From Challenges to Change: A Scoping Report on *Good* Psychosocial Care in Paediatric Congenital Heart Disease

Recommendations for Psychosocial Provision Across the North East and North Cumbria

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Executive Summary

- The North East and North Cumbria Congenital Heart Disease Network (NENC-CHD) in collaboration with the Children's Heart Unit Fund (CHUF) funded a nine-month project to explore the wellbeing challenges for children, young people, and families living with CHD across the Network region, and identify how to put support in place to help address these challenges.
- The NENC-CHD Network includes 13 NHS Hospitals; 12 of which are Level 3 centres, and one is Level 1. NHS England standards specify that each Level 1 Surgical Centre should employ 1 WTE practitioner psychologist for each Network. Alongside this, a minimum of 0.25 WTE practitioner psychologist appropriately trained and experienced in working with CHD for every 100 children undergoing cardiac surgery per year. Within the Level 3 centres across the Network, NHS England standards indicated that there must be a Practitioner Psychologist working to help support children and families.
- Current psychological provision for the Network is based at the Freeman Hospital (Level 1 Centre) with no current Network Psychologist employed. Children and families within the NENC-CHD Network can access psychology at the Freeman Hospital if they are under a consultant there. However, this poses inequity in care offered due to some families having to travel long distances and therefore opt for videocall or telephone appointments. It demonstrates current practice is not in-line with proposed standards, with less psychology provision available than recommended.
- A needs assessment was conducted using Group Concept Mapping methodology, and a total of 9 themes that illustrated what the wellbeing challenges are for children and families living with CHD (N = 73) and staff (N=19) in the Network were identified. These included: i) lack of facilities and support; ii) unfairly missing out; iii) burden of travel and hospital appointments; iv) managing physical signs and symptoms; v) impact on family; vi) procedural anxiety and worries about the future; vii) adjustment; viii) social understanding; and ix) psychological difficulties. A total of 20 children, families and staff members rated the statements within each of the 9 themes on: a) current success in services supporting them; and b) how important they were for children, young people, and families.
- A focus group (N=6) and support idea generation task (N= 30 approx.) were implemented to gather ideas on how children, young people and families would like support with the specific wellbeing challenges they identified. Following data collection, a list of recommendations was proposed and alongside this it is outlined who is responsible for driving the specific recommendations (these include, but are not limited to: an education strategy, resource development, exploring service provision, and exploring opportunities for new roles).
- Two models have been suggested regarding setting up a Psychologically Informed Network and a Tiered System to Psychological Care.
- To reduce inequity and promote psychological care across the Network, this report highlights gaps in current provision across the Network regarding Psychology provision offered and highlights a need to explore funding opportunities to address this.

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Introduction

Background

Psychosocial impact of living with congenital heart disease: children and young people

Within the United Kingdom (UK), between ten to thirty percent of children and young people live with a chronic illness or physical health condition (Kush & Campo, 1998). Reports such as *Treat as One,* have highlighted the importance of improving the parity of esteem between physical and mental health provided by UK general hospitals for chronic health conditions (The National Confidential Enquiry into Patient Outcome and Death, 2017). This reinforces the imperative argument for the integration of psychological practice within physical healthcare systems (Psychological Professions Network, 2020).

One such chronic condition is congenital heart disease (CHD) - the most common congenital malformation - affecting approximately 1% of live births worldwide (Van Der Linde et al., 2011). CHD ranges from what is defined as '*simple*'; CHD that has not required immediate or any surgical intervention, to *'complex'*; CHD that required surgical intervention within the first month or year of life (National Heart, Lung, and Blood Institute, 2020). Due to medical advances, >90% of newborns now survive into adulthood (Kovacs et al., 2022), with long-term survival (>20 years) now estimated for children with complex CHD (Oster et al., 2013). These improved outcomes have brought new challenges, including the need to address non-cardiac comorbidities, meet psychosocial needs, and improve overall wellbeing and quality of life for parents and children living longer with CHD (Morton et al., 2017; Lui et al., 2017).

Children and young people living with CHD are at risk of a range of long-term physical, neurodevelopmental, and psychosocial sequalae, with risks increasing in complex CHD (Marelli et al., 2016; Marino et al., 2016; Sood et al., 2024; Simko & McGinnis, 2003; Ryan et al., 2019; Majnemer et al., 2006). Notably, 50% – 75% of children with complex CHD experience neurodevelopmental disabilities, which are associated with reduced quality of life (Verrall et al., 2019; Kovacs et al., 2009; Bellinger et al., 1995; Marino et al., 2012; Ryan et al., 2019; Latal et al., 2009). In comparison to healthy peers, children with CHD have a higher prevalence of emotional, behavioural and social difficulties (Kovacs et al., 2022) and lower reported scores of health-related quality of life (Mellion et al., 2014). Research continues to negate the perception that CHD primarily and solely has physical effects on functioning, with evidence indicating the greatest negative impact on health-related quality of life arises from issues in psychosocial and educational functioning (Latal et al., 2009; Mellion et al., 2014).

Psychological difficulties experienced by children and young people living with CHD include, but are not limited to, anxiety and depression (Gonzalez et al., 2021), psychological maladjustment (Latal et al., 2009), disease related chronic stress (Cassedy et al., 2023), and post-traumatic stress disorder (PTSD; Meentken et al., 2017). Approximately one third of children develop symptoms consistent with PTSD and one in ten develop clinically significant PTSD (Colville, 2008). Despite the high prevalence of psychological distress, relatively few children and young people with CHD access psychological assessment and intervention

(Loccoh et al., 2018). The reasons for this are not fully understood, though possible contributing factors include limited availability of specialist psychological services, barriers to access, or a lack of awareness among families and healthcare professionals about the psychological impact of CHD. These hypotheses remain speculative and warrant further empirical investigation.

Psychosocial impact of living with congenital heart disease: families

Receiving a diagnosis of CHD can occur at pregnancy, birth, first years of life, or later in life, and is often a distressing experience for parents due to the uncertainty surrounding medical decisions, prognosis, and potential mortality (Wei et al., 2015). Research suggests that the timing of diagnosis significantly influences wellbeing of parents. A systematic review found that prenatal diagnoses, which often involve complex decisions such as termination of pregnancy, can increase psychological distress (Blakeley et al., 2019). However, postnatal diagnoses have also been associated with heightened distress, with studies suggesting a greater negative impact than prenatal diagnoses (Blakeley et al., 2019; Pinto et al., 2016). While each timing presents unique challenges, professionals are advised to assess and address parents' psychological wellbeing, information needs, and understanding regardless of when the diagnosis occurred (Reid & Gaskin, 2018).

Parents whose child required an admission to a neonatal unit when born, experience significantly higher rates of mental health difficulties when compared to the general perinatal population (Malouf et al., 2021; Feeley et al., 2011; Lefkowitz et al., 2010). Parents of children with CHD are particularly vulnerable to stress, anxiety, depression, and poorer quality of life (Woolf-King et al., 2017; Lawoko & Soares, 2003). These experiences are often shaped by grief over the loss of a *'normal'* pregnancy, a healthy child, and their imagined future (Lou et al., 2017) and are commonly associated with shock, guilt, grief, anger, and anxiety (Bekkhus et al., 2020).

Parental stress is often elevated from the moment of diagnosis, particularly in cases requiring intensive or ongoing treatment (Cousino et al., 2022; Bishop et al., 2019). Sociodemographic variables, such as parents' ability to take time off work for their child's medical appointments can further intensify emotional, financial, and familial stressors, placing parents at elevated risk for distress and psychological maladjustment (Woolf-King et al., 2017; Lawoko & Soares, 2003).

Although caregiving responsibilities are commonly viewed as shared between family members (Avieli et al., 2019), as parents age, these often shift to siblings (Wofford & Carlson, 2017), who may perceive this role as an expected part of their role and future (Heller & Arnold, 2010). Siblings of children with CHD frequently take on increased responsibility yet have their social activities restricted (Williams et al., 1993). These demands can contribute to emotional, behavioural, academic, and quality of life difficulties (Parker et al., 2020). Compared to siblings with other chronic illnesses, such as cancer or type 1 diabetes, siblings of children with CHD report lower quality of life (Havermans et al., 2015) and have more concerns about their affected brother or sister (Menke, 1987). One study revealed that siblings of children with CHD experience psychological impacts that are nearly as severe as those felt by the affected children themselves (Azahr et al., 2016).

