

Network structure of epilepsy and SUDEP-related risk in a real-world digital self-assessment cohort

Jake Ahern¹, Sammy Ashby², Ben Donovan², Peter Hannon³, Lance V. Watkins^{1,4,5}, Richard Laugharne^{1,6}, Brendan Mclean^{1,7,8}, Rohit Shankar^{1,8,*} and John R. Terry^{1,9,*}

1. Background

Risk of sudden unexpected death in epilepsy (SUDEP) spans seizure control, mental health, substance use, medication and access to care. The SUDEP and Seizure Safety Checklist treats these as a list of separate items. **EpSMon, a self-monitoring app built on the checklist**, asks them repeatedly.

Here, we ask: how do the checklist's risk factors relate to one another?

2. Data and methods

Users answer about 30 yes/no risk questions, as often as they choose.

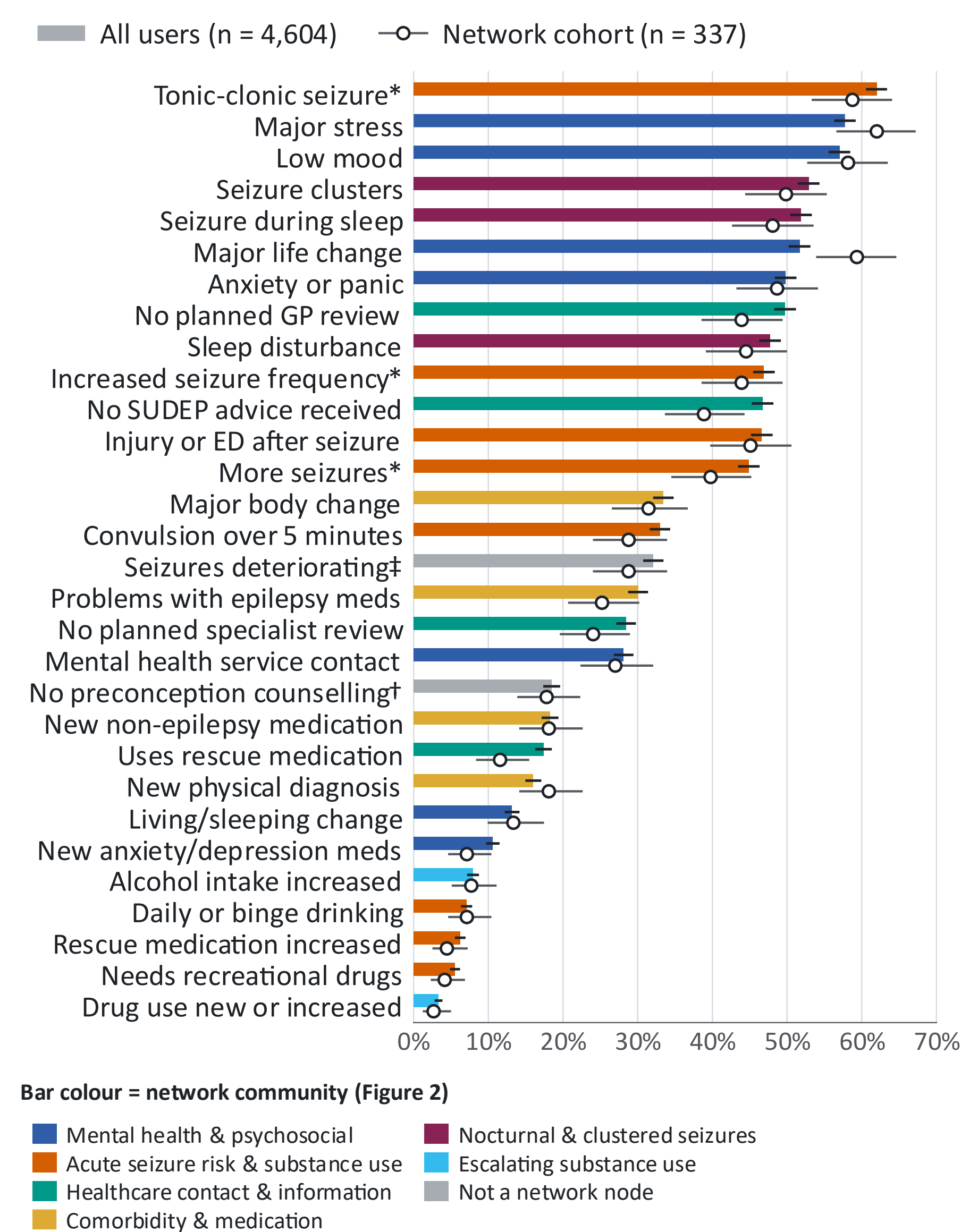
- **Prevalence:** first assessment of all 4,604 users.
- **Network:** 1,569 assessments from the 337 users with three to 40 (median 4).

