

Digital Application Usage in Epilepsy: Insight From Real-World Setting Studies

BRIVA-Reg and BRITOBA

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Poster 3.14

Background

- Digital health solutions are becoming integral to clinical practice, creating new information-sharing capabilities for patients and physicians. These tools facilitate data collection and consultations, enabling novel patient-physician interactions.¹
- The BRIVA-Reg study (EP0099), an observational study conducted across 6 mid-European countries, and the BRITOBA study (EP0103), an observational study conducted across 4 European countries and Canada, integrated the use of Helpilepsy (www.helpilepsy.com), a certified medical device consisting of a mobile health assistant for patients and a web-based dashboard for physicians.^{2,3}
- During those studies, participants and physicians used the Helpilepsy platform to share epilepsy-related data and complete patient-reported outcomes (PROs). (a) electronic PRO (ePRO) to be completed for BRITOBA: PGIC, NDDI-E, QOLIE-10-P, SSQ3, TSQM-9, WPAI-GH. (b) ePRO to be completed for BRIVA-Reg: TSQM-9, QOLIE-31-P, PGIC, PedsQL, Neuro-QoL SF.⁴

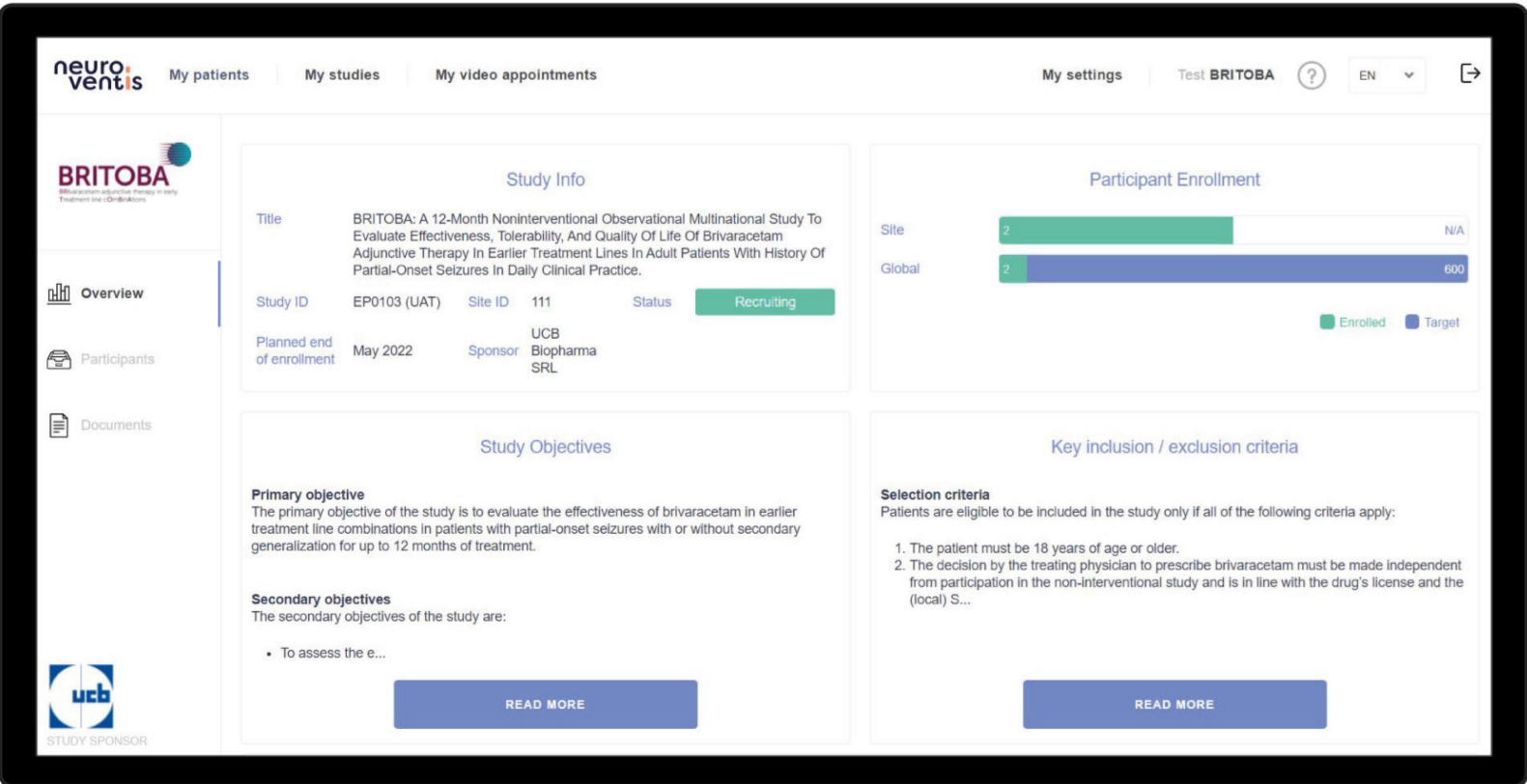
Objective

- The current analysis aims to summarize participants' experience using the app, compliance, and demographics across both studies.

Methods

- In both studies, participants or their legal representant (caregivers of minors [4-17 years of age] in BRIVA-Reg) could voluntarily answer PROs via the Helpilepsy app.
- This analysis assessed the proportion of Helpilepsy users, their characteristics, and PRO response rates by country, age, and gender.
- Feedback from physicians was also gathered through post-study sessions organized by UCB and Neuroventis during the 2024 European Epilepsy Congress.

Example of screens from the Helpilepsy app used for the BRITOBA study



QUESTION

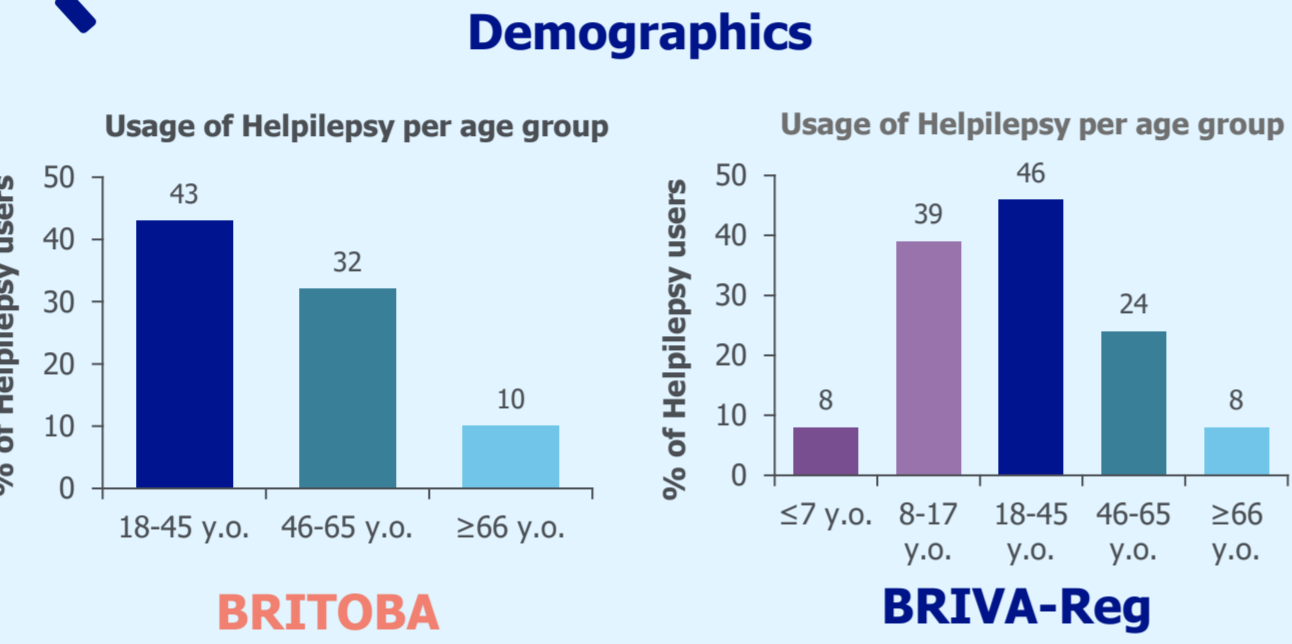
What were the participants' experiences using the Helpilepsy app, compliance rates, and demographic characteristics across the BRITOBA and BRIVA-Reg studies?



