

Patient Survey Health Data Basics

You may be aware that information about your health, also called “health data”, is securely passed from one place to another – from your doctor’s office to the pharmacy.

For example, when you are treated at a hospital dozens of health professionals may look at your chart to help you get the care you need. Your public health department might alert you when your child needs a booster shot because they keep a record of the immunizations your child had at the pediatrician’s office. Your insurance company may track your progress in physical therapy to find out whether it’s helping.

Your participation in this brief (10min or less) survey is very important and will help develop resources that make it clearer to patients and caregivers how health data is collected, shared and used.

Please answer all the questions; if you are unsure about how to respond, that's OK. Answer the best you can.

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Please tell us a few general things about you. This is a fully anonymous survey and we will not collect any information that could tie your answers back to you.

1. What is your age?
 - a. Under 18 – logic to ineligible page
 - b. 18-29
 - c. 30-44
 - d. 45-59
 - e. 60+
2. Do you live in the United States?
 - a. Yes
 - b. No – logic to ineligible page
3. What are the first two numbers of your zip code?
 - a. (OPEN TEXT FILL IN)
4. Which gender do you identify as?
 - a. Female
 - b. Male
 - c. Transgender
 - d. Non-binary
 - e. Prefer not to answer
5. Do you identify yourself primarily as a patient or a caregiver? LOGIC: slightly different survey questions
 - a. Patient (a person living with one or more health conditions that requires ongoing medical attention or support from healthcare professionals)
 - b. Caregiver (a person with caregiving responsibilities for another person with a health condition)
 - c. Neither (Send to Patient Survey)

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As you take this survey, please keep in mind that when we ask about “organizations” we mean organizations and groups such as doctor’s offices, hospitals, public health departments, insurance companies, and university researchers. All of these organizations handle patient health data as part of our health system.

Also, “health data” means a lot of different things, including medical records from your doctor or hospital visit, results from blood tests, insurance records, your immunization history, family health history, personal information you provide when you participate in a research study, or your health data as tracked by your phone or other wearable device (e.g. FitBit, SmartWatch).

[SAME LANGUAGE REGARDLESS OF PATIENT OR CAREGIVER TO THIS POINT]

[SEE BELOW FOR PATIENT VERSION, SEE OTHER DOCUMENT FOR CAREGIVER VERSION]

[PATIENT VERSION]

6. Have you ever tried to get copies of or look at your medical record(s) or other health data?

- a. Yes (LOGIC: GO TO #6a)
- b. No (LOGIC: GO TO #7)

[ONLY ASKED IF RESPONDENT SAYS THEY EVER TRIED TO GET MEDICAL RECORDS/HEALTH DATA]

6a. How many times did you get copies of or look at your health data over the last 12 months? (Choose one)

- a. Fewer than 3 times
- b. About 3-6 times
- c. About 6-12 times
- d. More than 12 times
- e. Not sure/don't know

6b. How successful were you? (Choose one)

- a. I got *none/very little* of what I needed/hoped
- b. I got *some* of what I needed/hoped
- c. I got *most* of what I needed/hoped
- d. I got *everything* I needed/hoped

6c. How useful did you find the health data that you accessed? (Choose one)

- a. Not at all useful
- b. Somewhat useful
- c. Very useful
- d. Extremely useful
- e. Doesn't apply/Interesting, but not useful

6d. What did you do with your health data? (Check all that apply)

- a. I downloaded the information to a computer or other electronic device (cellphone, tablet, USB/portable memory stick)
- b. I sent the information to a personal health record app or website (A personal health record, or PHR, is an electronic application that allows you to access, enter, and manage some of your health information.)
- c. I shared it with another health care provider treating me
- d. I shared it with a family member or someone else involved in my care
- e. I looked for errors in my health data and offered corrections/updates
- f. I used it to monitor my health (check my meds, date of last test, etc.)
- g. Nothing

6e. Did any of these sources help you figure out how to access your health data? (Check all that apply)

- a. My provider
- b. The hospital/clinic
- c. My family member
- d. Other patients
- e. Government agency (HealthIT, public health department)
- f. Insurance company
- g. Pharmacy
- h. TV, radio, and/or internet
- i. None

[ASK ALL PATIENT RESPONDENTS]

7. How much do you agree with the following statements?
(Agree, Somewhat agree, Somewhat disagree, Disagree, Not sure/Don't know)
- a. It is easy to access my health data online
 - b. I could access my medical record if I wanted to
 - c. My health data is useful to me even if it is incomplete
 - d. If I wanted to know with whom my health data had been shared, I would be able to find out
 - e. Safeguards are in place to protect my health data from being misused
 - f. I should be able to see all of my health data, including everything in my medical records
 - g. As long as my health data is anonymized (can't be tracked back to me) I would be okay with it being shared without my permission..
 - h. I should be able to share my health data, including my medical records, with any of my providers (or other members of my care team/people caring for me).
 - i. There are benefits to people/public health when organizations involved in health care share health data about individuals, including me.
8. If you had access to all of your health data and it was complete and accurate, how would you prefer to use it? (Check all that apply)
- a. I would like to be able to share it with any of the providers involved in my care
 - b. I would like to be able to share it with my family or other non-health professionals in my care
 - c. I would like to use it to help me better understand my health condition and/or care for myself and/or follow treatment recommendations.
 - d. I would like to be able to share it with researchers or give it to a research study
 - e. I would like it to be used to help other patients
 - f. I would like to share it with medical product developers (pharmaceutical and device companies)
 - g. I would like it to be used by hospitals and clinics to understand the quality of the care they provide to others
 - h. I would like it to be used by insurance companies to decide on what medical care they will provide coverage for.

9. How would you prefer to make decisions about how your health data is shared?(Choose one)
- a. I would like to be the only person making decisions about how my health data is shared
 - b. I would like to remain in charge of decision making, but consult with a health care professional, or other person I choose,. to help me make decisions about how my data is shared
 - c. I would prefer to delegate, or give over, decision making about how my health data is shared to someone I trust
 - d. I have no preference about how decisions are made about sharing my health data
10. How much do you trust the following organizations to manage how your health data is shared within the system?
(Do not trust at all, Somewhat trust, Fairly trust, Trust a lot)
- e. Health care providers
 - f. Insurance companies
 - g. Universities and/or academic medical centers
 - h. Hospitals
 - i. Public health departments
 - j. Patient organizations, patient registries
 - k. Pharmaceutical companies and/or medical device manufacturer
11. How much control do you feel you have over whether or not your health data is shared? (Choose one)
- a. None
 - b. Some
 - c. A lot
 - d. Total
 - e. Don't know/haven't considered
12. What do you think of the following statements? (True, False, Don't know)
- a. Most hospitals have electronic health records
 - b. Electronic health records are shared among providers (physicians, specialists, hospital systems)
 - c. The care anyone gets is tracked
 - d. The government uses health data provided by hospitals and clinics to track diseases
 - e. Pharmacies tracks purchases, including medical products and other things people buy from them
 - f. Health insurance companies cannot use health data to deny people coverage
 - g. A person's permission is required for their health data to be used in any type of health research
 - h. A person's permission is required for their health data to be shared with a loved one or caregiver