childhealthtechnology
CONFERENCE
VIRTUAL
2-5 MARCH 2021

2021

ABSTRACT BOOKLET

NIHR | Children and Young People MedTech Co-operative

Marketing Sheffield

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01 ACCEPTABILITY OF TEXT MESSAGES IN PROMOTING ORAL HEALTH FOR YOUNG PEOPLE IN THE BRIGHT INTERVENTION

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BACKGROUND

Brushing RemInder 4 Good oral HealTh (BRIGHT) is a complex behaviour change intervention investigating the clinical and cost-effectiveness of improving the oral health of young people, aged 11-14 living in deprived areas, through increased frequency of toothbrushing with a fluoride toothpaste. The intervention consists of a classroom-based session, embedded in the school curriculum, followed by a series of motivational text messages (SMS) delivered twice daily. Text messages were co-designed with young people to develop SMS appropriate for the age group.

AIMS

To explore young people's acceptability of the SMS reminders.

METHODS

Qualitative study, based on the concept of acceptability. Focus groups were conducted with a purposive maximum variation sample of 50 participants (25 girls, 25 boys) who had received the intervention, from 6 secondary schools across the UK. Data analysis was conducted using a framework approach.

RESULTS

Initial findings suggest that overall, young people found the SMS acceptable in terms of content, language and frequency and found them helpful reminders to brush their teeth. Participants appreciated the choice to stop the SMS if required and to restart them at a future date. To further improve acceptability, participants recommended more choice over the timing of SMS delivery and greater interactivity to reduce tedium and purposeful avoidance. This was particularly pertinent during school holidays as their daily schedule differed. Participants suggested that greater interactivity could be introduced through an app.

DISCUSSION

The SMS used in this trial were co-designed with a youth forum. This study explored the acceptability of the SMS for young people across the UK who have received the SMS twice daily for several months. The findings of this study have implications for promoting health among young people as mobile phones provide the potential to deliver large-scale health behaviour change interventions.

02 AUTONOMOUS CLASSIFICATION OF SLEEP DISORDER PATTERNS WITH OXIMETRY AND ECG DATA

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BACKGROUND

Nocturnal Pulse Oximetry estimates the peripheral blood hemoglobin oxygen saturation (SpO_2) in a non-intrusive way, which is more acceptable by children and convenient for home sleep monitoring. Electrocardiogram (ECG) data are among the most widely used signals for sleep apnea detection. Additionally, the signals of children show a significant variation due to different ages and differ from those of adults as well, making it more challenging to achieve automatic detection.

AIMS

The work aims at presenting a machine learning framework for automatic detection of sleep apnea of children using the SpO_2 and ECG signals and comparing the performance.

METHODS

Both the SpO_2 and ECG signals are segmented into non-overlapped sub-sequences and several features are extracted from each segment. The Gaussian mixture model is employed to model the distribution of features extracted, with the cluster numbers learned from training data using a Dirichlet process model in a Bayesian nonparametric framework.

RESULTS

The proposed framework is tested on a publicly available dataset of adults due to the lack of data of children currently. The framework using ECG achieves epoch-based accuracy of 96.91%, sensitivity of 97.82%, specificity of 96.28% for apnea-hypopnea detection, respectively, while the SpO_2 obtains similar performance of accuracy of 96.40%, sensitivity of 93.27%, specificity of 98.41%.

DISCUSSION

The results show that the detection of sleep apnea-hypopnea events using SpO_2 is promising as it achieves similar performance as ECG in the proposed framework. The proposed framework can provide the basis for algorithm development in children.

03 CUSTOM-MADE MASKS FOR NON-INVASIVE VENTILATION (NIV) FOR CHILDREN

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BACKGROUND

Non-invasive ventilation (NIV) is assisted mechanical ventilation delivered via a facemask for people with chronic conditions that affect breathing, for example neuromuscular and craniofacial problems. Masks that fit well are difficult to find for children who are small or have asymmetrical facial features. Clinical experience and early patient and parent engagement indicated that poorly fitting masks create discomfort, pressure sores, inadequate ventilation, non-adherence and facial deformity.

AIMS

To design and produce custom made masks for children using 3D scanning and printing and a pathway for clinical implementation.

METHODS

Selection of the most appropriate 3D scanning methods and materials were systematically evaluated. Four design concepts were tested using a 3D printed laboratory test head created from an amalgamation of children's facial scans and adult volunteers. Facial pressure, air leak and subjective measures of comfort were measured at increasing strap tensions using an array of force-sensing resistor (FSR) sensors, thermal imaging, ventilator leak parameters and questionnaires. NIV users were consulted to provide feedback on acceptability and design. Nineteen patients aged 1-24 years underwent a facial 3D scan using two different scan techniques. Ethics approval and informed consent were obtained.

RESULTS

Of the two scanners selected for the trial (3DMD and Artec Spider), the Artec Spider was superior in terms of data quality, acceptability and ease of use. Systematic materials evaluation resulted in selection of a polyamide 3D printed frame with silicon overlay. Two industrial partners were engaged for mask manufacture. Test-head and adult volunteer testing showed a correlation between higher tensions and reduced leak. The strongest concept was selected as a prototype for the clinical trial.

DISCUSSION

A trial to investigate potential objective and subjective clinical benefits for the patient as well as health economic benefits is underway. Service delivery pathways are being explored.

04 DEVELOPING A CHILD-CENTRED MOBILE HEALTH RARE DISEASE APPLICATION: THE CHILDHOOD UVEITIS PASSPORT

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BACKGROUND

Childhood uveitis is a chronic, sight threatening inflammatory eye condition, often associated with systemic inflammatory disorders. It is treated with systemic immunosuppression necessitating frequent monitoring. Care is multi-centre and multi-disciplinary, with an often geographically distant tertiary care team. Children may present acutely to local care teams with problems related to their disease or treatment.

AIMS

To create a digital mobile app specifically aimed at children and young people to support them, and their families, to take control of their condition.

METHODS

An existing paper based "Uveitis Passport", supporting self-care with uveitis was well received by adults, but was not designed for use in children and young people. The adult "passport" content and format was modified through face to face structured interviews with affected children and families. In collaboration with UCL computer science, through the UCL Industry Exchange Network, a mobile app was developed using this content, with the front-end developed in Ionic, and the back-end consisting of an internal SQLite Database providing direct read and write access to the data, stored locally in a single file.

RESULTS

The mobile app allows self-record of information about their care teams, condition, associated ocular or systemic complications, medication and general health. Up to date clinical information is accessible by all involved care teams, the family and the child. Patients can make notes and log symptoms they want to discuss at their next medical consultation. The app also contains information on how to access further information and support.

DISCUSSION

This young person centred application supports self-record of patient prioritised information, enabling patient self-management, and it empowers patients when accessing services outside of their normal care teams. The app could be modified to support a variety of childhood chronic conditions.
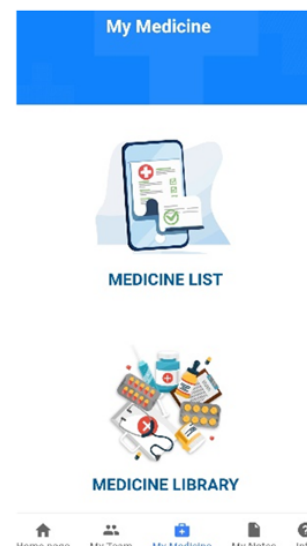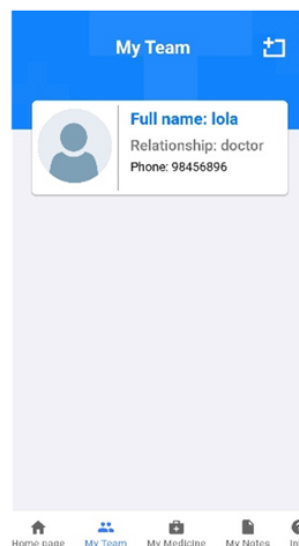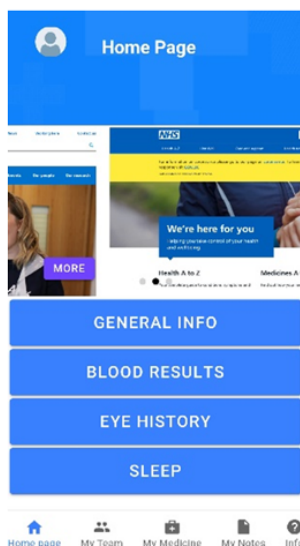
05 DEVELOPMENT OF HACKA HEALTH 4 CF USING A USER CENTRED DESIGN STRATEGY

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BACKGROUND

User centred design (UCD) is an iterative design process in which users are utilised throughout the design process. Physical activity (PA) and exercise are core physiotherapy components in the management of children and young people (CYP) with cystic fibrosis (CF). Traditional models of exercise and PA interventions are labour intensive and remote monitoring is currently not available. Digital technology has the ability to monitor and provide PA and exercise support in a novel and cost-effective way.

AIMS

The aim of this project was to develop Hacka Health 4 CF, a digital health technology for CYP with CF using a user centred design approach.

METHODS

A partnership between Innerstrength Health Ltd and Fluxx Ltd (a service innovation company) was formed and initial meetings were held. CYP with CF were recruited via social media. An ethnographic approach was used. Preferences for the technology, design features and functionality were investigated and discussed. In depth interviews with CF health care professionals (HCPs) were also undertaken.

RESULTS

Throughout the UCD process key insights were gained from all participants and are outlined in Table 1. Wireframes were then developed and a number of Hacka Health 4 CF technology iterations were created. Feedback from the participants was gained at all steps of the process, and adaptations were undertaken based on this.

DISCUSSION

Using a UCD approach Hacka Health 4 CF was developed using the unique and valuable insights from the participants to ensure that the technology is responsive to users needs and preferences. As a result Hacka Health 4 CF has been developed from the 'ground up' rather than depending on preconceived perceptions and ideas. A pilot study to investigate the acceptability of Hacka Health 4 CF as a novel and unique health technology platform is in progress.

PARTICIPANT GROUP	KEY INSIGHTS
CYP with CF (n=12)	1. Did not identify themselves as 'patients' or focus on the life limiting nature of the condition 2. Were keen to participate in 'normal' life and have more 'control' 3. Wanted a name for the technology that didn't reflect the condition.
Parents/carers (n=9)	1. Wanted oversight and assurance that treatments are undertaken 2. Wanted their own dashboard which could provide treatment adherence information.
HCPs (n=15)	1. Described the challenges of monitoring, prescribing and adjusting treatments remotely

Table 1. Key insights gained from participants (CYP, parents/carers and HCPs)

06 DIGITALISATION OF MYEYES, THE CHILDHOOD VISION RELATED PATIENT REPORTED OUTCOME MEASURES

Minu Choi[1], Simon Kamani[1], James Malkin[1], Daiana Bassi[2], Sue Conner[2], Yun Fu[2], Dean Mohamedally[1], Gemma Molyneux[2], Graham Roberts[1], Neil J Sebire[2], Alexandra Robertson[3], Jugnoo Rahi[3], and Ameenat Lola Solebo[3]

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BACKGROUND

Childhood visual impairment (VI) has significant impact on the child, with far-reaching consequences for the child's social and educational experiences and future career prospects. The VQoL_CYP and FVQ_CYP are validated patient-reported outcome measures (PROMs) which capture vision-related quality of life (VQoL) and functional vision (FV), and are designed for use by children and young people living with VI, to capture children's own perspectives of the impact of VI. They are currently used as paper based questionnaires for research into clinical outcomes, and for monitoring purposes in routine clinic practice.

AIMS

To digitise these vision related child centred PROMs, allowing patients to complete questionnaires electronically with data automatically collected into a database for analysis.

METHODS

In collaboration with UCL computer science, through the industry exchange network, researchers at GOSH and UCL GOS Institute of Child Health developed a proof of concept app. This was created to deploy both instruments digitally (collectively, "MyEyes"), complete with a database for analysis. The web application was developed using Django with a PostgresSQL database. The mobile app was developed using Ionic.