Each item was regressed on all others, plus age, sex and age at onset, by **mixed-effects logistic regression fitted by maximum likelihood**. Associations surviving false-discovery-rate correction were reduced to a backbone (disparity filter). A line joins two items if either one's model retained the association. Communities: Louvain consensus, tested against a random-network null.

3. How common are risks?

Risk-factor prevalence at first assessment

One assessment per person, two cohorts. Lines are 95% exact CIs.



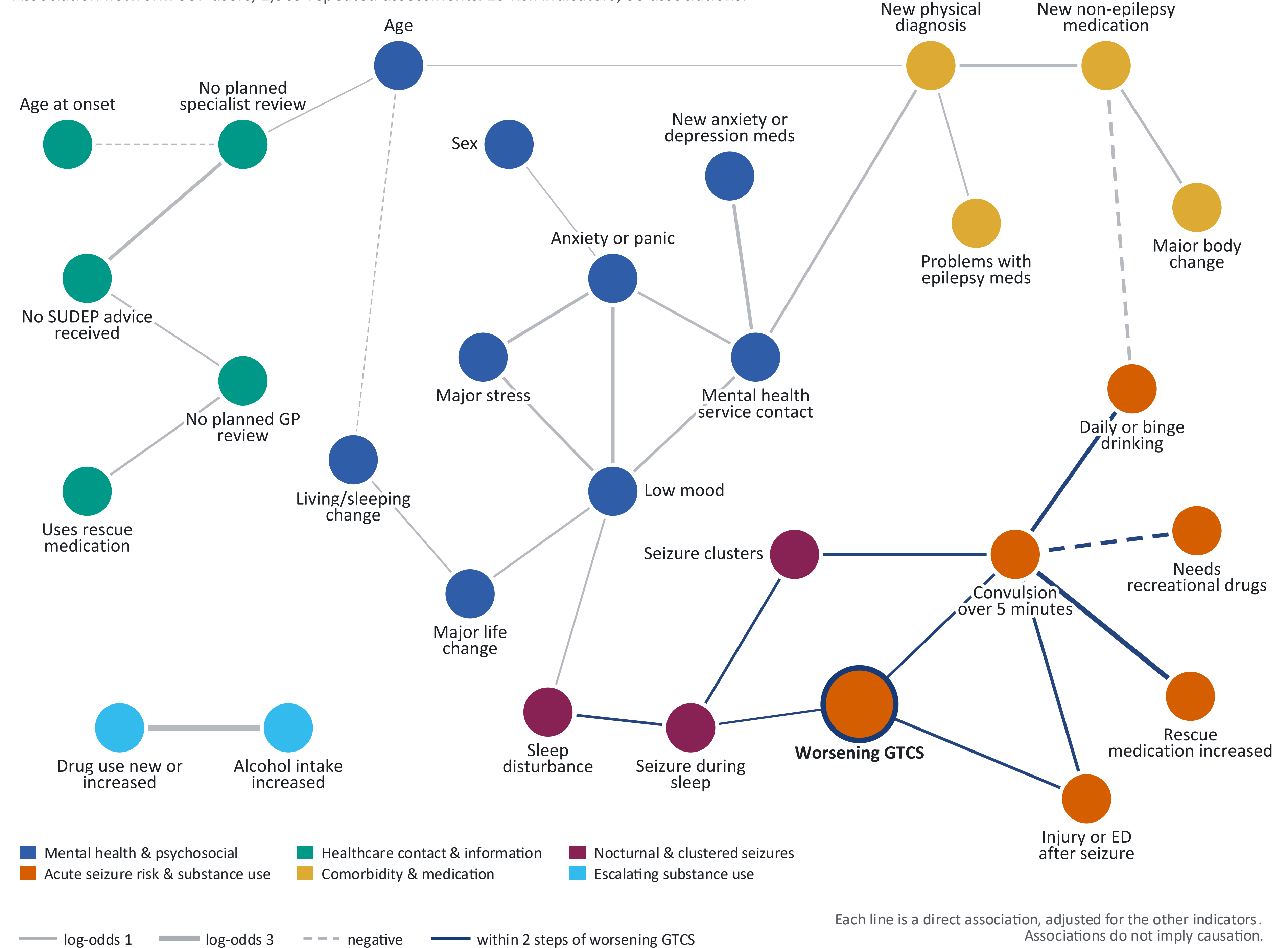
* Combined into the network outcome, worsening GTCS (all three answered yes).
† Asked of women of child-bearing age; shown as a share of all users.
‡ Left out of the network as a near-duplicate of worsening GTCS.
GP, specialist and SUDEP items are plotted as the risk state (answered no).

