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Technology Community



**ABSTRACT BOOKLET**

**NIHR** | Children and Young People  
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Marketing  
Sheffield

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# 01 CO-CREATION AND DISSEMINATION OF ACCESSIBLE, AGE-APPROPRIATE CORONAVIRUS EXPLANATORY INFORMATION MATERIALS FOR CHILDREN AND FAMILIES

Chris Evans<sup>1</sup>, Lucy Bray<sup>2</sup>, Sanjay Patel<sup>3</sup>, Damian Roland<sup>4</sup>, Karen Bartholomew<sup>5</sup>, Hannah Lonsdale<sup>6</sup>, Libby Beake<sup>1</sup>

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## BACKGROUND:

Little Journey, a digital platform designed to support children undergoing healthcare procedures, partnered with NHS England to create a set of freely available coronavirus information materials for children aged 8-12 years and their families.

## AIMS:

To enhance the understanding of, and access to, trusted, age-appropriate information regarding coronavirus and swab testing by children and families. To create a range of resources usable in multiple formats to support access for all.

## METHODS:

A previous study, investigating how families accessed coronavirus information and what this information was, was used to create a series of questions that children wanted answered. A group of subject matter experts co-authored answers to these questions. A Young Person Advisory Group was created to support storyline creation, character design and development, and voiceovers for the videos. Several families, plus experts at the NHS and Department of Health, provided feedback on the resulting animations which were then refined and used to create three videos and a printable leaflet. Little Journey partnered with NHS Digital, Public Health England, NHS Test and Trace to distribute these resources via websites, newsletters, social media and YouTube as well as updating the Little Journey smartphone app to include them.

## RESULTS:

Within the first three months of release (May 2021), the videos were viewed over 270,000 times. This continues to increase, with over 350,563 views by February 2022. The Little Journey app itself has a 4.7 app store rating and a 97% satisfaction rating.

## DISCUSSION:

Co-creation, using input from subject experts and representatives of the intended audience, is designed to result in content that is accurate, trusted and appropriate. The substantial number of views for the videos demonstrate that the information was widely accessed; no user comments are allowed on YouTube Kids content therefore effectiveness or ideas for new content is difficult to assess.



Figure: Screenshot of the Little Journey animation.



# 02 CO-DESIGNING A MIXED REALITIES PLAYKIT TO PREPARE CHILDREN FOR AN MRI SCAN WITHOUT A GA

Dylan Yamada-Rice<sup>1</sup>, Jill Thompson<sup>2</sup>

<sup>1</sup>Dubit, Leeds, UK. <sup>2</sup>University of Sheffield, Sheffield, UK.

## BACKGROUND:

This paper focuses on using design-based and playful methods to include children in the development of MedTech. This is done in relation to our Innovate UK funded R&D of an innovative mixed realities (virtual and augmented) playkit to help 4-10-year-olds undertake an MRI scan without a GA. The project team included researchers and developers from Dubit (a company specialising R&D of children's digital products), Sheffield Children's Hospital NHS Trust, the University of Sheffield and the Glasgow School of Art.

## AIMS:

to present innovative methods from games design that were used to include children directly in the project's R&D, and how these facilitated understanding elements fundamental to the successful uptake of medtech used in the preparation of children for medical procedures and treatments.

## METHODS:

The 30-month project included methods of co-design and production that used drawing, model-making, user testing, and character design. We will discuss the benefits of including children in the design of health products and interventions and the means used to analyse the outputs of design-based methods. As well as, how these outcomes were implemented into the development phases via design summits that included hospital specialists, games designers, and academics.

## RESULTS:

Our findings show that when children are the end users of medical products their input is vital to the success of what is produced.

## DISCUSSION:

is centred on how these methods led us to understand that the ways in which children make sense of medical information and procedures is fundamentally different from adults. In particular, children's desire for medtech that is playful, has spaces for open-ended play and storytelling to exist alongside the dissemination of medical information.



# 03 A DIGITAL SYSTEM OF CARE: SUPPORTING CHILDREN WITH MENTAL HEALTH ISSUES AND THEIR CAREGIVERS

Michael Gibson, Keith Owens

The University of North Texas, Denton, USA.

## BACKGROUND:

This presentation describes the knowledge that was constructed as a university-based user experience design (UXD) team worked with four stakeholder groups to design a responsive website to improve children's mental health across a diversely populated county in a large, American metropolitan setting.

## AIMS:

The essential functionalities of this digital system of care (DSC) were designed to meet the extant and future needs of parents and other childcare givers raising children and young adults with mental health issues in the county, as well as the affected young people themselves, and county school district personnel—teachers, nurses, counselors, and administrators—who regularly interact with these three- to eighteen-year-olds. The fourth stakeholder group consisted of county-based children's mental healthcare providers. As the other three stakeholder groups made regular use of the website and the services-cum-information it was designed to provide, data sets would be generated that could guide how this last group might marshal their individual and collective resources to meet various children's mental health challenges as they evolved.

## METHODS:

The faculty and graduate students on the user experience design team facilitated a series of focus group interviews, open and closed card sorts, and empathy mapping exercises to inform how the design of this website should be operationalized to address key unmet needs, pain points and aspirations of all four stakeholder groups. This kind of qualitatively rooted data gathering also ensured that key tasks could be fulfilled on behalf of each of them.

## RESULTS:

The interactions between the UXD team and the four stakeholder groups informed the iterative stages of development and design of a website prototype that was christened "C.H.I.L.D.," an acronym that signifies "Children's Health Information Links of Denton."

## DISCUSSION:

How might this digital system of care be sustained over time as a viable community resource?

# 04 PPI-DRIVEN DEVELOPMENT OF NOVEL DEVICES AND PROTOCOLS FOR THERAPEUTIC DRUG MONITORING IN PAEDIATRIC ONCOLOGY

Lisa Pfaffenrath<sup>1</sup>, Alaric Taylor<sup>2</sup>, Deirdre Leyden<sup>3</sup>, Jo Ball<sup>4</sup>, Neil Davidson<sup>4</sup>, Neil Ranasinghe<sup>5</sup>, Gareth Veal<sup>6</sup>, Stefan Guldin<sup>1</sup>

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## BACKGROUND:

ChromaDose is a NIHR (National Institute of Health Research) funded project that aims to develop a bedside drug monitoring technology, enabling children receiving anthracycline chemotherapy to benefit from the safety and effectiveness of a personalised approach to treatment.

## AIMS:

Public and Patient Involvement and Engagement is a core element of the project to provide feedback and advice on product development, sampling protocols and information materials.

## METHODS:

Various stakeholder groups are actively involved, including the Young Persons Advisory Groups (YPAGs) at Great Ormond Street Hospital (GOSH) and North England (NE) and the Paediatric Oncology Reference Team (PORT). Herein, we are presenting the outcomes obtained during the initial phase of the 30-month project. A plain English summary was co-created during the project planning stage with over 60 participants in an iterative consultation process. Pre-award engagement was conducted online with both YPAG NE and YPAG GOSH via an interactive questionnaire with embedded videos. Live sessions were subsequently carried out with the aim to consult the groups for the correct interpretation of the results and deepen the findings for implementation in the project. Participants were shown the raw data of the pre-award questionnaire. A parallel form of consultation through online surveys and interactive workshops was conducted with the parents recruited through PORT and Parent and Carer Advisory Group at GOSH.

## RESULTS:

Example hypotheses included discrepancies between patients and siblings in their willingness to provide additional blood tests for TDM and the participant's trust in an automated technology.

## DISCUSSION:

In the future, online and in-person sessions are planned on improving the end-beneficiary experience with a particular focus on co-creation of patient information resources and device design. Outreach events are also in planning to raise awareness of the capability of TDM and to highlight our approach of co-creation in product development.

# 05 PARTICIPATORY DESIGN OF A COMMUNICATION AID FOR PEDIATRIC EMERGENCIES: LEARNING FROM MIGRANT PATIENTS AND NURSES

Kerstin Denecke, Frederike J.S. Thilo, Loraine Olalia, Anouk Haldemann, Beatrice Kaufmann

Bern University of Applied Sciences, Bern, Switzerland.

## BACKGROUND:

Language barriers are the most common obstacles to emergency care for migrant children and young people, seriously impacting on patient safety. Understandable communication in care is therefore essential for safe, high-quality and equitable healthcare.

## AIMS:

The aim of this work was to develop an image-based digital communication aid to support non-verbal communication in pediatric emergencies.

## METHODS:

The tool was developed in a participatory design process involving potential users (pediatric emergency nurses, migrant children, and parents) and an interdisciplinary team of researchers from communication design, nursing research and medical informatics. Requirements were collected through interviews and questionnaires shared with nurses. During the entire development process feedback from all stakeholders was collected. The final prototype was evaluated regarding usability in role plays between nurses and migrant parents.

