

Glucose Monitoring in Congenital Hyperinsulinism

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Why Glucose Monitoring is important in Congenital Hyperinsulinism?

Children with CHI at at risk of episodes of hypoglycaemia which can cause irreversible damage in the developing brain

Accurate and patient-friendly methods of measuring glucose levels are crucial to CHI successful management

Available methods

- **Blood draw measurement**
 - **Gold standard for diagnostic purposes**
 - **Self-monitored blood glucose (SMBG)**
 - **Capillary measurement with point-of-care glucose meters**
 - **Hospital and Home use**
 - **MARD 5-10%**
 - **Continuous glucose monitoring (CGMs)**
 - **Interstitial measurement with CGM devices, retrospective or real time**
 - **Hospital and Home use as per regional guidelines and on individual basis**
 - **MARD variable but higher than 10%**
-

Self-monitored blood glucose (SMBG)

1

- Provide
Glucometer

2

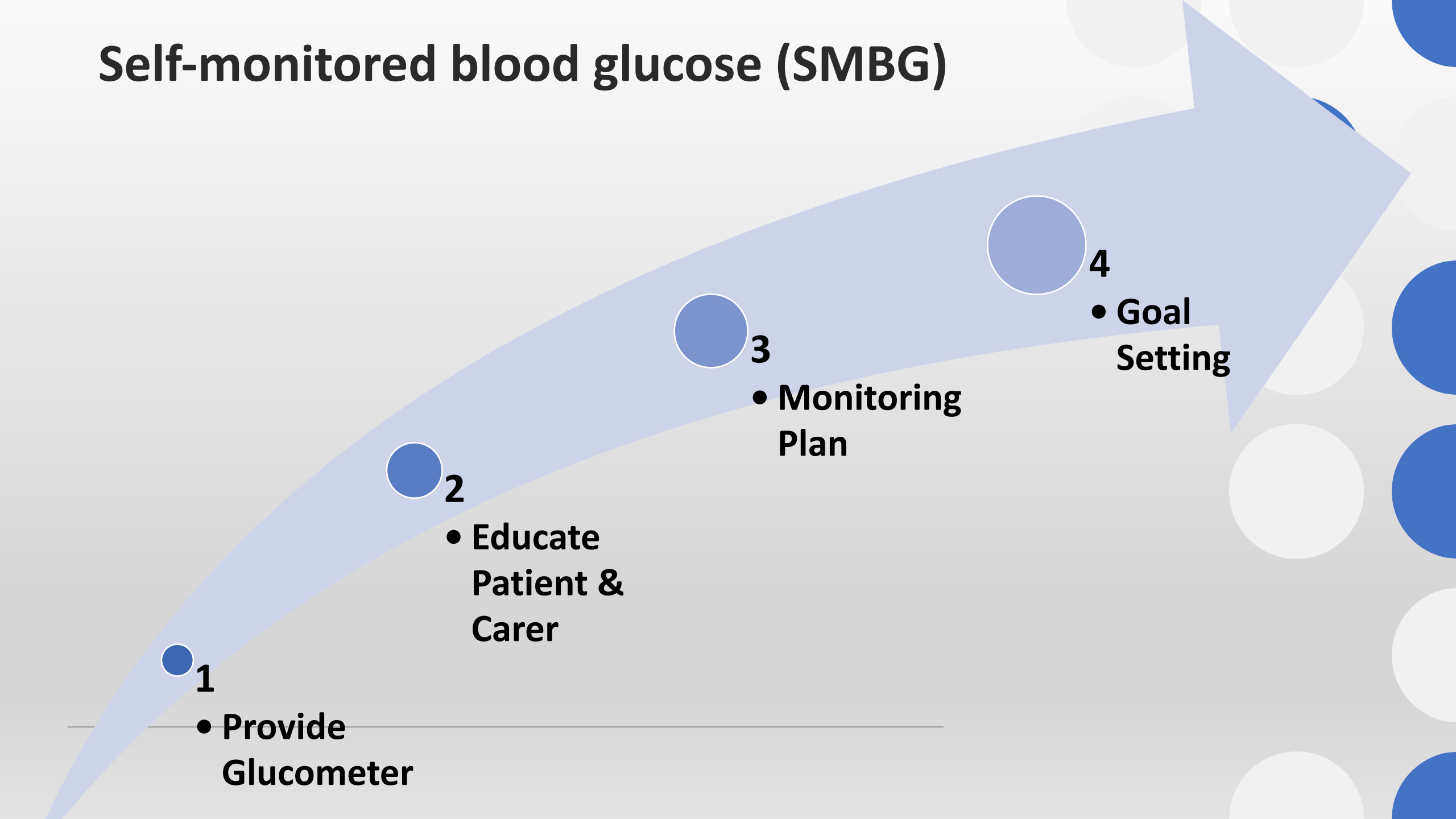
- Educate
Patient &
Carer

3

- Monitoring
Plan

4

- Goal
Setting



Provide glucometer

ISO system accuracy standards for blood glucose meters

2013 (ISO: 15197:2013) 95% of blood glucose results should be:

