



Impact and Influence in Epilepsy services

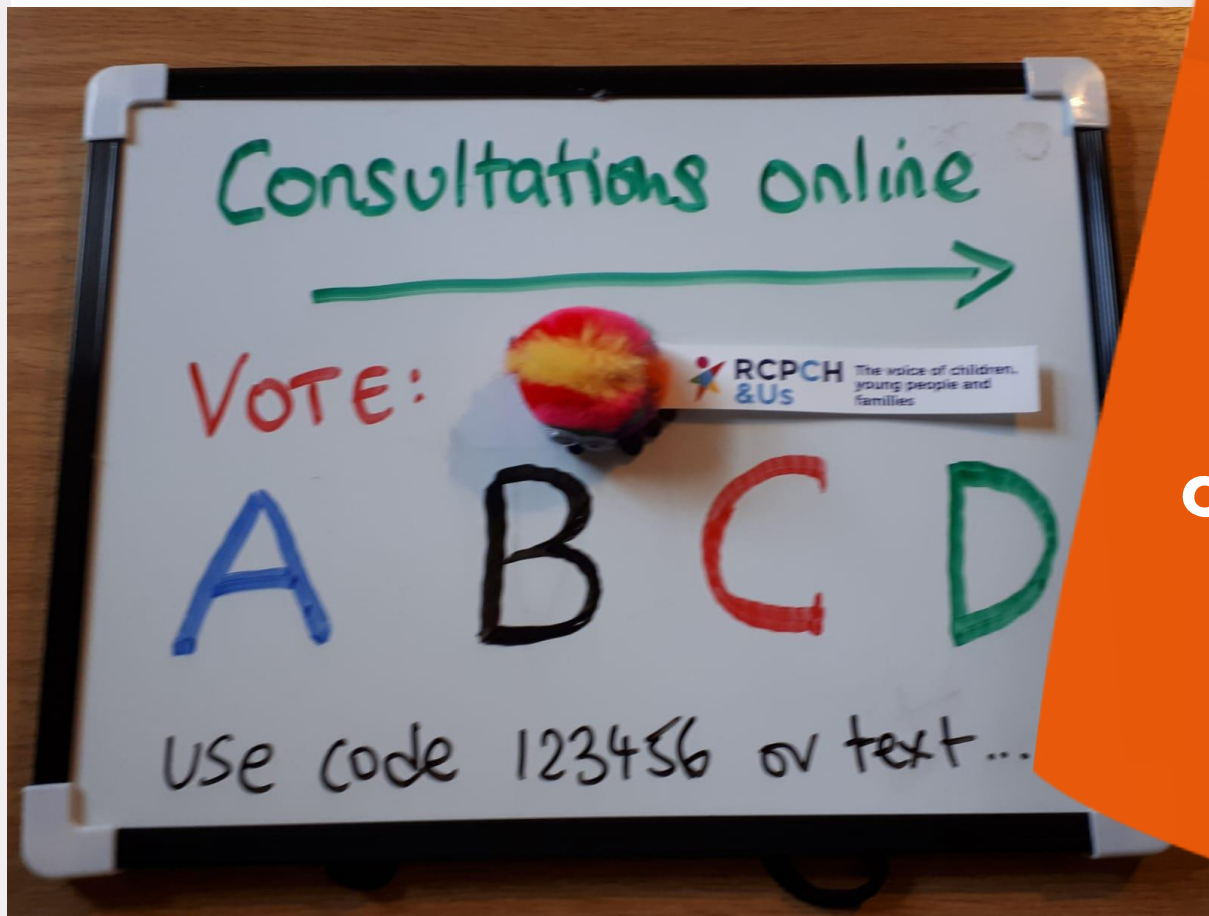
Esta Orchard, Youth Voice Advisor

Children, Young People's and Engagement Team, RCPCH 18.09.24

