Understanding and Optimising the Seizure Emergency Pathway

Noem Sain[1]
Milena Blyth[1]
Beth Clark[2]
An-hwa Lee[2]

1. UCB, Brussels, Belgium
2. Basis Health, London, UK

Overview

QUESTION

What is the end-to-end care pathway from home setting to discharge from hospital setting of a seizure emergency event (abnormal seizure, prolonged seizure, seizure cluster, or status epilepticus) based on reference guidelines? What are the management care gaps and improvement opportunities along the seizure emergency pathway that could ultimately prevent avoidable seizure escalation, risk of injury, and death?

INVESTIGATION

60-minute in-depth qualitative interviews with key stakeholders involved in the seizure emergency pathway (epileptologists, emergency doctors/paramedics, epilepsy nurses, and patient association experts) across the UK, France, Italy, and Germany, with a 10-minute pre-task to capture key guideline sources before the interviews. Qualitative research was accompanied by a review of publicly available online literature and seizure emergency guidelines.

RESULTS

Each country included in the analysis has both national and specific hospital or regional guidelines that outline seizure emergency care pathways.

There are, however, **inconsistencies across countries** regarding management recommendations between at-home care, paramedic care, emergency and hospital care, and discharge.

UK (NICE) and German guidelines emphasise strict timing protocols for administering medications and escalating care (5–10 minutes).

French and Italian guidelines lack strict timing but highlight rapid escalation.

Most guidelines focus extensively on the management of seizure emergencies within the hospital setting, with a **limited focus on prevention guidance for patients and caregivers**.

Individuals who experience a seizure emergency can be discharged at any stage of the pathway (ambulance, emergency room, inpatient care).

However, there are **no specific recommendations on discharge protocols**, with little to no mention of developing individualised seizure action plans, or consideration of acute treatments or other preventative measures.

Rapid and Early Seizure Termination (REST) has been proposed as a new management paradigm for early initiation of rapid treatment to terminate ongoing seizures as quickly as possible, to avoid progression in seizure severity, and to improve quality of life.[8]

REST has not yet been included in national or regional guidelines.

NICE, National Institute for Health and Care Excellence.

CONCLUSIONS

Pain points identified in current pathways provide opportunities to optimise seizure emergency guidelines. A stronger focus on at-home guidelines could empower patients and caregivers to manage acute seizures in the community setting, potentially avoiding unnecessary seizure escalation, injury, hospitalisation, and death. The management of seizure emergencies can involve many different stakeholders along the pathway and can therefore be societally burdensome. The inclusion of REST in guidelines could lead to a behaviour shift to earlier management and prevention of seizure emergency escalation in the community setting, preventing negative patient outcomes and decreasing unnecessary economic burden.

For a copy of the poster, scan:

Background

- Up to 40% of patients with epilepsy on stable antiseizure medication treatment will experience breakthrough seizures.[1] These seizures can become prolonged or progress to a more severe seizure type, including status epilepticus (SE), which requires emergent treatment to lower morbidity and mortality.[2]
- The management of acute seizures begins in the community, and escalation can involve transfer of care across the full end-to-end seizure emergency pathway, from outpatient to emergency to inpatient care.[3,4]
- Because most seizure emergencies begin outside of a medical facility, efforts have been made to find an ideal, prehospital, non-intravenous, acute treatment.[5] By stopping a prolonged seizure rapidly or preventing further seizures, acute treatments may avoid the need for subsequent invasive interventions and reduce medical costs related to emergency room visits and hospitalisation.[5] Access to acute treatments may also provide patients and caregivers with a greater sense of security and control over at-home seizure management and increase their ability to travel.[5-6]

