

# EQIP: Patient Experience to QI Engagement

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# Welcome

**September:** explored children and young people's views, wishes and needs for our services and how to create foundations for engagement

**Today:** we'll be hearing about EQIP engagement intentions, examples of engagement in practice and thinking about the key element for successful engagement

# Having a good virtual meeting



Have slides



Stay on topic in the chat & use inclusive language



Don't take screen grabs/record it



Different ways to share views



Be kind, supportive and fair



We may follow up

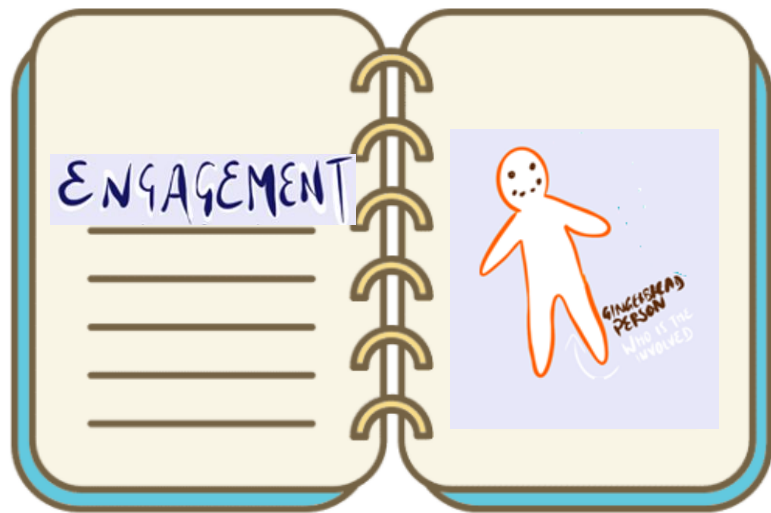


Mute yourself if there is background noise



Share what you feel safe to do so and keep things confidential

# The Great Engagement Bake Off!



**Signature Challenge** – your engagement intentions

**Technical** – building on foundations sharing our case studies

**Showstopper** – your chance to plan your showstopper

Count the Bake Off references for the chance for a team prize!

# Signature Challenge

**Signature Challenge** – 1 minute for each team to tell us what engagement means for your QI programme: your signature challenge. We're starting with Barts... **on your marks, get set, BAKE!**



# Signature Challenge

## Our engagement ideas and intentions

post it  
ideas

survey

text  
ideas

ask 3  
questions

CYP  
ideas  
in a jar

1:1 discussions

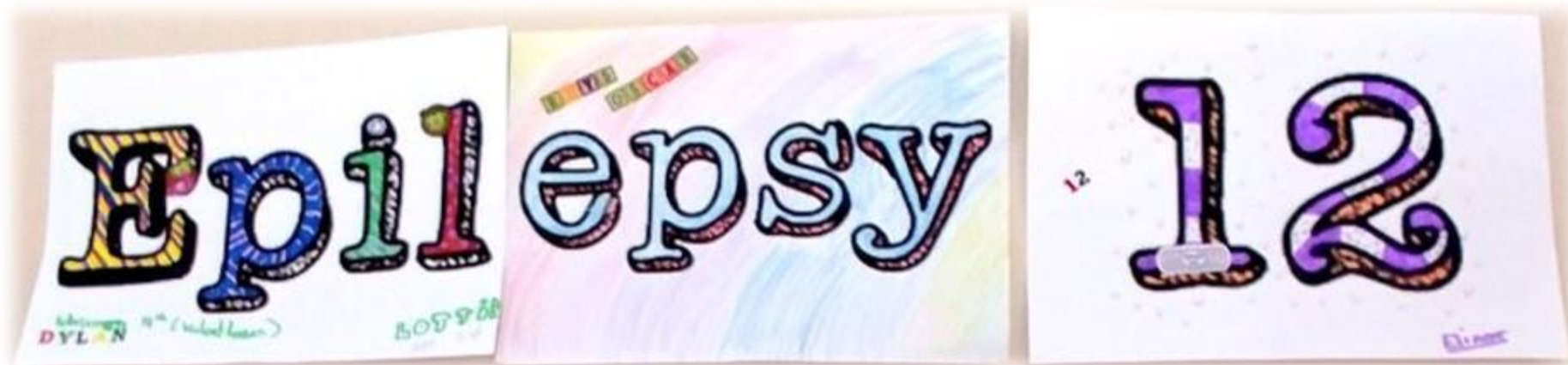
mapping  
patient  
journey

ask what  
helps /  
could be  
helpful

ask others -  
charities and  
clinicians  
(sensitive  
topics)