*What are we going
to do today?*

**Share learning from the
programme**

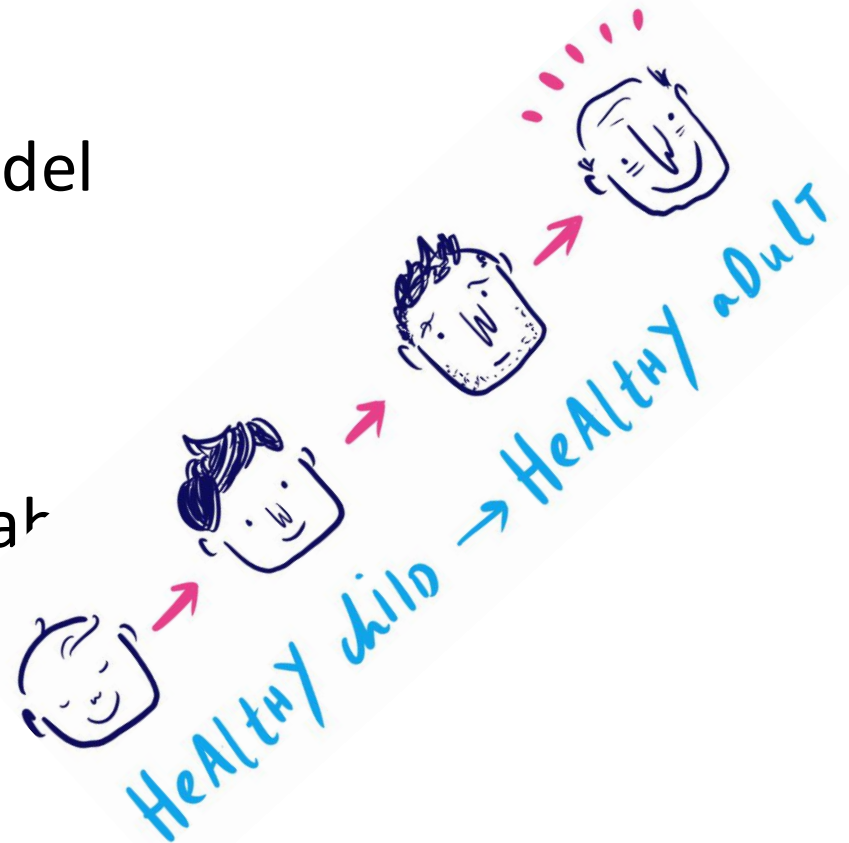
**Sneak preview of the
contents of the upcoming
toolkit**



