



CGM research in HI

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Plan

What am I going to talk about?

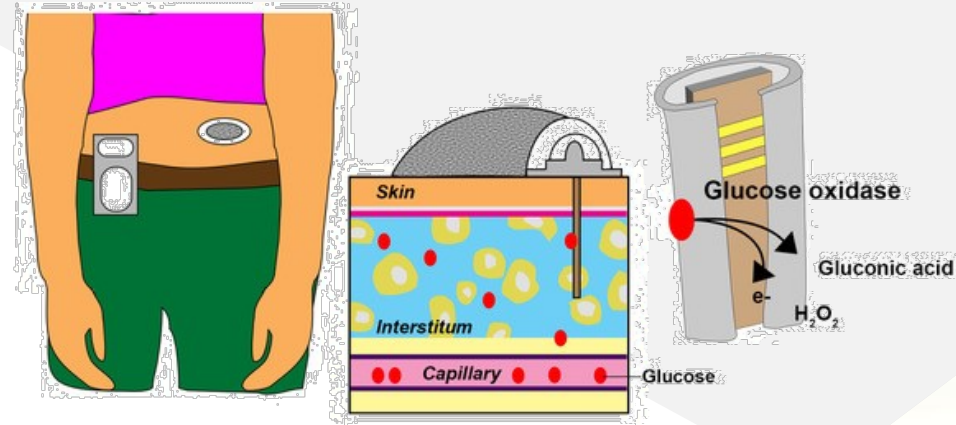
- Brief background
- Research in **HI**
 - What's **been** done?
 - What's **being** done?
 - What **should/could/will** be done?
- Questions



Background

What is CGM?


- Continuous glucose monitoring
- Measurement of interstitial glucose every 1-5 minutes
- This approximates blood glucose
- Well established for people living with diabetes
- Sporadic use for children with HI



Research – patient experience

- CGM is anecdotally useful for children with HI

Continuous Glucose Monitoring in the Management of Neonates With Persistent Hypoglycemia and Congenital Hyperinsulinism

Myat Win, Rowan Beckett, Lynn Thomson, Ajay Thankamony, Kathryn Beardsall 

The Journal of Clinical Endocrinology & Metabolism Volume 107 Issue 1 January 2022

JOURNAL OF MEDICAL INTERNET RESEARCH

Braune et al

[Original Paper](#)

Open-Source Technology for Real-Time Continuous Glucose Monitoring in the Neonatal Intensive Care Unit: Case Study in a Neonate With Transient Congenital Hyperinsulinism

Katarina Braune^{1,2}, MD; Mandy Wäldchen³, MSc; Klemens Raile¹, MD; Sigrid Hahn⁴, MD; Tebbe Ubben⁵; Susanne Römer⁴, MD; Daniela Hoerber⁶, MD; Nora Johanna Reibel⁴, MD; Michael Launsbach^{2,4}, MD; Oliver Blankenstein^{7,8}, MD; Christoph Bühner⁴, MD

Continuous Glucose Monitoring System for Congenital Hyperinsulinemia

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Blood glucose monitoring is a way of testing the concentration of glucose in the blood. The most recent advance is the development of continuous glucose monitoring system (CGMS) which gives 24 hour trend of blood sugar levels thus helping both the patient and the physician in achieving better glycemc control. CGMS in pediatric population is generally used for those on insulin pumps and those who are having fluctuating blood glucose levels. This case highlights the use of CGMS for a child with congenital hyperinsulinemia. It helped in close monitoring of blood glucose levels thereby identifying recurrent hypoglycemia, leading to a better control of blood glucose levels.

