NIHR | Children and Young People MedTech Co-operative

BIENNIAL REPORT

JANUARY 2020 - DECEMBER 2021

CONTENTS

FOREWORD

It is with great pleasure that I present NIHR Children and Young People MedTech Co-operative's (NIHR CYP MedTech) second biennial report. NIHR CYP MedTech was launched in January 2018, bringing together seven paediatric NHS centres across the nation to develop health technologies to support the health and care of children, young people and their families. This has the potential to impact on future health for the next century.

The COVID-19 pandemic brought unprecedented challenges for the NHS and for the delivery of research and technology development. Teams were tasked with developing new and innovative ways of delivering healthcare which has paved the way for some of the most innovative technological solutions used in the NHS to date. Given the challenges, our team created novel methods to work with collaborators, children, young people and their families, and developed new methods of care delivery in the NHS.

In the last two years, NIHR CYP MedTech recognised the need to extend support to newborn babies including preterm babies to develop novel technological solutions to this vulnerable group. Our new neonatal theme in NIHR CYP MedTech led by Professor Don Sharkey focuses on diagnostics, monitoring, and inter-hospital transfer of neonates to reduce complications and improve their long-term outlook.

The NIHR CYP MedTech team has had a highly productive two years supporting the development and clinical evaluation of technologies for child health using virtual and augmented reality, robotics, 3D printing, artificial intelligence, data analytics, digital platforms, remote monitoring, advanced design, and biosensor technologies. We continually strive for the best and most advanced healthcare for children and young people through developing cutting edge technologies in key areas of unmet need. Key to this is developing meaningful collaborations with children and their families, industry partners, engineers, computer scientists, and designers as well as many other professionals.

I would like to personally thank all those who have worked hard in the last two years with and within our NIHR CYP MedTech team to ensure that children receive the best healthcare and a brighter future.

Professor Paul Dimitri
Director, NIHR CYP MedTech

STRATEGIC INTRODUCTION

Investing in research and innovation focused on children is key to ensuring effective and efficient treatments for childhood illnesses and conditions can be delivered. The health and wellbeing of children and young people is crucial to enable them to develop into healthy adults. However, children and young people are particularly vulnerable to a range of health challenges, including long-term conditions such as asthma, diabetes, epilepsy, neurodisability, and mental health disorders. This can have a profound impact on their physical and mental health, and affect millions of children and young people in the UK, costing the NHS and wider economy billions of pounds annually.

Children have been disproportionately affected by the COVID-19 pandemic. The disruption of daily routines, education, social lives, and healthcare services has presented significant challenges, especially for disadvantaged children who lack access to technology and supportive home environments. As a result, their mental health and wellbeing has suffered, highlighting the need for innovative solutions to these challenges.

NIHR CYP MedTech has recognised the need to develop innovative solutions to address the healthcare challenges faced by children and young people, which have only increased during the COVID-19 pandemic. As a result, we have increased collaboration with our partners to develop new ways of working, share best practices, and connect more groups through our networks.

This report highlights some of the projects and initiatives we are leading, and are partners on, to improve child health technology. Given the significant impact of childhood health on individuals and society, we continue to work across boundaries to push forward the innovative development of technology for children and young people.

We take pride in our contribution towards the development of effective and innovative child health technology, which will improve the health and wellbeing of children and young people both now and in the future.

> *“We take pride in our contributions to the development of effective and innovative child health technology”*

Our Mission

Our mission is to become a leading consortium for the development of child health technology, where we prioritise cutting-edge research and innovation to address the unique healthcare needs of children and young people with long-term conditions.

Our Vision

We are committed to developing safe, evidence-based, and cost-effective technologies that address the unique healthcare needs of children and young people.

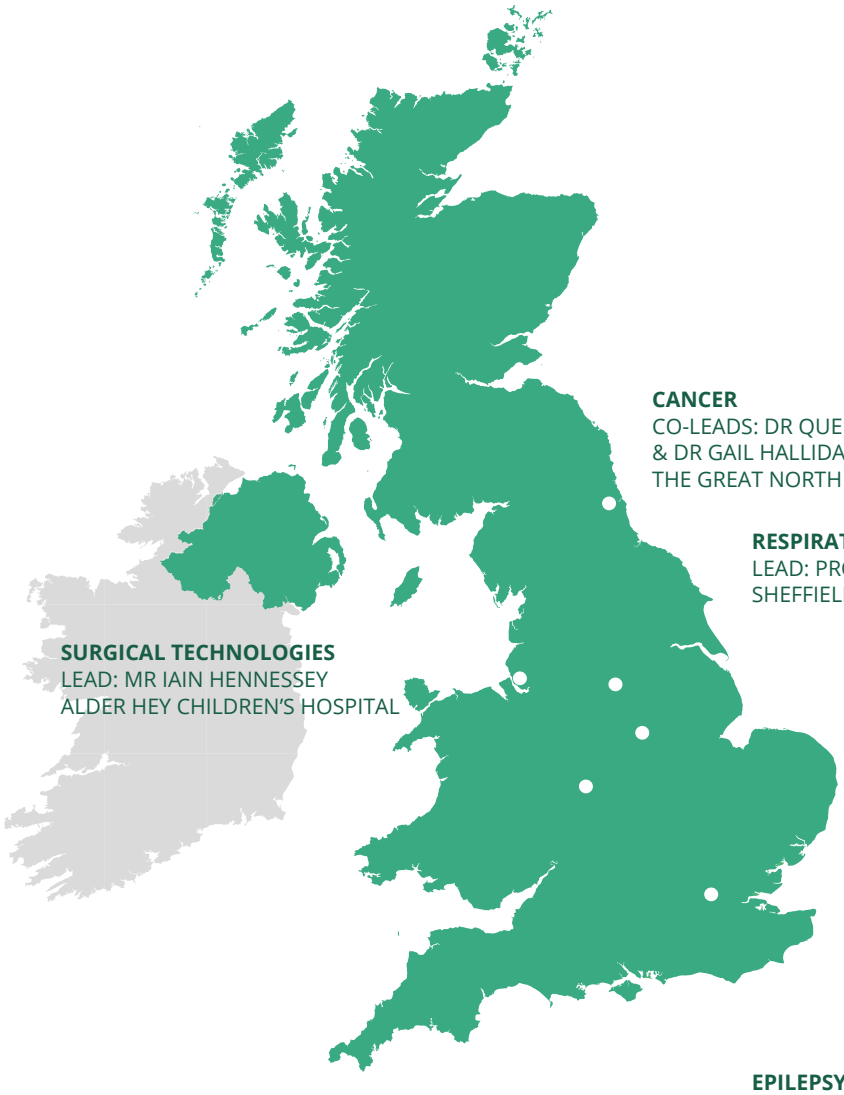
Our goal is to work cross-sector to improve treatment outcomes, reduce healthcare costs and enhance the quality of life for children and young people, and their families, living with long-term conditions.