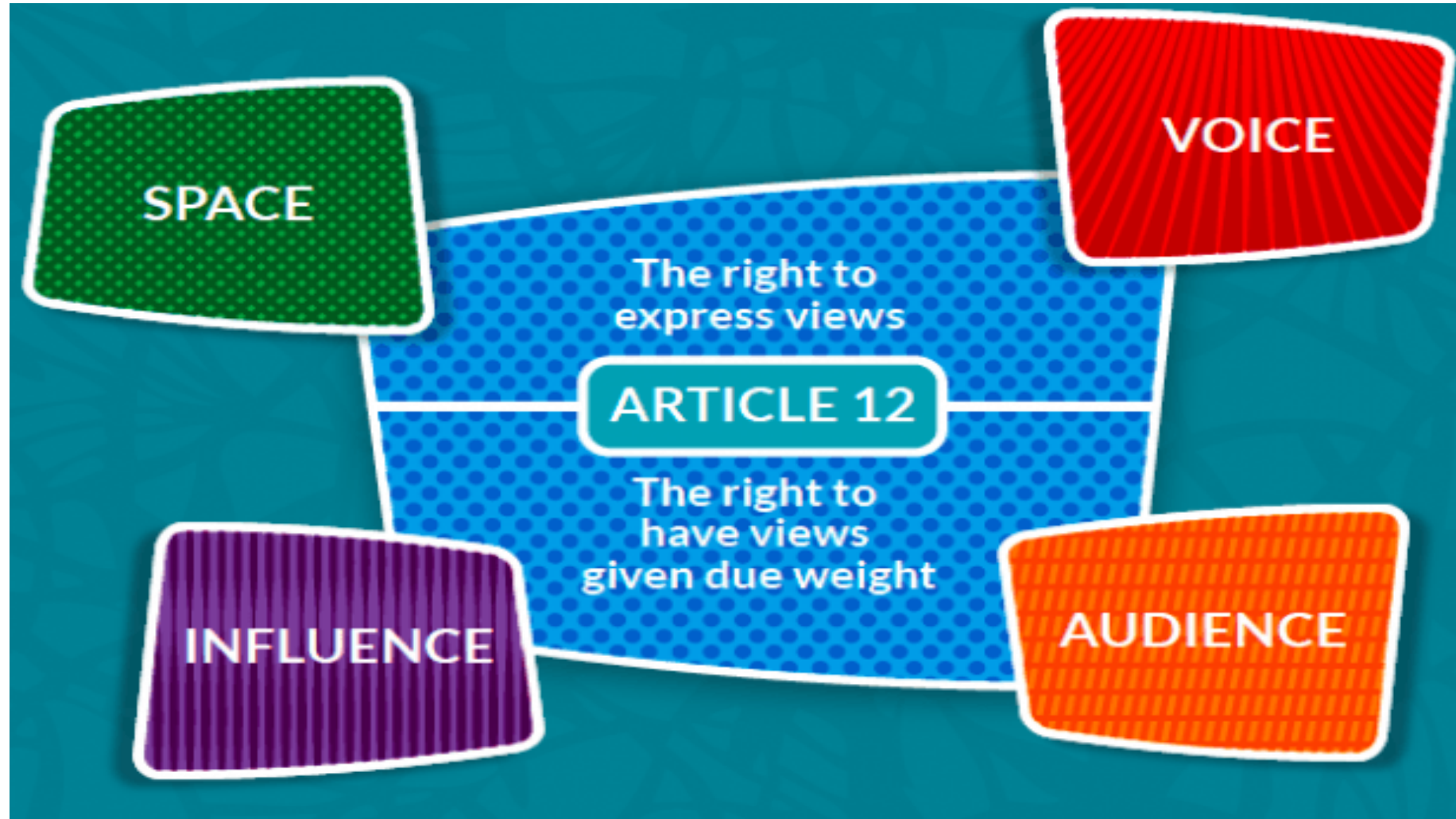
Impact and Influence - Project overview

Increase the voice of children, young people and families in Epilepsy services.

- Try out new approaches based on Lundy model (Space, Voice, Audience, Influence) in nine Epilepsy services
- Lead a series of RCPCH &Us led Innovation lab bringing C&YP and families together
- Create a toolkit for other Epilepsy services across England and Wales