Psychosocial impact of living with congenital heart disease: staff

As children with CHD are embedded within complex systems involving family, education, community, and healthcare, addressing psychological wellbeing requires attention to all elements of this ecosystem. Healthcare professionals, specifically those working in paediatric and cardiology settings, are an essential part of this system and are themselves at risk of psychological distress. For instance, approximately 40% of staff in paediatric settings experience one or more of burnout, moral injury, or post-traumatic stress symptoms (Jones et al., 2020). Within cardiology, rates of burnout among physicians have doubled since 2015 (ACC Survey, 2021), with physicians managing acutely ill patients and dealing with the issues surrounding death and dying, being particularly vulnerable (Trufelli et al., 2008).

High rates of anxiety, depression, and burnout have also been documented among UK cardiology doctor trainees (Jenner et al., 2024). Contributing factors include, excessive workload, misalignment between job demands and skills, and a lack of control (Shanafelt et al., 2017). Such occupational stress not only affects staff wellbeing but is also associated with reduced job performance and, by extension, the quality of care provided to children and families with CHD (Bhat & Tariq, 2022). These findings underscore the reciprocal nature of systemic stress: just as families are impacted by the child's diagnosis, so too can professional distress influence the child's environment, illustrating the interdependence of all actors within the care system.

Context

Given the substantial impact that CHD can have on children and the wider systems that support them, the North East and North Cumbria Network (NENC), in partnership with the Children's Heart Unit Fund (CHUF), has commissioned a nine-month scoping project to explore and enhance the psychosocial support services. The primary aim of this initiative is to identify what constitutes high-quality psychosocial care across paediatric and transition CHD services within the NENC region, with a view to informing future service development and addressing the unmet psychosocial needs of children and families.

The NENC-CHD covers a population of 2.9 million and is hosted by Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH). The host Trust is commissioned by the National Health Service (NHS) England, enabling the Cardiothoracic Directorate to provide specialist care for CHD adults and children as a Level 1 surgical centre in the UK. The vision of the NENC-CHD network is:

> *"Our vision is to provide high quality, equitable care for congenital heart disease patients wherever they live within our region; provided closer to home when possible, ensuring seamless transition between fetal, paediatric, and adult services and providing a holistic approach to care."*

North East and North Cumbria Network

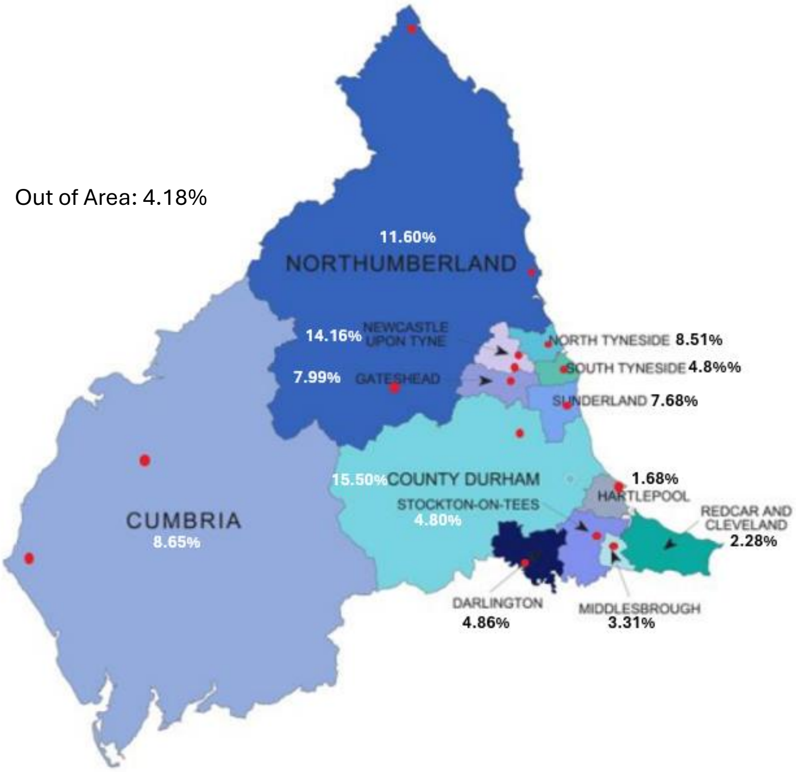


Figure 1: Map of The North East Congenital Heart Disease Network (percentage indicates where patients visiting Freeman Hospital in the 2024 calendar year reside).

The region covered by the NENC Network spans both urban and rural communities and is marked by some of the highest levels of health inequalities in England. It also faces persistent socioeconomic challenges, including higher than average unemployment rates, a shortage of quality housing – particularly in older generations- and widespread deprivation (Ministry of Housing, Communities & Local Government, 2019). Figure 1 demonstrates that the highest percentage of the paediatric CHD population reside in County Durham and visually demonstrates the widespread geography of the Network. Table 1 also indicates the demographic information of the patients who have attended the Freeman Hospital (Level 1 centre) from across the NENC Network, demonstrating the population ethnicity varies however is primarily White British and there is a slightly higher number of females to males attending the Freeman as a result of living with CHD.

Table 1. The Patient Mix of Patients Attending the Freeman Hospital for CHD from across the North East and Wider regions in 2024.

	Descriptives
Age (years), mean (SD)	18.89 (18.16) Range 0-18
Gender	
Male	2276 (46.25%)
Female	2644 (53.78%)
Not Known	1 (.02%)
Ethnicity	
Any other Asian Background	39 (0.79%)
Any other Black Background	22 (0.45%)
Any other ethnic group	57 (1.16%)
Any other mixed background	33 (0.67%)
Any other White background	66 (1.34%)
Bangladeshi	34 (0.69%)
Black African	65 (1.32%)
Chinese	21(0.43%)
Indian	45 (0.91%)
Pakistani	59 (1.19%)
White and Asian	18 (0.37%)
White and Black African	17 (0.35%)
White and Black Caribbean	6 (0.12%)
White British	681 (74.80%)
White Irish	12 (0.24%)
Not Stated	745 (15.14%)

Table 2 indicates that there are eight NHS Trusts within the NENC-CHD Network. Due to the widespread geography of the Network and the Trusts it encompasses, children, young people, and families could be expected to travel more than two hours by car from the furthest Trust to the Level 1 Centre (Freeman Hospital). NHS Trusts that are relatively closer in geographical proximity may also require a one-hour drive to reach the host centre. The geographical spread of the network creates a challenge. Any service provision needs to take this into account to ensure equitable care in provided to services across the Network.

Table 2. Trust, Hospitals and their Level in the NENC Network

Trust	Hospitals	Level
County Durham and Darlington NHS Foundation Trust	Darlington Memorial Hospital University Hospital of North Durham	3
Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital	3
Newcastle upon Tyne Hospitals NHS Foundation Trust	Freeman Hospital	1
	Royal Victoria Infirmary/ Great North Children's Hospital	3
North Cumbria Integrated Care NHS Foundation Trust	Cumberland Infirmary	3
North Tees & Hartlepool NHS Foundation Trust	University Hospital of North Tees	3
Northumbria Healthcare NHS Foundation Trust	Hexham General Hospital	3
	Noth Tyneside General Hospital	3
	Wansbeck General Hospital	3
	West Cumberland Hospital	3
	Northumbria Specialist Emergency Care Hospital	3
South Tees Hospital NHS Foundation Trust	James Cook Hospital	3
South Tyneside and Sunderland NHS Foundation Trust	Sunderland Royal Hospital South Tyneside General Hospital	3

Purpose and Scope

Within the North East and North Cumbria region, significant progress has been made in improving medical outcomes for children with CHD, with more children now surviving into adulthood. However, as growing evidence highlights the psychosocial challenges associated with living longer with CHD, there is an increasing need to prioritise improvements in quality of life alongside physical health outcomes.

The purpose of this scoping project is to respond to that need by engaging children, families, and healthcare professionals across the NENC-CHD Network to identify and prioritise key psychosocial needs. These needs will be ranked based on perceived importance and current levels of success in meeting them. The project aims to co-develop and deliver targeted interventions and educational resources, to address identified gaps, and contribute to the Network’s broader education strategy.

The project was led by Dr Helena Widdrington, Clinical Psychologist and overseen by Consultant Clinical Psychologist, Dr Emily Bell and Highly Specialist Clinical Psychologist, Dr Katherine Barlow. Terry Philips and Kaye Walsh (NENC-CHD) were also part of the project team and helped coordinate work that could be implemented across the network. The project team commenced the project on 7th October 2024 and concluded on 3rd July 2025.