THEMES

The NIHR CYP MedTech portfolio focuses on developing early stage technology, guided by key themes that are representative of the challenges children and young people face in their healthcare today.

Since our previous report covering activity in 2018-2018, our theme leads have continued to demonstrate excellence and leadership in core areas of MedTech development. New and exciting opportunities for collaboration across the UK have also highlighted the importance of a network approach to innovation in this area.

Our national network of experts in healthcare, academia and industry continues to grow, as does the scope of our work in response to emergent priority areas of high clinical need. As such, we have introduced a new theme to the NIHR CYP MedTech offering; Neonatal Technologies, led by Dr Don Sharkey (Clinicial Associate Professor of Neonatal Medicine at the University of Nottingham). We are delighted to welcome Professor Don Sharkey to the team, who gives more detail on this theme overleaf.



CANCER
CO-LEADS: DR QUENTIN CAMPBELL HEWSON
& DR GAIL HALLIDAY
THE GREAT NORTH CHILDREN'S HOSPITAL

RESPIRATORY, SLEEP & VENTILATION
LEAD: PROFESSOR HEATHER ELPHICK
SHEFFIELD CHILDREN'S HOSPITAL

SURGICAL TECHNOLOGIES
LEAD: MR IAIN HENNESSEY
ALDER HEY CHILDREN'S HOSPITAL

TRANSITION
CO-LEAD: DR PRIYA NARULA
SHEFFIELD CHILDREN'S HOSPITAL

CO-LEAD: DR HELENA GLEESON
QUEEN ELIZABETH HOSPITAL

NEONATAL TECHNOLOGIES
LEAD: DR DON SHARKEY
QUEEN'S MEDICAL CENTRE

RARE DISEASES
LEAD: DR LARISSA KERECUK
BIRMINGHAM CHILDREN'S HOSPITAL

EPILEPSY, MOVEMENT, AND MUSCLE DISORDERS
LEAD: PROFESSOR HELEN CROSS
GREAT ORMOND STREET HOSPITAL

NEONATAL TECHNOLOGIES

THEME LEAD:

DR DON SHARKEY
Professor of Neonatal Medicine and Technologies, Faculty of Medicine & Health Sciences, University of Nottingham

45%

45% of mortality in **under 5 year olds** happens in the **first 28 days** of life

Newborn survival is improving, but many preterm babies have long-term health conditions such as brain injury and chronic lung disease

FOCUS

- Improve **neonatal monitoring and resuscitation immediately after birth** to reduce potential injuries and associated long-term conditions
- Optimise **inter-hospital neonatal transfer** to reduce complications related to transport
- Advance neonatal care through **artificial intelligence and computer science** for diagnostics and monitoring

“ Neonatal technologies is a new theme to the CYP MedTech and crucial to babies and their families. Many newborn problems can end up with life-long complications and disabilities. If we invest in new neonatal innovations, we can reduce these and ensure many more families go through life with better outcomes. ”

- Dr Don Sharkey

REFLECTIONS ON 2020-2021

We asked our theme leads across the UK to reflect on what has truly been an unprecendented year, what lessons they have learned, and what they imagine the impacts on child health technology will be moving forwards.

- Cancer
- Rare Diseases
- Respiratory, Sleep & Ventilation
- Epilepsy, Movement & Muscle Disorders
- Transition
- Surgical Technologies
- Neonatal Technologies

What are some of the issues and challenges you face when seeking to secure funding for new innovations?

One of the main issues is the tolerance of risk. The traditional research mind frame seems to gravitate towards safe bets, which often isn't the way to a truly breakthrough product. Another big issue is that clinical founders are unable to drop their day job entirely to attract commercial funding.

The scale of development of new technology for asthma monitoring has been explosive over the last few years. This presents a challenge in terms of funding as there are so many potential solutions in development. The funding pathway still requires several years from development to NHS adoption, and the mechanisms for adoption are still very difficult to navigate. Good technologies are potentially missed because the route to adoption was not available to them.

One of the biggest issues is personally engaging the right stakeholders to ensure that any innovations will have the maximum impact and have the best chance of being adopted widely. Identifying funding calls for pilot work is also a challenge.

Over the past two years, what have been the biggest challenges in your specialty?

COVID has been a challenge for parents and families visiting on neonatal units as we tried to keep the most vulnerable babies safe through a great deal of uncertainty. However, we all adapted and adopted new technological ways to link with parents and keep them updated on their baby's progress.

One of the biggest challenges was being able to keep track of patient requirements using a balance of necessary hospital visits and virtual consultations. Accessibility has been key. Developing virtual assessment packages has also been a challenge.

Across the specialty we were impacted by COVID in different ways at different sites and at different times. A general feature was the decrease in interaction between the children's cancer sites. Prior to COVID, there were very frequent face to face meetings at a wide range of venues. During the pandemic, everything became virtual and the personal interaction largely went, which made ad hoc negotiations and collaborations challenging. The basic children's cancer work continued irrespective of COVID but resources were redeployed from many sites, and everyone was restricted to basic service provision.

The biggest challenge for respiratory services over the last year was keeping our children safe whilst being unable to monitor them face to face. One specific problem was the inability to directly monitor the lung function of children with asthma. However, this has opened up new opportunities in terms of finding different technologies to use for remote monitoring, which may prove to be beneficial in the longer term.

Why is it important to include CYP in the development of new innovations in your speciality?

Including parents of children who have required neonatal care is crucial in neonatal medicine. Family integrated care can improve outcomes, reduce length of hospital stay, and parental wellbeing.

Because they have the best ideas! There is nothing better than CYP if you want a fresh view. Alder Hey Children's Hospital was inspired by the thoughts, drawings, and wishes of the children that use it.

CYP are vital in any new developments and innovations in rare diseases as they are the experts in their conditions. Including CYP improves disease outcomes, such as quality of life which is often disproportionately impacted in CYP affected by rare diseases.

Any new developments need to be practical and user friendly. It is therefore vital to include users in the development process.

