

# Patient and Caregiver Preferences for Acute Seizure Medications: A Quantitative Survey

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## QUESTION

What are the preferences of people with epilepsy or an epilepsy syndrome (PwE) and their caregivers (CGs) for attributes of acute (on-demand) seizure medications for prolonged seizures (PS)?

## INVESTIGATION

Preference survey of adult (≥18 years of age) PwE who had experienced ≥1 PS in the past 12 months, and adult CGs of adolescent (12-17 years of age) or adult PwE who had experienced ≥1 PS in the past 12 months. PS were defined as generalised seizures of ≥2 minutes or focal seizures of ≥5 minutes. Participants were recruited from France, Italy, Poland, Spain, the United Kingdom, and the United States (N=374).

## RESULTS

### Participants’ preferences regarding different attributes of acute seizure medications (discrete choice experiment [DCE])

- All attributes examined (time to stop the seizure, mode of administration, treatment time window, probability to stop the seizure within the time frame, and no seizure recurrence for the next 12 hours) significantly influenced treatment preferences.

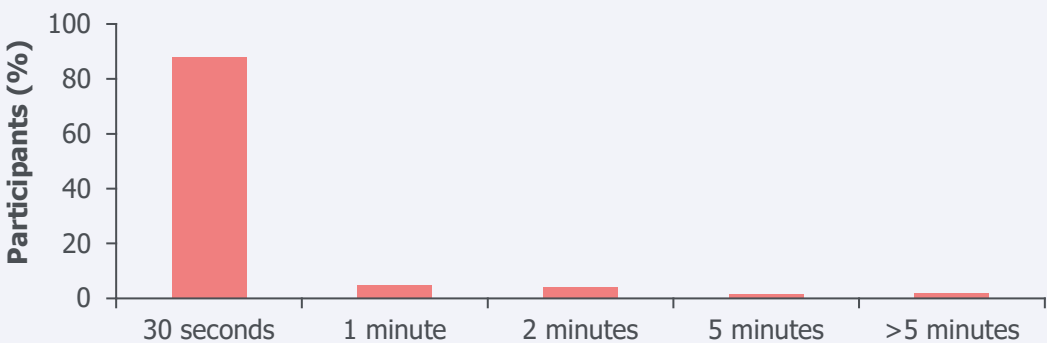


<sup>a</sup>Images: FlatIcon.com. <sup>b</sup>Markers indicate the following time points: at the first symptoms of seizure, once the seizure has become prolonged, and once a seizure has progressed to status epilepticus.

## CONCLUSIONS

- Discrete choice experiment results showed that adult PwE and CGs of adult and adolescent PwE value fast-acting acute seizure medications (those that can stop a seizure within 1-2 minutes, the shortest times proposed).
- Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred.
- Participants also indicated a preference for administering these treatments early in the seizure, either at the first symptoms or once the seizure has become prolonged.
- In the willingness-to-wait exercise, most participants would not wait longer than 30 seconds (the shortest time proposed) before administering an acute seizure medication.
- The importance of the treatment attributes suggests an unmet need for a fast-acting medication with an appropriate mode of administration, as well as a need to reassess the recommendation to wait for several minutes before administering treatment for PS.

### Participants’ willingness to wait when experiencing a seizure before deciding to administer an acute seizure medication



## Background

- Rapid and Early Seizure Termination (REST) is a new treatment paradigm potentially involving future fast-acting medications used very early in an ongoing seizure to prevent it from becoming prolonged or progressing in severity, whereas acute cluster treatments (rescue medications) are given to prevent the next or further seizures in a cluster.<sup>1</sup>

## Objective

- To explore the preferences of people with epilepsy or an epilepsy syndrome (PwE) and their caregivers (CGs) for attributes of acute (on-demand) seizure medications for prolonged seizures (PS), using preference elicitation exercises.

