

SPSP Perinatal and Paediatric Learning Session

Including children and families in
the co-design of improvement
work

14th March 2024

Welcome



Dr Sonia Joseph

National SPSP Paediatric Clinical
Lead



Tim Shearman

Improvement Advisor



Sara McIvor

Project Officer



- Explore some of the methods that can be used to engage children and families in quality improvement work
- Hear from two Boards with examples of quality improvement work that engaged children and families
- Identify existing resources to help you engage children and families in your work



Agenda

Time	Topic	Lead
13:40-13:45	Welcome & Introduction	Dr Sonia Joseph, National Clinical Lead, SPSP Paediatrics Tim Shearman, Improvement Advisor
13:45-13:50	Listening to children in QI	RCPCH & Us
13:50 - 14:00	NHS Greater Glasgow & Clyde	Dr Aly Walker, Consultant Cardiac Anaesthetist, Royal Hospital for Children, Glasgow
14:35-15:00	Identifying and dismantling barriers to engagement	Following 'Wise Crowds' Liberating Structures format Liberating Structures - 13. Wise Crowds
14:25-14:35	NHS Lothian	Zoe Paige, Project Manager, Children's Services
14:00-14:25	Identifying local resources that can help with engagement	Following '1-2-4-All' Liberating Structures format Liberating Structures - 1. 1-2-4-All
15:00-15:05	Summary and Close	All

Essentials of Safe Care Driver Diagram

Aim

To enable the delivery of
Safe Care for every person
within every system every
time

Primary Drivers

Systems and culture for Person
Centred Care are embedded and
support safety for everyone

Safe communications within and
between teams

Leadership to promote a culture of
safety at all levels

Safe consistent clinical care
processes across health and social
care settings

Secondary Drivers

Structures & processes that enable safe, person centred care

Inclusion and involvement

Workforce capacity & capability

Skills : Staff are supported & trained to use appropriate language, format
and content

Practice : Staff can use standardised tools for communication appropriately:
structured handovers, admission, discharge and care planning.

Critical Situations : Staff are prepared and capable to manage communication
in different situations: emergency / crisis, transition of care, MDT meeting

Psychological safety

Staff wellbeing

Learning System

Reliable implementation of Standard Infection Prevention and Control
Precautions (SICPS)

Safe Staffing

- 16th July: UNCRC (Incorporation) (Scotland) Act 2024 enacted
- Every service within the NHS has a responsibility to uphold children's rights.
 - **Article 24:** Children have the right to be as healthy as possible
 - **Article 12:** Children have the right to be listened to and taken seriously

Getting Ready for UNCRC
Wednesday 27th March 2024
WCYPF Webinar Registration



Including Children & Families in the Co-Design of Improvement Work

Dr Alyson Walker

Consultant Paediatric Anaesthetist
NHS Greater Glasgow & Clyde



What is “co-design”?

CO-

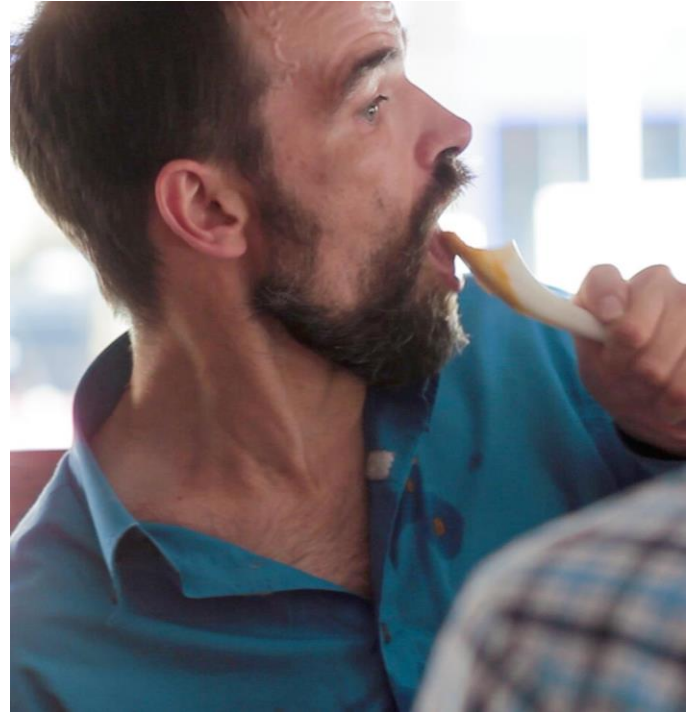
Bring together lived experience, lived expertise and professional experience.

DESIGN

“A plan for arranging elements in such a way as best to accomplish a particular purpose”
(Charles Eames)

CO-DESIGN

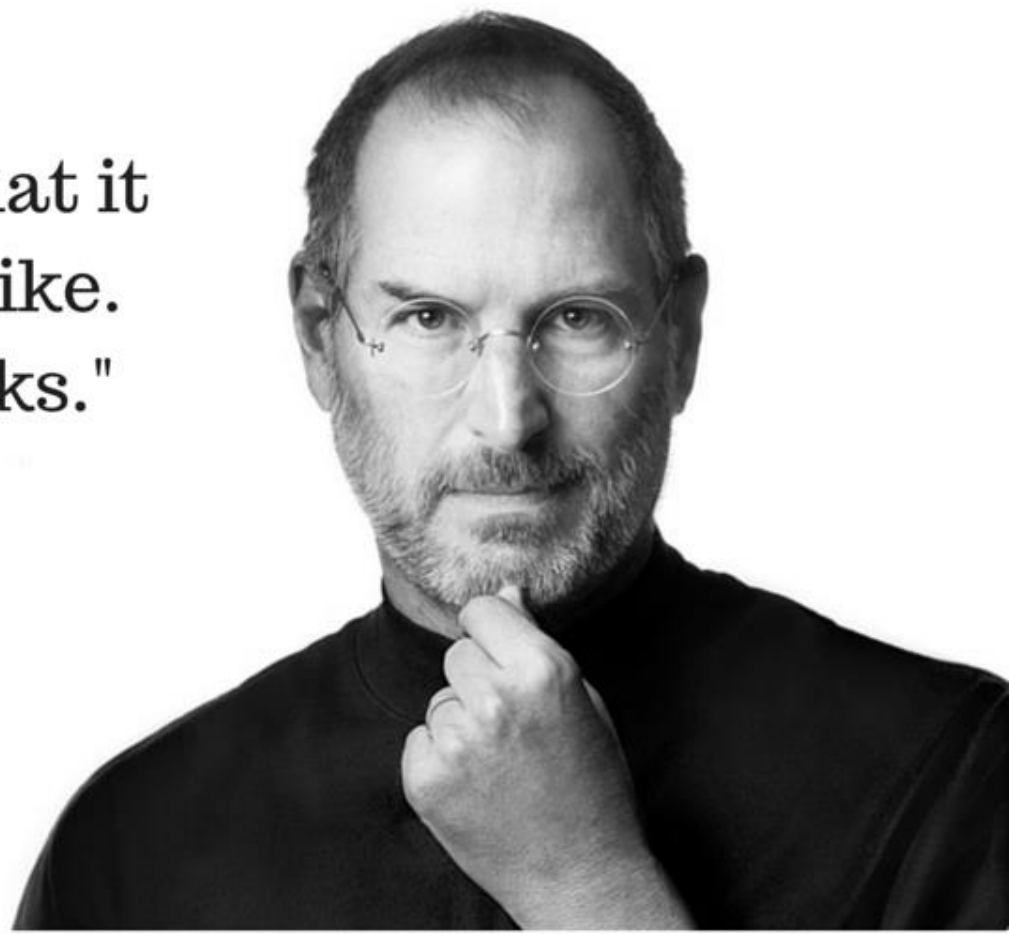
Designing WITH, not for.



