Co-design approaches with children, young people and families in healthcare

Dr Gemma Wheeler, National Institute for Health and Care Research
HealthTech Research Centre in Paediatrics and Child Health

Co-design in child health technology webinar – 07/05/2024

NIHR | HealthTech Research Centre Paediatrics and child health

Overview

An introduction to the NIHR HealthTech Research Centre in Paediatrics and Child Health

What is PPI, Co-design, and Experience-Based Co-design?

Key frameworks for co-design

Examples of tools in practice

A community of learning

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OUR THEMES ACROSS THE EARLY LIFE COURSE:

BIRTH TO 25 YEARS

An evolution of: NIHR | Children and Young People MedTech Co-operative

www.cypmedtech.nihr.ac.uk

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Health Inequalities

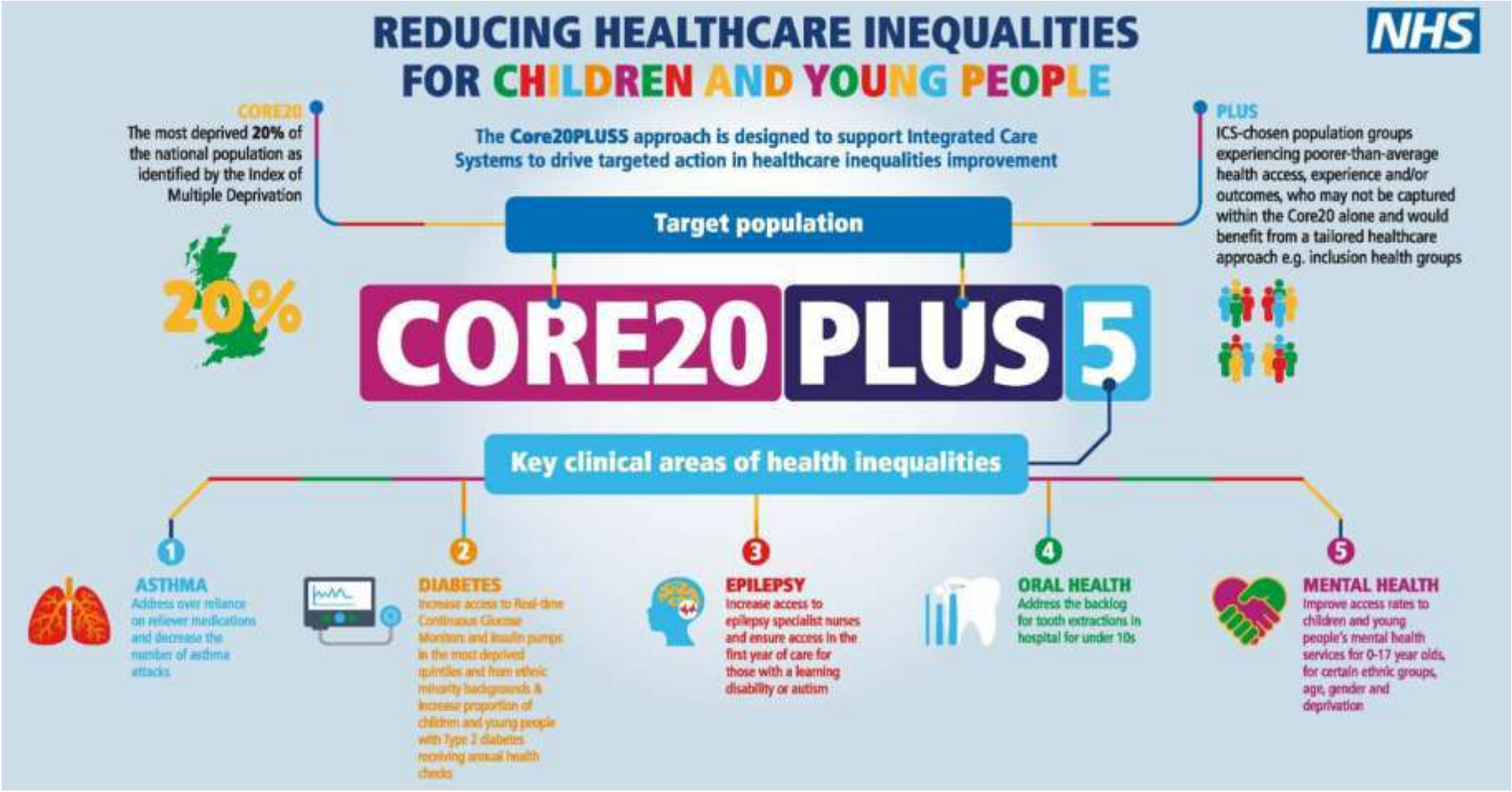
Unfair and **avoidable** differences in health across the population

4.3 million children live in poverty in the UK, almost **1 in 3**
(Child poverty action group)

A child born in the most deprived part of the country can expect to **die 10 years before** a child born in the least deprived areas *(ONS 2020a)*

1 in 5 child deaths might have been avoided if they had the same mortality risk as those in least deprived areas *(NCMD 2020)*

Health inequalities are **growing,** leading to **short-** and **long-term** implications for children & families



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A rights-based approach to involving CYP

Led by Jennifer Preston: PPIE Executive Lead

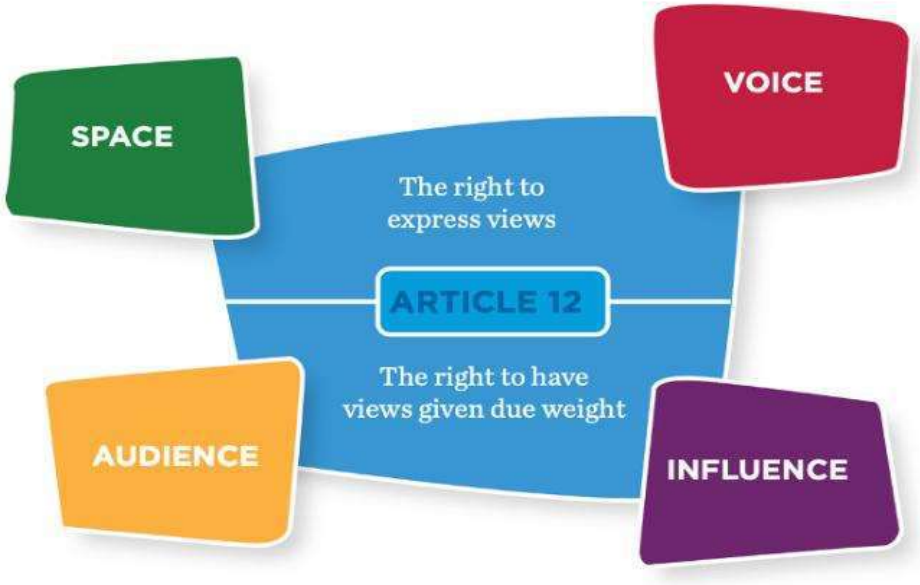
GenerationR
young people improving Research

