



The Caregiver and Patient Perspective on Glucose Monitoring

Learning from the HI Global Registry



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Continuous Glucose Monitors for HI

Careful glycemic monitoring is essential in HI

- Glucometer and/or continuous glucose monitor

Continuous glucose monitors (CGMs):

- Developed for people with diabetes, age 2+ years
- Not approved for use in people with HI
- Used off label

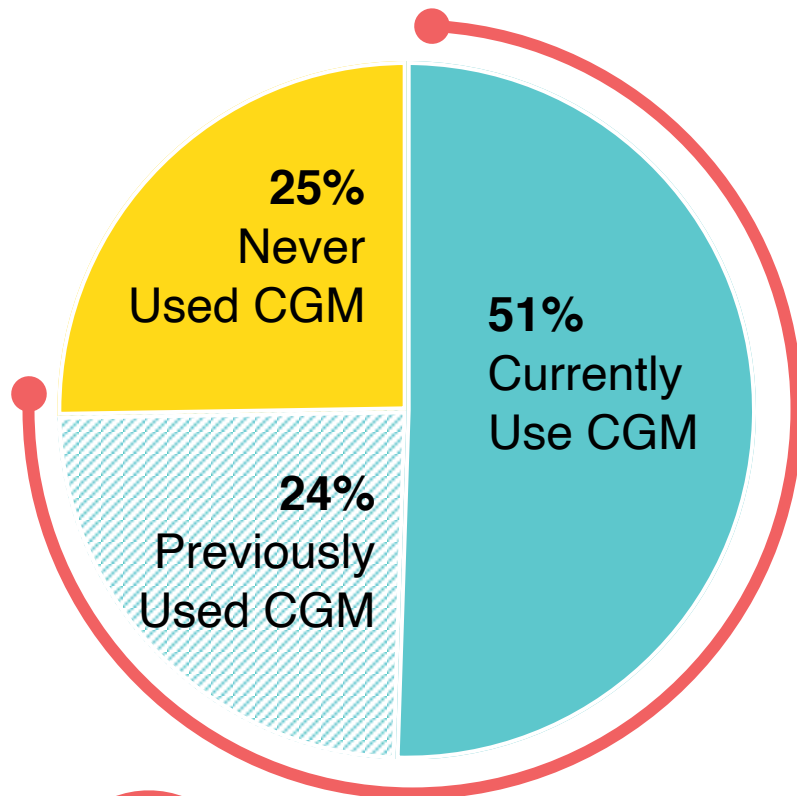


The HI Global Registry (HIGR) data includes:

- **Surveys:** Experiences and opinions about glucose monitoring and CGMs from HI families
- **Glucose values:** Data directly from CGMs and glucometers of participants who choose to share this data