"Design is not just what it
looks like and feels like.
Design is how it works."

Steve Jobs

1955-2011



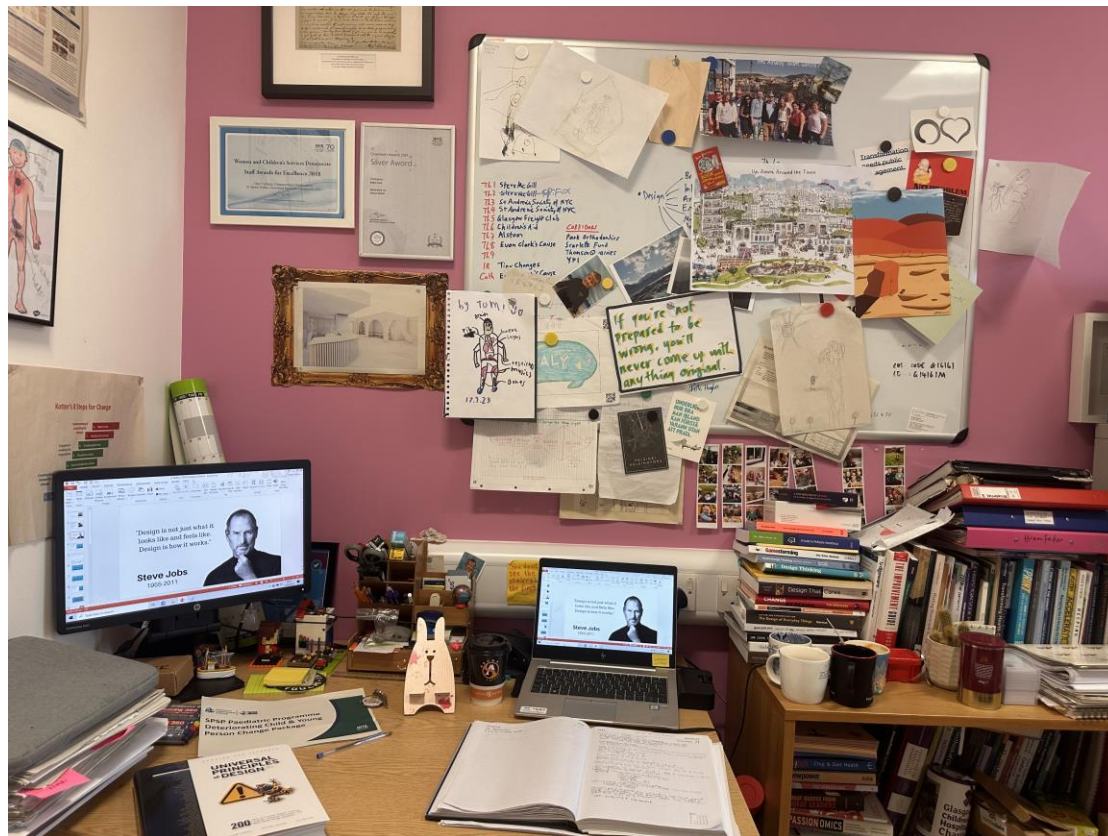
Scottish Approach to Service Design

“We explore and define the problem BEFORE designing the solution.”

