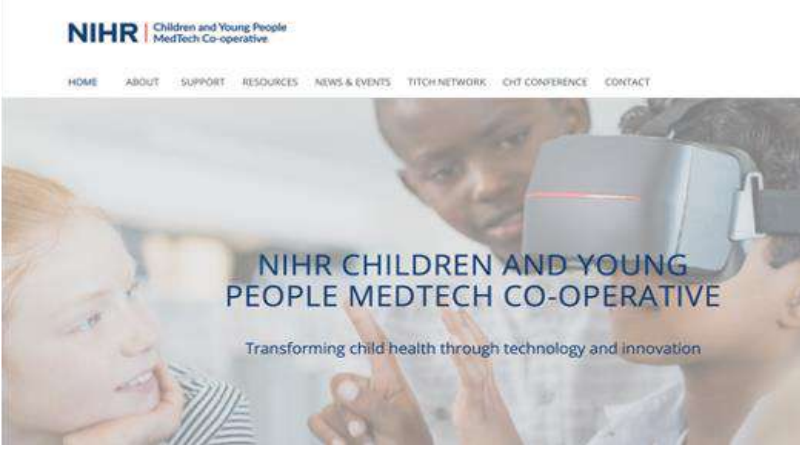
EPTRI®
EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

Patient and Public Involvement and Engagement in Child Health Tech Development

Jennifer Preston - University of Liverpool

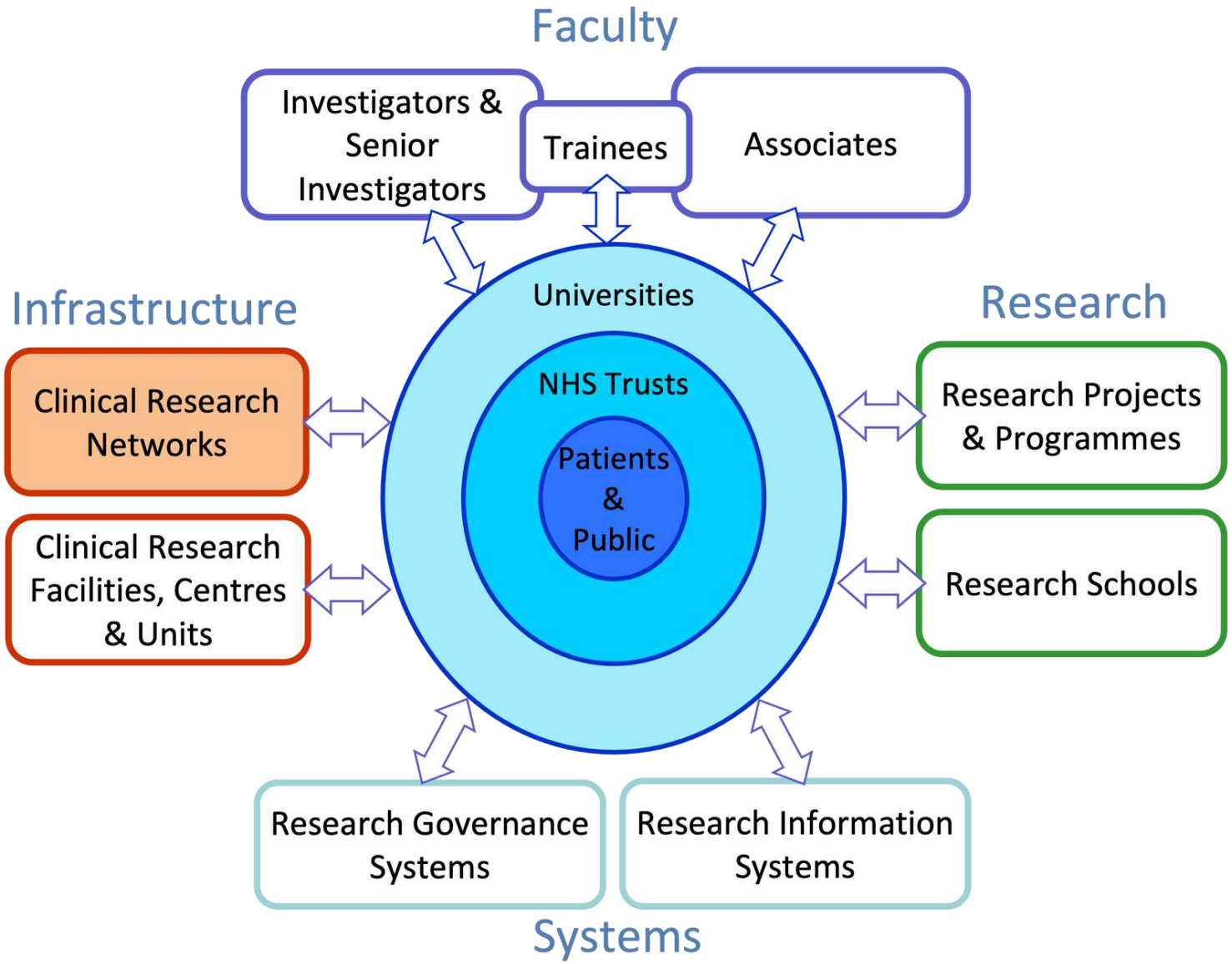
The EPTRI Paediatric Medical Devices Platform Webinar
05/03/2024



