



# Consumer Voices Workgroup

## Report of Findings & Recommendations

July 1, 2023

### Overview

The Sequoia Project convened the Consumer Voices Workgroup as part of the Interoperability Matters cooperative to ask a diverse group of patients and caregivers across the country about their experiences accessing, using, and sharing their health records and what can be done to make it better. The workgroup's perspectives will inform cross-industry strategies to address barriers that prevent all of us from realizing the intended benefits and potential of health data interoperability and individual online access to our health records.

**Bottomline, people want all their health records in one place, organized so they can find what they need when they need it, written in plain language so they can understand it, with the ability to share as they wish.** The more chronic or serious health conditions people have, the more critical accessing, using, and sharing health records becomes. The more health providers a patient sees, the more scattered their health information is. Access to health records remains fractured and frustrating. People want one place to go to easily access all their health records regardless of how many health providers they have, which health systems their health providers work for, and how many different electronic health records (EHRs) their health providers use. It is not reasonable access if playing telephone tag or going in-person to multiple providers' offices is required to access one's own health records. Not all providers have EHRs, not all EHRs have patient portals, not all information is accessible in the patient portals (i.e., images). It is a heavy administrative burden for patients and caregivers to access the information they need to manage their care across multiple silos of information, each with their own unique user IDs, passwords, authentication methods, and user interfaces.

**People expect more based on how they digitally interact in other areas of their lives.** While there remain pockets of paper-based health records, much of the workgroup's discussion focused on experiences using EHR patient portals as the vehicle for accessing, using, and sharing their health records. Consumer access to their health records should be designed with patients in mind to reduce patient and caregiver burden. 100% of the workgroup's recommendations to improve accessing, using, and sharing health records is achievable using current technology.

Of what use is access to one's own health records if the records aren't understandable? Usability of health records for most people is a non-starter given medical jargon-laden test results and diagnostic reports that are written by medical professionals, for medical professionals. **People want plain language results and reports** so they can be more engaged in managing their

health. Until reports are written for consumption by patients, the full benefits of patient access to their health records will not be achieved.

**People want more control over easily sharing their own health records** and view the patient portal as the mechanism that could allow them to self-direct specific health records to specific recipients, for specific time periods. Sharing is important for both treatment (e.g., specialists, referrals, second opinions) and non-treatment (e.g., disability, life insurance, school) uses. Additionally, people want to know who their health records are shared with, without their expressed consent. For instance, people are not aware of health information exchanges (HIEs), if their providers participate in them, and if so what hospitals, urgent care centers, pharmacies, or other providers will have access to their health records. People are not aware if they need to opt-in or out of HIEs.

**People are unaware of their patient rights regarding access to health records.** While most patients have heard of HIPAA, there is a general admission that they don't read the multiple page legalese document on the rare occasion the actual form is still presented to them, for fear they won't be able to see the provider if they don't "check all the boxes" on the tablet or kiosk at the front desk. This negates the informed part of informed consent. People want simple forms in plain language that are standard across all their providers, and they want access to any forms they digitally or otherwise sign available for viewing in their patient portals. People do not know that HealthIT.gov exists and do not know where or how they would file a complaint should they believe their rights to access their health records have been violated. People want to be better educated and informed about their patient rights.

The Consumer Voices Workgroup Report of Findings and Recommendations concludes the work envisioned under the 2022-2023 workgroup's inaugural charter. The Report of Findings & Recommendations will serve as a basis for Sequoia's newly formed Consumer Engagement Strategy Workgroup. This workgroup will be comprised of The Sequoia Project members and is set to launch in Summer 2023 to undertake work to gain an understanding of these findings and recommendations and develop short and long-term cross-industry strategies for meeting consumer needs.

Sequoia values consumer perspective across interoperability topics. A new 2023-2024 charter will be created for approval by Sequoia's Interoperability Matters Leadership Council to retain and augment the Consumer Voices Workgroup to serve as an ongoing sounding board for the Consumer Engagement Strategy Workgroup and other Interoperability Matters workgroups (e.g., Public Health, Information Sharing, Data Usability).

The Sequoia Project is grateful to the patients and caregivers that gave voice to the consumer experience and to the workgroup co-chairs that passionately led this initiative. The Sequoia Project is a 501(c)(3) non-profit and trusted advocate for nationwide health information exchange in the public interest. Our work is made possible through annual dues from our member organizations and the generosity of collaborative partners, sponsors, and grants. To join us in this vital work, contact us at **memberservices@sequoiaproject.org**.