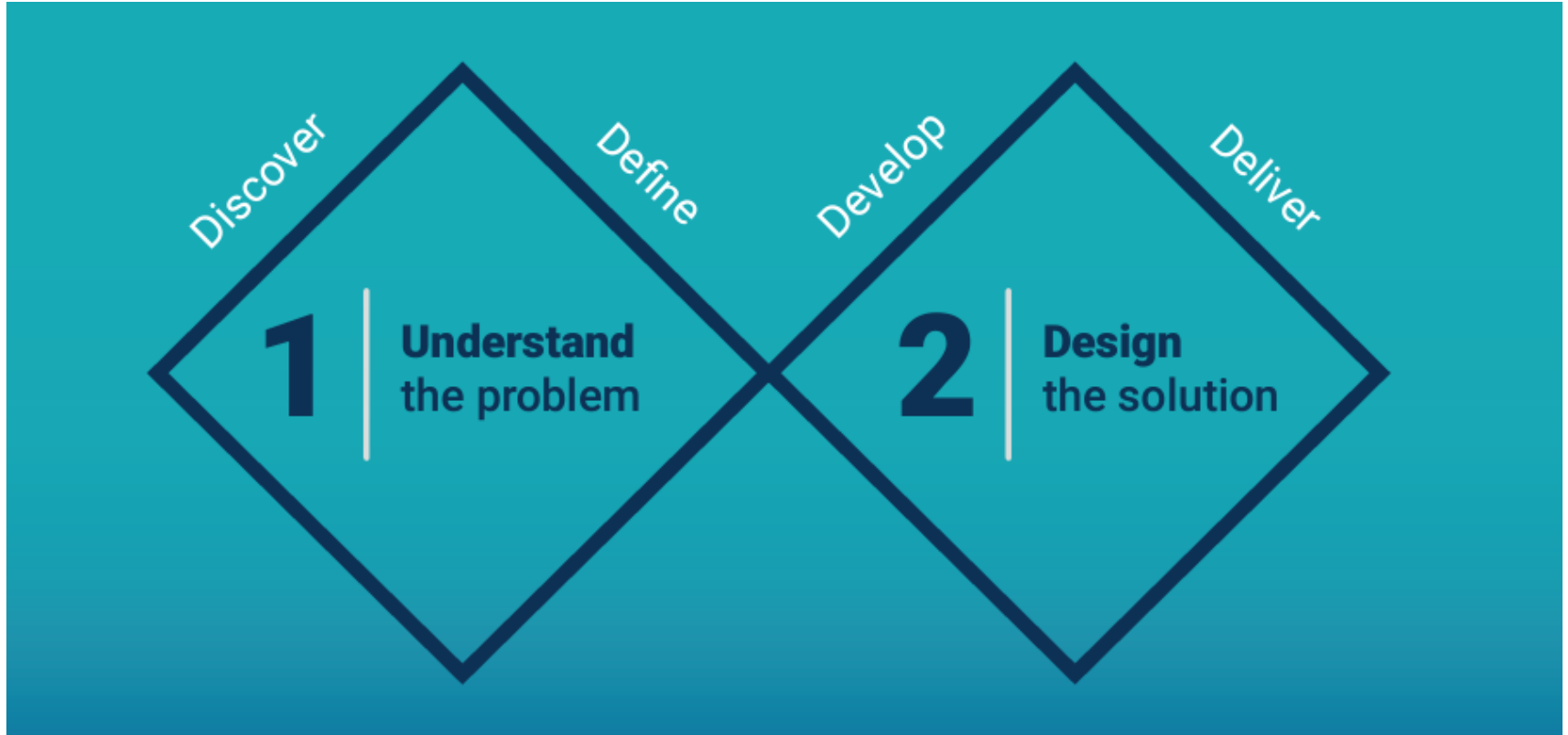
“We seek citizen participation in our projects from day one.”



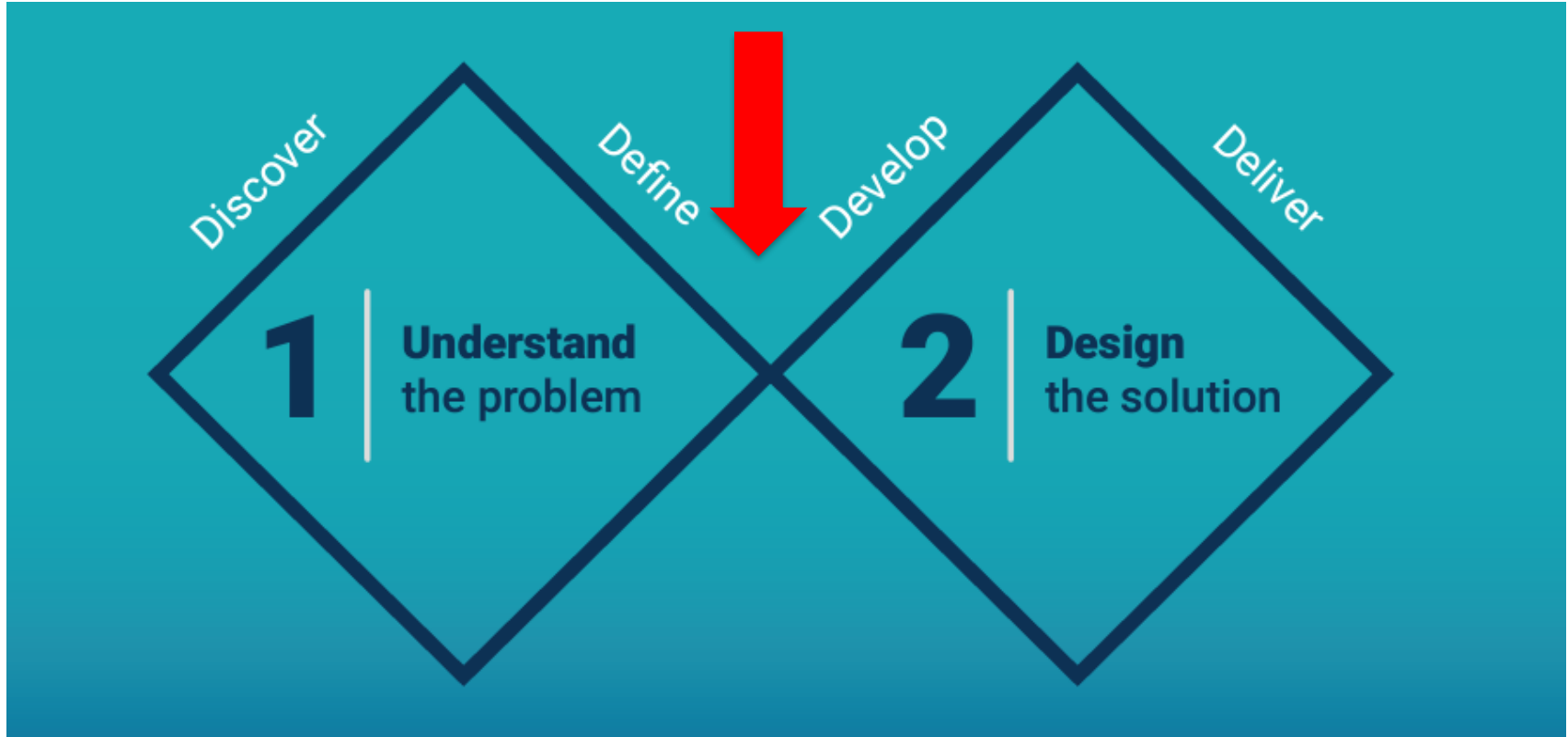
A desk is a dangerous place from which to view the world.



Double Diamond



“How might we....?”