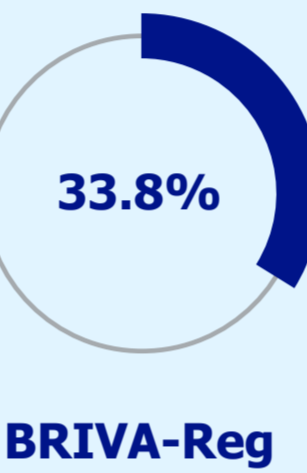
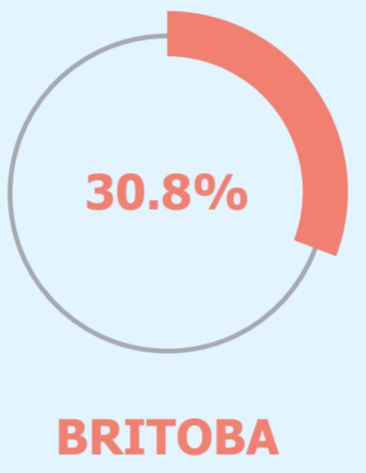
INVESTIGATION

The analysis examined the proportion of the Helpilepsy app users, their demographic characteristics, and PRO response rates analyzed by country, age, and gender. Completion of PROs for the two studies was voluntary for participants. Physician feedback was collected through post-study sessions organized by UCB and Neuroventis during the 2024 European Epilepsy Congress.

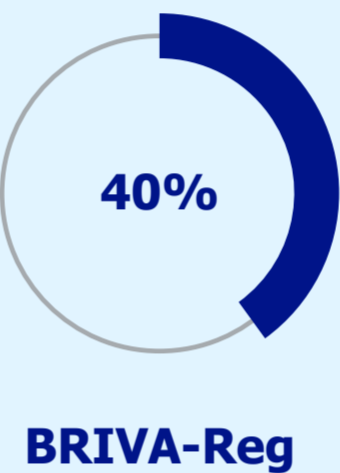
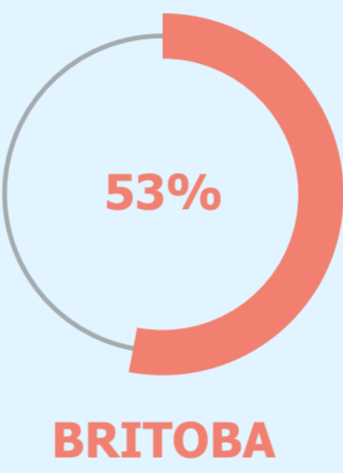
RESULTS



Usage of Helpilepsy



Compliance – ePRO answer rate



Healthcare professional qualitative feedback positive

Post-study interviews conducted by Neuroventis and UCB highlighted that physicians found the app valuable, noting it enhanced doctor-patient interactions when patients actively input data. They emphasized the increasing role of digital tools in managing epilepsy and suggested future improvements. Personalization, simplicity, AI integration, and additional features like period tracking for women were recommended for further development.

CONCLUSIONS

These two real-world studies provided valuable data on the usage of the Helpilepsy app. These data allow us to identify the patient groups most likely to engage with the app in its current form for these types of studies. These insights are contributing to the development of a new generation of electronic clinical outcome assessments (eCOA) platforms for the epilepsy population, aimed at enhancing protocol compliance and providing benefits to both patients and investigators.

