

Reducing variation case studies 2023-2024

Developing a children and young people engagement strategy across the ICB/ICS

Organisation

York and Scarborough and Hull Integrated Care Board (ICB)

Project team

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Project aim

To develop a strategic framework for children and young people engagement across the Integrated Care Board (ICB) by May 2024.

Background/rationale

The Integrated Care System (ICS) encompasses York and Scarborough, Hull, Harrogate, and North Lincolnshire and Goole. Approximately 1,300 children and young people with epilepsy are under the care of paediatric epilepsy services within the ICS. Humber and North Yorkshire cover a vast area, with several regions facing deprivation, including limited access to psychological support and epilepsy specialist nurses.

In 2019, the York and Scarborough paediatric epilepsy team participated in an RCPCH EQIP pilot, collaborating to improve emergency plans and develop their Trust's version of an Epilepsy Passport. The ICB epilepsy network is currently investigating methods to include vulnerable and Core20PLUS5 children and young people in initiatives to address health inequalities.

What was the problem?

The National Epilepsy Bundle of Care outlines standards of care, including addressing care variation and transitioning to adult services. However, a key aspect of implementing these standards is co-production with children, young people and their families. National youth

forums represent children and young people with epilepsy but do not always reflect the unique experiences of those living in Humber and North Yorkshire.

Currently, the ICS lacks a comprehensive engagement plan that includes the voices of children and young people in co-designing processes to inform service improvement. To address this, ICB leaders plan to develop a written strategy and engagement model to enable children and young people to contribute to service design, evaluation, and change. This model will aim to standardise engagement practices across service-level projects, forming a written engagement strategy for epilepsy.

What was the solution?

The initial aim of the project was to develop a clinical initiative across the ICB, focusing on creating a youth-informed pack for 12 to 16-year-olds to provide epilepsy signposting. However, as the project progressed, it became clear that implementing this across the entire ICB was challenging. Consequently, the plan evolved, as reflected in the Plan, Do, Study, Act (PDSA) cycles, to develop a strategic framework for children and young people engagement across the ICB by May 2024.

The project focused on improving patient engagement by prioritising the voices and involvement of children and young people with epilepsy. Recognising the importance of their engagement, the project aimed to support their input within the epilepsy service, involving various stakeholders in the care process. The primary drivers included co-production and clinical networks, aligned with national deliverables. The project identified existing engagement with children and young people across services and sought to utilise and enhance this. Efforts included engaging networks to ensure an ICB-level response, considering the national care bundle in relation to children and young people.

The PDSA cycles evolved over time. Initially, the project directly asked children and young people about their concerns and developed a frequently asked questions (FAQ) survey, although initial responses were limited. The survey was redesigned to encourage more responses. The project also investigated the work being done in different areas to engage children and young people and gathered data from an NHS England-funded psychology pilot.

To centralise information for children and young people, a landing page on the Healthier Together website was developed. This became a strategic development for children and young people engagement across Humber and North Yorkshire. The project engaged with patients and families, using survey feedback to understand children and young people concerns about epilepsy and leveraging information from the ongoing NHS England psychology pilot, which included youth and parent groups.

Activities and tests explored:

- Developing a landing page for epilepsy on their [Healthy Together website](#).
- Researching a wellbeing pack for young people with epilepsy.
- Collecting feedback from patients through a pilot project.
- Starting to develop FAQ for the website.

- Engaging with young people and parents to gather their input and ideas.
- Exploring partnerships with organisations like Epilepsy Action for further engagement opportunities.