> *"Family integrated care can improve outcomes, reduce length of hospital stay, and parental wellbeing."*

What is your vision / hope for new innovations in your speciality over the next five years?

My vision for research in rare diseases is to translate the advances that genomics has made over the past five years to develop new treatments and technologies to improve the challenges that our patients affected by rare diseases face: speeding up diagnosis, coordinating care, better information and support, and access to research itself – every rare disease patient needs to be offered the opportunity to take part in as that is the only way to improve outcomes.

I hope that we can use augmented technologies for triage and outpatient therapy delivery. I would regard it as a significant win if we could diminish or remove the needless disturbance caused by infusion pump alarms.

Deconstructing the clinic appointment has offered lots of opportunities for flexible working, which could support a more responsive young person service, including innovations that allow healthcare organisations to provide virtual 'visits' to adult services to support transition. Digital interactive tools that support the delivery of developmentally appropriate health education resources would also help adolescents to gain more confidence in managing their healthcare. Finally, a way of benchmarking services within NHS trusts and across specialties in real time would provide managers and clinicians with feedback from young people and their carers, and would to support constant service refinement.

PROOF OF CONCEPTS

An overview of some of the Proof of Concept projects supported by our theme leads, with seed funding from NIHR CYP MedTech.

Online diagnostic platform for rare diseases

UNMET NEED

There are over 8000 known rare diseases, affecting 1 in 17 people. Families affected by rare diseases often wait 5-30 years to receive a diagnosis, and 40% report being misdiagnosed. Accurate and rapid diagnoses are essential for prompt and effective treatment.

PROJECT

The team aim to evaluate the accuracy and acceptability of an online diagnostic platform powered by Microsoft Cloud (Dx29). Dx29 uses artificial intelligence, natural language processing, databases, and genetic variant analysis tools to synthesise huge quantities of data and suggest potential diagnoses.

PARTNERS

Birmingham Women's and Children's NHS Foundation Trust, Foundation 29, NIHR CYP MedTech

Self-management platform for young people with asthma

UNMET NEED

The National Review into Asthma Deaths found that 65% of asthma-related deaths were associated with potentially avoidable factors, including inadequate information and education on managing asthma. Recent studies have shown that educational interventions and written action plans improve asthma control in young people.

PROJECT

The team are developing a developmentally appropriate digital learning platform for young people with asthma that aims to educate and improve self-management skills. This high-quality resource is being developed in collaboration with young people which will be widely shared across NHS services.

PARTNERS

Sheffield Children's NHS Foundation Trust, Rich Wells, NIHR CYP MedTech

Sensory bedding for children with autism spectrum disorder

UNMET NEED

Sleep problems affect 60-90% of children with autism spectrum disorder (ASD). While weighted blankets are often used to improve sleep, the Royal College of Occupational Therapy has recommended that they should not be used for more than 20 minutes without continuous supervision.

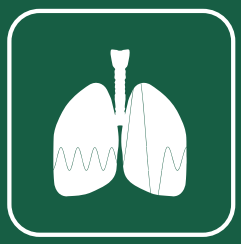
PROJECT

The Fidgetbum provides an alternative to a weighted blanket, and is a stretchy cotton compression sheet that wraps around the mattress to hold bedding in place. The team are assessing the effect of the Fidgetbum on the quality and duration of sleep in children with ASD.

PARTNERS

Sheffield Children's NHS Foundation Trust, University Hospital Southampton NHS Foundation Trust, Brunel University, Oxford Brookes University, Fidgetbum, NIHR CYP MedTech

Remote lung function tests in children



UNMET NEED

Portable spirometry devices have been widely used by children and young people at home during the COVID-19 pandemic. However, the use of portable spirometry devices to measure lung function in children and young people has not yet been validated.

PROJECT

The team are comparing portable spirometry devices with the gold-standard lung function test in children with and without respiratory conditions. The team are also comparing the accuracy of using portable spirometry devices in healthcare settings with using the devices at home.

PARTNERS

Sheffield Children's NHS Foundation Trust, Great Ormond Street Children's Hospital NHS Foundation Trust, Leeds Teaching Hospitals NHS Foundation Trust, Royal Hospital for Children, Glasgow, Intermedical, Rich Wells

Educational app for families affected by rare diseases

UNMET NEED

Parents of children who are newly diagnosed with a long-term health condition report feeling incompetent, stressed, and overwhelmed. Accessing reliable and accurate information is one of the main challenges faced by patients and families affected by rare diseases.

PROJECT

The team are developing a personalised rare diseases app to provide information and support for patients and families affected by rare diseases. The team are also identifying alternative ways of sharing information with patients and families who would prefer not to use the app.

PARTNERS

Birmingham Women's and Children's NHS Foundation Trust, Roald Dahl's Marvellous Children's Charity, Schappit Ltd, NIHR CYP MedTech

Novel device to collect midstream urine in infants

UNMET NEED

Urinary tract infections account for 14% of paediatric emergency department visits. Collecting urine samples from infants is challenging and about 30% are contaminated by bacteria. Although contamination can be reduced by collecting midstream urine, no device can currently achieve this in infants.

PROJECT

Taking a user-centric approach, the team are developing a novel device to collect urine in infants that reduces contamination by separating midstream urine. This device will benefit both patients and the NHS, and will reduce unnecessary prescriptions for antibiotics.

PARTNERS

University of Oxford, Community Healthcare MIC, NIHR CYP MedTech

Earlier movement disorder detection using Artificial Intelligence

UNMET NEED

Movement disorders (e.g. cerebral palsy) are typically diagnosed at 18 months of age, however specialist long-term observation could reduce this diagnosis to 6 to 9 months. Neural plasticity decays with age and early specialist intervention could have a profound impact on the development of children with movement disorders.

PROJECT

The team are investigating the use of artificial intelligence (AI) to track and classify infant movements into normal and abnormal patterns. This will be developed into an app allowing parents to record their infant's movements to support detection of abnormal patterns, aiding in the diagnosis of movement disorders at a younger age.

PARTNERS

Dr Alexander Turner, Prof Don Sharkey, University of Nottingham, NIHR CYP MedTech

Multi package approach to priming key neonatal technologies

UNMET NEED

Neonatal complications are the leading cause of death and life-long disability among children in the UK. Despite this a recent survey of leading paediatric and neonatal resuscitation experts suggests that 69% believe delivery room technology research was poorly funded and 74% say the technology has fallen behind relative to other areas of clinical medicine.