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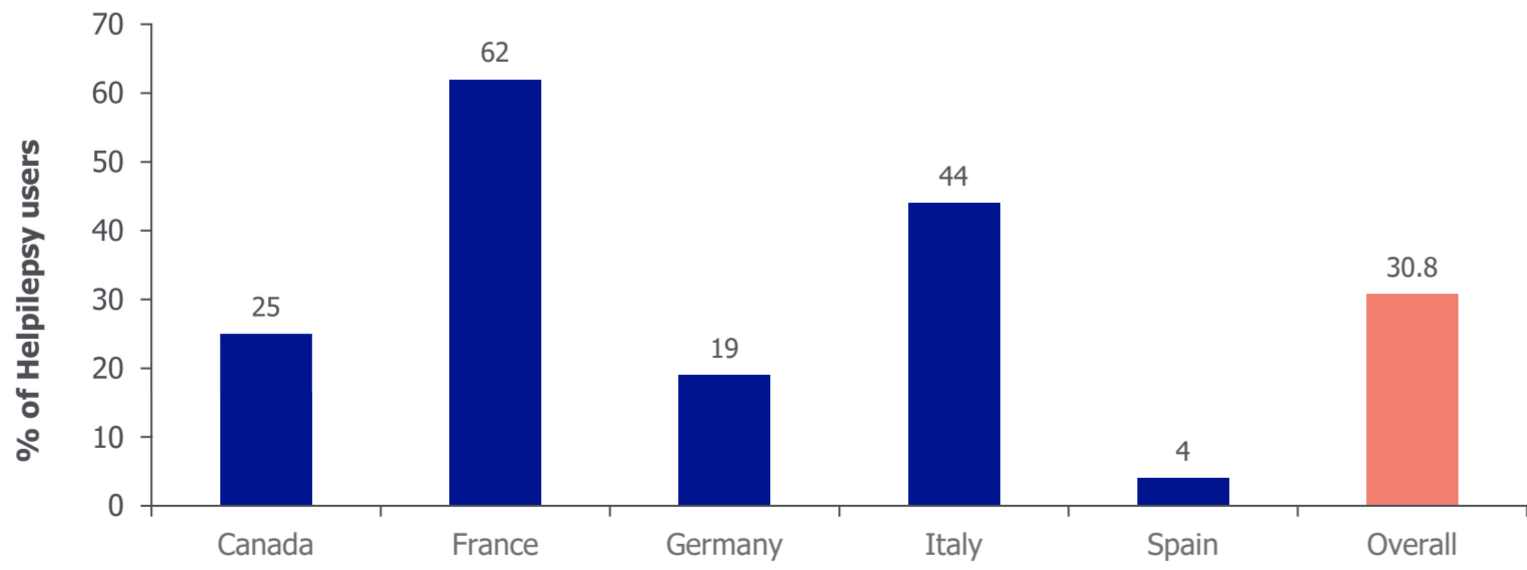


Results

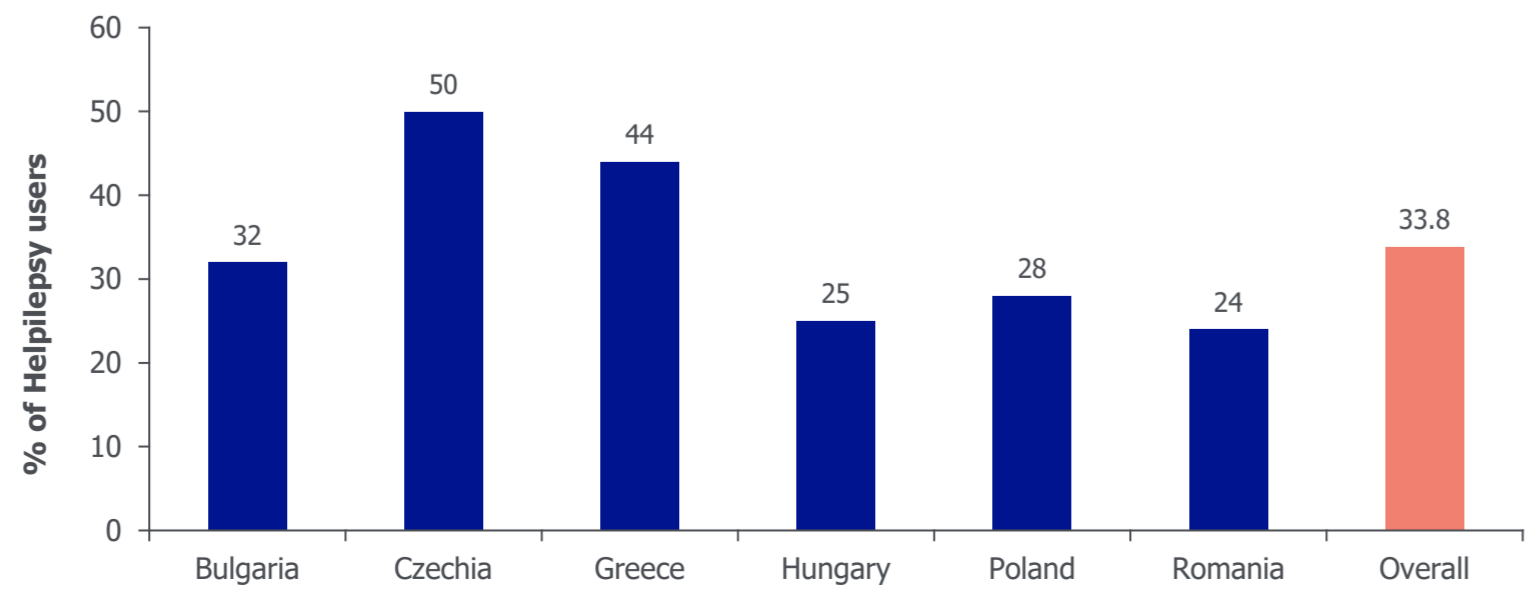
- In the BRITOBA and BRIVA-Reg studies, 137/403 participants enrolled (34%) and 280/801 participants enrolled (35%), respectively, agreed to use the Helpilepsy app.

