

# Involving children and young people in health technology development

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EPTRI Meeting – 16<sup>th</sup>  
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Q. If you were a business developing a new soft drink, would you bring the product to market without consulting your target audience?



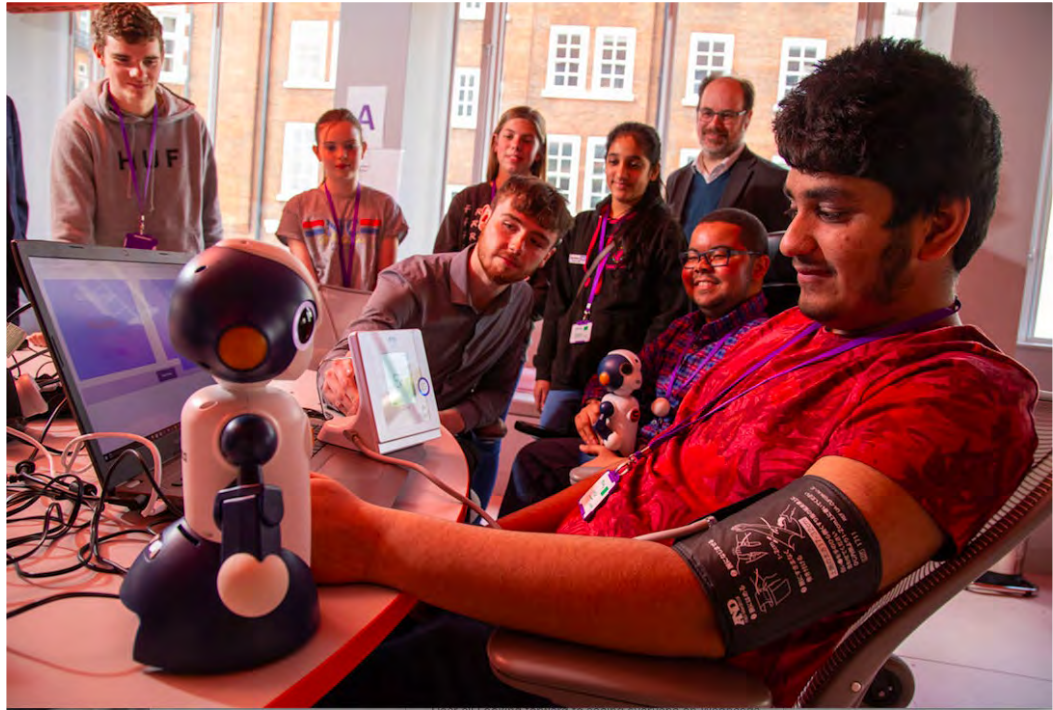


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Q. Should it be any different  
when designing and designing  
health technology for children  
and young people?