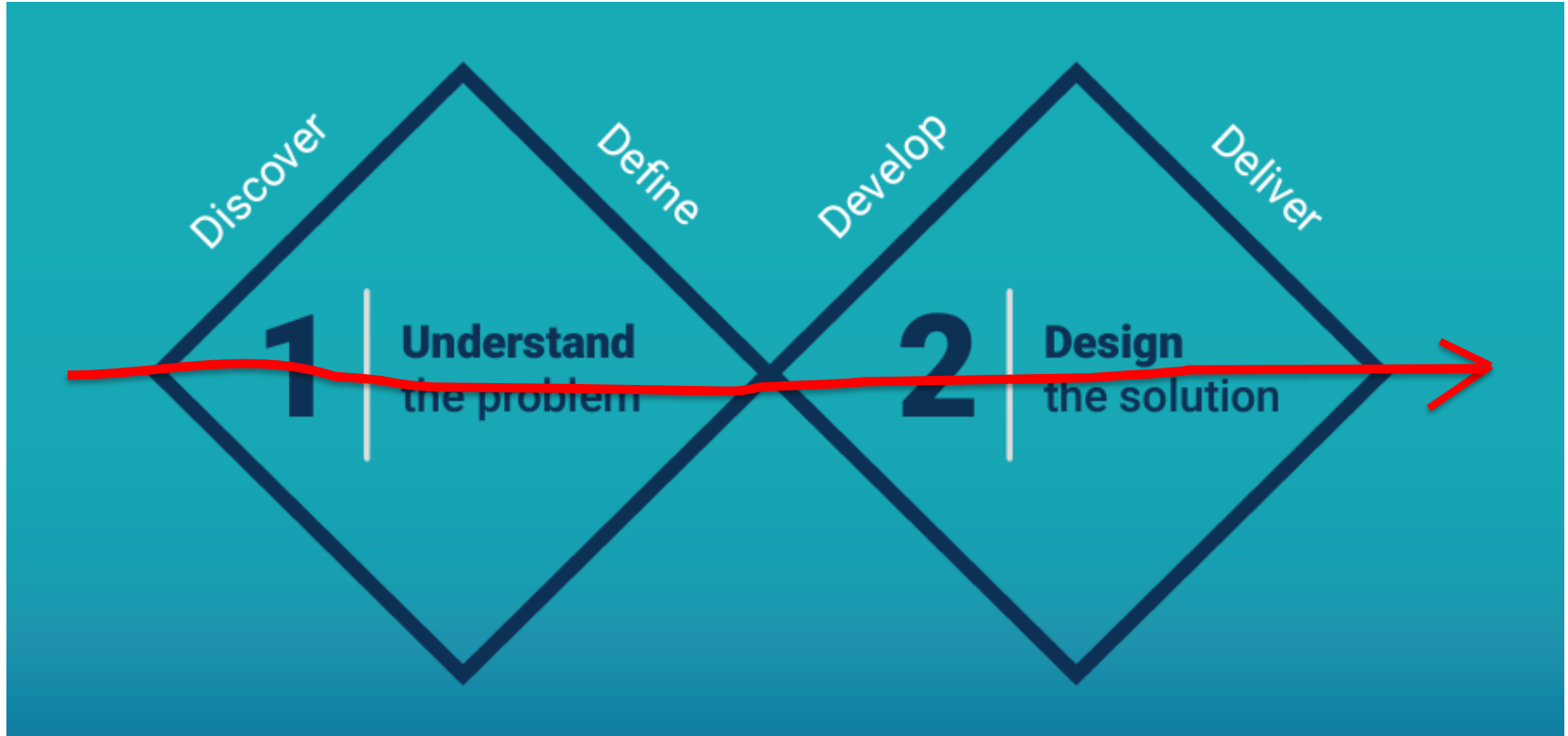


Develop and Prototype

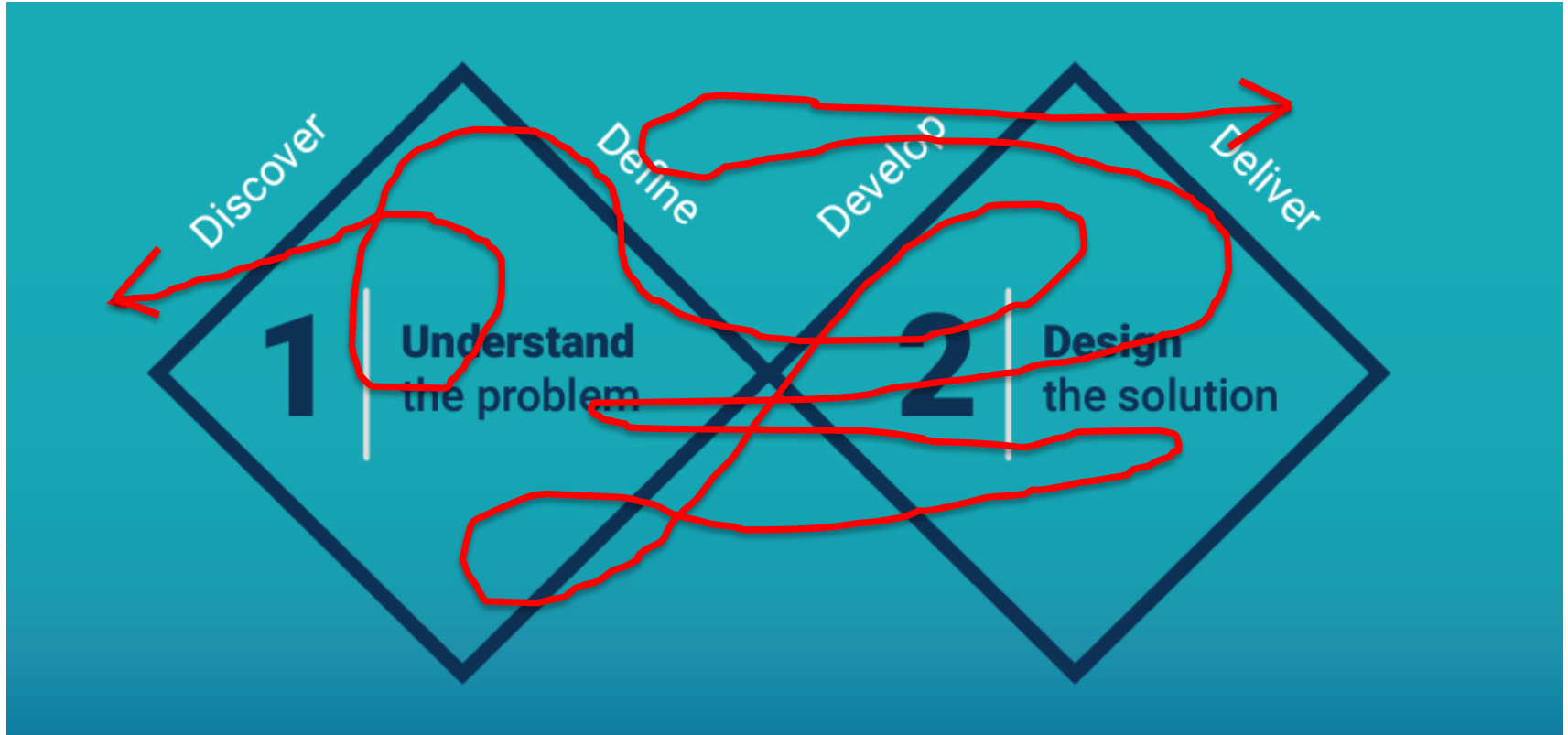
- Ideate (“brainstorm”)
- Avoid ‘group think’
- Hear all the voices in the room
- Be creative and wild
- Prototype your best ideas



Double Diamond



Double Diamond



Case Study: The Wee Room



2023 Deteriorating Child & Young Person Driver Diagram



Healthcare
Improvement
Scotland



What are we trying to achieve...