The Lundy model

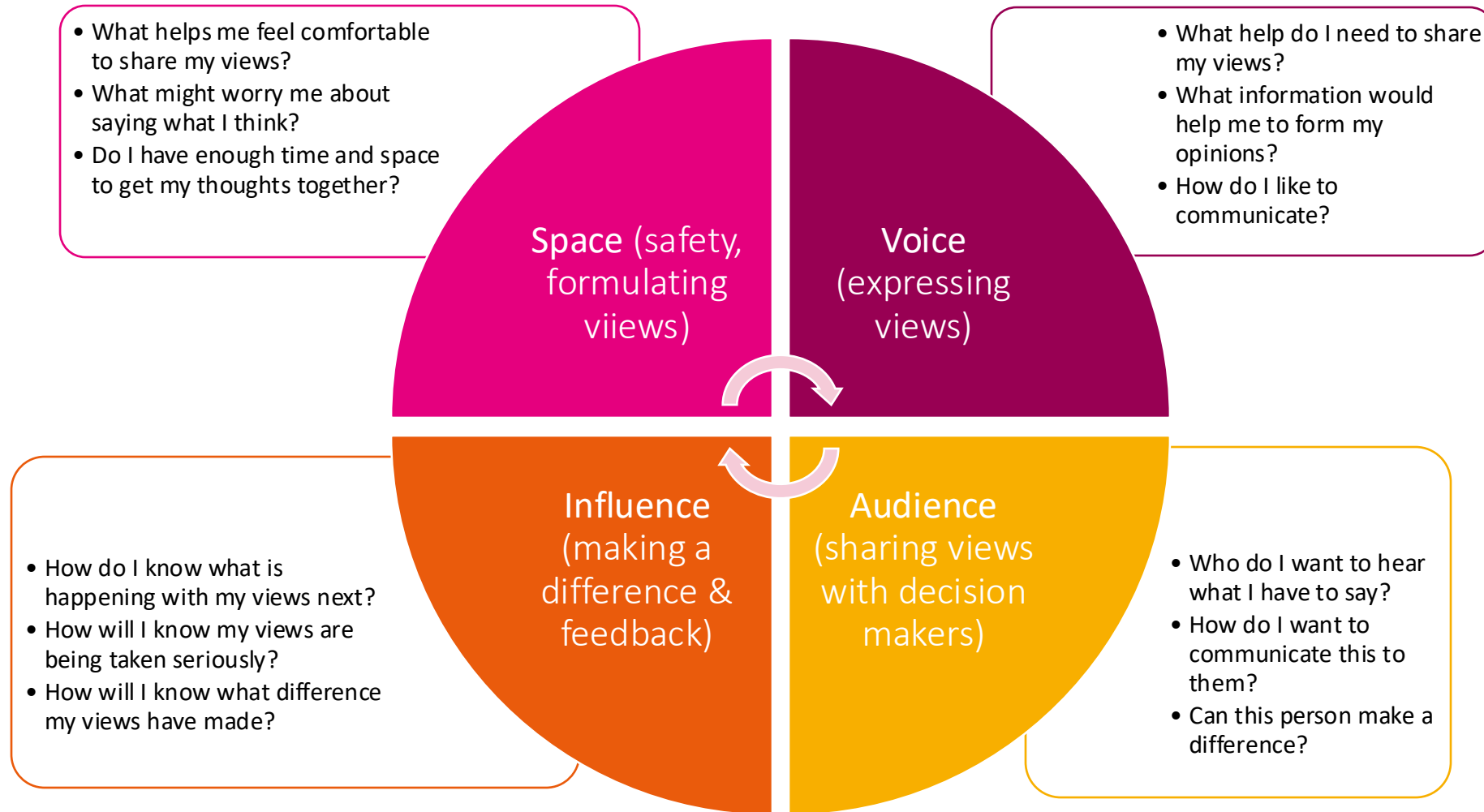


Being listened to about....