their ideas  
to create  
a pathway

# Technical – individual engagement



# Technical – individual engagement

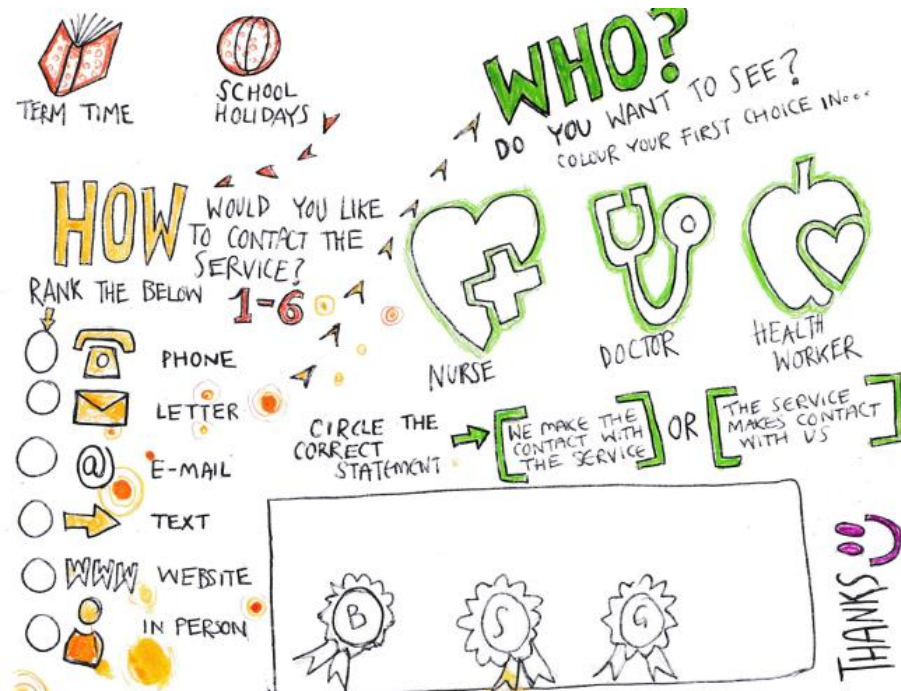
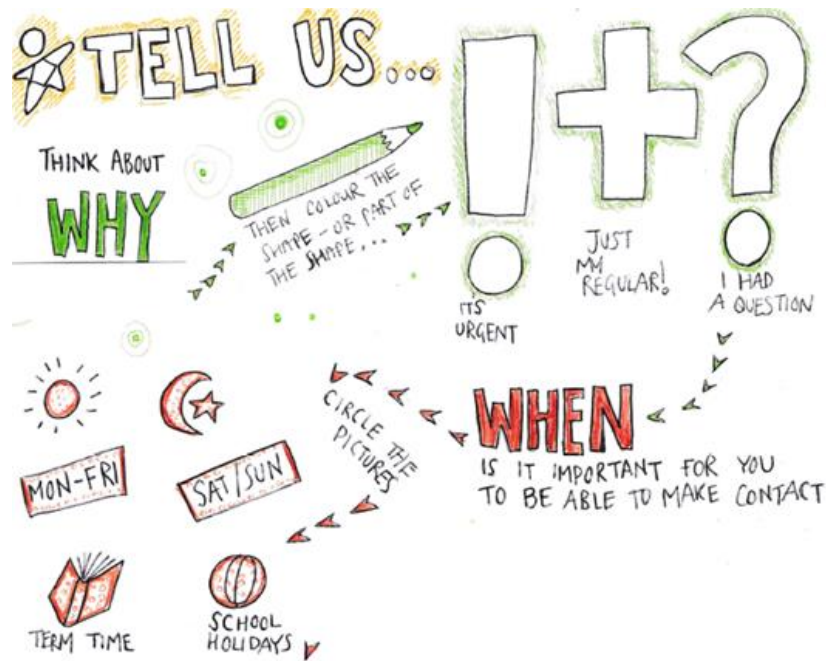
A total of...

23 children,  
20 young people,  
6 young adults  
and 75  
parent/carers...