PROJECT

The team is receiving pump-priming funding to strengthen three areas of neonatal MedTech : 1) provide pilot data on advanced newborn resuscitation system with multi-parameter vital sign capabilities, 2) use AI to predict death and severe morbidity, and 3) investigate novel anti-microbial polymers ability to inhibit biofilm build up on neonatal technologies.

PARTNERS

Prof Don Sharkey (theme lead), Dr Tng Chang Kwok (neonatal clinical fellow), University of Nottingham, SurePulse Medical Ltd (SPM), NIHR CYP MedTech

EVENTS

Engagement with our key stakeholders, including professionals from healthcare, academia, industry and third sector organisations, as well as children and families, remains a key focus for NIHR CYP MedTech. Now, more than ever, it is crucial to understand the multiple perspectives and expertise needed to tackle the emergent, and ongoing, challenges in paediatric healthcare.

In light of the COVID-19 pandemic, the NIHR CYP MedTech team has adopted a range of new approaches to bringing diverse groups together, to ensure the momentum for innovation in this area is not lost.

We continue to host a range of events, including workshops, patient and family focus groups, showcases, and even conferences, online.

A selection of key events are showcased below, with further details available on request.

KNOWLEDGE TRANSFER NETWORK WEBINARS

WORLDWIDE

NOVEMBER 2020

In collaboration with the Knowledge Transfer Network (KTN) and Innovate UK, NIHR CYP MedTech helped to plan, organise and facilitate two separate child health innovation events in November 2020. The purpose of the events was to determine industry and regulatory challenges for product development, areas of unmet clinical need, gaps in funding sources, collaboration opportunities, and strategies to accelerate paediatric product development. The events were attended by leading experts in healthcare, industry, academia, patient representatives, funding bodies, and charities. The first event focused on challenges and opportunities in child health technology and the second event focused on innovations in child medicines and advanced therapies. Crucial information from both events is being discussed with key stakeholder organisations to inform new strategies to overcome barriers and accelerate innovation for child health. NIHR CYP MedTech will help to disseminate the results of the events and the planning of future events to take outcomes forward.

NEONATAL TRANSPORT WORKSHOP

WORLDWIDE

SEPTEMBER 2021

NIHR CYP MedTech helped to facilitate a virtual workshop hosted by the University of Nottingham and supported by the newborn charity Bliss and the UK Neonatal Transport Group. The aim of the workshop was to identify the top ten research priorities for neonatal transport.

The workshop was well attended by representatives of neonatal transport healthcare professionals across the UK, organisations and charities involved with neonatal care, and parents/carers of infants that have undergone neonatal care. The workshop was run by an independent chair, Dr Andy Leslie and supported by Dr Don Sharkey, the NIHR CYP MedTech Neonatal theme lead.

The workshop participants took part in three breakout sessions to prioritise 22 research questions previously identified by surveys in 2019 and 2021. At the end of the workshop, the top ten list of research priorities for neonatal transport were agreed upon by attendees. This list is due to be published and reported widely such that research funding organisations consider these prioritised unmet needs in future funding calls to help improve the care and outcomes of newborns undergoing inter-hospital transfer.

The workshop is linked to some of the key objectives and work packages of the NIHR CYP MedTech Neonatal theme, to improve neonatal inter-hospital transport and reduce complications secondary to the transport of sick preterm and term babies.

Child Health Technology conference

WORLDWIDE

March 2021

In March 2021, NIHR CYP MedTech successfully organised and hosted the UK's first conference dedicated to technology for child health and paediatrics; the Child Health Technology (CHT) conference.

Across four memorable afternoons, the conference played host to 238 delegates from 16 countries across the globe, including healthcare professionals, industry experts, engineers, designers, academics, and patient representatives. CHT2021 received 45 abstract submissions from multidisciplinary teams based across 12 countries; 16 abstracts were selected for oral presentations and 25 were selected for poster presentations.

Conducted entirely virtually due to the ongoing COVID -19 pandemic situation, the purpose of the conference was to bring together experts to drive innovation by sharing their intricate knowledge of their chosen fields and encouraging interdisciplinary collaboration in the child health technology sector. To reflect this, the CHT2021 programme included inspirational keynotes from experts, interactive seminars, and live demonstrations of innovative technology that can improve the quality of lives of CYP with long-term disorders.

Key topics explored across the conference included Virtual Reality-assisted limb rehabilitation, mental health support for CYP in the internet age, pandemic and beyond, advancing the future of paediatric healthcare, and innovation to transform the NHS, to name but a few.

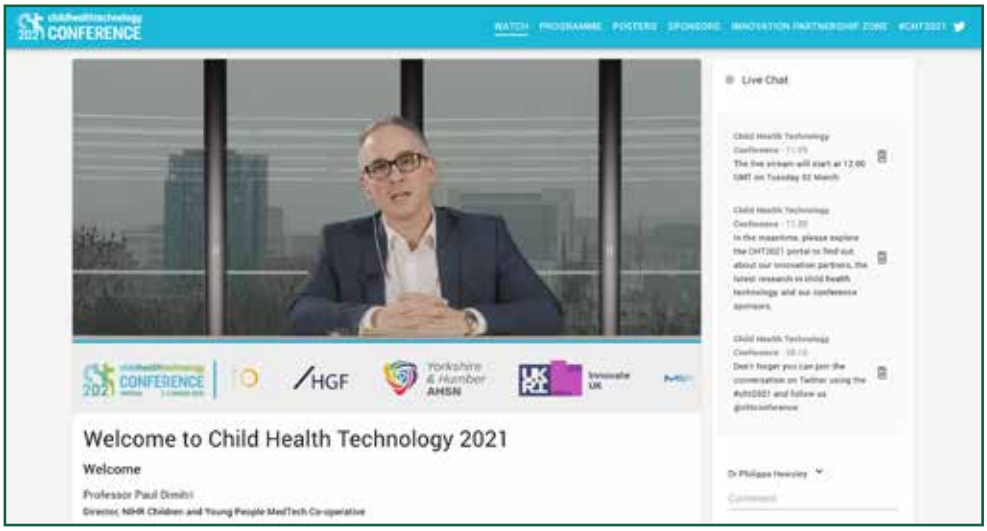
Numerous important points have been reinforced by the event; there is a need to **include children and young people in the development of technology** tailored for their use, **digital inclusion must be addressed**, and there is a **need to work collaboratively** to ensure that we develop the best technology for children and young people.

