

Evaluating Continuous Glucose Monitoring Metrics in Congenital

Hyperinsulinism Compared to Diabetes



Kristen E. Rohli¹, Lauren N. Lopez¹, Tai L.S. Pasquini¹, Julie Raskin¹, and George Couch²

¹Congenital Hyperinsulinism International, Glen Ridge, New Jersey, USA; ²Cambridge University Hospitals, Cambridge, UK

CONGENITAL HYPERINSULINISM (HI)

- HI is a rare condition where excessive insulin secretion leads to persistent hypoglycemia.
- Uncontrolled hypoglycemia can cause neurological damage.
- In the HI Global Registry, 51% of 255 participants reported using a continuous glucose monitor (CGM), even though **CGM is not approved for HI**.
- The purpose of this study is to determine whether CGM analysis metrics developed for diabetes directly apply to hypoglycemic disorders, such as HI.

METHODS

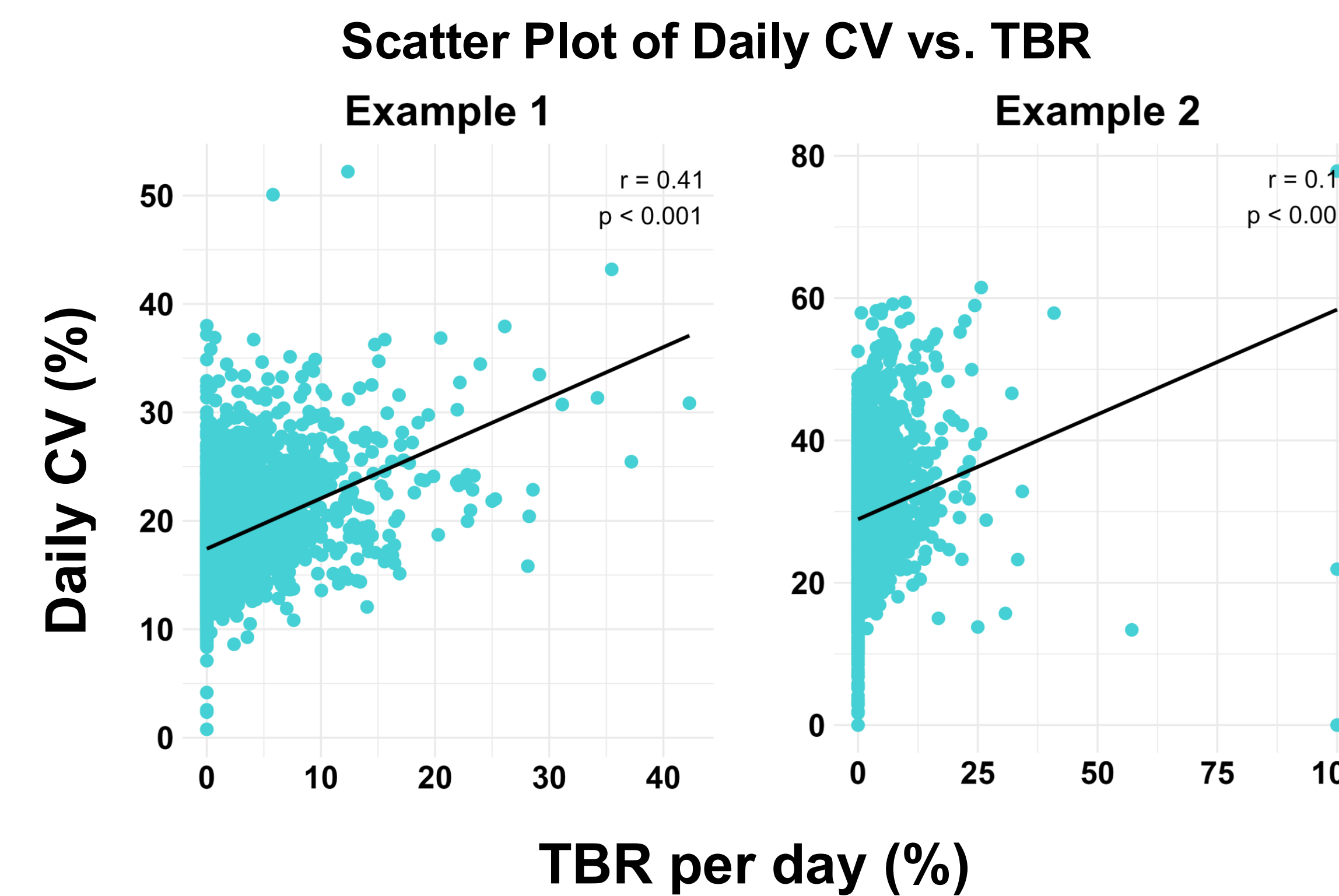
- CHI maintains the HI Global Registry (HIGR) study, with over 600 registrants.
- In November 2024, HIGR enabled users to contribute historical and prospective Dexcom CGM data (any generation).
- Participants who ever experienced HI were included in this study.
- 40 participants with HI shared their Dexcom CGM data, and 5 participants have also shared their glucometer device data.
- Pilot data were analyzed to assess the utility of standard diabetes-based CGM metrics in HI.