PREPARE

Developing a best-PRacticE ParticipAtion fRamEwork with children and young people involved in the design and conduct of clinical studies

My Role



Child Health Technology in the UK

NIHR | Children and Young People MedTech Co-operative

NHS
Sheffield Children's
NHS Foundation Trust

Health technology – what do we mean?

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Neonates Nottingham University	Paediatric Surgical Technologies Alder Hey	Respiratory and Ventilation SCH	Epilepsy, Muscle and Movement Disorders GOSH
Rare Diseases BWCH	Cancer RVI Newcastle	Transition SCH & BWCH	

NIHR | Children and Young People MedTech Co-operative

2018 - Oct 2023

NIHR | Children and Young People MedTech Co-operative

LEADERS IN CHILD HEALTH TECHNOLOGY

£23 million secured for the **UK's first National Centre for Child Health Technology, Sheffield**

UK's first Robotics in Paediatrics and Child Health Showcase

UK's first **2 annual** conferences dedicated to child health technology
- **106** speakers
- **384** delegates
- **27+** countries

ENGAGEMENT & DISSEMINATION

40 peer-reviewed papers published

127 newsletters published

showcased at **58** events

Twitter followers gained:
- **1409** NIHR CYP MedTech
- **1147** TITCH Network
- **488** CHT Conference