- Within ± 0.83 mmol/L of laboratory results under 5.6 mmol/L
(Within ± 15 mg/dl of laboratory results under 100 mg/dL)
- Within $\pm 20\%$ of laboratory results 5.6 mmol/L (100 mg/dL) or more



Educate patient & carer

Technique

Symptoms of hypoglycaemia

Emergency treatment

How to Use a Glucometer



SYMPTOMS



Asymptomatic

Product	Age of patient	Hypo management (glucose in gram)
Glucogel (10g glucose/tube)	Neonate–6 months	1/3 rd tube 3.33g
	6 months–2 years	½ tube 5g
	2-5 years	1 tube 10g
Glucojuice (15g glucose in 60mls)	>5 years	1 ½ tube 15g
	>5 years	60mls (15g)
Glucose tablet (4g glucose)	2 -5 years	2 ½ tabs (10g)
	>5 years	4 tabs (16g)

Challenges of measuring accurately: Coding mistakes, Contamination on skin, Alternate site testing, Expired test strips, Testing in very warm or cold temperatures or in humid condition

Monitoring Plan

- **Individualised plan**
- **Pre-meals & bedtime**
- **If symptomatic**
- **If unwell**

Goal Setting

- **Target 3.5-10 mmol/l**

asymptomatic hypoglycaemia

- No indication of the direction or rate of change of glucose levels
- Obtaining data upon the patient's decision to self-monitor