Objectives

The project sought to map current services for children and young people with CHD, consult with staff team and patients, and report on recommendations for cardiology services across the network. The aims were:

- To identify the current psychosocial needs of children, young people, and families living with CHD across the NENC-CHD network.
- To rank these psychosocial needs in regard to their importance and current success in practice.
- To understand how children, young people, and families would like our services within the Network to support them with the identified needs.
- To co-develop and deliver appropriate psychosocial interventions to help address the identified psychosocial needs across the network.
- To use the findings to inform policies, guidelines and recommendations for service provision and delivery across the North East and North Cumbria region.

Methods

This service evaluation project was registered on the Clinical Effectiveness Register at the host NHS Trust (Newcastle Upon Tyne Hospitals NHS Trust) prior to commencement. This project followed the work done by Attenborough & Wilmott (2023) who completed a psychosocial scoping exercise with adults living with CHD within the North East and North Cumbria region.

Scoping Approach

To help achieve the aim of identifying the wellbeing challenges of children, young people, and families living with CHD across the NENC Network, a scoping approach was implemented. This approach was chosen for its broad and flexible exploration of the area, which helps aid the identification of key concepts, patterns and gaps in services and knowledge. The scoping approach was conducted in two stages: i) Information Gathering and Relationship Building and ii) Needs Assessment and Intervention Development. These will be discussed in-turn.

1. *Information Gathering and Relationship Building*
    - Mapping of existing service and gathering information in the Network.
    - Identifying the relevant national guidance and service specifications.
    - Reviewing psychological services in paediatric CHD across the UK.

Data Collection

1. *Information Gathering and Relationship Building*

The project lead reviewed relevant documents and reports to contextualise findings. These included:

- A national strategy to address the James Lind Alliance priorities for children and adults with congenital heart disease (Transforming Collaborative Research, 2023)
- Congenital Heart Disease Standards & Specifications (NHS England, 2016a)
- Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children's Surgical Centres (NHS England, 2016b)
- Paediatric Congenital Heart Disease Specification (NHS England, 2016c)
- Psychology Provision across all NHS cardiology departments within England.

Alongside this, the project lead met with key stakeholders working within the Network across the region to introduce the project and help build relationships.

Results: Information Gathering and Relationship Building

Good Practice Indicators

There are several documents pertaining to proposed guidance and standards for psychological services for children with CHD. The Paediatric Congenital Heart Disease Recommendations (Level 1 Centre) is part of a number of documents setting out guidance in England, as agreed by the NHS England Board on 23 July 2015. The table below depicts recommendations relevant to psychology from the NHS England report.

Paediatric Congenital Heart Disease Standards: ***Level 1 Psychology Provision***

Table 3. Level 1 Centres

	Psychology	Implementation Timetable
B30(L1)	Each Specialist Children's Surgical Centre must employ a minimum of 0.25 WTE practitioner psychologists (with experience of working with CHD) per 100 children and young people undergoing cardiac surgery each year. In addition, 1 WTE practitioner psychologist must be employed for each network. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network. The lead psychologist should provide training and mentorship to the other psychologists in the network.	Within 3 years
C8(L1)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
D22(L1)	Child Psychiatry (with dedicated sessions and 24/7 on call). Should ideally be located on the same hospital site as Specialist Children's Surgical Centres Consultants from Child Psychiatry must be able to provide urgent telephone advice (call to advice within 30 minutes) and a visit or transfer of care within four hours if needed. The services must be experienced in caring for patients with congenital heart disease.	Immediate
D34(L1)	Psychology, with dedicated sessions for CHD must be able to provide advice and consultation at least by the next working day. The services must be experienced in caring for patients with congenital heart disease.	Immediate
F23(L1)	Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals	Immediate
F24(L1)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.	Immediate
H3(L1)	Children and young people, family and carers must be helped to understand the patient's condition, the effect it may have on their health and future life, what signs and symptoms should be considered 'normal' for them and the treatment that they will receive, including involvement with the palliative	Immediate

	care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person, parents' and carers' understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. school and careers; g.travel; h. welfare benefits; i. social services; and j. community services.	
H26(L1)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months
I12(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate
J5(L1)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Within 1 year
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate

As summarised above, each specialist paediatric CHD surgical centre (Level 1 centre) must provide a minimum of 0.25 WTE practitioner psychologist appropriately trained and experienced in working with CHD for every 100 children undergoing cardiac surgery per year. Activity data shows that between April 2024 and March 2025 there were 160 cardiac and equivalent surgeries in children and 246 catheter procedures within the Level 1 centre in NENC-CHD Network. These numbers exclude admissions for diagnostic procedures and non-procedural based treatments (for example optimisation of therapy and long-term medication by intravenous infusion). The surgery figures for 2024-2025 were significantly lower than previous years. The mean figure over the period 2020-2025 for surgeries per year is 178.4. An average figure will be used for provision planning purposes due to year-on-year variation.

In addition, it is specified within Table 3 that there must be 1 WTE practitioner psychologist employed for each Network.

It also adds "*The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network"*. This is particularly important to highlight, given the large geographical area the Network covers and over 8 NHS Trusts. Given that the table also highlights that a practitioner should be available to children and families at any stage of their journey and open to see children and parents both separately, this would be difficult to achieve with covering a large geographical patch.

Paediatric Congenital Heart Disease Standards: ***Level 3 Psychology Provision***

The NHS England report also pertains the recommendations for psychological provision within Level 3 centres within the Network.

Table 4. Level 3 Centres.

	Psychology	Implementation timescale
C1 (L3)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
H3 (L3)	Children and young people, family and carers must be helped to understand the patient's condition, the effect it may have on their health and future life, what signs and symptoms should be considered 'normal' for them and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person's, parents' and carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. school and careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H11 (L3)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child/young person's condition, and providing psychosocial support to promote parental (and child's/young person's) adaptation and adjustment.	Immediate
H23 (L3)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly	Within 1 year

	at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.	
I12 (L3)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Within 1 year
J5 (L3)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate

As is also summarised above, within the Level 3 centres across the Network, there must be a Practitioner Psychologist working to help support children and families with psychological needs. In addition, the recommendations suggest *"where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre"*. However, as highlighted previously, given the large geographical spread of the Network this could result in individuals travelling approximately 1-2 hours for psychological therapy weekly. Given advances in technology, therapy can be provided to children and families via videocall. However, this has negative implications for therapy especially for a young population group in terms of engaging the child, building trust, and removing distractions in their space at home for promoting good psychological outcomes.

Current NENC-CHD Psychological Provision

The Paediatric Congenital Heart Disease Standards for Level 1 and Level 3 centres when applied to our population mean the region should have a **minimum** psychological care provision of:

Level 1: <u>1.5 WTE Psychologists</u> (1 WTE Psychologists for whole network + 0.5WTE Psychologists); plus, Child Psychiatry sessions and 24/7 on call accessible on level 1 site.

Level 3: <u>All eight level 3 centre trusts</u> must have Psychologists experienced with paediatric cardiac care working into their services.

Note that where level 3 centres are not providing the required access to a psychologist, level 1 centres are required to pick up referrals from these areas. So, where there are gaps in level 3 provision, the level 1 centre would require more than minimum provision detailed.

<u>The current provision funded for NENC-CHD Network is:</u>

Level 1: 0.8WTE Psychologists*; No Child Psychiatry.

Level 3: No provision for any of the eight centres.

This is far below the minimum standards for psychological care provision agreed by NHS England.

*This provision also must cover the care of children and young people in the region with Inherited Cardiac Conditions (ICC) which are often not congenital.

Mapping of Psychological Provision Across the UK

Within the UK, for children there are six Level 1 centres. Table 5 indicates that the majority of other Level 1 centres in the UK have more psychological provision than the Freeman Hospital. In addition, it is important to highlight that the Freeman Hospital and Great Ormond Street Hospitals are specialist centres for the UK and have separate provision for heart transplantations.

Table 5 also shows that many Level 3 centres nationally have the required psychology provision within their services.

It is a concern that both the Freeman Level 1 Specialist Surgical Centre and the NENC CHD Network Level 3 centres all fall so far behind the national level of psychological care provision.

Table 5. The Current Known Psychological Provision for Cardiac Centres within the UK.