...engaged in  
the project, with  
children as young  
as 3 contributing.



# Technical – individual engagement



# Technical – individual engagement

## Epilepsy12 hospital based clinic chats:

After our Epilepsy12 Youth Advocates looked at all the information, they chose three top priority areas;

- **Schools**
- **Support for worries and anxieties**
- **Face to face support**

The other topics that came up regularly were;

- **Having positive adult relationships**
- **More services to go to**
- **Practical Help and Tips**
- **Contacting your service**

# Technical – individual engagement

“

Mental Health is equally as important as physical health. It is fundamental to epilepsy treatment. In the UK 1/5 people suffer from depression. For people living with epilepsy, this is 1/3.

RCPCH &Us Member

”

## Technical – individual engagement



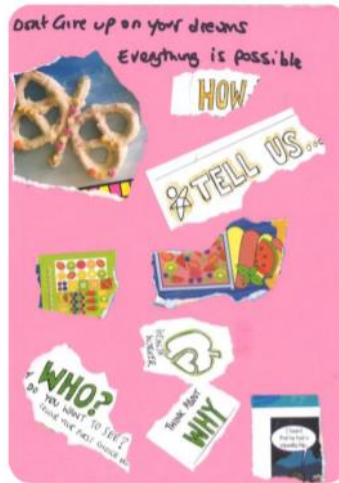
## Oscar

His superpower is to have air coming out to assist with CPR. He helps move people away when people are having seizures and ensures the hospital is told (this sibling carer is 5 years old)



## The Fairy Doctor

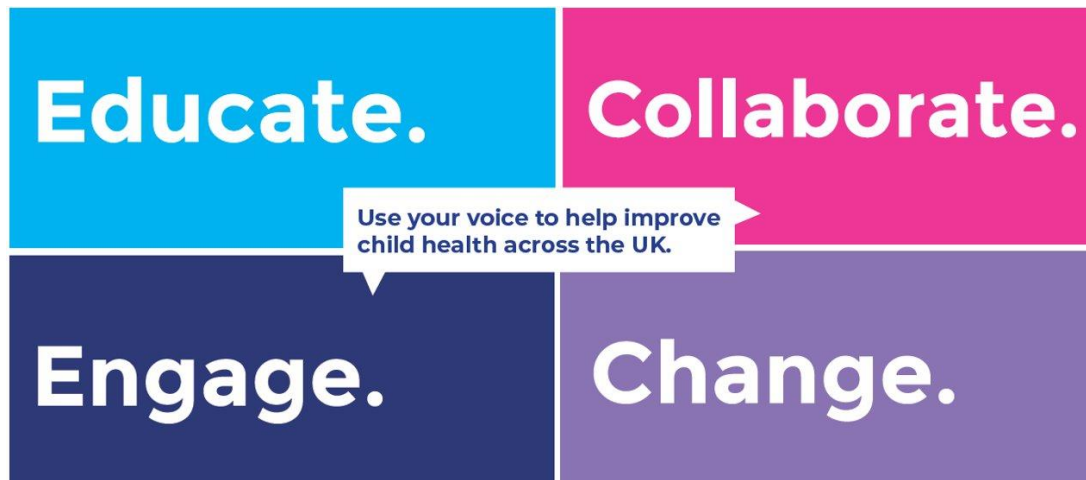
Her superpower is that she can talk in a magic language via blinking, since when mum has seizures she can't speak so they've worked out how to say yes/no in blinks, and helps by putting a pom pom by the bed after a seizure to protect the head and to make sure that nanny knows (this sibling carer is 7 years old)



**'My Health and Me'** image board compiled by children and young people with epilepsy.



# Technical – individual engagement



 **RCPCH**

# Technical – OPG MEG





# Technical – Epilepsy Space

**epilepsy** *action*

We exist to improve the lives  
of everyone affected by epilepsy

## The Epilepsy Space

Developing an online self-management resource  
for young people aged 16-24

# Technical – Epilepsy Space

**epilepsy** *action*

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## What was the issue?

Young adults (aged 16-24), like other adults with epilepsy, can find living with epilepsy a challenge. As well as the effects of seizures, they are at higher risk of anxiety and depression, cognition and memory problems. Fear of seizures, loss of independence leading to isolation and loss of confidence.

