Chuf. Wellbeing Challenges in CHD: Children and Families Summary of Project

What you did

Thank you so much for helping us learn more about what it's like to live with CHD (Congenital Heart Disease). You helped by:

- filling out a questionnaire
- rating and sorting wellbeing challenges on success and importance
- giving us brilliant ideas on how services can better support you with these challenges

What we found

You told us about 9 main challenges. These are the things you find hardest when living with CHD:

The hardest part? Anxiety and Worrying About the Future.

The least supported? Unfairly Missing Out. 3. Managing Lack of urden of Trave **Impact on** Infairly missing physical signs and Hospital Family and Facilities and out (events/ and symptoms Family System Appointments opportunities) Support Procedural Social Psychologica Anxiety and Difficulties Jnderstandind

You gave us amazing ideas! Here's what you said would help:

the Future

Better Education and Information

2. Support That

Puts You at the

Centre

3. Calmer, Quieter **Facilities**

You told us it would help if:

- families, schools, and staff knew more about CHD and the wellbeing challenges.
- there was more tools (videos, leaflets, website)

You told us it's important when:

- care is personal and makes you feel listened to.
- you are treated as the expert of your own experience
- your strengths are spoken about and shared

You shared that:

- quiet appointments, flexible times, or being seen closer to home can make a big
- calmer and quieter environments would help children feel better

4. A point of Contact Within the Team

You told us:

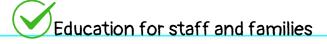
- It is really useful to have one person you can speak to
- Having someone to ask questions, share worries with, and get advice from would be a big help

Next Steps

Your voice helped us - but we are not finished yet!

We are working on: New resources







We need your help! Please get involved and have your chance of shaping how we develop services! Email us at: nuth.enquiries-nencchdn@nhs.net_and we will let you know about events coming up for you to have your say and help us make The Newcastle upon Tyne Hospitals positive changes! To read the full report, or find out more, scan the QR code.



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