Centre	Level	Funded Psychology Provision (WTE)
Alderhey Children’s Hospital	1	Band 8a 0.2 Band 8a 0.4
Addenbrooke Hospital	2	Band 8b 0.1 Band 7 0.4
Southampton Children’s Hospital	2	Band 8a 0.2 Band 8a 0.2
Evelina London Children’s Hospital	3	Band 8a 0.8 Band 8a 1.0
Royal Brompton Hospital	1	Band 7 1.0 Band 8a 1.0 Band 8b 0.55 Band 8c 0.3
Freeman Hospital	1	Band 8c 0.8
Leeds Hospital	3	Band 8c 0.4 Band 8b 0.8 Band 7 0.6 Band 7 1.0 Band 7 0.4 Band 7 0.6 (parents/adults only) Band 6 0.8 (parents/adults only)
Leicestershire NHS Trust	1	Band 8b 0.5 Band 8a 0.6 Band 8a 0.72
Royal Belfast Hospital	2	Band 8b Band 8a 0.7
Great Ormond Street*	1	Band 8b 0.5

		Band 8a 1.4
		Band 7 0.5
Royal Hospital for Children, Glasgow	3	Band 8a 0.5
Southern Health and Social Care Trust	2	Band 8a 0.7
		Band 5 1.0
South Wales Children's Hospital	2	Band 7 0.8
		Band 8a 0.2e
		Band 8a
University Hospitals Bristol and Weston	1	Band 8b 0.2
		Band 8a 0.6
		Band 8a 1.0

Note: Data obtained from Cardiology Specialist Interest Group for the UK. Professionals from each service across the UK shared their most up-to-date data for psychology provision. Data for hospitals includes Network Psychologist in post. Please note that the funded psychology provision for centres can be skill mixed to best meet service needs. *It is unclear if the provision reported for Great Ormond Street includes psychology funding for heart transplant as well as CHD support, or if it is solely the provision for CHD.

NUTH Wellbeing Support

Within NUTH at the Freeman Hospital and Great North Children's Hospital, there is a Family Hub Complex Care Coordinator (FHCCC; 1 WTE). There used to be a small team of children's hospital social workers at the Freeman Hospital and Great North Children's Hospital (2 WTE) and due to the local authority withdrawing the service, this has gone. The new NUTH FHCCC role is filled by one of the previous team members transferring to NHS employment. They are able to provide advice around safeguarding concerns, social and emotional wellbeing advice, as well as practical support with finances, accommodation, housing and more holistic care. They provide an initial containing response and space to talk for inpatient parents if they want this. They then refer to psychology if there are more complex psychological issues. The FHCCC also complete the psychosocial screening and assessment of patients scheduled for heart and lung transplant assessments. The FHCCC team aim to support families in hospital using the Early Help framework, this is to identify and support with issues that may delay a safe and timely discharge. This support is accessible to those families in inpatient care at the Freeman Hospital. The project team have not identified any similar roles offering provision within the NENC-CHD NHS services.

Current NUTH Paediatric Psychology Offer

At present the Paediatric Cardiology Psychology Team at NUTH provide care to children and young people living with a cardiac condition and their families in multiple ways:

- They work as part of a wider Psychology in Healthcare (PIH) Team offering universal resources accessible to any family seeking advice about emotional wellbeing.
- They work alongside other professionals providing care to children and young people with cardiac conditions offering supervision, consultation, staff support and training to support psychologically informed care.

- They provide specialist assessment and psychological therapies direct to children, young people, and their families both as inpatients at Freeman Hospital and as outpatients at any point from diagnosis until transition over to adult cardiac services.
- When assessed as required by a psychologist in the team, they can access additional specialist therapy through PIH service pathways (e.g. EMDR; Family Clinic; Neuropsychology).

Due to the limited capacity of the service at present, there are aspects of provision detailed in service standards that the psychology service cannot fulfil:

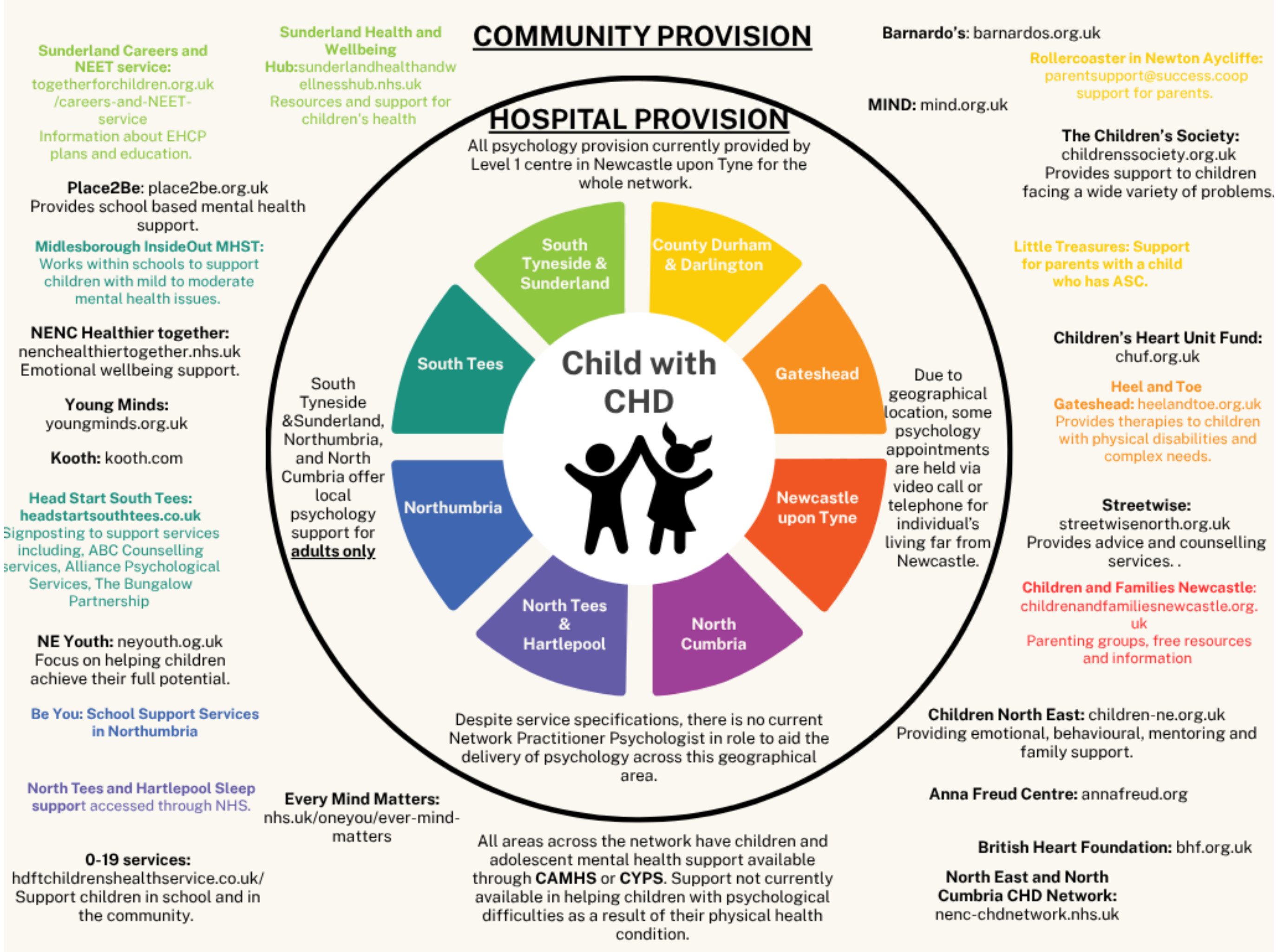
- Timely access to support for families/carers and children/young people at any stage in their care. Over the last few years, due to level of demand, there has consistently been a waiting list for routine psychology assessment that exceeds the recommendation for patients to be offered an appointment within 6 weeks. This is a significant concern due to the importance of being responsive to children, young people, and families in distress and the importance of early intervention. We have received feedback from a number of medical professionals particularly concerned about this wait as it puts patients at risk of emotional and physical harm, can delay medical care, and increase costs of treatment.
- Direct psychological assessment and therapy for siblings of children and young people with CHD. The psychology service offer family focused care that includes advice to parents and carers about meeting the needs of siblings and psychologists can refer on to internal family therapy provision if appropriate. Direct therapy work for siblings is not offered due to limited resources.
- Provision of psychological care over the period of transition from paediatric to adult healthcare. The team offer assessment and therapy to young people up to the age of 18 when they move to the adult service, but there is no adult CHD psychology service in the Level 1 centre and not in all Level 3 centres to continue psychological care. This presents a high risk of harm due to the mental health risks and risks of falling out of healthcare during young adulthood.
- Equity of access to support for families/carer and children/ young people referred from Level 3 centres compared to the Level 1 centre. Families that live geographically further away may be unable to access face-to-face appointments. Videocall and telephone call appointments are also offered when therapeutically appropriate, however this highlights the huge inequity for the children, young people, and families who live far from the Level 1 centre and cannot travel due to costs, time, and accessibility. The psychological work may also be limited by the psychologist not being embedded in the Level 3 centres due to remote communication between healthcare professionals and not being able to support young people in their hospital environment. The Level 3 centre medical professionals, psychology and network teams are very concerned that not having accessible psychological care at Level 3 centres contributes further to health inequalities experiences by families across the region.
- Access to a Psychologist in pregnancy when a heart defect is identified. Patients coming through foetal medicine, including those facing decisions around continuing pregnancies, are now able to be referred to a psychologist in the foetal medicine

team. This is a small amount of provision spread across all of foetal medicine so this cannot always be offered at the time point of decision-making, but follow-up can be accessed. Following a termination or loss, there is also availability of a maternity bereavement counsellor who can offer up to 6 sessions. It is a positive development that these services can be accessed, however they are limited in their capacity.

