

The Innovation Lab: North East and North Cumbria

Bringing together decision-makers and families



The RCPCH &Us team were invited by the Child Health and Wellbeing Network, part of North East and North Cumbria Integrated Care Board, to hold an Innovation Lab event in their region. The Innovation Labs brought together children, young people and families living with Epilepsy to share experiences, develop recommendations for service improvement and design resources that could inform these resources.

The team supporting this event from the North East included Louise Dauncey, Children and Young Persons Transformation Programme Delivery Lead from the Child Health and Wellbeing Network (ICB), Dr Ramesh Kumar, Consultant Paediatrician and Clinical Lead for Epilepsy and Sophie Gilmour-Ivens, Paediatric Epilepsy Nurse – strategic lead.

With RCPCH & Us, the team organised a one-day event for families to come together. In total, 5 families attended 5 parents/carers and 6 young people.

Space and Voice

The space used for the Innovation Lab was a community resource space in the centre of Newcastle. It had an informal, relaxed feel, comfy sofas, board games and flowing tea and coffee. The space was large enough that parents and carers and young people could find different zones of the space and allow for separate conversations whilst having the security of being in the same room (with parents on hand if children or young people wanted to check in with them).

Whilst the event had been offered out to families across the region, we found that the primary take-up was from families who had Sophie as their Epilepsy nurse. This highlighted again the value of the relationship with the Epilepsy nurse for supporting engagement activities. Her presence at the event was also a source of comfort for the families attending.

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Parents and children all took part in icebreaker activities and a group agreement setting at the beginning of the day to ensure that the space created felt comfortable and people got to know each other a bit. It was important for the families that it was a non-judgmental space and that it was well facilitated.

For many of the families, this was the first opportunity to meet other families living with Epilepsy, and they really valued the space to talk.

After the initial activities – parents/carers and young people split into two groups to allow for the different experiences and perspectives to have their own space. The young people used creative arts to help express themselves. They made models, lists and stories to represent their experiences, sometimes together and some preferring to work independently.

Dr Kumar and Sophie stepped out of these initial discussions so that the children, young people and parents felt comfortable to share their experiences frankly.

Audience and Influence

During the afternoon a key feature of the Innovation Lab was the sharing of ideas and work that had been generated during the session. This was the first opportunity for the children, young people and parents/carers' views to be shared with a relevant audience as they were able to directly express their views to Dr Kumar, Sophie and Louise.

Young people were also presenting to their parents and carers and vice versa. This was fed back as a highlight of the day and also allowed everyone to celebrate the young people's achievements during the day.

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The report that has been written up from the session has also been shared with the North East and Yorkshire Epilepsy Leadership group and presented at the Paediatric Epilepsy Network for North East and Cumbria (PENNAC), where over 50 clinicians working in epilepsy services were present, as well ICB Local Delivery Team Commissioning and Delivery Leads. Some of the video content from the day was also shown at the RCPCH Epilepsy12 conference.

One of the themes from the day was the need for more family support in the region. After the lab day Sophie sent a survey to 77 families in the region about what type of support they wanted, and since then has been working with 2 of the parents who attended the lab day, 5 other parents, and a parent who is also an independent advocate, to develop a region-wide Facebook support group for families with children and young people with epilepsy. The group is in its infancy, and it will be run / managed by parents, for parents and carers, but Sophie's regional role has allowed her to be able to bring people together and facilitate meetings at which ideas, aims, information and rules can be developed.

In addition to the active patient involvement work led by Sophie there has also been some further local Service Improvement planning with the local secondary care teams that responds to the requirements of the National Epilepsy Care Bundle and also the overall feedback from the innovation day for example information, advice and guidance and also supporting with Mental Health assessment, support and intervention.

Sophie, Dr Kumar and Louise continue to work to take forward some of the recommendations from the day.

Thank you to the team for being involved in our pilot and sharing your experience.

**To find out more, please contact
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