

huf. Wellbeing Challenges in CHD: Summary of Project



What you did

We invited children, young people, families, and staff members to share their experiences of CHD. They participated by:

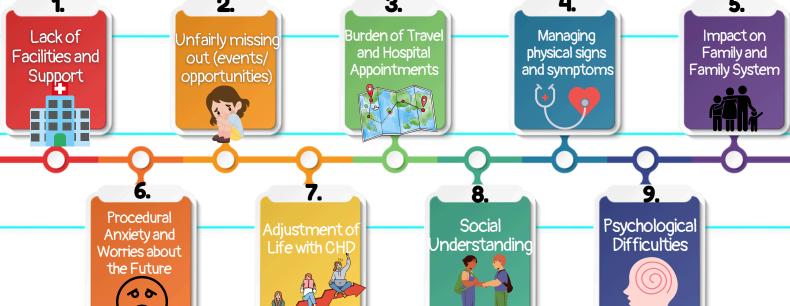
- completing a questionnaire about wellbeing challenges
- sorting and rating these challenges on success and importance
- generating ideas and joining group discussions to understand how services can provide better support for those challenges

<u>What we found</u>

We identified 9 main challenges, experienced by children living with CHD.

The challenge rated most significant: Procedural Anxiety and Worrying About the Future.

The least successfully addressed challenge: Unfairly Missing Out. Managing Lack of Infairly missinc



Four clear priority areas emerged from feedback and idea generation in regard to service improvement:

Education and Resource Development Families and young people would benefit from:

- increased access to clear, age-appropriate CHD information
- resources for families, schools, and professionals (e.g., videos, leaflets, website, groups)
- Community education to reduce stigma and raise awareness

2. Empowerment and Person **Centred Care**

Young people value services that:

- encourage active participation in decision-making
- use strength-based, developmentally appropriate communication
- recognise them as experts in their own condition

3. Adapting **Facilities**

4. Clear Point of

Contact Within

the Team

Feedback suggested:

- small environment changes (e.g., quiet spaces, flexible appointment times, being seen closer to home) can significantly improve patient experience
- design of services should reflect the emotional and developmental needs of young people

Families highlighted the need for:

- · consistent access to advice, reassurance, and mental health input
- a named professional to provide ongoing advice and information
- better continuity of care through transition
- exploring funding opportunities to fill gaps of support across the region (i.e., psychology, play team, social work).
- highlighting the risk when support is not available across the region to support funding applications.

<u>Next Steps</u>

You told us what matters - now it's time to act. We need your help to embed these recommendations into everyday practice.

- Reflect: What can you and your team do differently?
- Act: Identify small, practical changes in-line with recommendations that you can lead on in your setting
- Connect: work with others to build on ideas and strengthen support

The Newcastle upon Tyne Hospitals