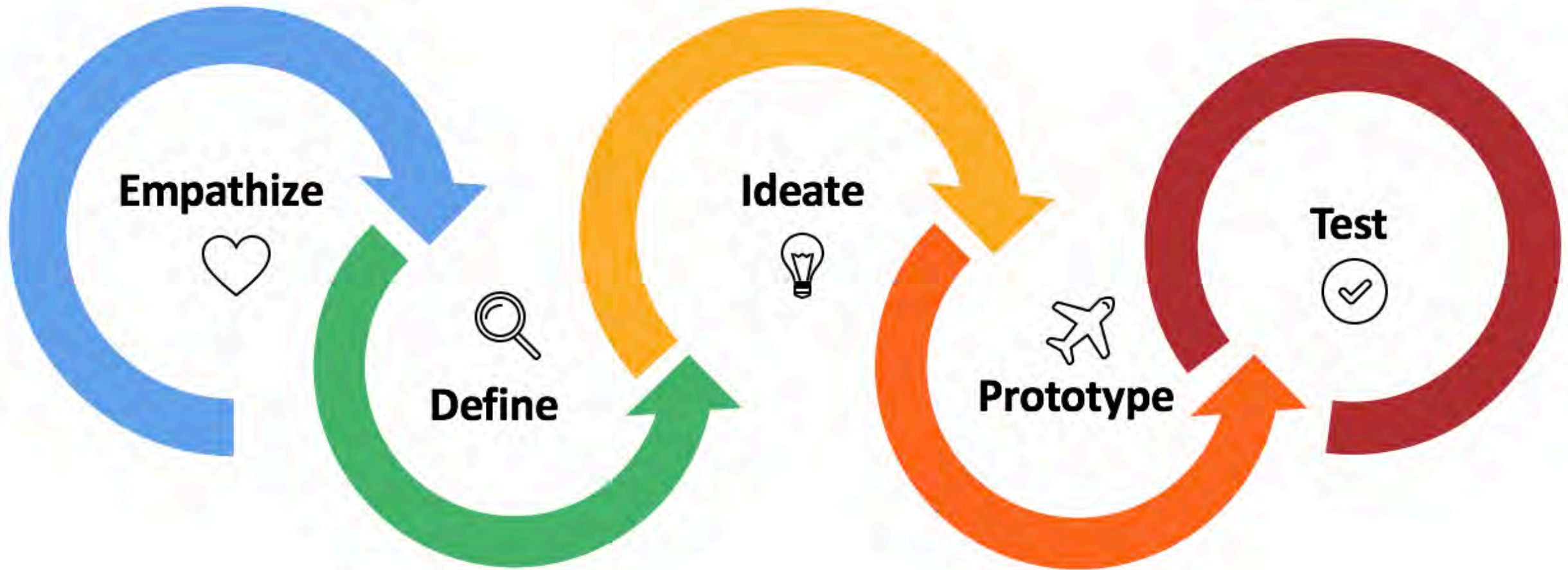
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An **active** partnership between patients and the public and researchers in the research process, rather than the use of people as '**subjects**' of research



# User-centred design





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# Benefits of listening to children