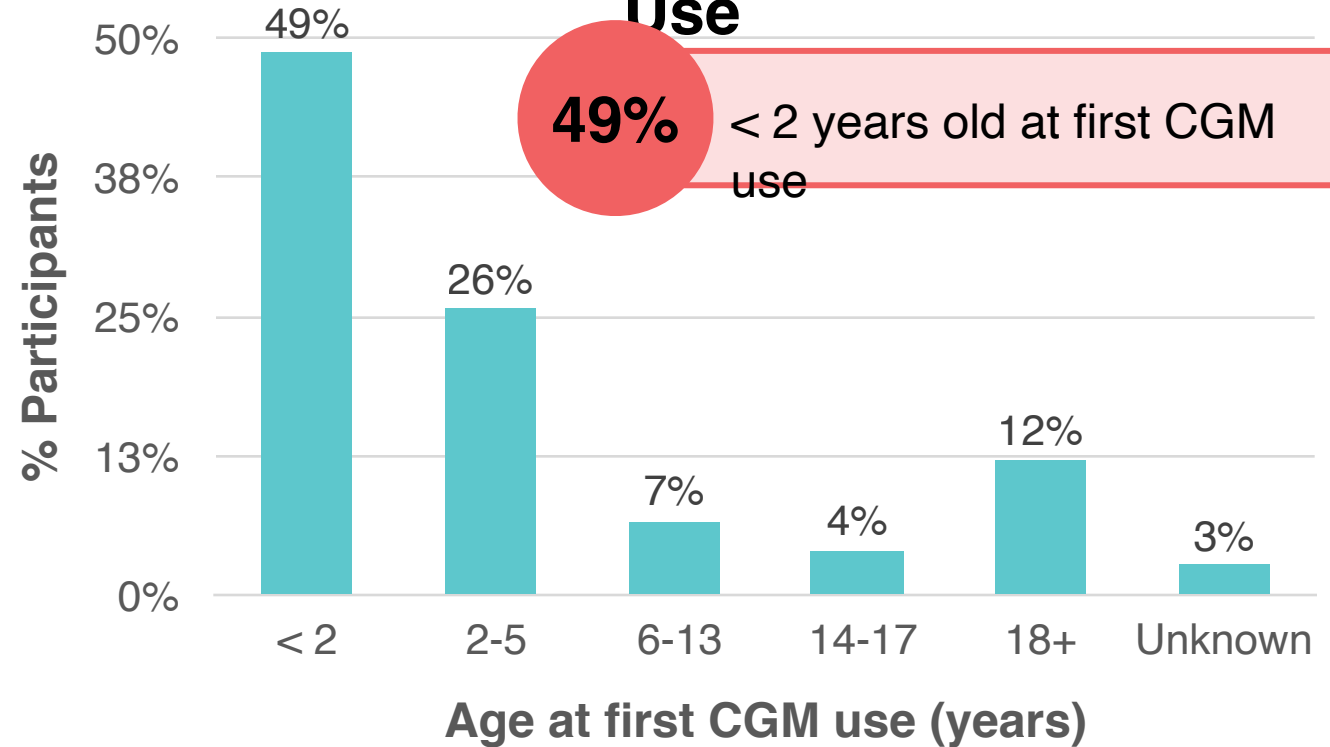


CGM Use History

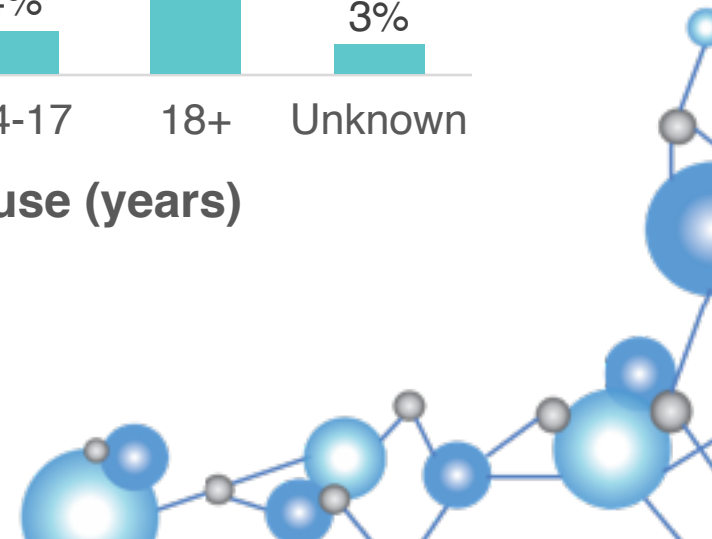


75% of people with HI have used a CGM

Age at First CGM Use

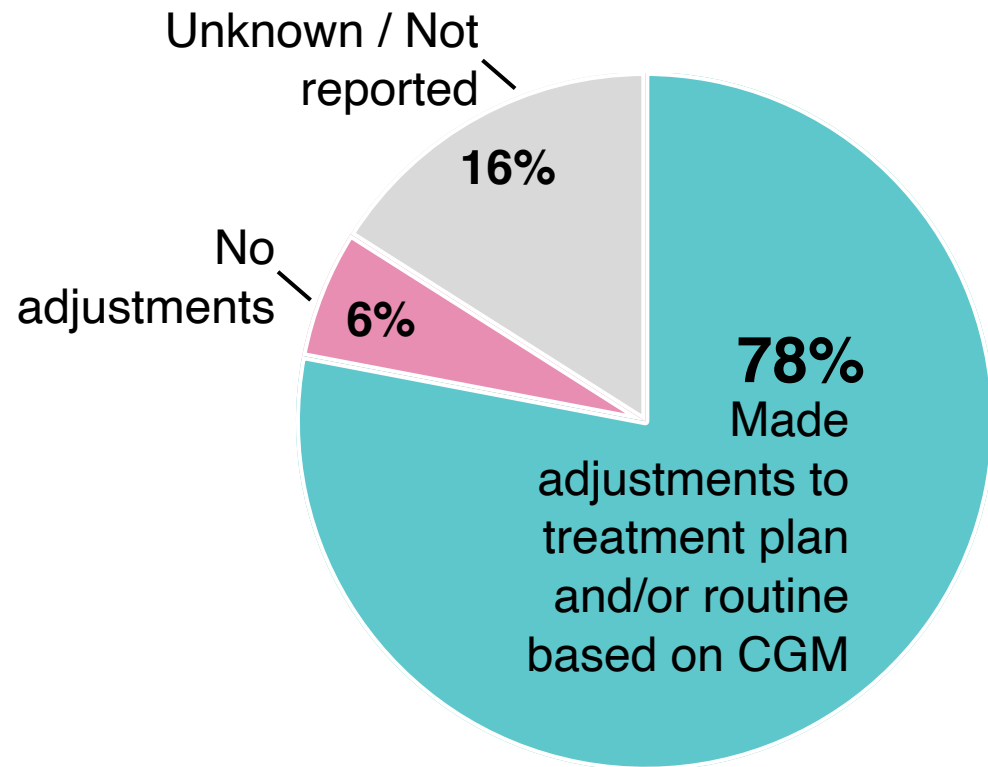


49% < 2 years old at first CGM use

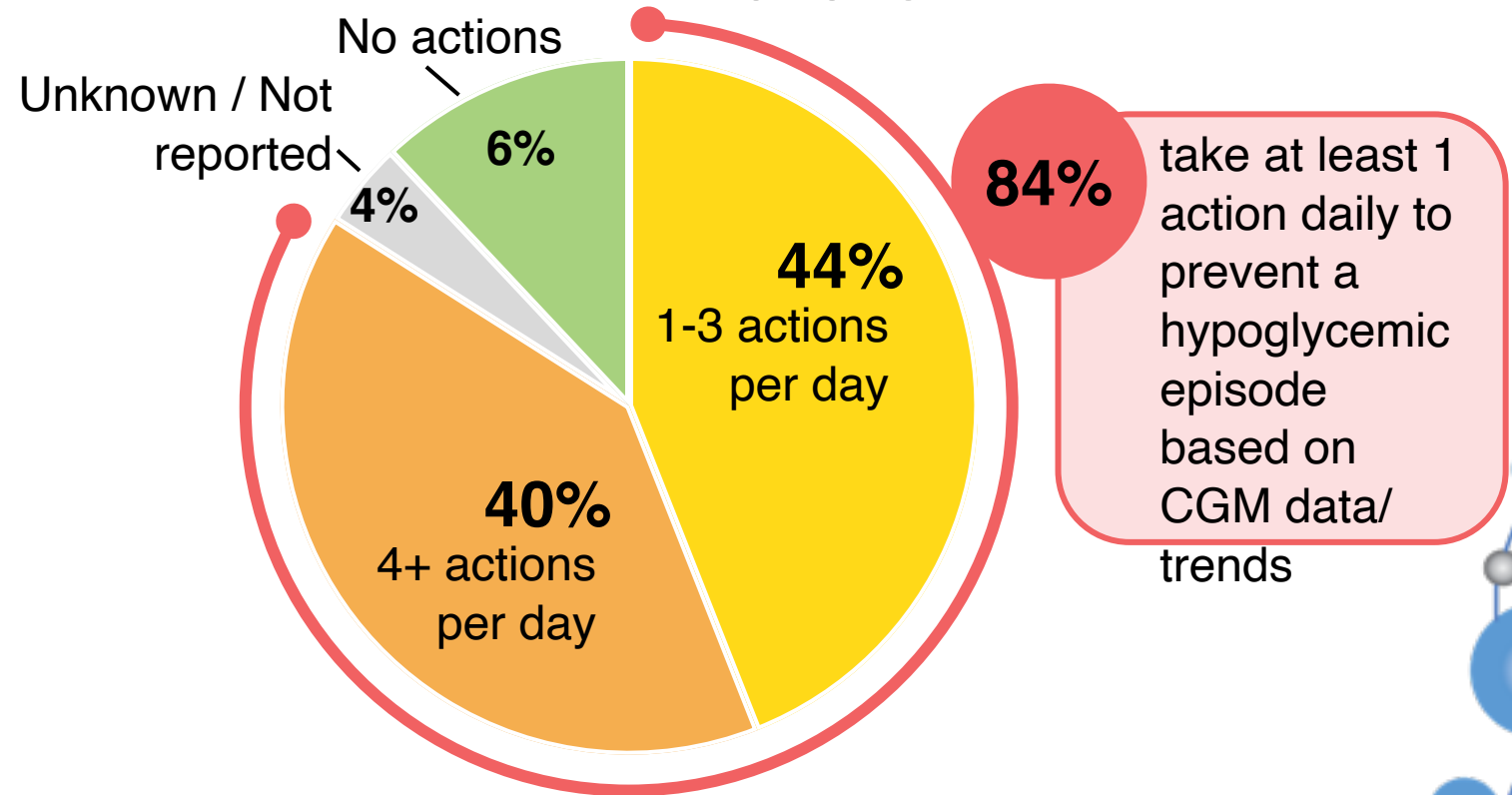


HIGR: Impact of CGM - Medical

Impact of CGM on Treatment Plan / Routine

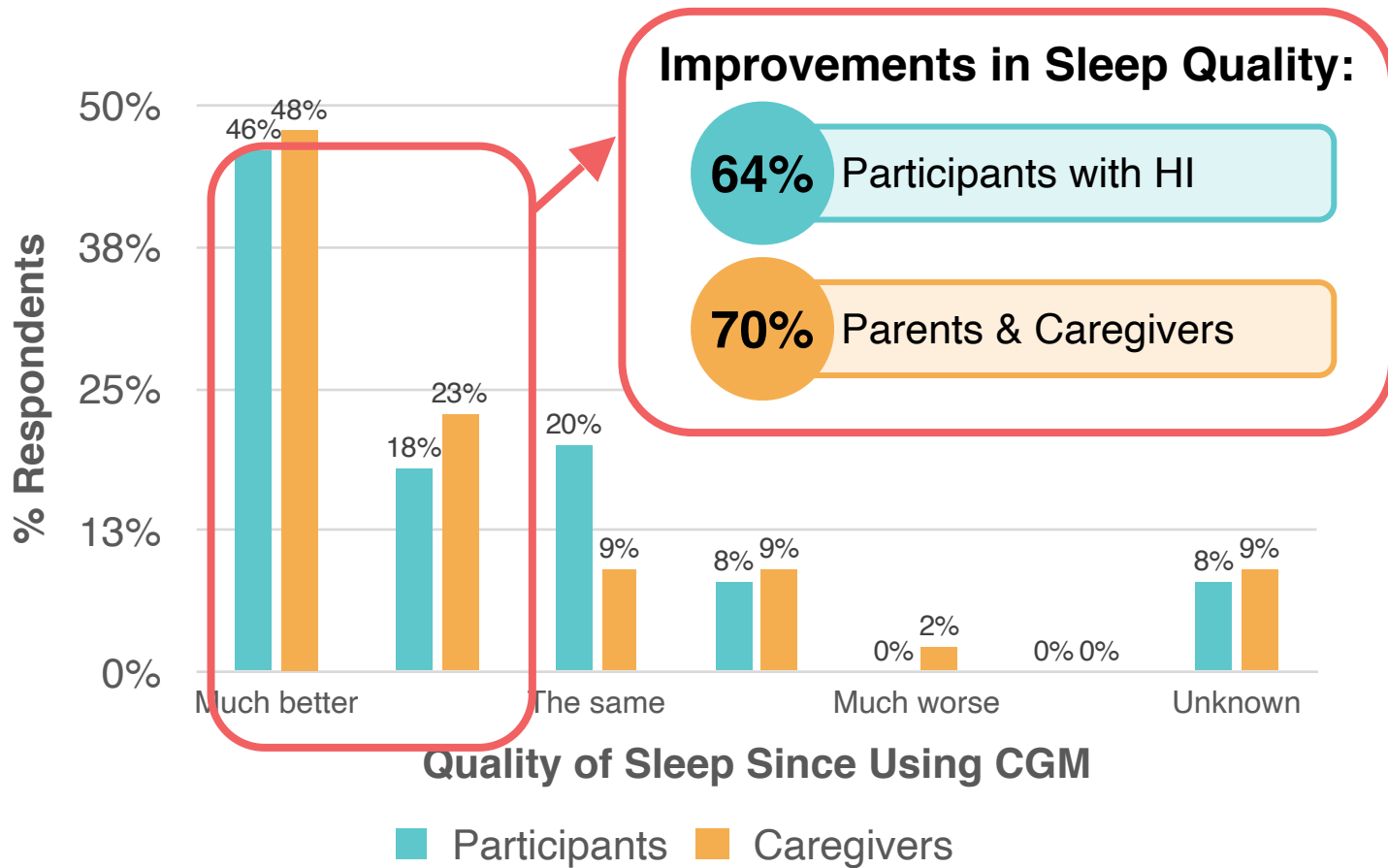