3044

68 conference & event presentations

GROWING AND EXPANDING OUR REACH

6 key themes established

4 websites launched

increased our capacity from **2 → 5**

PROJECTS & COLLABORATION

£17 million leveraged in funding

81 funding applications submitted

Worked with **135** SMEs and **44** global companies

13 PhD students hosted

92 collaboration requests received

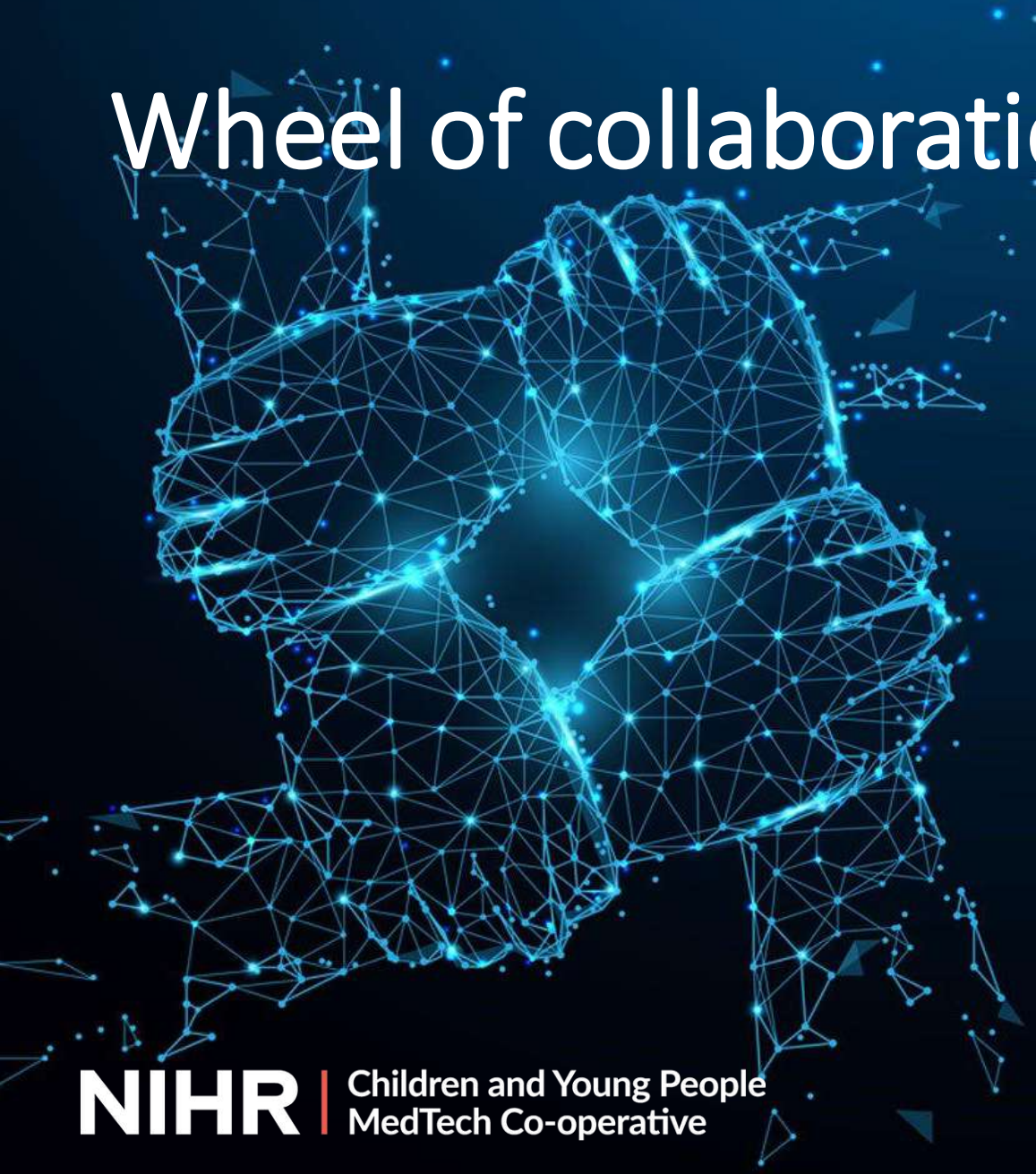
159 workshops, events & interviews engaging CYP & families

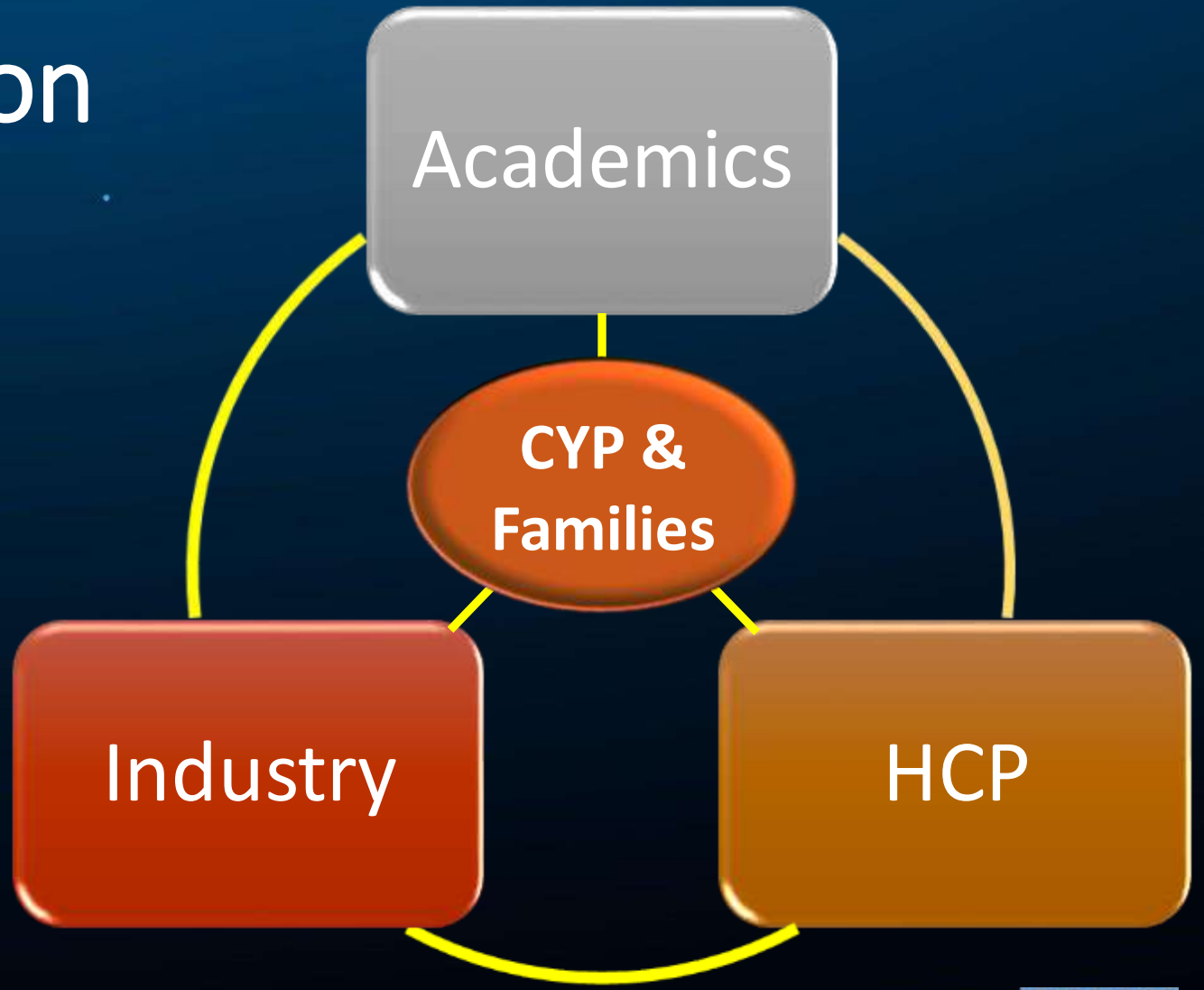
Of **176** projects worked on...