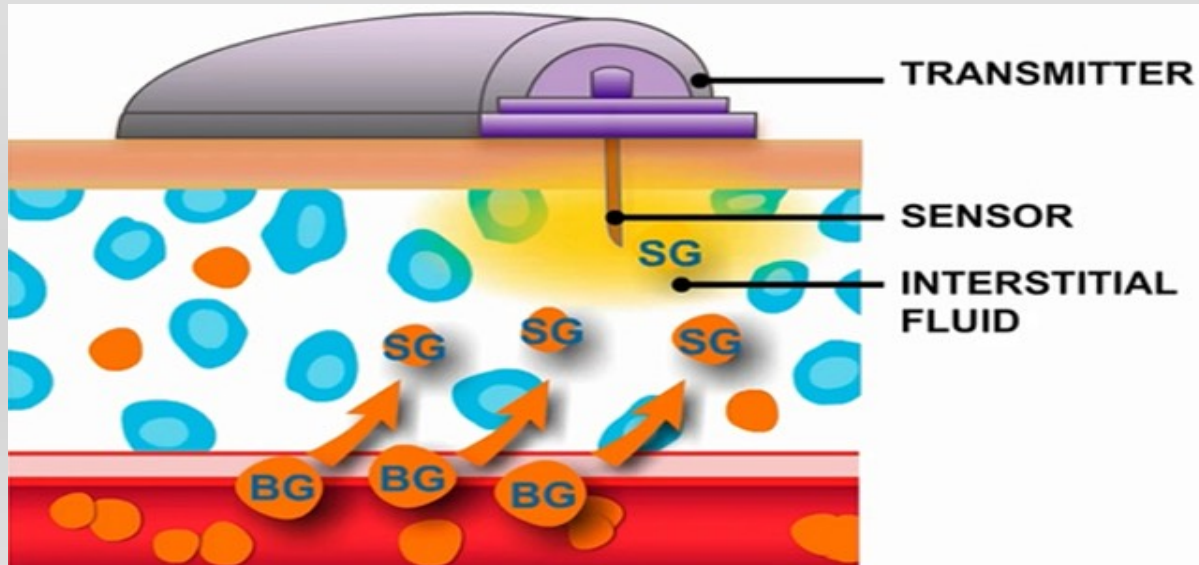


levels changes

- Obtaining data real-time or intermittently

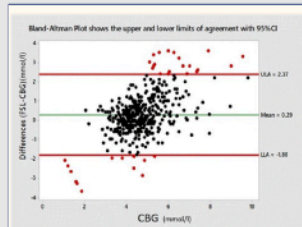
- Sensor under the skin measures the glucose in the interstitial space
- Glucose measurements every 1-5 minutes
- Lag of 5-25 minutes with SMBG
- Readings reviewed Real-time & intermittently
- Approved for DM if frequent /severe hypoglycemia, Nocturnal hypoglycemia, Hypoglycemia unawareness

- There is no consensus
- CGM data as primary or secondary endpoints in CHI clinical trials
- In-hospital use as part of research protocols or regional policy or on an individual basis
- Home use as part of research protocol or on an individual care plan
- Concerns for accuracy & Limited user feedback



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

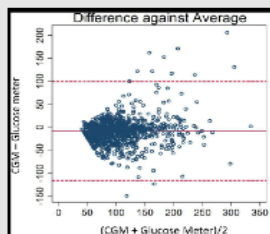
Hussain Alsaifir¹, Lucy Turner², Zoe Yung², Mohammed Didi², Senthil Senniappan²



- ✓ MARD was 17.9%
- ✓ Despite the ease of using the FSL system, **concerns related to accuracy**, especially at low glucose values do remain although **parents find the glucose trend to be very useful**
- ✓ Majority of the parents found the glucose trend on FSL to be useful to detect and prevent hypoglycaemic episodes. All parents felt that FSL is a very easy and convenient method to measure the glucose especially during sleep. A significant proportion of parents felt that FSL readings were not accurate and 56% of parents expressed interest to continue using FSL after the trial period

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

Arpana Rayannavar¹, Okan U Elci^{2,3}, Lauren Miltoer³, Divya D De León^{4,5}



- ✓ MARD was 17.47%
- ✓ **CGM is not a reliable method** to monitor for hypoglycemia, given the high number of false positive hypoglycemia readings.
- ✓ CGM can be useful in preventing unnecessary checks by glucose meter during times of normoglycemia. Therefore, the benefits of using CGM in patients with HI would be in guiding the need to check plasma glucose by glucose meter rather than point accuracy

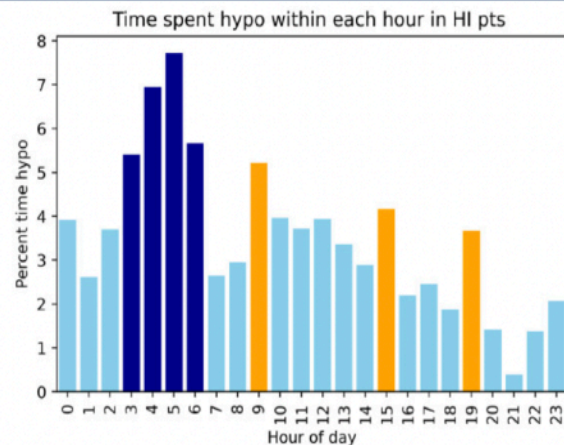
Open-Source Technology for Real-Time Continuous Glucose Monitoring in the Neonatal Intensive Care Unit: Case Study in a Neonate With Transient Congenital Hyperinsulinism