Objective

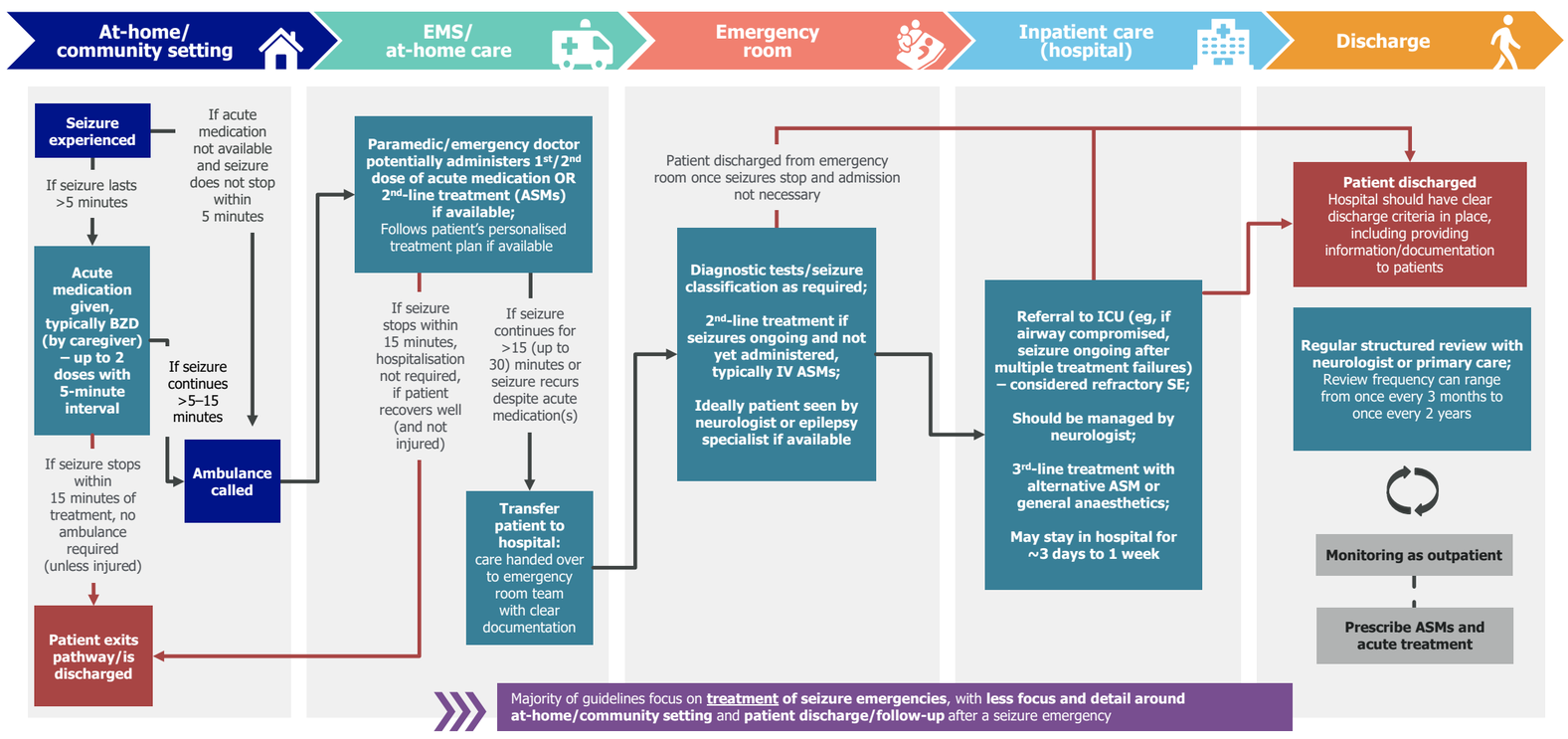
- Understand the end-to-end care pathway of a seizure emergency event (abnormal seizure, prolonged seizure, seizure cluster, or SE) based on the various guidelines/recommendations for different stakeholders who act along this pathway (from at-home guidelines to paramedic guidelines to emergency room standard operation procedures to inpatient care guidelines), and then to identify management care gaps and opportunities to improve patient experience and ultimately prevent avoidable seizure escalation, risk of injury, and death.