USAGE OF THE HELPILEPSY APP BY COUNTRY

Percentage of participants who used Helpilepsy - BRITOBA

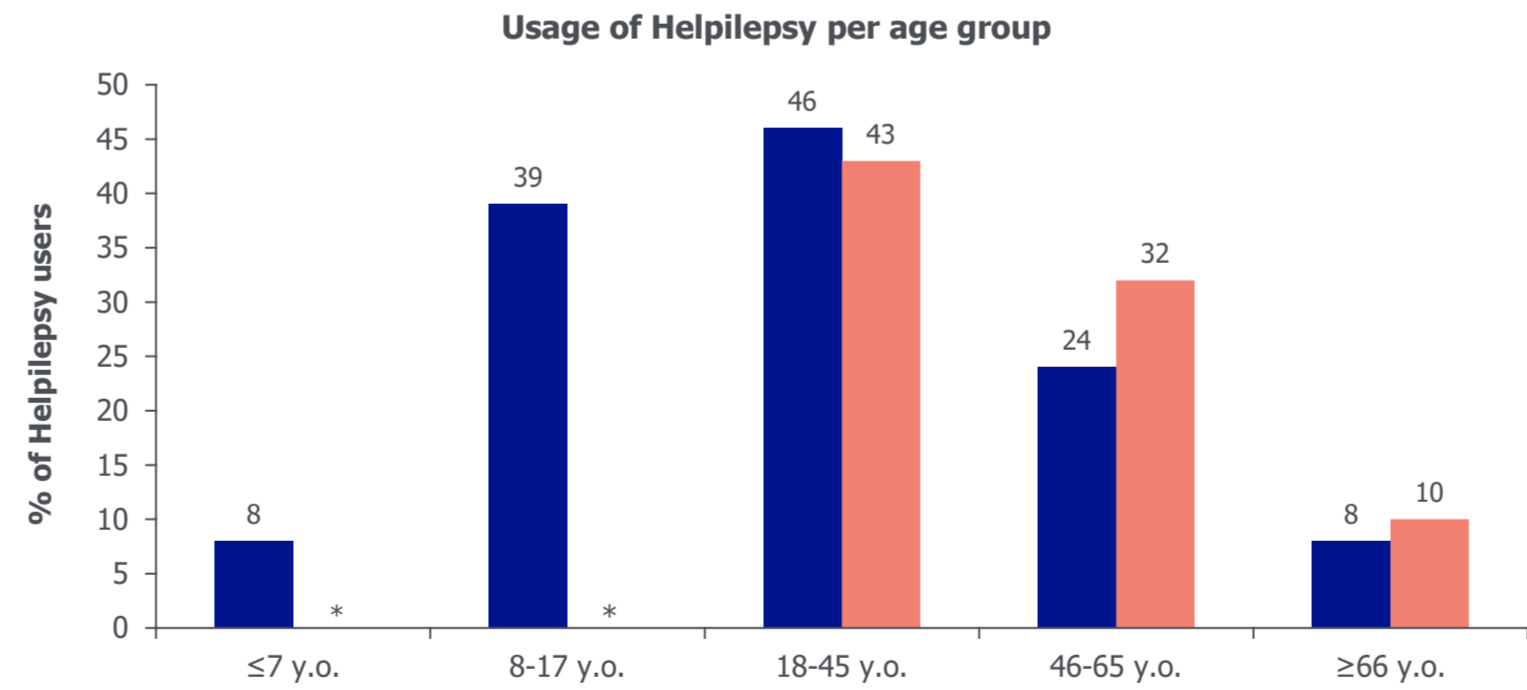


Percentage of participants who used Helpilepsy – BRIVA-Reg



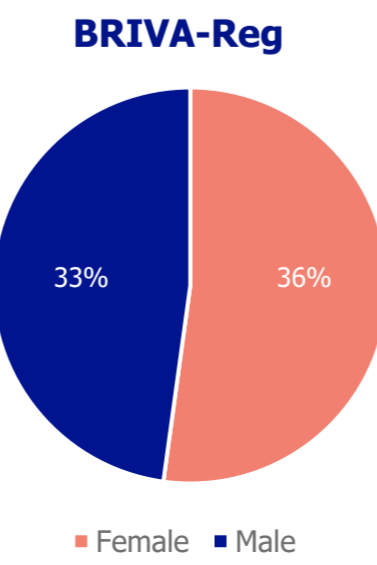
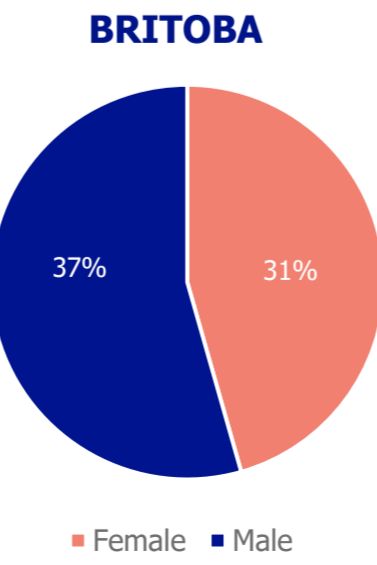
HELPILEPSY USER DEMOGRAPHICS

Percentage of participants who used Helpilepsy by age group – BRITOBA and BRIVA-Reg