## Methods

- This was a preference survey of adult (≥18 years of age) PwE who had experienced ≥1 PS in the past 12 months, and adult CGs of adolescent (12-17 years of age) or adult PwE who had experienced ≥1 PS in the past 12 months. Participants were recruited from France, Italy, Poland, Spain, the United Kingdom, and the United States.
  - PS were defined as generalised seizures of ≥2 minutes or focal seizures of ≥5 minutes.
- Participants completed a discrete choice experiment (DCE) involving a series of choice tasks in which they selected between 2 hypothetical treatment options comprising 5 attributes (mode of administration, treatment time window, time to stop the seizure, probability to stop the seizure within the treatment time frame, and no seizure recurrence for the next 12 hours); and an exercise assessing their willingness to wait when experiencing a seizure or an aura before deciding to administer an acute seizure medication.
- Descriptive analyses were conducted on participant characteristics and results of the willingness-to-wait exercise.
- DCE results were analysed using multinomial logit (MNL) models, including a linear-coded MNL model for the overall analysis and interacted MNL models for subgroup analyses.
  - Relative attribute importance (RAI) was calculated using the full-sample linear-coded MNL model.

## Results

### PARTICIPANT CHARACTERISTICS

- A total of 526 candidates were screened. Of these, 48 failed screening and 478 proceeded to open the survey. Among the 478 participants, 104 withdrew and 374 completed the survey and were included in the analysis.

#### Characteristics of PwE and CG participants

|                             | Overall (N=374) | Adult PwE (n=135) | CG of adolescent (n=119) | CG of adult (n=120) |
|-----------------------------|-----------------|-------------------|--------------------------|---------------------|
| Country, n (%)              |                 |                   |                          |                     |
| United States               | 148 (40)        | 65 (48)           | 42 (35)                  | 41 (34)             |
| Italy                       | 69 (18)         | 24 (18)           | 23 (19)                  | 22 (18)             |
| Poland                      | 46 (12)         | 14 (10)           | 16 (13)                  | 16 (13)             |
| France                      | 40 (11)         | 10 (7.4)          | 14 (12)                  | 16 (13)             |
| United Kingdom              | 40 (11)         | 10 (7.4)          | 14 (12)                  | 16 (13)             |
| Spain                       | 31 (8.3)        | 12 (8.9)          | 10 (8.4)                 | 9 (7.5)             |
| Age, median (Q1, Q3), years | 45 (35, 54)     | 38 (28, 52)       | 45 (39, 50)              | 49 (40, 56)         |
| Female, n (%)               | 242 (65)        | 73 (54)           | 82 (69)                  | 87 (73)             |

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome; Q1, 25th percentile; Q3, 75th percentile.

#### Characteristics of CG participants

|                                                                                                                                                                            | Overall (n=239) | CG of adolescent (n=119) | CG of adult (n=120) |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|--------------------------|---------------------|
| Age of person with epilepsy, median (Q1, Q3), years                                                                                                                        | 18 (14, 40)     | 14 (13, 16)              | 40 (24, 59)         |
| Current highest level of caregiving responsibility, n (%)                                                                                                                  |                 |                          |                     |
| Sporadic care (eg, accompaniment to physician’s appointments, light errands, sporadic in-house or telephone check-ins)                                                     | 33 (14)         | 11 (9.2)                 | 22 (18)             |
| Household care (eg, more frequent monitoring of symptoms and medications, support with finances and/or household tasks, coordinating the patient’s care plan)              | 83 (35)         | 38 (32)                  | 45 (38)             |
| Personal care (eg, household help, additional support with tasks of personal care like dressing up and hygiene, providing acute care to manage symptoms on the day to day) | 64 (27)         | 30 (25)                  | 34 (28)             |
| Advanced care (when the CG completes all day-to-day activities)                                                                                                            | 59 (25)         | 40 (34)                  | 19 (16)             |

CG, caregiver; Q1, 25th percentile; Q3, 75th percentile.

#### Seizure experience: most common seizure type<sup>a</sup>

| n (%)                                                                      | Overall (N=374) | Adult PwE (n=135) | CG of adolescent (n=119) | CG of adult (n=120) |
|----------------------------------------------------------------------------|-----------------|-------------------|--------------------------|---------------------|
| Focal seizures/without loss of awareness                                   | 91 (24)         | 34 (25)           | 31 (26)                  | 26 (22)             |
| Focal seizures/with loss of awareness                                      | 91 (24)         | 32 (24)           | 34 (29)                  | 25 (21)             |
| Generalized or bilateral seizures/tonic-clonic                             | 173 (46)        | 52 (39)           | 56 (47)                  | 65 (54)             |
| Generalized or bilateral seizures/non-motor                                | 72 (19)         | 33 (24)           | 20 (17)                  | 19 (16)             |
| Unknown offset/present visible physical movement, jerks, or body stiffness | 36 (9.6)        | 13 (9.6)          | 11 (9.2)                 | 12 (10)             |
| Unknown offset/without any visible movements of the body or as an absence  | 12 (3.2)        | 6 (4.4)           | 4 (3.4)                  | 2 (1.7)             |