Risk is common: 13 of 30 risks were reported by 40% or more at first assessment, led by tonic-clonic seizures (62%) and major stress (58%). The network cohort was similar, differing on 3 of 30 items after FDR correction.

4. The risk-factor network

Six communities, and the neighbourhood of worsening seizures

Association network: 337 users, 1,569 repeated assessments. 29 risk indicators, 33 associations.



Each line is a direct association, adjusted for the other indicators. Associations do not imply causation.

5. Six communities

The 29 indicators formed **six communities**, more modular than chance ($Q = 0.64$ vs 0.50 in random networks) and stable across runs (adjusted Rand index, ARI 0.96).

They only partly match the instrument's own domains (ARI 0.44). Sleep and seizure clustering group together, and healthcare contact forms its own community.

Substance use splits in two: **baseline drinking and drug use sit with acute seizure severity**, while recent escalation forms a separate pair.

7. Conclusions

- Self-reported epilepsy risk factors are **structured, not independent**. They form six stable communities that only partly match the a priori clinical groupings.
- **Worsening convulsive seizures sit in a tight neighbourhood** of nocturnal, prolonged and injurious seizures.
- **Using and escalating substance use behave as different risks**.
- A self-monitoring app captures this structure from repeated patient reports.

Lines show associations, not causes. Findings are **hypothesis-generating**; no clinical recommendations follow.

6. Around worsening GTCS

Worsening generalised tonic-clonic seizures (GTCS) is directly associated with just three items: **seizures during sleep, convulsions over 5 minutes, and injury or emergency care after a seizure**.

Within two steps sit seizure clusters, sleep disturbance, increased rescue medication, and alcohol and drug use.

Mental health and comorbidity are three steps away, with no direct association. The escalating substance-use pair is not connected to it at all.

8. Limitations & next steps

Limitations

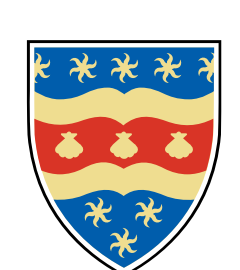
- **Selected sample:** everyone here has epilepsy and chose to download a self-monitoring app, and the network uses its most engaged 7%.
- Self-report, with no clinical verification and no SUDEP outcomes. Worsening GTCS is a proxy.
- Associations are conditional, not causal.

Next steps

- Replicate the structure in the full 4,604-user cohort with a pre-registered cross-sectional network (in progress).
- Validate in independent cohorts.
- Co-design with patients and clinicians before any change to how risk is presented.



Contact: jake.ahern@plymouth.ac.uk



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Physical Sciences
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Affiliations: ¹CIDER, University of Plymouth Peninsula School of Medicine, Truro, UK. ²SUDEP Action, UK. ³Suvo Limited, Derriford, Plymouth, UK. ⁴University of South Wales, Pontypridd, UK. ⁵Mental Health and Learning Disabilities Service Group, Swansea Bay University Health Board, Port Talbot, UK. ⁶Department of Intellectual Disability Neuropsychiatry, Cornwall Partnership NHS Foundation Trust, Truro, UK. ⁷Neurology Department, Royal Cornwall Hospitals NHS Trust, Truro, UK. ⁸Cornwall Partnership NHS Foundation Trust, Truro, UK. ⁹Neuronostics Ltd, Engine Shed, Station Approach, Bristol, UK. *Joint senior authors.