About my own care and health

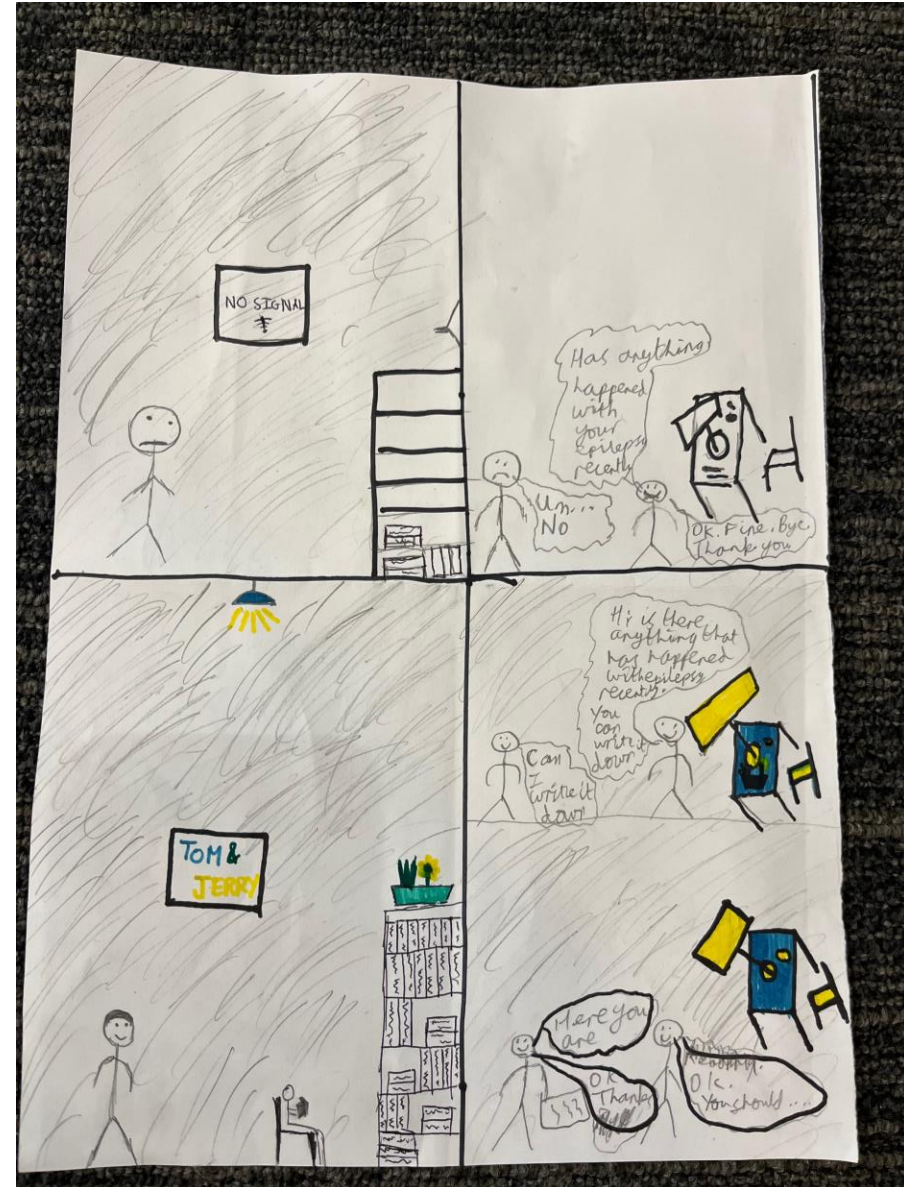
About how Epilepsy services can improve.

