Epilepsy Innovation Institute (Ei²)

2016 COMMUNITY SURVEY
INTRODUCTION

From September 8th to November 9th, 2016, epilepsy.com hosted a survey that asked the community the following:

What are the aspects of epilepsy that have greatest impact on patients’ lives?

Where should epilepsy researchers focus?

What are your biggest frustrations?

What is your biggest hope in the next five years?

1,056 INDIVIDUALS PARTICIPATED IN THE SURVEY
WHO WERE THESE INDIVIDUALS?

Most of you came from the U.S. At least one person from every state responded.

Geographical Distribution of Respondants

# of Respondants
- 61-75
- 46-60
- 31-45
- 16-30
- 1-15

41 INTERNATIONAL RESPONDANTS
69 DID NOT SAY

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Of respondents were people living with epilepsy or family members and caregivers.

All seizure frequency types were represented in the survey.

76% of respondents identified as having been diagnosed with generalized or focal seizures.
WHAT DID THESE INDIVIDUALS SAY?

When asked to write down what aspects of epilepsy impacted individuals the most, these were the most common words used:

“Frustration of trying different medications and their side effects with no improvement.”

Which of the following aspects of epilepsy impact your life the most?
(Summary Broken Down by Seizure Frequency)

As one might expect, the aspects that affect people living with epilepsy shift depending on how frequently the seizures occur.
When asked to write down what frustrated individuals the most, these were the most common words used:

"There is too much time spent worrying about a cure. There can’t be a cure until we know the reason."

**Researchers should be focusing their efforts on:**

| (Summary Broken Down by Seizure Frequency) |

When respondents were asked to rank what researchers should focus on, stopping seizures and improving quality of life were the top choices.