

# Testing a Continuous Glucose Monitoring Assessment Tool for Congenital Hyperinsulinism

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## 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**.
- Early studies in CGMs mirror successes in diabetes.
- **CGMs may improve independence and quality of life** for HI families by decreasing frequent glucose checks, alleviating anxiety around unrecognized hypoglycemia, and enabling safer participation in daily activities.



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## METHODS

### Continuous Glucose Monitoring Assessment Tool:

1. What is the patient's fasting duration on treatment?
2. Does the patient need continuous enteral D20% or feed? \*
3. Is the patient taking daily medication requiring multiple daily injections or pump use? \*
4. Has the patient undergone near total pancreatectomy?
5. What is the patient's frequency of glucose checks per day with a glucometer? \*
6. How frequently does the patient have episodes of hypoglycemia? \*
7. Does the patient need external decision-making on a regular basis?
8. Is the patient unable to do care independently?
9. Does the patient have hypoglycemia unawareness? \*

\*indicates significant association found between the response to the question and the final scoring outcome for CGM benefit

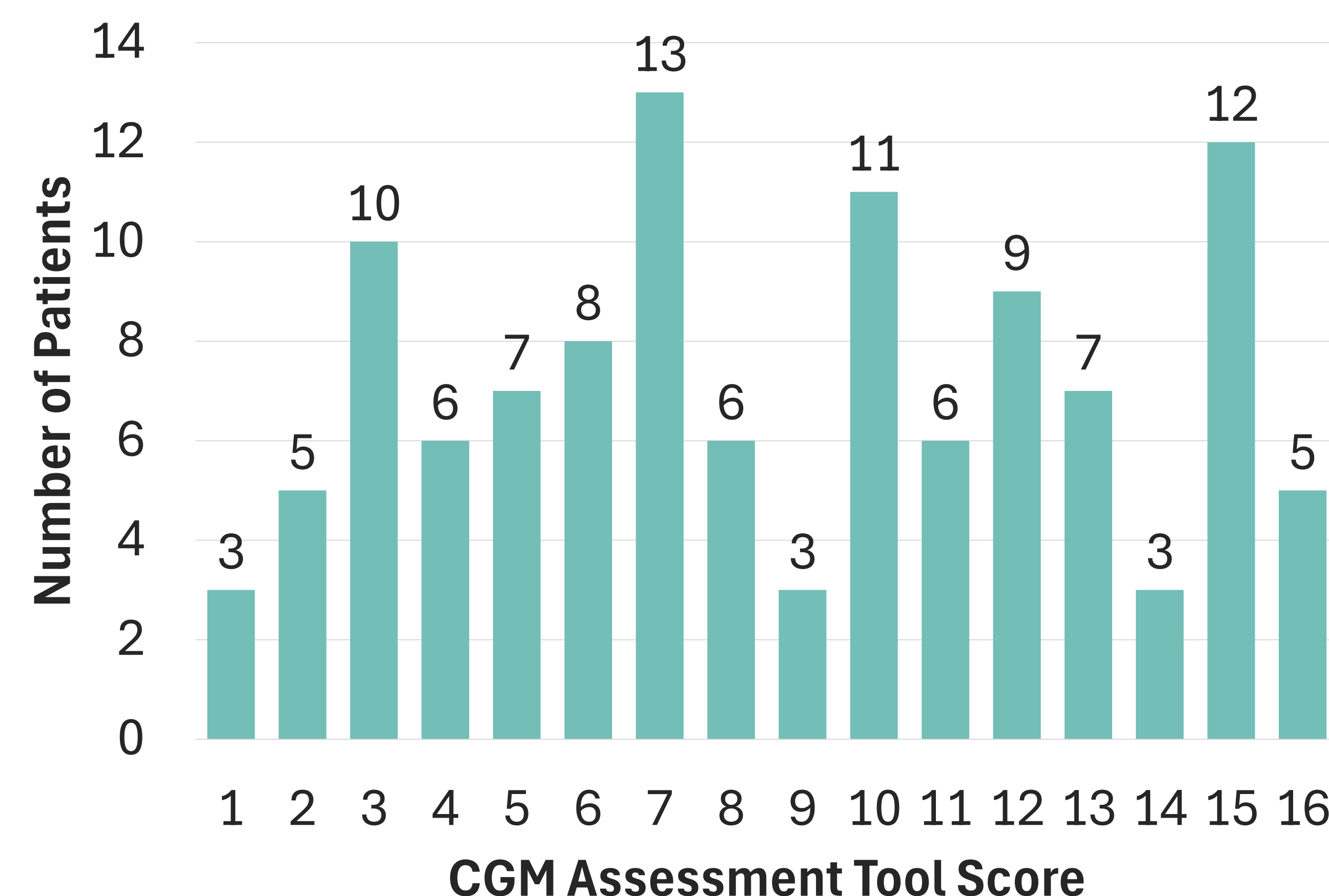
- The CHI Collaborative Research Network's Glucose Monitoring group developed a CGM assessment tool evaluating 9 factors of life with HI.
- Six **HI Centers of Excellence (COE)** used the tool to retrospectively assess up to 20 people with HI per center.
- Each response to a tool question was scored 0-2 based on impact to HI management, with a minimum of 0 and maximum of 17 points for the whole assessment.
- **Tool scores were compared with real physician decisions.**

## RESULTS

COE ID	Avg. pt. score	Min. score	Max. score	% pts using CGM
1	13.1	2	16	80%
2	6.6	2	15	30%
3	10	6	15	40%
4	7.3	2	13	25%
5	9.8	1	16	22%
6	6.3	1	13	60%

The CGM tool and real-world physician decisions were in agreement about potential CGM benefit in 87/99 cases (88%).

CGM Assessment Tool Score Distribution (n = 116)



## CONCLUSIONS

- This CGM tool is the **first structured framework** to assess the potential benefits of CGM use for people with HI.
- This tool can be used to facilitate **clinician-family discussions** about CGM use to improve HI management and enhance quality of life for people with HI and their families
- Collaboration with additional HI centers will further refine and evaluate this tool's effectiveness across global populations.

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