Some issues previously identified as relevant to the age group included:

- Transition to adult health services
- Social pressures – going out, drinking alcohol
- Stigma from peers
- Gaining independence / moving away from home
- Further/higher education and employment
- Contraception



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**epilepsy** *action*

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## Engagement intentions

We set out to develop an online programme/toolkit that young people could access via their smartphones. We aimed to:

- Provide young people with the knowledge, skills and confidence they needed to manage their epilepsy
- Cover topics important to young people such as alcohol, staying safe when going out, talking to friends, independence and transition to adult services
- Base the resource on extensive user research so that all the content was relevant and engaging
- To do this, we worked with a youth participation worker to engage young people in the design and testing of the resource (discovery phase)
- Used the findings to develop a mobile-accessible programme/toolkit

# Technical – Epilepsy Space

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## Barriers and risks

- Some young people did not want traditional patient information or self management courses adult or child style
- Safeguarding concerns re user contact
- Blending professional input and young peoples suggestions to create safe content
- Raising enough funds for cool workshop venues and video production



# Technical – Epilepsy Space

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## Recruitment of advisory group of young people with epilepsy

- We contacted voluntary organisations, schools, further and higher education institutions, our social media channels and health service contacts.
- We focused on Yorkshire as we were planning the youth advisory group meetings in Leeds, but we had interest from across the country. 21 young people expressed an interest, though some couldn't make the dates of the meetings or had to withdraw for personal reasons. 16 joined us

Regional demographic	Diversity Information	Occupation
Shipley	3 Male / 13 Female	6 Full time employment
Halifax	.....	3 Mature students
Glasgow	1 Black/British	2 University Students
Surrey	1 British/Pakistani	2 College Students
York	2 White/Scottish	1 Learning provision for those with disabilities
Farnborough	12 White/British	1 Unemployed/volunteering
Lancashire	.....	1 Expectant mother
Hereford	1 Atheist	
Cornwall	1 Muslim	
London	1 Hindu	
Hertfordshire	2 Christian	
Winchester	11 No religious belief	

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## Workshop one

Understanding the users - 2 hours

- Characterisations of young adults with epilepsy
- Exploring feelings about epilepsy and the issues they face in a range of areas of life (e.g. Social life, work, studies, independence, relationships etc)
- Identifying what information/content these users would most want from our online resource



# Technical – Epilepsy Space

epilepsy *action*

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## Workshop two

Exploring format ideas - 4 hours

- Understanding what devices the users would use to access the resource, and when and where they would use these
- Understanding pros and cons of the resource being an app, or website, or anything else
- Exploring good/bad examples of online resources (not just epilepsy related)
- Exploring the look and feel (e.g. Mood boards) of the resource we want to create



# Technical – Epilepsy Space

**epilepsy** *action*

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## What does self-management mean to you?

- Being on track – something that's making you be independent
- Managing our wellbeing
- Managing it yourself
- Promotes your independence and confidence
- Having the skills and knowledge to be able to cope everyday
- Having the strategy and coping skills to get through each day independently
- In between appointments, the day to day bits, independently and confidently
- It's formal
- To do list – I have Google keep with my to do list
- Self-management doesn't sound great but it is functional
- Other people could put what they do, to prep for a night out or a wedding, bit like a Pinterest
- Diary, repetition





# Technical – Epilepsy Space

**epilepsy** *action*

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of everyone affected by epilepsy

## Workshop three

- Bringing together the project results – 4 hours
- Reviewing potential design routes (reacting to design stimulus)
- Consolidating conclusions and recommendations of project
- Making a final decision about the format of the tool
- Develop ideas on the content and features of the resource
- Discussing next steps and future involvement



# Technical – Epilepsy Space

epilepsy action

We exist to improve the lives  
of everyone affected by epilepsy

## Measures of success from young people

- Make it accessible to as many people as possible Target of 2,000 users in year one exceeded
- Make it mobile-friendly because we are all on the phones all the time Done
- Have 'top tips' with short information Done
- Lived experience really important so you can see what others do when they go on nights out etc Done
- Connected to Epilepsy Action website for people who want to know more Done
- Long-term maintenance – keep updating blogs and vlogs, we thought this content might create a community
- Making sure no ones getting bullied Not measurable
- Needs to be current as there are always things coming up with the science Updated
- Use videos. I saw a video from epilepsy action with a real life experience – showed a video with an absence seizure and that was really good Done
- As long as the security side of things makes it safe No personal contacts enabled



