PGHD Semi-structured interview protocol – Patients

Background/Context

Thank you for taking time to talk with us today. We are currently working on a project to understand implications for patient-generated health data or PGHD. When I refer to PGHD I mean health-related data created, recorded, or gathered by patients (or family members or caregivers) to help address health or a health concern.

PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways:

1. Patients, not providers, are primarily responsible for capturing or recording these data.
2. Patients decide how to share or distribute these data to health care providers and others.

Some examples are exercise and diet tracking using a wearable device, blood glucose monitoring or blood pressure readings using home health equipment, or health tracking through a mobile app.

I want to emphasize that I’m interested in learning about your perspective and experiences. My team and I are doing interviews with lots of people, including other patients, healthcare providers, and other healthcare stakeholders to understand different views to understand how PGHD fits into the landscape for healthcare delivery. We’re talking with lots of people, so don’t worry about speaking for other patients or what the doctors think.

Section I: Experience with PGHD.

First, I would like to understand your experience tracking your health data.

1. What type of data do you currently track?
   • What area(s) of health were you focusing on?
   • **How did you collect the data?** (mobile app, paper diary, tracking device?)
   • What data were you tracking?
   • **How often did you plan to take measures** (e.g., hourly, daily, weekly)?
   • **How often did you actually take measurements?** [Probe: ask for explanations of any differences between plan and reality, but make sure not to make them feel like they need to “defend” their actions. Be empathetic.]
   • Did you track this data for the length of time you expected?
     o If no, what was the main reason for stopping?

2. Please tell me about one experience (perhaps your best, worst, or most memorable) when you tracked your health data? Note: current or past experiences
   • What motivates you to collect the health data?
• **What were your goals for tracking the data?** [*Probe: Did you plan to share the data with your health provider when you first started tracking? *If not, when did you decide to share your data?*]

• In thinking about your experience, to what extent did you meet your goals for tracking?
  o What did you find helpful about your experience? What did you learn or gain from your experience? [*probe to understand values, constraints, etc. For each, ask “why?”*]
  o What did you find to be challenging about your experience?

• **With whom did you share the data?** (*e.g. employers, insurers, other companies, social network, healthcare providers, other*)
  o For each individual listed, inquire about the motivation to share, challenges, barriers.
  o Did sharing data with others require any consent processes? How is data transmitted? Stored?
  o What happened with the data shared? Did this meet your expectations?

• How do you incorporate this data into your health management? (Probe on self-management, if not shared)
  o If use with provider: did your provider ask you to collect it or did you bring the data in on your own?
  o What – if any – instructions were you given or how were you told to collect the information?
  o When did you provide the data in the context of your visit (i.e., before the visit, during the visit, after?)
  o How did you present the data to your provider (e.g., as a download of data? In a report form, on your phone?)
  o How much time did you and your provider spend discussing the data?
  o How would you describe your experience using the data as part of your healthcare? What was your provider’s reaction? What changes or decisions occurred (if any) as a result of sharing/discussing this data?
  o How frequently did (do) you share this data with your provider?
  o Do you feel that sharing your data with your provider was helpful to your provider?
  o Can you describe any specific instance when the data you shared with your provider influenced or changed your treatment as a patient? [*Probe: Do you know how your provider uses/used the data in your treatment?*]

**TIME PERMITTING**
  o If a device, app, or paper journal was used:
    i. Do you recall if your provider retained a copy of the data or if it is still in your health care record?
    ii. Have you ever shared data with your provider outside of the healthcare visit electronically?
Section II: *Value of PGHD in healthcare delivery*

For the following questions, we would like to understand your thoughts about the value of patient-generated health data given your experiences and considerations for future efforts.

1. What do you think the value of PGHD is to you? More broadly for healthcare delivery?
2. If another person in a similar situation was considering tracking their health data and sharing it with their health provider, what advice would you give them?
3. **Based on your experiences, what do you think are the potential benefits of having patients track data?**
4. **What are the potential downfalls or concerns (e.g., cost, privacy, time, access, etc)?**
5. Do you think patient-generated health data could still be valuable to patients even if it was not shared with their medical providers? In other words, does a provider always need to be involved reviewing self-collected data for medical care?
6. How do you think your relationships with your health providers are affected by your tracking and sharing your data? [probe to understand values, constraints, etc. For each, ask “why?”]
7. Who else do you think this data should be shared with as part of the healthcare team? What do you feel needs to be in place to make the experience successful for patients (e.g., technical problem solving, access to the data with clear explanation of what they mean)
8. If you could give one piece of feedback to your doctor or other health provider about how they used – or didn’t use – the data you collected, what would you say?

Before we wrap up, are there any other issues or points you would like to raise that we haven’t yet discussed?