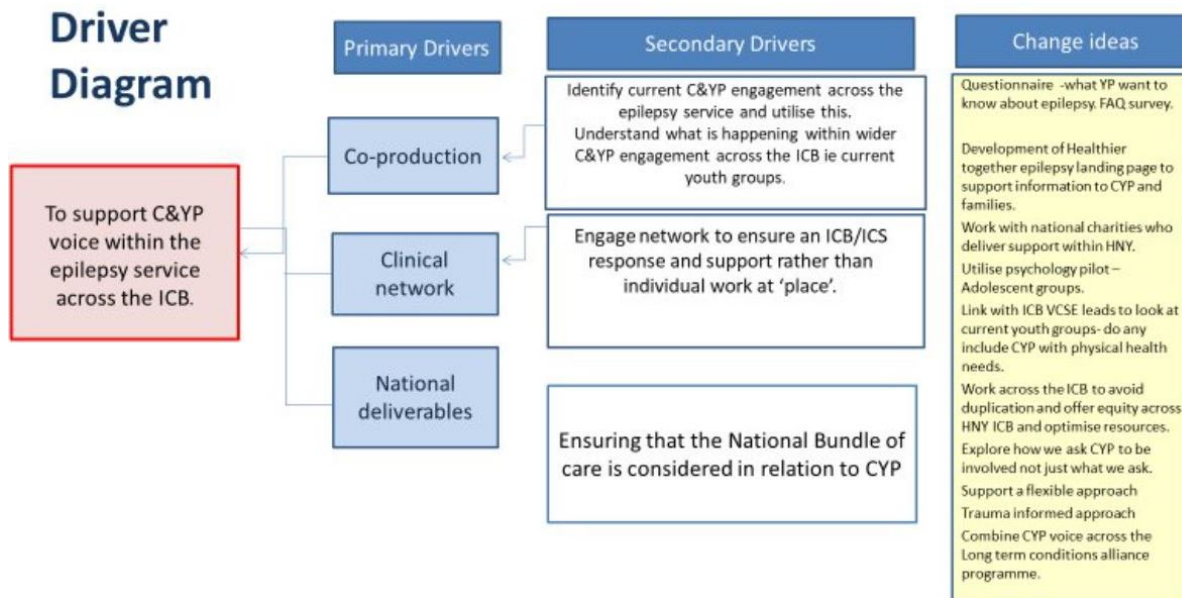


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team’s theory of what “drives”, or contributes to, the achievement of a project aim.

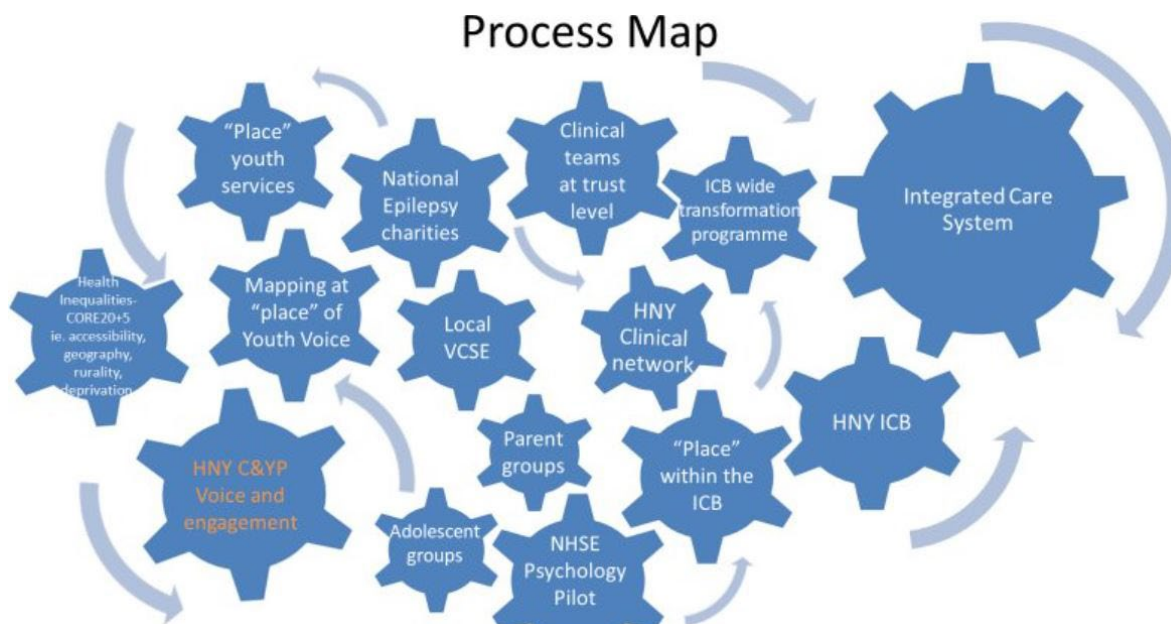


Figure 2: Shows the process mapping of pathways involved in implementing a patient engagement plan.

What were the challenges?

The project faced several challenges, primarily the difficulty of working across the ICB. The data received consisted of feedback captured from children and young people, requiring further work to understand the improvement work taking place within services and identify areas of excellence to engage across the ICB. Although the project had not yet directly changed clinical care as originally intended, it has shifted focus towards prioritising the voices of children and young people to co-design services as part of ICB engagement development. There is now consideration of how to incorporate their input, not only for epilepsy but also for long-term conditions like asthma and diabetes. The aim is to progress these efforts over time.

The ICB clinical lead faced challenges in engaging service teams within the ICB to participate in the project, resulting in limited success.

Capacity issues, lack of full service team engagement, and internal struggles within paediatric epilepsy services limited progress at times and the project became slightly abstract in achieving tangible results. Despite this, there was still motivation to advance the project, though there was uncertainty about how to effectively implement it within the ICB.

What were the results?

