

The Diagnostic Odyssey

Perspective in the HI Global Registry (HIGR)

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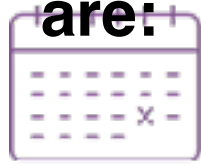
- **Real lived experience from HI families**
- How many people had risk factors for hypoglycemia and *should* have been tested ?
- How many people had their blood sugar checked within 24h?
- How many people report neurodevelopmental challenges?



Hypoglycemia Screening Guidelines

- Vary throughout the world
- Most focus on infants who

are:



Preterm (< 37 weeks)



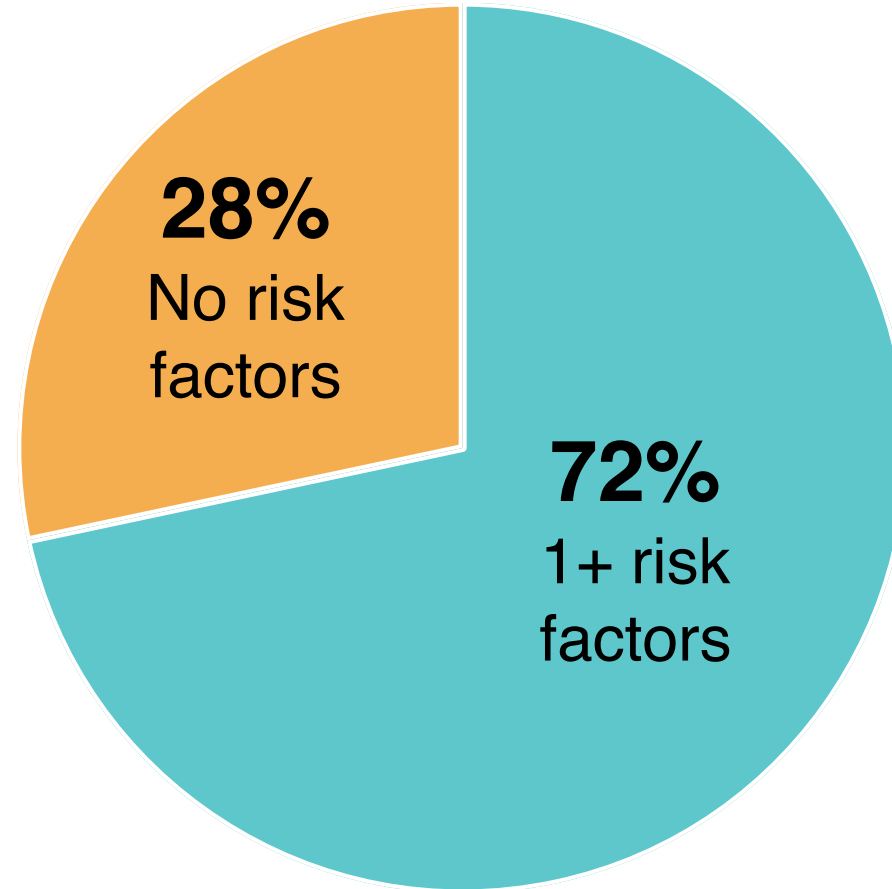
Small for gestational age (< 10th percentile)



Large for gestational age (> 90th percentile)