The Lundy Model

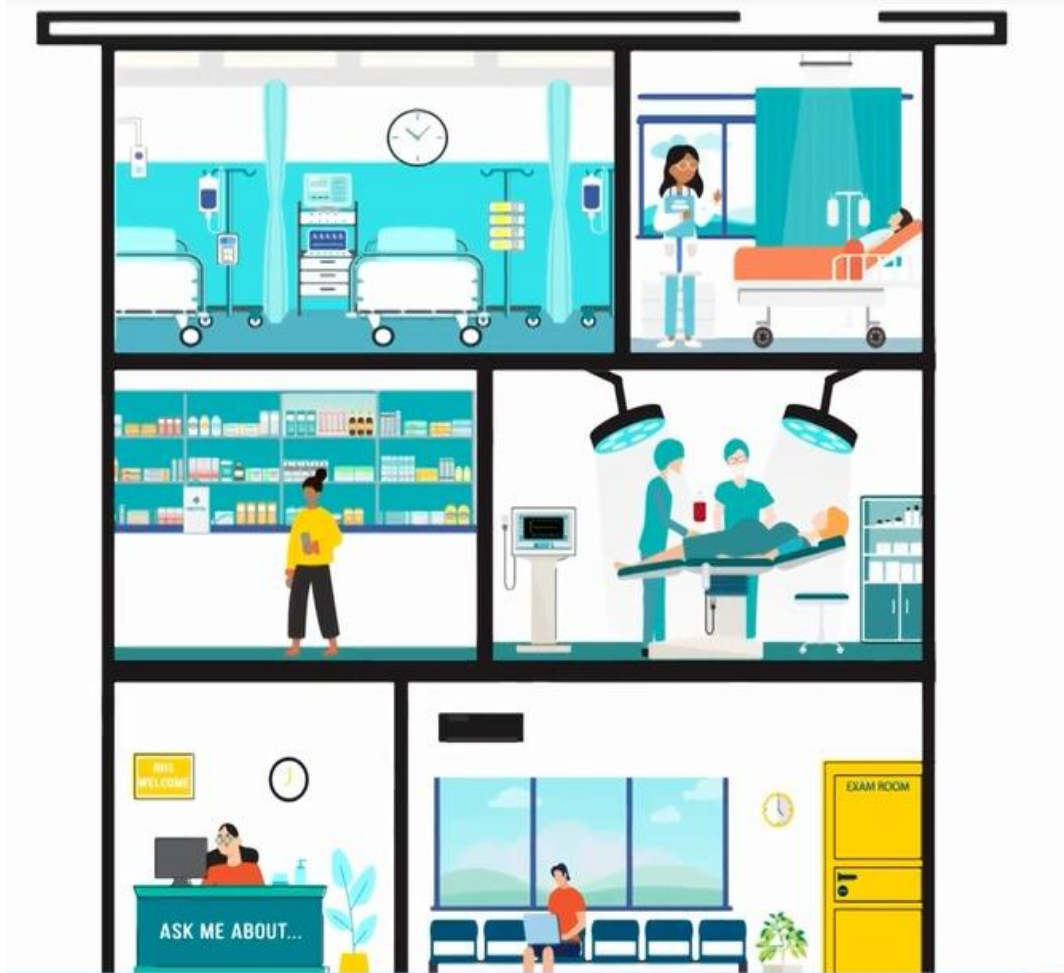


Being listened to about your
care

Being listened to about how
services can be improved



Nine services took part



1. University Hospital Southampton
2. Young Epilepsy
3. Great Western Hospital, Swindon
4. Coventry and Warwickshire Hospital
5. Wythenshawe Hospital (Manchester)
6. Hull University Teaching Hospitals Trust
7. Norfolk Community Health and Care NHS trust
8. Chelsea and Westminster Hospital
9. Medway NHS Foundation trust

During the year three services formally stepped down due to staff changes or capacity, two paused the projects.

Challenges

Distance and venue
logistics
Fear of raising expectations
No funding
Staff moving on
Lack of teamwork
Clinical workload growing
Facilitator
Being inclusive
Time
Lack of enthusiasm
Making assumptions
Selling the concept

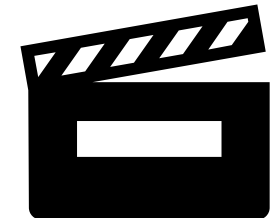
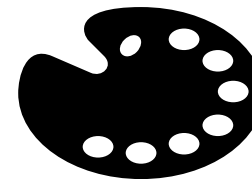
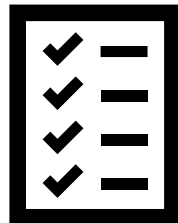
What helped?

Build your support network:

- Team
- Senior leaders, management
- Integrated care boards
- Youth services, participation networks, LA public health teams etc
- RCPCH &Us

Find a bit of extra resource (time or money)

- Hospital charities
- In-kind support from your network (venues, facilitation support, etc)
- Prioritise it as part of your QI work



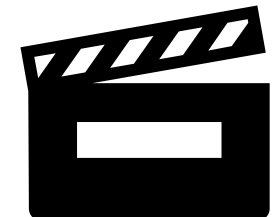
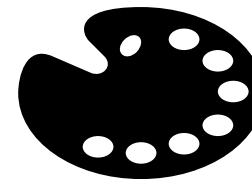
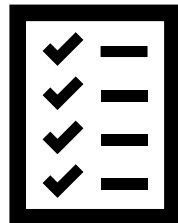
What helped?

Recruit families (children, young people, parents carers)

- Epilepsy nurses – personal touch makes a big different
- Opportunity where families can meet, have fun etc
- Asset based approaches!