Methods

- 60-minute in-depth qualitative interviews (four per country) were conducted with key healthcare providers involved in the seizure emergency pathway across the UK, France, Italy, and Germany, with a 10-minute pre-task to capture key guideline sources before the interviews.
- Respondents included a mix of epileptologists, emergency doctors/paramedics, epilepsy nurses, and patient association experts (one of each per country).
- Qualitative research was accompanied by a review of publicly available online literature and seizure emergency guidelines.

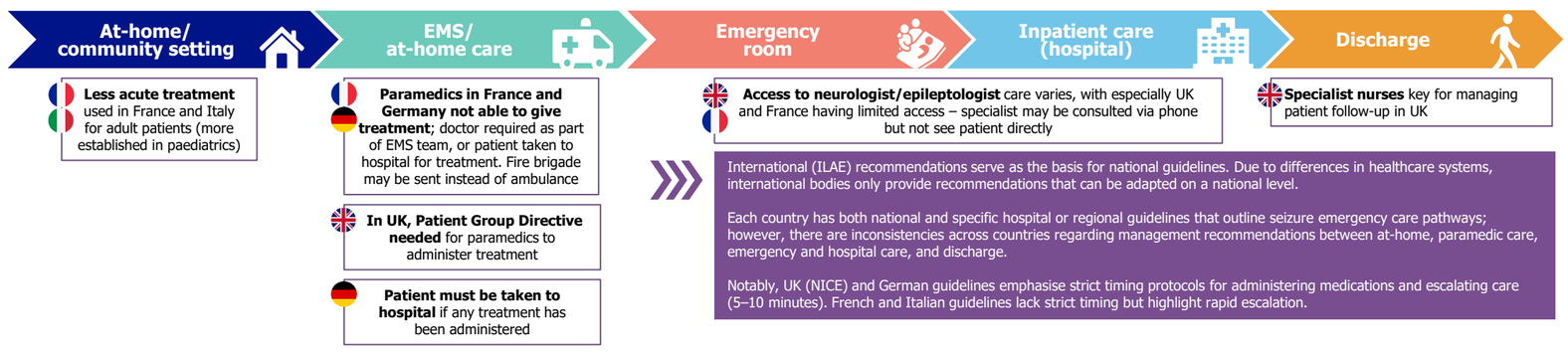
Results

Seizure emergency patient journey based on guidelines across EU[a]



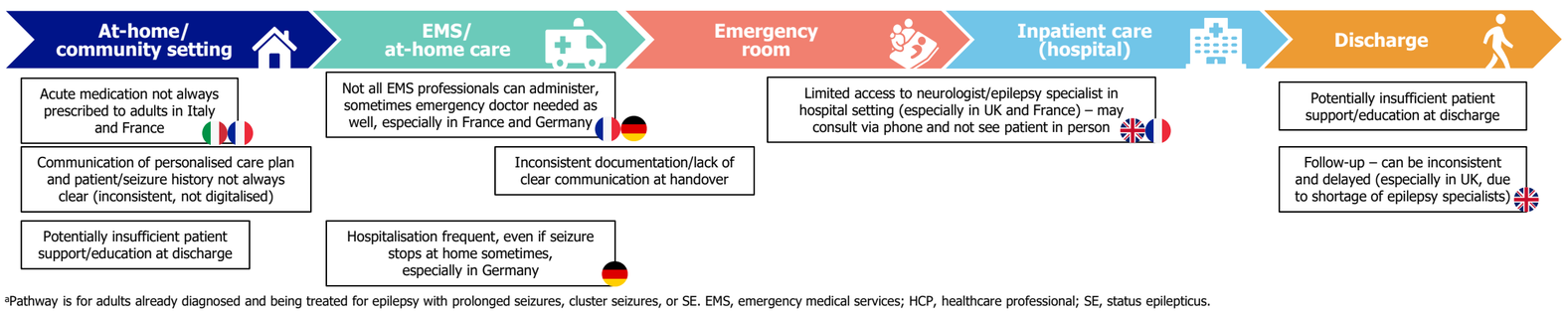
[a]Pathway is for adults already diagnosed and being treated for epilepsy with prolonged seizures, cluster seizures, or SE. ASM, antiseizure medication; BZD, benzodiazepine; EMS, emergency medical services; EU, European Union; ICU, intensive care unit; IV, intravenous; SE, status epilepticus.