BeGOOD Citizens	Bristol	CA:RING
Eye-YPAG	Hertfordshire	Imperial YPAN
Kent, Surrey & Sussex	Leeds Young Research Owls	Leicester
Liverpool	London	Manchester VoiceUp
North East	Nottingham	ScotCRN
Sickle Cell Superheroes	Southampton (8-18)	Southampton (16-24)
West Midlands	YourRheum	Young Dynamos

www.generationr.org.uk/

Article 12 of the United Nations Convention on the Rights of the Child

Image credit: Dual Frequency



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(6) p927-942

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A rights-based approach to involving CYP

Patient and Public Involvement & Engagement
Development, **M**ethodologies and
Equality, **D**iversity and **I**nclusion
(DeMEDI) Programme

- Creating and piloting new **tools** and **methodological frameworks**
- Approaches for inclusion of hard to reach and seldom heard groups
- Systems for monitoring and tracking PPIE
- Developing education platforms
- Tools for CYP self-reflection on their PPIE
- Health Inequalities in Technology (HIT) OUT Workshop

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Co-design and design-led approaches to involving families in research & innovation

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PPIE, EBCD and Co-design

Meaningful involvement of children and young people in health technology development
Journal of Medical Engineering and Technology

PPIE / PPI

- "Nothing about us, without us" [1]
- Contributing to **how** research studies are designed, conducted, and disseminated

Co-design

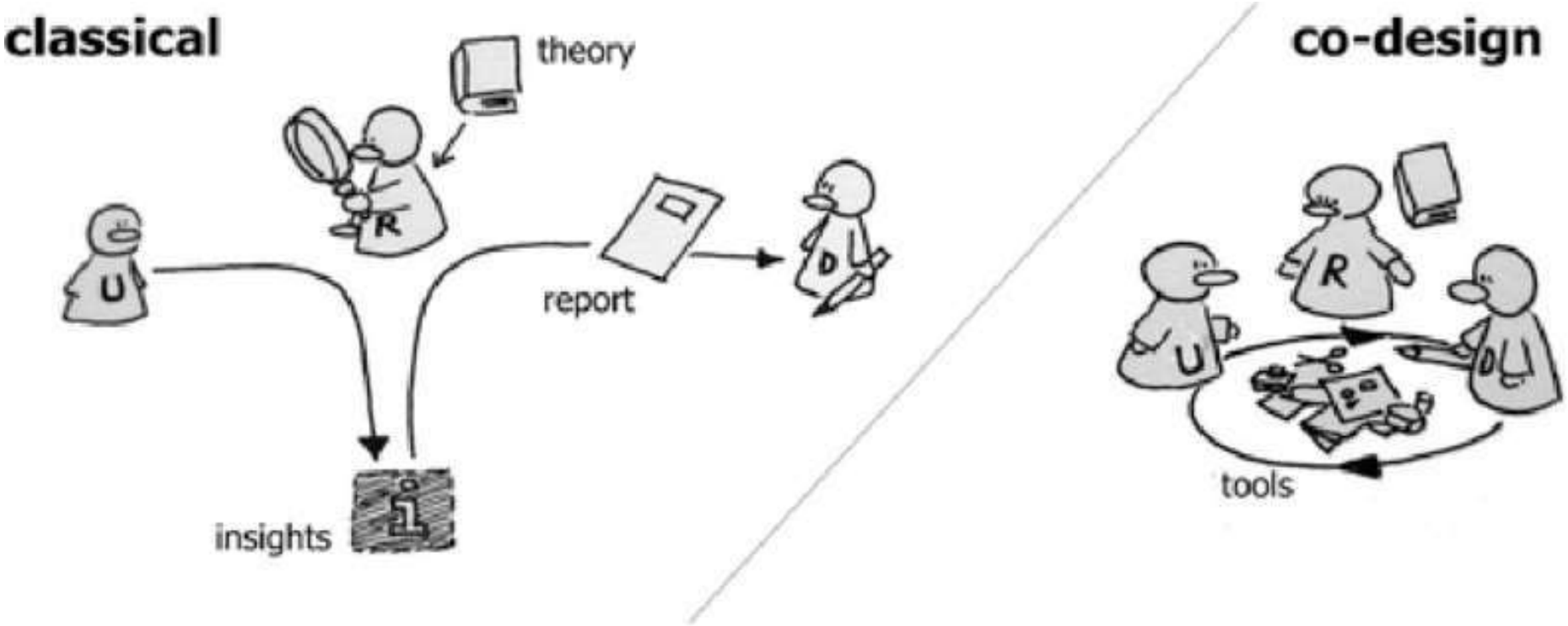
- "the creativity of designers and people not trained in design coming together in the design development process" [2]
- characterised by use of creative methods & adaptable process

Experience-based Co-design (EBCD)

- "design-like" rather than "designerly" [3]
- Repeatable method with a track record in healthcare

[1] NIHR Oxford BRC: a researchers guide to PPI [Internet]; [cited 2021 Nov 09]. Available from: https://oxfordbrc.nihr.ac.uk/wp-content/uploads/2017/03/A-Researchers-Guide-to-PPI.pdf
[2] Sanders E, Stappers P. Co-creation and the new landscapes of design. CoDesign. 2008;4(1):5–18
[3] Robert G, MacDonald AS. Infrastructuring for organisational creativity and quality improvement in the healthcare sector: 'designerly' or 'design-like? In: Sangiorgi D, Prendiville A, editors. Designing for service: contemporary issues and novel spaces. London: Bloomsbury; 2017