<sup>a</sup>This study was completed before the 2025 updated seizure classification by the International League Against Epilepsy<sup>2</sup> was published. CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

#### Frequency and duration of seizures during the past 12 months

| n (%)                                                                                     | Overall (N=374) | Adult PwE (n=135) | CG of adolescent (n=119) | CG of adult (n=120) |
|-------------------------------------------------------------------------------------------|-----------------|-------------------|--------------------------|---------------------|
| Average number of seizures per month during the past 12 months                            |                 |                   |                          |                     |
| <3                                                                                        | 86 (23)         | 34 (25)           | 23 (19)                  | 29 (24)             |
| 3-5                                                                                       | 193 (52)        | 69 (51)           | 66 (55)                  | 58 (48)             |
| 6-10                                                                                      | 55 (15)         | 14 (10)           | 21 (18)                  | 20 (17)             |
| 11-20                                                                                     | 18 (4.8)        | 8 (5.9)           | 3 (2.5)                  | 7 (5.8)             |
| >20                                                                                       | 22 (5.9)        | 10 (7.4)          | 6 (5.0)                  | 6 (5.0)             |
| Average duration of the most common type of seizure experienced during the past 12 months |                 |                   |                          |                     |
| <1 minutes                                                                                | 27 (7.2)        | 16 (12)           | 9 (7.6)                  | 2 (1.7)             |
| 1-2 minutes                                                                               | 86 (23)         | 29 (21)           | 27 (23)                  | 30 (25)             |
| 2-4 minutes                                                                               | 128 (34)        | 46 (34)           | 43 (36)                  | 39 (33)             |
| 4-5 minutes                                                                               | 65 (17)         | 20 (15)           | 23 (19)                  | 22 (18)             |
| >5 minutes                                                                                | 68 (18)         | 24 (18)           | 17 (14)                  | 27 (23)             |

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

#### Current acute (on-demand) medications to treat PS

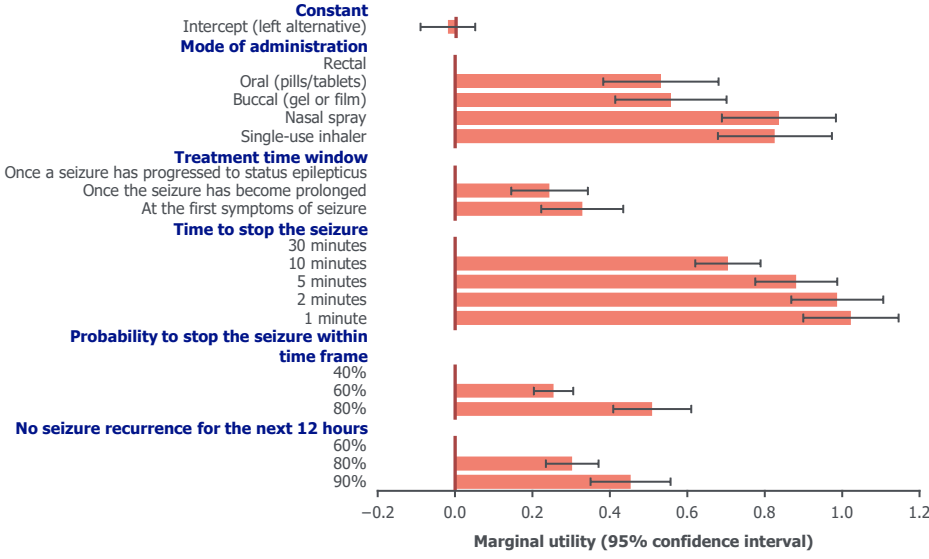
| n (%)                                                                   | Overall (N=374) | Adult PwE (n=135) | CG of adolescent (n=119) | CG of adult (n=120) |
|-------------------------------------------------------------------------|-----------------|-------------------|--------------------------|---------------------|
| Oral                                                                    | 212 (57)        | 72 (53)           | 65 (55)                  | 75 (63)             |
| Rectal                                                                  | 72 (19)         | 18 (13)           | 33 (28)                  | 21 (18)             |
| Intranasal spray <sup>a</sup>                                           | 39 (10)         | 20 (15)           | 8 (6.7)                  | 11 (9.2)            |
| Intravenous or intramuscular injection                                  | 60 (16)         | 21 (16)           | 19 (16)                  | 20 (17)             |
| Buccal <sup>b</sup>                                                     | 59 (16)         | 15 (11)           | 24 (20)                  | 20 (17)             |
| Not using benzodiazepines as acute (‘on-demand’) medication to treat PS | 27 (7.2)        | 16 (12)           | 4 (3.4)                  | 7 (5.8)             |