Differences across EU countries in seizure emergency patient journey based on EU guidelines[a]



[a]Pathway is for adults already diagnosed and being treated for epilepsy with prolonged seizures, cluster seizures, or SE. EMS, emergency medical services; EU, European Union; ILAE, International League Against Epilepsy; NICE, National Institute for Health and Care Excellence; SE, status epilepticus.

Pain points in seizure emergency patient journey[a] as perceived by HCPs



[a]Pathway is for adults already diagnosed and being treated for epilepsy with prolonged seizures, cluster seizures, or SE. EMS, emergency medical services; HCP, healthcare professional; SE, status epilepticus.

Key challenges with current EU guidelines

Limited focus on seizure prevention and early termination	× More focused on seizure management by EMS/hospital after seizure has happened × **Limited integration of patients'/caregivers' role** in early seizure management and termination in community
Do not always facilitate easy decision making	× **Lack of fully integrated, interdisciplinary epilepsy-specific** guidelines might lead to inconsistent, inadequate, or interrupted care, ie, guidelines exist for EMS, emergency room, ICU, hospital discharge that cover only parts of epilepsy care pathway or are generic × **Ambiguity or gaps** leave room for interpretation, potentially leading **to inconsistent or suboptimal care,** particularly around **patient discharge and patient education** in the community setting
Guidelines not necessarily aimed at optimal use of resources	× **Lack of clarity and gaps** might duplicate efforts or manage patients suboptimally (eg, unnecessary hospitalisation), ultimately leading to higher burden to healthcare

EMS, emergency medical services; EU, European Union; ICU, intensive care unit.

Pain points in seizure emergency patient journey as perceived by HCPs in each country

COUNTRY	KEY CHALLENGES/PAIN POINTS	IMPLICATIONS
	At-home guidance is not comprehensive enough and not focused on prevention: patient education is not covered in NICE guidelines and lack of guidance in cases where paramedics/ambulance is not called	• **Inconsistent follow-up and reporting of seizure events** with epilepsy care team • **Lack of guidance for preventative measures**, leading to potentially more dependence on emergency services
	Limited and delayed access to neurologists and nurse specialists	• HCPs have **limited time to educate or develop individual seizure action plans**; patient and caregiver **education and support are inconsistent** • May impact **access to acute treatments** if patient is not able to see specialist for several months after seizure emergency • **Long wait times for follow-up** (typically >2 weeks, which is recommended in guidelines)
	Guidelines **not always up to date** with recent antiepileptic treatments	• Some physicians **disregard treatment recommendations from guidelines** they perceive to be out of date • **International (UK) guidelines** may be implemented at hospital level instead • Out-of-date guidelines could be a **barrier for patients to receive newer medications**
	Guidelines on **calling ambulance and escalating** emergency situation are ambiguous	• **Unclear whether acute treatment should be administered** by caregiver following seizure episode
	Personalised patient care plan with acute treatment not always implemented for adult patients	• **Access to acute treatments can be limited** for adult patients due to lack of indication/approval in adults
	Paramedics unable to prescribe acute treatment without a doctor present	• **Restricts capabilities of paramedics** and adds **burden to emergency doctors** • If emergency doctor is not immediately available, **access to acute treatment can be delayed**
	Smaller/more local hospitals that do not see as many cases **less prepared to manage seizure emergencies**	• May **not handle seizure emergencies optimally** currently • May be **slower to uptake new changes** to treatment recommendation
	Lack of consistency in patient follow-up after being discharged from a seizure emergency	• Some patients experience **delays in treatment reviews** after a seizure emergency due to lack of specific guidelines on timing and procedures • Patients may also not see a specialist within hospital setting; thus, there could be **limited opportunity to review acute treatment**
	Limited guidance on patient discharge, follow-up, and education across the journey	• Some patients **may not have treatment reviews in a timely manner** following a seizure emergency, as guidelines do not specify how and when to conduct these • **Discharge process may not cover key information points** as there is no specific guidance
	Information transfer can be inconsistent, particularly in the at-home, paramedic, and emergency room stages	• Potential for information errors to occur, and therefore patients' **treatment plans may not be followed**

HCP, healthcare professional; NICE, National Institute for Health and Care Excellence.

Conclusions

- Pain points identified in current pathways provide opportunities to optimise seizure emergency guidelines.
- National/regional guidelines focus on management after the seizure emergency has happened, with gaps and unclarity in some areas, especially in the community setting.
- Most guidelines focus on SE and therefore provide minimal guidance on the first minutes of a seizure's progression.
- Current guidelines do not recommend individualised seizure action plans.
- A stronger focus on at-home guidelines could empower patients and caregivers to manage acute seizures in the community setting, via more detailed recommendations and first aid at home, more training, better discharge instructions, and seizure action plans.
- This would potentially avoid unnecessary seizure escalation, injury, hospitalisation, and death.
- The management of seizure emergencies can involve many different stakeholders along the pathway and can therefore be societally burdensome.
- The development and implementation of care pathways is part of the World Health Organization's intersectoral global action plan on epilepsy and other neurological disorders 2022–2031.[7]
- Rapid and Early Seizure Termination (REST) is a new management paradigm for early initiation of rapid treatment to terminate ongoing seizures as quickly as possible, to improve quality of life and avoid progression in seizure severity.[8]
- While REST medications are in development, a recommendation to treat earlier with existing rescue medications already has the potential to optimise treatment of seizure emergencies at home.

References

1. Bonnett LJ, et al. *PLoS One* 2017;12(12):e0190035.
2. Brophy GM, et al. *Neurocrit Care* 2012;17(1):3-23.
3. Scenario: Managing an epileptic seizure. National Institute for Health and Care Excellence. 2025. https://cks.nice.org.uk/topics/epilepsy/management/managing-an-epileptic-seizure/ Accessed July 7, 2025.
4. Galizia EC and Faulkner HJ. *Clin Med (Lond)* 2018;18(5):409-413.
5. Samanta D. *Neurol Sci* 2021;42(10):4017-4027.
6. Penovich P, et al. *Epilepsy Behav* 2021:123:108264.
7. Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031. World Health Organization. 2023. https://iris.who.int/bitstream/handle/10665/371495/9789240076624-eng.pdf Accessed July 16, 2025.
8. Pina-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497.

UCB-sponsored. The authors were involved in the design of the study, the collection, analysis, and interpretation of data, and review of the poster. The authors thank the healthcare professionals and patient association experts who contributed to this study. The authors acknowledge Tom Grant, PhD (UCB, Slough, UK) for managing the development of the poster, and Emily Chu, PhD (Envision Spark, an Envision Medical Communications agency, a part of Envision Pharma Group, Horsham, UK) for writing assistance, which was funded by UCB. Author contributions: All authors designed the study, analysed the data, and interpreted the data. All authors critically reviewed the poster and approved the final version for presentation. Author disclosures: N Sain and M Blyth are employees of UCB. B Clark has no conflicts of interest to disclose. A Lee was employed by Basis at the time of the study, and is currently employed by Genactis Ltd (London, UK).

For a copy of this poster, use your smartphone to scan the QR code or contact UCB**Cares**®

Phone: +32 2 559 92 00

Email: UCBCares@ucb.com

36th International Epilepsy Congress
Lisbon, Portugal | 30 August–3 September 2025