpful in a research study that could help many others, or in the design of an app or device that could help many others.

The following section asks about your willingness to share your data in scientific studies or technology development in support of better health.

[SciShare1]

Would you be willing to share your personal health and activity data with researchers who hope to gain insight into social group behaviors related to health and well-being?

Please choose only one of the following:

- Definitely would
- Probably would
- Unsure / It depends
- Probably would NOT
- Definitely would NOT

[SciShare2]

Would you share your personal health and activity data for a specific scientific study, for example, if you had an interest in the topic?

Please choose only one of the following:

- Definitely would
- Probably would
- Unsure / It depends
- Probably would NOT
- Definitely would NOT

[SciShare3]

Would you donate your personal health and activity data to a scientific database?

Please choose only one of the following:

- Definitely would
- Probably would
- Unsure / It depends
- Probably would NOT
- Definitely would NOT

[SciShare4]

Which ONE of the following statements comes closest to your view about donating your personal data to a public scientific database?

Please choose only one of the following:

- I would share my data
- I would only share my data if I were compensated for it
- I would only share my data if I were assured privacy
- I would only share my data if I had BOTH compensation AND assurance of privacy
- I would not share my data

[SciShare5]

If you were offered modest monetary compensation for use of your personal health and activity data in a scientific study, how likely would you be to share your data?

Please choose only one of the following:

- Much more likely
- More likely
- No difference
- Less likely
- Much less likely

[SciShare6]

How important is it to you that your shared personal health and activity data be kept anonymous?

Please choose only one of the following:

- Not at all important
- Somewhat important
- Very important
- Extremely important

[SciShare7]

Under what agreements and constraints would you share your health and activity tracking data?

Please tell us in a few words:

Please write your answer here:

[mot1]

What was your initial motivation to start tracking your health and activities?

Tell us in a few words:

Please write your answer here:

[mot2]

What keeps you going with self-tracking your health?

Tell us in a few words:

Please write your answer here:

[mot3]

What do you like best about the health and activity tracking tools that you're using?

Tell us in a few words:

Please write your answer here:

[mot4]

What do you like least? How could the tools be better?

Tell us in a few words:

Please write your answer here:

[mot5]

What would you like to see in self-tracking tools, "apps" and devices?

Tell us in a few words:

Please write your answer here:

[mot6]

What's your ideal for how self-tracking tools, "apps" and devices could be designed and evolve to help you and others the most?

Tell us about your ideas:

Please write your answer here:

[mot7]

Would you be interested in having additional tools that would allow you to analyze or compare your data to others' data?

Please choose only one of the following:

- Yes
- No

[mot8]

What would you like additional analytical tools to be like?

Tell us in a few words:

Only answer this question if the following conditions are met:

Answer was 'Yes' at question '53 [mot7]' ( Would you be interested in having additional tools that would allow you to analyze or compare your data to others' data? )

Please write your answer here:

[mot9]

What kinds of data analysis would you like to be able to do, e.g., to compare your data with others beyond what you're able to do now?

Tell us in a few words:

Please write your answer here:

[mot10]

What excites you or motivates you the most about tracking tools?

Tell us in a few words:

Please write your answer here:

[mot11]

What excites you or motivates you the most about the Quantified Self trend?

Tell us in a few words:

Please write your answer here:

[school]

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

Please choose only one of the following:

- Less than high school (Grades 1-8 or no formal schooling)
- High school incomplete (Grades 9-11 or Grade 12 with NO diploma)
- High school graduate (Grade 12 with diploma or GED certificate)
- Some college, no degree (includes community college)
- Two year associate degree from a college or university
- Four year college or university degree/Bachelor's degree (e.g., BS, BA, AB)
- Some postgraduate or professional schooling, no postgraduate degree
- Postgraduate or professional degree, including master's, doctorate, medical or law degree (e.g., MA, MS, PhD, MD, JD, MBA)

[employment]

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

[hispanic]

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:

[relstatus]

What is your current relationship status?

Please choose only one of the following:

- Married
- Living with a partner
- Divorced
- Separated
- Widowed
- Never been married

[parent]

Are you the parent or guardian of any children under age 18 now living in your household?  
Please choose only one of the following:

- Yes
- No

[income]

Last year -- that is in 2012 -- what was your total household income from all sources, before taxes?

Please choose only one of the following:

- Less than \$10,000
- \$10,000 to under \$20,000
- \$20,000 to under \$30,000
- \$30,000 to under \$40,000
- \$40,000 to under \$50,000
- \$50,000 to under \$75,000
- \$75,000 to under \$100,000
- \$100,000 to under \$150,000
- \$150,000 or more

[zip]

What is your ZIP code?

Please write your answer here:

[sector]

In what sector are you employed?

Check the main sector that you work in:

Only answer this question if the following conditions are met:

Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? ) and Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? ) and Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? )

Please choose only one of the following:

- Corporate
- Government
- Academic
- Non-Profit
- Self-employed
- Other

[industry]

Are you employed in one of the following industries or industry sectors?

Only answer this question if the following conditions are met:

Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? ) and Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? ) and Answer was 'Have own business/self-employed' or 'Employed part-time' or 'Employed full-time' at question '59 [employment]' (What is your current employment situation? )

Please choose all that apply:

- IT Information technology, consumer products and services
- 'High tech' R&D including design of software, “apps,” devices, social media
- Arts, Entertainment, Culture and other creative industries
- Telecommunication devices, products and services
- Consumer devices, goods & services (everyday life)
- Health care, medical care, social care
- Biomedical sciences
- Pharmaceutical sciences,
- Education (all levels)
- University-based academic research & teaching (all kinds)
- Data Science & Data Analytics
- Computer Science including software, digital products & services, social media
- Engineering and manufacturing
- Law, Policy
- Government (Federal, State, Local)
- Other

[orgsize]

How big is the organization you work for?

Please choose only one of the following:

- Less than 10 employees
- 11 – 100 employees
- 101 – 1000 employees
- 1001 - 5000 employees
- More than 5000 employees



[wrkgrp]

How big is your laboratory group or work group? For example, if you work for a big company, about what size is the office or company site where you work?

Please choose only one of the following:

- Less than 10 employees
- 11 – 100 employees
- 101 – 1000 employees
- 1001 - 5000 employees
- More than 5000 employees

[orgarea]

How would you describe the industry or area that your organization is in?

Please write your answer here:

[org\_age]

How old is your organization?

Please choose only one of the following:

- Less than 1 year
- 1-3 years
- 4-10 years
- 11 or more years
- I don't know

[org\_employ]

How long have you worked for your organization?

Please choose only one of the following:

- Less than 1 year
- 1-3 years
- 4-10 years
- 11 or more years

[title]

What is your job title?

Please write your answer here: