

Utilizing PES hypoglycemia guidelines to evaluate presence of known risk factors in HI Global Registry participants

Tai L.S. Pasquini, MPA, PhD and Julie V. Raskin, MA; Congenital Hyperinsulinism International, Glen Ridge, New Jersey, USA; Contact: info@congenitalhi.org

Objectives

Retrospectively determine if Congenital Hyperinsulinism International (CHI) HI Global Registry (HIGR) participants had documented PES hypoglycemia screening factors and report if these neonates were identified as at risk by their birthing facility prior to discharge.

HI Global Registry

- CHI is a leading nonprofit dedicated to improving the lives of individuals living with HI
- HIGR was launched by CHI in 2018 as the only global patient-powered hyperinsulinism registry.
- Consists of 13 surveys about the patients' and caregivers' experience with HI over their lifetime including medication, diet/feeding, and QOL.

Hypoglycemia Guidelines

The PES guidelines expand upon previous guidelines to ensure physicians recognize persistent hypoglycemia disorders, guide their diagnosis, and treatment.

According to the guidelines¹, neonates are at increased risk of hypoglycemia and require glucose screening under the following conditions:

- symptoms of hypoglycemia
- large for gestational age
- perinatal stress
- premature or postmature delivery
- infant of diabetic mother
- family history of a genetic form of hypoglycemia
- congenital syndromes or abnormal physical features known to be associated with HI

Methods

We utilized HIGR data² collected from 2018-2022. Self-reported variables from the birth and pregnancy surveys were matched to the listed risk factors of hypoglycemia outlined in the PES guidelines.

All variables were categorical and Chi-square analysis was completed in Stata.

Limitations

- As a retrospective registry, there is a risk of selection bias and recall bias.
- Individuals may be misclassified, especially if the outcome is impacting their memory of events.
- HIGR does not include a question related to perinatal stress one of the screening factors.
- Individuals can choose which questions they answer, therefore, we may have incomplete data for some participants.

Acknowledgments

The authors would like to thank the patients and caregivers for their contribution to HIGR and the HIGR Steering Committee for their guidance.

Results

Of 197 participants in HIGR, 66.0% (n=130) self-reported one or more of the factors that put them at increased risk of hypoglycemia when applying the PES guidelines retrospectively.