Impact of CGM on Hypoglycemia-Preventing Actions

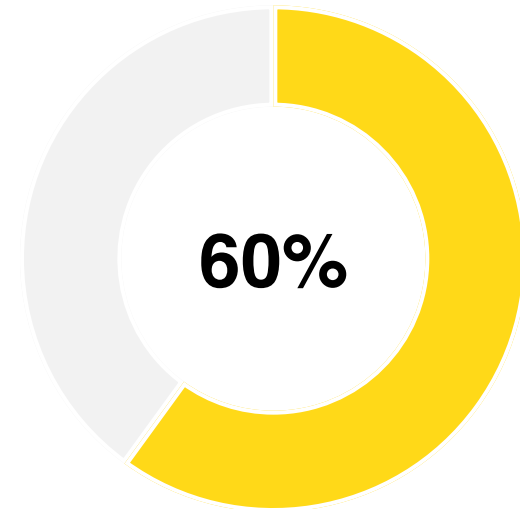


Data from the HI Global Registry, September 2025
(Current CGM users only, n = 50)

Impact of CGM on Sleep Quality



Impact of Remote Monitoring



Remote monitoring allowed the participant to be **cared for by someone other than the primary caregiver/parent** (e.g. babysitter or other family members)

Data from the HI Global Registry, September 2025
(Current CGM users only, n = 50)

GM data collection in HIGR

DEXCOM CGM DATA



- Launched Nov 2024
- Collects **ALL historical data**
- How do I share my Dexcom data in HIGR?

- "Apps and Devices" → "Connect"
 - **Smart device- all done!**
 - **Receiver-** connect receiver to Clarity once per month

All data in HIGR is de-identified to protect your privacy and is only made available by request to qualified researchers.