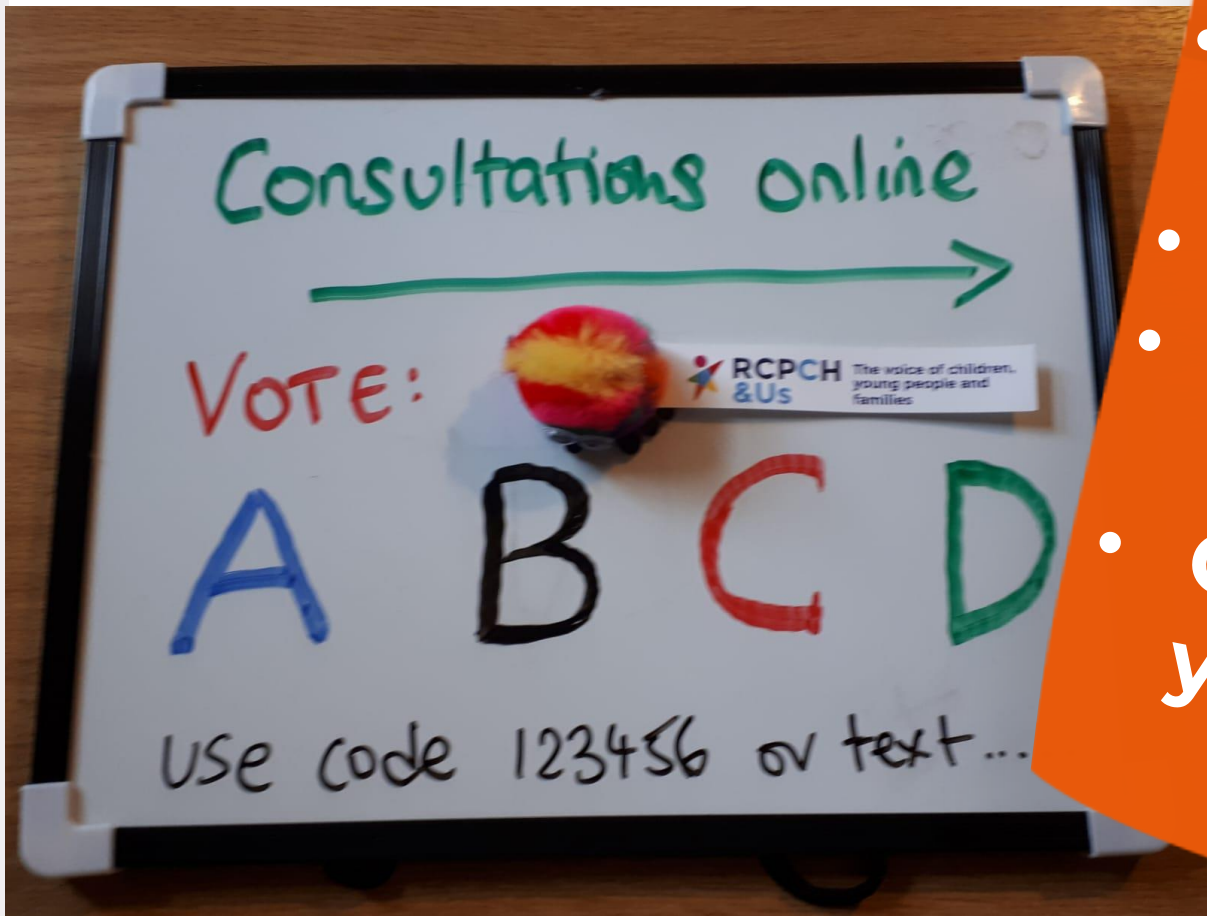
Open minded and enthusiastic approach!

- Don't make assumptions about what CYP and families are finding challenging
- Let them help come up with solutions
- Listen with an open heart



What happened?

- Feedback calls to parents
- Clinic chats
- Workshops (short and day long events)
- Ongoing projects with young people



Children and young people

- Education – links and support in school
- Stigma around condition – people not understanding differences
- Socialising and peers – others knowing how to support you
- Information that you can understand
- Being listened to

Parents / carers

- Info about meds
- Anxiety about meds supply
- SUDEP communication
- Support and connection for their children
- Education
- Peer support
- Practical aids and equipment
- Filming seizures
- WhatsApp
- Consultant listening style

Southampton YP film



<https://youtu.be/sAQjB4KNm8U>

Innovation labs – an approach

Space – children and young people, parents and carers.
Facilitated session.
Not in hospital.

Voice – creative, peer support,
action focused, individual or group

Audience – directly or where it will
be shared...