# Technical – Epilepsy Space

**epilepsy action**

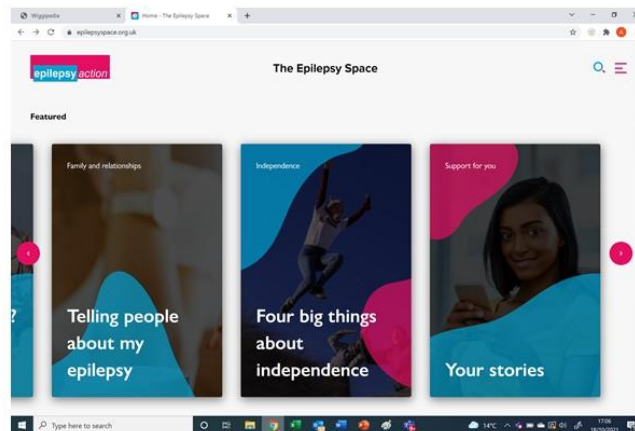
We exist to improve the lives  
of everyone affected by epilepsy

The Epilepsy Space <https://epilepsyspace.org.uk/>

**Participation**  
May-Dec 2020  
**6,794**

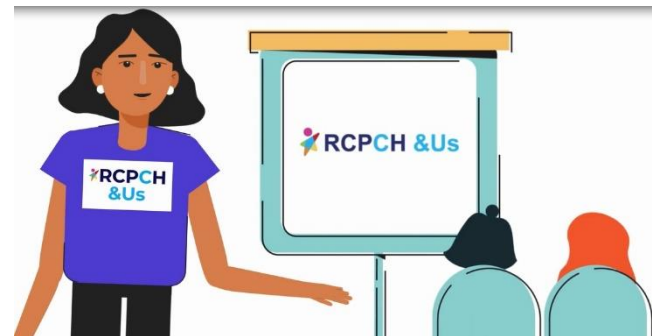
Jan-Sep 2021  
**15,864**

Some could be  
outside target  
age group



# Recipes for engagement

- What was issue?
- Opportunities or limitations of activity? (Time, resources, impact etc)
- Which children or young people?
- Recruitment plan?
- What did you (professionals) hope to achieve?
- What did children /young people hope to achieve?
- How did you do it? (method)
- How did it impact change?
- What worked, what didn't, limitations?
- How did you celebrate / reward young people input?

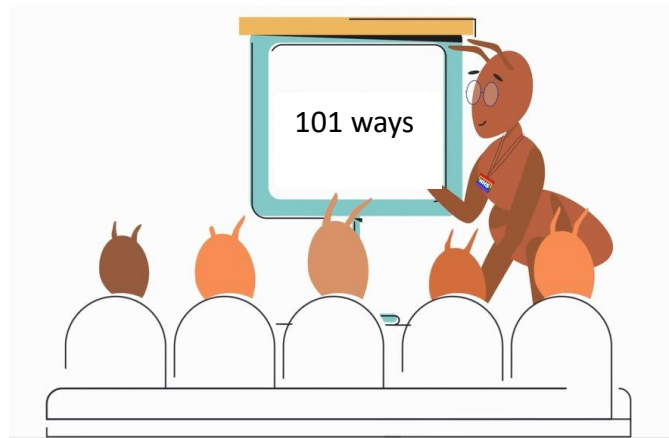


Case studies to be shared from today

# Recipes for engagement

How many ways can you think of to engage children and young people in shaping services?

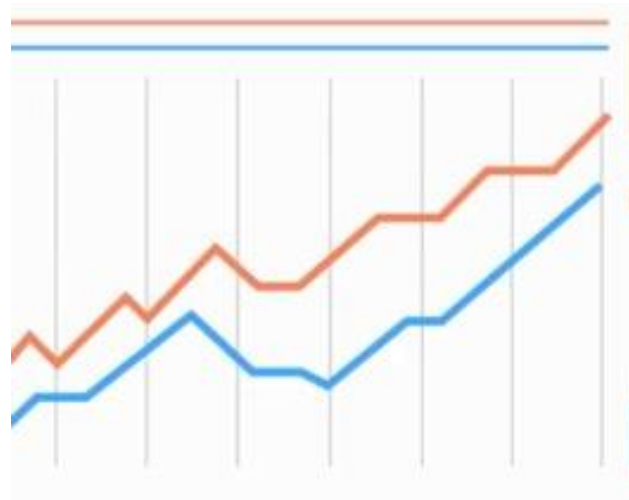
- Nerf gun voting
- Smartie voting
- Festivals
- Skittles voting
- Fancy dress outfits
- Through hobbies / sports friendlies / sports day
- Pizza party
- Floor painting / drawing (large brainstorm)
- Art canvas
- Air drying clay
- Murals
- Brainstorming with post its notes for drawing/writing on
- Gaming groups/computer games
- Playdough superhero
- Lego building for areas in clinic