Access To Wider Psychosocial Support

Figure 2 below shows the psychosocial support available to a child living with CHD and their family within the NENC- CHD Network. The figure is colour coordinated with the services in black indicating universal access for children and families, and then the services in colours match up to the colour of the specific area of the Network. These colour matched service demonstrate specific support within each locality. Interestingly, Figure 2 indicates that adults have more local psychology provision at Level 3 centres within the NENC-CHD Network than there is for children. The information in Figure 2 was collected from websites (incl. healthier together and other local resources/websites) and put together in the diagram below for the purpose of this report as a visual aid of the current support provision offered universally and locally.

Current Psychosocial Support Across the NENC-CHD Network – Services Around a Child with CHD



COMMUNITY PROVISION

HOSPITAL PROVISION

All psychology provision currently provided by Level 1 centre in Newcastle upon Tyne for the whole network.

South Tyneside &Sunderland, Northumbria, and North Cumbria offer local psychology support for **adults only**

Due to geographical location, some psychology appointments are held via video call or telephone for individual's living far from Newcastle.

Despite service specifications, there is no current Network Practitioner Psychologist in role to aid the delivery of psychology across this geographical area.

All areas across the network have children and adolescent mental health support available through **CAMHS** or **CYPS**. Support not currently available in helping children with psychological difficulties as a result of their physical health condition.

Sunderland Careers and NEET service: togetherforchildren.org.uk/careers-and-NEET-service Information about EHCP plans and education.

Sunderland Health and Wellbeing Hub: sunderlandhealthandwellnesshub.nhs.uk Resources and support for children's health

Place2Be: place2be.org.uk Provides school based mental health support.

Midlesborough InsideOut MHST: Works within schools to support children with mild to moderate mental health issues.

NENC Healthier together: nenchealthiertogether.nhs.uk Emotional wellbeing support.

Young Minds: youngminds.org.uk

Kooth: kooth.com

Head Start South Tees: headstartsouthtees.co.uk Signposting to support services including, ABC Counselling services, Alliance Psychological Services, The Bungalow Partnership

NE Youth: neyouth.og.uk Focus on helping children achieve their full potential.

Be You: School Support Services in Northumbria

North Tees and Hartlepool Sleep support accessed through NHS.

Every Mind Matters: nhs.uk/oneyou/ever-mind-matters

0-19 services: hdftchildrenshealthservice.co.uk/ Support children in school and in the community.

Barnardo's: barnardos.org.uk

Rollercoaster in Newton Aycliffe: parentsupport@success.coop support for parents.

MIND: mind.org.uk

The Children's Society: childrenssociety.org.uk Provides support to children facing a wide variety of problems.

Little Treasures: Support for parents with a child who has ASC.

Children's Heart Unit Fund: chuf.org.uk

Heel and Toe Gateshead: heelandtoe.org.uk Provides therapies to children with physical disabilities and complex needs.

Streetwise: streetwisenorth.org.uk Provides advice and counselling services. .

Children and Families Newcastle: childrenandfamiliesnewcastle.org.uk Parenting groups, free resources and information

Children North East: children-ne.org.uk Providing emotional, behavioural, mentoring and family support.

Anna Freud Centre: annafreud.org

British Heart Foundation: bhf.org.uk

North East and North Cumbria CHD Network: nenc-chdnetwork.nhs.uk

Figure 2. Shows the provision around a child in the NENC-CHD Network living with CHD.

Scoping Approach

The second part of the scoping approach involved identifying what the wellbeing challenges were and how children, young people, and families would like support from services with them.

2. *Needs Assessment and Intervention Development*
    - Group Concept Mapping (GCM) was utilised to identify the wellbeing challenges for children, young people, and families living with CHD across the North East and North Cumbria.
    - Focus groups and idea generation tasks were conducted to understand how stakeholders would like these needs/challenges identified to be met by the services across the region.
    - Findings from both methods informed the development of education, training and interventions to help address the needs as proposed by the stakeholders.

Data Collection

2. *Needs Assessment and Intervention - Group Concept Mapping*

Group Concept Mapping (GCM) methodology aligns well with a scoping approach as it gathers data from key stakeholders, then creates clusters of ideas whilst also creating a visual representation of the key results and areas to focus on. GCM was utilised in this project as it incorporates qualitative and quantitative measures to identify the wellbeing challenges and then organises these in regard to success and importance. There are six steps to GCM that were followed, these include:

i) Preparation – The project team defined the focus prompt as *"In your experience, the wellbeing challenges for children and families living with congenital heart disease are…"*. To help support young children participating, a social story was provided in conjunction to the focus prompt. Participants were recruited in-person by the project lead in clinics across the Network and were also able to participate online.

ii) Idea Generation – The project lead asked participants to generate as many responses to the statement as possible. After approximately 400 statements were collected, they were then reviewed and revised by members of the project team (HW and KB). This followed a stepped process, whereby first, statements that included more than one idea were split into separate statements. Second, statements were grouped according to key words or ideas, and a representative statement was generated. Statements that were considered duplicates, hard to determine, or did not make logical sense, were removed. Following this process, the refined list included 69 statements.

iii) Sorting and Rating –The project lead recruited participants to categorise and prioritise the 69 statements. These statements were printed out on individual cards for the sorting task. Participants were asked to sort the cards into groups with a similar meaning. Participants were then asked to name each pile they had created to encompass what they had placed together. For the rating task, participants were asked to rate each statement on two scales, one of which was a scale of 1 to 5 where 5 represented *"extremely important"* and 1 represented "*relatively unimportant"*. The other scaled asked participants to rate how successfully they believe they are currently being supported with the statement on a scale of 1 = *"support need not currently being met"* to 5 = *"support need is successfully being met"*.

iv) Analysis – Multidimensional scaling and hierarchical cluster analysis was implemented to create a concept map.

v) Interpretation – Stakeholders reviewed the maps and there were no further refinements to the clusters.

vi) Utilisation – The findings were used to inform the focus group prompts to help produce recommendations for the needs/challenges identified.

3. *Needs assessment and intervention – Support Idea Generation*

Following the formal GCM data analysis, specific needs/challenges that were generated were taken to back to children, young people, families, and staff in ward and clinic spaces. The needs/challenges were placed in communal areas on blank pieces of paper and individuals waiting in clinic areas/staying on the wards were invited to share ideas of how services within the Network could help support specific needs identified. Participants were given a pen and sticky notes and were free to place as many ideas as possible on the pieces of paper displayed. Participants could see other participants responses; however, all responses were kept anonymous. Staff and patients were invited to take part in this task.

4. *Needs assessment and intervention - Focus Groups*

To aid the collection of rich and deep data, a focus group was also conducted with children, young people, and families exploring potential strategies and preferences for addressing identified needs/challenges. The focus group was held online through Microsoft Teams platform and facilitated by the project lead (HW) and a member of the project team (KW). Discussions were guided by predefined prompts and the group lasted approximately one hour.

Participants

For stage 2 of the scoping approach, a total of 91 participants (73 children, young people and families living with CHD, and 18 staff members) were recruited to the idea generation task. Table 6 demonstrates that most children and families identified as female (n = 47), white (n = 57), with an age range of 5-66 years old.

Table 6. Demographic Information for Children, Young People and Families in Stage 2 of Scoping Project.