GLUCOMETER DATA

- Launched April 2025
- How do I share my glucometer data in HIGR?

- "Apps and Devices" → "Connect"
- Log-in or pair your device through Matrix DataSync

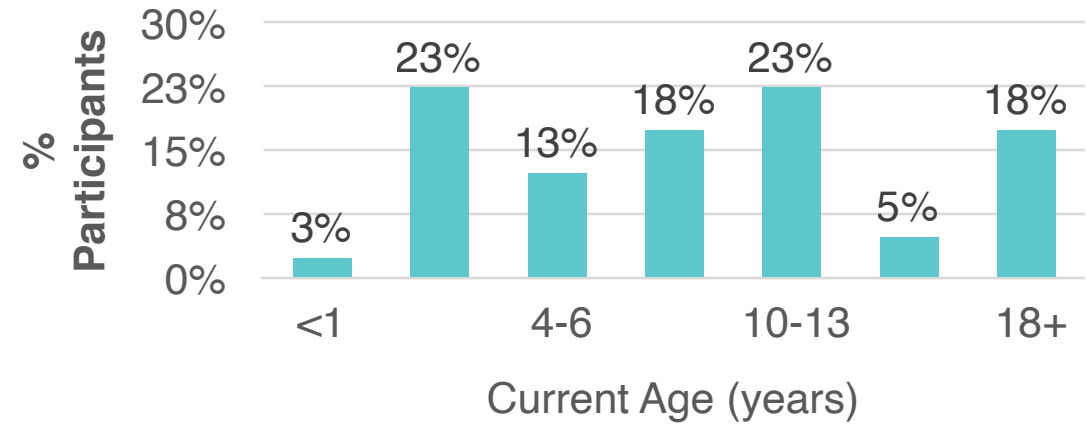


Everyone is encouraged to share

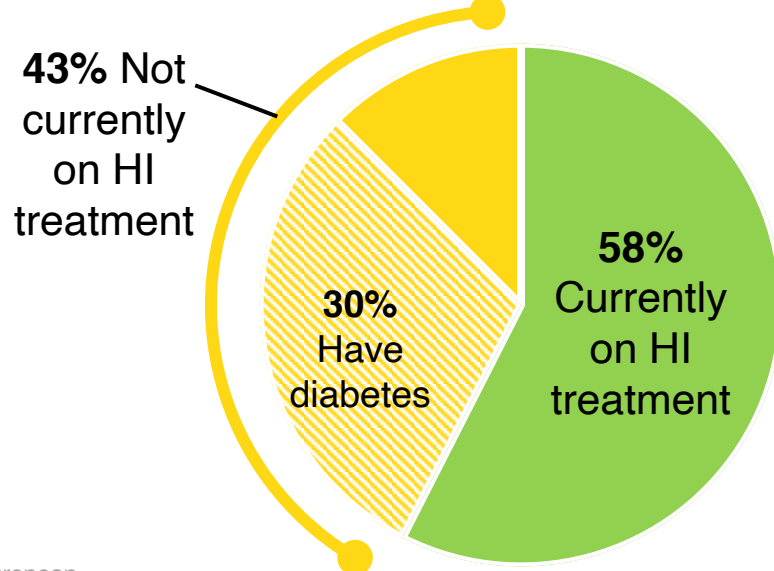
CGM data, n = 63
Glucometer data, n = 27 } n = 9 sharing both

