

Voice-first symptom logging with assessments in decentralized pediatric studies



RareKids-CAN Strategic Priority 2, Key Initiative 2.1.
Explore and pilot a platform that uses real-time data capture and artificial intelligence to monitor patient outcomes in pediatric rare disease clinical trials.

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Log App turns families' voice notes into structured data for clinical trials

WHAT THE CAREGIVER SAYS

"Just now Liam had a mild seizure that lasted about 45 seconds. He bit his tongue and has been stressed."

WHAT THE STUDY RECEIVES

Topic Seizure	Severity Mild (3/10)	Duration 45 sec	Trigger Stress
Injury Tongue bite	Time 6:15 AM today	Location (Automatic) 53.5344, -113.4902	Weather (Automatic) 23° 83% 997.4mb

1 Decentralized Clinical Trials

Reliable, real-time data from home, without adding burden for families

THE GAP

Decentralized trials depend on reliable, real-time data from patients. Diaries and recall at visits lose detail and add bias.

THE APPROACH

Families describe a seizure, symptom, or medication change by voice, text, or quick taps. Trained AI turns each entry into timing, severity, trends, and more.

AVAILABLE LANGUAGES

English French Spanish

BUILT FOR STUDY TEAMS

- Remote consent
- Daily reminders
- Connected wearables
- Symptom / meds logging
- Validated, compliant, secure
- Real-time structured data

2 TaurineLC PEDS

Taurine supplementation in adolescents with post-COVID condition

THE STUDY

Design Decentralized, open-label Phase I/II
Participants Adolescents 10 - 17 with Long COVID
Timeline 6 months
Target accrual 30 participants

OUTCOMES

Primary: Change in plasma taurine levels after three months of supplementation.
Secondary: Safety and efficacy for Long COVID symptoms; focus on fatigue, cognition, quality of life.

HOW THE LOG APP IS USED

- Virtual study visits with cognitive assessments
- Daily logging of symptoms, medication use, and autonomic, cardiovascular, and neurological events
- Heart rate from an arm band via secure Bluetooth

THE LOG APP

Participant assent

Voice input

Structured output

Home

10 second surveys

THE DCC PORTAL

Holistic study overview → Participant details

3 Pediatric Epilepsy Monitoring

A configurable app with disease-specific inputs for caregivers of children with medically refractory epilepsy