<sup>a</sup>Intranasal spray option was only available to participants in the United States; <sup>b</sup>Buccal option was only available to participants in Europe. CG, caregiver; PS, prolonged seizure; PwE, people with epilepsy or an epilepsy syndrome.

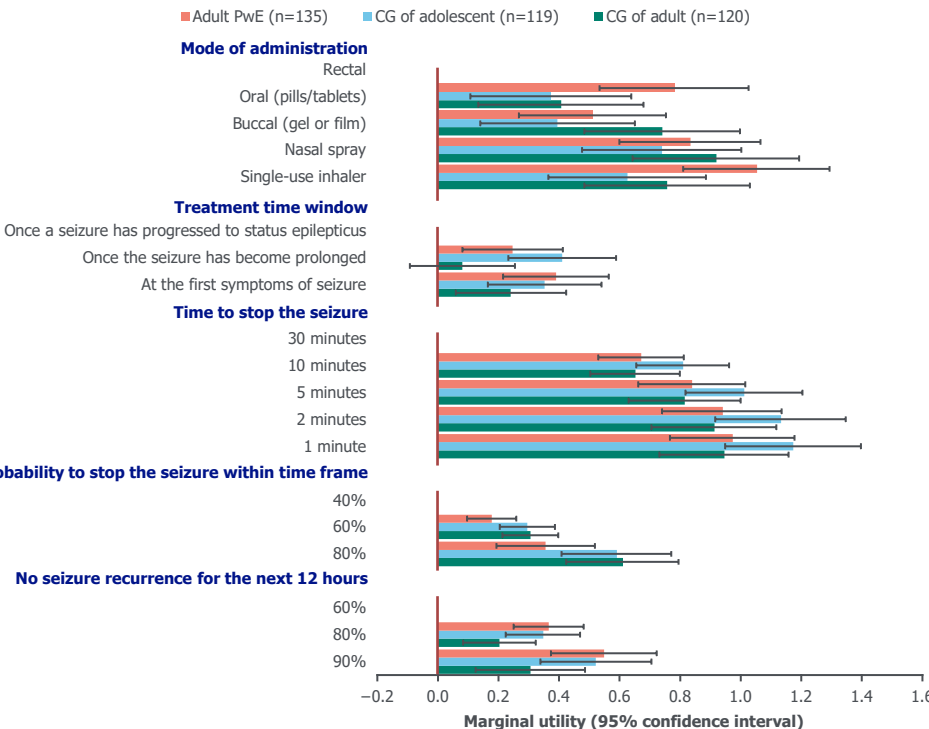
### PARTICIPANTS’ TREATMENT PREFERENCES

- All attributes significantly influenced participants’ treatment preferences (all p<0.001).
- The most important was time to stop the seizure (RAI=32.4%) and mode of administration (RAI=26.6%), then probability to stop the seizure within the time frame (RAI=16.2%), no seizure recurrence for the next 12 hours (RAI=14.4%), and finally treatment time window (RAI=10.4%).
- Participants preferred acute seizure medications that can stop a seizure within 1-2 minutes.
- Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred.
- Participants also preferred administering acute seizure medications early in the seizure, either at the first symptoms or once the seizure has become prolonged.