Improved functionality



Reduction in  
product failure



Quality



Effective Usage



Usability



Customer  
satisfaction



Acceptability



Product sales

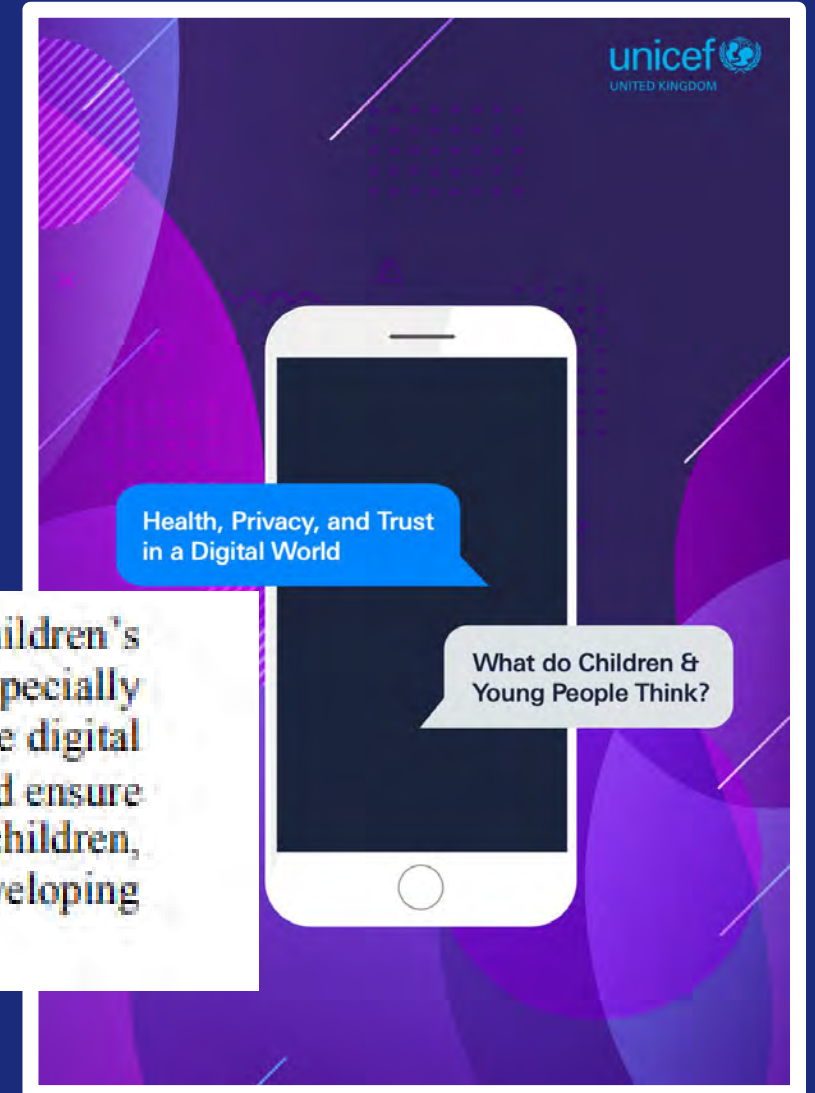


# Child Rights & Technology

CRC<sub>C(00)</sub>

103. States should encourage and invest in research and development that focus on children's specific health needs and promote positive health outcomes for children through technological advances. Digital services should be used to supplement or improve in-person provision of health services to children.<sup>46</sup> States should introduce or update regulation that requires providers of health technologies to embed children's rights in their functionality, content and distribution.

19. When developing laws, policies, programmes, services and training on children's rights in relation to the digital environment, States should involve children, especially children in disadvantaged or vulnerable situations, and victims of harm related to the digital environment, listen to their needs and give due weight to their views. States should ensure that designers and providers of digital technologies and services actively engage children, applying appropriate safeguards, and give their views due consideration when developing their services.



<https://bit.ly/3gePJeB>



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

**Protection** – CYP 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** – CYP are actively involved in the work we do, and we encourage providers of digital technologies and services to involve them throughout the design process.





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**HEALTH & TECHNOLOGY**

*WHAT YOUNG PEOPLE REALLY THINK*  
AUGUST 2019

foundation BOTNAR    devex Do Good. Do It Well.™    PATH FO::AO+//ZOO    WOMEN DELIVER    The Partnership for Economic, Random & CHAI health

### SURVEY QUICK FACTS



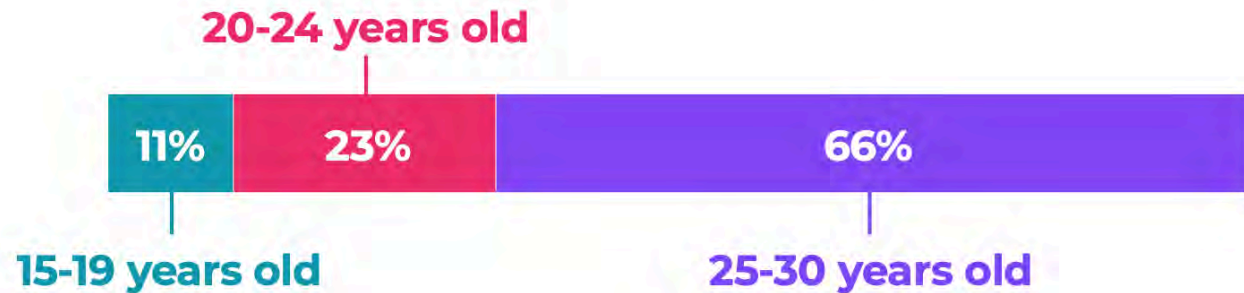
**+ 1.5K  
RESPONDENTS  
> 50% FEMALE  
PARTICIPATION**