To reduce harm from deterioration by improving the recognition, response and review of the deteriorating child and young person**

By [locally agreed %] by
31st March 2025

**Essentials of Safe Care*

***Measurements may include
existing Excellence in Care data*

We need to ensure...

Person-centred care

Recognition of acute
deterioration

Standardised, structured
response and review

Safe communication across care
pathways*

Leadership to support a culture
of safety at all levels*

Which requires...

Patients, families and carers are listened to and included

Person-centred care planning

Anticipatory care planning & CYPADM

Discussions with families are well managed

Observations using PEWS (Scotland)

Action on staff concern

Action on patient, family and carer concern

Timely review by appropriate decision maker

Assessment for causes of acute deterioration

Escalation

Regular review and assessment

Interdisciplinary teamwork and collaboration*

Use of standardised communication tools*

Effective communication in different situations*

Psychological safety for staff*

Staff wellbeing*

Safe Staffing*

System for learning*

Primary Driver

Person-centred care



Healthcare
Improvement
Scotland



Secondary drivers

Patient, families and carers are listened to and included

Person-centred care planning

Anticipatory care planning & CYPADM

Discussions with families are well managed

Change ideas

Access to tools, resources and education to support compassionate care

Local method for documenting unique physiological baseline

Use of tools for anticipatory care planning e.g. ReSPECT, CHAS

Access to tools and resources to support difficult conversations

Use of 'what matters to me?'

Local mechanism to discuss environmental needs of the child/young person

Use of tools & resources for setting and reviewing goals & treatment plans

Identified area to hold sensitive conversations

Use of patient passports

Use of specialist resources to support care-experienced young people

CYPADM and anticipatory care plans discussed in huddles and handovers

Local process to help families identify key clinicians

Principles of Trauma Informed Practice included in local education programmes

Use of standardised tools to include the voice of the child/young person

Case Study: 'Identified Area To Hold Sensitive Conversations'



Identified area to
hold sensitive
conversations

Case Study: 'Identified Area To Hold Sensitive Conversations'

"A room that does not meet its full potential."
- Member of Staff



Case Study: 'Identified Area To Hold Sensitive Conversations'



Police interview centre.

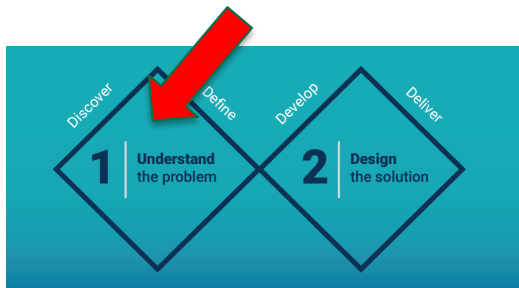


Spot the difference.



User Research

- Observation
- Interviews
- Empathy mapping
- Journey mapping
- Personas
- Scenarios



01

How does this room
make you feel right
now?

02

How can we make
your short visit here
better?

03

What sorts of things
would you like to be
made available
while you are in this
room?

01

How do you feel
when you are in
this room?

02

What would you
like to be available
while you are in
this room?

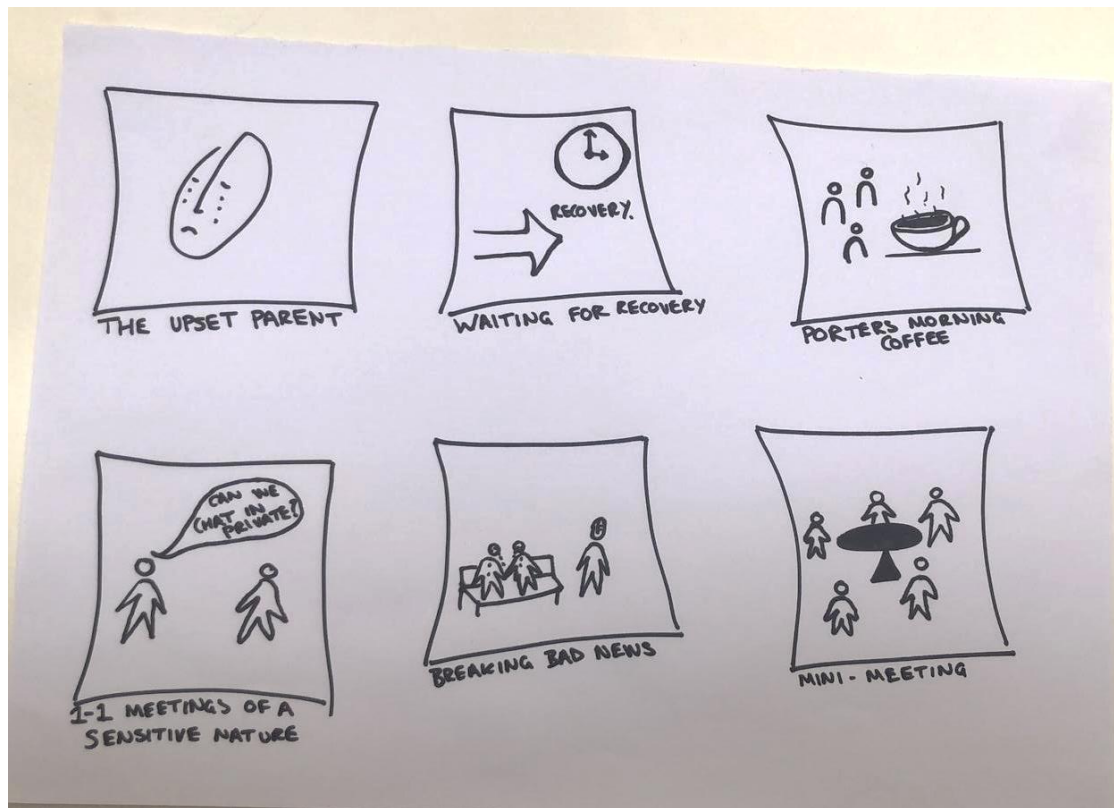
03

In your opinion
what are the
absolute essentials
for this room?