The project results revealed several insights into the concerns and preferences of children and young people with epilepsy. They are worried about driving, employment, mood changes, relationships, and sports. In response, adolescent groups were developed and are ongoing within the region. However, many adolescents expressed discomfort with group settings, citing nervousness, inconvenient timing, and a preference for online formats.

The testing highlighted the challenges of working across an ICB and the difficulty of getting the approach right. The project questioned whether it was engaging children and young people correctly and providing the appropriate opportunities and environments. It also considered the needs of those with comorbidities, such as learning disabilities or autism, and those facing access issues due to deprivation.

Overall, the findings indicated a need to strive for changes at a system level, rather than just an operational level.

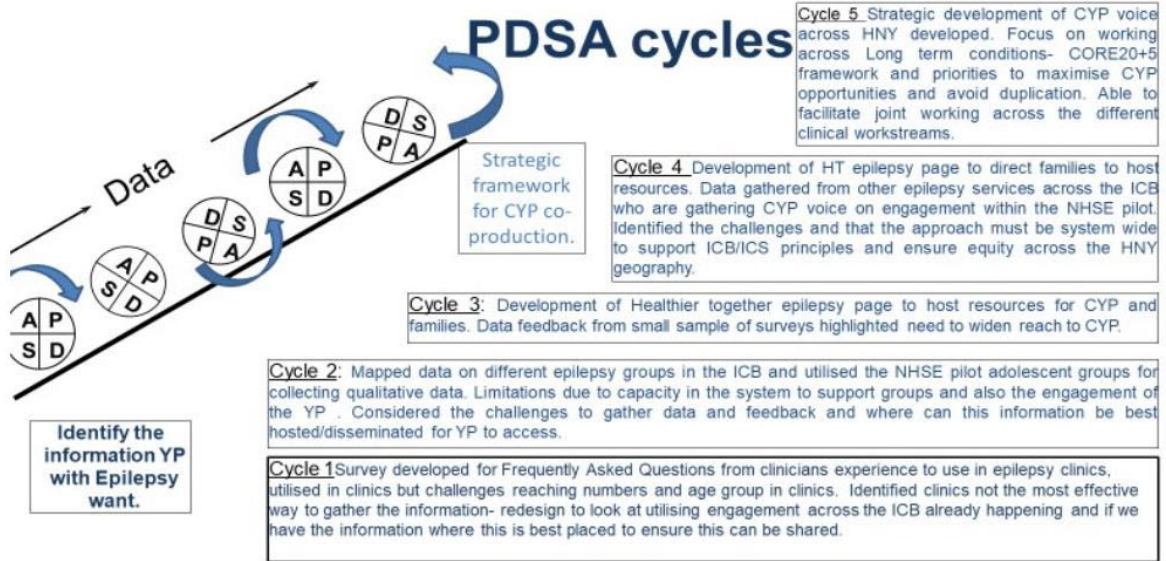


Figure 3: Shows the PDSA cycles of change ideas to engage with young people and families within the driver diagram being tested.



Figure 4: Shows examples of children and young people’s feedback captured from the FAQ questionnaire.

What was the outcome?

The project aimed to broaden current practices and achieved several key outcomes:

- The collection of patient and family feedback was collected to further meet the project’s needs and exploration goals.

- As part of a psychology pilot, children and young people's groups have been initiated, with parent groups also in the process of being implemented.
- Resources and support links collated across the Trust, including FAQ topics highlighted from feedback has been used as content on epilepsy on the [Healthier Together Trust website landing page](#).

What were the learning points?

The project has provided several important lessons. From a wider ICB perspective, there is a desire to develop a support pathway for long-term conditions by integrating various work streams and involving children and young people groups across the ICB. These groups can provide insights into their struggles and challenges, working in co-production with healthcare professionals to improve services.

The ICB Children and Young People's Long-Term Conditions Lead aims to support services by engaging the children and young people's steering groups within the Trust to determine if they have access to engagement groups and leveraging the young people networks to facilitate co-production.

Connecting systems across the ICB through clinical networks has been instrumental to the project. The various work streams have provided valuable lessons and reflections on delivering national standards and engaging with children and young people. The project has highlighted the need to think strategically, rather than focusing solely on local implementation.

Next steps and sustainability

Sharing the work across the ICB at clinical networks. We plan to involve epilepsy charities, youth charities, and the Association of Young People's Health, building on previous co-production efforts in mental health projects. A proposal will be made to develop a platform for young people's voices, potentially forming a forum or board of young people.

In the future, they envision conducting a next quality improvement project with children and young people with epilepsy as leaders, collaborating with the multidisciplinary team within the wider system.

Want to know more?

If you would like to know more about this project, please contact:

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