History of co-design



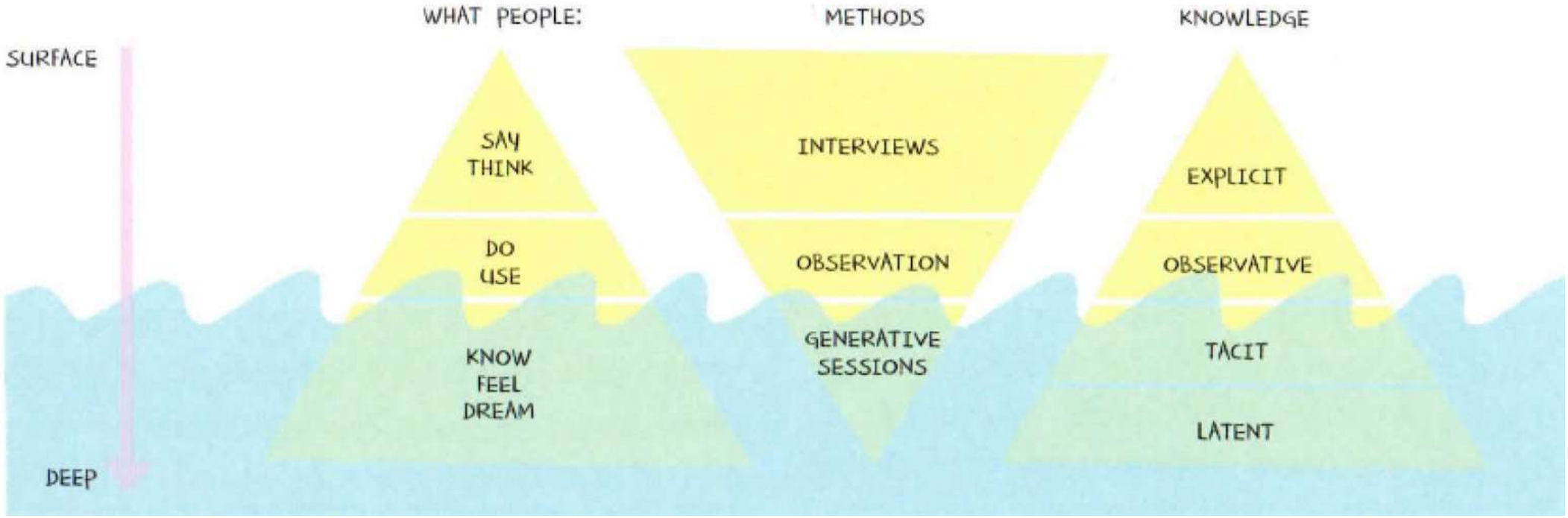
Designer as expert → User-centred design → Human-centred design → Participatory / Co-design

[2] Sanders E, Stappers P. Co-creation and the new landscapes of design. CoDesign. 2008;4(1):5–18

Why use co-design?

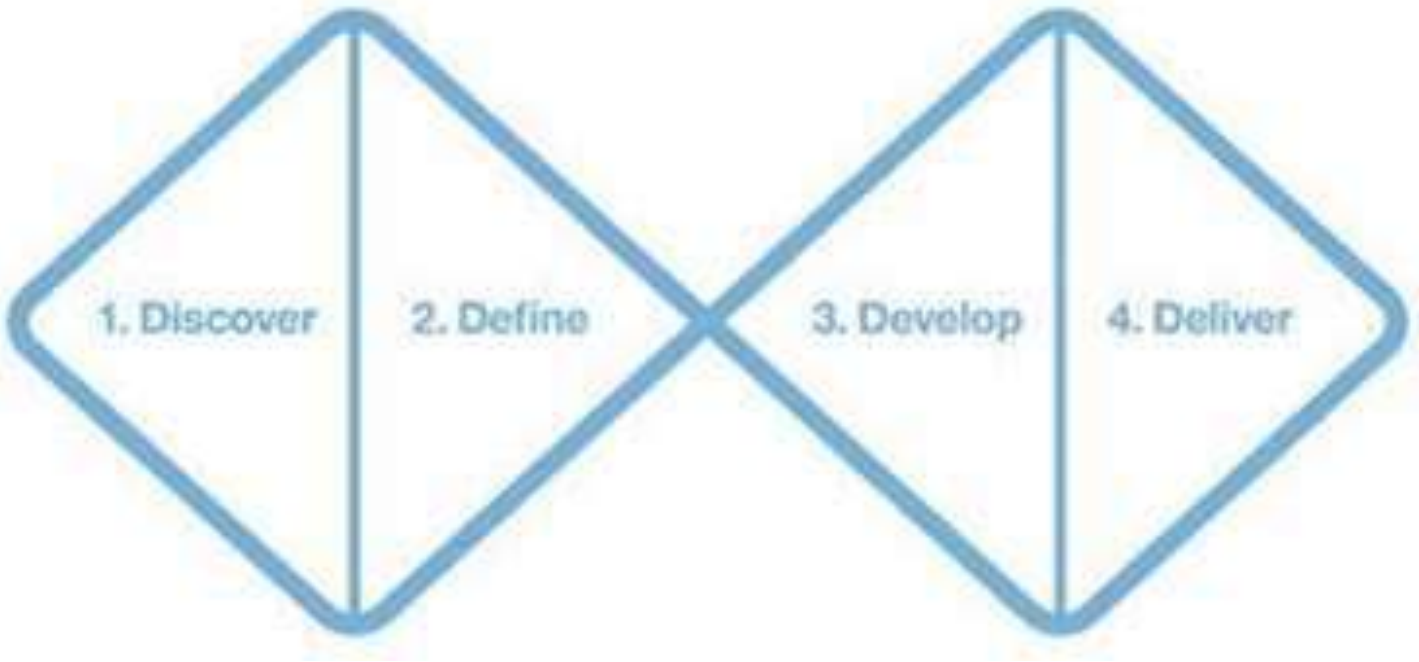
- Practically - it leads to better outcomes
- Politically - patients (including children and young people) have a right to be involved
- Patients are people, not symptoms
  - And children are **not** little adults!
- Innovation in healthcare occurs in complex systems
- Power dynamics and hierarchies in terms of people and types of knowledge can hinder innovation

Why use “Creative” methods?



[4] Convivial Toolbox: Generative Research for the Front End of Design, Sanders and Stappers, 2012

Double Diamond framework (The Design Council, UK)