Reviewing the conference, the CHT2021 Founder Professor Paul Dimitri said:

"The Child Health Technology conference has been a great success. We have experienced excellent keynote presentations, seminars, and technology demonstrations on a diverse range of child health technology subjects. I have really enjoyed speaking with colleagues from across the country and other parts of the world sharing their knowledge, expertise, and experience."

NIHR CYP MedTech would like to thank everyone who made the conference such an interesting, informative and enjoyable event. This includes the Sheffield-based teams Marketing Sheffield, Events Management Direct, and Technative solutions, as well as the CHT sponsors, speakers, delegates and partners.

After the resounding success of the inaugural CHT conference, it has become clear that there is a need to continue building this community with further events. To expand the reach of this network, our next conference will focus on the theme of 'Global Child Health Technology.' CHT2022 is due to take place virtually on 11-12 May 2022. Visit the conference website to find out more: **www.childhealthtechnology.com.**



UK's first
conference dedicated to
child health technology

59 speakers
238 delegates
19 countries

PATIENT AND PUBLIC INVOLVEMENT

JEN PRESTON
PATIENT AND PUBLIC INVOLVEMENT LEAD

Our Patient and Public Involvement and Engagement Strategy promotes the involvement of children and their families in all CYPMedTech activities including user-centred design and identifying unmet needs. We believe this has many benefits including improved functionality, quality, usability, and acceptability of child health technologies, ultimately leading to a reduction in product failure, effective usage, customer satisfaction, and product sales.

Equally listening to and acting upon the views of children and young people acknowledges that they have the right to have a say in decisions that impact their lives, including involvement in technological advances that have an impact on their health. Our strategy is guided by the United Nations Convention on the Rights of the Child (UNCRC), which is a global framework for children's rights. The UNCRC was developed around the themes, Provision, Protection and Participation. These themes guide how CYPMedTech functions to ensure:

Provision – children and young people have access to age-appropriate, safe, and effective medical devices, healthcare technologies, and technology-dependent interventions in the NHS.

Protection – children and young people are protected from harm. Providing clear accessible information and guidance on navigating the digital environment is required, which includes information about how their data is being used, and how to stay safe online.

Participation – children and young people are actively involved in the work we do, and we encourage providers of digital technologies and services to involve them throughout the design process.

The case studies included in this report hopefully highlight our commitment to fulfilling children and young people's rights to have their views heard and acted upon in the design of child health technologies.

LESSONS LEARNED IN 2020

1 Using online platforms to collaborate with children, young people, and families

During the pandemic, our team utilised online platforms to collaborate with children, young people, and families. To ensure we reached the right groups of children, young people, and families, we worked closely with national charities and NHS clinical teams to develop and distribute surveys using social media and mailing lists. Online platforms, such as Trello and MiRo, have also been incredibly useful for communicating with young people and families.

2 Being mindful of the risk of digital exclusion

Throughout the pandemic, we were highly conscious of the problem of digital exclusion. As various aspects of daily life shifted to online platforms, individuals who lacked access to technology or were not familiar with its usage encountered significant difficulties. With schools, workplaces, and healthcare services being heavily dependent on digital tools, it was vital to look to address this issue. We implemented innovative methods of engaging with children and young people, taking into account their unique circumstances and backgrounds, ensuring that all voices were heard. We gained invaluable insights during this time and will apply these learnings in the future.

3 Consenting children, young people, and families remotely

Research studies during the pandemic needed to be adjusted to limit unnecessary in-person visits. One particular challenge was how to consent new participants remotely. After many discussions, our team found that emailing study documents to families, having a conversation with potential participants using phone or video calls, and using secure platforms for e-consent was an acceptable approach that complied with research governance.

4 Blending digital and physical methods to engage diverse groups

Challenging circumstances can often be a catalyst for innovation, and indeed taking the time to critically reflect on how we work with children and young people during the pandemic has also challenged us to develop new methods of engagement. Alongside our collaborators at Lab4Living (Sheffield Hallam University), we have found a 'blended' approach to co-design with children and young people to be particularly effective, for example by sending paper-based activity packs for families to complete ahead of online group workshops. This has been useful in supporting sensitive reflection on, and sharing of, healthcare experiences, as well as creative ideation around a given topic.

CASE STUDY:
TOOKIE
Workshops
February 2020

tookie
#ALifeMoreNormal

Our agility and approach to innovation allows us to work cross-sector to support both large-scale unmet needs and more specific bespoke issues for children and young people. A unique opportunity arose for us and Tookie Ltd to work with Josh and his family to design a bespoke garment, as his family did not feel existing solutions and previous prototypes produced by Tookie would meet Josh's highly complex enteral needs and autism.

Tookie Ltd, NIHR CYP MedTech, and the Gastroenterology Services Clinical Team at Sheffield Children's NHS Foundation Trust (SCH) met several times during early 2020 as a clinical focus group. Together, they worked to consider these unmet needs and to investigate the design of a wearable medical device to be offered to patients to improve patient well-being and safety. It was clear this approach would not be suitable for Josh and his family.

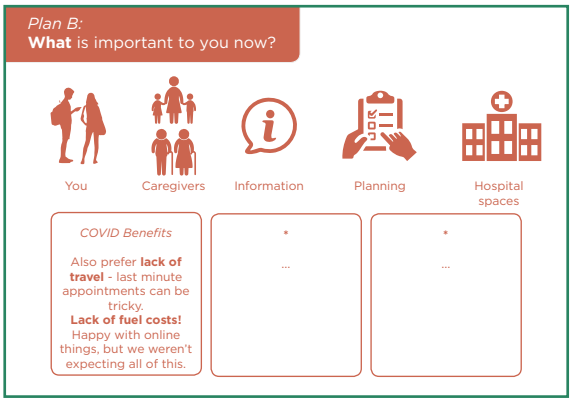
NHS patients and families across the UK face a number of challenges when securing and maintaining the array of enteral feeding lines and devices that are vital to patients' survival and management of their

conditions, including preventing children pulling and removing their devices. No product exists to resolve this clear need; consequently, parents are often driven to develop bespoke solutions to secure their children's feeding lines and carry the weight of their fluid bags, or having to resort to purchasing expensive online products which may not be fit for purpose.