**RESPONSES  
FROM +125  
COUNTRIES**

Provision

Of the 1,510 young people that participated in the online survey:





# Provision

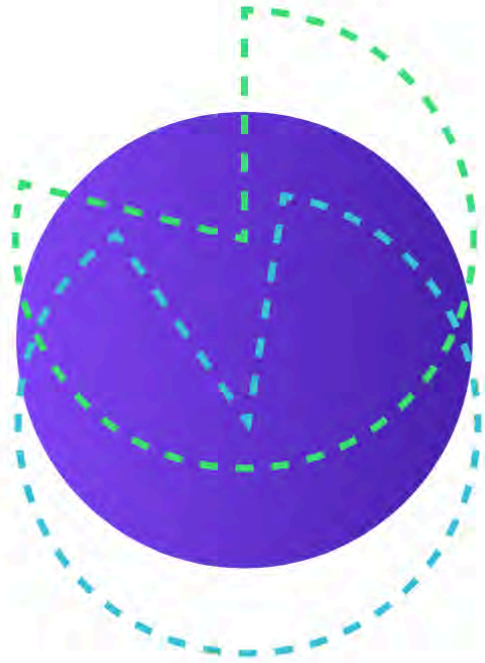


**92% OF YOUNG PEOPLE AGREE THAT TECHNOLOGY IS A CRITICAL ENABLER OF HEALTH CARE SOLUTIONS**

And:

**OF THE YOUNG PEOPLE WE SURVEYED 62% SAY THAT THEY ALREADY USE TECHNOLOGY FOR THEIR OWN HEALTH-RELATED NEEDS**





**79% OF YOUNG PEOPLE AROUND THE WORLD THINK THAT THEIR HEALTH CONCERNS ARE NOT ADEQUATELY ADDRESSED**

**88% THINK THAT GOVERNMENTS NEED TO DO MORE TO PROVIDE ACCESS TO AFFORDABLE AND QUALITY HEALTH CARE**



## **YOUNG PEOPLE AGREE: INVESTMENT IN TECHNOLOGY IS CRITICAL**



**YOUNG WOMEN ARE EVEN MORE WORRIED.**

**86% SAY THAT THEIR HEALTH CONCERNS ARE NOT ADEQUATELY ADDRESSED COMPARED TO 74% OF YOUNG MEN**

Provision



## **BIGGEST CONCERNS REPORTED BY YOUNG PEOPLE WHEN USING APPS AND TECHNOLOGY FOR HEALTH:**



Personal data  
security  
**67%**



Inaccurate  
information  
**46%**



High cost of entry  
& maintenance  
**29%**



Bias in  
algorithm  
**28%**

Protection



# What we want to know about **our data**

'Who uses it? What is it used for?  
Can I keep it safe? How long do you  
keep it? Can I get it back?'

'EVERYTHING. Your data is your  
property. Fundamental right to  
know how it's being used. How  
easy would it be to misuse my  
data and is it being monetised?'

