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.

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)

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 LANUGAGE REGARDLESS OF PATIENT OR CAREGIVER TO THIS POINT]

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

6. As a caregiver, you may care for more than one person. For this survey, please select one category that best describes your current situation (Select one)
   a. I am caring for my child or a child in my custody (under the age of 18)
   b. I am caring for my child or a child in my custody (over the age of 18)
   c. I am caring for my spouse or partner
   d. I am caring for a parent
   e. I am caring for a someone other than the above

7. As a caregiver, do you have the necessary permissions (medical power of attorney and/or HIPPA authorization) to access the health data of the person you are caring for?
   a. Yes
   b. No
   c. I don't know

8. Have you ever tried to get copies of or look at the medical record(s) or other health data of the person you are caring for?
   a. Yes (LOGIC: GO TO #8a)
   b. No (LOGIC: GO TO #9)

8a. How many times did you get and/or look at their 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

8b. 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

8c. 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

8d. What did you do with their 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 who is taking care of them
   d. I shared it with a family member or someone else involved in helping me provide care
   e. I looked for errors in their health data and offered corrections/updates
   f. I used it to monitor their health (check their meds, date of last test, etc.)
   g. Nothing

8e. Did any of these sources help you figure out how to access the health data of the person you are caring for? (Check all that apply)

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

9. Assuming you have permission to access the health data of the person you are caring for, 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 their health data on their behalf online
   b. I could access their medical record if I needed to
   c. Their medical record is useful even if it is incomplete
   d. If I wanted to know with whom their health data had been shared, I would be able to find out
   e. Safeguards are in place to protect their health data from being misused
   f. I should be able to see all of their health data, including everything in their medical records.
   g. As long as the health data is anonymized (can't be traced back to the person in my care), I would be okay with it being shared without my permission.
   h. I should be able to share their health data, including their medical records, with any of their providers (or members of their care team/others caring for them).
   i. There are benefits to people/public health when organizations involved in health care share health data about individuals, including me.
   j. Laws get in the way of my having access to their health data to help them with their care.

10. If you had access to all of the health data of the person you are caring for 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 the providers involved in their care
   b. I would like to be able to share it with family or other non-health professionals in their care
   c. I would like to use it to help me better understand the health condition of the person I am caring for and/or care for them better and/or help them 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.

11. How much do you trust the following organizations to manage how their health data is shared within the system?
    (Do not trust at all, Somewhat trust, Fairly trust, Trust a lot)
    a. Health care providers
    b. Insurance companies
    c. Universities and/or academic medical centers
    d. Hospitals
    e. Public health departments
    f. Patient organizations and/or patient registries
    g. Pharmaceutical companies and/or medical device manufacturers

12. How much control do you feel you have over whether or not their health data is shared?
    a. None
    b. Some
    c. A lot
    d. Total
    e. Don't know/haven't considered

13. 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