Key words: Blood glucose, Management, Monitoring.

et al. *International Journal of Pediatric Endocrinology* (2018) 2018:3
doi.org/10.1186/s13633-018-0057-2

International Journal of
Pediatric Endocrinology

RESEARCH

Open Access

Continuous Flash Glucose Monitoring in children with Congenital Hyperinsulinism; first report on accuracy and patient experience



Hussain Alsaffar¹, Lucy Turner², Zoe Yung², Mohammed Didi² and Senthil Senniappan^{2*}

Research – patient experience

- CGM is anecdotally useful for children with HI
- Opinions, when sought, are variable

Families' Experiences of Continuous Glucose Monitoring in the Management of Congenital Hyperinsulinism: A Thematic Analysis

Sameera Hannah Auckburally^{1,2*}, Chris Worth^{1,3}, Maria Salomon-Estebanez¹,
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¹ Department of Paediatric Endocrinology, Royal Manchester Children's Hospital, Manchester, United Kingdom, ² Faculty of Health and Medicine, Lancaster University, Lancaster, United Kingdom, ³ Department of Computer Science, University of Manchester, Manchester, United Kingdom, ⁴ Paediatric Psychosocial Service, Royal Manchester Children's Hospital, Manchester, United Kingdom, ⁵ Faculty of Biology, Medicine and Health, University of Manchester, Manchester, United Kingdom

Research – patient experience

TABLE 2 | Description of 5 major themes and subthemes in families' experiences of CGM use in CHI.

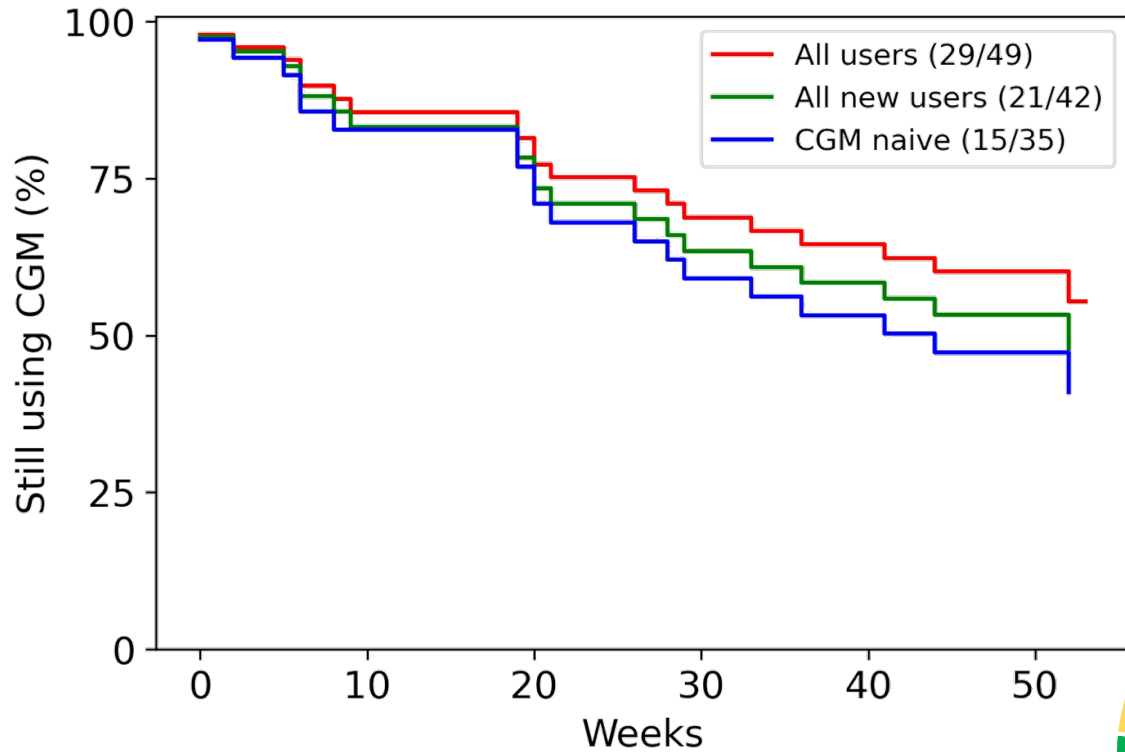
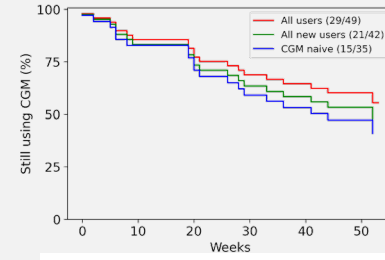
Theme	Positive Experiences	Educational Tool	Behavioural Change	Negative Experiences	Design Improvements
Theme Description	Factors regarded as positive/helpful by participants	Learning from CGM to improve management	Changes to routine due to CGM	Factors regarded as negative by participants	Refinements to design of CGM
Subthemes	<p>Reassurance</p> <p>Less stressful management</p> <p>Reduced fingerprick tests</p> <p>Glucose trend predictions</p> <p>Objective evidence of low glucose</p> <p>Optimisation of blood glucose control</p>	<p>New knowledge of glucose trends</p> <p>More hypoglycaemia than previously thought</p> <p>Heightened awareness of hypoglycaemic times of the day</p> <p>Reflection on reasons for hypoglycaemias</p> <p>Adhesive problems</p>	<p>Timing of meals changed</p> <p>Ensured medications given on time</p> <p>Improved family dynamics</p> <p>Adolescents taking increased responsibility for own condition</p>	<p>Alarms</p> <p>The need to carry receiver due to range</p> <p>Accuracy</p> <p>Sensor insertion</p>	<p>Increase receiver range</p> <p>Incorporate wearable receiver</p> <p>Sensor size</p> <p>Tailor CGM for those with CHI e.g. improve accuracy at lower glucose levels</p>