## RESULTS:

Based on the collected requirements, we designed a mock-up for our communication aid. In several iterations and in strong collaboration with nurses, it was improved until a version was implemented as functional prototype. The images that make the most important part of the tool have been created by the design researchers. Images are grouped along 10 relevant categories and can be displayed during triage by nurses, migrant children, and parents. Understandability of the images was tested in an online survey with 22 individuals (11 parents, 4 children, 7 nurses). 10 images were not recognized and were improved with user feedback. The role plays demonstrated that the tool is easy to use and can be well exploited to support emergency communication.

## DISCUSSION:

Comprehensive involvement of users throughout the development process helped us to learn about image understandability and develop an image-based communication tool that is perceived useful. We recognized that many aspects can be communicated using images, however, there are limitations in purely image-based communication.

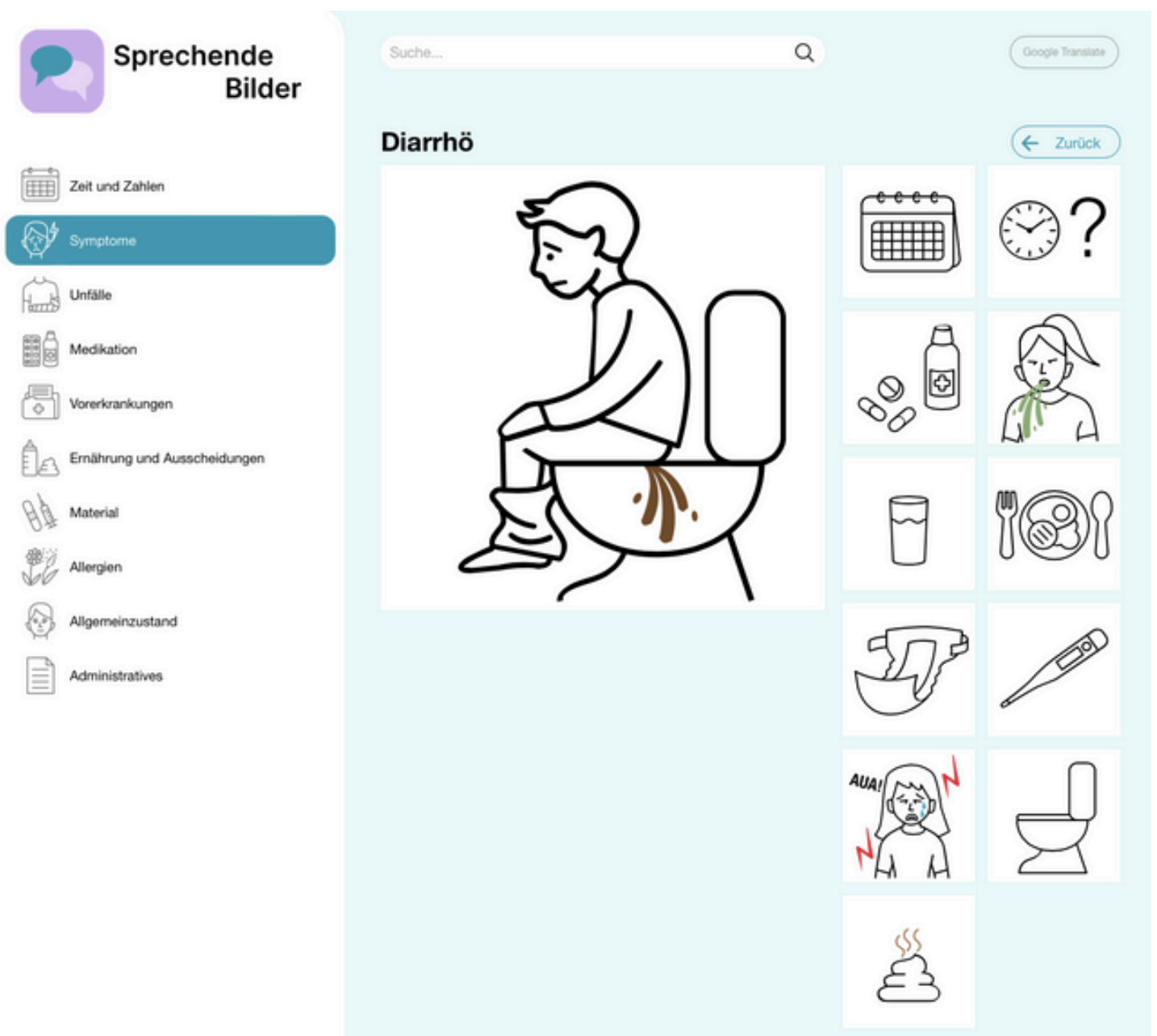


Figure: The image referring to diarrhea has been selected from the list of categories. Related images are shown.

# 06 NON-CONTACT NEONATAL MONITORING AND RESPIRATORY RATE MEASUREMENT USING A 3D CAMERA

Alex Grafton<sup>1</sup>, Oliver Bonner<sup>1</sup>, Lynn Thomson<sup>1,2</sup>, Joan Lasenby<sup>1</sup>, Kathryn Beardsall<sup>1,2</sup>

<sup>1</sup>University of Cambridge, Cambridge, UK. <sup>2</sup>Cambridge University Hospitals NHS Trust, Cambridge, UK.

## BACKGROUND:

Babies in the neonatal intensive care unit (NICU) require continuous monitoring, including vital sign measurement and subjective detection of changes in behaviour. Current vital sign monitoring uses adhesive sensors which can be damaging to the friable skin of pre-term neonates. Additionally, behavioural changes can be missed due to busy staff caring for multiple babies. We have designed an intelligent, camera-based, continuous monitoring system, using a camera that 'sees' in 3D.

## AIM:

To collect proof-of-principle data from babies in the NICU, demonstrating the potential of a camera-based monitoring system and its ability to measure respiratory rate.

## METHODS:

Up to one hour of 3D video and patient monitor data was recorded from infants (n=24) in a single-centre study at the NICU at Cambridge University Hospitals. Infants in cots and incubators, in various poses and clinical conditions (e.g. ventilation) were included. Suitable regions on the infant where respiratory motion is visible were identified to produce a respiratory waveform comparable to that captured by the patient monitor. The monitor's proprietary respiratory rate algorithm was replicated and applied to our camera-derived waveform.

## RESULTS:

Our dataset contains 23 hours of 3D video and patient monitor data, the largest dataset of its kind. Our preliminary respiratory rate algorithm measures within five breaths per minute of the patient monitor's reading over 80% of the recording, excluding unreliable patient monitor data. A comparison between these measurements over a one-hour period is shown in Figure 1.

## DISCUSSION:

The camera-derived respiratory rate is well-matched to the clinical monitor rate. Erroneous readings occur in both our measurement and the clinical measurement when the infant is moving. We will continue to develop the respiratory rate algorithm and exploit the huge potential of this dataset to develop activity monitoring algorithms.

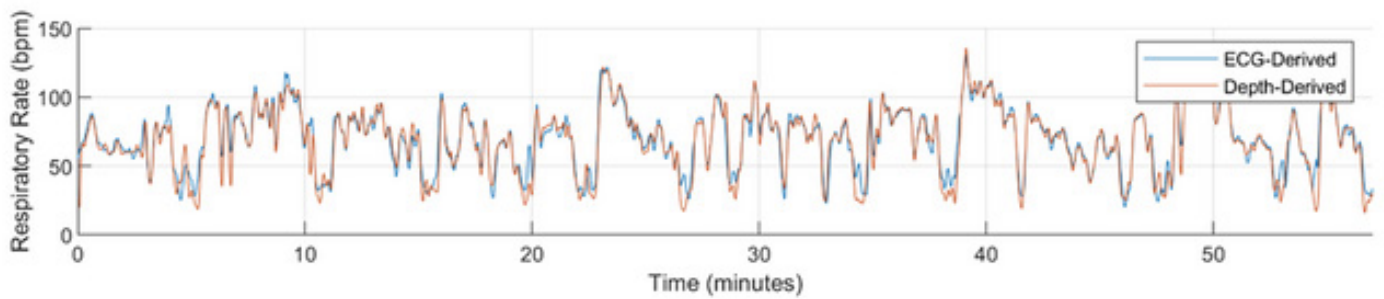


Figure 1: Respiratory rate from patient monitor (ECG-derived) and camera (depth-derived).

# 07 CHATBOT FOR FACILITATING FAMILY CONVERSATIONS ABOUT GENETIC RISK

Susan Wakefield<sup>1</sup>, Richard Moore<sup>1</sup>, Alison Metcalfe<sup>2</sup>, Gemma Wheeler<sup>3, 4</sup>, Paul Dimitri<sup>3, 4</sup>

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## BACKGROUND:

Autosomal dominant polycystic kidney disease (ADPKD) is an adult-onset genetic condition. The severity of disease can often be delayed using prophylactic anti-hypertensive medication. However, before young people start anti-hypertensive medication they need to be educated about ADPKD, which many parents find difficult. Parents are concerned about their child's and their own emotional reaction. We have previously designed therapeutic interventions to facilitate this conversation about genetic risk. Our plan now was to test whether we can design a chatbot to prepare parents and support them in discussing ADPKD using natural language and therapeutic questioning techniques.