CGM DATA SHARING COHORT

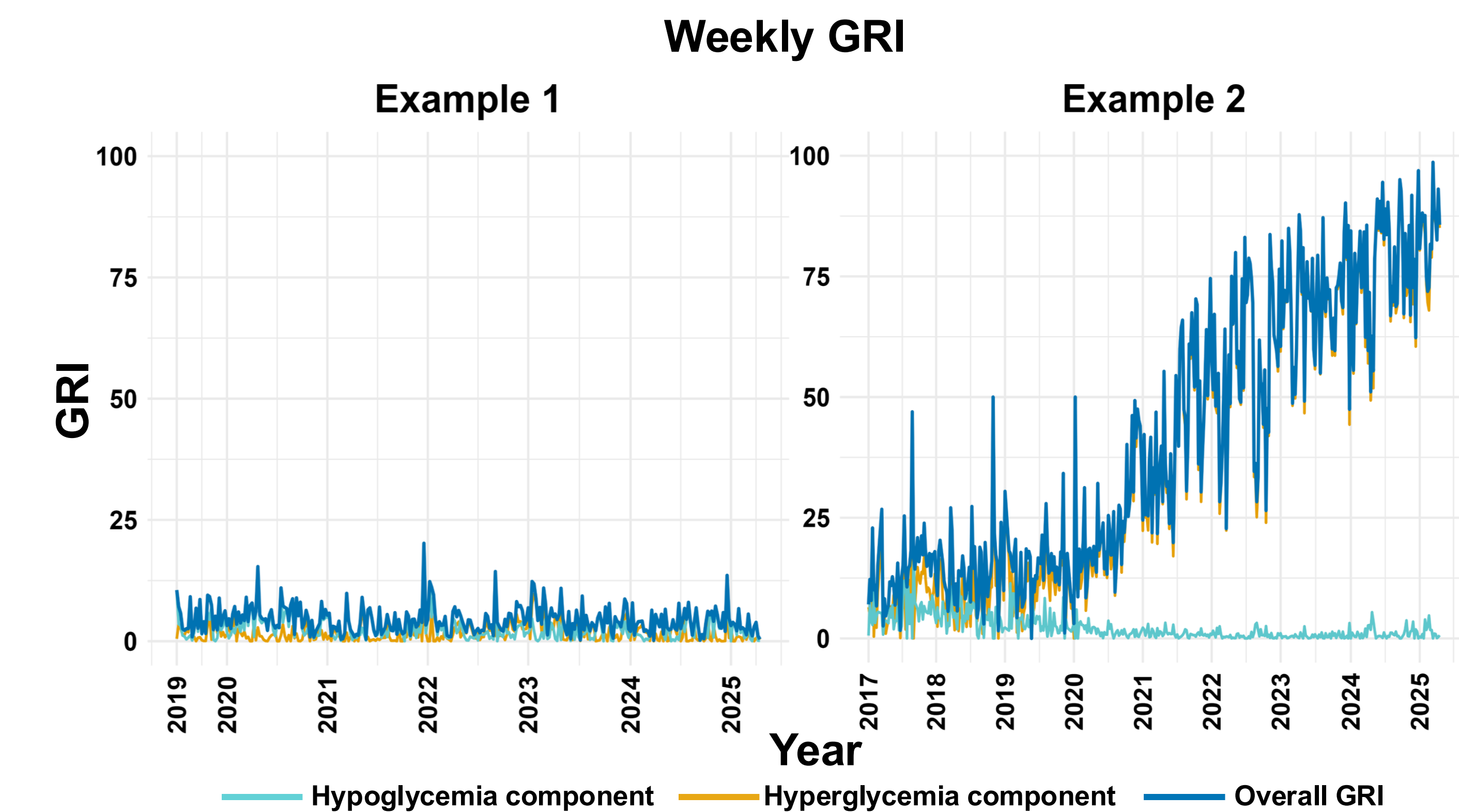
Avg # data points per participant	267,016
Min and max	4,186-696,572
Avg # yrs of CGM data per participant	2.8 (max: 7 yrs)
Avg age of participant	11
Age range (years)	<1-42
HI Type:	
Focal	2
Diffuse	28
Unknown or not reported	10
Pancreatectomy status:	
No pancreatectomy	24
Pancreatectomy, no diabetes	5
Pancreatectomy, has diabetes	10