#### Overall results (N=374)

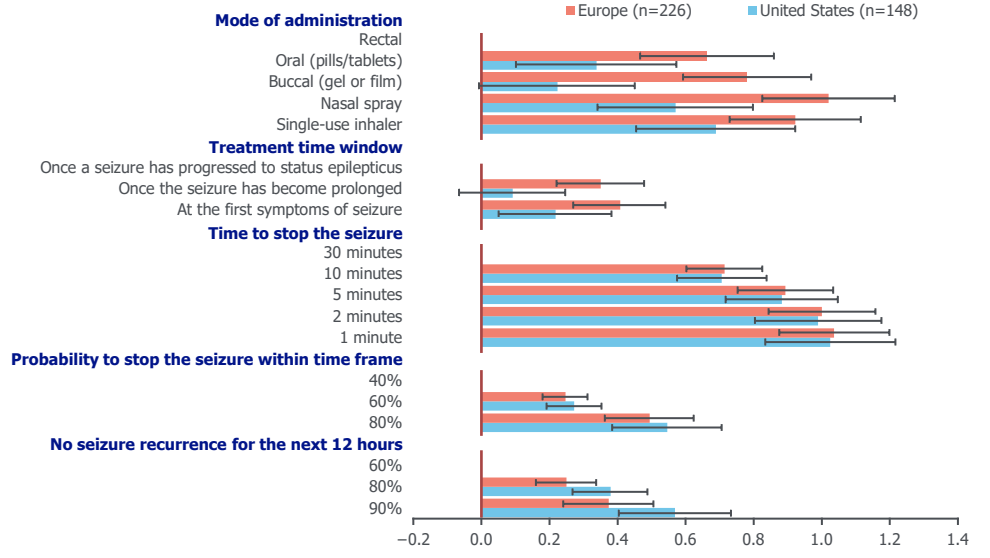


#### Subgroup analyses by participant type (N=374)



- Single-use inhaler was valued more by adult PwE than by CGs of adolescents (p<0.05).
- Improving the chance of stopping the seizure within the provided time frame was valued more by CGs of adults and CGs of adolescents than by adult PwE (p<0.05 and p=0.06, respectively).
- Improving the chance to avoid seizure recurrence for the next 12 hours was more important to adult PwE than to CGs of adults (p=0.06).

#### Subgroup analyses by region (N=374)



- European participants valued oral, buccal, and nasal spray administration more than US participants (p<0.05, p<0.001, and p<0.01, respectively).
- Treatment time window was more important to European participants, who wanted to treat seizures earlier than US participants (p<0.05 for ‘once the seizure has become prolonged’ and p=0.08 for ‘at the first symptoms of seizure’).
- Improving the chance to avoid seizure recurrence for the next 12 hours was somewhat more important to US vs European participants (p=0.07).

#### Willingness to wait before deciding to administer an acute seizure medication

| n (%)      | Overall (N=374) | Adult PwE (n=135) | CG of adolescent (n=119) | CG of adult (n=120) |
|------------|-----------------|-------------------|--------------------------|---------------------|
| 30 seconds | 328 (88)        | 125 (93)          | 97 (82)                  | 106 (88)            |
| 1 minute   | 18 (4.8)        | 4 (3.0)           | 8 (6.7)                  | 6 (5.0)             |
| 2 minutes  | 15 (4.0)        | 4 (3.0)           | 9 (7.6)                  | 2 (1.7)             |
| 5 minutes  | 6 (1.6)         | 0 (0)             | 2 (1.7)                  | 4 (3.3)             |
| >5 minutes | 7 (1.9)         | 2 (1.5)           | 3 (2.5)                  | 2 (1.7)             |

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

# CONCLUSIONS

- DCE results showed that adult PwE and CGs of adult and adolescent PwE value fast-acting acute seizure medications (those that can stop a seizure within 1-2 minutes, the shortest times proposed).
  - Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred.
  - Participants also indicated a preference for administering these treatments early in the seizure, either at the first symptoms or once the seizure has become prolonged.
  - In subgroup analyses:
    - Single-use inhaler was valued more by adult PwE than by CGs of adolescents
    - Improving the chance of stopping the seizure within the provided time frame was valued more by CGs of adults and CGs of adolescents than by adult PwE
    - Improving the chance to avoid seizure recurrence for the next 12 hours was more important to adult PwE than to CGs of adults.
- In the willingness-to-wait exercise, most participants would not wait longer than 30 seconds (the shortest time proposed) before administering an acute seizure medication.
- The importance of the treatment attributes suggests an unmet need for a fast-acting medication with an appropriate mode of administration, as well as a need to reassess the recommendation to wait for several minutes before administering treatment for PS.

## References

- Pina-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497.
  - Beniczky S, et al. *Epilepsia* 2025;66(6):1804-1823.
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