Katarina Braune^{1,2}, Mandy Wäldchen³, Klemens Raile¹, Sigrid Hahn⁴, Tebbe Ubben⁵, Susanne Römer⁶, Daniela Hoerber⁶, Nora Johanna Reibel⁴, Michael Launsbach^{2,4}, Oliver Blankenstein^{7,8}, Christoph Bührer⁴

- ✓ **TIR for CGM remained consistently >90%**, whereas time in hypoglycemia (<45 mg/dL) decreased.
- ✓ Mean glucose >70 mg/dL at 72 hours of life and thereafter
- ✓ Real-time information allowed us to better understand glycemic patterns and to improve the quality of glycemic control accordingly.
- ✓ Severe hypoglycemia was prevented, and measurement of serum levels of insulin and further lab diagnostics were performed much faster, while the patient's individual burden caused by invasive procedures was reduced.

Clustering of Hypoglycemia Events in Patients With Hyperinsulinism: Extension of the Digital Phenotype Through Retrospective Data Analysis

Chris Worth^{1,2}, Simon Harper², Maria Salomon-Estebanez¹, Elaine O'Shea¹, Paul W Nutter², Mark J Dunne³, Indraneel Banerjee^{1,3}



Conclusions

- ✓ **Digital phenotype of HI by describing the glycemic trends and identifying the timing of hypoglycemia measured by CGM**
- ✓ We have identified the early hours as a time of high hypoglycemia risk for patients with HI and demonstrated that simple provision of CGM data to patients is not sufficient to eliminate hypoglycemia

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

Myat Win¹, Rowan Beckett², Lynn Thomson³, Ajay Thankamony^{1,3}, Kathryn Beardsall^{1,3}

- ✓ Mean absolute relative difference of 11%.
- ✓ CGM highlighted the challenges of preventing hypoglycemia in these babies when using intermittent blood glucose levels alone, and the potential application of CGM as an adjunct to clinical care.

Efficacy of use of Continuous Glucose Monitoring System in patients with Congenital Hyperinsulinism



Neha Malhotra¹, Yesica Tropano¹, Preetba Parushothaman¹, Clare Gilbert¹, Kate Morgan¹, Louise Doodson¹, Antonia Dastaman¹
1. Endocrinology Department, Great Ormond Street Hospital for Children, London, UK

Figure 1: Change in time in range in normoglycaemia (TIRN) in our patients after 12 months

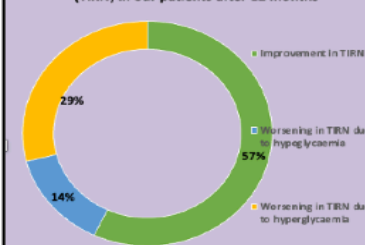
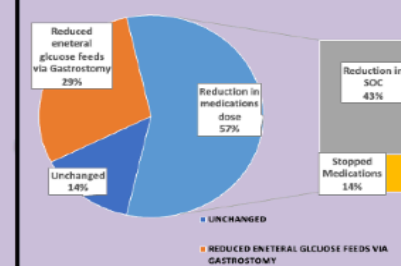


Figure 3 Change to SOC



METHOD: Cohort of 7 patients with CHI using a Dexcom G6 real time CGMS (rtCGMS) over 12 months. Mean age of participants was 10.47 years (range 4.1 – 18.2).

CONCLUSIONS

- ✓ After 12 months of use of rtCGMS in patients with CHI at our centre, we noticed in the majority of the patients an improvement of TIRN and a decrease in number of monthly hypoglycaemic episodes. All the participants achieved SOC treatment changes in a safe manner.
- ✓ The rtCGMS device can assist CHI patients and families with more effective glycaemic control. This way, we may avoid hypoglycaemic brain injury and optimize treatment.