# Recipes for engagement

How many ways can you think of to engage children and young people in shaping services

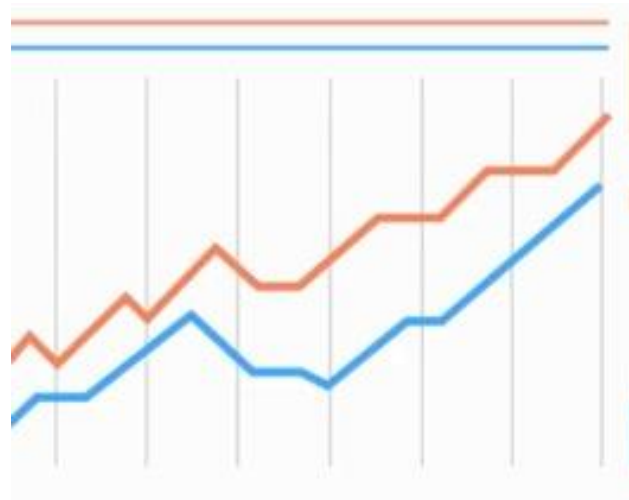
1. Speak to young people in clinic – see [clinic chats](#)
2. Meet with your hospital youth forum
3. Run a workshop at local school, youth centre, PRU, children's centre
4. Attend a local youth forum (council or third sector led)
5. Run a photography / art / film competition
6. Commission a visual art facilitator
7. Work with [young peer researchers](#) / outreach team
8. Use forum theatre approaches to explore issues
9. Host an open day – meet the doctor
10. Gather some young volunteers to plan an event to hear from other young people...



# Recipes for engagement

How many ways can you think of to engage children and young people in shaping services

1. Box stack
2. [Visual Voting](#) / Menti Voting
3. Week of action – ask one question
4. Create an activity sheet to do in clinic waiting areas
5. Gingerbread people – you / the support around you
6. [Takeover challenge](#) to review consultation feedback
7. [Youth social action](#) projects
8. Host a [roundtable](#) / learning conversation
9. Involve them in [interviews](#) or [board level discussions](#)
10. Ask them for their ideas :-D



# Showstopper



**Time to create your showstopper!**

**Chocolate:** what do we already do well?

**Flour:** what is the plan?

**Eggs:** what are the barriers/risks?

**Milk:** what are the measures/impact?

**Bowl:** what is the project/activity?

**Gingerbread person:** who is involved?

In your teams over the next week –  
please share in your progress meetings

# Support for you

Questions, comments, requests:

[and\\_us@rcpch.ac.uk](mailto:and_us@rcpch.ac.uk)

60+ free online resources to support children and young people in their health journey / involvement

[www.rcpch.ac.uk/and\\_us](http://www.rcpch.ac.uk/and_us)



Free resources /support through the Engagement Collaborative

Sign up at

[www.rcpch.ac.uk/join-engagement-collaborative](http://www.rcpch.ac.uk/join-engagement-collaborative)



OPEN UK

RCPCH &Us  
The voice of children, young people and families



RCPCH &Us

Young Epilepsy

EPILEPSY12

**RCPCH EQIP**  
Epilepsy quality improvement programme

# Bake Off Challenge – how many refs did you spot?



Congrats Epsom & St Helier –  
look out for your prize  
coming your way soon!



# Next steps

1. Build on your showstopper sheet and research who you can work with locally to support your engagement journey. Have you got a youth forum, school, youth centre, clinic, inpatient, hospital school, uniformed groups, colleagues others?
2. Consider your engagement recipe – what do you need to do now, soon, later to further your engagement intentions
3. Consider what will be the impact of **not** engaging children, young people / families in your QI work

Consider in your team and add your reflections to your progress report and your call this month.