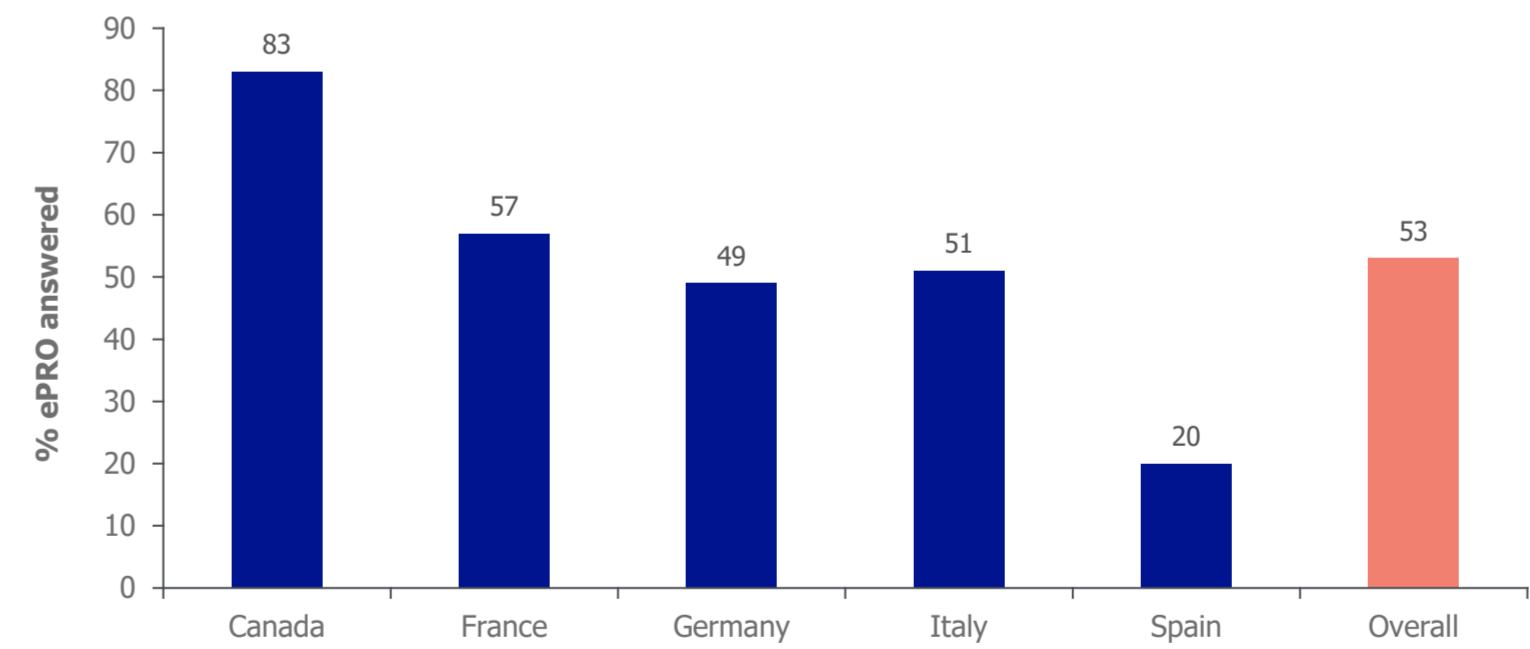
*Not applicable: BRITOBA did not include patients <18 years of age.