[5] See: https://www.designcouncil.org.uk/our-resources/the-double-diamond/

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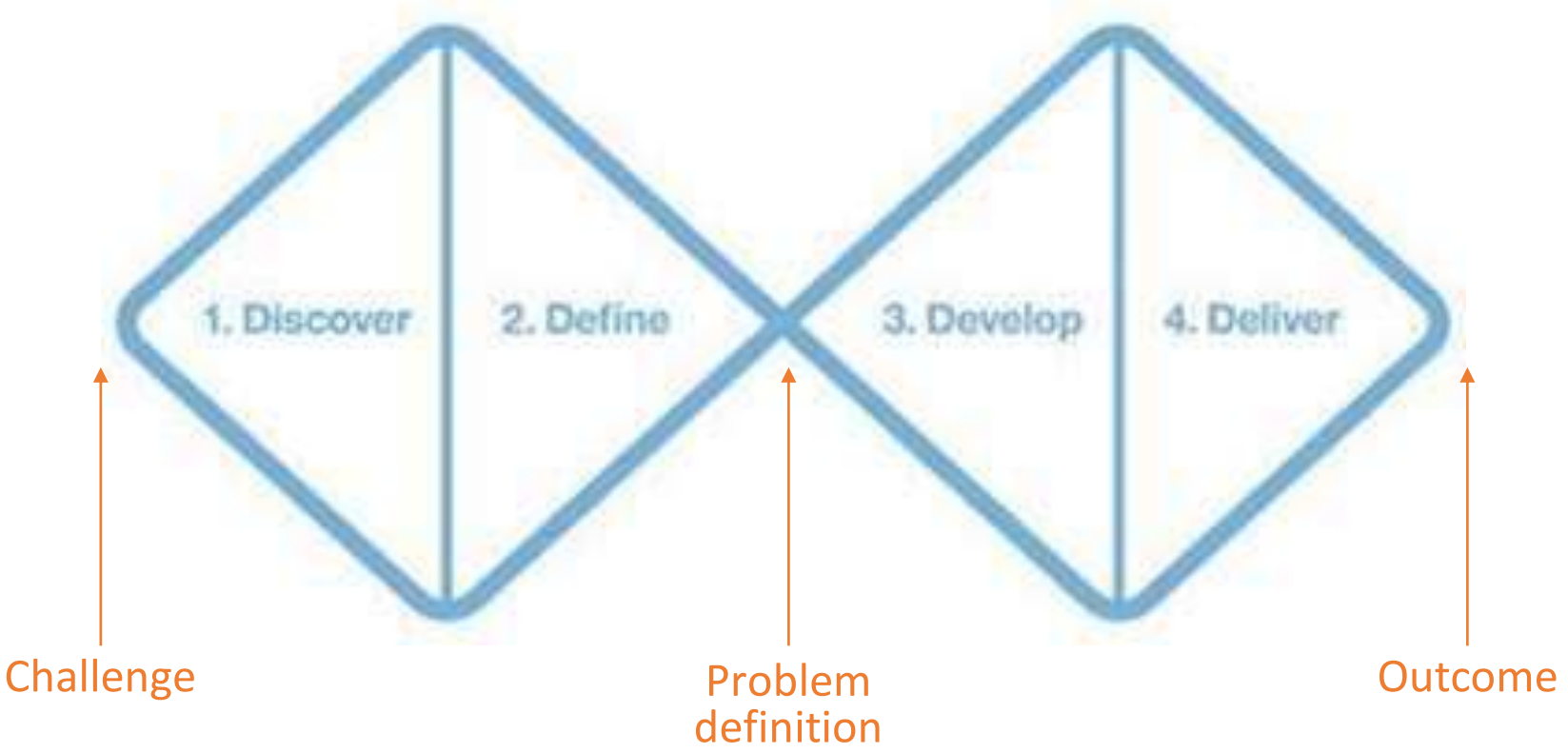

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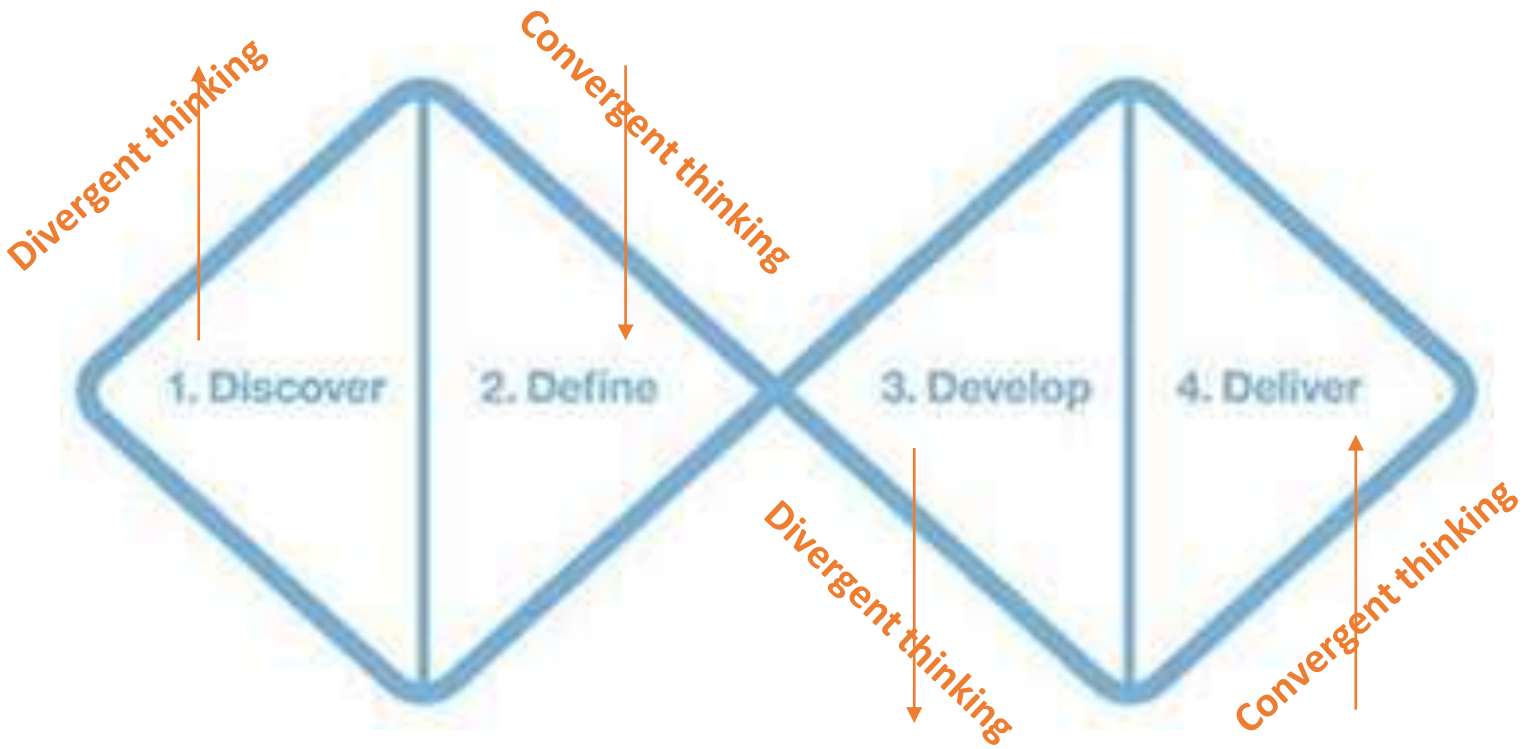