>11.3 million CGM data points
As of September 10, 2025

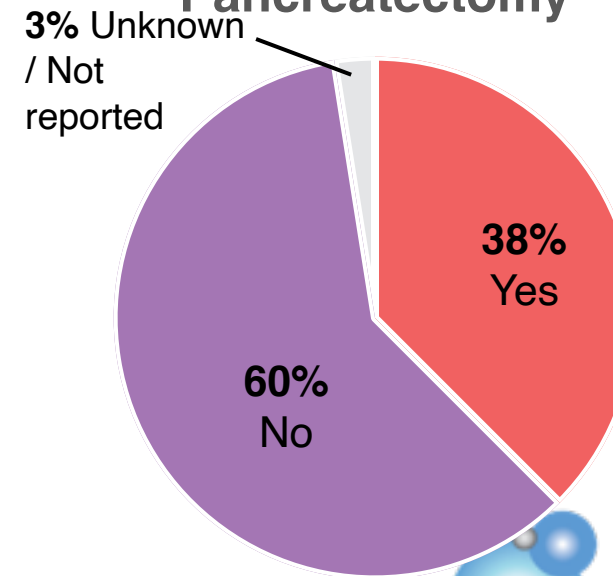
Current Age



Current Treatment Status

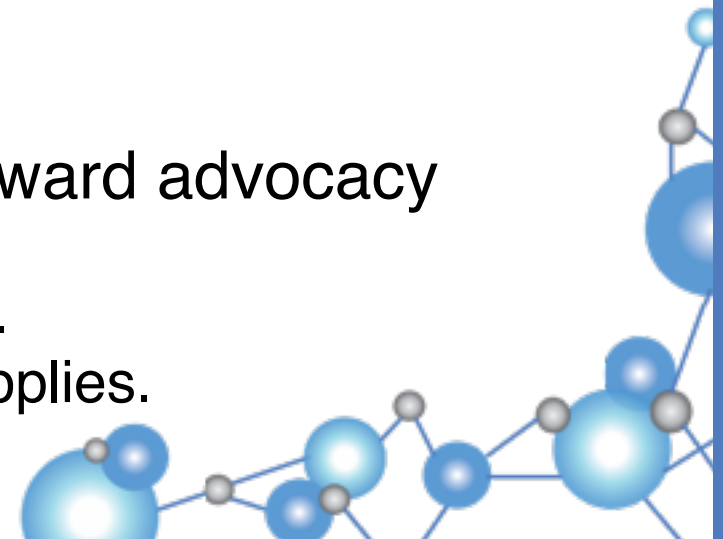


Pancreatectomy



Data collection in HIGR

- By sharing your CGM and glucometer data in HIGR, you can help us better understand glycemic levels in people with HI.
 - This data source helps demonstrate the unmet need to insurance providers, device makers, and pharmaceutical companies.
- We can analyze trends from people with common experiences to better support people with HI.
 - Are there more commonalities between people on the same treatment than we thought? What about post-pancreatectomy? How do seasonal changes affect glycemic levels?
- Sharing your CGM and glucometer data contributes toward advocacy and access initiatives.
 - More accurate technologies are needed by people with HI.
 - HI families deserve better access to devices and CGM supplies.



More about CGM

To learn more about using a CGM as a tool to support HI families, visit our website!

Two HI parents led the creation of a **FAQ guide** about the uses for CGM in



“
Connecting my son's Dexcom to HIGR was quick and easy! It's a simple way to provide a wealth of information on how HI impacts glucose.



HI GLOBAL
REGISTRY

A graphic featuring a quote from a parent about connecting their child's Dexcom to HIGR. The quote is in white text on a teal background. To the right of the text is a photograph of a young boy in a green shirt, smiling and looking towards the camera. At the bottom left of the graphic is the HI Global Registry logo, which includes a globe icon and the text 'HI GLOBAL REGISTRY'. The entire graphic is set against a background of blue molecular structures.