Congenital Hyperinsulinism International
Collaborative Research Network

# Advancing Continuous Glucose Monitoring for Children and Young People with Hyperinsulinism

***A White Paper from the Congenital Hyperinsulinism International Collaborative Research Network***

Helen Couch[1], Kristen E. Rohli[2], Tai LS Pasquini[2], Julie Raskin[2], Antonia Dastamani[3] and the Congenital Hyperinsulinism International Collaborative Research Network[3]

1. Cambridge University Hospitals NHS Foundation Trust, Cambridge, United Kingdom. 2. Congenital Hyperinsulinism International, Glen Ridge, NJ, United States. 3. Great Ormond Street Hospital for Children NHS Foundation Trust, London, United Kingdom.

## Introduction

Hypoglycaemic brain injury is a persistent threat to children and young people (CYP) with hyperinsulinism (HI).[1–3] Rapid diagnosis and intervention are critical to prevent irreversible hypoglycaemic brain injury by reducing hypoglycaemia exposure.[4] Current self-monitoring techniques encourage a reactive approach to hypoglycaemia and are unable to anticipate or warn caregivers.[5] This white paper has been developed by Congenital Hyperinsulinism International's Collaborative Research Network, comprising HI patients and caregivers, clinicians and industry partners. We are united in calling for improved access to real-time continuous glucose monitoring (CGM) for CYP with HI.

### Neurodisability

50% of CYP with HI experience neurodisability, including cortical blindness, motor, cognitive, and speech delays due to recurrent non-ketotic hypoglycaemia.[6]

### Clinically silent

CYP with HI experience hypoglycaemia that is often clinically silent.[7-10] Therefore, some caregivers may be dependent upon frequent finger-prick checks to identify lows.

### Rare inequality

CGM has transformed diabetes care,[11-12] enabling automated insulin dosing, yet access for CYP with HI is restricted by licensing and lack of clinical guidance.[7,10]

**CURRENT STANDARD**

## Blood glucose meters

- Finger-prick checks are painful and burdensome for children and families.[2,7,13]
- They provide a single glucose data point with no trend information. Blood glucose meters cannot anticipate or warn of imminent hypoglycaemia[5] and are therefore poorly suited to managing rapid, unpredictable glucose shifts in HI.
- Children with HI are typically asymptomatic, therefore 3 hourly or pre-meal checks are likely to miss significant periods of hypoglycaemia (Figure 1). Especially around high-risk time periods: mealtimes, physical activity and sleep.[2,6,7,10]

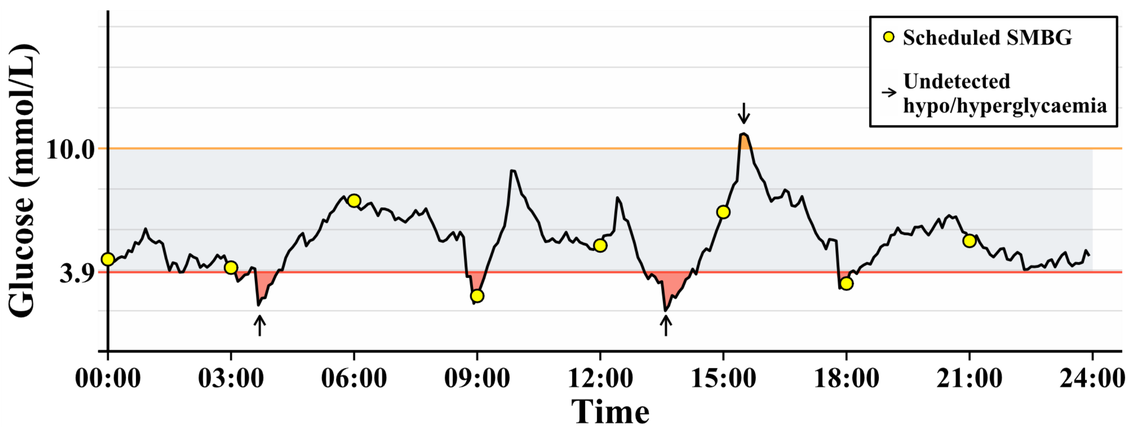


**Figure 1.** Illustrative 24-hour blood glucose profile for an infant with HI, generated from CGM profiles, demonstrating the limitations of 3-hourly SMBG alone in detecting hypoglycaemia and hyperglycaemia.

**AVAILABLE TECHNOLOGY**

## Continuous glucose monitoring

- Provide real-time trend information rather than isolated readings with predictive alerts for hypoglycaemia[7] enabling timely intervention by caregivers through the day and night.
- 55% of HI Global Registry participants reported using CGM,[14] with satisfaction surveys demonstrating improved quality of life (QoL).[7,10]
- CGM accuracy has steadily improved as technology as evolved, demonstrated by decreasing MARD (Figure 2),[15] with recent devices sufficiently reliable for automated insulin dosing in diabetes (iCGM standard).[16]

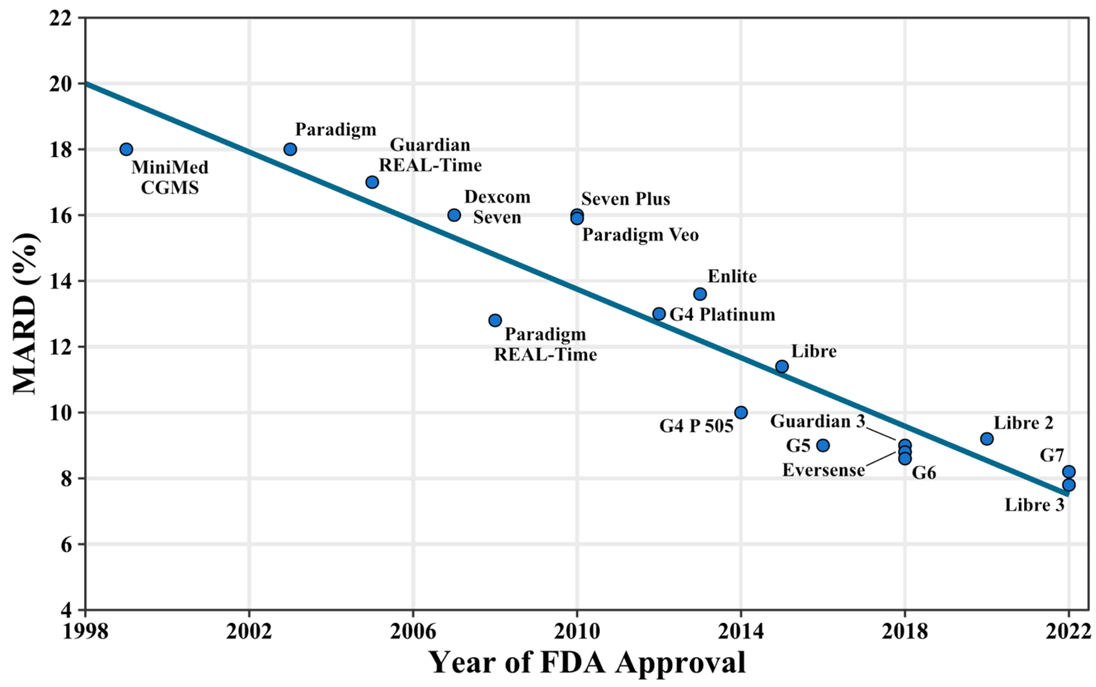


**Figure 2.** Accuracy represented by MARD (%), presented for each continuous glucose monitoring system over time in diabetic cohorts by year of Food and Drug Administration (FDA) approval. Adapted from Morales et al. 2024.[15]

## A Call to Action

**We urge policymakers, funders and device manufacturers to:**

### 1 DEVELOP POLICY AND GUIDELINES

Recognise CGM as a tool to improve care for CYP with HI, with the aim of safeguarding neurodevelopment, wellbeing and future productivity.

### 2 FUND EQUITABLE ACCESS

Secure sustainable funding and equitable access to CGM devices for CYP with HI.

### 3 ACCELERATE DEVICE INNOVATION

Advance device development and regulatory approval so that CGM can be accessed by CYP with HI from the neonatal period.

## Conclusion

- There is a disconnect between current regulatory frameworks and the needs of people living with HI.
- Integration of CGM into HI care from diagnosis has the potential to reduce preventable neurological injury and enhance quality of life.

## References

1. Avatapalle et al. Front Endocrinol 2013
2. Banerjee et al. Orphanet J Rare Dis 2022
3. Eljamel et al. Orphanet J Rare Dis 2018
4. Helleskov et al. Front Endocrinol 2017
5. Win et al. J Clin Endocrinol Metab 2022
6. Roeper et al. Front Endocrinol 2020
7. Couch et al. J Clin Endocrinol Metab 2026
8. De Leon et al. Horm Res Paediatr 2023
9. Stanley. J Clin Endocrinol Metab 2016
10. Ng et al. J Endocr Soc 2023
11. Tauschmann et al. Horm Res Paediatr 2025
12. Chaugule et al. Eur Endocrinol 2017
13. Selvanathan & Miller. Pediatr Res 2024
14. HI Global Registry 2025
15. Morales-Dopico & MacLeish. Pediatr Res 2024
16. Klonoff et al. J Diabetes Sci Technol 2024

Read the CGM white paper here!

CHI receives funding for the CRN from Zealand Pharma, Rezolute, Hanmi Pharmaceutical, and Rhythm Pharmaceuticals. CHI also receives funding from the EU LightCure grant #101080327