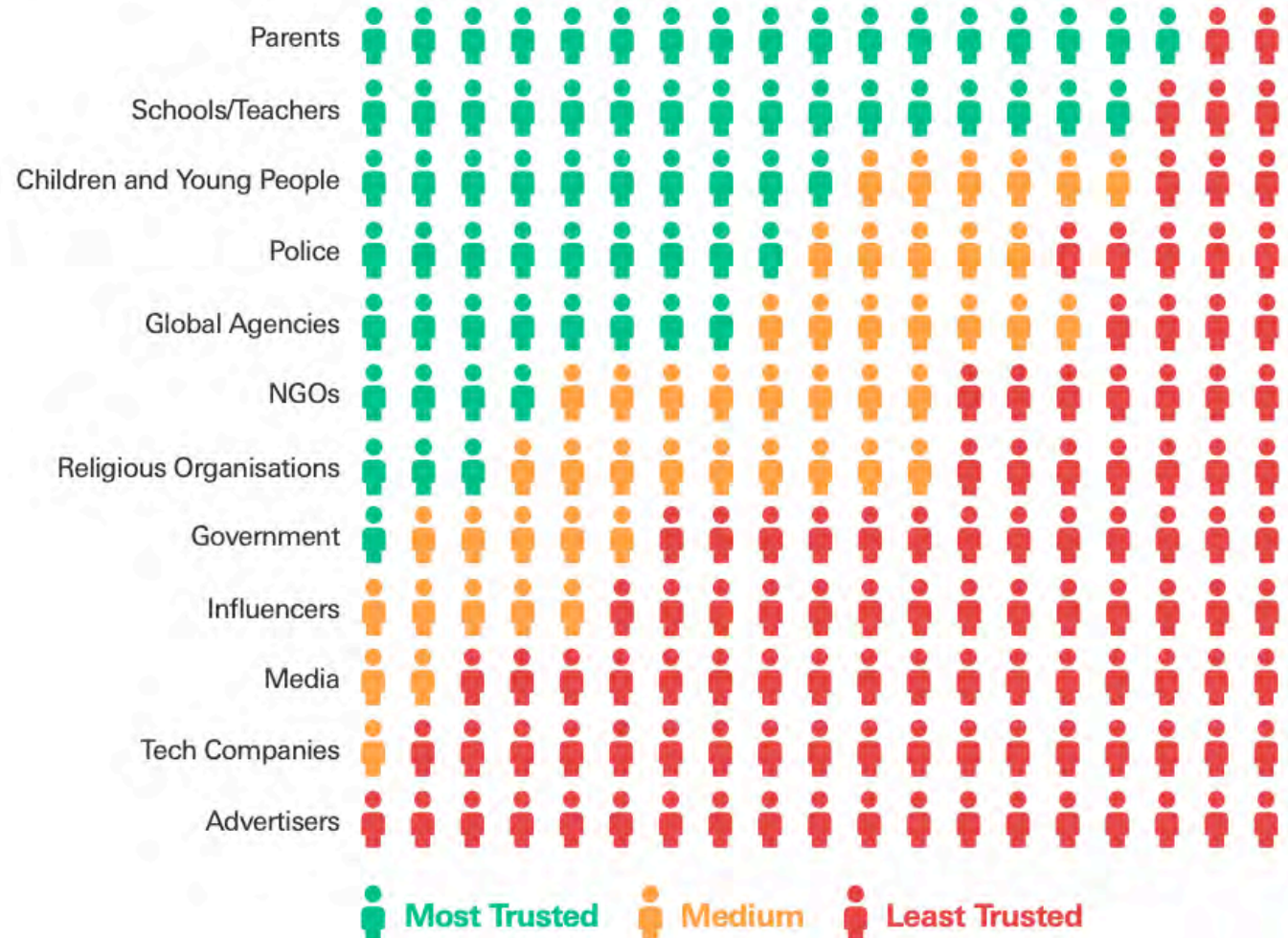
'I would like to know how  
they got the information.'

Protection



# Who can we **trust**?

Most trusted to least trusted



Protection



# Participation

## ARTICLE 12: You have the right to an opinion and for it to be listened to and taken seriously.

United Nations Convention on the Rights of the Child



**83% OF YOUNG PEOPLE THINK THAT THEY MUST BE INVOLVED IN THE DECISIONS THAT GOVERNMENT AND POLITICIANS MAKE ABOUT HEALTH CARE**