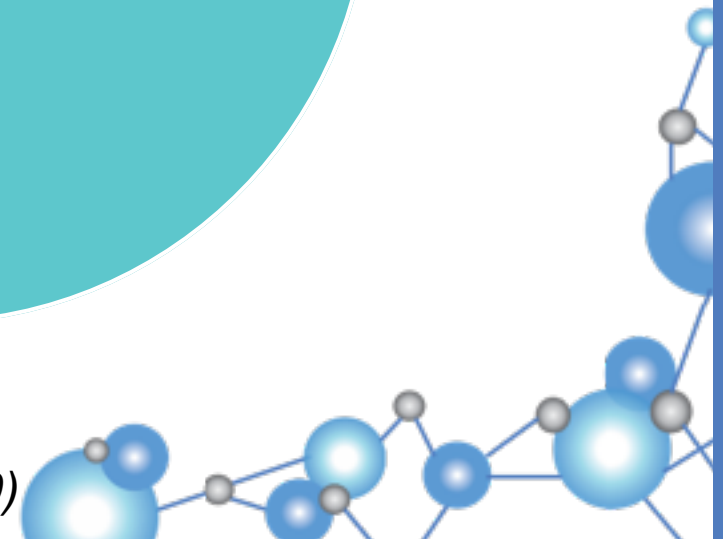
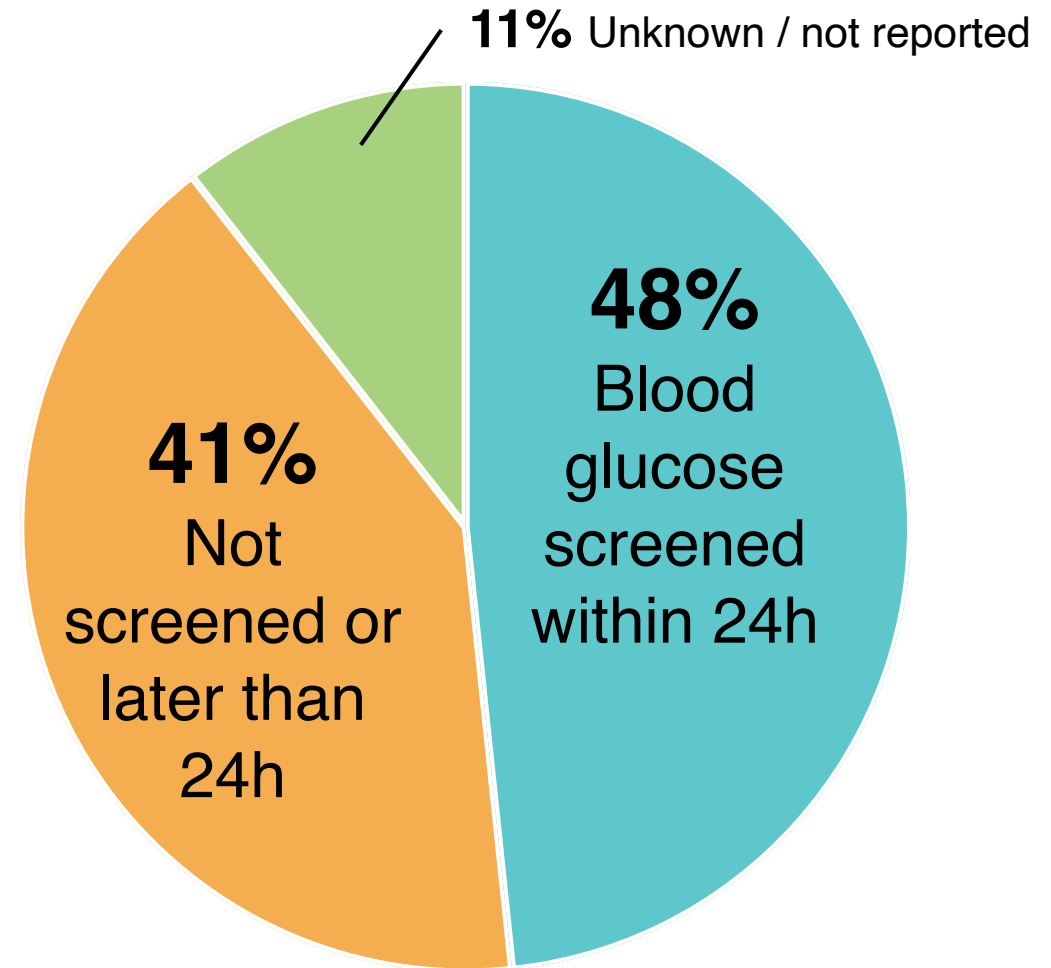