Our approach to support Josh and his family was to support the use of pioneering 3D body mapping technology to map the medical lines and devices on the patient's torso. This negated any undue emotional stress the patient would have experienced by encroaching upon his personal space, to take repeated physical measurements. NIHR CYP MedTech and Tookie have worked with the parents to design a garment that is fit for purpose, ergonomic, and will improve the patient's quality of life, preventing him from accessing his devices and preventing recurrent infections and consequent hospital visits.

This project highlights how the expertise and agility of small companies and the NIHR MedTech and In Vitro Diagnostics (NIHR MIC) network, along with meaningful PPI initiatives, can enable the development of novel products that have both short- and long-term benefits for the health and wellbeing of children, young people, and their families.

CASE STUDY: Youth Forum Workshops
October 2020



NIHR CYPMedTech have been working with Sheffield Children's Hospital (SCH) Youth Forum to explore modes of engaging information provision. This project originally focused on the idea of making a Transitions information leaflet accessible and engaging to an even wider audience, looking at physical platforms and gamification. Initial workshops with the SCH Youth Forum highlighted the diversity of experiences of transition, and that children and young people might wish to hear about and learn from the experiences of others.

In response to the COVID-19 pandemic, we returned to the Youth Forum in an online workshop to see what is important to them, and how they want to access services, now. This highlighted the potential to develop a suite of videos to share information about transition, both nationally and on a Trust-specific basis.

We will be exploring this idea further through early co-design work with children, young people, caregivers, and healthcare professionals with an interest in Transition.

CASE STUDY: GiveVision Focus Group
November 2020

NIHR CYP MedTech is collaborating with an Small-Medium Enterprise (SME) Give Vision and the Ophthalmology clinical team at Sheffield Children's Hospital to evaluate a low vision aid (SightPlus) for CYP with visual impairment (VI).

VI can negatively impact CYP's social, educational, psychological and physical development, and quality of life. Although low vision aids can improve functional vision, these are currently limited in their functionality. The innovative device, SightPlus, has potential to enable CYP to perform a greater range of activities, having an impact on their education, independence, and social well-being.

As part of the study, PPI focus groups were performed with patients and their carers to obtain feedback on project information sheets and consent forms. This was crucial to ensure that the research documents were suitable for CYP of different ages and visual abilities. PPI focus groups will also be performed at the end of the study to get feedback on the study and ideas for dissemination of the results.

CASE STUDY:
SCH PPI Event
November 2020

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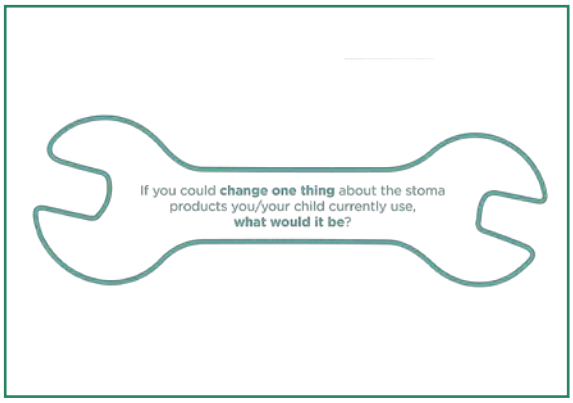
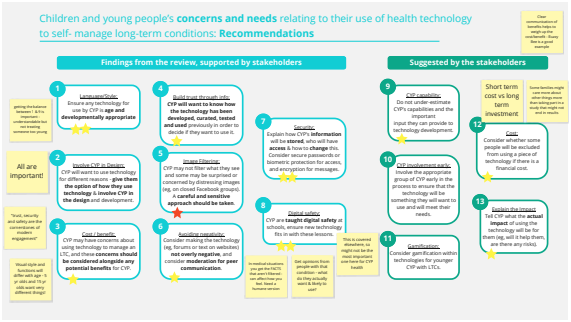
CASE STUDY:
Ostique Ltd: Ostomy Care Workshops
Sep-Oct 2021



NIHR CYP MedTech is collaborating with Ostique Ltd to evaluate their novel range of ostomy care devices with improved functionality and customisable aesthetics for paediatric ostomates. The current ostomy products that are available to CYP may not always respond to the unique needs of paediatric ostomates (e.g. their active lifestyles can cause products to leak, and the clinical aesthetics of current products may negatively impact on the child's confidence).

To learn more about the challenges caused by existing products, and to gain greater insight from CYP ostomates as to what their ideal ostomy appliance would look like, a range of co-design activities were organised by NIHR CYP MedTech in collaboration with Ostique Ltd and Sheffield Children's Hospital. Parents and children (aged between 6-15 years) participated utilising postal activity packs, online surveys and two online workshops. These activities helped to obtain feedback on CYP's current products, Ostique Ltd's current prototypes, and highlighted further unmet patient needs to support future research and developement.

CASE STUDY:
White Rose Consortium
June 2021 - present



Funded by the White Rose Collaboration Fund, this project aims to:

1. Establish a regional consortium to discuss key issues about how CYP are informed about health technology, including delivery in the context of families;

2. Undertake a scoping review to explore the positive elements of health technology design and implementation for CYP and families;

3. Advance the field by developing recommendations and research objectives for a research proposal to develop a conceptual framework for use when developing health technology for CYP.

NIHR CYP MedTech will be supporting the project through planning and facilitating PPI workshops with young people with long-term conditions, as well as supporting the delivery and dissemination of the scoping review.

CASE STUDY:
ADPKD Family Chatbot
Feb 2021-present

Autosomal dominant polycystic kidney disease (ADPKD) is an inherited genetic condition, with symptoms that typically appear in late adolescence or early adulthood. Naturally, parents can find it difficult to talk to their children for the first time about ADPKD, and the risks of inheritance, and as such many families choose not to discuss this during childhood. Family therapy approaches can support families to have these difficult conversations, however they are not yet widely funded or facilitated.

Recent research suggests that taking antihypertensive medication in early adolesence can delay onset and reduce severity of the symptoms of ADPKD, giving new incentives for parents to discuss ADPKD with their children earlier. Advances in genetic testing mean that children who will go on to develop ADPKD can be identified earlier, and begin this preventative treatment.

This team, funded by The Children's Hospital Charity and Sheffield Hallam University, aim to co-create a chatbot that draws on family therapy approaches, to support more families in this difficult situation.

PARTNERSHIPS

Working collaboratively with children and young people, families, health professionals, businesses, academics, and charities is vital for developing effective innovations that meet the needs of both patients and the NHS.