## AIM:

To co-design of a prototype chatbot to support parents in explaining the risks from ADPKD with their children and managing their own and their children's' emotional reactions.

## METHODS:

We used modified Experience Based Co-Design (EBCD) principles to design a prototype therapeutic chatbot with families (parents and young people aged 13-17years). This process included refining the problem before designing and testing two prototype modules delivered via a chatbot. The chatbot's unique feature is that it attempted to facilitate a conversation between family members rather than share or gather pre-scripted information.

## RESULTS:

Our initial findings from interviews with five families showed they were interested and positive about the idea of the chatbot. Families were interested in the Chatbots potential role in providing information about ADPKD, sharing other families' experiences and its potential applicability to other health contexts. The concerns families raised were about the suitability for a range of ages and its adaptability to different families' dynamics and communication styles.

## DISCUSSION:

The work is in the final stage, with workshops underway for the families to feedback about the two prototype modules that we designed to test the family experience of using this type of therapeutic chatbot, which moves beyond simply sharing information.



# 08 AN END-TO-END REAL-TIME SITUATION AWARENESS SOLUTION FOR IN-PATIENT DETERIORATION FOR CHILDREN IN HOSPITAL: DETECT STUDY

Gerri Sefton<sup>1</sup>, Bernie Carter<sup>2</sup>, Dr Chin-Kien Eyton Chong<sup>1</sup>, Steven Lane<sup>3</sup>, Fulya Mehta<sup>1</sup>, Sarah Siner<sup>1</sup>, Caroline Lambert<sup>1</sup>, Dawn Jones<sup>1</sup>, Holly Saron<sup>4</sup>, Sarah Dee<sup>1</sup>, Hannah Hughes<sup>1</sup>, Jenny Preston<sup>1</sup>, Matthew Peak<sup>1</sup>, Enitan D. Carrol<sup>5</sup>

<sup>1</sup>Alder Hey Children's NHS Foundation Trust, Liverpool, UK. <sup>2</sup>Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, UK. <sup>3</sup>Institute of Translational Medicine, University of Liverpool, Liverpool, UK. <sup>4</sup>Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, UK. <sup>5</sup>Institute of Infection, Veterinary and Ecological Sciences, University of Liverpool, Liverpool, UK.

## BACKGROUND & AIMS:

Smart technology to provide real-time situation awareness about evolving in-patient deterioration in adults, have been used for more than fifteen years. Development of similar technology for use in children was hampered by the cost and complexity of developing evidence-based age-specific risk models. Having established proof-of-concept of a paediatric prototype, a whole hospital mixed-method study was implemented to establish the clinical effectiveness, cost effectiveness and clinical utility of the technology.

## METHODS:

This bespoke development was delivered using the Careflow Vitals and Connect platforms (System C), incorporating the Alder Hey age-specific Paediatric Early Warning score (PEWS) and modified NICE pro-active screening for signs of sepsis. Deployment on Apple devices occurred across ten wards (240 beds). Automated alerts were set for high PEWS, critical PEWS or new sepsis concerns. Compliance with a chain of deterioration prevention was tracked. Quality improvement methodology supported the implementation.

## Results:

Rapid whole hospital culture change occurred, affecting all areas of clinical areas. The software captured key data, but there was a significant organisational requirement for real-time oversight to ensure compliance. Technology use was mandated for the ward teams and compliance was easier to attain in that established workforce. Sustaining change was more challenging with junior medical staff working in clinical teams due to rotational placements. Additional challenges associated with the COVID pandemic altered the way of working due to staffing pressures and some remote working.

## DISCUSSION:

The system effectiveness of the end-to-end deterioration solution relies on high levels of compliance from nursing and medical teams, which has required ongoing project management and clinical presence to sustain. However real-time data provided opportunity to optimise clinical care delivery to improve organisational safety.

# 09 “MOVING ON ASTHMA”, AN EDUCATIONAL VIDEO RESOURCE FOR YOUNG PEOPLE WITH ASTHMA

Moira Gibbons, Nicki Barker, Nichola Butler, Heather Elphick

Sheffield Children's Hospital NHS Foundation Trust, Sheffield, UK.

## BACKGROUND:

The National Review into Asthma Deaths found potentially avoidable factors in 65% deaths, including inadequate information, education and advice on managing asthma. However, there are no nationally endorsed educational resources for children and families to address this. The team has produced Moving On Asthma (MOA), video-based materials for young people.

## AIMS:

- To assess the impact on young people's knowledge;
- To understand how the resources would be used within a tertiary setting;
- To assess professional perceptions of the material.

## METHODS:

Young people were approached in respiratory clinics at Sheffield Children's Hospital. Four pieces of educational content addressing asthma knowledge were selected from the resource. A self-assessment questionnaire was completed before and after watching the videos. A consultation with healthcare professionals occurred virtually via Microsoft Teams and feedback was obtained interactively using SmartSurvey.

## RESULTS:

Mean knowledge scores amongst the 12 young people interviewed increased from 5.6/10 to 7.8/10 after exposure to the educational material (0 = poor perception of knowledge, 10 = very good). Of 23 professionals, 87.5% would include the website link in the patient's clinic letter, 31.2% would share it by text, 37.5% by email and 87.5% would give out written material in clinic. 82.4% would discuss the resources after the clinic consultation, 5.8% by creating a break within the consultation, 41.2% would direct patient to it in the waiting room, and 47.1% within the consultation itself. Mean scores for knowledge and depth: 5.9/10 (0= not enough, 5= just right 10 = too much); presentation and delivery: 7.2 (0= very poor and 10 = very good).

## DISCUSSION:

The feedback obtained confirmed the potential of the MOA educational materials to increase patient knowledge. Ultimately it is believed that MOA will result in improved outcomes for children with asthma including fewer symptoms, ED attendances and hospitalisations.

## ACKNOWLEDGEMENTS:

Innovate UK, NIHR CYP-Medtech, makebetter.studio, Websites by Lucy, Asthma UK.

# 10 HYPO-CHEAT: IMPROVING THE EFFICACY, COST AND GLOBAL SCOPE OF CGM FOR HYPOGLYCAEMIA PREVENTION

Chris Worth<sup>1,2</sup>, Paul Nutter<sup>2</sup>, Mark Dunne<sup>3</sup>, Maria Salomon-Estebanez<sup>1</sup>, Simon Harper<sup>2</sup>, Indraneel Banerjee<sup>1,3</sup>

<sup>1</sup>Dept Paediatric Endocrinology, Royal Manchester Children's Hospital, Manchester, UK. <sup>2</sup>Dept Computer Science, University of Manchester, Manchester, UK. <sup>3</sup>Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK.

## BACKGROUND AND AIMS:

Hypoglycaemia is a life-threatening risk for many patients and prevention is complex. Continuous glucose monitoring (CGM) and Machine Learning are increasingly used in prevention techniques but fail to recognise the value of human behaviour in glycaemic control. Long term CGM is also simply too expensive for the majority of patients globally. Children with congenital hyperinsulinism (CHI) have recurrent and severe hypoglycaemia (hypos) and we have developed HYPO-CHEAT (HYpoglycaemia-Prevention-thrOugh-Cgm-HEatmap-Assisted-Technology) to reduce hypoglycaemia through targeted behaviour change without the need for ongoing CGM.

## METHODS:

HYPO-CHEAT provides completely novel aggregation of short term CGM data to generate personalised weekly heatmaps demonstrating the timing and severity of hypoglycaemia as well as offering individualised reflections for patients to target behaviour change and reduce hypos. Ten patients with CHI used a blinded CGM for four weeks (baseline assessment) and then unblinded for four weeks. Families then used HYPO-CHEAT and CGM was subsequently re-blinded for four weeks.

## RESULTS:

In the five patients with initial time below range (TBR) >1%, TBR improved from mean 7.1% to 4.5% when devices were unblinded. After using HYPO-CHEAT, families identified specific behaviours contributing to their hypoglycaemia "hotspots". Within targeted hotspots, families did 67% more fingerpricks than outside hotspots and reduced TBR by 67%, despite CGM re-blinding. Total TBR was 25% below baseline at 5.4%. For those without initial hypoglycaemia and thus no use for HYPO-CHEAT, TBR increased from 0.2% at baseline to 3.2% when reblinded, strengthening the association between using HYPO-CHEAT and a reduction in hypos.

## CONCLUSIONS:

HYPO-CHEAT's short-term (8 week) CGM-informed phenotyping and subsequent heatmap analysis and behaviour change reduces hypoglycaemia even when CGM is removed. HYPO-CHEAT offers a novel and immediately available way to effectively prevent hypoglycaemia while making significant cost savings, minimising family burden and empowering patient self-care.

# 11 PERSONALISED HEALTHCARE MONITORING PLATFORM FOR IMPROVING CARE-PATHWAYS & QOL OUTCOMES IN CHILDREN & YOUNG PEOPLE WITH DISABILITIES

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## BACKGROUND:

In the UK nearly 1.2 million children and their parents/carers face the challenge of managing their complex treatment and care pathway. For most this involves seeing a range of 15 to 20 different health and care professionals in multiple locations. Consequently, everyday their parents/carers and school staff are expected to carry out multiple therapies, medication, and treatment plans. More than 25% of parents are providing 100+ hours of care every week with lifetime cost of care ranging from £650k to £2.5 million. Their multidisciplinary professionals including Community paediatricians, Surgeons, Physiotherapists and OTs find care coordination, on-going monitoring, and proactive management extremely difficult particularly with huge caseloads of children with varying and complex needs.

## AIMS:

To validate the challenges experienced by parents/carers and their professionals and evaluate if a personal health and care monitoring platform would improve the care pathways and QOF outcomes in children with disabilities

## METHODS:

Qualitative exploratory and cross-sectional survey research involving semi-structured interviews

## RESULTS:

More than 95% of the research participants validated the problem hypothesis and 80% of the participants approved the solution hypothesis

## DISCUSSION:

Survey results using thematic analysis revealed that most parents/carers compared their care experience to a soldier constantly fighting a losing battle. The myriad of challenges experienced made it difficult to clearly articulate. The professionals, particularly those in the community care services are often made to support non-health related issues, regular monitoring of the compliance to their therapy plans was extremely difficult making proactive management impossible. Parents/Carers welcomed the idea of having a personal health app, a one-stop place to manage all the records, record health status and therapy compliance, and access relevant information. Interestingly, though professionals found the monitoring dashboard to be helpful in proactively managing their care plans, there was some scepticism with meeting the expectations of the parents/carers to swiftly respond to their queries.

# 12 ADOPTION OF REHABILITATION TECHNOLOGY: USING A PARTICIPATORY DESIGN TO IDENTIFY STENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS

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## BACKGROUND:

While virtual and augmented technologies have the potential to assist adults and children with disabilities, usage has not yet reached its full potential. Reasons are varied, including limitations in human resources and institutional infrastructure, high costs and skepticism and apprehension by children, family and clinicians.

## Aims:

To identify rehabilitation technology usage barriers and facilitators.

## METHODS:

The authors, experienced in clinical and research applications of rehabilitation technologies, moderated two focus groups with a total of 13 participants (clinicians, researchers and rehabilitation-technology developers and distributors). They independently conducted a thematic analysis from the transcripts. The themes were categorized via a SWOT analysis to identify the Strengths, Weaknesses, Opportunities and Threats related to current clinical applications of rehabilitation technology.

## RESULTS:

The SWOT themes (see table) were used to develop guidelines for successful incorporation of technology into four different levels. Highlights included: (1) at the Technology-Development Level, clinicians focused on (i) user-friendliness of the interface (very simple to operate and adjust for different patients), (ii) very short set-up time, (iii) importance of participatory design when developing technologies to prevent abandonment in the clinic; (2) at the Institutional Level, technology usage should be facilitated by dedicating (i) physical space in very close proximity to therapy rooms, (ii) information-technology personnel for timely technical support of devices; (3) at the Clinical-Team Level, (i) a team member should be appointed as the go-to person to advocate for day-to-day operation of technologies, (ii) incentives to promote technology usage (e.g., time to learn about new devices; at the Clinician-Patient Level, (i) identifying individuals who will benefit most from working with the technology, (ii) managing expectations is crucial to avoid disappointment and resentment and (iii) enabling both guided and independent usage of technology.

## DISCUSSION:

The implications of implementing these guidelines will be discussed within the context of current health care models.

**Table: SWOT analysis of facilitators and barriers to the adoption of rehabilitation technologies**

Strengths		Weaknesses	
<ul style="list-style-type: none"> <li>• Prestige value in clinic being associated with advanced technologies</li> <li>• Literature supports use of technology</li> <li>• Provides objective documentation of performance and results</li> </ul>	<ul style="list-style-type: none"> <li>• Current technologies are not robust or user friendly enough</li> <li>• Robotic technologies represent a greater technology challenge</li> <li>• Difficulty in matching technology to patient's abilities; often personalization is not available</li> <li>• Some technologies require time and skills at a higher level</li> <li>• Turn-over of trained clinicians</li> <li>• Inconvenient physical location of technology</li> </ul>	<ul style="list-style-type: none"> <li>• Increase treatment time</li> <li>• Technology can be an additional therapeutic tool</li> <li>• When used together with gamification, it can increase motivation and participation</li> <li>• Treatment can be much more varied</li> <li>• Client can be more independent in therapeutic process</li> <li>• Provides options that not available during conventional treatment</li> <li>• Potential to achieve more effective/efficient therapy</li> <li>• Technology can be used as priming be followed up by conventional tools</li> <li>• Possibility of using more than one technology at a time can be powerful</li> <li>• Quantitative outcome measures.</li> <li>• More positive image of disability</li> </ul>	<ul style="list-style-type: none"> <li>• Personal characteristics and attitudes of clinicians</li> <li>• Fear of abandonment of the patient by the clinician</li> <li>• Patients need a certain cognitive level to be able to use technology</li> <li>• Need for extra time for technology setup</li> <li>• Technology should not be used just as a game without sufficiently taking advantage of its full rehabilitation potential (e.g., provision of meaningful feedback)</li> </ul>
Opportunities		Threats	
<ul style="list-style-type: none"> <li>• Select and train few therapists to support rest of team</li> <li>• Define and promote role of administration in supporting technology usage</li> <li>• Work with technology developers as design team partners</li> <li>• Greater technology support at all levels leads to more willingness to use technology: 1. incentives, 2. Training, 3. Encourage demand by patients</li> <li>• Recognize that not all technology is suitable for use by all therapists for all patients.</li> <li>• Recognize other specializations that can perhaps support OTs and PTs when using technology</li> <li>• Technology should not usurp therapy</li> <li>• Optimal timing of training to clinician on device usage (should be close to when used clinically)</li> <li>• Promote more focus on technology in academic courses</li> <li>• Encourage developers to make applications as functional as possible</li> </ul>	<ul style="list-style-type: none"> <li>• Therapist "burn out" attitudes: "Been there, done that"</li> <li>• Trade-off between the time to reach the location where technology is located and/or set it up and the actual time left for therapy</li> <li>• Lack of clarity of what device contributes to therapy</li> <li>• Timing and circumstances of training in device usage is essential</li> <li>• Risk to patients if technologies used unsafely</li> <li>• Physical location of technology may not sufficiently support device usage</li> <li>• Technology adoption is a process that needs time to accommodate</li> <li>• Cost of technology is still very high</li> </ul>		

Figure: SWOT analysis of facilitators and barriers to the adoption of rehabilitation technologies.

# 13 USING MACHINE LEARNING TO PREDICT THE RISK OF CHILDREN NOT BEING BROUGHT TO BOOKED APPOINTMENT

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## BACKGROUND:

One in 20 outpatient appointments in England were not attended, estimated to cost around £1 billion, and over 15% of the missed appointments were in those less than 19 years. Developing a risk-predictive Machine Learning algorithm that can predict which patients are most likely to miss their appointments could save the NHS billions of pounds.

## AIM:

To predict the risk of paediatric patients in an Orthopaedic Department not attending individual outpatient appointments (labelled as Was-Not-Brought).

## METHODS:

We used longitudinal data from linked electronic health records retrieved from Orthopaedic Department in Alder Hey Children's Hospital between 2018 and 2021. The patient cohort was divided into 80% training and 20% validation groups using the stratified random sampling technique to ensure original class distribution is maintained. Class imbalance in the data was addressed using One-Sided Selection with Random undersampling technique. Internal validation was carried out on the 20% validation set using 5-fold cross-validation, and external validation was carried out on a whole month worth of never-seen dataset (n=1,789) that was not used for modelling.

## RESULTS:

A total of 86,188 appointments were evaluated and 10,527 (12%) of these were Was-Not-Brought (WNB) cases. Sixteen important features were selected from the 52 possible risk-factors considered, including social determinants of health such as patient demographics and distance from healthcare provider. Catboost was the best algorithm from the list and produced an ROC-AUC score of 78% on internal validation and 80% ROC-AUC when evaluated using the unseen dataset, and the top three risk factors were distance from healthcare provider, history of previous WNB and elapsed time since booking the appointment.

## DISCUSSION:

Modelling of scheduled outpatient appointments from a large standalone Children's Hospital demonstrates that factors responsible for WNB episodes in paediatric patients are multifactorial and therefore requires high-dimensional modelling. Targeted intervention of high-risk patients could ensure that hospital resources are maximised and are equitable.



# 14 CO-CREATING INNOVATIVE ANIMATIONS TO COMMUNICATE CHILD HEALTH SERVICES TO FAMILIES AND PROVIDERS

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## BACKGROUND:

Navigating care options for children with disability can be challenging and clear and encouraging communication of available services for supporting their emotional, social and physical development is lacking. To address this problem, a university research team co-created two animations related to National Disability support for children and their families in collaboration with an Australian government organisation.

## AIMS:

The aim was to explain the complex service structure of six collaborating health care providers to families across diverse cultural backgrounds. A secondary aim was to create a shared vision and brand for this new network.

## METHODS:

A co-creative process combined; (i) three co-design workshops (script, storyboard and animatic) with the health organisation (18 members) for content, story generation, character design and voice selection, (ii) four site visits to learn about the services depicted in the animations, (iii) questions administered by the health teams to clients and staff regarding their experiences (survey/interview, 16 participants), and (iv) a post-completion evaluation with diverse clients represented by characters.

## RESULTS:

Research identified parents' concerns about their children's wellbeing and showcased possible results of early intervention through success stories as priorities. We took personalities and story traits from the interview data and amalgamated them into a "down to earth" story with real dialogue to emphasise the benefits of the services in an accessible manner. Families reported the visual language made the information friendly, engaging and meaningful.

## DISCUSSION:

The animation was accepted by all organisations as authentic representation of their complex joint service offerings. The multi-staged process leading to this communication design outcome can be described as best practice for co-creation. Finally, staff reported that including clients in the process had a marked, positive effect in clients communicating their appreciation of the service.

Design Brief and Strategy
<b>THE DESIGN TASK</b>
Develop a script, illustrate a series of bespoke characters and animate as well as sound design.
<b>THE GOAL</b>
To explain the various service touchpoints with a focus on the clients' perspective, e.g. the family's needs and goals.
<b>THE MESSAGE</b>
Keep it simple and to the key messages. It was decided that in some instances the animation has to 'show' and not 'tell' "our story". The animation needed to adhere to health literacy guidelines.
<b>THE TONE</b>
The reference group felt that the tone of the animation should not be overly emotive. The families in these situations are already under stress so they wanted the animation to be upbeat and practical. The goal being there are accessible options that can help to find answers and move forward in practical ways.
<b>THE CHARACTERS</b>
Include diverse people and try to position the brand as being accessible for everyone.
<b>THE SOUND</b>
Voice overs were specified as well as background music, songs and sound where selected.

Table 1: Design Strategy



Figure 1: Animation

For families: <https://accesshc.org.au/services/introduction-child-family-services/>  
 For industry: <https://www.idesignawards.com/winners/zoom.php?eid=9-39944-21>

# 15 DEVELOPMENT AND CONTROL OF A ROBOTIC SIMULATOR FOR PERISTALTIC MOTION

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## BACKGROUND:

Medical robotics is seeing fast-paced progress, providing efficient therapies and reducing patient trauma. Many of these technologies feature novel designs, smart materials and complex control to match the dynamic conditions of the treated disease. It is thus important to also develop testing platforms which can exhibit realistic biological conditions to extensively optimise and validate these novel technologies towards their progression to the clinic.

## AIM:

This paper introduces a novel simulator that replicates the peristaltic motion of the gastrointestinal(GI) tract to enhance the optimisation and testing of invivo medical robots(IMR).

## METHODS:

The simulator is composed of aligned plates which can be individually indented by DC motors to create a linear peristaltic wave. A soft phantom GI tubular organ was developed and encapsulated in-between the simulator and an observation panel. The actuators provides a one-dimensional wave of contractions along which it deforms the phantom organ.

## RESULTS:

Wave amplitude, length and velocity were varied and quantified. The resultant motion was model-matched to patient data. By comparing the obtained results to data of a patient swallowing water, the following equation of the peristaltic wave was derived.

$$r(x,t) = r_0 + 0.2\sin[2\pi/16(x-0.06t)]$$

## DISCUSSION:

The mean relative error indicates a similarity of 79.9% between invivo data and experimental results, showing promise as a baseline for future peristaltic simulators. However, the current simulator is restricted to uni-axial contractions and to be addressed in future work. We envisage this simulator to aid the evaluation of future IMR and minimise the number of animal trials.

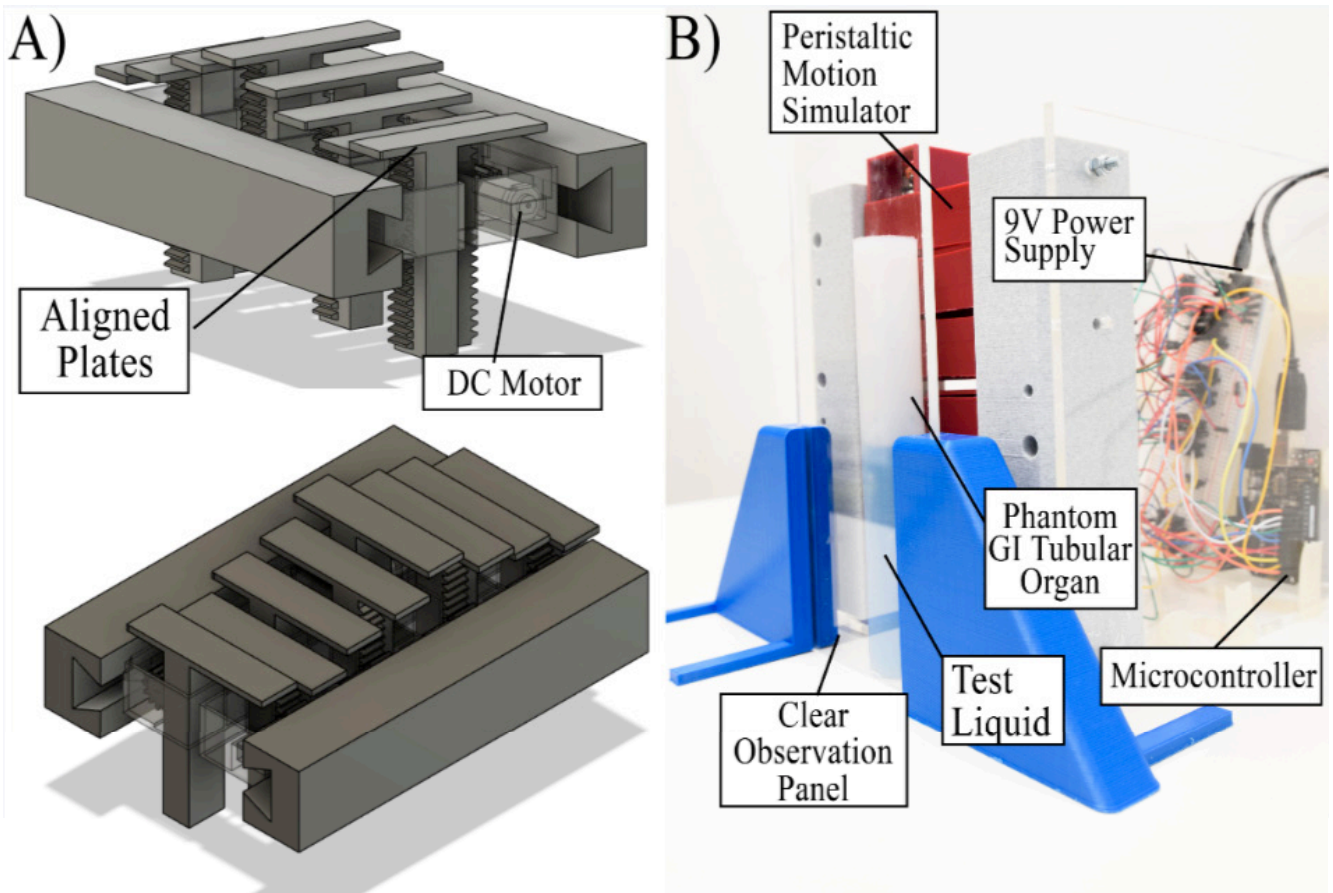


Fig.1. A)Computer Aided Design of the simulator showing the motion (horizontal view) B) Experimental setup of the simulator (in red) with the phantom organ with test liquid and an observation panel. C)Vertical bolus displacement of a test sample in a model-matched simulator overlaid with patient data.

# 16 CO-DEVELOPING A TEXT MESSAGE-BASED BEDTIME ROUTINES INTERVENTION FOR FAMILIES WITH YOUNG CHILDREN

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## BACKGROUND:

Bedtime routines are the most common family activity encompassing a wide range of behaviours starting the hour before bed. Optimal bedtime routines can lead to benefits for children's wellbeing and development and benefit parents too. The purpose of this study was to co-develop and test a novel bedtime routines intervention using text messages with first-time parents with young children.