55% included an industry partner

13 projects with other NIHR MICs to support innovation in child health

Wheel of collaboration





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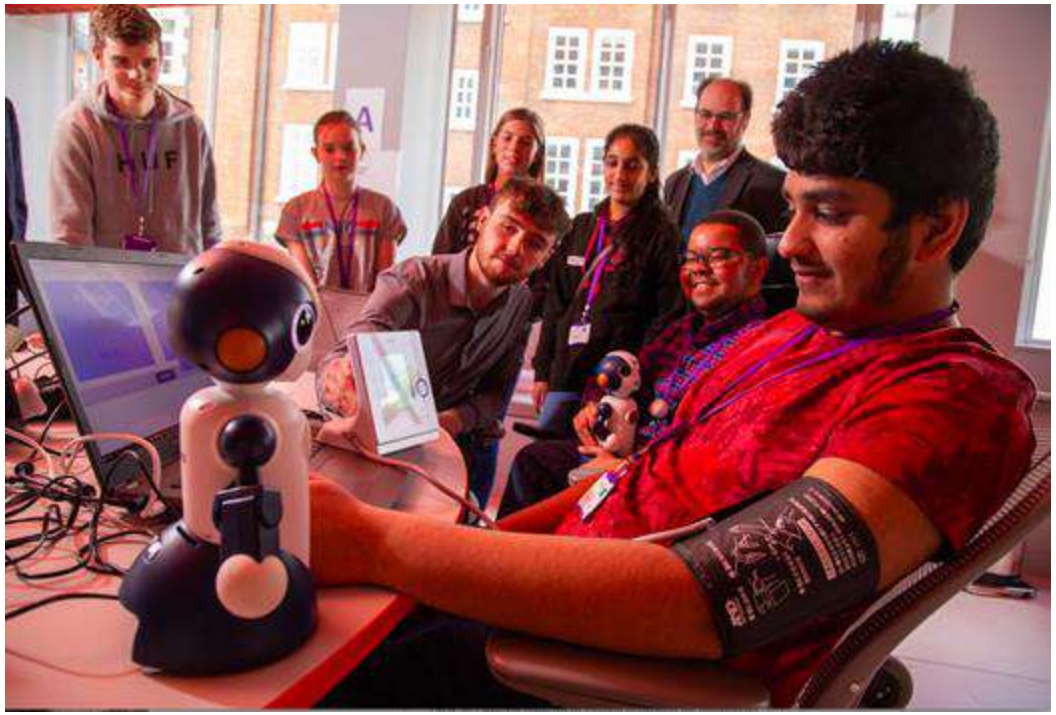
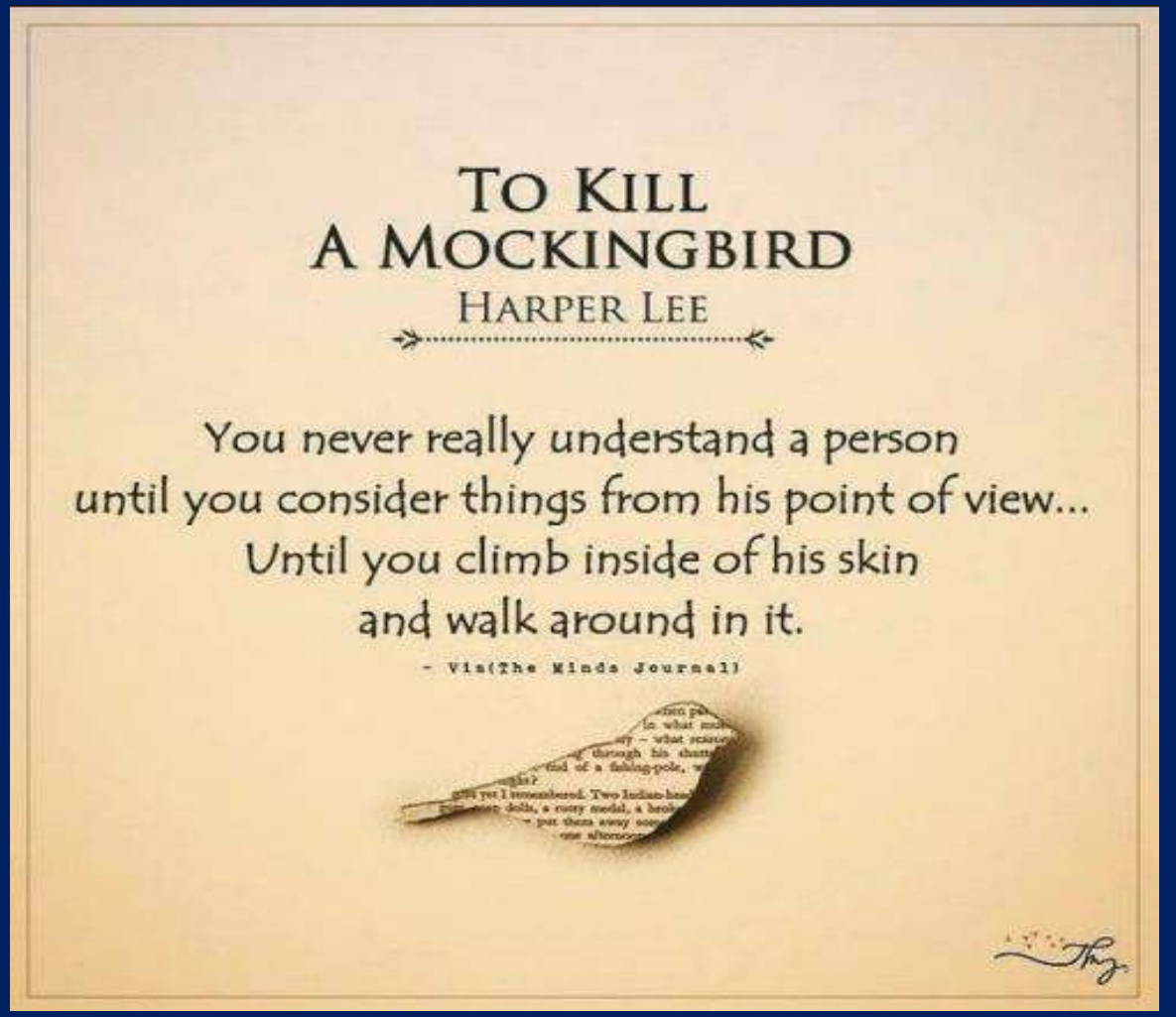
Involving CYP & Families





"research…carried out 'with' or 'by' CYP & families rather than 'to', 'about' or 'for' them". (National Institute for Health and Care Research)

Research ON, ABOUT, WITH and BY children & young people

Mary Kellett was founder and Director of the Children's Research Centre at the Open University in the UK. She identified four types of research involving children in the research literature:

- Research **ON** children;
- Research **ABOUT** children;
- Research **WITH** children;
- Research **BY** children.