RESULTS

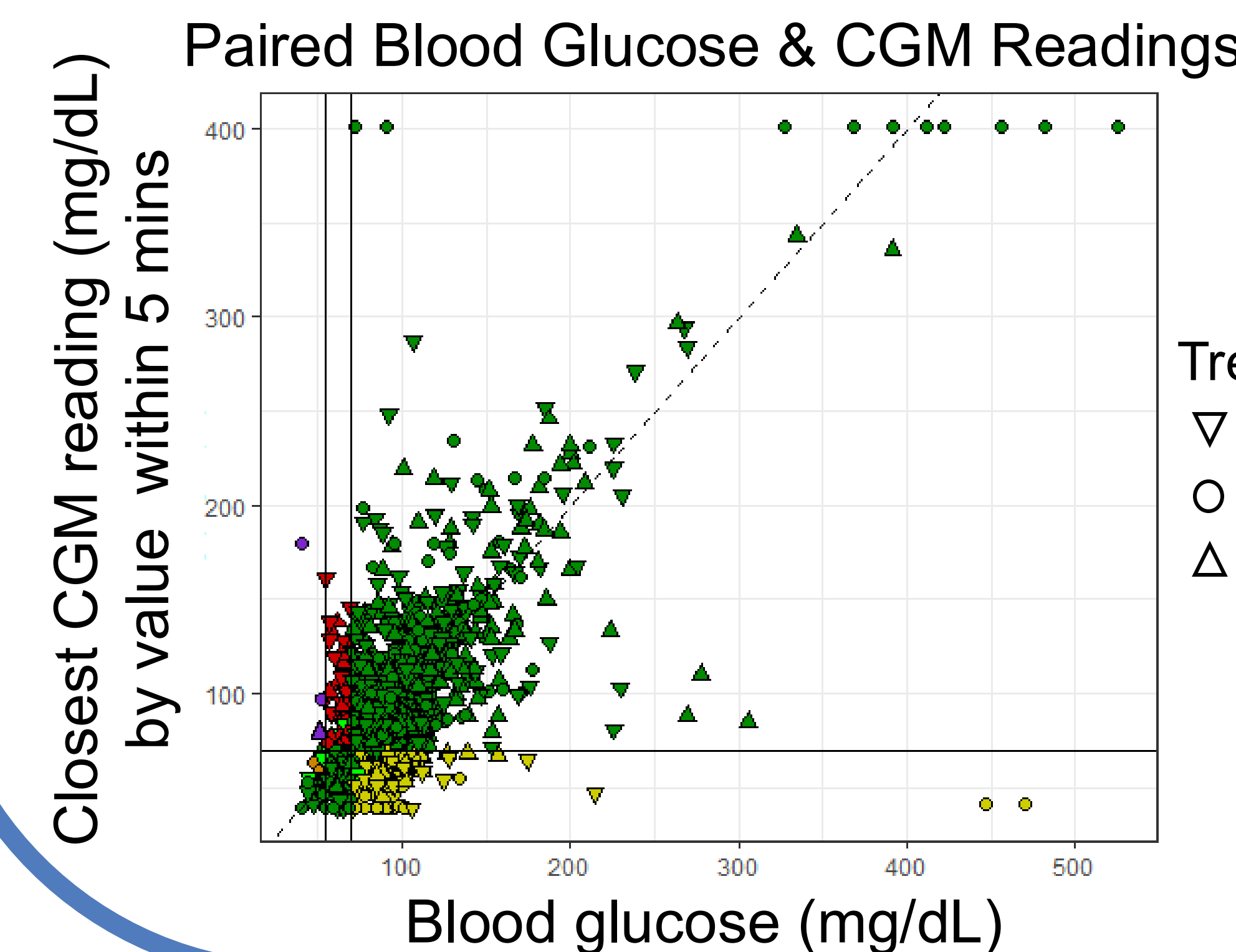
Coefficient of variation (CV) is a poor surrogate for time below range (TBR; <70 mg/dL) in HI.