## METHODS:

A stepped, user-inclusive, co-design and co-development approach was undertaken. Firstly, N=30 parents were interviewed to explore common barriers in achieving optimal bedtime routines. Then, a group of 12 parents participated in the co-design and co-development workshops where all aspects of the intervention were discussed and finalised. Finally, N=50 families received the text message intervention for 7-consecutive nights. Parents completed pre- and post-intervention questionnaires on children's sleep, quality of bedtime routines and parental mood. Feedback was provided at the end of the study too.

## RESULTS:

High recruitment target and high retention with 98%, or 49 out of 50 participants completing the study were achieved. Pre- and post-intervention, there were improvements in total children's sleep with children sleeping longer and having less disrupted sleep overall (MD = -7.77 (SD= 17.91),  $t(48)=-3.03$ ,  $p=.004$ , CI (-12.91, -2.63) and in overall quality of bedtime routines (MD=-5.00, SD=7.01,  $t(48)=-4.98$ ,  $p<.001$ , CI (-7.01, -2.98). Parental mood disturbance decreased pre to post intervention (MD= 5.87, SD=15.43,  $t(48)=2.66$ ),  $p=.010$ , CI (1.44, 10.30) ). Parents provided positive feedback about the intervention and valued the support that was provided to them.

## DISCUSSION:

The co-development and co-production of the intervention played a major role in the successful pilot. With positive preliminary results and positive participant feedback there is a need to explore the (long term) effects of the intervention in a larger, longitudinal, controlled study.



# 17 BRIDGING THE VIRTUAL DIVIDE: CO-DESIGNING TECHNOLOGICAL INNOVATIONS WITH THE JUVENILE IDIOPATHIC ARTHRITIS (JIA) POPULATION

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## BACKGROUND:

Involving people with lived experience when designing technological interventions is known to lead to better outcomes and implementation. COVID-19 presents challenges to this involvement, due to the inability to have in-person workshops. Digital platforms are therefore often used as an alternative. However, the reality of the virtual space is very different: participants can feel put on the spot, those more introverted, retreat and those more outspoken, dominate. This can result in design solutions that do not address the unmet needs of a wider patient population.

## AIMS:

This study aims to explore how best to engage Children and Young People (CYP) in designing technological interventions for the JIA population, when in-person methods aren't appropriate. The methods used need to go beyond purely online activities, incorporating 3D formats to enable deeper insights.

## METHODS:

Planned methods include a series of three online workshops with CYP with JIA and their parents. Families will be sent making materials in advance, then CYP and the researcher will make 'ideal' versions of the devices together over Zoom, utilising the act of prototyping as a vehicle for deeper discussion.

## RESULTS:

This research is ongoing but results are expected in early Spring 2022. The co-designed devices will be trialled in late 2022.

## DISCUSSION:

The COVID-19 default of purely digital user involvement can be problematic, particularly for CYP. A hybrid approach, combining elements of in-person and digital is the ideal - facilitating creativity, ensuring a productive process and resulting in stronger technological interventions. There are strengths in the digital, but researchers need to be aware of the barriers and adapt accordingly to enable equal collaboration, such as using prototypes to bridge the virtual divide. This conference presentation will focus on sharing approaches and techniques to enable an effective co-design process for developing technological interventions with CYP during and post-pandemic.

# 18 ASSESSING AN AUGMENTED REALITY LOW VISUAL AID IN CHILDREN AND YOUNG PEOPLE WITH VISUAL IMPAIRMENT

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## BACKGROUND:

The Royal National Institute of Blind People (RNIB) calculate there to be 24,500 children and young people (CYP) in England with a moderate or severe visual impairment (VI). These children currently have access to traditional low vision aids such as magnifiers and binoculars. However these aids have limited functionality, as they are typically hand held or placed directly over text, making them unsuitable for activities such as learning a musical instrument or socialising with friends and family. There is a need for these children to have access to innovative low vision aids to improve their independence, access to education and quality of life (QoL).

## AIMS:

This study aims to assess the impact of a head-mounted augmented reality low vision aid (SightPlus) on vision and QoL in CYP aged 8-16 years with moderate or severe VI (6/18-3/60). This project follows a pilot study from 2017 and is the first in the UK to assess the functionality, usability and acceptability of SightPlus in a paediatric population.

## METHODS:

This study has a longitudinal repeated-measures design, comprising two study visits and a four-week trial of SightPlus. The participants were asked to keep a home diary documenting their experiences of trialling SightPlus. Their clinical and functional vision was assessed both with and without the aid of the device and age appropriate vision-related QoL questionnaires were completed at the beginning and end of the study period.

## RESULTS:

Based on previous work the predictions for the study are that use of SightPlus will significantly improve clinical and functional measures of vision as well as vision-related QoL in CYP aged 8 - 16 years with moderate to severe VI.

## DISCUSSION:

This study will provide a real insight into how low vision aids can have a potential impact on visual function and vision-related QoL of CYP with VI.



# 19 PHOTOVOICE AS A CO-DESIGN TOOL: EXPLORING THE LIVED EXPERIENCE OF MANAGING TYPE 1 DIABETES

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## BACKGROUND:

Emerging adulthood, defined by its instability and increasing independence (Arnett, 2000), can clash with the needs of self-management making it difficult to both have control over one's diabetes and/or to fully participate in society. This can cause distress for emerging adults caught between health and social pressures, leading to guilt, fear and isolation. To address this challenge, research is being undertaken to co-design and test a self-management intervention to support emerging adults with type 1 diabetes.

## METHODOLOGY:

Photovoice as a method is of growing interest in health and health education for its ability to gain and illustrate an extensive understanding of unique and challenging lived experience (Wang & Minkler, 2010). It has been used both within communities of diabetics (Fritz, 2015; Scavarda et al., 2021) and young adults (Mahalingam & Rabelo, 2019; Shea et al., 2013; Wang, 2006).

Over the course of a week, 5 participants (aged 18-25 with type 1 diabetes) took and narrated photographs that illustrated challenges faced self-managing their diabetes. The data collected was co-analysed with the participants through a 3-hour online workshop making use of the online tool Miro.

## RESULTS:

The photographs were co-curated into a map of participant's emotional experiences and self-management practices. The results highlight common feelings and experiences as well as barriers and catalysts to self-management.

## DISCUSSION:

The results will inform a series of co-design workshops and specification of a targeted self-management intervention for young type 1 diabetics.

The use of photovoice, as the first stage of a co-design approach, provided an engaging experience as well as nuanced and in-depth understanding of the lived experiences of managing a chronic health condition. This understanding will inform subsequent design practice and be shared with a wider public audience through a curated exhibition.

# 20 MEDICAL STUDENTS AND DOCTORS NEED IMPROVED DIGITAL HEALTH EDUCATION, TRAINING AND SUPPORT

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## BACKGROUND:

Thousands of health apps exist; the majority not reaching NHS quality standards. A vast increase in health app downloads was seen during COVID-19 pandemic. Patients need direction towards quality, safe, health apps appropriate to their age, understanding, and health condition. Doctors need digitally literacy skills to identify apps, understand risks/benefits and maximise digital care potential particularly during COVID-recovery and extended waiting lists.

## AIM:

The aim was to understand digital health experience, training and education of medical students and consultant paediatricians.

## METHODS:

32 medical students and 20 NHS consultant paediatricians in one teaching hospital, were surveyed about their experience and use of health apps and digital health education/ training.

## RESULTS:

Most medical students (66%) had not observed any doctors recommending any health apps to patients. 33% of consultant paediatricians report having recommended an app to a patient.

90% students and 3/4 of paediatricians were unsure/did not know how or where to find trusted medical apps.

Despite little experience of digital health, 90% medical students rated it a highly important topic.

Paediatricians report they would be most likely to recommend an app if it was on a list recommended by the Royal College of Paediatrics or recommended by their own hospital (less so if recommended by another hospital). Doctors reported wanting to check an app themselves, read research and discuss with colleagues before recommending to a patient. Medical students based opinions on the star-rating review (70%).

80% doctors felt that if they were more familiar with using health apps themselves, it would help to understand what might be useful for patients.

## DISCUSSION:

Digital health education urgently needs including in the medical student curriculum and staff training in-line with the 'digital first' agenda and NHS long-term-plan. A Royal College or local Hospital App Library is likely to be most valuable to students and doctors, with forums to share professional opinions.

# 21 SHOULD WE USE SUMMARY CARE RECORDS TO ACCESS VACCINATION DATA IN THE PAEDIATRIC EMERGENCY DEPARTMENT?

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## BACKGROUND:

Vaccines save millions of lives globally each year. However, UK uptake of vaccines such as MMR remains below target. Annually in England, millions of children and young people (CYP, aged < 16) go to hospital. This attendance offers a chance to improve health more broadly, especially for those who experience greater inequalities e.g. difficulty accessing routine childhood immunisation. To offer a vaccination intervention, however, we need to be able to identify those who are under-immunised.

## AIMS:

This work is part of a larger project looking at sources of vaccination data during a Paediatric Emergency Department (PED) attendance, with a view to offering an intervention to under-immunised CYP. The aim of the component of work presented here was to explore the vaccination data available to PED-based clinicians via the community-based Summary Care Record (SCR).