ARTICLE 12:

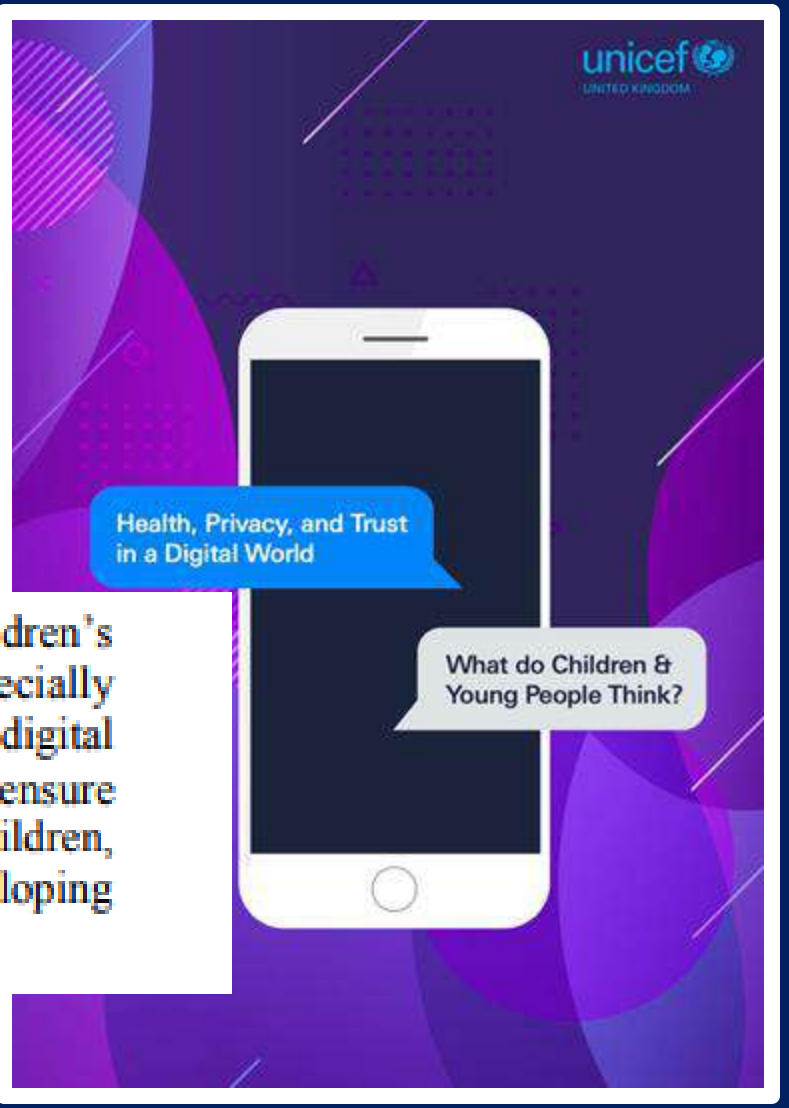
United Nations Convention on the Rights of the Child

You have the right to an opinion and for it to be listened to and taken seriously.