	N
Gender	
Male	24
Female	47
Age	
Average	27.78 years (14.82)
Range	5-66 years old

Situation	
Wider Family Member	29
Person Living with CHD	31
Carer	10
Sibling	3
Location	
Sunderland	3
Darlington	9
Northumberland	7
Gateshead	5
South Tyneside	4
Carlisle	7
Newcastle upon Tyne	13
Durham	10
Middlesborough	10
Stockton-On-Tees	3
Out of Area	3
Ethnicity	
White	57
Asian or Asian British	7
Black, Black British, Caribbean or African	3
Other Ethnic Group	3

Table 7 below also indicates that of the 18 staff members who participated, 77% identified as female. A range of professional job roles were recruited and Table 7 indicated that despite most being recruited from the host Trust, there was also representation from the other Trusts within the network.

Table 7. Demographic Information for Staff within Stage 2 of Scoping Project.

	N
Gender	
Male	4
Female	14
Ethnicity	
White	14
Asian or Asian British	3
Other Ethnic Group	1
Job Role	
General Paediatrician with Expertise in Cardiology	1
Nurse	6
Consultant	4
Cardiac Physiologist	2
Social Worker	1
Nursery Nurse/Play Specialist	1
Clinical Psychologist	1
Location	

Newcastle upon Tyne	13
County Durham and Darlington	1
South Tees	2
South Tyneside and Sunderland	1
North Cumbria	1

For stage 3 of the data collection, a total of 20 participants were recruited for the sorting (15 staff members, 5 children and families) and rating (11 children and families, 9 staff members) tasks see Table 8 for demographic details. A total of six participants (adolescents and adults) attended the focus group and approximately 30 (children, staff, families) completed the *'Support Idea Generation Task'*.

Table 8. Demographic Information for Participants in the Sorting and Rating Activities.

	N
Gender	
Male	6
Female	14
Ethnicity	
White	18
Asian or Asian British	1
Other Ethnic Group	1
Recruited From	
Freeman Hospital	20

Participants were recruited through purposive sampling via social media, NENC-CHD Network events, and hospital clinics/wards across the North East and North Cumbria NHS Trusts. Participants were eligible to participate if they were i) a young person living with CHD up to the age of 25 years old; ii) the parent/carer/family member of a young person (up to the age of 25 years old) living with CHD; or iii) a staff member working with young people and families living with CHD.

Data Analysis

Data for the GCM was uploaded onto an online platform called GroupWisdom. This platform helped analyse the raw data through hierarchical cluster analysis to create a concept map. This created a scatterplot with all 69 statements plotted according to how commonly they were sorted into the same piles by our participants (see appendix). Statement numbers which appear close to each other in the scatterplot were more often sorted into the same piles by participants, and statement numbers appearing further from each other were sorted into different piles by participants. These then were grouped by the software into clusters of statements which were most often seen as having similar meanings by participants. The map was then reviewed and refined by the project lead and utilised to generate reports. A Go-Zone (a quadrant-based ratings comparison of statements within a specific cluster, comparing success and importance ratings) and Pattern Match (a side-by-side comparison of ratings based on cluster averages, comparing success and importance ratings) report were also created that highlighted statements that were rated important and unsuccessful within each cluster.

For the focus group, the conversations were transcribed and analysed using thematic analysis following Braun and Clarke (2006) steps. The project lead familiarised themselves with the transcript through reading through this. The project lead then went through the transcript and highlighted key areas and generated initial codes. These codes were categorised then placed under themes that explained large areas of the data.

Results: Needs Assessment and Intervention

The Wellbeing Challenges within CHD in the NENC-CHD Network

The revised list of 69 statements were then placed into piles of similarity by children, families, and staff that helped created a 9-cluster map solution. Figure 3 below demonstrates the 9-cluster diagram that was created to group all the 69 the statements together into categories of similarity following the results from participants.