Influence – clear next steps



Innovation lab films



<https://youtu.be/hf9oyDh9wml>

The Voice toolkit

- 
- Your voice in your care for CYP and Parent / carers

- Voice and feedback about service delivery and design

Top tips, case studies or guidance

- Pilot site case studies
- Getting it off the ground (helps and challenges, making the case)
- **Audience / Influence** - making sure the work has an impact

Example or template postcards, posters, resources

- **Space and Voice** - Card sets
- **Space and Voice** - Prepping for appointment leaflet for parents
- Workshop flyer

Training / learning activities for Epilepsy teams

- **Space and Voice** - Creative methods for CYP (video)
- **Audience and Influence** – Analysis feedback and thinking through what it means for your service (parents audio, hospital video)

Autumn 2024 - Toolkit completed and launched

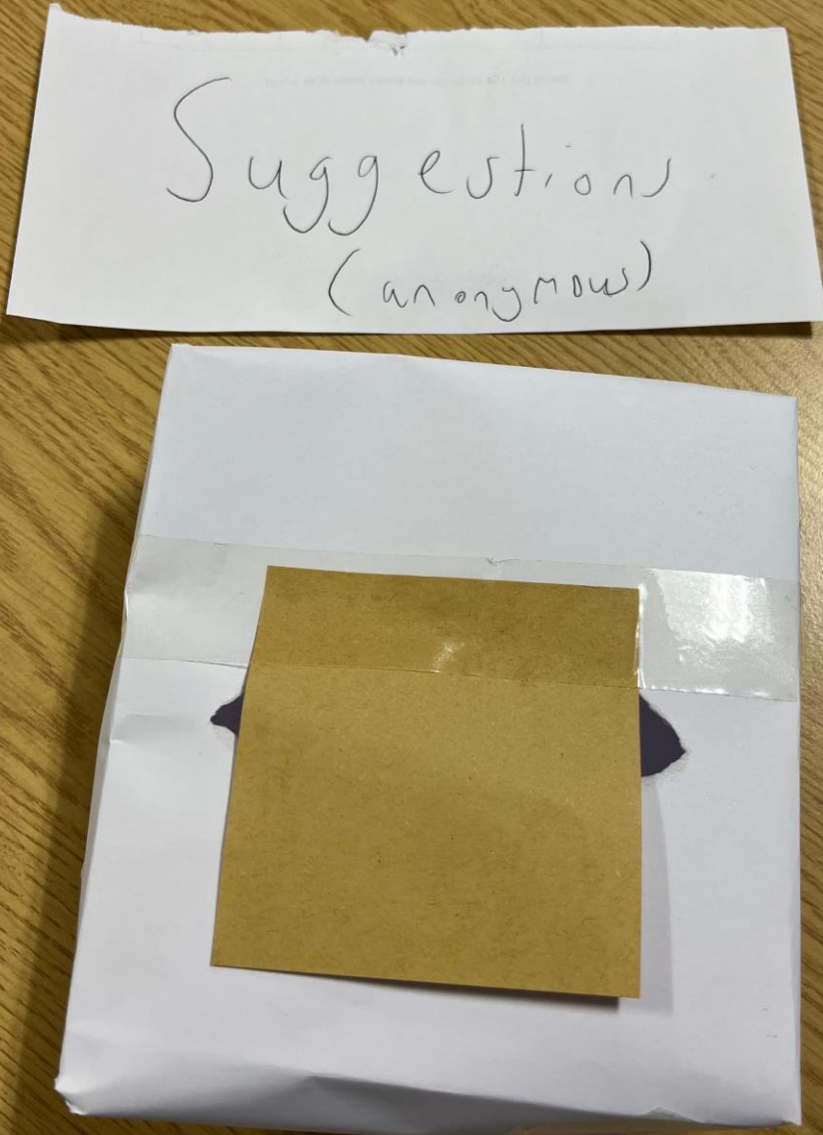
Card sets

It can be hard to speak up in appointments and ask questions



Sometimes its hard to share with your parents what you want to say

Sometimes you do want parents / carers / clinicians to lead the discussion but you also want a way to raise the issues you are worried about



Card sets

- A tool to support children and young people who are not so comfortable or not able to communicate verbally.
 - Communication preference – this is how I like to communicate
 - Agenda setting - these are the things I want to talk / ask about
 - Feelings – this is how I am feeling
- Children and young people can highlight issues but then responsibility shifts to adult to ask the right questions / provide right information about it.
- Can be used by children, young people, clinicians and parent / carers (by anyone!)




The voice of children,
young people and
families



THANK YOU!
**Sign up to RCPCH &Us for
volunteering opportunities to
support paediatrics and child health**


Royal College of
Paediatrics and Child Health
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