Child Rights & Technology

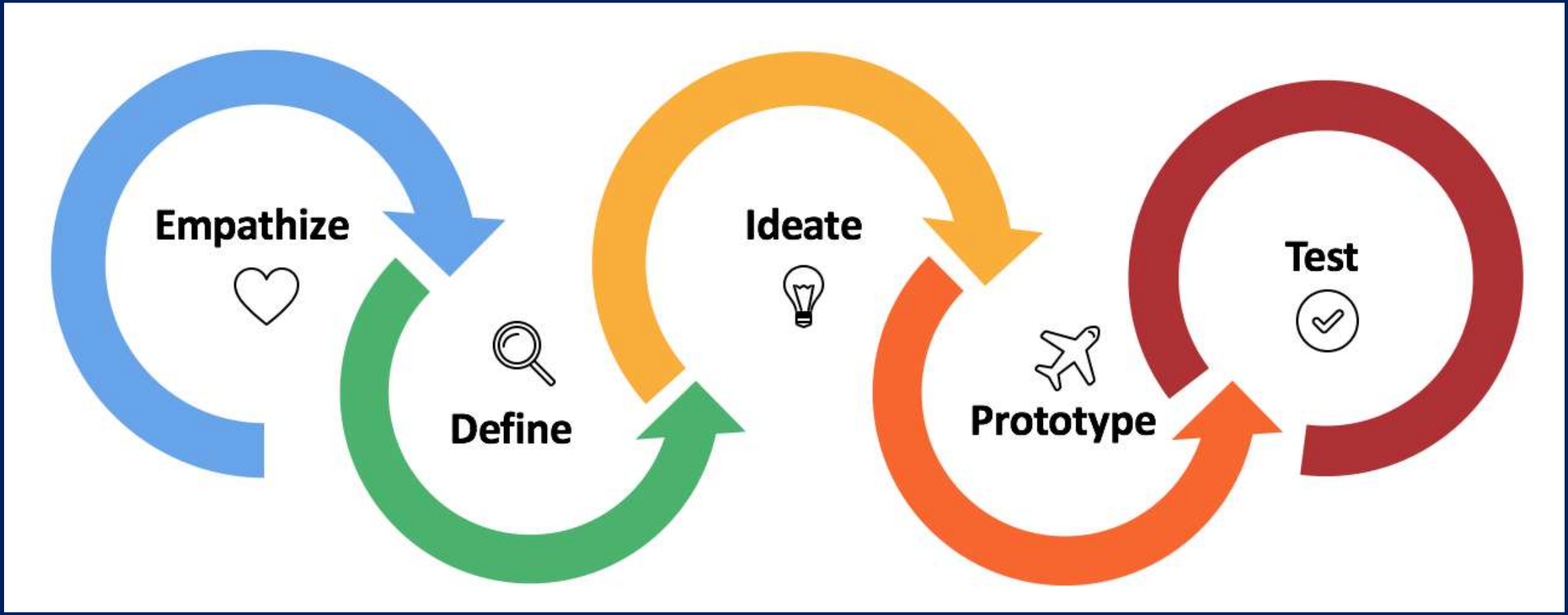
103. States should encourage and invest in research and development that focus on children's specific health needs and promote positive health outcomes for children through technological advances. Digital services should be used to supplement or improve in-person provision of health services to children.[46] 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

User- centred design



Lundy Model

This model provides a pathway to help conceptualise Article 12 of the UNCRC. It focuses on four distinct, albeit interrelated, elements. The four elements have a rational chronological order.

Space
Children and young people must be given safe, inclusive opportunities to form and express their views

Voice
Children and young people must be facilitated to express their views

Audience
The views must be listened to

Influence
The views must be acted upon, as appropriate

Space

HOW: Provide a safe and inclusive space for children to express their views

- Have children's views been actively sought?
- Was there a safe space in which children can express themselves freely?
- Have steps been taken to ensure that all children can take part?

Voice

HOW: Provide appropriate information and facilitate the expression of children's views

- Have children been given the information they need to form a view?
- Do children know that they do not have to take part?
- Have children been given a range of options as to how they might choose to express themselves?

Audience

HOW: Ensure that children's views are communicated to someone with the responsibility to listen

- Is there a process for communicating children's views?
- Do children know who their views are being communicated to?
- Does that person/body have the power to make decisions?

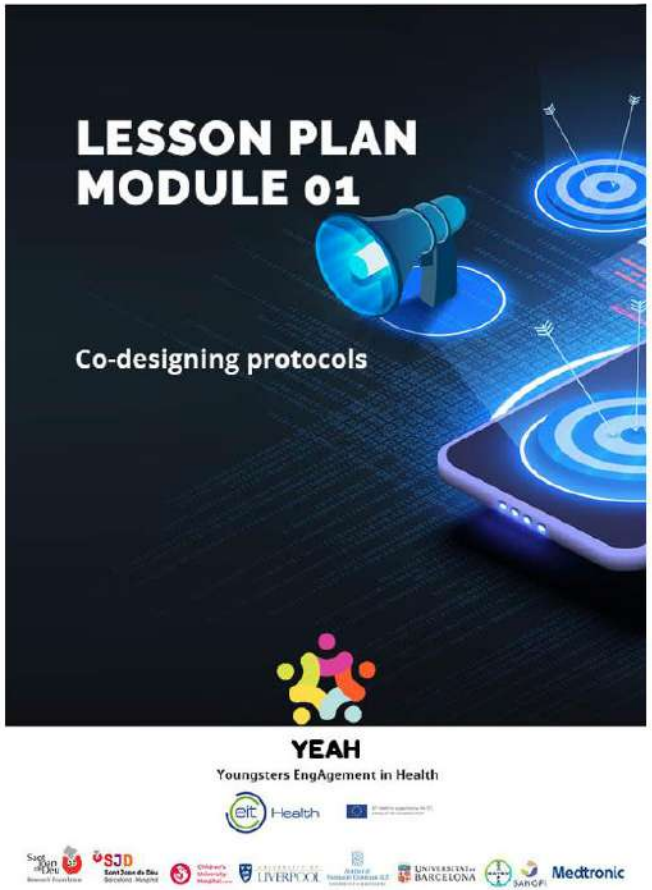
Influence

HOW: Ensure that children's views are taken seriously and acted upon, where appropriate