Glycemic risk index (GRI) is promising, but an individual approach to glycemic control is needed.



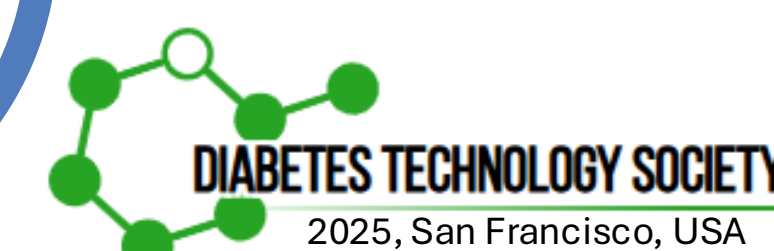
82% of paired CGM and glucometer data points reflect accuracy within 20 mg/dL and trending in the correct direction.



Label	Color	# points	% points
<20 mg/dl difference & correct trend	Lime	119	5.76%
Blood & CGM agree	Green	1585	76.68%
Blood <54 & CGM 54-70	Purple	3	0.15%
Blood <54 & CGM >70	Orange	4	0.19%
Blood <70 & CGM >70	Red	61	2.95%
Blood >70 & CGM <70	Yellow	295	14.27%

CONCLUSIONS

- CGM technology and analytical frameworks remain biased toward hyperglycemia.
- A **longer analysis window** better aligns with glycemic patterns in HI and sensor variability, while decreasing the standard deviation.
- GRI and CV require adaptation to reflect the hypoglycemia-dominant characteristics of HI.
- There is a **critical need** for more robust analytical CGM models for dysglycemia conditions and diabetes.



The authors would like to thank the patients and caregivers for their contribution to HIGR and the HIGR Steering Committee for their guidance. CHI receives funding for the Collaborative Research Network from Zealand Pharma, Rezolute, Hanmi Pharmaceutical, and Rhythm Pharmaceuticals. CHI also receives funding from the EU LightCure grant #101080327. Have questions or comments? Email krohli@congenitalhi.org