PGHD Semi-structured interview protocol – Clinicians

Background/Context

Thank you for taking time to talk with us today. We are working on a project to understand implications for patient-generated health data or PGHD for clinical care. For this discussion, when we refer to PGHD, we are defining it as health-related data created, recorded, or gathered by patients (or family members or other caregivers) to help address a health concern. PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways:

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

Examples include 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.

You recently completed a brief survey (Alt: you were identified as someone who uses PGHD) in your work as a healthcare provider. We are interested in learning about your perspective based on your experiences with PGHD. This is part of a series of interviews we are conducting with providers as well as other healthcare stakeholders (patients, healthcare system leaders, employers, payers) to understand different perceptions of how PGHD fits into the landscape for healthcare delivery.

Before we start, I want to emphasize that we’re most interested in learning about your experiences. We’re talking with lots of people, so don’t worry about speaking for other clinicians or the patient perspective.

Section I: Experience with PGHD.

1. First, could you please describe for me your current area of practice/focus as a provider? (E.g., family practice, specialty practice, etc.).
2. Broadly speaking, could describe how patient-generated health data fits within your current practice (e.g., do you request it, do patients bring it to you, etc)?
3. Could you please tell me about one experience – maybe your best experience, maybe your worst, or just the most memorable – when you worked with patient-generated health data?
   a. What condition or conditions were you focusing on?
   b. What data did you work with?
   c. Did you ask them to collect it, or did they bring the data in on their own?
   d. [If the provider asked the patient to collect it:]
      i. What caused you to make that suggestion or recommendation?
      ii. How did you instruct the patient to collect this data?
      iii. Did you provide them with any written instructions or pre-formatted record sheets?
      iv. How much time did you spend explaining how to collect this data?
      v. Did you plan to review it, or just for the patients to collect it and review it themselves?
   e. [If the provider asked the patient to collect it:]
      i. How did their collection and your review of the data come up?
      ii. What was your reaction at first?
      iii. What was your reaction afterward?
   f. How was the data collected (e.g., mobile app, paper diary, excel sheet, handout or form)?
   g. How did you review that data?
i. Do you think it supported any of your goals for providing patient care? **Probe:** What? How?
ii. Did you put this into the patient’s medical record?
iii. What helped it go well?
   h. What could have helped it go better?
4. Now, I’d like to ask you to compare that experience with how you typically use patient-generated health data.
   a. In what ways is it similar?
   b. In what ways it is dissimilar? [Follow up: **Why do you think it went differently that time?**]
5. Now, thinking about your experiences in general, how often do you review this data when you work with your patients?
   a. Unless it is never or almost never:
      i. [Depending how they answered part 1.] Could you please describe your best/worst experience with using patient collected data?
      ii. What would you say help use of a patient’s data go well?
      iii. And are there things that make it go poorly?
      iv. What conditions or diseases did you find patient-collected data the most useful for? The least useful for?
   b. [If never or almost never]:
      i. Why not? [probe for what might reduce those barriers]
      ii. Do patients ever ask you to review their data, without you suggesting it? [probe for what they bring and why]
      iii. Have you ever not reviewed a patient’s data they brought in with them? Why not?

Section II: Use of PGHD and Workflow Considerations

(For interviewer: If this is a provider who actively uses PGHD, place the below in that context. If the PGHD collection is part of a research study or pilot study, place in that context for implementing/scaling-up as part of routine care. Otherwise, continue as more generic use as currently stated.)

Next, I’d like to step back and ask some about how your use of patient generated health data fits – or doesn’t fit into your workflow and what you need as a healthcare provider.

1. Can you walk me through your typical workflow for a clinic visit? [Both during a visit and outside of a visit]
2. What is your goal for a patient visit? What is your overall goal for a patient over time across multiple visits?
3. How do you foresee patient-generated health data best fitting into this workflow? When should it be reviewed?
4. How much time do you realistically think you can or would you be willing to spend reviewing the data? Why?
   a. Would you do this before, during, or after the clinic appointment?
5. Who do you think is the “right” person or people to review the data? Why?
   a. Would you consider hiring or allocating time to medical staff to review patient-collected data if it would add value to patient care? If yes, what, if any training/experience do you feel would be necessary for the designation person(s)?

Section III: Value of PGHD in healthcare delivery

For the following questions, we would like to understand your perceived value and adverse effects of PGHD even if you don’t review them right now.
1. If a colleague asked you for advice about
2. What do you think are the potential benefits of having patients self-collect data?
3. What are the potential downfalls of having patients self-collect data? [Follow-up: Have you experienced any of these downfalls or negative effects?]
4. What are the potential benefits of patients sharing the data they collect with you or their other providers?
5. What are the potential downfalls of them sharing that? [Follow-up: Have you experienced any of these downfalls or negative effects?]
6. Do you think patient-generated health data could still be valuable to patients even if they don’t share it with you or with other providers? In other words, does a provider always need to be involved reviewing self-collected data for medical care? [Probe: What would be your main contribution (or another provider’s) in reviewing patient-generated health data? Probe for what benefits they get now versus which are hypothetical/aspirational.]
7. How do you think your relationships with your patients are affected by asking patients to collect data, and then reviewing that data? [probe to understand values, constraints, etc. For each, ask “why?”]
8. Are there enough incentives for you at this time to review patient-generated health data? Is it worth the trouble? [probe to understand values, constraints, etc. For each, ask “why?”]
9. What would give you the incentives to review patient-generated health data? (i.e. patient clinical improvement, ability to bill for its review, less patient phone calls, time saved in clinic, decreased healthcare utilization)
10. What can make certain patient-generated health data challenging to review or not useful?
   a. If the difficulties you mentioned were removed, what medical conditions and/or patient population would most benefit from patient-collected data?
      i. What type of data would you want patients to collect?
      ii. How would you use them?
      iii. What would you want to see?
      iv. What would you look for in their data?
      v. Are there patient characteristics that facilitate or hinder collection of PGHD? [Probe: How do you account for these differences in your work? Are there ways you think medical providers should account for these differences?]
11. If you could give your patients one piece of advice about tracking their health data and sharing it with you, or make one request of them, what would it be?