- Were the children's views considered by those with the power to effect change?
- Are there procedures in place that ensure that the children's views have been taken seriously?
- Have the children and young people been provided with feedback explaining the reasons for decisions taken?

Lundy, L. (2007), 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. British Educational Research Journal, 33: 927-942. https://doi.org/10.1080/01411920701657033

Educating young people about medical devices



Benefits of involving CYP

Improved functionality

Quality

Usability

Acceptability

Reduction in product failure

Effective Usage

Customer satisfaction

Product sales

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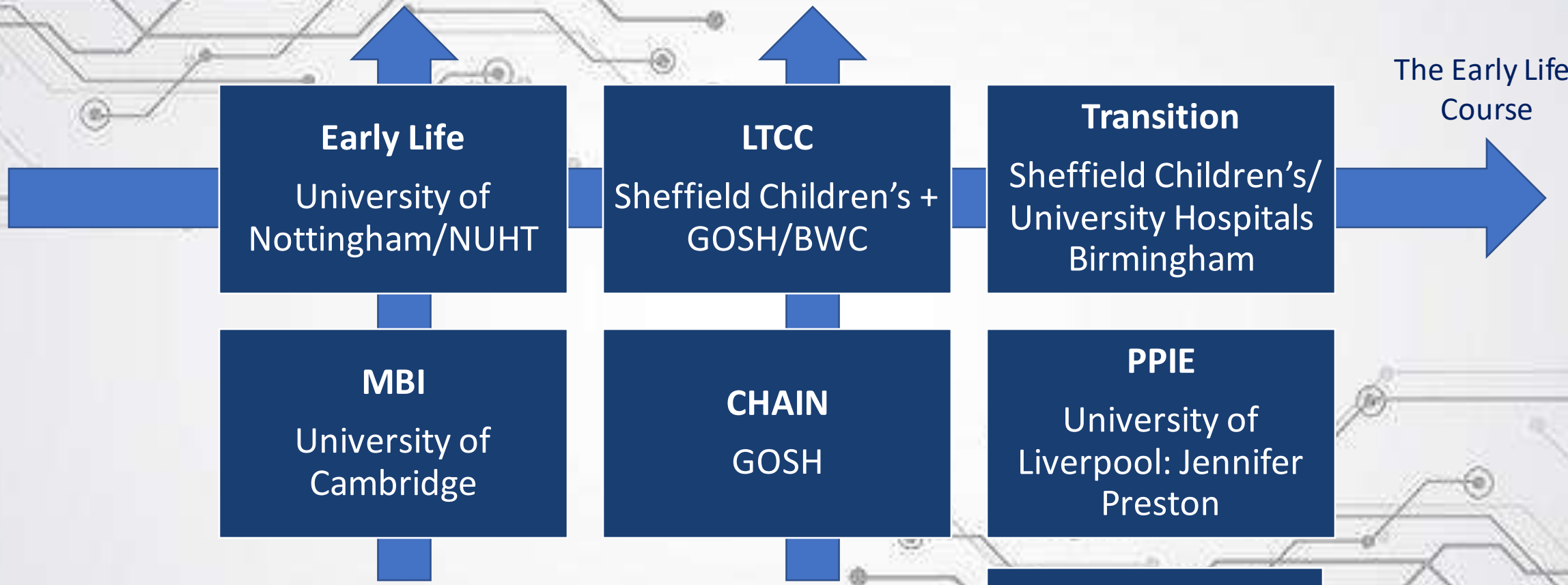

Cross-cutting Themes

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For more information:

Jennifer.preston@Liverpool.ac.uk

www.cypmedtech.nihr.ac.uk

Twitter: **@cypmedtech**

NHS Sheffield Children's NHS Foundation Trust

Sheffield Hallam University Knowledge Applied

The University Of Sheffield.