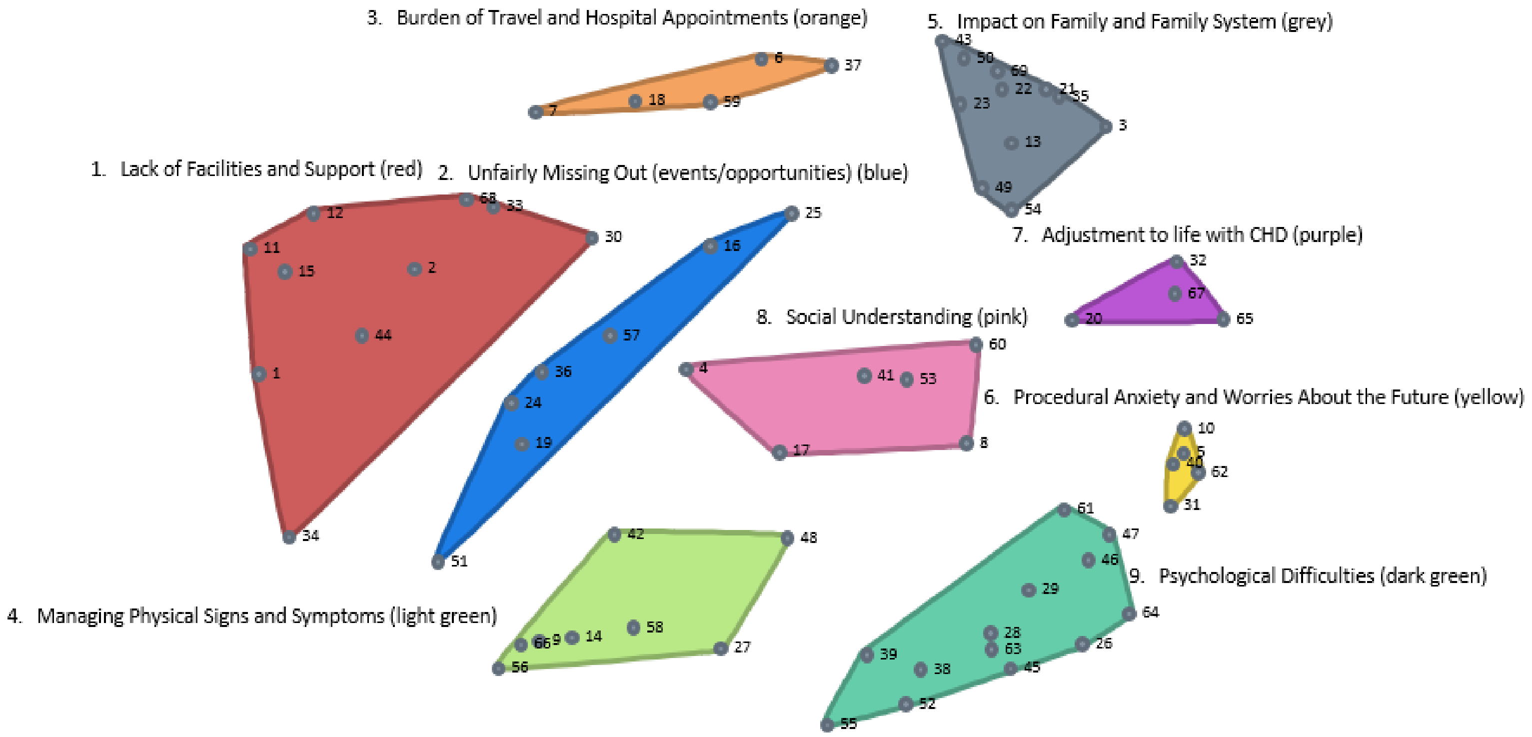


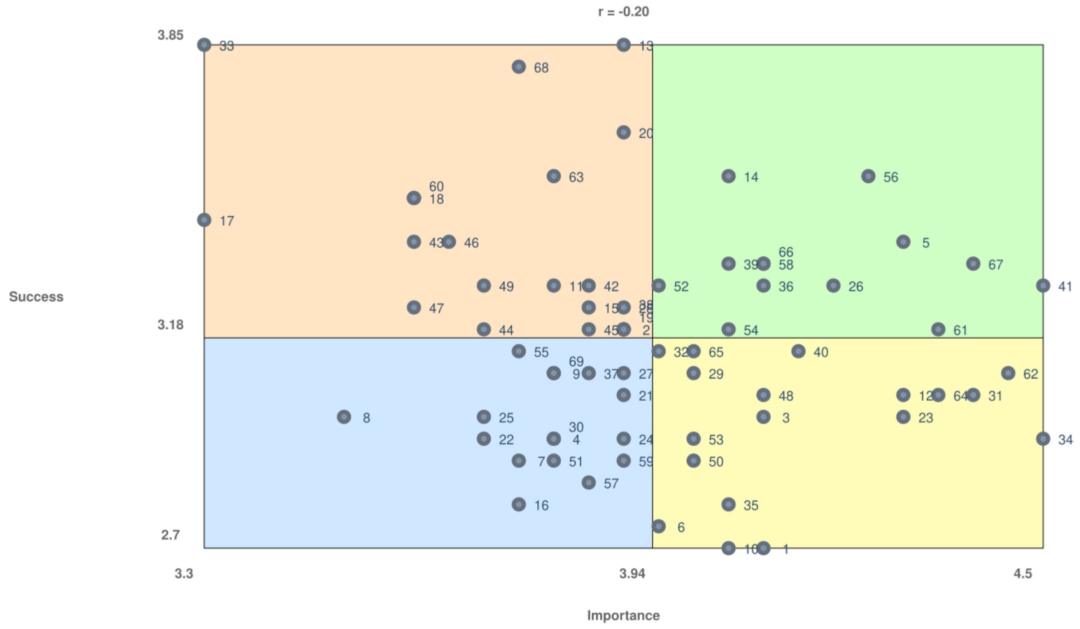
Figure 3. Cluster Map Solution

The clusters were named by key stakeholders in collaboration with the project team. Figure 3 indicates that cluster 6 is the smallest, indicating that most participants placed the statements within this category together during the sorting task. Cluster 1 encompasses more statements that cover a larger surface area, indicating these statements were grouped as similar but less so than those within cluster 6. The clusters will each be defined in turn:

1. **Lack of Facilities and Support**
   These statements were about participants reporting a lack of facilities (i.e., hoists, changing space, access to cardiac imagery machines) and support (i.e., wellbeing support). These statements also included participants indicating a lack of integrated care between health care professionals and challenges in the amount of information shared by professionals to young people and their families.
2. **Unfairly Missing Out (events/opportunities)**
   This cluster includes statements participants generated that suggested children and young people living with CHD miss out on several events/opportunities including at school and participating in sports. Participants indicated that it felt they missed out on these activities unfairly.
3. **Burden of Travel and Hospital Appointments**
   Within this cluster, the statements were about participants travelling far for hospital appointments, missing work/school because of appointments, and the frequency of hospital appointments. The financial impact of missing work was also included.
4. **Managing Physical Signs and Symptoms**
   Statements within this cluster were about participants reporting challenges of managing the physical signs and symptoms of CHD (i.e., breathlessness, difficulties walking, lack of energy). They were also about the worry of interpreting physical signs and symptoms when a child/young person is unwell and being unsure if this was linked to CHD.
5. **Impact on Family and Family Systems**
   Within this cluster, the statements were about the difficulties of having a child living with CHD on the family and family system (i.e., care of siblings, marital relationships, parental role/identity) and child care.
6. **Procedural Anxiety and Worries About the Future**
   Statements generated by participants in this cluster included worries about the future, surgery and managing procedures at hospital.
7. **Adjustment to Life with CHD**
   These statements were about adjusting to a new ‘normal’ when living with CHD, including the reality of this being a lifelong condition.
8. **Social Understanding**
   Participants generated statements within this cluster regarding a lack of understanding from others of their CHD condition. They also reported difficulty in explaining and understanding their own CHD condition and how this could lead to feelings of difference from others.
9. **Psychological Difficulties**
   Statements within this cluster were about the psychological impact of living with CHD and included difficulties such as trauma, anger, stress, shame, and self-consciousness about scars.

There was some overlap between clusters on the map, however this 9-cluster solution appeared to capture the statements clearly. Go-Zone Maps were then generated to understand areas that were rated as important but not successful. Figure 4 shows a Go-Zone Map produced encompassing all clusters. Within the box on the bottom right-hand side there are 18 statements that have been rated as very important and not successful. The box above this one, shows 12 statements that have been rated as very important and successfully supported with.

Figure 4. Go-Zone Map for all Clusters.



This Go-Zone Map was utilised to identify areas that participants rated as high success (feeling successfully supported with the identified challenges by services) and high importance (identifying challenges that feel most important to them) indicating areas the services across the Network were performing well in. It was also used to identify areas of high importance and low success indicating areas that may need improvement. Go-Zone Maps were created for each individual cluster to highlight key areas of importance and success; these will be reported in-turn. All individual Go-Zone Maps can be found in Appendix.

1. **Lack of Facilities and Support**
   Within this cluster, there were no statements that were rated as very important and successful. However, statements 1, 2, 12 and 34 were within the box rated by participants as important but not successful. These included:
   Statement 1: Limited access and long wait times for psychological input.
   Statement 2: Wellbeing support is lacking.
   Statement 12: Lack of joined up care between health care services.
   Statement 34: Children with CHD having additional needs and/or neurodevelopmental disabilities.

2. **Unfairly Missing Out (events/opportunities)**
   Participants rated statements 19 and 36 as high on importance and success. Statements were defined as:
   Statement 19: Children with CHD being unfairly treated at school, for extensive time off or for not being alert enough to attend all sessions throughout the day.
   Statement 36: Education Struggles
   On the other hand, statements 24 and 57 were areas of less success:
   Statement 24: Missing a lot of school impacts children's educational progress, friendships and confidence as they are aware that they are behind their peers.
   Statement 57: Having to miss out on opportunities (e.g. social opportunities/ school trips and residentials).
3. **Burden of Travel and Hospital Appointments**
   Within this cluster one statement was rated as an area of accomplishment by participants (statement 37). This statement related to the financial impact of having a child with CHD:
   Statement 37: Financial impact and burden.
   Areas that require more attention due to ratings of high importance vs low success include statements 6 and 59 within this cluster:
   Statement 6: Regular travel and long trips to hospital.
   Statement 59: Taking time off work to attend hospital appointments.
4. **Managing Physical Signs and Symptoms**
   For this cluster, most statements were rated as high importance and also managed with high success. These included statements:
   Statement 14: Experiencing pain as part of CHD journey (i.e., medical interventions, progression of illness).
   Statement 56: The effects of CHD on other aspects of health.
   Statement 58: Challenges eating.
   Statement 66: Managing physical symptoms of CHD (i.e., breathlessness, difficulties walking)
   One statement was rated as requiring improvement in success:
   Statement 48: Challenging when feeling unwell and worry if it's linked to CHD.
5. **Impact on Family and Family System**
   Within this cluster it was dominated by areas that may require improvement. For example, statements 3, 23, 35, and 50 were rated as high importance and low success:
   Statement 3: Parents facing difficulty during the transition years and learning to first share that responsibility and then hand it over to the young person.
   Statement 23: Parents finding it difficult and upsetting to support child in distress during appointments/treatments.
   Statement 35: Wellbeing of siblings.
   Statement 50: Juggling family life.
   An area of good performance was rated by participants for statement 54.
   Statement 54: Children and families with CHD must do many things that their peers without CHD do not have to do (e.g. attend clinic, take medication, have surgery).

6. **Procedural Anxiety and Worries About the Future**
   Within this cluster, all statements were skewed towards a high importance rating. Two statements were ranked as more successful (5, 62):
   Statement 5: Worries about surgery.
   Statement 62: Worry about the future.
   One statement was rated as requiring improvement (31):
   Statement 31: Anxiety about waiting for surgery plan and date.
7. **Adjustment to Life with CHD**
   Statements were similarly skewed towards high importance within this cluster. There were no statements within the cluster that were rated as high importance and low success. However, there was one statement rated as important and successful (67):
   Statement 67: Learning to accept that the care and treatment for CHD is life long and the reality of needing further intervention and surgery throughout their lives.
8. **Social Understanding**
   Within this cluster, statement 41 was rated by participants as the most important and above average on success:
   Statement 41: Many young people with CHD moving into transition have questions about how it may impact on their adult life (i.e., friendships/relationships, drugs, alcohol, work prospects and future fertility).
   Statements 4 and 53 were within the box that indicates room for improvement:
   Statement 4: Explaining CHD to others.
   Statement 53: Finding it very hard to explain what is wrong with their heart in a way that they and others understand.
9. **Psychological Difficulties**
   There were two statements within this cluster rated by participants as high importance and high success (26 and 39).
   Statement 26: Experiencing trauma symptoms (i.e., flashbacks, daily reminders of negative experiences).
   Statement 39: Feeling different from others.
   There were three statements rated by participants as high importance and low success (29, 61, 64).
   Statement 29: Experiencing stress.
   Statement 61: Hospitals can be scary places for children.
   Statement 64: Experiencing anxiety.