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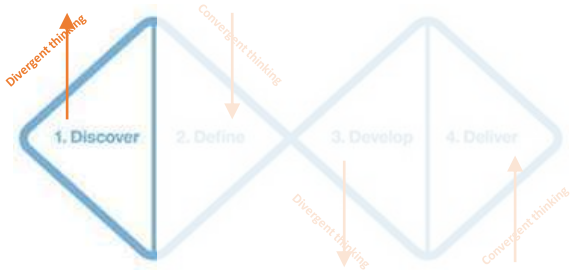
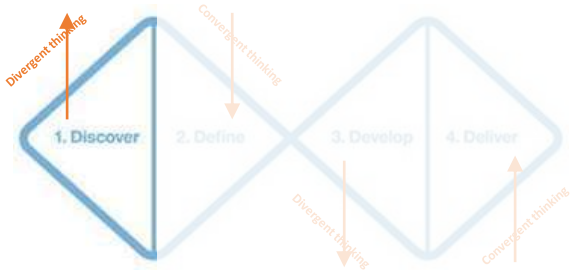
Double Diamond framework: DISCOVER



- Immersion in a context, or using visuals to support this

Sheffield Children's Hospital waiting room

Double Diamond framework: DISCOVER



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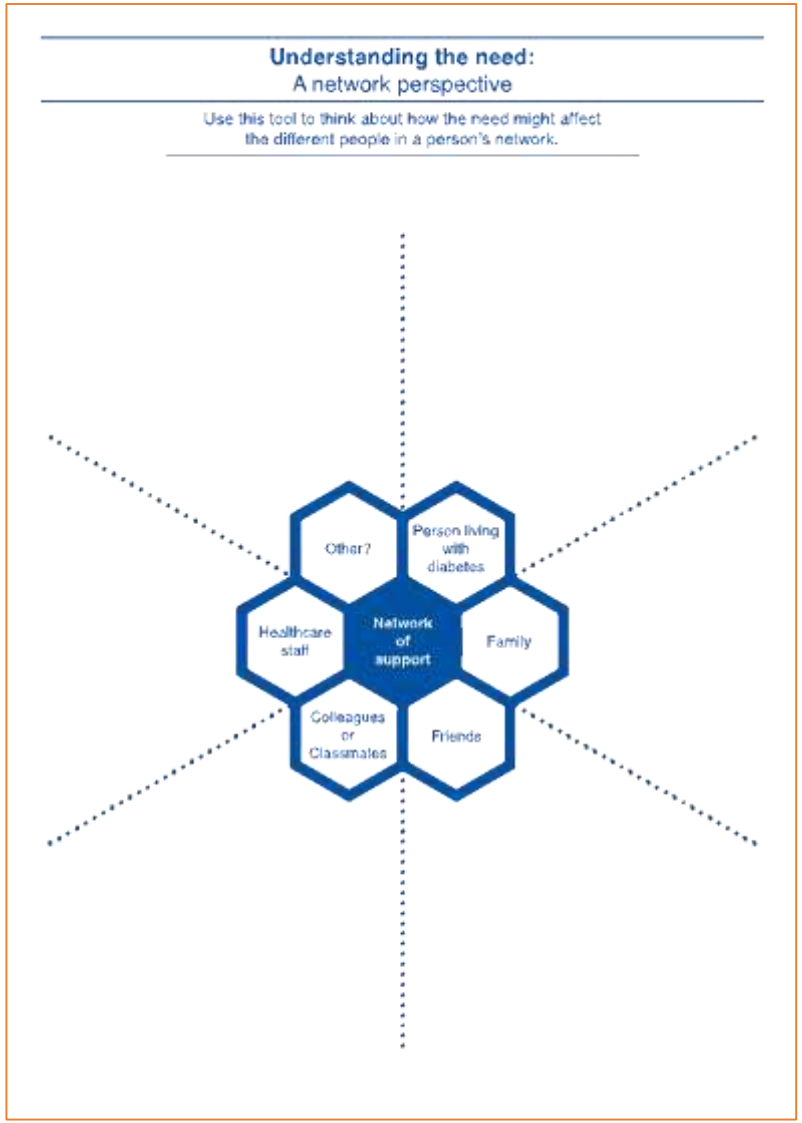
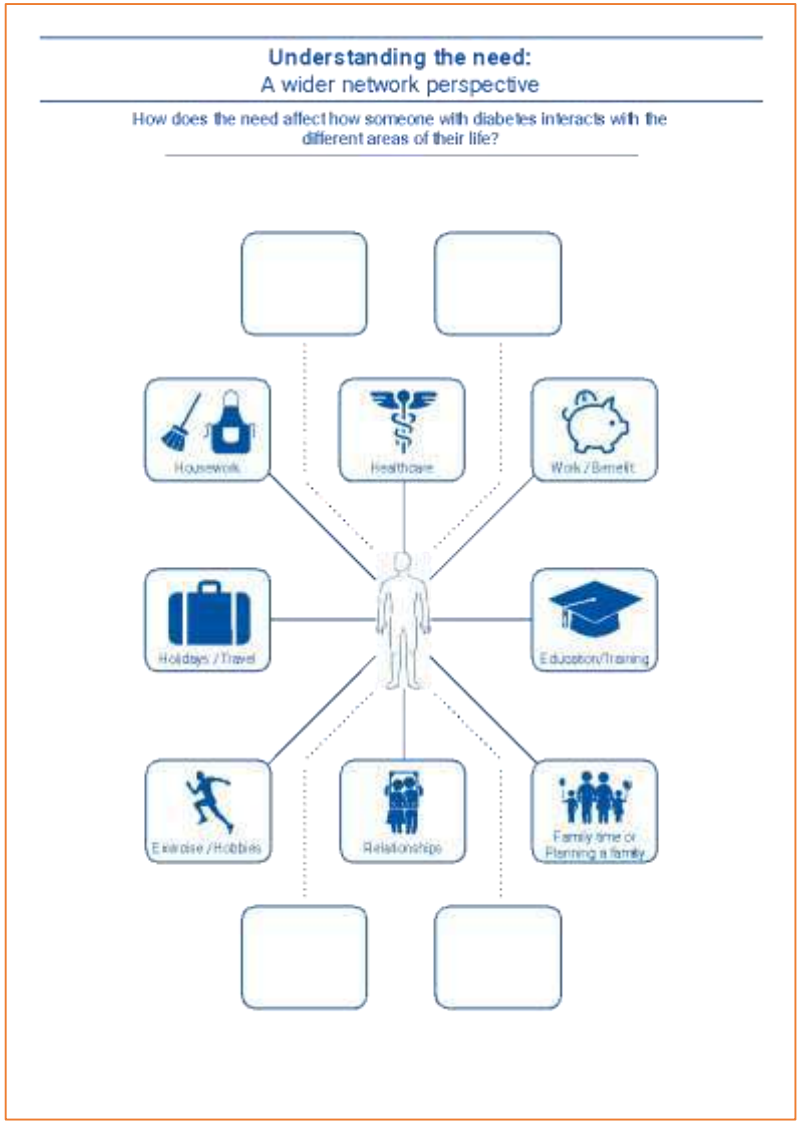
- Tools to consider **who** is involved, or how a condition affects different areas of a person's life