Research – patient experience

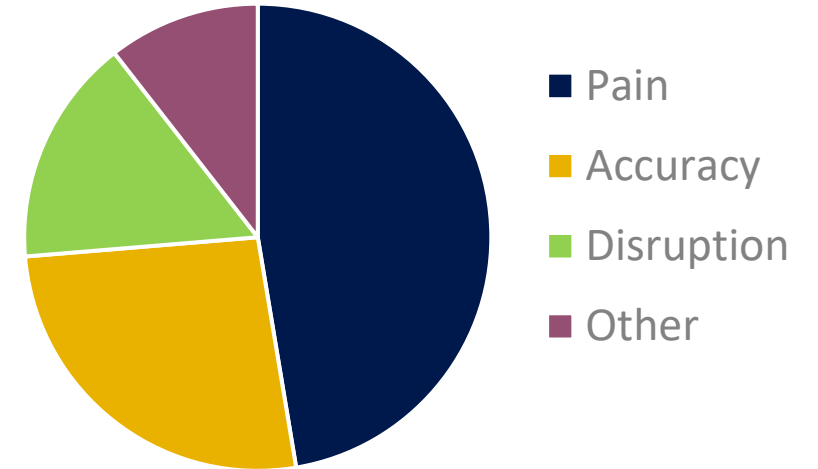
- 46 families were given free CGM for 12 months
- Did they want to keep using it?
- Reasons for stopping?



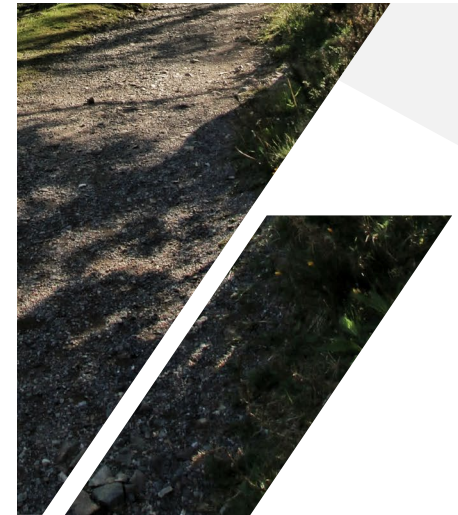
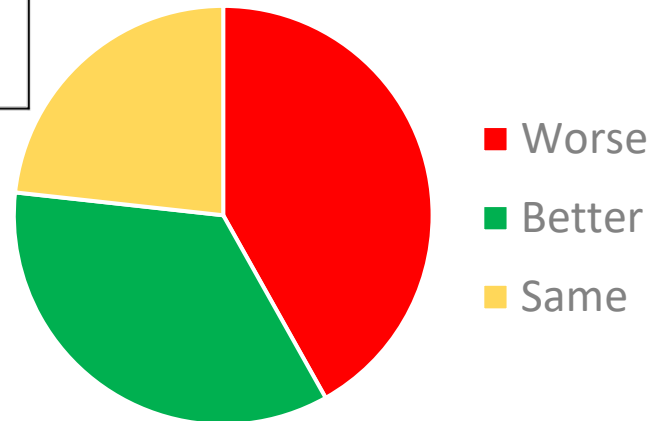
Research – patient experience



Primary reason for stopping



Sleep



Research – accuracy

Clinical Trial > [Horm Res Paediatr. 2019;92\(5\):319-327. doi: 10.1159/000506230.](#)

Epub 2020 Mar 24.

