

BASS-IV Study - Mak-SOMREC-2022-505

Focus Group Discussion Questions for Adolescents with Epilepsy

1. **Tell us a bit about your story of having epilepsy. When did you begin having seizures, when and where did you seek treatment?**

Potential queries:

- *When did you begin having seizures? What did you think about it, how did you understand the experience? Did you and your family think something triggered it?*
- *What did you and/or your family do in response to the first seizures? Describe any effort to seek information or help.*

2. **We want to begin by understanding what having seizures and epilepsy is like. How are you treated by others now?**

Potential queries:

- *When you come out of a seizure, what do you notice about how people respond/react?*
- *What do you and/or your family think about epilepsy (e.g. its cause, effects, treatment, etc.)?*
- *What do people in your community in general think about epilepsy (e.g. its cause, effects, treatment, etc.)?*

3. **How does your epilepsy impact your daily life related to school, work, or home life?**

Potential queries:

- *Do you tell others about your condition?*
- *What happens whenever someone discovers that you have epilepsy?*
- *As a person with epilepsy, how is your life different from that of people of your age (age-mates) who do not have epilepsy?*
- *How does your epilepsy impact your ability to have meaningful social relationships?*

4. **What do you wish people (your family, teachers, and community) would know about you and your epilepsy?**

Potential queries:

- *Do people in your community talk about epilepsy (programs, groups, etc.)? Through which channels and at what places is epilepsy most talked about in your community?*
- *What do people in your community say about epilepsy?*
- *In what ways does the discussion about epilepsy impact your life?*
- *Are there people in your home area, school, or community who know that you have epilepsy? If yes, which people, and how did they come to know that you have epilepsy?*
- *Are there people in your community who talk to you about epilepsy? If yes, who are these people, and what issues do they talk to you about?*

5. **How do you and your friends/elders usually learn about topics?**

Potential queries:

- *What forms of media do your friends/ elders interact with most frequently? (Social media/ radio).*
- *Who are you and your peers most likely to listen to (parents, teachers, tribe/community leaders, etc.)?*

6. **What do you think the most important challenges are to address in your home, school or community life? Where is help most needed?**

Potential queries:

- *Do you have ideas on how these challenges could be addressed? What are they? Who would be involved and how might they be receptive to your proposed solution?*

7. What do you need to know more about related to your epilepsy?

Potential queries:

- Tell us about the challenges associated with having to take medicines for epilepsy.
- What resources have helped you the most in learning about and managing your epilepsy?

8. Do you have access to a smartphone or computer? (*Invite all to stay and inform discussion*)

Potential queries:

- *What do you use your device for the most?*

9. If there was an APP or Computer Program that could help you to track your seizures and medications, would you be interested in using that?

10. It might be interesting if such a program/APP also had interactive features about mood, building resilience, good coping skills. What would you think about this?