## METHODS:

Full ethical approval was obtained and data collected from the SCRs of individuals visiting a single PED in Greater Manchester. Alongside extraction of vaccination data, detailed notes were made on data issues for the first 200 participants.

## RESULTS:

Approximately 1 in 10 SCRs either didn't load fully or contained limited/no information. Within SCRs, data were unstructured and there was variability in how the data were coded e.g. children the same age might have 11 records (listed by vaccine) or 48 (listed by disease). There were also some obvious errors e.g. administration of too many doses of a vaccine. Whilst it was relatively simple to look for the presence (or absence) of a single vaccine (if the SCR loaded in full) it was virtually impossible to assess if a child was under-immunised overall.

## DISCUSSION:

It is not currently possible to easily and routinely identify under-immunised CYP using SCRs alone, but they may be a useful source for checking protection against an individual disease e.g. tetanus.

# 22 FEASIBILITY OF FACIAL EXPRESSION ANALYSIS AS AN OBJECTIVE PALATABILITY ASSESSMENT OF PAEDIATRIC MEDICINE

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<sup>1</sup>Aparito, Wrexham, UK. <sup>2</sup>University College London, London, UK.

## BACKGROUND:

Palatability of drug formulations is an important factor to consider when developing paediatric medicines, as it has a strong impact on treatment adherence and clinical outcomes. Videos captured in the home setting, to assess palatability, elicit more natural behaviour with minimal burden for study participants.

## AIMS:

We look at the feasibility of analysing facial expressions using pose-estimation software to explore how facial points move in response to children's reactions to different appetitive and non-appetitive tastes.

## METHODS:

Children aged 5 – 11 years tasted four different, flavoured strips: no taste (control), bitter, sweet and sour. (UCL REC 4612/029) Data was collected in a home setting under the supervision of a parent/guardian, with responses recorded using the Aparito Atom5™ app and smartphone camera. Participants reported a score for each strip, on a 5-point hedonic scale. Movement of facial points was analysed using pose-estimation software. Facial reactions classified with the software are compared to the self-reported scores and the strip's taste.

## RESULTS:

We received 215 videos and 252 self-reported scores from 64 participants. Nine videos were excluded from the analysis as they did not include the participant tasting the strip. Scoring using the 5-point hedonic scale elicited the expected results: children like sweetness (predominant score: 5), dislike bitterness (predominant score: 1) and have different opinions for sourness (various scores). The predominant score for the control strip was 3. Changes around the eyes, nose and mouth were seen in response to the tastes. The magnitude of reaction varied across participants, highlighting the utility of the control strip.

## DISCUSSION:

This approach to palatability assessments helps better assess children's taste specificities, making paediatric medicines safer and more acceptable. Being able to objectively measure non-verbal cues of how children feel about the taste of medicines has great potential in helping find the most acceptable product.

# 23 INVESTIGATING WALKING BALANCE AND FALLS IN CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY: PPIE REPORT

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## BACKGROUND:

Cerebral palsy (CP) is associated with problems with movement and posture that result in walking difficulty. Falls are a common complaint, which in adults negatively affects quality of life, self-confidence, and participation in daily activities. However, little is known about the impact of falls on the lives of children and young people with CP (CYPwCP) or whether instrumented measures of walking balance during gait analysis (GA) are predictive of fall frequency. A patient and public involvement and engagement (PPIE) project was designed to support the development of a research proposal to address this knowledge gap.

## AIMS:

- Confirm falls as a research priority for CYPwCP.
- Determine what term(s) should be used in future proposals.
- Explore experiences of falls and walking balance for CYPwCP.
- Explore the acceptability and utility of GA and wearable technology for CYPwCP.

## METHOD:

CYPwCP aged 12-18 years from one gait analysis service in the UK were invited to contribute. Two online workshops were designed to address the key objectives. Workshops consisted of structured discussions, practical activities, photographs shared by the contributors and live polls.

## RESULTS:

Six CYPwCP aged 13-17 years contributed and established 'walking balance' as an acceptable term. Falls and walking balance affected CYPwCP throughout their lives. Psychological (e.g. confidence), emotional (e.g. anxiety), environmental (e.g. cobbles) and social factors (e.g. expectations of others) were strongly linked to CYPwCP's experiences of falls and were key determinants of participation in activities of daily life. Four contributors reported previous use of biometric data to support functional goals.

## DISCUSSION:

The future research proposal will consider: how falls change with age; the impact of falls on participation and psychosocial wellbeing; how they relate to walking function; how walking balance behaves relative to energetics, fatigue and environmental factors; and how biometric health data is utilised by service users and clinicians alike.

## 24 PARENTS' EXPERIENCES OF THE ACCEPTABILITY OF AN ELECTRONIC PAEDIATRIC EARLY WARNING SYSTEM (THE DETECT STUDY)

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### BACKGROUND:

Failure to recognise and respond to clinical deterioration in a timely and effective manner is an urgent safety concern, driving the need for early identification systems to be embedded in the care of children in hospital. Paediatric early warning systems (PEWS) or PEW scores alert health professionals (HPs) to signs of deterioration, trigger a review and escalate care as needed. PEW scoring allows HPs to record a child's vital signs and other key data including parent concern.

### AIM:

This study aimed to explore the experiences and perceptions of parents about the acceptability of a newly implemented electronic surveillance system (the DETECT surveillance system), and the factors that influenced acceptability and their awareness around signs of clinical deterioration and raising concern.

### METHOD:

Descriptive, qualitative semi-structured telephone interviews were undertaken with parents of children who had experienced a critical deterioration event (CDE) (n=19) and parents of those who had not experienced a CDE (non-CDE parents) (n=17). Data were collected between February 2020 and February 2021.

### RESULTS:

Qualitative data were analysed using generic thematic analysis. Analysis revealed an overarching theme of trust as a key factor that underpinned all aspects of monitoring and recording children's vital signs. The main themes reflect three domains of parents' trust: trust in themselves, trust in the HPs, and trust in the technology.

### DISCUSSION:

Parents' experiences and perceptions of the acceptability of a whole-hospital, pro-active electronic paediatric early warning system (The DETECT system) were positive; they found it acceptable and welcomed the use of new technology to support the care of their child.

# 25 IMAGING BASED ASSESSMENT OF CHILDHOOD EYE INFLAMMATION: RESULTS OF A MULTI-CENTRE MIXED-METHODS STUDY

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## BACKGROUND:

Anterior uveitis is an inflammatory eye disorder which can cause blindness in childhood if untreated. Children at known risk (those >10,000 UK children with juvenile idiopathic arthritis) undergo hospital-based examinations with an eye specialist every 3-4 months to detect this often asymptomatic disorder. This standard test is subjective, and was developed for adult care. Anterior segment optical coherence tomography (OCT, currently being adopted across community opticians) is a non-contact, non-irradiating imaging tool. We describe the performance of AS-OCT in children with uveitis.

## METHODS:

A mixed-methods prospective study, using routine clinical examination as reference standard, and AS-OCT, with Tomey CASIA2 or Heidelberg Spectralis HS1, as index test, with data collected on patient perceptions of imaging. Repeatability, diagnostic indices, responsiveness to clinical change, and clinical correlations of imaging-based metrics (image cell count, size, density and brightness) were assessed, with construction of receiver operated characteristic (ROC) curves. Exploratory thematic analysis of responses from families was undertaken.

## RESULTS:

A total of 90 children (180 eyes) underwent imaging. CASIA2 imaging had higher sensitivity of 0.92 (95%CI 0.78 to 0.97) for detection of inflammation versus HS1 imaging 0.17 (95%CI 0.07 to 0.34), with positive correlation between clinical grade and CASIA2 cell count (coefficient 12.8,  $p=0.02$ , 95%CI 2.2 to 23.4). Change in clinical grade at follow up examinations correlated with change in image based 'cell' count ( $r=0.79$ ,  $p<0.001$ ). Patients reported positive impact of seeing their disease activity ("people could...look and see what is happening with their eyes"), and positive perceptions of potential standardisation of care and community based assessments.

## CONCLUSION:

Our findings suggest that OCT based imaging holds the promise of improved patient experience, and more granular monitoring of activity with resultant improved outcomes. Performance differs across imaging platforms. Further work is underway to refine and standardise acquisition and analysis protocols across different platforms.



# 26 CODESIGNING THERAPEUTIC AND STERILISABLE SOFT TOYS FOR PAEDIATRIC INPATIENTS

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## BACKGROUND:

Surgery for very young patients is a challenging time as they are not fully aware of why the surgery is needed, what it entails, and they may not have the presence and support of their family all the time because the rules of clinical environments do not allow that.

Throughout NHS England, the average time spent by a child in the Paediatric Intensive Care Unit (PICU) is 7 days. In 2015 alone, 60,082 children were admitted to NHS England PICU wards and this is not inclusive of those staying overnight in other wards.