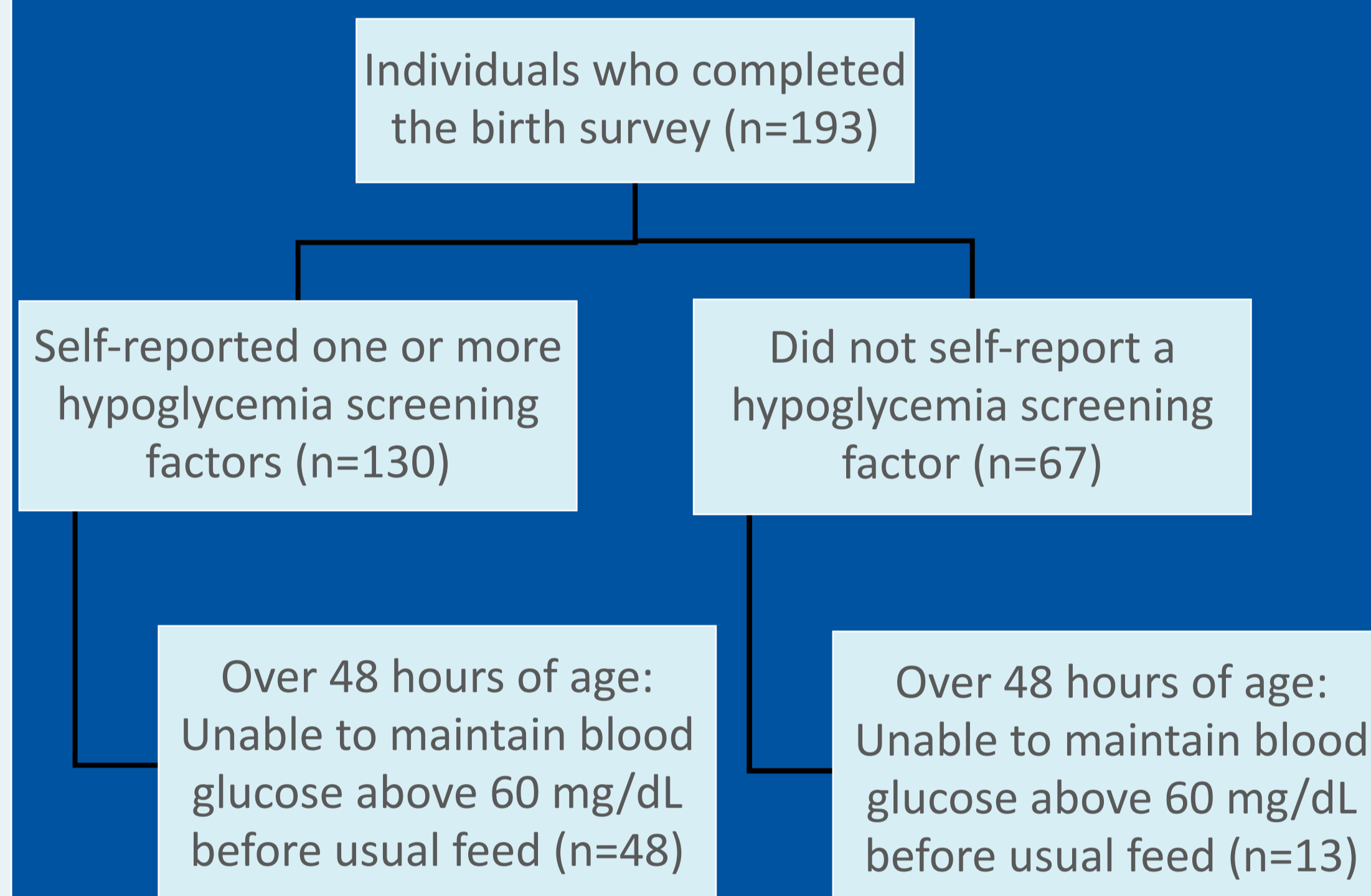
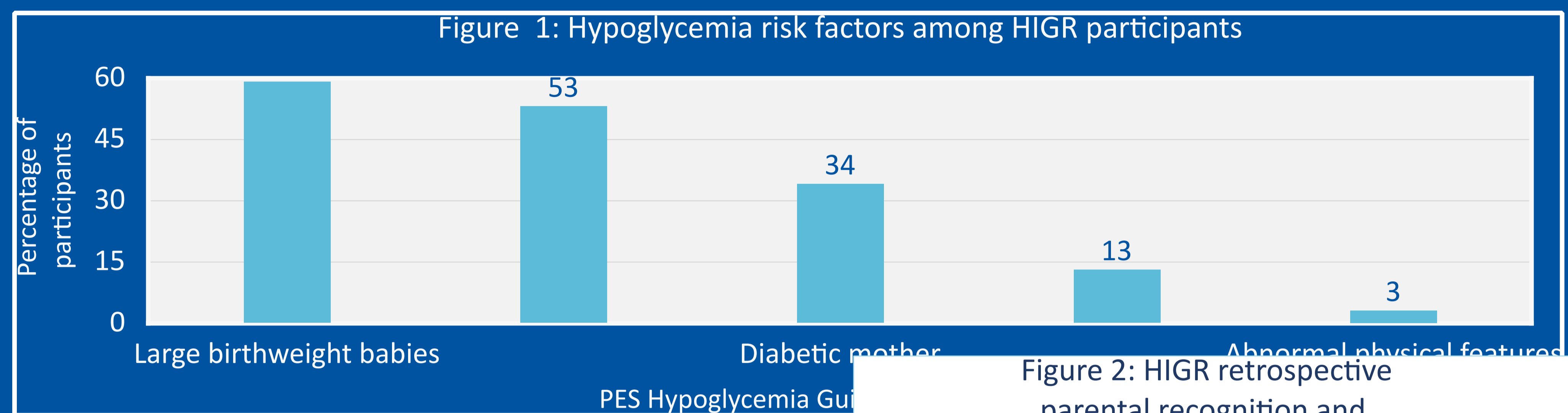
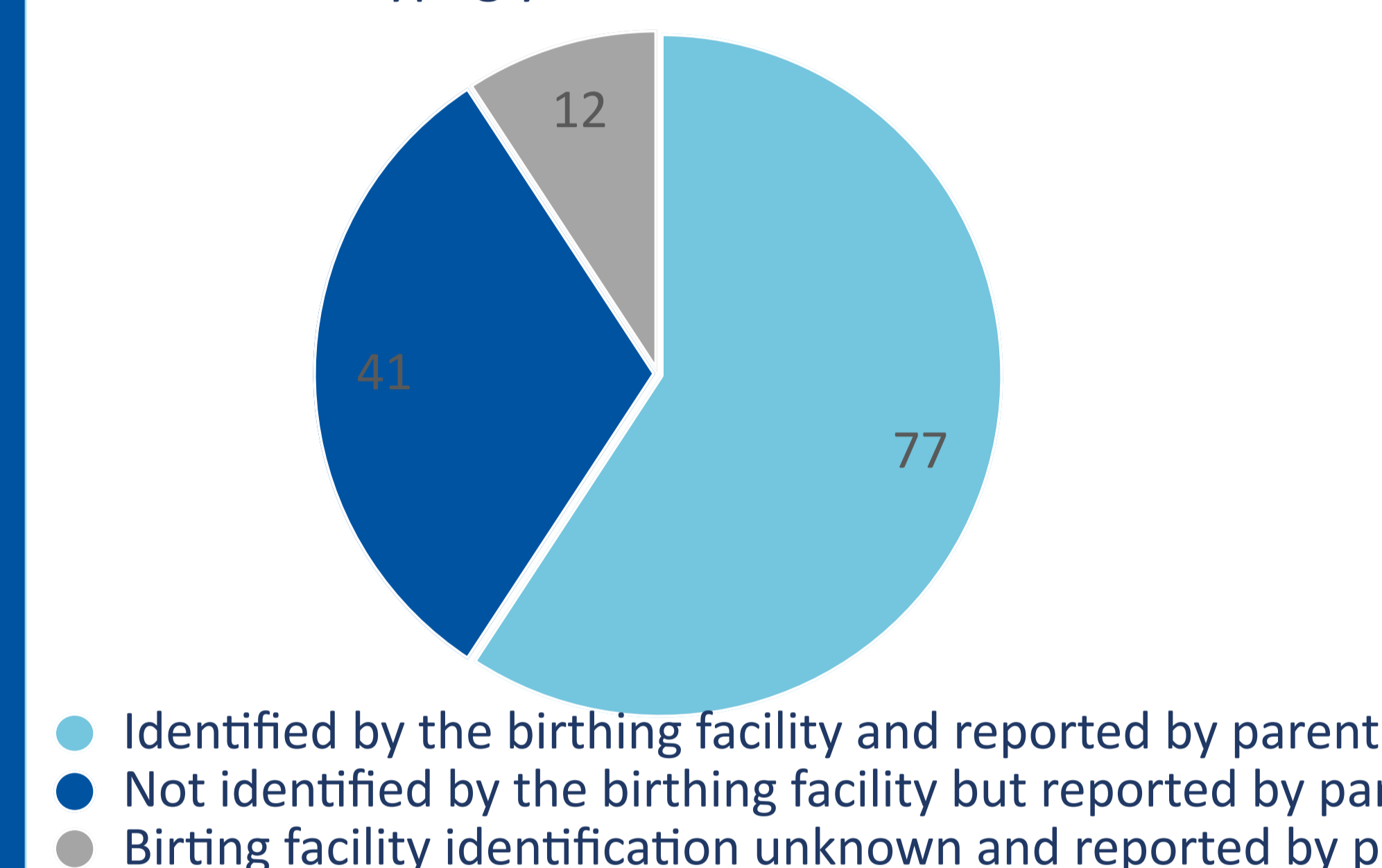
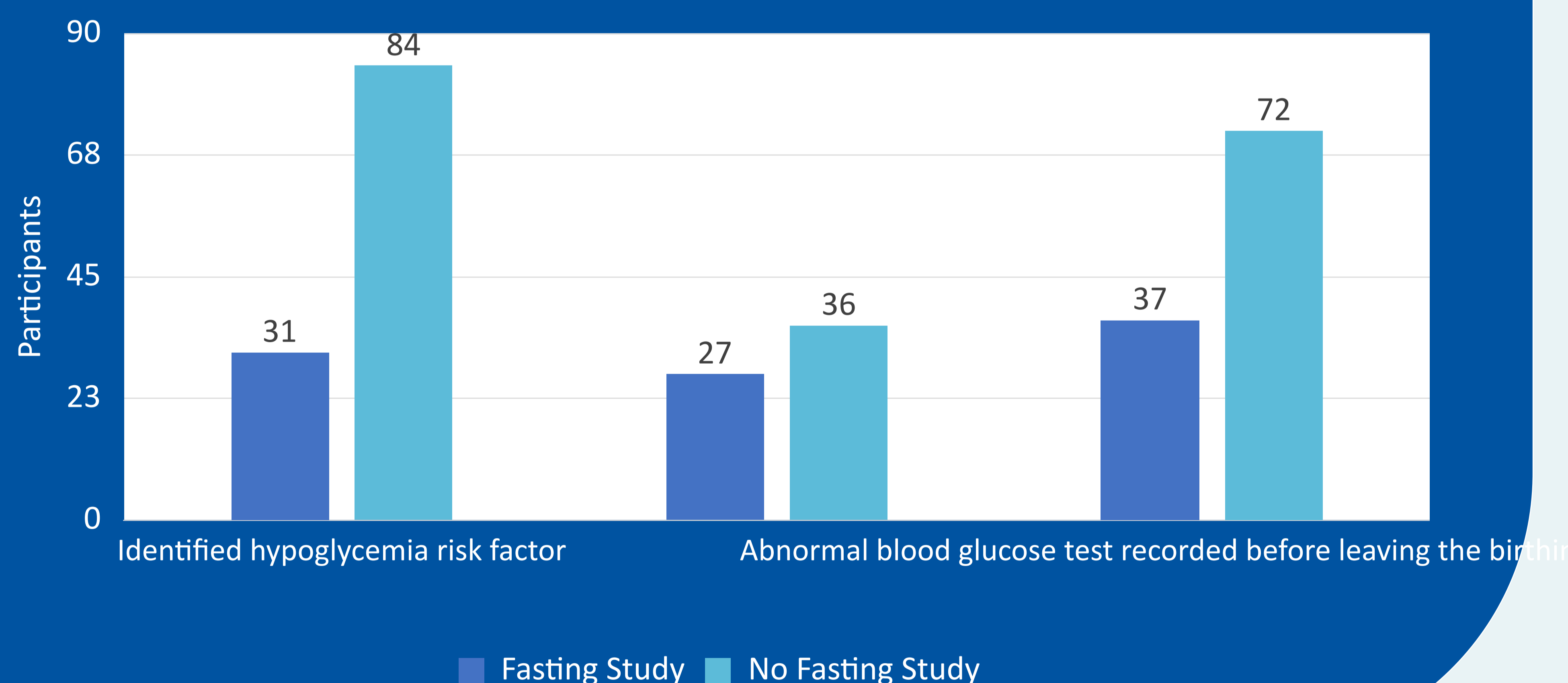


Figure 2: HIGR retrospective parental recognition and reported birthing facility identification (prior to discharge) of hypoglycemia risk factors



Fasting Studies



Conclusions

- 31.5% of individuals with a known risk factor of hypoglycemia and 10.8% of individuals who could not maintain blood glucose above 60mg/dL after 48 hours were not identified as being at risk prior to leaving the birth facility.
- It is critical to identify and manage hypoglycemia from HI in neonates to avert preventable brain damage.
- Outreach needs to be conducted at birthing facilities to increase awareness of the hypoglycemia guidelines.
- More widespread screening, such as recognizing glucose as a vital sign, could help identify individuals who do not have an identified risk of hypoglycemia.
- In 2022, MaxHIGR a physician reported complement to HIGR will launch to provide more insight into the HI natural history.



1. Thornton PS, Stanley CA, De Leon DD, et al. Recommendations from the Pediatric Endocrine Society for Evaluation and Management of Persistent Hypoglycemia in Neonates, Infants, and Children. *J Pediatr*. 2015;167(2):238-245. doi:10.1016/j.jpeds.2015.03.057

2. HI Global Registry. Congenital Hyperinsulinism International Accessed April 18, 2022. <https://www.higlobalregistry.org/>