> [Front Endocrinol \(Lausanne\)](#). 2022 Jul 19;13:894559. doi: 10.3389/fendo.2022.894559. eCollection 2022.

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, Jacqueline Nicholson⁴, Simon Harper³, Paul W Nutter³, Indraneel Banerjee^{1 5}

Results

- Favorable use as offering parental reassurance, reduced fingerprick tests and predictive warnings
- Unfavourable aspects of alarms and questionable accuracy at low glucose levels
- Adolescents frustrated by the short proximity range for data transmission resulting in the need to always carry a separate receiver
- Overall, families were positive about the use of CGM but expected application to be tailored to their child's medical condition

[J Endocr Soc](#). 2023 Feb 9; 7(4): bvad021.

PMCID: PMC9942542

Published online 2023 Jan 30. doi: [10.1210/jendso/bvad021](https://doi.org/10.1210/jendso/bvad021)

PMID: [36824585](https://pubmed.ncbi.nlm.nih.gov/36824585/)

Paediatric Society and Hyperinsulinism Charity National Surveys on CGM Access for Patients With Recurrent Hypoglycaemia

[Sze May Ng](#),[✉] [Sarah Dearman](#), [Mark Fisher](#), [Talat Mushtaq](#), and [Tabitha Randell](#), on behalf of the British Society of Paediatric Endocrinology and Diabetes UK and the UK Children's Hyperinsulinism Charity

Results

- Responses from 55 units and 69 individual families. Funding streams for CGM were highly variable. Only 29% were able to access CGM for recurrent hypoglycemia and from these, 65% were self-funding CGM.
- Quality of life benefits were evident from the UK CHC survey on the utility of CGM in reducing worry, improving sleep, lessening the burden of frequently finger-pricking and reducing out-of-hours appointments as a result of hypoglycemia.
- Patient-reported utilization rates of blood glucose test strips per week were significantly reduced.

Monitoring Glucose in CHI with SMBG or a CGM?

- **If your BG is rising or falling rapidly, CGM will often be more inaccurate**
 - **CGM provides more data points and helps to ease the burden of daily management and learn how your body uniquely responds to different factors**
 - **CGM along with SMBG can assist CHI patients with more effective glycaemic control and optimize their treatment**
 - **Cost and insurance coverage of CGM devices can sometimes be a barrier**
 - **The decision to use CGM along with SMBG should be determined with your healthcare team**
 - **Efficient BG monitoring with a robust plan in place can help to achieve glucose targets while avoiding potential hypoglycaemia's complications in CHI patients**
-

What is next?

Noninvasive and CGM

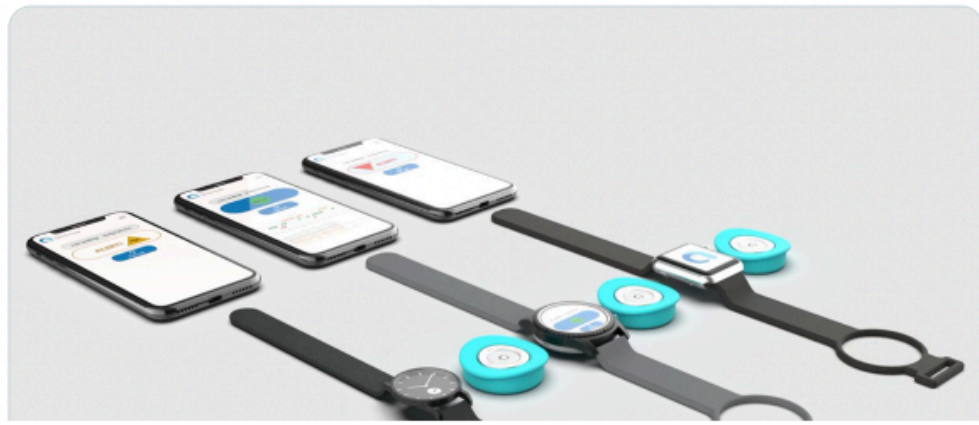


➔ Imagine not being restricted by your finger stick blood glucose monitor.