**14% EVEN THINK THAT YOUNG PEOPLE SHOULD LEAD THE DISCUSSION ON HEALTH CARE**

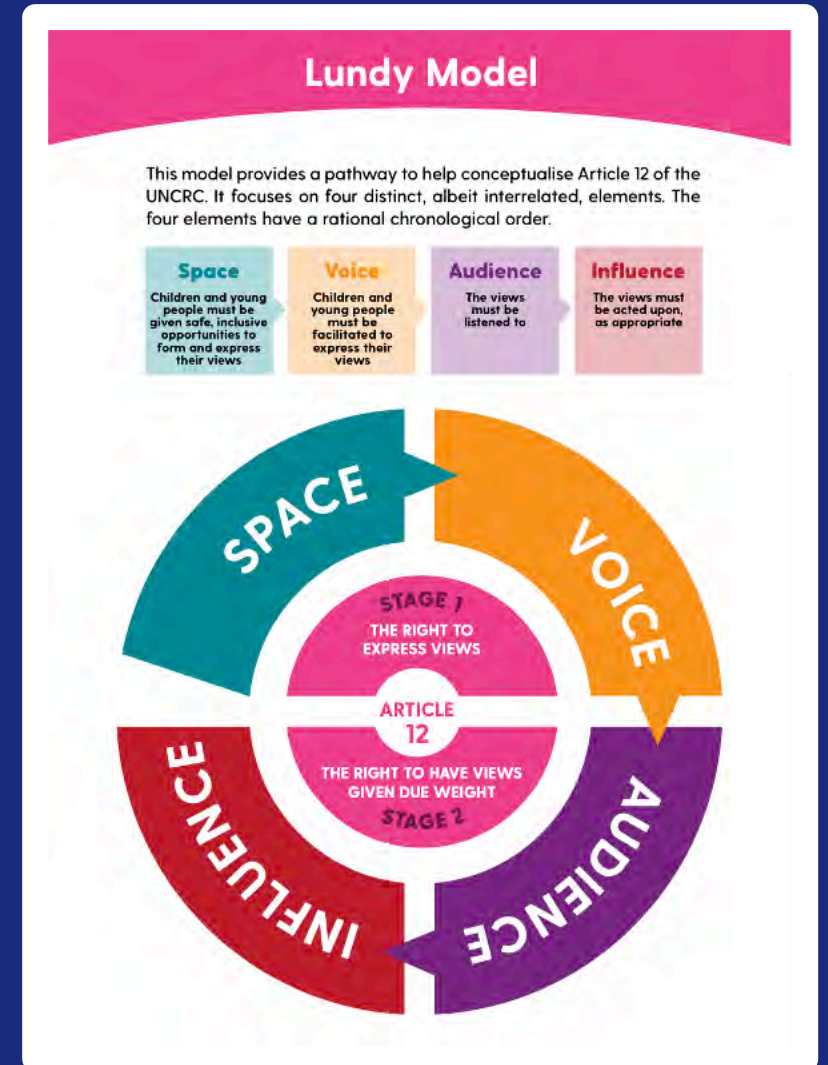




# Participation with purpose

“Participation with purpose means that when children and young people are involved in decision making, their views are listened to, taken seriously and given due weight with the intention of leading to an outcome or change”