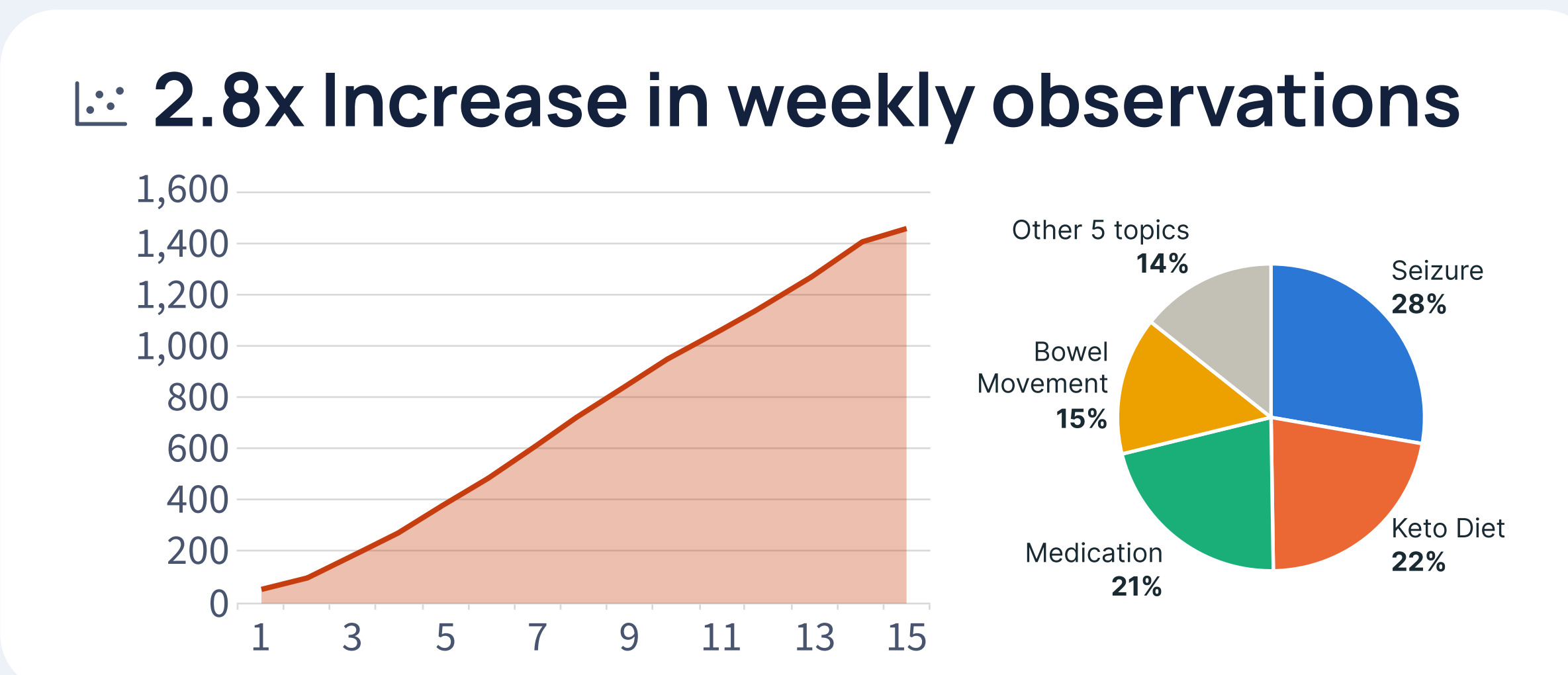
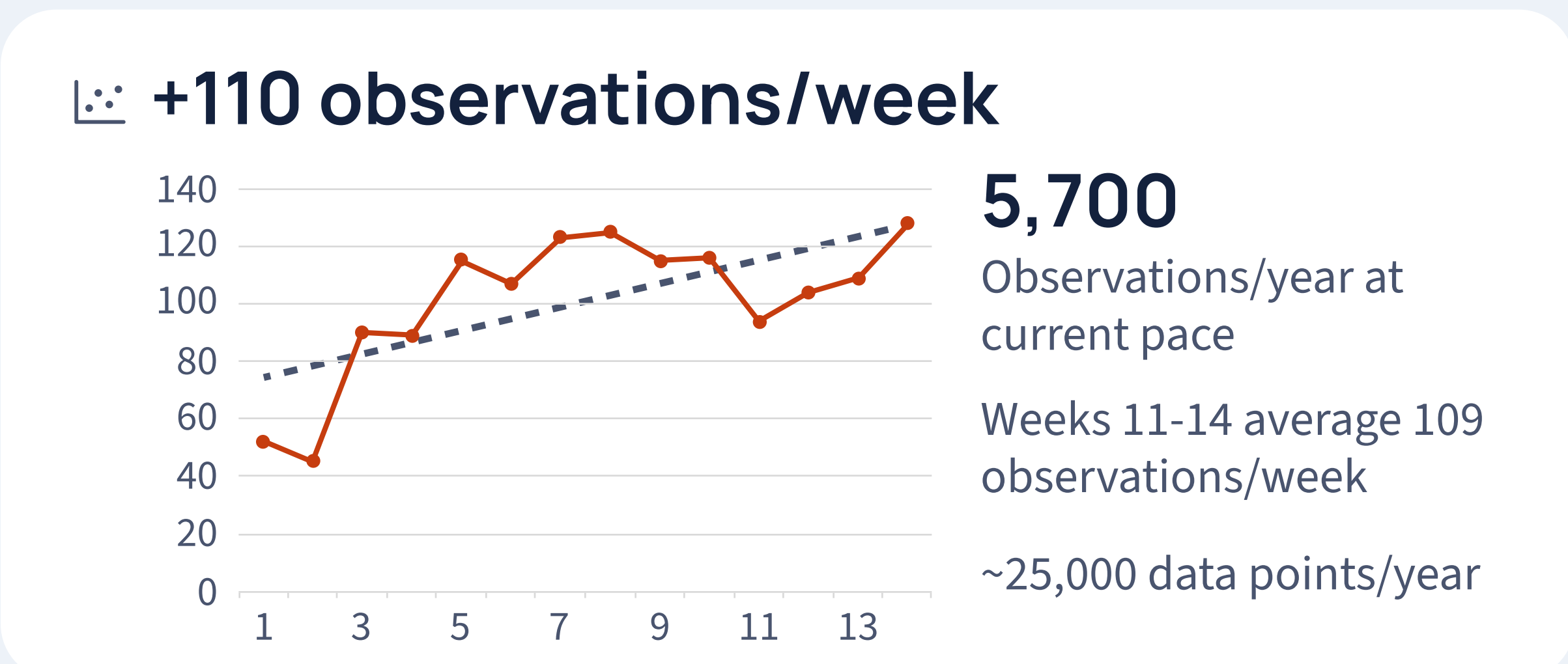
THE STUDY

Design Proof of concept and feasibility
Participants Ketogenic diet program families
Timeline 6 months
Participant count 7 (4 active)

WHAT WE EVALUATE + EXPECTED RESULT

Feasibility, usability, and caregiver burden, using modified System Usability Scale and the QOLCE-55. Lower caregiver burden, more accurate information for the neurometabolic and epilepsy care team.

THE PHYSICIAN PORTAL



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