04

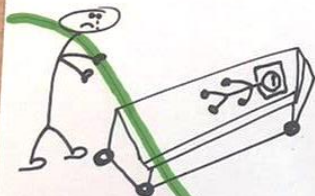
How would you
like to feel when
you are in this
room?

What is the room used for?



Journey Map

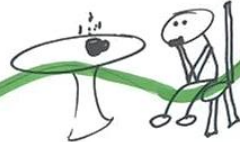
PARENT LEAVES CHILD IN THEATRE



USHERED TO THEATRE RECEPTION BY PORTER STAFF



GO SOMEWHERE TO DECOMPRESS + HAVE A CUP OF TEA



PHONES PARTNER + GETS FOOD



GETS SOME FRESH AIR



GETS UPDATE FROM THEATRE: STILL A WHILE TO WAIT



REUNITED WITH CHILD



FRONT STAGE: THE USER EXPERIENCE
LINE OF INTERACTION

ANAESTHETISTS + OTHER
HEALTHCARE STUFF



PORTER



COFFEE SHOP
BARISTA



CASHIER AT
M+S



PARTNER



THEATRE STAFF



RECOVERY STAFF



BACK STAGE: ROLES + SYSTEMS

CLEANERS

HEALTHCARE ASSISTANTS

ADMINISTRATION

MANAGEMENT

CORPORATE COMPANIES

Cardboard Design Lab and Scenarios

- Acted out scenarios
- An opportunity to make mistakes, no risk
- Changes could be made live
- An opportunity to get excited







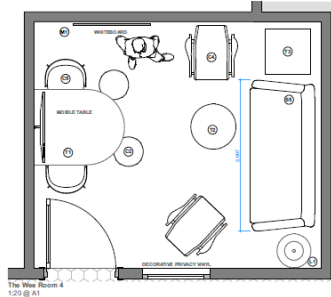
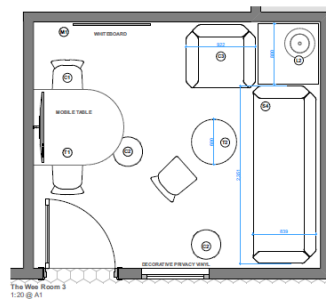
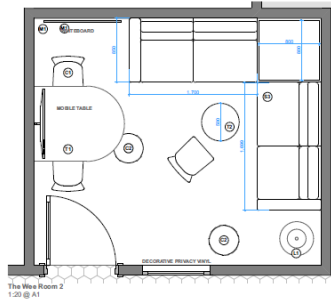
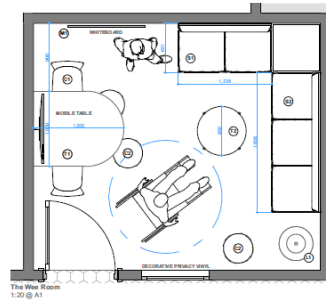
Prototyping



Bring together lived experience, lived expertise and professional experience.



Interior Design Room Layout



LAYOUT KEY:

- ① Small 2 seater sofa
- ② Small 3 seater sofa
- ③ Corner sofa with integrate table
- ④ 3 Seater sofa
- ⑤ 3 Seater sofa
- ⑥ Side chair (Seat Height 450)
- ⑦ Stackable stool
- ⑧ Lounge Chair
- ⑨ Lounge Chair
- ⑩ Side Chair with curved back
- ⑪ Mobile table
- ⑫ Round Coffee table - various sizes
- ⑬ Square side table
- ⑭ Floor Lamp
- ⑮ Table lamp
- ⑯ White board

Notes

1. We set out all drawings. Use typical dimensions only.
2. Contractor must ensure fitment of the fit sheet and position of the drawing and specification.
3. Contractor to check all dimensions and location during work for alterations. Do not change from design or specification without notifying the Architect / Interior Designer and the Engineer and any other relevant information.
4. This drawing is to be used in conjunction with all relevant drawings by the Architect, Interior Designer, Structural Engineer and M&E Engineer and any other relevant information.
5. All work shall be completed by contractor prior to installation.
6. Contractor to supply photographs to manufacturer.
7. Contractor to supply verification of materials to the satisfaction of the respective authority authorities.
8. Contractor to ensure that all construction work is in accordance with the relevant building regulations and in full accordance with the relevant building regulations.
9. Architect / Interior Designer to be notified in writing of any discrepancies and contractor to obtain instructions before proceeding.
10. Copy right of design and drawing reserved.

View	Date	Notes	Rev.
Series		"JOB NO"	
Project		Theatre Improvement	
Client		Royal Hospital for Children	
Drawing Title		The Wine Room Furniture Layout	
Scale	Rev.	Scale 1:20	
1:20	1:20	1:20	1:20
1:20	1:20	1:20	1:20
Scale		CONCEPT	
Issued For			

Interior Design Colour Palette



Illustrator collaboration



Co-Designed Area To Hold Sensitive Conversations



Identified area to
hold sensitive
conversations

Medical students see The Wee Room for the first time

“I’m actually really emotional”

“Can’t believe that we



Feedback on The Wee Room

- “It feels like an oasis within our hospital”
- “I was able to have a really difficult conversation with a mother in there, and it made it feel better somehow”
- “I was upset after a difficult situation in theatre and just went in and lay on the couch”
- “Someone really thought about this”



What is “co-design”?