To keep our valued networks up to date with out latest work and opportunities to collaborate, we continue to follow our communications strategy developed in the first two years of NIHR CYP MedTech. This includes a monthly newsletter, regular updates to our TITCH and CHT conference mailing lists, and regular engagement with the Twitter and LinkedIn child health communities. Please visit our website for more details.

Working with industry

Working with industry is essential for developing novel innovations for the NHS. However, successful innovations require more than great ideas and the latest technology. In our experience, innovations are much more likely to be successful if the right stakeholders are involved from the beginning. NIHR CYP MedTech is central to bringing these diverse groups together at any early stage.

Our ethos is to ensure that children, young people, and families are involved at every stage of the innovation pathway, and therefore patient and public involvement is at the centre of all the projects we are involved in.

The end goal of all our projects is to have innovations accepted by and adopted into NHS clinical pathways. This requires collaborations with commissioners, policy makers, health economists, and regulatory experts to ensure that innovations align with NHS strategic objectives.

If you have a great idea for an innovation, please visit our website and complete our collaboration request form.

Grow MedTech Secondments

Grow MedTech funded two PhD students interested in health technology development to join NIHR CYP MedTech for a three month secondment. These secondments enable early career researchers to gain knowledge and experience of how to work collaboratively to develop innovative technology for children and young people with long-term health conditions.

Grow MedTech a major UK programme providing specialist support for innovation in medical technologies.

Linda Olubajo

Linda Olubajo is a PhD student at Sheffield Hallam University researching health technology collaborations involving universities, industry, and clinicians.

The secondment provided valuable context for my doctoral research, enabling me to learn about the innovation pathway, the systems and processes used, and the funding landscape. Most importantly I was able to meet the people who help to drive MedTech innovations forwards, including the CYP MedTech team, clinicians and industry partners, all of whom offered great insight and have become valued contacts since. Having worked in universities for most of my career it was hugely beneficial to see collaborations from a different perspective.

Matthew Culbert

Matthew Culbert is a PhD student at the University of Leeds researching tissue engineering and regenerative medicine.

My secondment with CYP MedTech has been invaluable in allowing me to gain an insight into the process of developing technology that can be translated into the NHS. The technology being investigated utilises a wide range of technology and it was great to work with teams of people from different professions with the common goal of providing medical technology for children and young people. Observing a focus group of young people providing feedback was a great experience which showed the importance of PPI groups for researchers but also the willingness of the public to help and provide useful information that would otherwise be missed.

Case studies

tytocare™
Your On Demand Medical Exam

Yorkshire & Humber AHSN

TYTO Care

NIHR CYP MedTech is working alongside Yorkshire & Humber AHSN (Academic Health Sciences Network) to facilitate and evaluate the deployment of handheld all-in-one remote examination devices by telehealth company, TytoCare. We have led on the paediatric specific evaluation of 15 projects across different NHS trusts around the country, collaborating with young people, families and healthcare professionals across a range of disciplines.

The TytoCare platform enables clinicians to perform remote examinations on the patient, with features designed specifically for heart, lung, ear, throat, skin, abdomen, and body temperature measurements. Using TytoCare devices, appointments that could only previously have taken place in person can be conducted remotely providing a potentially safer and more comfortable environment for the patient.

TytoCare has the potential to alleviate some of the burdens of outpatient visits, with a myriad of benefits for the patient including a reduced need for travel and increased confidence in managing their condition.

Over recent years, with enhancements in healthcare technology, there has been a growing demand for the exploration of virtual wards. This has been expedited by the COVID-19 pandemic, which has made hospital visits particularly dangerous for the most vulnerable in society. NIHR CYP MedTech's work with TytoCare aims to contribute to the national effort of exploring the potential of the virtual ward with CYP with long-term conditions.

To evaluate the use of the TytoCare device, focus groups are being used to gather the opinions of both the clinicians and the end user, reinforcing our commitment to Patient and Public Involvement and Engagement in MedTech development. Taking this qualitative approach, and complementing it with analysis of quantitative data from the devices themselves (i.e. reduction in number of hospital admissions), we hope to better understand the lived experience and impacts of using the devices from multiple perspectives. This will in turn inform future decisions around implementing virtual healthcare technology into different NHS workflows.

Immersive Virtual Reality for Duchenne muscular dystrophy

NIHR CYP Medtech is collaborating with clinicians and researchers from Sheffield Children's Hospital, Leeds Teaching Hospital and Sheffield Hallam University on an exciting new project using Immersive Virtual Reality (IVR). The team was recently awarded funding from The Children's Hospital Charity, Sheffield to develop IVR to deliver novel physiotherapy for paediatric patients with Duchenne muscular dystrophy (DMD).

DMD is a genetic disorder causing muscle weakness and wasting and affects 2,500 people in the UK. DMD patients need to undertake a daily stretching programme to maintain maximum muscle extensibility and optimise function. However, a lot of children are not motivated to perform these exercises, leading to earlier complications, reduced function and a poorer long-term prognosis.

The collaborative research group have previously demonstrated that an interactive IVR system can improve the delivery, engagement, and success of physiotherapy for adult amputees, burn patients, and children with upper limb injuries. In the current study, the team will work with clinicians, physiotherapists, parents, carers, and patients, to explore core IVR rehabilitation scenarios. The IVR platform will subsequently be developed to emulate current DMD physiotherapy regimes which will be tested in a trial with 16 DMD patients aged 6-12 years. The effect of the IVR system on improving physiotherapy adherence and muscle strength testing will be determined. Qualitative interviews and questionnaires will also be conducted with patients and clinical staff to obtain feedback on acceptability and practicality of using IVR for clinical use.

The team is hugely grateful for the support of The Children's Hospital Charity for facilitating this innovative clinical research aiming to improve the lives of young people with DMD.

Digibete

NIHR CYP MedTech is leading on an NIHR-funded project to develop and evaluate the first NHS clinically approved chatbot to support young people with type 1 diabetes mellitus (T1DM) as they move from paediatric to adult health services.

This user-led project is a collaboration between NIHR CYP MedTech, IBM, DigiBete (SME), three universities (Sheffield Hallam University, University of Sheffield, University of Leeds), four NHS Foundation Trusts (Sheffield Children's NHS FT, Leeds Teaching Hospitals NHS FT, University Hospitals Birmingham NHS FT, Liverpool University Hospitals NHS FT), and mHabitat (an NHS digital inclusion and innovation team). The team are also partnering with two other SMEs to deliver aspects of the design work (HMA, The Capture Lab).