➔ Imagine having a device automatically alerting you when your blood sugar levels are going high or low and all that without taking a single drop of blood.

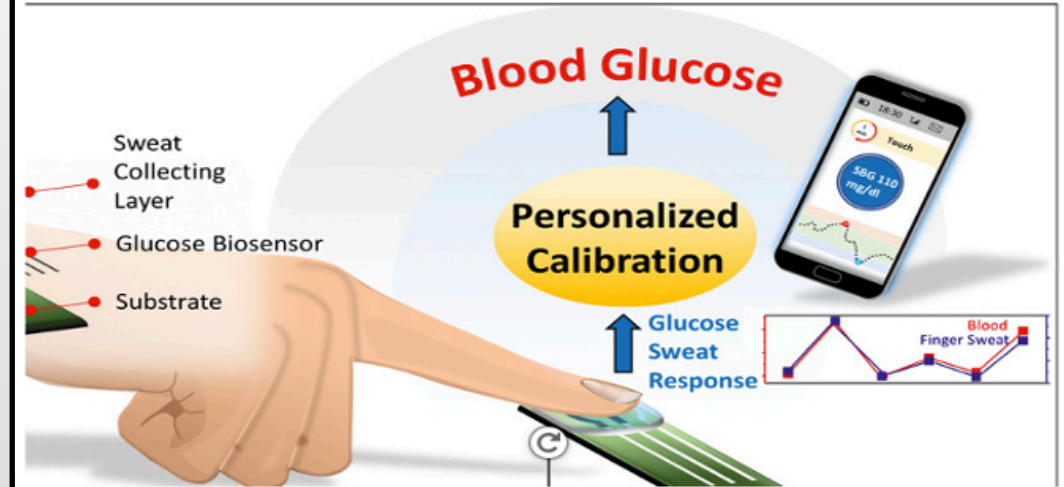
Watch this space!

RCD No: 008213961-0001



Touch-Based Fingertip Blood-Free Reliable Glucose Monitoring: Personalized Data Processing for Predicting Blood Glucose Concentrations

Sempionatto J et al. *ACS Sens.* 2021, 6, 5, 1875–1883

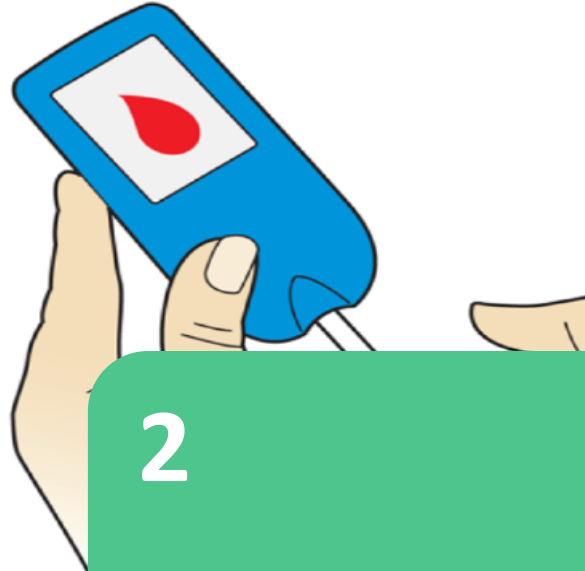


- ✓ Different biofluids have been explored recently for replacing current blood finger-stick glucose strips with noninvasive painless sensing devices.
- ✓ There are mixed reports on correlating the sweat results with blood glucose levels.
- ✓ New rapid and reliable approach that combines a simple touch-based fingertip sweat electrochemical sensor with a new algorithm that addresses for personal variations toward the accurate estimate of blood glucose concentrations.



1

- Determine device works better for you and is affordable
- Learn how & when to use it



2

- Agree an ongoing monitoring plan
- Understand what action you need to take



3

- Track the data and use reports from your device