Gender distribution of Helpilepsy users

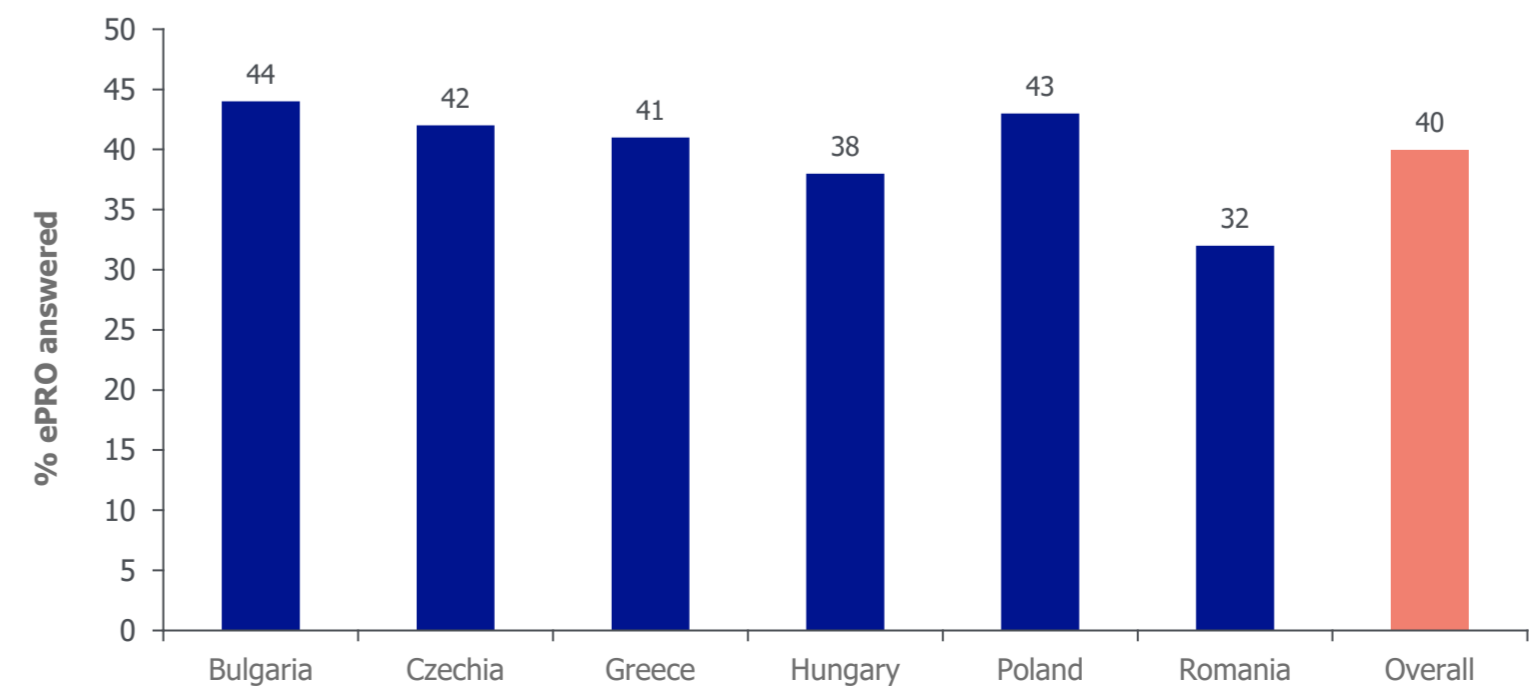


ELECTRONIC PATIENT-REPORTED OUTCOMES (ePRO) COMPLETION RATE

ePRO answer rate by country - BRITOBA



ePRO answer rate by country - BRIVA-Reg



FEEDBACK SESSIONS WITH PHYSICIANS

- At the 2024 European Epilepsy Congress, physicians shared their experiences with the Helpilepsy platform in BRIVA-Reg. They noted that when participants engaged actively, the platform clearly improved the quality of clinical visits by enabling more structured discussions and providing additional insights into patients' daily lives. Physicians viewed this as an important step toward closer collaboration and more personalized care.
- Several challenges were also discussed. Because data entry was voluntary, some participants lacked motivation to use the app regularly. Technical issues, especially slower performance on certain devices, occasionally hampered sustained engagement. In addition, the app was less suitable for patients with limited digital skills or cognitive impairments, and some questionnaire translations required refinement.
- Despite these limitations, physicians emphasized the strong potential of digital tools in epilepsy management and research. The integration of connected devices such as NightWatch was seen as a valuable addition, and suggestions for further improvements included simplifying onboarding, adapting content to patient characteristics, and adding supportive features such as menstrual cycle tracking.
- These learnings from BRIVA-Reg and BRITOBA directly informed the design of Neuroventis' new eDiary and electronic clinical outcome assessment (eCOA) platform.

Conclusions

- The BRITOBA (EP0103) study, conducted across 4 European countries and Canada, and the BRIVA-Reg (EP0099) study, conducted across 6 mid-European countries, provided first valuable statistics on the usage of the Helpilepsy app.
- These data allow us to identify the patient groups most likely to engage with the app in its current form for these types of studies.
- These insights are contributing to the development of a new generation of electronic clinical outcome assessments (eCOA) platforms for the epilepsy population, aimed at enhancing protocol compliance for clinical research and providing benefits to both patients and physicians.

References

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- Leunikava I, et al. *Epilepsia* 2022;63(Suppl 2):126; Abstract 307.
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*NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; Neuro-QoL SF, Quality of Life in Neurological Disorders - Short Form; PedsQL, Pediatric Quality of Life Inventory; PGIC, Patient Global Impression of Change; QOLIE-10-P, Patient-Weighted Quality of Life in Epilepsy Inventory-10-P; QOLIE-31-P, Patient-Weighted Quality of Life in Epilepsy Inventory-31-P; SSQ3, Seizure Severity Questionnaire 3; TSQM-9, Treatment Satisfaction Questionnaire for Medication-9; WPAI-GH, Work Productivity and Activity Impairment - General Health; y.o., years old.

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