Infants of diabetic mothers

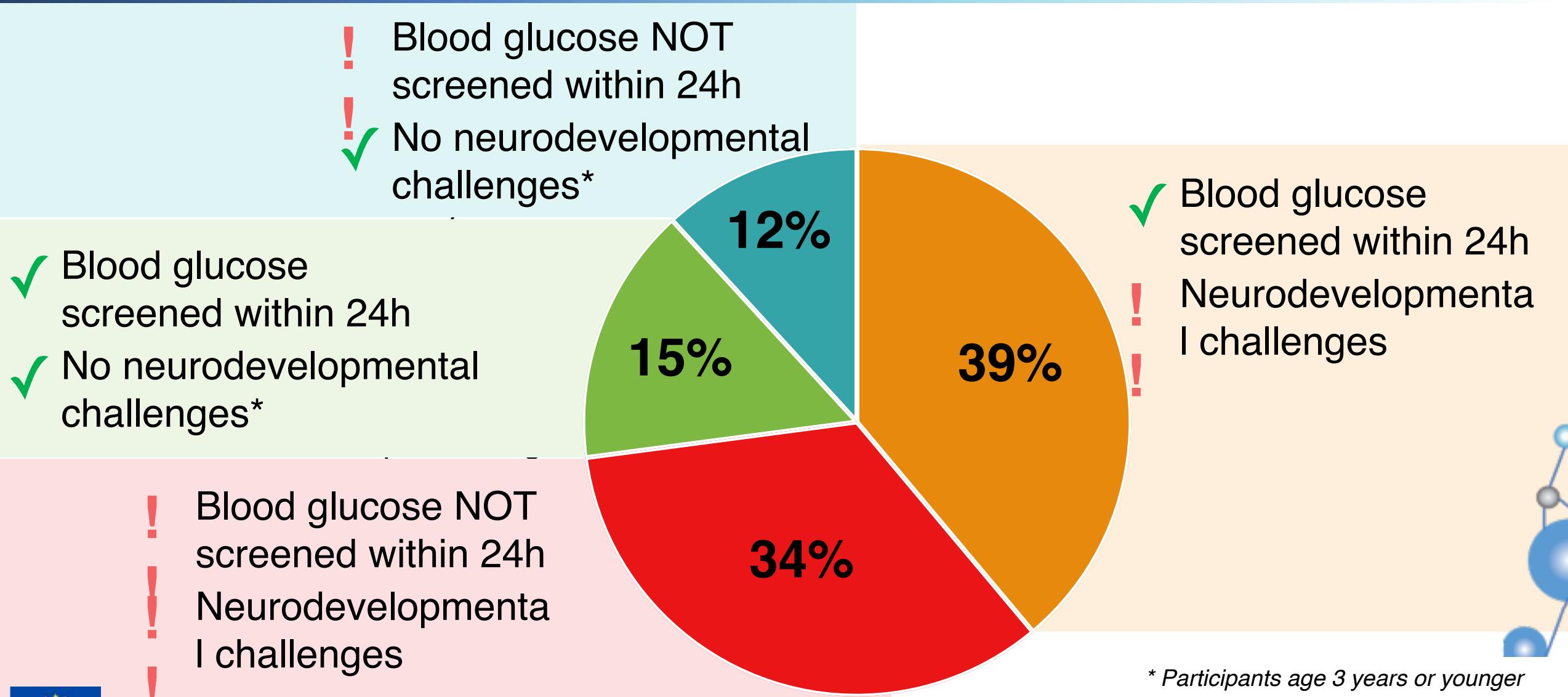


Hypoglycemia Screening Guidelines

- **How many people with HI had a blood glucose screen within 24h of birth?**
- Many infants with HI are not being screened or are being screened later than 24h



Neurodevelopmental Challenges



! Blood glucose NOT screened within 24h
! No neurodevelopmental challenges*

✓ Blood glucose screened within 24h
✓ No neurodevelopmental challenges*

✓ Blood glucose screened within 24h
! Neurodevelopmental challenges

! Blood glucose NOT screened within 24h
! Neurodevelopmental challenges

* Participants age 3 years or younger excluded – too young to assess many neurodevelopmental challenges

Next Steps

- This data was presented at **Hot Topics in Neonatology 45th Annual Conference** (*Washington DC, December 2025*)
- A larger subset of data was submitted for publication in a **scientific journal** (*target submission December 2025*)
- **Future research studies on this topic and more:**
 - Diagnostic journey
 - Experience with feeding issues
 - Glucose monitoring practices
 - CGM use & satisfaction
 - **More!**



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QUESTIONS?

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