Continuous Glucose Monitoring Systems: Are They Useful for Evaluating Glycemic Control in Children with Hyperinsulinism?¹

Arpana Rayannavar¹, Okan U Elci^{2,3}, Lauren Mitteer¹, Diva D De León^{4,5}

> [Front Endocrinol \(Lausanne\). 2022 Nov 2;13:1016072. doi: 10.3389/fendo.2022.1016072.](#)
eCollection 2022.

The hypoglycaemia error grid: A UK-wide consensus on CGM accuracy assessment in hyperinsulinism²

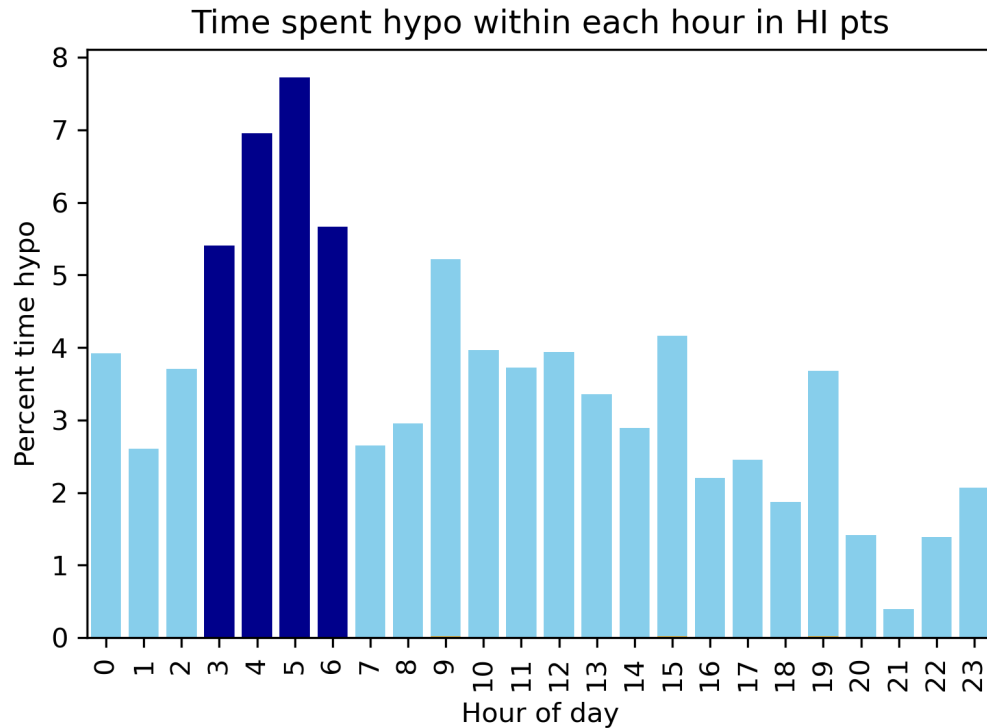
Chris Worth^{1,2}, Mark J Dunne³, Maria Salomon-Estebanez¹, Simon Harper², Paul W Nutter²,
Antonia Dastamani⁴, Senthil Senniappan⁵, Indraneel Banerjee^{1,3}

- Average error 17.5%¹ - 19% (17mg/dL)²
- CGM detected 45%² – 86%¹ of hypos



Research – understanding

- CGM can tell us things



Worth et al. JMIR. 2020

Worth et al. BMJ Open Diabetes. 2022

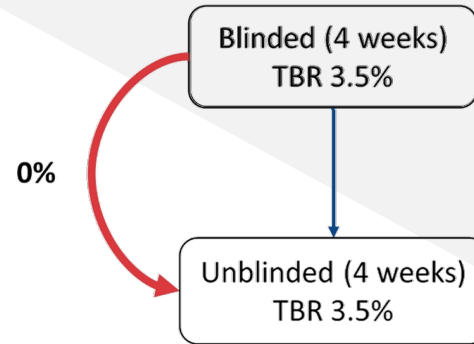
varying thresholds for hypoglycemia

3.5 mmol/L (63 mg/dL)			
% time hypo	P value	Hypos/day	Mean duration (min)
3.26		1.3	36.4