RESULTS

The digitalisation of the questionnaires was successful, resulting in a mobile app which has the potential to improve the child's experience of self-completion. Deployment via a mobile app allowed patients to complete questionnaires at sequential time-points, in-between normal clinic visits, thus providing clinicians with more information about their eye condition over time.

DISCUSSION

Clinicians and families have benefitted from the digitalisation of the process of gathering self- (child and young person) reported measures of the impact of visual disability using robust, validated instruments. This project demonstrates how child health PROMs can be digitalised, supporting a more efficient collection process for important patient-generated data. This prototype could serve as an example of how other PROMs in use at the hospital could be deployed digitally.

07 DIGIVIS: A DIGITAL, HOME-BASED VISUAL ACUITY TEST TO SUPPORT REMOTE CONSULTATIONS AND VISION SCREENING

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BACKGROUND

Covid-19 has caused severe backlogs in paediatric ophthalmology clinics, with approximately 400,000 children having missed vision screening — risking preventable visual impairment. DigiVis, a web-app recently developed to enable self-assessment of visual acuity (VA) at home, may address these issues. VA is measured as the Logarithm of the Minimal Angle of Resolution (LogMAR) where 0.00 is normal (6/6 Snellen).

AIMS

To evaluate the accuracy and reliability of DigiVis home VA assessment in 5-10 year old children. Additionally, to determine whether parents would consider using DigiVis to monitor their children's vision at home.

METHODS

Parents of 20 children aged 5-10yrs (median = 6yrs) used DigiVis to assess their child's uniocular VAs twice within 2-3 weeks of a scheduled clinic assessment. Bland-Altman plots and intraclass correlation coefficients (ICC) were used to compare DigiVis and clinic VA measurements and evaluate test-retest reliability. User feedback was appraised. Analysis was conducted in R (v3.6.1).

RESULTS

There was strong correlation between DigiVis and clinic VA: ICC = 0.88 (p = 0.0005), with Bland-Altman plot (Figure 1a) exhibiting a bias of +0.04 LogMAR, with 95% Limits of Agreement (LOA) at ±0.15 LogMAR. Test-retest agreement was statistically significant (ICC = 0.51, p = 0.0007), with 97% of differences within ±0.21 LogMAR (Figure 1b). Feedback was positive, with most parents (15/15) and children (16/18) rating DigiVis as good/excellent. All but one family were willing to use DigiVis regularly at home.

DISCUSSION

VA measurements in children vary considerably with concentration and observer bias. Since standard LogMAR testing in children has a reported 95% LOA of ±0.21, these interim data from an ongoing validation study support a high level of accuracy, repeatability and patient acceptability with DigiVis home testing, suggesting that it could be a useful method for monitoring children's vision in the community.
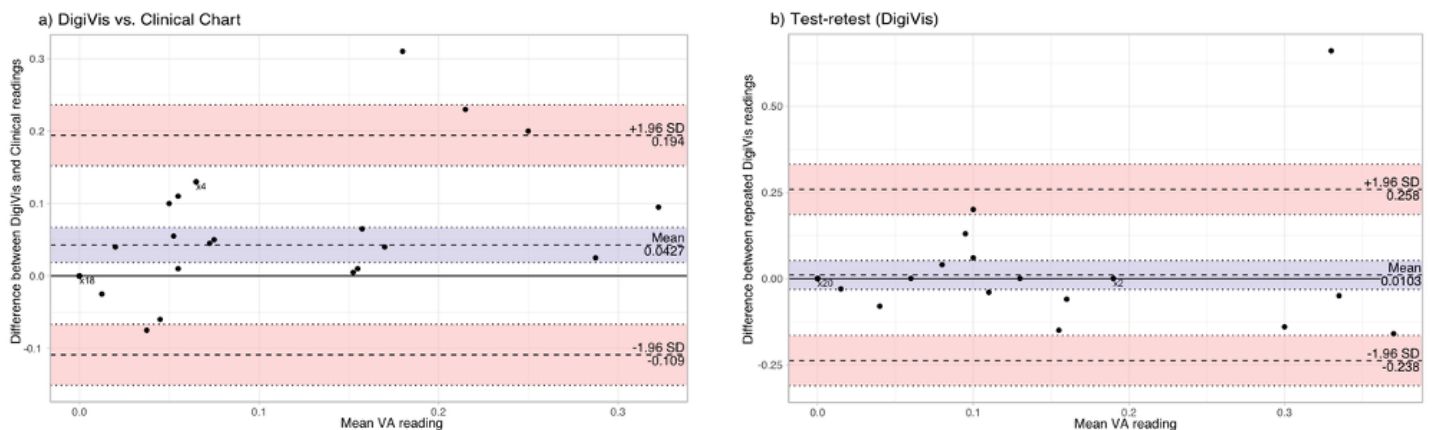
Figure 1. Bland-Altman plots exhibiting agreement between DigiVis and clinical readings of visual acuity (a), and between DigiVis readings (b). 95% confidence intervals for the bias and limits of agreement are shaded. Overlapping data points are labelled, xN.

08 END-USER LED EVALUATION OF APPLICATION TECHNOLOGY TO SUPPORT YOUTH MENTAL HEALTH (ELEVATE-MH)

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BACKGROUND

Youth and young adults worldwide are uniquely affected by mental health concerns. The wide-spread use of smartphones provides a unique opportunity to increase access to mental health resources. The growing number of mobile, mental health-oriented applications has the potential to improve mental health knowledge and supplement treatment. However, the majority of available applications are not grounded in empirical work. They are largely ranked based on popularity and user experience, making selecting an effective and evidence-based application problematic for end-users. Given the fact that the target users of mental health applications are youth and young adults, developing a rating platform that is primarily end-user driven would be beneficial in popularizing safe and effective resources that young people are willing to use.

AIMS

As the existing evidence-based app rating platforms fail to incorporate end-users' priorities, the goal of the ELEVATE-MH project is to develop a sustainable methodology and platform to enable an ongoing, end-user driven evaluation of mobile applications for mental health.

METHODS

We conducted a series of 4 focus groups with teenagers and young adults to identify: 1) priorities when using mental health apps; and 2) rating criteria that reflect these priorities. We analyzed the data using qualitative content analysis and quantitative methods.

RESULTS

Data analysis from 47 participants suggests that the top three priorities when selecting mental health apps include affordability, whether the app can accomplish what it promises, as well as accessibility. Ethical considerations such as privacy, transparency of app owners and grounding in evidence were also important. The participants expressed several preferences that are not currently standard in mental health apps.

DISCUSSION

Participatory and co-creation approaches are necessary to ensure that novel mental health apps are being developed with the needs, values and preferences of target end-users in mind.

09   HOW FEASIBLE IS IT TO MONITOR YOUNG PEOPLE WITH CYSTIC FIBROSIS AT HOME?

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BACKGROUND

Young people with cystic fibrosis (CF) routinely attend clinic every 2 to 3 months regardless of their clinical need. Home monitoring offers the potential to rationalise these appointments.

AIMS

The aim of CLIMB-CF was to explore the feasibility of remotely monitoring young people with CF and to explore the amount of requested data that was completed over the study period.

METHODS

We designed a study specific mobile phone app with input from the CF Trust Youth Advisory group which incorporated no-touch Bluetooth technology. We recruited participants aged 2-17 years of age from 8 sites in 2 countries. Each participant was recruited for 6 months and was asked to collect certain measures daily (wellness, cough severity, appetite, sputum volume, breathlessness and tiredness scores, heart rate, oxygen saturations, temperature, respiratory rate, activity and sleep disturbances), others twice weekly (weight and lung function). At the end of the study period children and families completed acceptability questionnaires.

RESULTS

We recruited 148 participants, 2 withdrew prior to starting due to social issues, 2 failed to achieve clinical stability and 8 withdrew during the study. Median age was 7.9 years; females comprised 57%. Over the 6 months the median completion of all measures was 40.1% (13.6-69.9%). Parents who felt home monitoring did not, or only slightly, interfered with their usual activities completed 52% (28.3-77.6%) of measures; those perceiving it interfered completed 29.9% (9.2-74.5%). Teenagers who felt home monitoring did not interfere with their usual activities completed 37.8% (14.5-73.2%) of measures; only 9.6% (5.6-22.3%) of measures were completed by those who felt it interfered with their usual activities.

DISCUSSION

Parents and participants who thought home monitoring did not negatively impact their lives collected more data Teenagers, a high risk group for clinical deterioration, entered the least data. These findings will impact future study designs of home monitoring strategies; co-design with the CF population is essential.

10 NECK SUPPORT FOR CHILDREN AND YOUNG PEOPLE WITH NARCOLEPSY: THE "BELT-UP!" PROJECT

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BACKGROUND

Narcolepsy is a disabling sleep disorder characterised by excessive daytime sleepiness and muscle weakness precipitated by strong emotions, known as cataplexy. Children with narcolepsy inevitably fall asleep on car journeys and the loss of head control causes immense parental anxiety as well as pain and discomfort for the child. There is currently no effective support for these children.

AIMS

To design and develop a neck stabilising aid for children with narcolepsy to use in the car.

METHODS

Three co-design workshops took place, including the Narcolepsy Family Day in March 2019 (approximately 110 attendees). Participants included patients aged 6-16 years, parents and families, healthcare professionals and members of the research team.

• Workshop 1: Needs capture and initial specification (challenges encountered, current 'hacks' and key criteria to consider in the design of a new product).

• Workshop 2: Children and families tested existing commercial products that aim to support sleep during travel, to learn more about the features desired in a new product.

• Workshop 3: Feedback and ideas for further development on a range of prototypes built in response to the insights from children and families.

RESULTS

A range of bespoke co-design tools were generated to suit the emerging needs of the project. Sketch ideas based on the collated input from children and families were generated, and sent back to the families for their feedback. Nine prototypes were built based on the sketches described above. The prototypes were designed to be fully functional (although not safety tested) and were tested in the final workshop with children and families.

DISCUSSION

Initial testing of these prototypes has given some early indication of which concepts warrant further development. Further funding will be sought to develop and evaluate the prototype.

There can be challenges when you have narcolepsy and travel by car, bus or train - here are some that we have found, feel free to add some more!
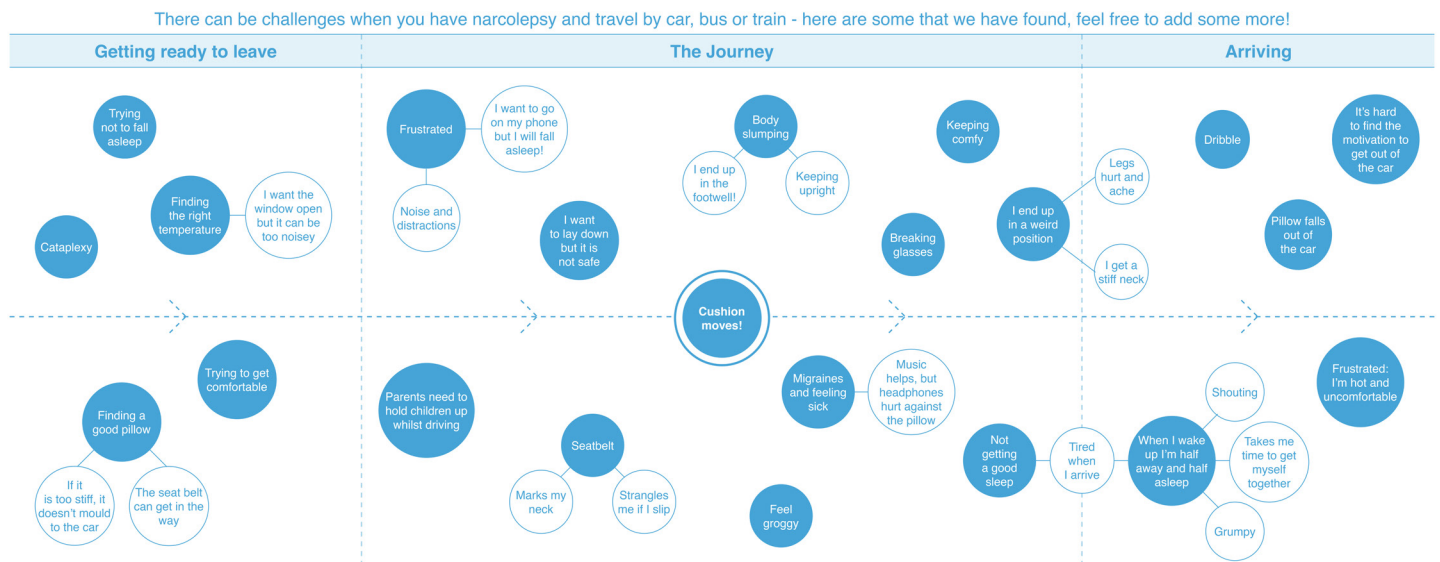
11 NEONATAL WIRELESS TRANSMISSION SYSTEM—ADULT VALIDATION

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BACKGROUND

Neonatal intensive care provides life-saving medical support for critically ill babies, whilst also enabling skin-to-skin parental contact. Skin-to-skin contact is known to be extremely important for health outcomes of babies and parents. Monitoring of vital signs is a key part of intensive care; however, the wires can present a barrier to the provision of this care, and to parents bonding with their babies. We have developed a novel wireless vital sign monitoring system that aims to remove this barrier.

AIMS

To verify the design of the wireless system against the current standard of care, wired monitoring, within an adult cohort, supporting transition to testing within the neonatal population.

METHODS

Ten healthy adults had the wireless and wired sensors attached for 15 minutes to collect concurrent data. The sensors measured 3-lead ECG, oxygen saturation, and skin temperature. Data was captured anonymously from two separate monitors. Key markers in the waveform data (e.g. P-wave amplitude) and parameter data (e.g. heart rate) were compared to evaluate the similarity between the systems.

RESULTS

Bland-Altman plots for were used to visualise the comparison between the two systems. These plots showed that the wireless data was within the tolerance of the patient monitor's specifications. The extracted features indicated good similarity between the data sets, concurring with the visual similarity of the waveform morphology (Figure 1).

DISCUSSION

This study provided initial verification of the design of a wireless neonatal vital sign monitoring system in a low-risk setting. This evidence has supported an application for ethics approval to undertake a further study within the high-risk neonatal population. Clinical studies are needed to demonstrate that removing the wires for these babies will reduce nursing workload and improve parent-baby bonding.
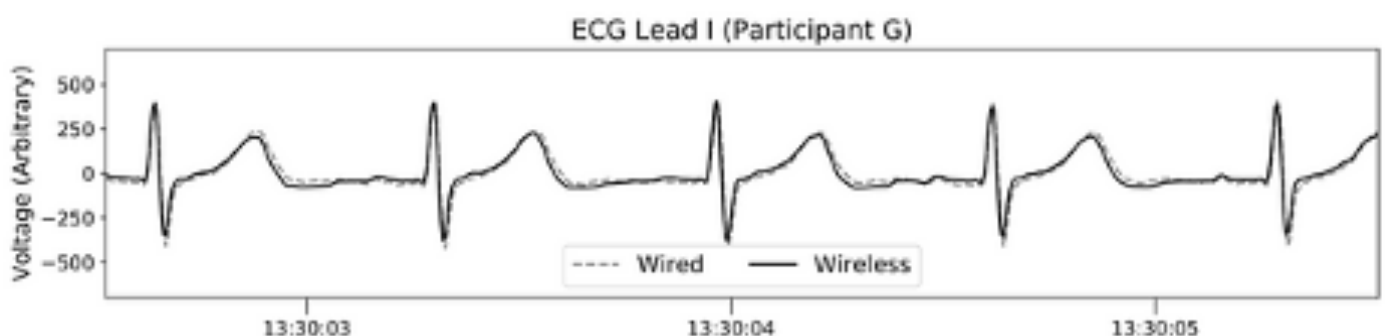
Figure 1. Lead-1 ECG traces comparing the wired (dashed) monitoring system against the novel wireless (solid) system.

12 POWERED MOBILITY: EVIDENCE BASED PRACTICE AS A BASIS OF HEALTHCARE POLICY CHANGE IN ISRAEL

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BACKGROUND

Healthcare policy as defined by the World Health Organization (WHO) refers to decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. Healthcare policy is key in defining a vision to establish targets and points of reference for the short and long term goals. It identifies priorities and the expected roles of different stakeholders, builds consensus and informs people. In 1994, Israel proclaimed that all citizens are entitled to healthcare under a universal program. A list of authorized services was defined under the "Healthcare Basket", including powered mobility (PM) for people aged 6 to 65 years. All potential drivers needed to prove proficiency via an outcome measure that had not been demonstrated to be reliable or valid. The procurement process was lengthy and restrictive.

AIMS

To achieve evidence-based changes in Israel's Ministry of Health (IMOH) healthcare policy regarding PM for children 18 years and younger.

METHODS

Evidence was gathered in four studies briefly described below.

RESULTS

The first study (n=80) identified four variables that predict PM proficiency in 80% of cases. The IMOH used these data to refine their policy in ways that greatly enhanced the procurement process. The second study (n=30) demonstrated the validity and reliability of three key outcome measures of wheelchair proficiency. The third study (n-30) validated a simulator-based PM practice protocol. The fourth study (n=30) demonstrated that PM proficiency is achievable via simulator-based practice via conventional or simulator. The IMOH accepted these research findings and changed their policies.

DISCUSSION

In countries where PM is provided via insurance or government funding, it is imperative to provide evidence-based practice options, either via real powered wheelchairs or other options such as a simulator. The process described above may serve the basis of achieving healthcare policy changes in a range of clinical applications.

13 PREDICTING LONG LENGTH OF STAY IN A PAEDIATRIC INTENSIVE CARE UNIT USING MACHINE LEARNING

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BACKGROUND

Length of stay (LOS) prediction modelling in intensive care units is a valuable capacity planning tool as hospitals attempt to clear the backlog of surgical patients resulting from the COVID-19 pandemic. Recent work in adults has demonstrated the benefits of using machine learning over statistical methods for LOS prediction, however machine learning approaches have not been applied to paediatric populations.

AIMS

The study set out to develop machine learning models to predict long LOS in the paediatric intensive care unit at Great Ormond Street Hospital using electronic patient records.

METHODS

Paediatric intensive care patients between 1st May 2019 and 30th April 2020 were extracted from electronic patient records. Random forest, XGBoost, and multilayer perceptron models were built to predict LOS greater than three or seven days. The dataset contained demographics, ventilation data, and summary statistics of physiological time-series data, taken from the first twelve hours of admission. The performance of the machine learning classifiers was compared to a baseline logistic regression model.

RESULTS

There were 564 patients in the study population, of whom 307 had a LOS greater than three days and 105 had a LOS greater than seven days. Using the seven-day threshold, the optimal model was the random forest, which achieved an AUC of 0.785 and correctly classified 42.9% of long LOS patients. Using the three-day threshold, the optimal model was the multilayer perceptron, which achieved an AUC of 0.737 and correctly classified 85.7% of long LOS patients. The performance of the machine learning models was variable, and they did not unanimously outperform the baseline models.

DISCUSSION

The machine learning models performed poorly in predicting long LOS. Further work is required to assess the clinical utility and value of deep learning methods in an operational setting.

14 ROBOT INTERACTION EFFECTS ON CHILDREN EXPERIENCING A STRESSFUL SITUATION (RECESS)

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BACKGROUND

Socially Assistive Robots (SARs) have the potential to help address some of children's mental health needs. Although there is preliminary evidence that SARs may improve some mental health outcomes such as stress and anxiety in children, there is a need for focused and real-world evidence of their impact.

AIMS

This project has two stages with distinct goals: 1) to characterize how parents and children perceive socially assistive robots and determine their preferences about robot use in a surgery waiting room and 2) to implement and evaluate a SAR in an acute children's hospital environment.

METHODS

1) We developed an online questionnaire to be administered to parents and children who undergo surgery at a children's hospital. It includes a video of the robot that we will use in the in-person study that shows its abilities. 2) Protocol is under development for a mixed methods study in the brain surgery unit of BC Children's Hospital. It will be patient-centered and informed by the outcomes of the questionnaire. We will measure the impact of a pet-like SAR, MiRo, on outcomes related to anxiety and patient experience for the child and their family members.

RESULTS

We anticipate to obtain actionable data from children and their parents on their preferences, priorities and values regarding social robot use in a hospital waiting room setting. Preliminary results from the questionnaire will be available by the end of January 2021. Full results will then inform a mixed methods protocol for a robot intervention in the second phase of the study.

DISCUSSION

As the international robotics research community continues to grow and investigations into novel mental health care application areas emerge, high quality evidence about the impact of SARs on mental health will propel the development of translational solutions for the benefit of children worldwide.

15 THE IMPACT OF VIRTUAL REALITY ON PSYCHOLOGICAL AND PHYSIOLOGICAL VARIABLES IN CHILDREN RECEIVING CHEMOTHERAPY

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BACKGROUND

Improving the general well-being of paediatric oncology patients is as important as their medical treatment. Virtual reality (VR) is an immersive, 360-degree artificial environment providing a great opportunity to reduce some of the negative effects of chemotherapy.

AIMS

In our pilot study, we studied the feasibility of using VR in pediatric oncology centres and its effects on psychological and physiological variables during chemotherapy.

METHODS

23 paediatric oncology patients (age: 10-18 years) receiving intravenous chemotherapy were included. A repeated measures crossover design was used in which all children participated in both the VR and control conditions during the same type of chemotherapy. Psychological and physiological variables (heart rate, blood pressure, electrodermal activity) were measured immediately before and after the session. Mood, anxiety, patience, nausea were measured by questionnaires. In the VR session, children played with the Night Sky videogame on the Samsung Gear VR/Oculus Go device for 20-30 minutes, while in the control session they could play a mobile game. Data was analysed with linear mixed modelling.

RESULTS

A significant improvement in mood was shown after the VR session compared to control. Anxiety was significantly reduced in both conditions. Nausea was less prevalent in the VR condition. No significant effect on patience was found. Symptoms of kinetosis was only detected in one case. No significant interaction effects were found for physiological variables.

DISCUSSION

Children and health care workers all had positive attitude towards VR, which usage was shown to be feasible in the paediatric oncology department. A VR session had a positive impact on the mood of the children as well as it decreased the prevalence of nausea. Further investigations are needed to determine whether these effects belong to the novelty or the specific attributes of VR.

16 TIMING OF HYPOGLYCAEMIA IN PATIENTS WITH HYPERINSULINISM (HI): A TECHNOLOGY-ASSISTED ANALYSIS OF GLYCAEMIC PHENOTYPE

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BACKGROUND

Hyperinsulinism (HI) is the most common cause of severe and recurrent hypoglycaemia in childhood with an unacceptably high incidence of hypoglycaemia-induced brain injury. Prediction and prevention is the cornerstone of management but current techniques risk missing hypoglycaemia. High cerebral glucose utilisation in the latter part of the night results in a higher risk of hypoglycaemia particularly in those unable to mount a corresponding increase in gluconeogenesis due to hyperinsulinism. Neither the risk of nocturnal hypoglycaemia nor the timing of hypoglycaemia in children with HI have been studied.

AIMS

To investigate the timing of hypoglycaemia in patients with HI to describe glycaemic phenotypes.

METHODS

Patients underwent Continuous Glucose Monitoring (CGM) with a Dexcom G4 or G6 CGM device as part of clinical assessment for HI (n = 23) or Idiopathic Ketotic Hypoglycaemia (IKH) (n = 24). CGM data were analysed using the Python programming language.

RESULTS

449 hypoglycaemia events (blood glucose < 3.5mmol/L) totalling 15,610 minutes were captured over 237 days from 47 patients (29 male, mean age 70 months). There was a clear tendency to hypoglycaemia in the late night (0300H to 0700H) (Figure 1) particularly in those HI patients over 10 months of age where 7.6% of minutes in this period were hypoglycaemic compared to 2.6% outside (P < .001). This tendency was less pronounced in HI patients under 10 months and those with IKH.

DISCUSSION

We have identified late night as a time of relatively high risk for hypoglycaemia in patients with HI. We have also demonstrated that even when families are provided with a state of the art CGM device hypoglycaemia events are neither eliminated nor reliably corrected even in those with HI. Future work must concentrate on late night as a period of high risk for hypoglycaemia with interventions to target nocturnal hypoglycaemia prediction and prevention.
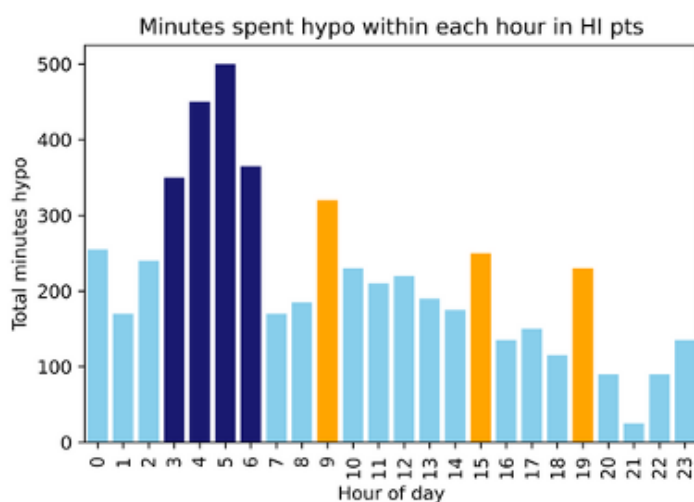
Figure 1. Total number of minutes spent in hypoglycaemia by hour of the day in HI patients. This illustrates the total amount of time spent hypoglycaemic by HI patients by hour of the day. There is a clear period of high risk for hypoglycaemia between 0300H and 0700H (dark blue) which represents the late night. There are also three distinct spikes of increased hypoglycaemia prevalence at 0900H, 1500H and 1900H (orange) which may represent post-prandial hypoglycaemia.

17 A GAME-BASED MYOELECTRIC TRAINING SYSTEM FOR CHILDREN

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BACKGROUND

Children born with upper limb differences typically reject a prosthesis unless it provides significant functional gain. In the case of myoelectric prostheses (powered devices controlled by muscle activity in the residual limb) a core factor which limits any functional gain is the method of control.

AIMS

Our objective is to develop a child-friendly game-based myoelectric muscle training system based on the principles of biofeedback. The system is designed for home-use and aims to be low cost. The assumption underlying our project is that myoelectric control can be implemented separately from a prosthetic device, allowing children to learn control before they are fit with a prosthesis.

METHODS

Prototypes have been tested on small groups of children who volunteered to provide feedback as part of an ongoing co-design process. Children play games using controllers placed on their residual limb. Controllers detect and communicate both limb position and muscle activity which is used to control a virtual terminal device, as shown in the figure. After playing, children, and optionally their guardians, answered a short set of open questions.

RESULTS

We are currently developing the system based on the second round of user feedback. During initial tests all children were able to use the system and feedback on the perceived level of control was positive. Second phase tests successfully trialled a bespoke game controller designed for younger users based on dry EMG electrodes. The most significant issue arising is how to ensure games are sufficiently engaging for longer-term use.

DISCUSSION

Designing myoelectric games for the home environment raises a number of challenges. At the prototyping stage, most devices for acquiring EMG are not appropriate for use with young children. The central issue for rehabilitation games such as this is how to sufficiently engage users such that they willingly perform repetitive activities that would otherwise be considered tedious.
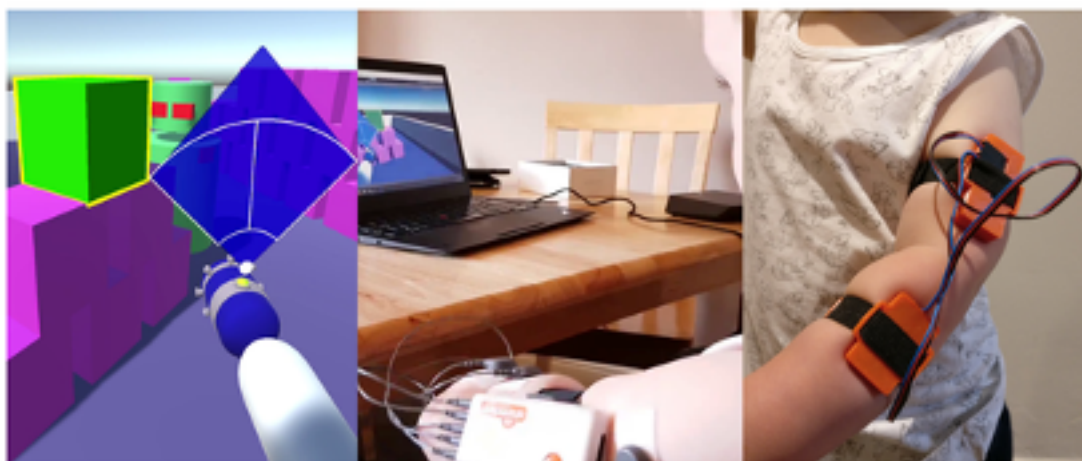
L to R: early prototype gameplay with virtual limb, child playing using Shimmer3 EMG, bespoke dry EMG controller.

18 A NOVEL TOOL TO MEASURE BALANCE DURING STEPPING IN CHILDREN WITH AND WITHOUT CEREBRAL PALSY

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INTRODUCTION

Stepping and walking requires anticipatory postural adjustments (APAs) to create an accurate 'throw' of the centre of mass (COM) and 'catch' by the stepping leg (Lyon and Day, 1996). The 'Next Step' test aims to measure APAs during a simple stepping task.

METHODS

This test used four randomly lit electroluminescent targets set at 0o or 25o angles. Data was collected using a force plate (Kistler UK), single CODAmotion (UK) camera, four markers on each foot and three on the pelvis (figure 1). Stepping error was defined as the absolute distance of the cluster of foot markers from the 'test' step for each target. The APAs were measured from the medio-lateral (ML) and anterior-posterior (AP) acceleration of the COM estimate, via markers on the pelvis, 150 ms prior to lifting the stepping leg. Foot placement error and group differences for each target were assessed using a Mann Whitney test. The ML and AP COM motion were assessed using between-groups repeated-measures ANOVA with factors being targets (four levels).

RESULTS

Fourteen typically developing (TD) children (8 females) aged 11.7 (+/- 2.9) years and sixteen ambulant children with cerebral palsy (CP) (9 females), aged 12.1 (+/-2.2) years participated. Stepping error was significantly higher in children with CP (30.4mm +/- 29.6) versus TD (15.6mm +/- 8.4) and worst in children with bilateral CP. Children with CP have smaller ML and larger AP motion of the COM. They showed reduced ability to modulate the ML COM motion compared to TD peers (ratio central/lateral target COM motion CP=0.76mm +/-3.6 TD=3.9mm+/- 3.0, $p < 0.05$). Children with right sided lesions (left hemiplegia n=5) showed the greatest difficulty in APAs, which warrants further investigation.

CONCLUSION

The 'Next Step' test quantifies differences in APAs and stepping accuracy. Further development using inertia sensors and a pressure mat will make it more clinically applicable.
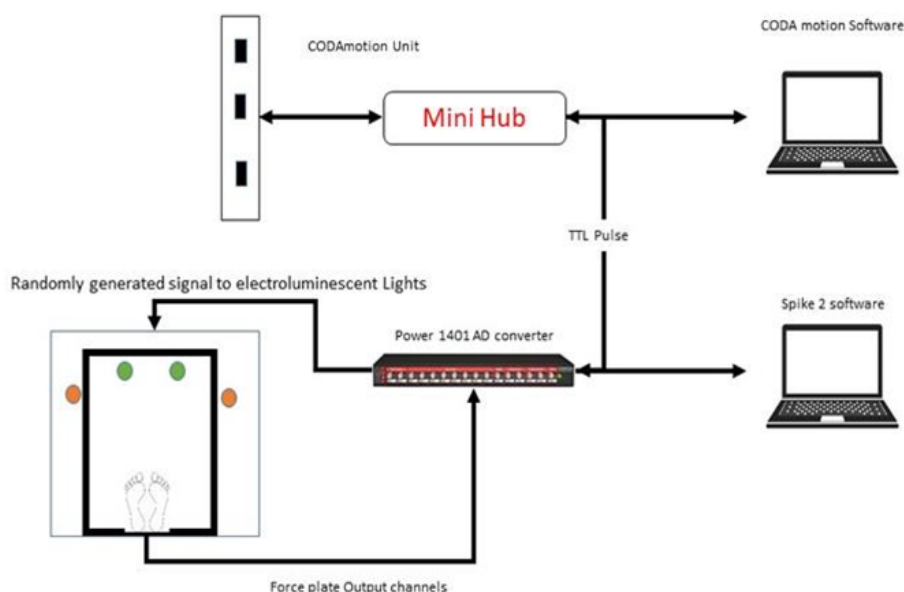

Figure 1. The Next Step data collection hardware.

19 ARE INTERMITTENT VITAL SIGNS RECORDINGS IN CLINICAL TRIALS ACCURATE?

Gareth Jones[1,2], Samiran Ray[1,2], Daisy Wiley[3], and Mark Peters[1,2]

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BACKGROUND

Attempts have been made to utilise data from high-frequency patient monitoring for direct clinical benefit and for wider benefit in research. It is unknown how representative these values are of the true distribution of vital signs.

AIMS

To understand if case report form (CRF) data in a trial of oxygen saturation (SpO_2) thresholds for children admitted to a paediatric intensive care unit represents true distribution of SpO_2 values as collected by high-resolution SpO_2 data monitoring systems.

METHODS

We conducted a post-hoc comparison of CRF SpO_2 and high-resolution SpO_2 (recorded every 5 seconds). Forty-four of 53 children recruited to the Oxy-PICU pilot trial of SpO_2 targets of 88-92% (conservative) or >94% (liberal)at a single site (Great Ormond Street Hospital, London) had high resolution SpO_2 recordings.

RESULTS

Twenty-four participants from the conservative group and 20 from the liberal intervention group had high resolution data available. The median SpO_2 was 96% (IQR 92-99%) for CRF (n=815 values) and 95% (IQR 92-98%) for T3 (n=549 values) and were significantly different (signed Wilcoxon rank; p=0.02; Figure 1a). The median SpO_2 was 97% (IQR 95-99%) for CRF (n=978 values) and 97% (IQR 95-99%) for T3 (n=542 values) which were not significantly different (signed Wilcoxon rank; p=0.50; Figure 1b). In the conservative group, the mean difference in 503 paired CRF and T3 values was 0.5 (95% limits of agreement -7.8 to 8.6) whilst in the liberal group the mean difference of 560 paired values was 0.3 (95% limits of agreement -9.1 to 9.7) (Figures 1c -d).

DISCUSSION

There is a reasonable overall agreement between trial recorded values and high-resolution values, validating the current approach to data collection. However, clinical differences according high-resolution values may need to be evaluated further to uncover subtle differences between the two arms.

Case report form SpO_2 interval	High resolution SpO_2 range corresponding to CRF interval
Hourly	30 minutes before and 30 minutes
4-hourly	120 minutes before and 120 minutes after
12-hourly	6 hours before and 6 hours after

Table 1. Case report form and high-resolution median SpO_2 timings.
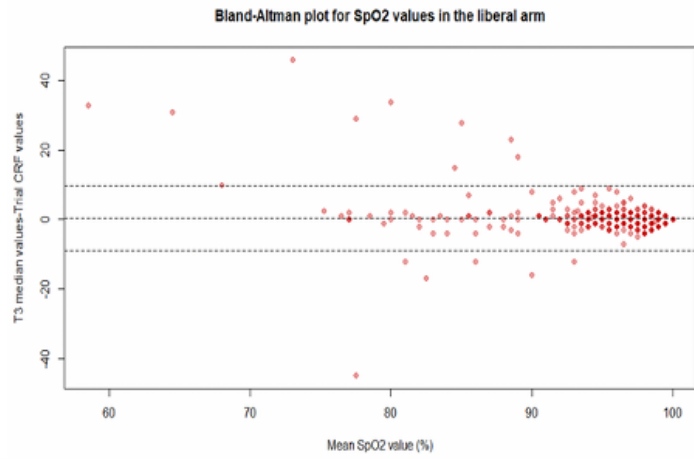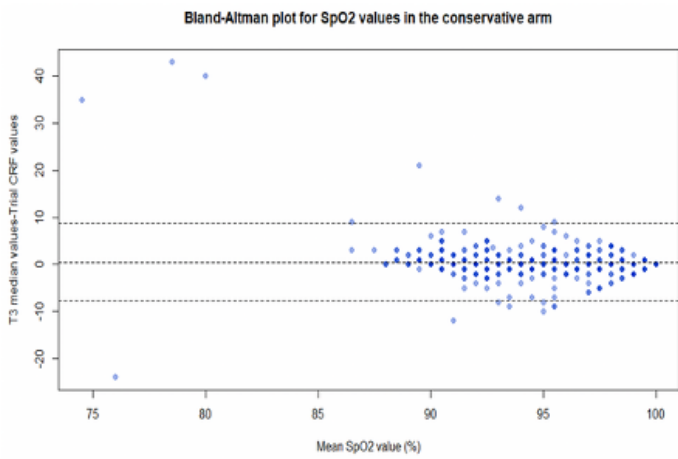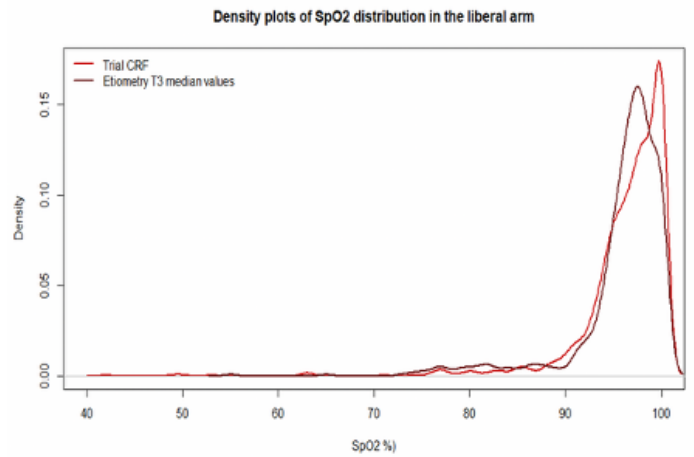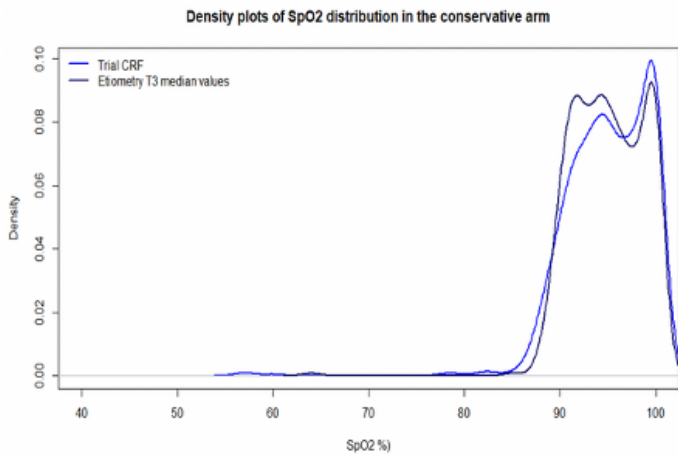
Figure 1. Density plots of SpO_2 values in the OxyPICU pilot trial enrolled in the conservative (a) and liberal (b) arms. Bland Altman plot showing the difference in CRF recorded and median T3 values in the conservative (c) and liberal (d) arms.

20 ASK TEDDI: PAVING THE WAY FOR AI'S ROLE IN IMPROVING THE WELLBEING OF 0-5YR OLDS

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BACKGROUND

Studies have shown that early childhood intervention would have a positive impact on the economy, suggesting that for every £1 invested in parenting skills and support, £8 is saved over 25 years. In response to this we co-produced the Ask Teddi app, an evidence-based 0-5 robo-expert, designed to tackle multiple issues from eating behaviours and breastfeeding, to active families and emotional wellbeing, to name a few.

AIMS

To provide an evidence-based, personalised, on demand early years support to parents at scale to empower them to give their children the best start in life, and consequently reduce health inequalities and improve life outcomes.

METHODS

This app was co-produced with public health experts who have been delivering behaviour change services for over 15 years, key subject matter experts, resources from trusted sources, insights from over 100 School Nurses, Health Visitors, and user feedback to create a robot early years (0-5) support called Teddi. Users can ask Teddi questions, talk about daily challenges, and receive personalised evidence-based support. We have trained over 80 health visitors, school nurses, youth workers, children centre staff and family support workers to implement the app in their service. The app has been launched in Thurrock and Slough.

RESULTS

A formal evaluation is due from both Swansea University and the University of Essex. The app has received positive testimonials from parents such as 'I like the quick tips and useful advice Teddi gives', as well as professionals stating that 'Ask Teddi will provide support on demand when we can't be in touch with families'.

DISCUSSION

Our long-term outcomes are to have a formal evaluation to solidify that Ask Teddi will cause positive behaviour change, and thus proving that AI has a role in the future of healthcare, not replacing, but supporting families and healthcare professionals.

21 CHILD LED DESIGN OF ASTHMA EDUCATION PACKAGE

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BACKGROUND

The overarching project involved the development of a solution to enhance parental management of childhood asthma, through medication monitoring, education, reminders, and incentives. Education is key to effective asthma care, but families told us in our earlier feasibility study that the education component needed to be more engaging and accessible to children to maximise its impact.

AIMS

We therefore aimed to: Create educational content for children aged 6-12 years old that was interesting, informative, engaging and age appropriate.

METHODS

10 children, who were known asthmatics and within this age bracket, were accompanied by their parents and took part in 2 co-design workshops held 4 weeks apart. The workshops were hosted by an experienced designer and supported by members of the research team. Activities were designed to enable us to hear children talk about asthma, learn what would appeal to them in terms of design and content, develop the children's ideas, show we have listened to them and, above all, have fun.

RESULTS

The insights collected, including those in Table 1, were used to create 4 different design options for the educational content. The children then chose their favourite design. Feedback on the most popular design included the following - "cartoony, colourful, not too much information and it catches your eye" Zack, aged 12 (see figure 1).

DISCUSSION

It was challenging to find a design that appealed to children across this age range, but the simplicity of the chosen design appealed to all ages. The design was driven entirely by children who live life with asthma, but the methodology could be used for creating educational materials for any childhood condition. An additional and unexpected benefit from the co-design workshops was families then asking to take part in the associated clinical study.

Children's Likes	Children's Dislikes
Colourful	Boring
Simple	Bland
Quirky	Graphic
Active	Realistic
Rainbows!	Childish

Table 1. The children's design likes and dislikes.

Figure 1. Activities and outputs from the co-design workshops.

22 CHILDREN AS EXPERTS; A CHILD-CENTRED APPROACH TO DEVELOPING AND EVALUATING THE XPLORO DIGITAL THERAPEUTIC PLATFORM

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BACKGROUND

Xploro is a digital therapeutic (DTx) platform designed to inform children and empower them to have a better hospital experience through the use of gamification and augmented reality.

AIMS

This presentation will discuss and reflect on the integral role children have played in the development and subsequent evaluation of Xploro.

METHODS

The initial Xploro development work involved over 70 children and young people through; user experience interviews within a hospital, workshops at child orientated events, consultation with children's charity patient groups and facilitated sessions within the company labs and studio. This engagement with children, who were experts by experience, helped shape the content and format of the DTx. Children and young people also acted as advisors to the research team to ensure that the evaluation design, recruitment processes and methods were child-centred. Over several sessions we provided research training and used creative consultation methods such as road journey maps and word sequencing games with a group of 12 children and young people within a local school. Following this, within the research project, over 100 children within a children's hospital shared their views through the use of thought clouds, speech bubbles and the write and tell technique. These views helped ensure that the Xploro avatar chatbot was child-centred and prioritised children's concerns and information needs. Children and young people continue to underpin Xploro's development through key roles on the expert advisory board. 10 children provide ongoing advice on usability, content, features and design.

RESULTS

We used creative and flexible child-centred methods to gain the views and opinions of children. Children's involvement varied from short-term engagement, consultation and research participation to more established advisory roles.

DISCUSSION

Our positioning of children as experts and the use of child-centred methods facilitated children to inform and shape the development and evaluation of Xploro.

23 CONFIGURABLE SOFT TOOL FOR MECHANOTHERAPY BASED TISSUE REPAIR

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BACKGROUND

Current therapies are typically short-term and generally invasive. New technologies are needed that can address these challenges effectively. We developed a soft surgical minimally-invasive tool that can be configured to different organs anatomies to apply mechanical stimulation via tissue tensioning or stretch, to repair and regenerate tissue (Damian D., Science Robotics, 2018). Broader applications include muscle repair and regeneration using mechanotherapy that can be applied to various organs: bowel growth for short bowel syndrome (SBS), oesophageal growth for long-gap oesophageal atresia (LGOA), aorta growth for midaortic syndrome treatments, heart conditioning for fibrillation treatment, etc (Fig. 1a-b).

AIMS

We aim to evaluate the configurability of a soft robotic strand (SRS) as a tool for mechanotherapy based tissue repair.

METHODS

We measured SRS expansion under various angles of bending. We pressurised a section of the SRS at 18 kPa under stress angles (SA) of 15° to 120° (Fig. 1c-d). We represented homogeneity of expansion among different balloons using error bars (Fig. 1e).

RESULTS

Balloons X, Y and Z (Fig. 1d) are affected differently by the SA. X showed the maximum expansion among all SA and trials, while Y expanded more than Z until reaching 90° of SA, where their expansion became similar. This implies that the change in volume of the chamber caused by the SA decreases the airflow that pressurises different sections of the SRS.

DISCUSSION

The SRS is a potentially versatile clinical tool for tissue stimulation that could be configured into different geometries. Although the body does not have sharp angles, we evaluated the SRS under extreme scenarios. Intricate shapes may require the SRS to adopt different bending angles and radii, causing the balloons to expand at different sizes. However, we demonstrated that the SRS can be configured around different anatomical geometries without stopping its function.
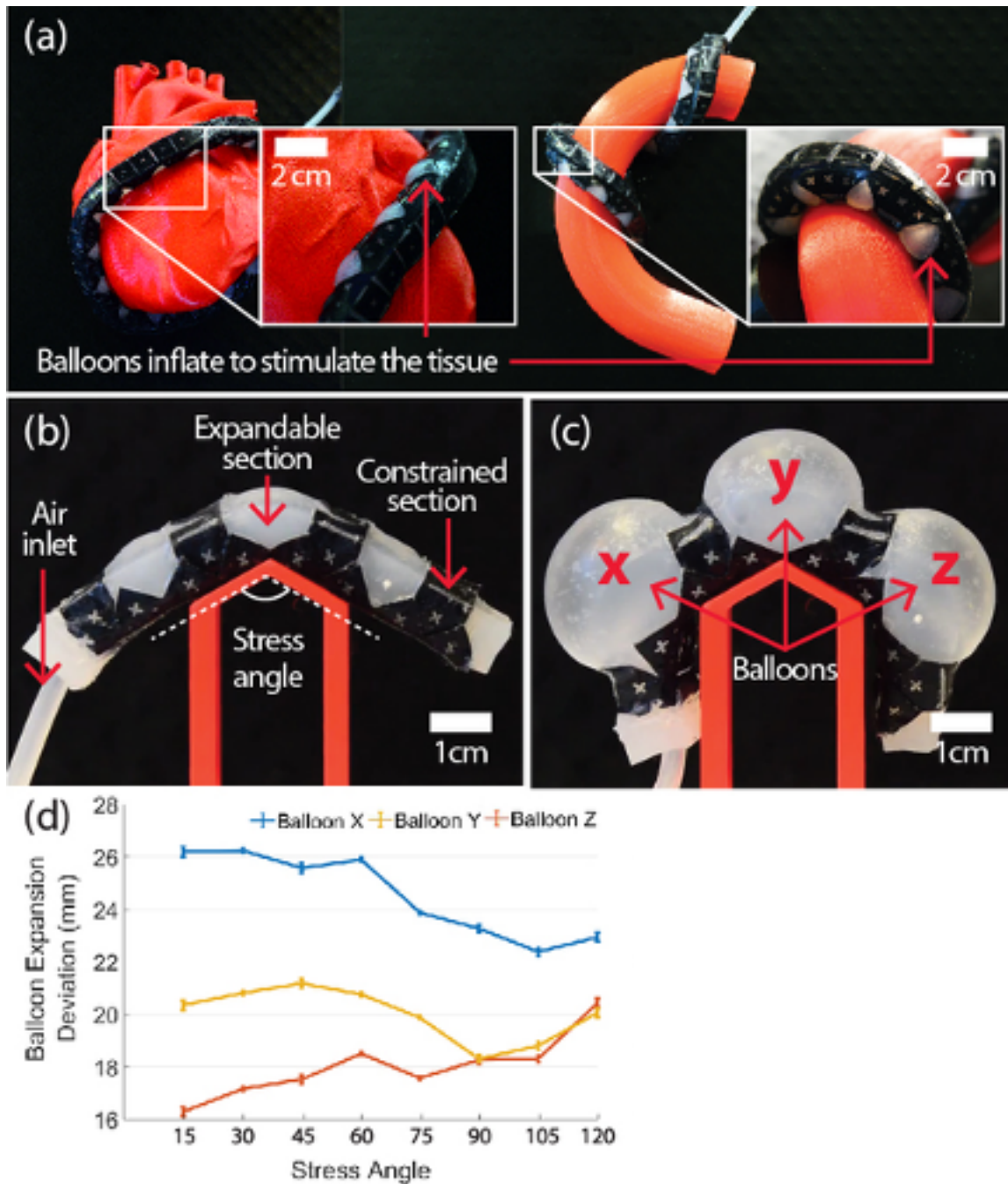
Figure 1. The configurable soft tool for mechanotherapy based tissue repair (SRS). (a) Examples of how the SRS can be configured around different organs. (b) Experimental rig and the SRS in a relaxed state. (c) The SRS expanded at 18 kPa of pressure under a SA of 15°. (d) Expansion of the balloons X, Y and Z under different stress angles. As the SA becomes sharper, expansion uniformity decreases. However, the SRS remains functional under all SAs.

24 DEVELOPING A MOBILE CLINICAL LANGUAGE ANALYSIS TOOL: CAPTURING CHILDREN'S STORYTELLING SAMPLES THROUGH CITIZEN SCIENCE

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[1]Therapy Box, London, United Kingdom. [2]Newcastle University, Newcastle, United Kingdom. [3]Bristol Speech and Language Therapy Research Unit, Bristol, United Kingdom. [4]Sirona, Bristol, United Kingdom.

BACKGROUND

Speech and language therapists (SLTs) use assessments of children's storytelling to support the diagnosis and treatment of language disorder. However, this is labour intensive involving manual transcription of the child's spoken output analysis of language complexity and comparison to normative data. An NIHR i4i funded collaboration between industry, clinical and academic partners is designing, developing and evaluating an application for SLTs: 'Language Explorer'. This app will record a child's storytelling in a controlled context, uses speech recognition to aid rapid transcription and complete analysis of the sounds, words, sentences, grammar and story structures the child uses.

AIMS

To gather the normative data and provide data for the machine-learning driving the language analysis functions a novel citizen science project was undertaken.

METHODS

A mobile app was co-designed with clinicians and children within the target age range. A proportionate stratified sampling technique was used and stratified with reference to age bands (six bands from 4;0-7;11), gender and five socioeconomic status categories. This was supported by targeted marketing and social media activity. Manual transcription and analysis of 600 language samples was undertaken and compared with automated analysis and the semi-automated transcription process for agreement level and time taken.

RESULTS

In total 4000 samples were received. The stratified sampling goals were achieved across each sub-group within the sampling framework; having been graded to meet audio quality levels sufficient for transcription and analysis.

DISCUSSION

Using a citizen science approach to data collection for the purposes of standardisation of a future clinical tool for children is a time-effective and feasible process. Quality of data collected via mainstream mobile phones is sufficient for the purposes of language sampling. Importantly collection of more than six times the target number of samples was required to fulfil our stratification strategy.

25 DEVELOPMENT OF A DIGITAL DESIGN AND MANUFACTURING WORKFLOW FOR PERSONALISED PAEDIATRIC PROSTHETIC SOCKETS

Simin Li[1], Theodoros Marinopoulos[1], James Smith[1], James Gardner[1], Brad Kennon[1], Jatin Kumar[1], Nuradilla Alias[1], Todd Shepherd[2], and Thomas Allen[2]

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BACKGROUND

The functionality of socket-based prosthesis has improved since its conception, due to advancements in microelectronic technologies and material science. However, the fabrication steps of the socket remain largely unchanged. Existing sockets have fixed shape and rigidity, and therefore, are not fit for residual limbs of children which grow non-uniformly and experience both long- and short-term volumetric changes.

AIMS

The project aims to develop a robust and personalised prosthetic socket that is comfortable, suitable for exercise, and adaptable to limb growth via digital design and manufacturing methods.

METHODS

Three main areas of research have been explored in this project: a) develop an automated design workflow which can generate anatomically conforming socket geometry with spatial-varying auxetic structure using Rhinoceros 3D, via a developed Grasshopper routine; b) select and characterise functionally gradable materials for additive manufacturing of prosthetic socket components using material extrusion; c) characterise the mechanical performances of the additively manufacture socket components and prototype.

RESULTS & DISCUSSION

Progress made on the project thus far has been directed towards the development of a proof-of-concept prototype in all three mentioned areas. A fully-parametrized Computer-Aided Design (CAD) software-routine with 27 parametric set-points (can be further added/removed based on prosthetists' requirement/input) was developed for increasing prosthetic forming efficiency with no or little requirement of CAD skills. A prototype socket with stiffness gradient stemming from novel CAD design, materials selection and auxetic structure design was realised. Each socket component was mechanically tested in both static and dynamic conditions, and the final prototype socket was tested using a simulated socket-testing apparatus in accordance with the standard (BS EN ISO 10328:2006). The result presented in this study demonstrated both the feasibility and challenge aspects of the proposed design and manufacturing workflow with recommendations for future improvement.

26 DEVELOPMENT OF A MOBILE APP 'HEAR ME OUT' TO SUPPORT AUDIOLOGY PATIENTS

Max Bosch[1], James Jason[1], Lucy Rothwell[1], Daiana Bassi[2], Sue Conner[2], Yun Fu[1], Dean Mohamedally[1], Gemma Molyneux[2], Graham Roberts[1], Neil Sebire[2], Raouf Chorbachi[2], and Natalie Stephenson[2]

[1]UCL Department of Computer Sciences, London, United Kingdom. [2]Great Ormond Street Hospital NHS Foundation Trust, London, United Kingdom.

BACKGROUND

Transition into adult services can be a challenging time, where young patients are very quickly expected to take responsibility for their own medical care. Studies have shown that transition can be linked to a decline in health, as patients struggle to cope with the stresses and demands that go with the change from paediatric to adult services. In order to support children through transition, GOSH launched 'Growing Up, Gaining Independence' support programme.

AIMS

To further develop the support available through this programme, the Audiology team designed a mobile app aimed at patients preparing to transition into adult care.

METHODS

As part of a joint collaboration between GOSH and UCL computer science (CS) through the industry exchange network, the prototype mobile app 'Hear Me Out' was developed using Ionic. In addition, a content management system was developed using NodeJS, with a MySQL database to allow content delivered via the app to be to edited and updated.

RESULTS

The mobile app provides helpful information to patients and families, including features such as 'MyStory' that allows patients to log important events such as appointments or symptoms. The app has support in the form of a glossary to help patients to understand medical terminology and includes information on NHS support services that provide further patient support. The app is ready to be trialled with patients and families, to gather feedback on how the design and content can be improved.

CONCLUSION

This app is an example of how technology can be developed to support children and young people gain independence and manage their medical care with confidence.

27 DEVELOPMENT OF AN APP FOR FAMILIES OF PATIENTS ON THE GOSH PAEDIATRIC INTENSIVE CARE UNIT

Yu Du[1], Yuexi Fang[1], Kamile Sakelyte[1], Daiana Bassi[2], Sue Conner[2], Yun Fu[1], Dean Mohamedally[1], Gemma Molyneux[2], Graham Roberts[1], Neil Sebire[2], Rufaro Ndokera[2], and Samiran Ray[2]

[1]UCL Department of Computer Sciences, London, United Kingdom. [2]Great Ormond Street Hospital NHS Foundation Trust, London, United Kingdom.

BACKGROUND

Paediatric Intensive Care Units (PICUs) can be very stressful environments for families of sick children. PICU has more restrictions than general wards, and activities such as visiting hours can be very different from other areas of the hospital. Currently, information is available to families in paper form and displayed around the unit.

AIMS

We would like to revolutionise our communication strategy to make information available digitally in the form of a mobile app, allowing families to engage with this information more flexibly.

METHODS

As part of a joint collaboration between GOSH and UCL computer science (CS) through the industry exchange network, a mobile app that delivers information to parents was developed using Ionic. A web application, which allows clinical teams to manage content, was developed using NodeJS with a MySQL database.

RESULTS

The mobile app delivers a broad range of information about the PICU ward, including information on access, staff groups, and equipment used. In addition, a FAQ section is included that was developed in partnership with patients and families. The submission of Feedback is also possible via the app; this allows users to submit questions, or comments, on the content and information.

CONCLUSION

This mobile app is an example of how the Hospital might develop new ways of communicating important information to patients and families using our services.

28 EDUCATING CHILDREN AND YOUNG PEOPLE ABOUT THEIR ACTIVE INVOLVEMENT IN THE DESIGN OF MEDICAL DEVICES

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[1]Sant Joan de Déu Children's Hospital, Barcelona, Spain. [2]University of Liverpool, Liverpool, United Kingdom.

BACKGROUND

Children and young people's participation in the design of health research and innovation is a fragmented practice across Europe. Children and young people have the same rights as adults and deserve the right to express and have their views heard. In the last decade, many industries have developed the right methodologies and processes to involve their customers in the design and delivery of its services or products, but often children and young people are not aware they can have a voice. To guarantee children and young people's active engagement for co-designing technologies and devices that will impact on their health it is essential to educate them in this role.

AIMS

To develop an online education tool, Youngsters Engagement Active in Health (YEAH) to educate children and young people in the field of patient engagement and their role in the development of medical devices designed for the paediatric population. The aim is to co-design four training modules: co-design of research protocols; Patient Reported Outcome Measures and Quality of Life measures; informed consent, and educational materials for young patient engagement in science communication.

METHODS

Active involvement of members of three Young Person's Advisory Groups (YPAGs) members from the teams of Liverpool, Riga and Barcelona to co-creation educational resources to be integrated into a digital toolkit.

RESULTS

Digital toolkit addressed to train members of YPAGs, High School students and young citizens. Accessible in English and in Spanish.

DISCUSSION

Involving children and young people in the co-design of medical devices guarantees suitable products to this target population. Prior to involving them and to guarantee meaningful participation it is essential to educate them in this innovative citizens' involvement field.

EMBEDDING PATIENT INVOLVEMENT IN DEVICE DESIGN FOR THE DIAGNOSIS OF INDUCIBLE LARYNGEAL OBSTRUCTION IN CHILDREN

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BACKGROUND

Inducible laryngeal obstruction (ILO) is a debilitating condition, leaving people unable to exercise or participate in normal daily activities. The best method of diagnosing ILO is continuous laryngoscopy during exercise but there is no equipment available to do this in children.

AIMS

This project aimed to design a device to enable continuous monitoring of the upper airway during exercise, allowing an accurate diagnosis to be made. A specific focus was the engagement of patients and parents/guardians in the design process.

METHODS

Children (aged 11-15 yrs), with a previous diagnosis of ILO, participated in co-design workshops, identifying current problems, providing design ideas, creating protypes and choosing the final concept. Remote participation was also supported through specially created workbooks.

RESULTS

Three concepts were developed from the children's initial outputs. Feedback from the children resulted in concept 3 being chosen and the capture of design developments (Table 1). A prototype was then created and successfully tested with an adult volunteer running on a treadmill.

DISCUSSION

Embedding the involvement of patients, with their experience of ILO testing, as an essential part of the design and development process enabled a smooth exchange of ideas and understanding between patients, clinicians and designers. The capture of valuable user insights resulted directly in the creation of a device which will be further developed and be comfortable, effective and fit for purpose. Timely and accurate diagnosis of ILO will significantly reduce morbidity by enabling patients to access appropriate therapy and a complete resolution of the physical problem. True involvement and engagement in healthcare improvement is empowering for young people and promotes mental health and wellbeing.

Design developments	
It must...	**It could...**
1. Be made from a more breathable material 2. Have mesh everywhere for choice when securing the scope 3. Have a mesh width of approximately 8cm 4. Have velcro fixings 5. More velcro on the back straps to suit a wider range of people	1. Have a modular design 2. Be black or have some colour 3. Have back straps that cross for extra secure fitting 4. Have additional mini velcro straps for securing the cables 5. Have stretchy under arm elastic for comfort 6. Have lower neckline

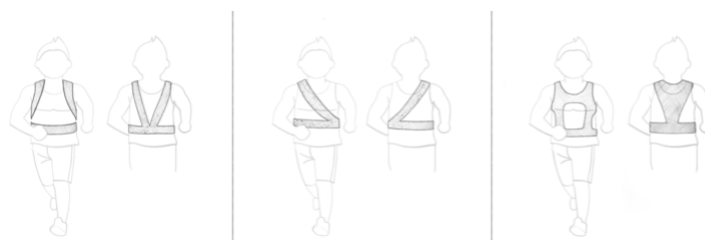**Table 1.** The children's design likes and dislikes.

Figure 1. Concept sketches.

30 IMAGE ANALYSIS AND MACHINE LEARNING FOR SKELETAL DYSPLASIAS RECOGNITION

Maria Luisa Davila Garcia[1], Maria-Cruz Villa Uriol[1], Vitaveska Lanfranchi[1,2], and Amaka Offiah[1,3]

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BACKGROUND

Skeletal dysplasias (SD) are a group of genetic disorders presenting with abnormal growth and development of bone and cartilage. Individually rare, together they are more common than many cancers (birth rate = 240-320/million). Diagnosis is dependent on accurate radiographic interpretation. Only a reduced number of doctors have that expertise, causing delays in diagnosis, complicating prognosis and the development of novel therapies.

AIMS

To design, develop and test the feasibility of a novel artificial intelligence framework based on automatic image analysis and machine learning (ML). Our model is trained with the "dREAMS" database (> 15,500 x-rays, 500 patients, 400 SD, with expert annotations).

METHODS

First, image processing (sharpening, image equalization, noise filtering and binarization with dynamic threshold) is used to enhance bone-area features from radiographs. Second, we calculate a number of keypoints representing the most informative part of the image. Scale invariant features such as SIFT, SURF, BRIEF and BRISK, build the feature vector characterizing an image projection of the diseased spine. New images are compared with the feature vector to determine the class with highest similarity, using an SVM (Support Vector Machine) as classification model.

RESULTS

Experiments performed on 21 images (lateral view, with achondroplasia). SVM (with gaussian kernel function and trained with features from dREAMS dataset) was fed a feature vector with 14x768=10,752 bins. The SVM was able to classify images with accuracy of 61.2% into two classes: with or without achondroplasia.

DISCUSSION

Currently the accuracy is low, and the model is being improved. To increase the model's accuracy, we will include more images in the training phase, and increase the dimension of the Feature Vector. We believe that by harnessing the capabilities of machine learning, the tool developed could contribute to increased speed and accuracy of the radiographic diagnosis of SD.
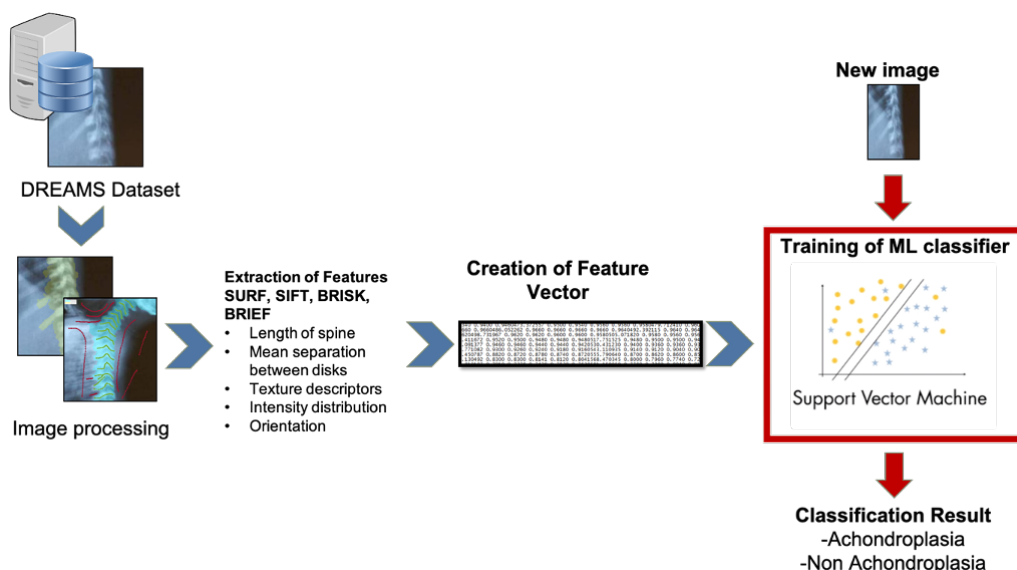

Figure 1. Methodology.

31 INVOLVING PARENTS IN THE DESIGN OF A CLINICAL EVALUATION OF A DIAGNOSTIC TEST FOR RSV

A Joy Allen[1], Rachel Dickinson[1], Kasia Kurowska[1], A John Simpson[1], and Malcolm Brodlie[2]

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BACKGROUND

Bronchiolitis, caused by Respiratory Syncytial Virus (RSV) infection, is one of the most common reasons for infants and young children to be admitted to hospital. Using conventional laboratory-based testing it can take over 24 hours for a result to become available. RSV is highly contagious so there is a need for fast and accurate diagnostic testing. Roche Diagnostics funded us to evaluate their point of care Cobas® Liat system for diagnosing RSV at the Newcastle Great North Children's Hospital and Sunderland Royal Hospital.

AIMS

To involve parent groups in our study design and thereby maximise the timely recruitment of participants to our study.

METHODS

We formed a focus group containing parents of infants and young children who reviewed our information packs and discussed how to improve the clarity and the perceived importance of our research. We also collected feedback on the acceptability of the proposed sampling procedure.

RESULTS

To help support informed decision-making by parents the focus group suggested we:
• provide a short lay summary
• include a statement around the benefits of this research beyond those included in the study
• remove all 'researcher style' statements
• reduce the length of the information sheet

The focus group also felt that the importance of the research would outweigh the concerns they had over the nasopharyngeal aspirate sampling technique and suggested how the research nurse could introduce the procedure.

DISCUSSION

The success of this research required seeking permission from parents of eligible participants at an incredibly stressful and vulnerable time within a clinical health care setting. Understanding parents view points and experience allowed the research to be more responsive to their unique needs. Our results indicate that involving the public in the design of diagnostic test evaluations can improve the study and support recruiting on time and on target.

32 NEEDLE FEAR IN DENTALLY ANXIOUS CHILDREN: COULD CO-DESIGNED TECHNOLOGY BE THE ANSWER?

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AIM

Needle fear is common amongst children (50%), and may lead to avoidance of medical or dental treatment.   However, there are few interventions available to reduce child needle fear. This study aimed to explore the concept of needle fear in children who have dental anxiety and identify their preferences for an intervention to reduce their anxiety.

STUDY DESIGN

A supplementary analysis of qualitative data was conducted. Transcripts were obtained from two interview-based studies with children with dental anxiety. Participants in both studies were children aged 10-16 years who had been purposively sampled from primary and secondary care dental settings. Transcripts from 22 interviews were available. The data were analysed using a framework approach by two researchers independently.

RESULTS

The analysis revealed three main themes: experiences of needles; nature of fear and desire to feel in control of the process. A range of experiences of needles were described. Children expressed a dislike of needles or injections, and the physical, emotional and behaviour impacts of their needle fear. For some, their fear was due to fear of the unknown. The nature of the fear related to the appearance of the needle (with children imagining what it might look like without having seen one before) and the feel of the needle (particularly anticipatory concerns about pain). Children described ways they tried to control the process through distraction, having choice over the level of information sought and development of trust in the dental professionals. Technological solutions to enhance control were suggested including webpages designed for children by children and an app for smartphones.

CONCLUSIONS

Findings from this study provide valuable insights which will help inform the co-design of an intervention, embracing new technology, to reduce needle fear. Children are also enthusiastic about their role in co-producing future research to evaluate the effectiveness of this intervention.

33 "SHOW, DON'T TELL": CO-DEVELOPMENT OF DIGITAL PATIENT INFORMATION FOR A RARE CHILDHOOD DISORDER

Young Persons Advisory Group (YPAG)[1], Childhood Uveitis Study Steering Group (ChUSS)[2], Deirdre Leyden[3], Salomey Kellett[2], Christine Twomey[1], Jugnoo Rahi[2], and Ameenat Lola Solebo[2]

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BACKGROUND

Childhood uveitis is a group of rare, heterogeneous, inflammatory, chronic and potentially blinding eye disorders. Affected children may have associated complex systemic disease. Research is currently underway to improve how we detect, monitor and treat disease in order to improve outcomes. However, there has been an absence of patient's voices in the development of research and care processes for children with this and other rare eye diseases.

AIMS

We aimed to inform and engage affected children, young people and their families through animations using language and pictures chosen by them, to show that there is "no research about them without them".

METHODS

In partnership with GOSH/UCL Creatives, a 'Generation R' Young Person's Advisory Group, and a patient and family Childhood Uveitis study steering group, the study team developed the content and script for the videos. Images were drawn by children to represent uveitis and uveitis research. Video narration was undertaken by affected children. The videos were disseminated through the steering group for final feedback and approval.

RESULTS

Three short animated videos were developed on childhood onset uveitis, describing the disease, treatment and research. These are hosted on an academic and hospital website, and on YouTube (https://www.youtube.com/watch?v=1vBzqS_HD_E). In recognition of their impact, these videos are also being adopted by the Paediatric Rheumatology European Society, Juvenile Arthritis Research, and the American Association for Paediatric Ophthalmology (AAPOS) for wider dissemination.

DISCUSSION

Our child, young person and family co-development approach has enabled creation of digital resources which engage affected children and families, are useful for organisations explaining uveitis to newly affected families, support study recruitment, and have increased visibility of the disease, a common concern for affected families.
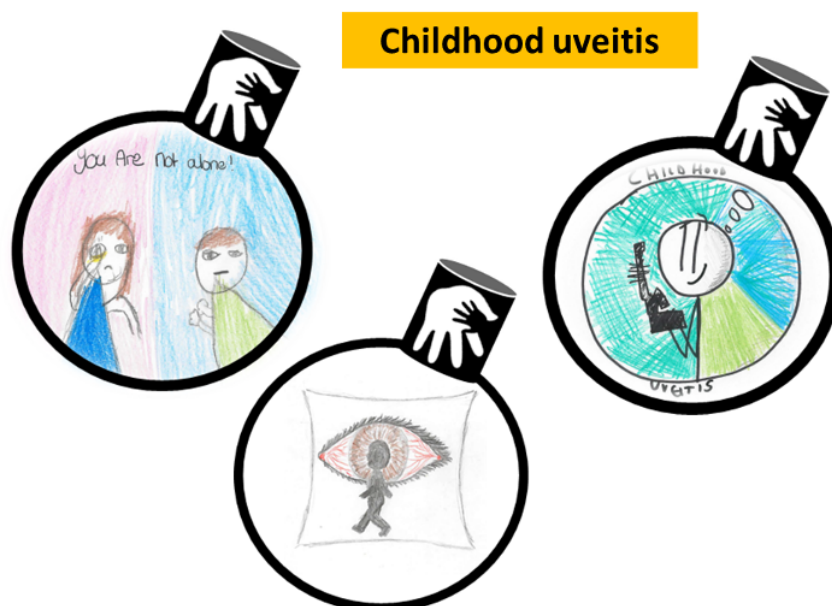
SMART ACTIGRAPHY SLEEP ASSESSMENT

Hajar Razaghi[1], Ruth Kingshott[2], Lowri Thomas[2], Heather Elphick[2,3], Abigail Needham[4,3], and Angel Jimenez-Aranda[4,5]

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Sleep is an essential basic human need. National Institutes of Health recommends at least 10 h of sleep for children, 9–10 h for teenagers, and 7–8 h for adults. However, it has been reported that almost 1/3 of the adults sleep less than 6 h per night and it is estimated that 11 million children have sleep-related difficulties in the UK. Hospital attendances in England for children under 14 with sleep disorders have tripled in 10 years.

While polysomnography is the gold standard approach for diagnosing specific sleep disorders, it is impractical and too expensive for use in the identification of more prevalent issues. An alternative is the use of actigraphy, accelerometer-based wearable technology which may be used as a diagnostic aid for specific sleep disorders.

In this study we collected stakeholders' feedback on current devices and clinical pathways for children and young people. 47 stakeholders were asked about sleep diaries and actigraphy considering all aspects in the process (referrals, completing a diary, wearing the technology, analysing and interpreting results…). Feedback received confirmed the current solution for paediatric sleep diaries and actigraphy is not ideal and there is a need to identify new approaches to increase usability, acceptability and stakeholder's satisfaction.

Based on these findings, a multidisciplinary team co-designed a user-friendly digital sleep diary app and a clinical sleep/wake report combining the data captured from the wearable device and the sleep diary. The app for families and young people simplifies the collection of accurate data and reduces missing values and data entry mistakes. The report facilitates diagnostics of behavioural sleep problems and saves staff time to analyse actigraphy and sleep diary data. This innovative technology solution solves main issues highlighted by the stakeholders. Next steps include the evaluation of this new approach in clinical environments.

35 SPOTTING THE SICK CHILD FOR FAMILIES: CO-DEVELOPMENT OF A MOBILE PHONE APP

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BACKGROUND

Acute childhood illness accounts for the majority of episodes of illness in children under 5 years of age. Although most acute illnesses are minor, parents need accurate and accessible information to help them know when to seek help for a sick child, even more so during a pandemic when access to health services is limited. The change from face-to-face to predominantly virtual consultations in primary care has highlighted a need for access to information in the home.

AIMS

The aim of this paper is to describe a research programme to co-develop the content for a mobile app designed to help parents know when to seek help for an acutely ill child under the age of five years. This is the work of the Acutely Sick Kid Safety Netting Interventions for Families (ASK SNIFF) collaboration of parents, academics, clinicians and NGOs.

METHODS

Working with parents and health professionals, we used a 6 step framework to guide our rigorous evidence based approach: from scoping and systematic reviews, mapping clinical guidelines and qualitative research to co-development of the content and expert review.

RESULTS

Few existing interventions have reported systematic co-development, which we found to be closely related to (in) effectiveness. Our participants want easy access to information on symptoms of acute illness, consequently together we developed the desired content, format and delivery methods for a mobile app. The resulting content is augmented by video clips illustrating symptoms.

DISCUSSION

Our collaborative approach, embedded in every stage of our work, ensured that the end result reflects the expressed needs of parents and the clinicians they consult. We have not found any other resources which have used this approach, which may explain why existing resources have yet to demonstrate significant impact on consultation rates for non-urgent illness or parents' knowledge and confidence.

36 THE EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE TO FOSTER RESEARCH ON PAEDIATRIC MEDICAL DEVICES

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BACKGROUND

Currently few medical devices (MDs) are designed for children, most are borrowed from adult applications and used without a specific indication. Designing paediatric medical devices can be challenging because children are smaller and more restive than adults, body structures and functions change throughout childhood, and children may be long-term device users bringing new concerns about device longevity and risks.

AIMS

The H2020 EU funded European Paediatric Translational Research Infrastructure (EPTRI) is working to establish thematic research platforms by networking the paediatric researchers and providing solutions to improve the development of medical devices dedicated to children as well as other fields of paediatric research.

METHODS

During the context analysis performed by EPTRI, a survey has been conducted at Pan-European level to map paediatric research facilities and expertise in several areas as, among others, the paediatric medical devices.

RESULTS

27 research units from 24 Institutions based in 12 different countries (particularly in UK, Italy and Germany) expressed their competence in medical devices research. They have mainly expertise in the design, development and prototype analysis of medical devices (Figure 1). Furthermore, over half of the respondents declared also expertise in end-user/usability assessment and device validation.

DISCUSSION

A large gap exists in paediatrics between the idea, the development and the clinical application of medical devices in the paediatric population, due to the physiological and ethical issues and the development costs. EPTRI will convey the identified experts in medical devices and will work to expand the critical mass of experts through an advanced survey and networking actions to provide services to the scientific community to develop tailored MD for paediatrics populations to help overcoming the gaps and needs in MD research, keeping pace with evolving technologies and innovations.
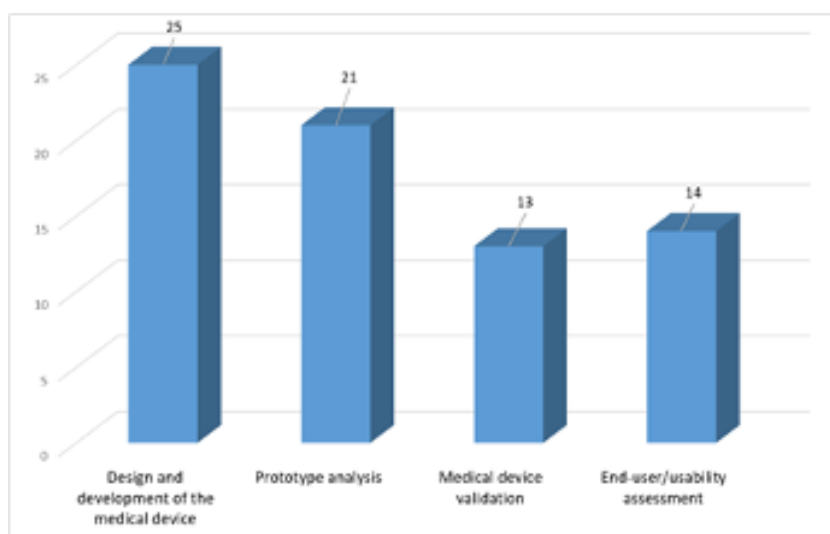
Figure 1. Expertise in MDs of the research units mapped by the EPTRI' survey.

37 THE IMPACT OF HEALTH TECHNOLOGY ON THE DELIVERY OF PAEDIATRIC CARE: A NARRATIVE REVIEW

Safya Benniche[1], Alison Firth[1], Charlotte King[1], Hannah Jacob[1], and Damian Roland[1]

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BACKGROUND

The use of technology in paediatrics is increasing, and new health technology will change the way in which paediatric care is delivered in the future. This review is part of the RCPCH Paediatrics 2040 project, which is developing a credible vision for the future of paediatrics in the UK.

AIMS

To summarise the impact of health technology on the delivery of paediatric care over the last ten years. To learn from existing technology use and make recommendations for future implementation.

METHODS

A search strategy was developed and two databases were systematically searched in August 2019 for relevant publications in English. Searches were limited to papers published between January 2009 and August 2019. We included papers that studied young people up to the age of 24. A thematic synthesis of the data from the included studies was undertaken using seven domains of paediatric care. Technology types included were: digital, communication, apps, diagnostics, AI/machine learning, genomics, virtual and augmented reality/gamification, sensors, wearables, big data, and assistive technology.

RESULTS

128 studies were included grouped by domain of care. Most included studies were defined as digital (n=55) or communication (n=37). Studies looked at the different types of health technology used within different domains of care, including secondary and tertiary care (n=39), public health and prevention (n=29), and community (n=20). Studies were assessed on delivery of care outcomes using positive, negative, mixed and no effect. The most common outcomes reported were adherence and satisfaction.

DISCUSSION

This review highlights the growing importance of technology in delivering paediatric care. Six themes emerged: the importance of clear guidelines, continuity of care, confidentiality and privacy, digital poverty, using a personalised approach, and using technology to supplement and not replace. In future, technology development should involve the end user throughout the design process.

38 USING TECHNOLOGICAL INTERVENTIONS TO HELP CHILDREN WITH ARTHRITIS TO BE MORE INDEPENDENT

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BACKGROUND

15,000 Children and Young People (CYP) in the UK have Juvenile Idiopathic Arthritis (JIA). 1,000-1,500 new cases are diagnosed every year. Currently there is no cure for JIA. Management interventions are available, but these are often stigmatising and children disengage. Improving self-management skills for children is particularly important as they transition to adulthood.

AIMS

The overall aim of this project is to develop technologies to improve the quality of life for children living with arthritis through co-design with diverse stakeholders.

METHODS

Co-design workshops (involving children with JIA, their parents, healthcare professionals and teachers) explored unmet needs from each perspective and how these could be addressed. Ideation techniques were used, such as storyboarding and prototyping, to facilitate discussion as the issues were explored.

RESULTS

A suite of three 'smart' JIA management tools and an app (which connects different users and records the data from the devices) were created. The 'smart' devices are: 1) a wearable that distracts children from joint pain, (2) a motivational physiotherapy tool that gamifies physiotherapy routines, (3) a device enabling better communication between child and teachers and (4) an app to track, record and display data. Initial feedback from users is positive. Further user insights are being incorporated into refinements for an upcoming proof of concept study.

DISCUSSION

Children with arthritis often struggle with the severity of their symptoms and the confusion of their condition management, so this intervention aims to address key symptoms and simplify self-management, enabling greater independence. The co-design process brought together the different perspectives and experiences of the stakeholders involved, identified overlapping priorities and used their knowledge to develop more engaging solutions to a previously unmet need.

Figure 1. Using prototype 1 to reduce pain.

39 UTILISING TECHNOLOGY TO INVOLVE CHILDREN IN RESEARCH ABOUT DENTAL DECAY

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BACKGROUND

Dental decay (caries) in primary teeth is common and disproportionately affects children from deprived backgrounds. Impacts include pain, difficulty eating and sleeping, and missed school. Silver diamine fluoride (SDF) is a new approach that appears to arrest caries, but further research is needed to determine its effectiveness and acceptability. PPI representatives of children with carious primary teeth and their parents, including those from deprived backgrounds, suggested the application of technology through videos was an important way to communicate about SDF research.

AIMS

To co-produce with children an information video about SDF to ensure it meets their needs.

METHODS

A video was co-produced with children aged 3-11 (n=7) that discussed caries, treatment options and SDF in the children's own words. Children designed the content, helped with filming and gave their own ideas to help explain and demonstrate the use of SDF (through the use of models and crafts) in ways other children would understand and engage with. The film was then professionally produced and children were asked for their input on post-production with adaptations made based on their feedback.

DISCUSSION

Children were involved throughout the production of the video and explained different aspects of SDF treatment they thought were important for other children to understand. The video also included subtitles which can be translated as required to aid inclusivity. The video will now be used for research, training and clinical purposes.

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