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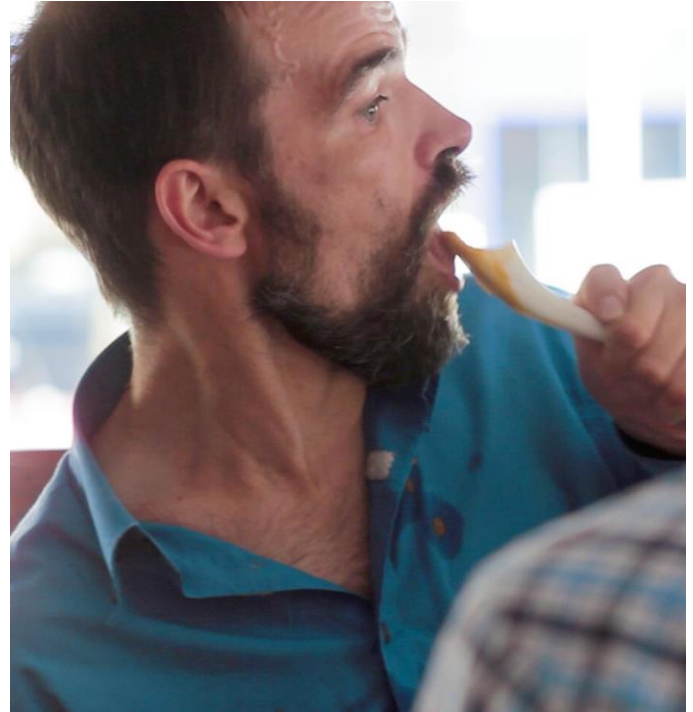
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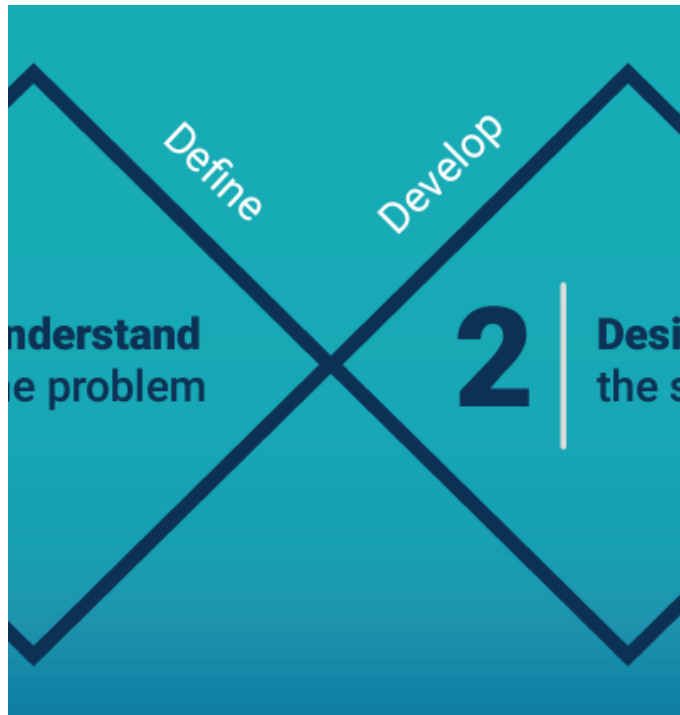
Conclusions

- Understand the problem before jumping to solutions
- Include users in the design or your service/improvement/change idea/physical space.
- Everyone will have more fun and feel more engaged this way!

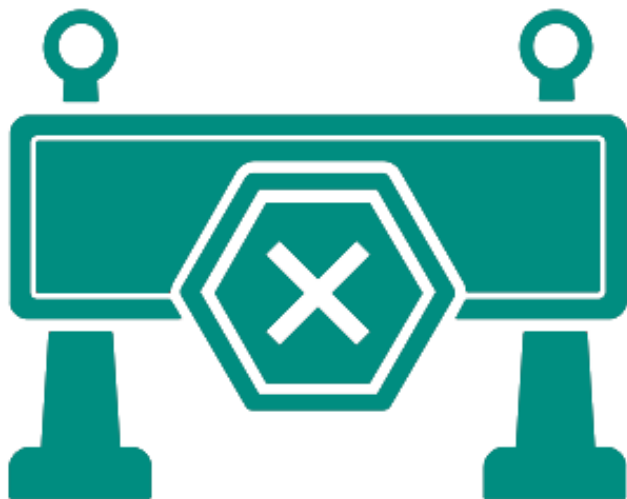


Reflect...

- Do you have a project you could use a co-design approach in?
- Have you jumped to a solution before understanding the problem?
- Have you spoke to your users?
- Have you been inclusive?



Barriers to engagement



- Groups of 4
- Introduce yourselves
- In turns, each member identifies one barrier and the other group members identify solutions and offer recommendations
- Write you're the 4 main points from your discussion down

Zoe Paige

Project Manager (Digital & Engagement)

NHS Lothian



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Engaging children & families at the RHCYP

The brief: Medical Specialities

1. Service improvement: use a co-design approach to support communication with families and children throughout the stages of their childhood.
2. To improve service efficiency by tackling frequently-asked questions (FAQs) with digital solutions.

Drivers:

- Patients, families and carers feel listened to and included.
- Person-centred care planning.



Medical specialities: Epilepsy, Asthma, Allergy, Diabetes

- Routine care is mainly nurse-led with nurse specialist clinics.
- All have helpline phone numbers, with feedback that this was an increasing time commitment impacting on clinical duties.
- Epilepsy service: also has an e-mail inbox for current patient cohort & families (not promoted for general enquiries or new referrals).



Engagement: how was data gathered?

1. Call sheets given to Nurse Specialists and admin team for data gathering from helpline calls and answerphone messages. Minimum 2-week period of calls, grouped into themes for analysis.
2. TRAK / SCI – records of recent review appts.
3. OPD clinics – interviews with parents & carers.
4. OPD clinics – interviews with children & young people.
5. Phone calls and texts to ‘hard to reach’ families, to ensure broad sample size and encourage engagement.
6. Support groups – e.g. Facebook closed groups run by parents, with admins sharing feedback.



Engagement templates



Patient feedback: improving knowledge and communication about epilepsy.

Question	Answer & comments
What information do you find yourself calling the nurse helpline (or searching online) for?	
What information would have helped you as a family at the time when your child first learned that they had epilepsy?	
Have you visited the RHCYP website?	
For children: What information would you like the hospital to give you about epilepsy that you haven't found or watched somewhere else?	

Improving digital information for children & families: Process Map



Who are our patients?

- Age
- Boys / Girls
- Languages spoken?
- Defined characteristics?
- Other demographics

How do they come to our service?

- Referral pathway
- Family doctor (GP)
- Emergency Dept
- Other specialists

What is the most common patient journey?

- How many appointments?
- Treatment pathways
- How long between stages?
- How long do they spend with the service?
- Locations & information

What problems to patients & staff face?

- How coordinated is care?
- Are there delays?
- What information is given at each stage?

How does their treatment develop?