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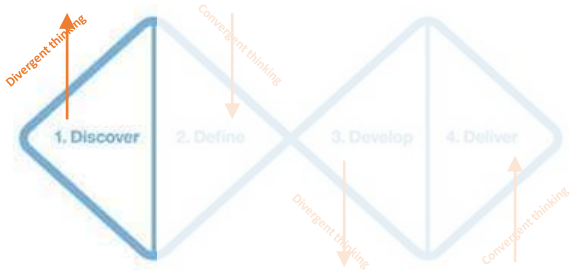

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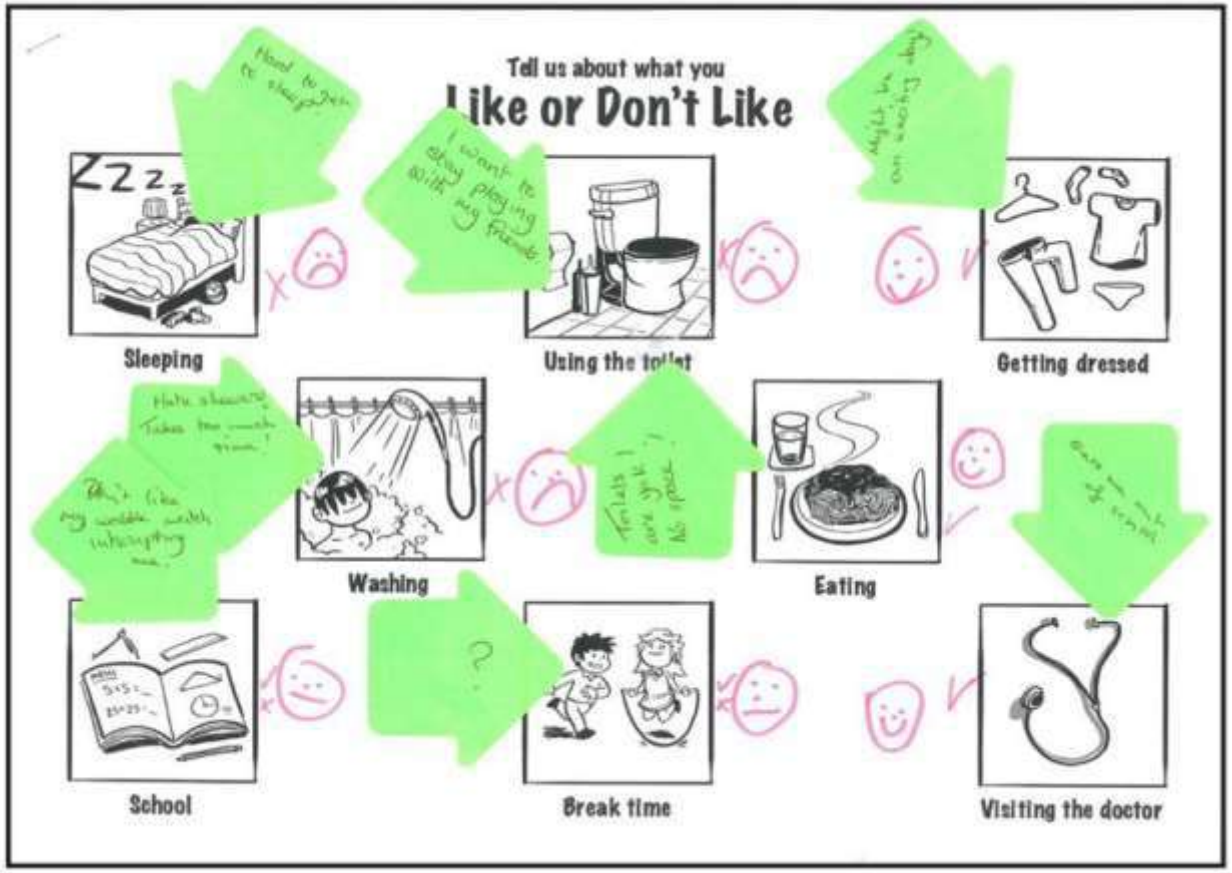

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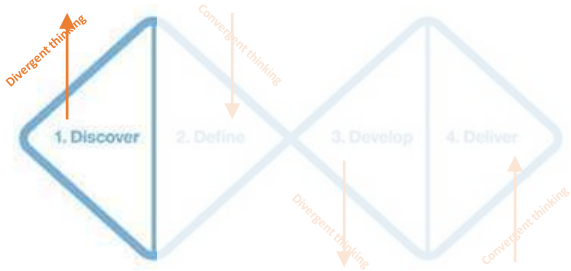