Often when children are admitted to hospital, they bring toys that function as objects of support and emotional reassurance. However, in an increasing number of NHS Trusts around England, soft toys are being banned from hospital wards due to infection control reasons.

## AIMS:

This project designed and developed a sterilisable therapeutic soft toy for paediatric hospital wards through a co-design approach which involved play therapists, nurses, patients, teachers and families. The paediatric patients and their families are also supported by a companion book, which includes with injury stickers, healing diary, and rewarding token for each therapy the child receives.

## METHODS:

The application of codesign methods allowed for the identification of the key requirements, the aspirations of the patients, their family and clinical staff. Creative workshops with the paediatric patients also enabled to explore the emotional connections with the toy that children sought.

## RESULTS:

The final design embodies therapeutic, educational and companionship attributes identified in the design process. Finally, as the toy has been designed to be sterilised following current NHS processes, it has been made with natural materials and can be enjoyed by several paediatric patients, with less impact for the environment.

# 27 IDENTIFYING RESEARCH PRIORITIES IN DIGITAL TECHNOLOGY FOR ADOLESCENTS AND YOUNG PERSONS WITH INFLAMMATORY BOWEL DISEASE

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## Background:

Rapid expansion of digital healthcare (DHC) offers opportunities to transform inflammatory bowel disease (IBD) care. Application of digital technology (DT) in clinical practice should be evidence-based. A Priority Setting Partnership (PSP) was set up in collaboration with James Lind Alliance (JLA) to prioritise research topics that are important to young people with IBD, carers and clinicians involved in their care.

## Aim:

A survey was designed to identify unanswered questions or evidence uncertainties in the use of DT for adolescents and young persons with IBD.

## Methods:

PSP meetings were held with key stakeholders in a Steering Group (SG): paediatric and adult gastroenterologists with an interest in adolescent and young person care from BSPGHAN and BSG respectively; IBD specialist nurses; representatives from the IBD charities CICRA and CCUK; patient and parent representatives. The survey was designed through an iterative process, considered complete when there was saturation of changes and approved by all stakeholders.

## Results:

The final survey consists of three sections. The first captures the respondent's role and connection with IBD. The second invites them to submit questions about DT in two areas: to support their condition and improve IBD care, and to improve communication with the healthcare team. Open-ended questions are used to allow elaboration of answers. Due to the range of DT examples are provided to assist respondents. The last section for demographic data is optional and not linked to responses in sections 1 or 2. A feedback questionnaire on the survey resulted in minor changes to the structure and content before dissemination.

## Discussion:

A survey (figure 1) was developed and piloted by a widely representative SG as a first step to identify unanswered questions. Research priorities will be identified using the JLA methodology and these will galvanise DT research to improve disease outcomes and quality of life.

Figure 1. Initial Survey

**DIGITAL TECHNOLOGY FOR ADOLESCENTS AND YOUNG PERSONS WITH INFLAMMATORY BOWEL DISEASE**

**A Priority Setting Partnership (PSP)**  
In collaboration with the British Society of Gastroenterology, Hepatology and Nutrition (BSGHN), British Society of Gastroenterology (BSG) and the James Lind Alliance (JLA)

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**WHO ARE WE?**  
We are a group of patients, carers, healthcare professionals and researchers who are passionate about improving the care and quality of life of people living with inflammatory bowel disease (IBD), such as ulcerative colitis and Crohn's disease. Together, we are collaborating on a project called a Priority Setting Partnership (PSP), to identify the top 10 research priorities for digital technology in adolescents and young persons with IBD.

**WHAT ARE WE DOING?**  
There are huge opportunities to transform IBD care with digital technologies, but we need to understand the impact that technologies will have and how to best use them. Digital technologies may include apps, websites, wearables, social media and patient controlled electronic medical platforms. We are asking people up to and including the age of 25 who are affected by IBD, their families, carers and friends, health and social care professionals to help us identify the top 10 questions that need to be answered by research in this area.

**WHY DO WE NEED YOUR HELP?**  
We would like to hear from you if you are:  
 a) an adolescent or young person up to and including the age of 25 with IBD  
 b) a parent, carer or friend supporting an adolescent or young person with IBD  
 c) a health or social professional involved in the care of IBD patients  
 Your views will ensure that we focus on the needs of adolescents and young persons living with the condition and guide future research.

**WHAT DO I HAVE TO DO?**  
We are asking you to complete a short, 10-minute survey. You don't have to be an expert in technology to take part. Ask us questions about the use of digital technologies based on your experience of living with IBD or supporting someone with the condition.

**WHAT HAPPENS AFTER THE SURVEY?**  
We will look at all of the questions that have been asked in the survey and check that they align with this project. For the questions that have not been answered already by research, we would welcome you to help to put these into order of priority. Please leave your contact details at the end if you wish to be involved in this part. Finally, we will come up with a list of the top 10 research priorities which will be published to researchers and organisations that fund IBD research.

**WHAT WILL HAPPEN WITH MY INFORMATION?**  
By taking part in this survey, you give us consent to use your anonymised answers and publish these in our project report. We rate your privacy seriously so we will not be able to personally identify you. You may also leave contact details at the end if you would like to continue to help with this project (optional). Personal contact details will be kept confidential.

**THERE ARE THREE SECTIONS TO THIS SURVEY:**  
 Section 1: This asks about who you are to help us understand your role and how you're connected with IBD.  
 Section 2: We would like you to ask questions about the use of digital technology in 2 broad areas. You may wish to focus on just one area or both.  
 Questions about digital technologies to support your condition and have the potential to improve IBD care. These technologies help your healthcare team with making decisions about diagnosis, treatment, and clinical care. They may also help you self-manage IBD, promote healthier ways of living and monitor your progress. Examples include mobile apps for recording your symptoms and disease activity or provide information.  
 Questions about the use of digital technologies to improve communication with your healthcare team. These technologies help to improve the two-way communication between you and the health professionals who look after you. Examples include instant messaging portals and video consultations that link you to healthcare teams.

Section 3 (optional): This asks for additional background information about you to help us understand who you are and to ensure that we have captured a range of different experiences. These answers will not be linked to your responses in section 1 and 2.

**SECTION 1. ABOUT YOU**  
It is important to know who you are, the person filling in the form, and how you are connected to IBD.

Which of the following describes you best?  
 I am an adolescent or young person with IBD  
 I am a parent or have experience as a carer of an adolescent or young person with IBD  
 I am a family member of an adolescent or young person with IBD  
 I am a friend of an adolescent or young person with IBD  
 I am a healthcare professional who looks after adolescents or young persons with IBD  
 I am a member of an organisation or charity representing persons with IBD  
 Other - please state.....

**SECTION 2. YOUR QUESTIONS**  
Write down 3 questions that you would like to see answered about the use of digital technology in inflammatory bowel disease. This can be in the form of a sentence or a question. We do not have to fill in all of the sections if you don't want to.

My first question/comment

My second question/comment

My third question/comment

Please write down any other questions/comments in the box below if you'd like to

**SECTION 3. ADDITIONAL INFORMATION ABOUT YOU (OPTIONAL)**  
This optional but it is important to understand who is filling out the form to ensure that we have collected views from a range of people with varied experiences.

1. What is your age?  
 <16     16-25     25-35  
 40-59     60-79     80+  
 I prefer not to say

2. Which of the following best describes your gender?  
 Boy/Man     Girl/Woman  
 Non-binary     I prefer not to say  
 I prefer to self-describe, please state.....

3. What is your ethnic group?  
 Asian or Asian British     Pakistani  
 Bangladeshi     Chinese     Indian  
 Any other Black/Asian/Pakistani background, please describe.....

Black/White/Caribbean/Black British  
 African     Caribbean  
 Any other Black/Asian/Caribbean background, please describe.....

Mixed/Multiple ethnic groups  
 Asian and White     Black Caribbean and White  
 Black African and White  
 Any other Mixed/Multiple ethnic background, please describe.....

White  
 English/Welsh/Scottish/Northern Irish/British  
 Gypsy/Irish Traveller     Irish  
 Any other White background, please describe.....

Any other ethnic group  
 Arab  
 Any other ethnic group, please describe.....  
 I prefer not to say

4. Where do you live?  
 England     Wales     Scotland  
 Northern Ireland     I prefer not to say

**WOULD YOU LIKE TO HELP US WITH THE NEXT STEP?**  
Once the survey has closed, we would like to get back in touch with the people who completed this survey for help with collating research questions into order of importance and urgency. If you would like to take part in this stage, please add your contact details below.

Name.....  
 Address.....  
 Telephone number.....  
 Email.....

Thank you for completing the survey. If you have any questions or would like any further information, please contact.....

Website: www.jla.nhs.uk/priority-setting-partnerships/ibd  
 Email.....  
 Twitter.....  
 Facebook.....

Figure 1: Initial Survey



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