Professor Laura Lundy

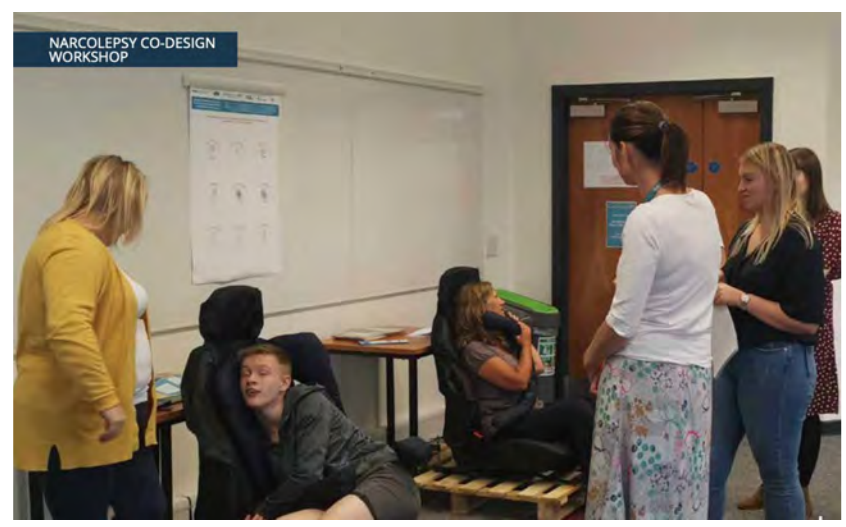






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# CYP Medtech PPI Strategy



- **Work in partnership** with children, young people, families, and members of the public in the design and delivery of paediatric medical technologies.
- **Continuously improve** through patient experience and public awareness.
- **Widen participation and involvement** of children, young people, families in NIHR CYP MedTech activities.
- **Grow the evidence base** of the impact of child, young people, and family involvement and engagement in the design and delivery of paediatric technologies.

## CONTACT

Do you have an unmet need, an idea for innovation, or would like some more information?

We'd love to hear from you.

t: @cypmedtech

e: cypmedtech@nihr.ac.uk

## NIHR CYP-MEDTECH



### Children, Young People (CYP) and Family Involvement Strategy.

#### 1. NIHR CYP-MEDTECH Vision

The National Institute for Health Research (NIHR) CYP-MEDTECH to become a world class organisation for the development of paediatric healthcare technology, driven by the views and opinions of children, young people (CYP) and family involvement. The national reach for identifying unmet needs amongst CYP and families and supporting paediatric technology acceleration is key to the success of CYP-TECH. The ethos of our paediatric medtech co-operative is to ensure that children and young people are involved at every step of the innovation pathway.

#### 2. Introduction

NIHR CYP-MEDTECH is dedicated to the development of healthcare technology specifically for CYP. Thus NIHR CYP-MEDTECH regards the involvement of CYP as a fundamental requirement. In addition, views of parents are vital in understanding the holistic needs of their children. Theme Leads involved in NIHR CYP-MEDTECH already have experience and access to specific patient groups through patient organisations, charities, Patient and Public Involvement & Engagement (PPIE) groups within institutions such as the Royal College of Paediatrics and Child Health

## PATIENT INVOLVEMENT

How we involve children, young people, and their families.





<https://generationr.org.uk>

# Medical Devices

Medical devices form an important component of healthcare and research.

A medical device may be defined as any appliance, instrument, material, apparatus or other article, either used in a singular form in combination with other equipment/devices, including the software essential for its intended purpose.

There are many intended uses of medical devices but mainly the most relevant are:

- diagnosis, prevention, monitoring, treatment or alleviation of disease.
- diagnosis, monitoring, treatment, alleviation of or compensation for an injury or handicap.
- research, replacement or modification of the anatomy or of a physiological process.



Examples of medical devices can be pacemakers, insulin pumps, operating room monitors, defibrillator and surgical instruments, but also a syringe or glasses, and virtual reality implementations to manage specific conditions. The list of medical devices is endless.

## Medical Devices

SEE TOOLKIT FOR RESOURCES

### Task overview

**Task 01:** Can we live without technology?

**Task 02:** How does technology improve/hinder our health?

**Task 03:** Technology and Medical Devices-How can they change lives?

**Task 04:** Are things Equal?

**Task 05:** The history of medical devices

**Task 06:** Involving patients in the design of medical devices



# LESSON PLAN MODULE 01

Co-designing protocols



**YEAH**

Youngsters EngAgement in Health





A capacity-building programme to involve young people in clinical trials and medical devices.



# Youngsters EngAgement in Health Science

Info and registration



FINAL EVENT  
MONDAY, 20TH OF  
DECEMBER  
5 PM CET



Programme and registration: <https://www.kidsbarcelona.org/en/noticia/yeah-project-final-event>



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