Research – efficacy

- CGM can tell us things
- But can it reduce hypos?
- 10 patients used CGM
 - TBR = time below range

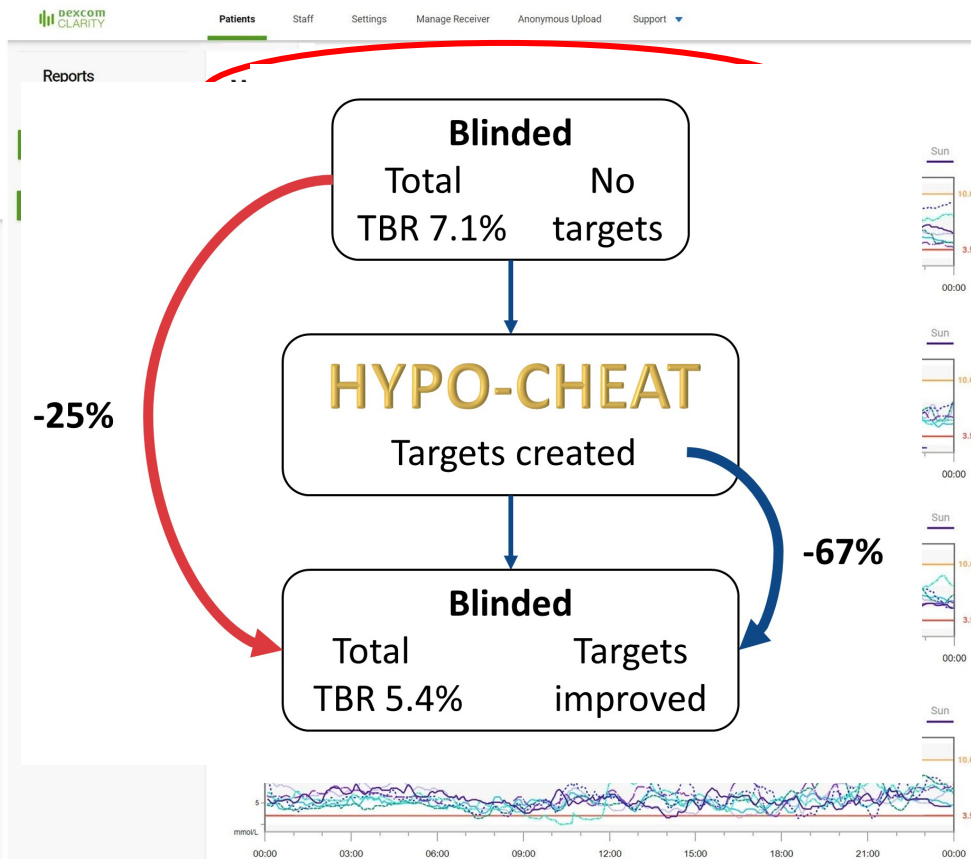
- So how can we help?