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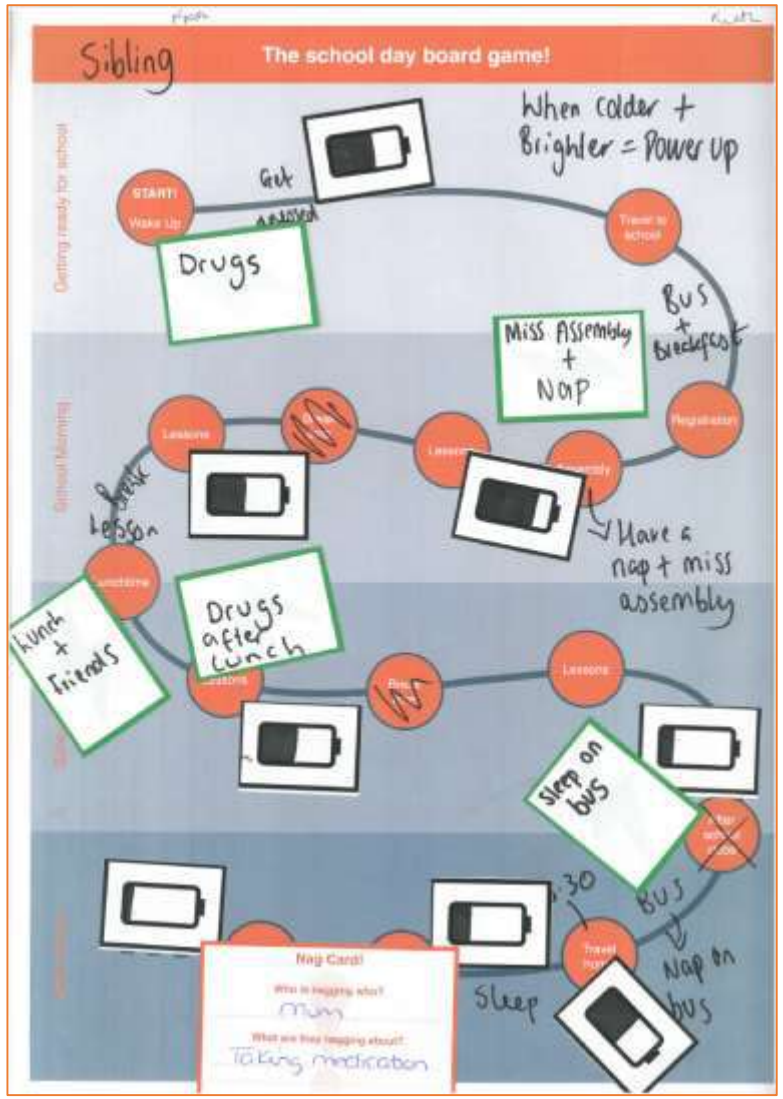
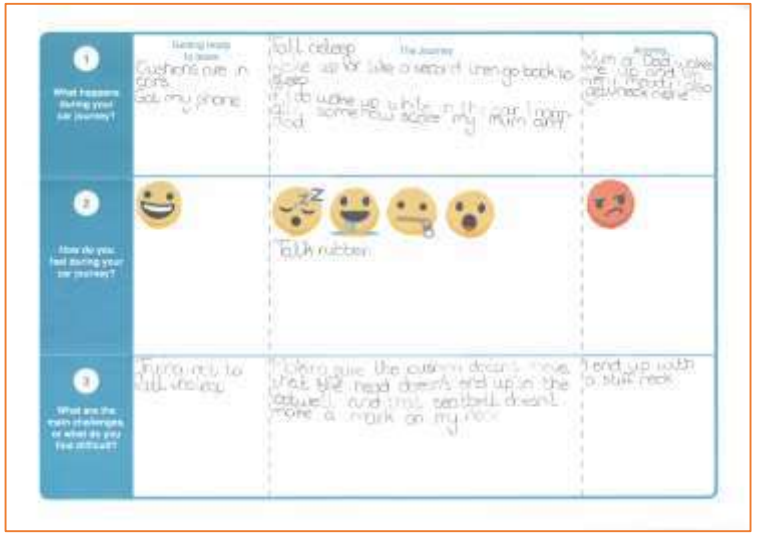
- Thinking about the "journey" (of a service, an interaction with your innovation, or a typical day)





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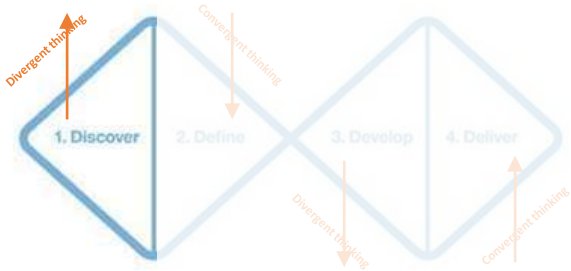
Double Diamond framework: DISCOVER



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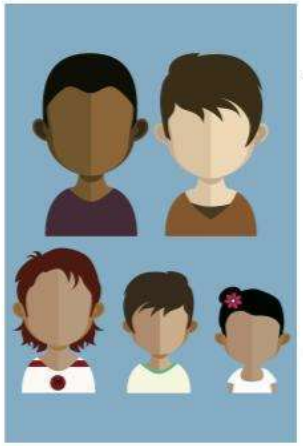
- Tools to consider **who** is involved, or how a condition affects different areas of a person's life
- Thinking about the "journey" (of a service, an interaction with your innovation, or a typical day)
- Consider who is missing from these discussions, how can we address this?

Kate and Dan are young first, time parents. While they have a relatively low income, they have a close and supportive family network close by.



This is **Mia and Sam** and their 3 children, **George, Isaiah and Poppy.** They have a lot of experience as parents, but the rest of their family live far away, so they can't rely on them to help out while Mia and Sam are busy with their demanding jobs.

Lucy has just met her new baby brother in the neonatal unit. She has some experience looking after young children already as she often takes on a caring role with her younger siblings.

Emma has just become a big sister! She's really excited to meet her new sister as she's been an only child until now. Her parents have been really busy looking after the new baby in hospital, so she's been staying with her grandparents a lot during this time.

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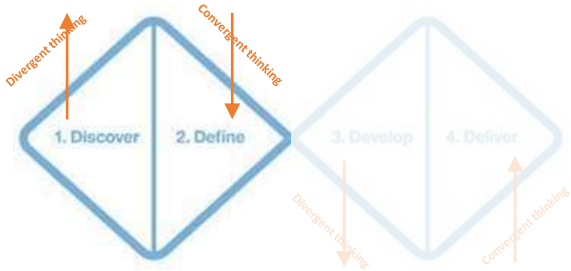
Double Diamond framework: DEFINE



- Who is affected most, and how?

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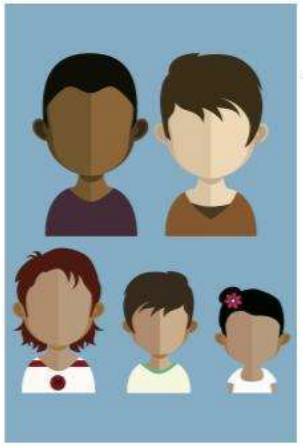

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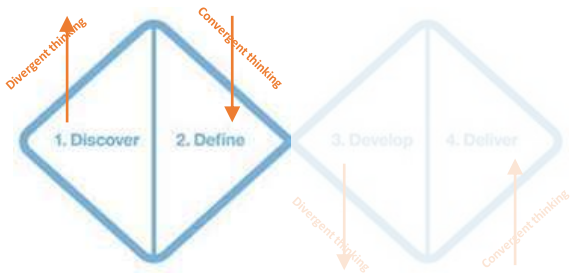
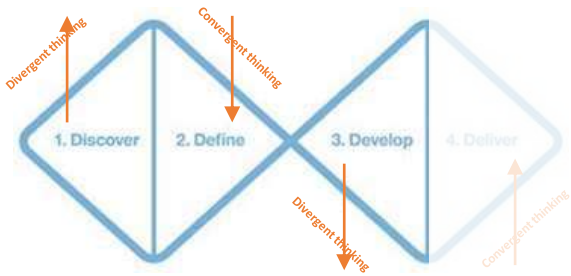
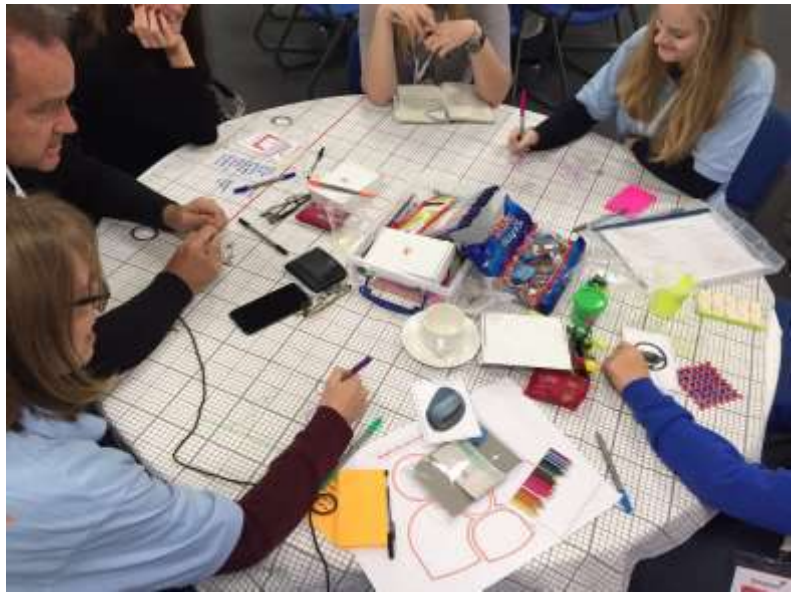