The project steering group are working in partnership with an expert user group – a diverse and inclusive group of young people who are helping to guide the project.

James Lind Alliance (JLA) Priority Setting Partnership

Research topics are usually chosen by researchers. However, researchers may not be fully aware of the issues and uncertainties that matter most to families and patients.

Priority Setting Partnerships (PSP) are projects where health professionals, patients, and parents/carers work together to identify and prioritise unanswered questions that can be addressed by future research projects. NIHR CYP MedTech is supporting a PSP that aims to identify and prioritise the top ten research priorities in digital technology for adolescents and young persons with inflammatory bowel diseases (IBD), such as ulcerative colitis and Crohn's disease.

To identify and prioritise research questions, we are carrying out two surveys with young people, parents/carers, and health professionals. We will aim to distribute the surveys as widely as possible to make sure that we receive a diverse range of responses. After these surveys, we will hold a workshop to agree the top ten research priority questions.

The steering group includes paediatric and adult gastroenterologists and specialist nurses from seven NHS trusts, patient and charity representatives, young people living with IBD, parents/carers of young people with IBD, a JLA representative, and an NIHR CYP MedTech project manager.

The PSP is supported by the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, the British Society of Gastroenterology, and NIHR CYP MedTech.

NATIONAL TITCH NETWORK

TITCH
Technology Innovation
Transforming Child Health

The TITCH network was established in 2014 to prioritise the unique needs of children and young people in research and innovation, and to address the previously fragmented approach to developing and evaluating child health technology across the UK.

The network is jointly managed by NIHR CYP MedTech and NIHR Devices for Dignity, and has been a fantastic place to support and develop research and innovation that falls outside of the key priority areas of those networks.

The main objectives of the TITCH network are:

- Identify and validate unmet needs in child health
- Facilitate collaborations
- Promote child, young person and family involvement
- Develop and evaluate child health technology
- Influence funding calls
- Identify ambassadors and clinical champions

Members of the TITCH network have a diverse range of backgrounds. We're keen to hear from anyone with an interest in, or experience of, child health or technology, including young people and parents/carers – please visit the TITCH website to find out more and/or enquire about joining the network.

TITCH.ORG.UK

Update on the TITCH Industry Ambassador

Our support of industry is vital to our progress and is evident throughout this report. Our dedicated collaboration request portal also allows industry to contact us and align with our themes, giving them the first vital step in sharing an innovation or idea that may lead to collaboration, identify clinical champions, or guidance on NHS pathways. Where we cannot offer direct support, we can then utilise the TITCH network and wider NIHR MIC networks.

As part of our wider offering, our Industry Ambassador Steve Tooke has been supporting and guiding SMEs to access and navigate the NHS' complex infrastructure to develop new ideas, innovations, and technologies. The guidance from Steve and NIHR CYP MedTech has given SMEs insights and knowledge on how to innovate in the field of child health technology for the NHS. During the reporting period, we have supported six SMEs and three academics.

The ambassador role has also supported new academics to understand the importance of collaboration and working alongside industry to innovate for CYP.

It can be incredibly challenging for new and exciting ideas and innovations from industry to gain a foothold in the NHS, successful SMEs that work with NIHR CypMedTech have utilised our expert approach and methodology to push forward and develop their innovation for patient benefit. The approach above shows the importance of the NIHR and industry working alongside each other in collaboration to benefit the NHS and UK.

> *One cannot just approach the NHS with an Innovation. A company needs to understand the entry point and Innovation Pathway which only becomes apparent when 'you know, what you need to know' which is the real challenge...*
>
> *...May I congratulate you on the concept of an Industry Ambassador role to support companies on their NHS journey. Individual aside it is a great asset for you to offer, especially free of charge when as a new company the next decision may be costly and potentially not the right one. Having approached the NHS for guidance on how to begin our what I now know is the 'Innovation Pathway' I remember how difficult it was to find advice, and more importantly sound advice on our next step.*
>
> - **Mel Wood**, lead of the 'Fidgetbum' Proof of Concept project

CORE TEAM

PROFESSOR PAUL DIMITRI
Director
2018 - present

DR CLARE BARTLETT
Project Manager
2018 - present

DR PHILIPPA HOWSLEY
Project Manager
2018 - present

NATHANIEL MILLS
Programme Manager
2018 - present

TOM HODGKINSON
Project Manager
2019 - 2020

ABIGAIL NEEDHAM
Project Manager
2019 - 2021

DR GEMMA WHEELER
Project Manager
2021 - present

JACOB BRANCHFLOWER
Project Manager
2021 - present

As the success of NIHR CYP MedTech has grown, so too has our capacity to expand our remit to explore further, important areas of research within child health technology. To support this, we are pleased to report that our team of dedicated Project Managers has doubled in size, creating an even richer service offering to the groups we work with.

We look forward to seeing what the next two years will bring for NIHR CYP MedTech.

STEERING GROUP

PROFESSOR NICK BISHOP
Vice President for Science and Research, Royal College of Paediatrics and Child Health

DAVID COLE
Head of Business Development and Innovation Europe, Middle East, and Africa, IBM Watson Health

PROFESSOR PAUL DIMITRI
Director, NIHR CYP MedTech

PROFESSOR SIMON KENNY
National Clinical Director for Children and Young People

PROFESSOR JEREMY KIRK
Clinical Director, NIHR Clinical Research Network West Midlands

KAREN LIVINGSTONE (FORMER CHAIR)
Chief Executive Officer, Bedfordshire and Hertfordshire Local Medical Committee

NICOLE MCGLENNON
Managing Director, East Midlands Academic Health Science Network

DR LIZ MEAR
Chief Executive Officer, Innovation Agency, the Academic Health Science Network for the North West Coast

NATHANIEL MILLS
Programme Manager, NIHR CYP MedTech

JEN PRESTON
Patient and Public Involvement Lead, NIHR CYP MedTech

RICHARD STUBBS (CURRENT CHAIR)
CEO, Yorkshire and Humber AHSN

PROFESSOR MEHDI TAVAKOLI
Knowledge Transfer Manager for Infrastructure, Medical Technology, and Therapies, Knowledge Transfer Network

PROFESSOR WENDY TINDALE
Clinical Director, NIHR Devices for Dignity MedTech Co-operative

DR NEVILLE YOUNG
Director of Enterprise and Innovation Yorkshire and Humber AHSN

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TITCH Network
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Child Health Technology Conference
@chtconference

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