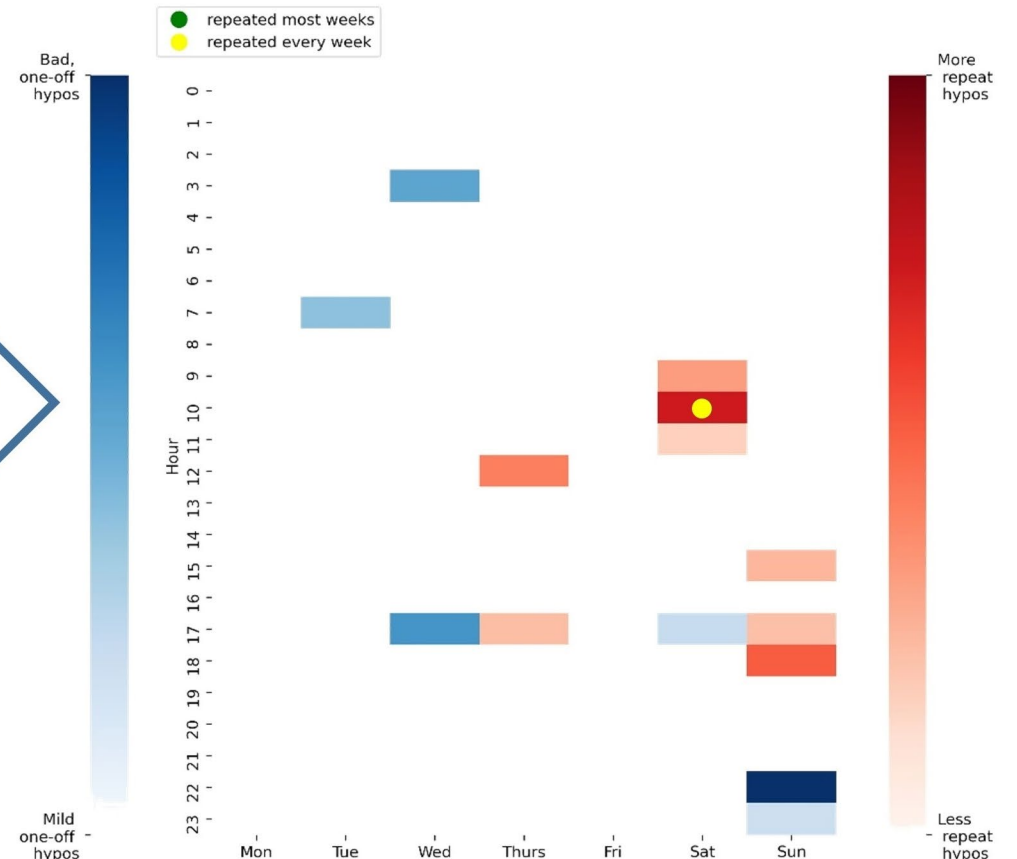
Worth et al. Digital Health. 2022

Research – efficacy

- Algorithms to help spot hypo patterns



Worth et al. Digital Health. 2022



Research – what's being done?

- UK national questionnaire re CGM
- Dexcom G7 vs G6 comparison
- Further work on algorithms to help pattern recognition



Research – future?

- International consensus on CGM
- Structured education for those using CGM
- Further improvement in device tech

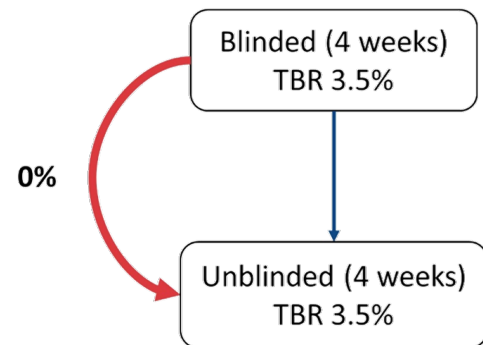
- Closed loop CGM-glucagon pump?
- CGM companies to consider rare diseases??

- Suggestions from you?

