



INTEROPERABILITY MATTERS CONSUMER WORKGROUP (“The Consumer Workgroup”)

Charter

The Consumer Workgroup was established by the Sequoia Project with the approval of the Interoperability Matters Leadership Council to (1) bring the consumer’s voice to Sequoia’s work, (2) better understand the barriers consumers face in health information exchange, and (3) inform strategies for Sequoia to address the barriers. The Consumer Workgroup will share experiences, priorities and recommendations which will be used by The Consumer Engagement Strategy Workgroup to develop short and long-term cross-sector strategies for consumer engagement, access, education, and policy.

Key Questions this workgroup will answer

2022-2023 | Establishing a Baseline of Understanding for the Consumer Experience

1. Have you tried to access your health records? How easy was it?
2. Have you experienced problems *easily obtaining* your health records?
3. Have you experienced problems *using* your health records?
4. Have you experienced problems when trying to *share* your health records?

2022-2023 | Understanding Consumer Priorities

1. What is most important to you about accessing and using your health records? As a patient? As a caregiver?
2. What are the ways you most easily access personal information using technology today?
3. How do you access your health information using technology today?

2022-2023 | Identifying Gaps Between Experience and Ideal

1. What were the most positive experiences you’ve had obtaining your health records?
2. If you’ve had problems *obtaining* your health records, what would have made your experience better for you?
3. If you’ve had problems *using* your health records, what would have made your experience better for you?
4. If you’ve had problems *sharing* your health records, what would have made your experience better for you?

2022-2023 | Establishing a Baseline of Understanding for Consumer Education Needs

1. How familiar are you with your rights to obtain, share, and protect your health records?
2. What information would be most helpful to you to understand and exercise your rights?
3. What are the best ways for people to receive and understand this information?
4. What do you think would help people learn about their rights? How do we get the word out?

Guiding Principles

The consumer’s voice matters.

Membership

The Consumer Workgroup is comprised of a diverse group of ~15 consumers, consumer-patients, and caregivers. Members will be able to serve on the workgroup as long as they have not missed three or more meetings.

Meeting Frequency

The Consumer Workgroup will meet virtually once a month. The Consumer Workgroup will meet as needed to collaborate with The Consumer Engagement Strategy Workgroup.

Meeting Preparation and Staffing

The Consumer Workgroup will initially be co-chaired by one Sequoia staff member and one Sequoia Board Member with the potential for a Consumer Member co-chair. Meeting materials will be posted to the Consumer Engagement webpage on Sequoia’s website.

Member Stipends

Each Consumer Workgroup member will receive a stipend in the amount of \$500 every three months for participating in monthly meetings.

Meeting Ground Rules

1. **Attend** virtual meetings consistently to ensure active participation.
2. **Prepare** for meetings by: a. planning a quiet location to join forum meetings virtually without distraction; b. making sure you can open the virtual meeting link on your computer, phone, or other device; c. reviewing materials distributed prior to the meeting, and d. preparing to raise questions and comments about issues being discussed.
3. **Listen** respectfully and learn from other points of view
4. **Speak** respectfully and share your point of view
5. **Respect** diversity, there are many different perspectives
6. Respect any **confidential discussions** held within the Workgroup

Evaluation

Consumer Workgroup members will be asked to participate in online surveys to provide insights to the Consumer Engagement Strategy Workgroup.