DRAFT INTERVIEW GUIDE  
  
Thank you for agreeing to speak with us by phone to inform our PCORI-funded project, “Educate to Engage Patients: Health Data.” A brief description of the project can be found at the end of this interview guide.

Our objectives for the 30-minute call are to:

* Develop a better understanding of factors you believe limit patients’ awareness, understanding, use and sharing of their own health data.
* Probe traits or attributes you have found to make an individual more likely (or less likely) to engage with their health data.
* Surface other projects or initiatives you’re aware of that may be aligned with project goals to avoid duplication of efforts.

We would like your permission to record our conversation for our reference only. Is that okay? Also, we will not quote you by name, but plan to include your name in an Acknowledgement section of the final report. Please let us know if you prefer to remain off that list.

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Do you have a preferred definition of “health data”? How would you describe “health data” to someone outside the health field?

**How well do you perceive patients (individuals) understand what constitutes his/her “health data”?**

* Is there an emphasis on certain types of data (i.e., the electronic health record maintained by their primary care physician) vs. a more comprehensive understanding of the range of data types and sources that comprise their own health data?
* How important do you feel it is that individuals understand the sources and uses of their health data?

**What gaps do you see in what patients (individuals) generally know about what makes up their health data, how it is collected, used and shared, and by whom?**

* Do you perceive that data ownership and data control are understood by most patients (individuals) as separate issues or one in the same? Which do you think is of greater general concern to individual patients?
* Do you perceive that data privacy and data security are understood by most patients (individuals) as separate issues? Which do you think is of greater general concern?
* Are there good information resources you cite to patients (individuals) interested in learning more about how to access their health data?

**What barriers do you see patients (individuals) encounter as they attempt to access and/or use their health data?**

* You may wish to consider technical, cognitive, emotional, behavioral and practical issues, among others.
* Which of these barriers is most important to overcome?
* Which of these barriers can education help address?
* What other types of approaches and/or interventions are needed?

**Are there traits or attributes you believe make an individual more or less likely to access/use their own health data?**

* You may wish to consider zip code (geography), age, gender, education level and other demographic factors.
* How does an individual’s experience with the healthcare system, including their primary/co-morbid diagnosis(es), impact the likelihood? How might the nature of their primary/co-morbid diagnosis(es) (rare vs. prevalent, acute vs. chronic, of new onset vs. lifelong, etc.) bear on their orientation to data engagement?
* Do you predict we’ll identify differences in the access and use of health data between individuals who self-identify as primarily being patients (with lived experience with one or more diagnoses) and those who self-identify as primarily being caregivers for patients?
* How does “trust” influence understanding and behavior with regard to health data?

**What can we learn from other efforts/initiatives?**

* Are there other individuals or initiatives that we should be aware of?
* Are there lessons learned about information resources to follow or avoid that we should consider?

**PROJECT DESCRIPTION**

Patient health data are used by an ever-expanding variety of stakeholders (e.g., health systems, payers, industry) to support health-care decision-making and generate evidence of patient preferences, behaviors and comparative effectiveness. Yet even savvy patients who regularly interact with the healthcare system may struggle to understand what information is collected about them and their health condition, who uses and shares that information and for what purpose.

The project begins with a patient survey and interviews with key opinion leaders to understand patients' baseline knowledge about what health data is, who collects and uses it, and what barriers – technical, cognitive, emotional, behavioral, practical – deter patients from accessing it and harnessing it. With this enhanced understanding of the current state of “patient health data awareness,” the project team will employ a user-centered design process to develop and refine a prototype for a patient-centered educational tool to address knowledge gaps. User testing and evaluation will narrow the design concepts, inform possible future steps of tool development, and identify other interventions that might be needed to achieve greater patient activation. The interim and final project deliverables will be publicized widely so they have broad impact beyond this project.

This project is supported by a $250,000 [Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award](http://www.pcori.org/funding-opportunities/programmatic-funding/eugene-washington-pcori-engagement-awards) (#4202-MI) and is led by the Patients Count team at *FasterCures*. A panel of experts representing several different disciplines and with experience in several disease areas and patient communities will advise each phase of the project. Involution Studies will provide user-centered design services to the project team.