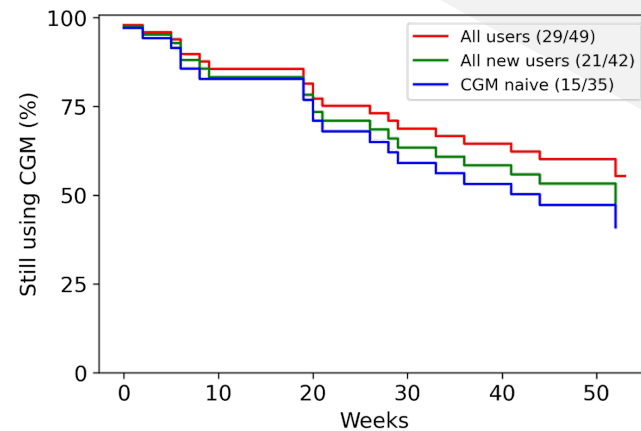


Conclusions

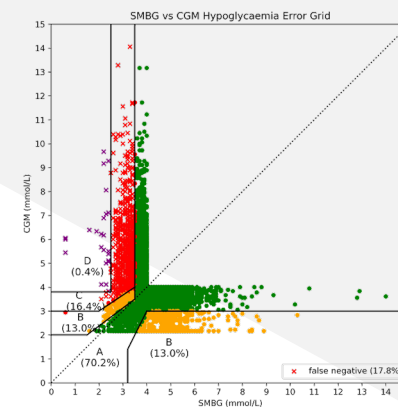
- No evidence for unsupported use yet



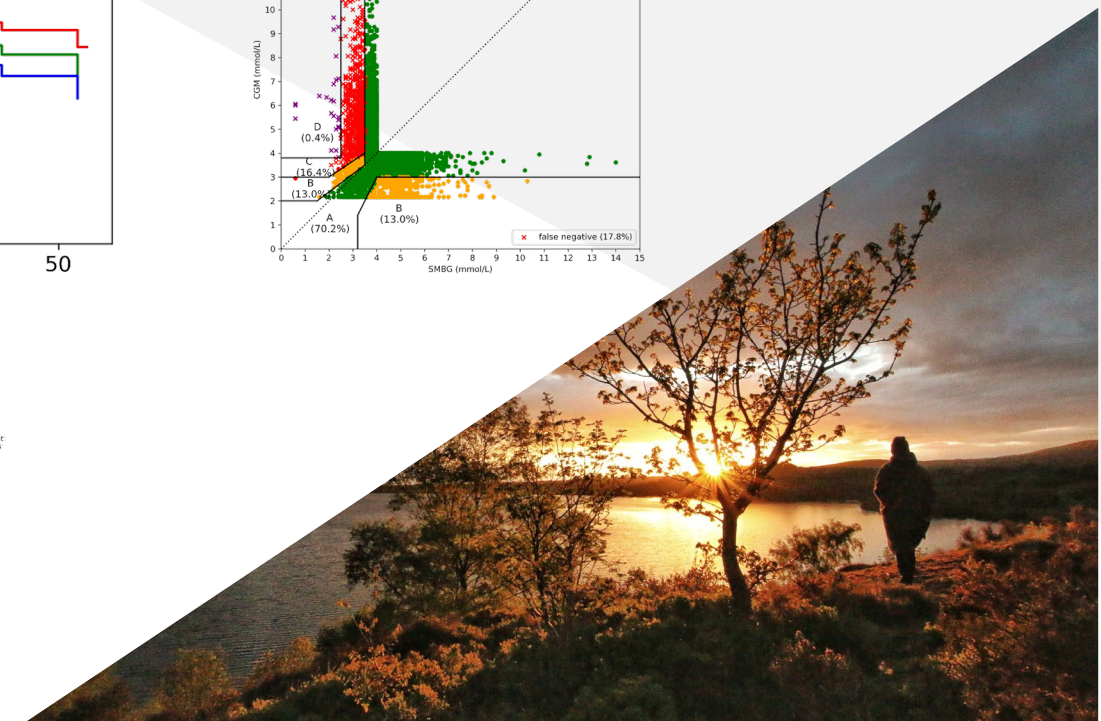
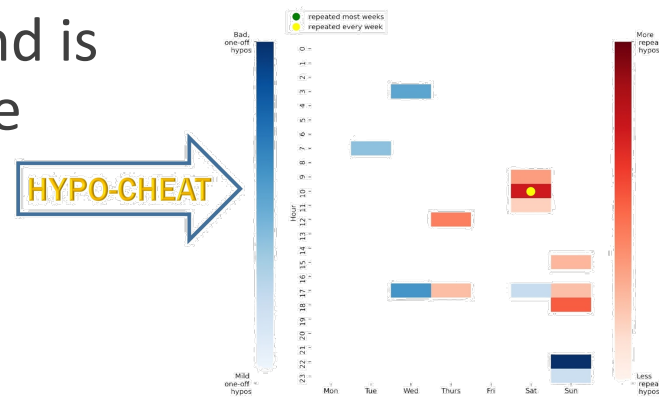
- Long term CGM is not as popular as expected



- Accuracy remains an issue



- But CGM can work and is life changing for some families!





Thank you Questions?

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