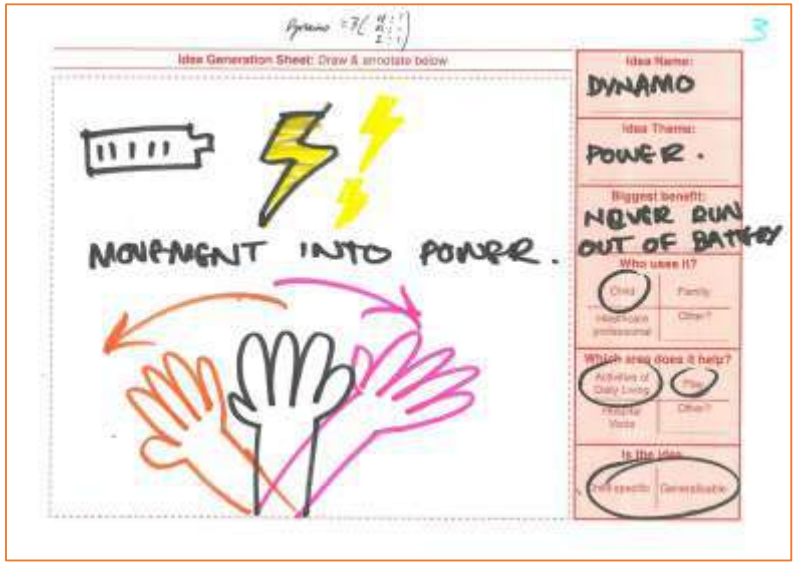
- Who is affected most, and how?
- Mapping key factors

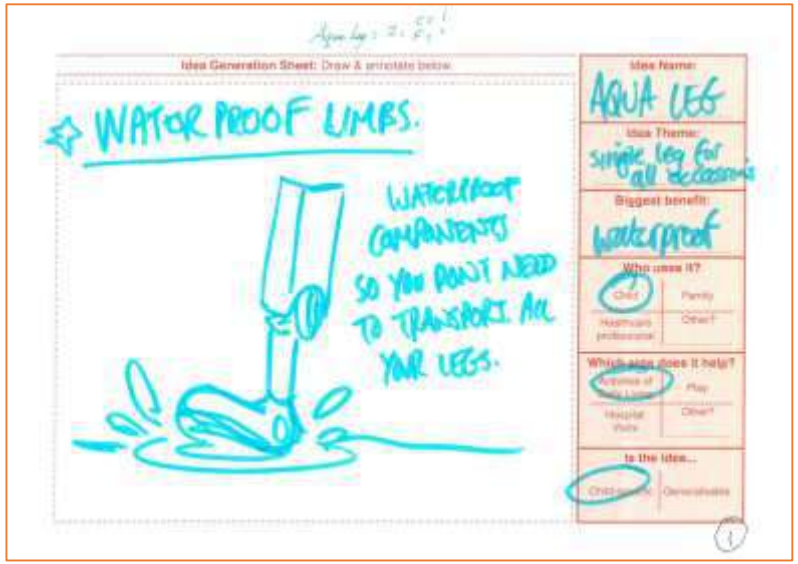
Double Diamond framework: DEVELOP



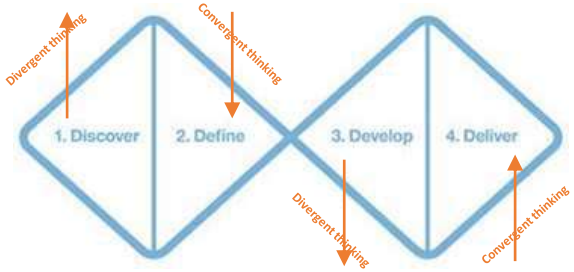
- Everyone is capable of creativity!
- Idea generation can be asset-based, and fun
- Go for quantity, not quality, to begin with





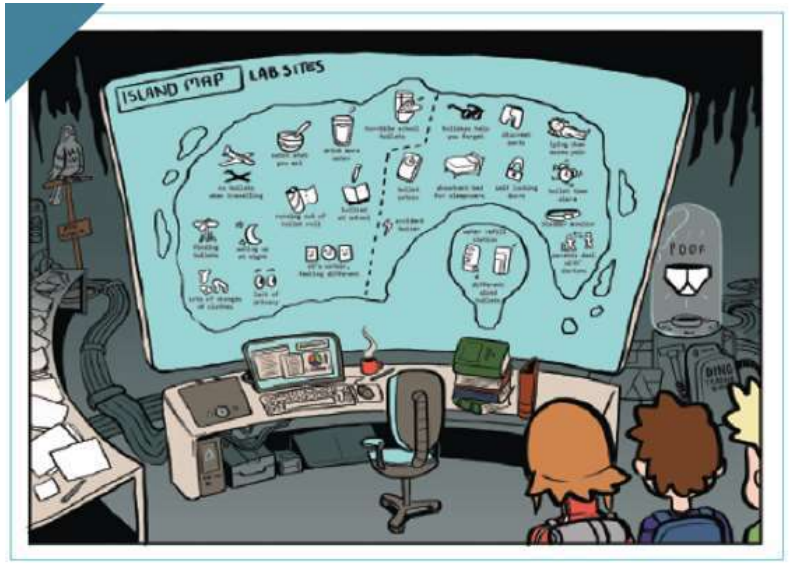


Double Diamond framework: DELIVER



- Voting
- Low-fidelity prototypes (This can still be drawings, or service journey maps)
- Dissemination and regular feedback can help promote long-term, mutually beneficial working relationships

- …and be ready to iterate!



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Creating a community of learning

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ONLINE 11 - 12 JUNE

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Thank you for listening!

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