- Are other MD teams involved?
- Is internal communication good?
- Does the family know what will happen next at all stages?
- How coordinated are the steps?
- Are points of contact made available?

What questions do patients always ask? What information is missing or hard to find?

What happens when they leave the service?

- How is discharge communicated?
- Ongoing advice & signposting
- Is there a route back in if a family has concerns?



children.nhslothian.scot



LothianChildHealth

Being in hospital: my experience

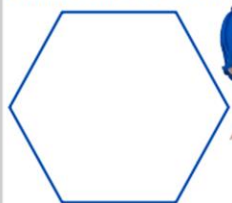


Good things:

Bad things:

What could be better?

I would improve:



I felt better when...

Information I needed:

What matters to me?

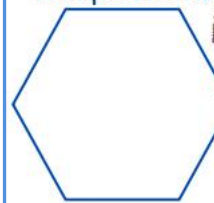


About me:

Hospital should be:

To help me I need:

I like to know:



I worry about:

I feel better when...

Person-centred care planning in practice

‘What Matters to Me’ admission sheets for children and young people to fill out and personalise. Fixed to their bed space.

Rolled-out across 2x in-patient wards at the RHCYP and the day case surgery unit, Crichton.

Gives children & families a voice, to share important non-clinical information about how their child feels, their comforts, fears and character traits, which are used for care planning and give valuable context for signs of deterioration.



Gathering data – who can help?

Clinical staff were not directly involved, to allow families to speak openly and relax, taking away any fear of being seen to be critical of their child's care.

- Medical students (as part of SSC module)
- NHS Lothian Volunteers
- Play specialists
- Non-clinical staff – e.g. project manager / admin
- Charity partners – ECH Charity volunteers
- Nursing students

Clinical teams have knowledge – include them too!



Engagement styles: open-ended questions

WHAT, WHY, HOW, WHERE, etc.

Tell me about a time when...

What did we want to know?

- What information was difficult to find?
- What were the gaps – particularly from a trusted source?
- What would have been most helpful after diagnosis, on reflection, thinking back?
- What format did children & families want information in?

Be flexible – e.g. drawing, votes with sticky dots, online surveys.



What were the outcomes?

Children wanted to hear from other children like them.

Families wanted to feel connected to others, particularly at key points in a child's life – e.g. P7 / S1.

Video – overwhelmingly most popular format.

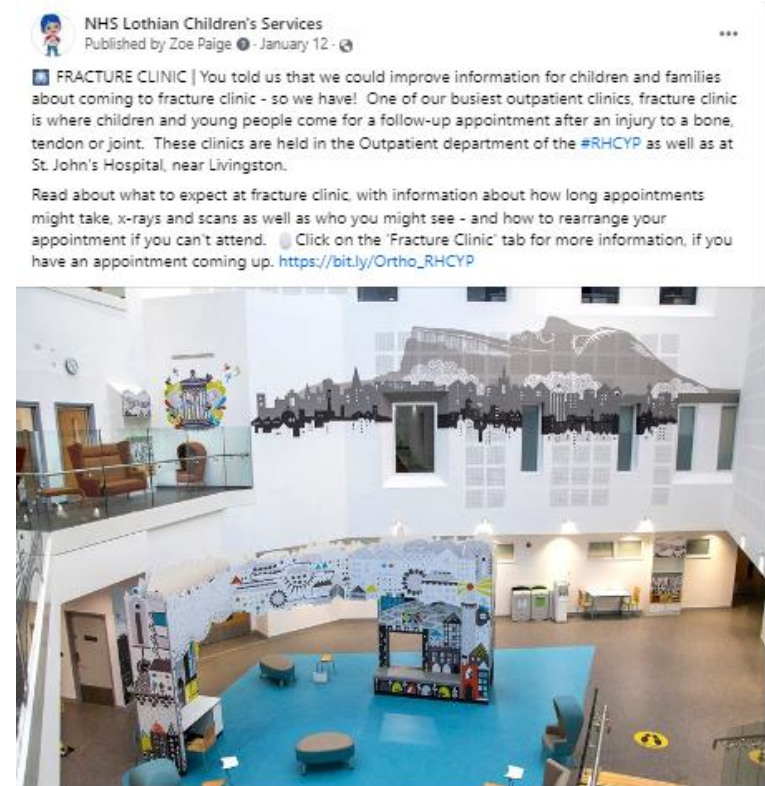
Animations, improved digital information on RHCYP website, and family learning events.

FAQs – clinical teams had a clearer idea of what questions were really common – and a strategy to reduce them through clearer digital signposting, e.g. QR codes to their website pages.



How could this engagement inform further QI projects?

- Nursing leadership in Children's Services and the RHCYP are adopting engagement templates, feeding into LACAS standards work and improvement plans for wards.
- Engagement case studies have been brought into QI meetings to encourage all teams to think about how to include children and families in QI work.
- Communication channels are used to promote examples of QI work and engagement to wider audiences.

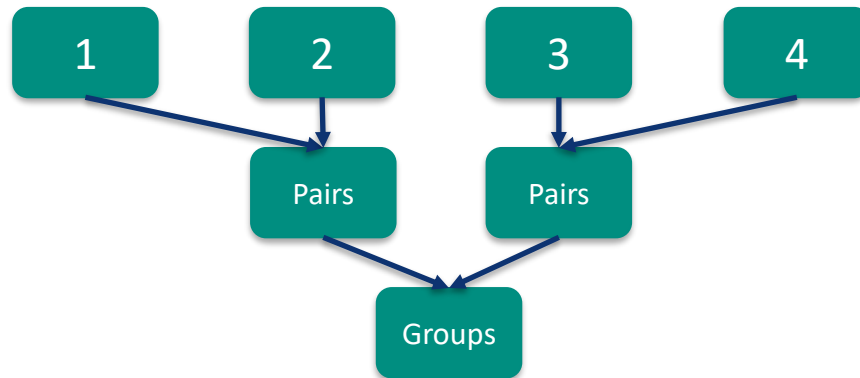


Identifying Resources



Created by Critical_icon
from Noun Project

- Same groups of 4
- Identify local procedures, groups or people that can help you with engagement
- Write the four main points from your discussion down.



Closing remarks

- Sign-up to the NES UNCRC Webinars
- Add any comments to the flipcharts, we will share main themes back to you
- Take away the engagement guidance, share with colleagues, and send your comments back by 1st April 2024
- Place an agenda item on your next SPSP Paediatric team meeting to discuss engagement with children and families