Pattern Match for Cluster Averages

Figure 5 shows a side-by-side comparison of ratings based on cluster averages, comparing success against importance ratings. It demonstrates that the highest average rating cluster for importance was cluster 6: Procedural Anxiety and Worries About the Future. Figure 5 also indicates that Cluster 6 on average was rated the third lowest on success. Cluster 2: Unfairly Missing Out (events/opportunities) was rated on average by participants as the lowest on success, closely followed by Cluster 3: Burden of Travel and Hospital Appointments. Figure

5 suggests that Cluster 7: Adjustment to Life with CHD was rated best on both success and importance by participants.

Figure 5. A Pattern Match Graph of Ratings for Cluster Averages.

Focus Group and Idea Generation

The findings from the Go-Zone Maps and Pattern Match Map informed the focus group prompts to help understand how participants felt about areas that were highlighted within the high importance and low success boxes, and what support they felt they needed to help improve the success scores. These questions were also taken to wards/clinic waiting areas, where individuals waiting could share ideas they had of how/what support they would like to receive for each wellbeing challenge. A total of four themes were identified and will be discussed in-turn and related to clusters where appropriate.

Theme i: Education

Theme i is identified as ‘*Education*’, and this speaks to participants in the focus group and clinic idea generations tasks identifying that the NENC-CHD Network would benefit from developing training and education in different areas. For example, for Cluster 8: Social Understanding, participants reported that providing schools with training and education on what CHD is, and what impact it can have on a child, could help with children feeling more understood, and parents feeling more confident in leaving their child under the care of the school. Some participants acknowledged that they had resorted to home schooling due to the lack of understanding, *"Luckily, I was able to homeschool, X 'Cause, I think school he went to nursery were terrified. I had to go to the nursery. So, it was pointless ... So, I ended up home educating X. So, it was just easier."*. Participants reported that they would like the Network to *"provide more support to teachers so they can better support pupils"* and have *"better information sharing between schools/GP/hospitals"*. One participant also commented that *"school/college should take time to research the condition that they do not understand and putting them in touch with relevant resources (BHF website has useful info)",* indicating that schools/colleges should try and take initiative and be proactive in learning about CHD if there is a child that is attending who is living with it.

Education was also a theme that appeared in regard to participants sharing ideas that may help with Clusters 1, 6, 7 and 9. For example, participant discussed difficulty understanding conversations with medical professionals due to medical jargon and terminology utilised within Clusters 1, 7 and 9. For example, participants shared *"someone who checked-in with patients after clinics/appointments and discussed concerns and simplified "doctor talk" into lay man language"* and *"a booklet to explain medical jargon"* would help improve their wellbeing.

For Cluster 6: Procedural Anxiety, a lot of participants discussed that it would be helpful to *"have a clear plan of what is going to happen"* in regard to a procedure. For example, one participant reported *"but if you prep them [children and families] 2-3 months beforehand... There'll be ...less stress, potentially".* They shared that often plans are changing and are not concrete when it comes to surgery as they may experience several cancellations. Frequent changes to a plan when trying to manage procedural anxiety can be traumatic for individuals and this may lead to negative implications for recovery (i.e., heightened anxiety impacts the body and the mind and can delay rates of recovery). Providing education and training to medical professionals on how to manage procedural anxiety could help these experiences for children and families across the Network.

Theme ii: Empowerment and Person-Centred Care

Theme ii is understood as children and families wishing to feel empowered on their CHD journey (i.e., throughout the service and as they transition into adult teams). Participants acknowledged that person-centred care comes hand-in-hand with this. For example, for Cluster 5: Impact on the Family and Cluster 7: Adjustment to Life with CHD, participants commented on wanting to promote a positive narrative of living with CHD, particularly when transitioning from paediatric to adult services. They shared *"it's just it's almost made out of being negative, the transition thing, but actually it's a good thing. It's actually your next part of life."* Participants acknowledge that there could be more put in place to promote a more positive narrative of transition that would help young people and families feel better about the process. Other participants commented on this in regard to living with CHD more generally and shared *"empowering the young person"* and *"strength-based interactions"* would support wellbeing.

This was something participants discussed as a result of feeling unable to ask questions and share how they were feeling with professionals during clinic and hospital visits. Communication aids for children, young people and families to utilise when in clinic/hospital that empowers them to think, share, and ask questions and queries they have, as supported by the team, may be of benefit.

Participants in the focus group and in clinics/wards also reported that it would be helpful to have more resources they could utilise to help them with specific wellbeing challenges. For example, when supporting children with additional needs, *"hand massages*", "*fidget toys", and "calm-down kits*", were reported to be helpful. Other participants also discussed how having a *"book to read and understand my feelings"*, *"more information leaflets", "booklet about my heart just for me"*, *"comics that might explain what is wrong with my heart"*, and *"videos/animations that explained my heart condition"*, would also help support individuals in managing wellbeing challenges identified.

They also acknowledge that having therapeutic groups for adults and children would be beneficial in helping improve wellbeing challenges. Participants shared that *"more psychological support to help with procedural anxiety, 1:1 or group. Perhaps even materials and workbooks for kids and parents*" and groups for parents managing children with additional needs. They also highlighted the benefit of peer support and suggested that it should be embedded more to help improve wellbeing. For example, *"monthly 'older kid' meet-up so kids can support each other"*, *"an online chat group that could help for peace of mind for people experiencing same/similar things",* and *"while waiting - group therapy. A place for people to share their difficulties, challenges, and diagnosed issues to connect with others who share them".*

Theme iii: A Point of Contact Within the Team

Theme iii, is understood as children, young people, and families indicating that they would like more regular and frequent contact with the team. Participants within the focus group and in clinics, acknowledged that it would feel helpful if there was a person who they could go to as a point of contact, who may be able to provide reassurance, advice, and ad hoc check-ins. For example, participants reported *"somebody available to parents for them to ask questions - face to face not an online forum"*, *"someone to call 24/7 to get advice", and "emotional check-ins for parents".* This highlights that parents would find it helpful to have someone readily available within the team that they could speak to, and for this to be more personal in a face-to-face style.

Theme iv: Adapting Facilities

The final theme was named *'Adapting Facilities'* and is understood as participants indicating that the facilities and services across the Network would benefit children and families with CHD, if they were adapted appropriately to their needs. For example, participants spoke about the clinics spaces across the region contributing to psychological and physiological stress responses being exacerbated. In response to this, participants discussed that they would like *“virtual appointments where appropriate”,* “*weekend appointments*”, and changes to the waiting spaces to accommodate more people.

Other participants discussed the added challenges of coming to hospital appointments when they or their child has neurodevelopmental disability (i.e., Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder). They reported that offering *“quiet appointment times”* and having *“more quiet spaces available”* could help children that are neurodivergent. Alongside this, they reported that having *“visual timetable of activities”* of what the child will have to undergo, could be helpful in preparation for their appointment. Participants also reported that having *“fidget toys and activities”* for neurodivergent children in hospital would be of benefit to improving their experiences and wellbeing.

Alongside these difficulties, participants discussed Cluster 3: Burden of Travel and Hospital Appointments and shared *“being seen closer to home”, “more notice given for appointments”, “more parking spaces and free parking”, “appointment letters sent in advance to avoid unauthorised absences”,* and *“weekend appointments”* as responses for how they wish the service would help them with the challenges that present within Cluster 3. As well as this, participants reported on how the current facilities available within the Network when they are attending clinic for appointments contributes to them experiencing heightened anxiety. For example, one individual commented *“there are no seats, long appointment times and this impacts stress and anxiety experienced”.*

Adapting Facilities was also a key theme for Cluster 5: Impact on the Family in regard to the transition from paediatric to adult services. Participants reported how difficult this transition was for the child and the family, for instance one parent commented on the changes to the rules on wards when moving to adult services and how this change felt particularly difficult, “*I'm gonna be stressed to hell if they tell me I can go and sit from 1:00 till 2:00 and 6:00 till 7:00 and that's all I can see of her.”.* In response to this, participants reported *“flexibility”* from the hospital during transition would help improve their wellbeing. They also reported that it would be helpful to see the facilities/ward before going there. Participants suggested ‘*video tours of the adult wards with a paediatric member of staff showing a child around whilst asking questions’* would be helpful. They also reported that “*if the child nurse introduced the adult equivalent at the end”* it would help children and families feel less anxious by seeing a familiar face.

As part of this theme, participants also acknowledged wishing to integrate more technology into interventions offered by the department. For example, individuals were wondering if there could be technology integrated into therapy when working with children on procedural anxiety. Participants shared *“my child is very afraid of needles – could you use VR to help with anxiety and new phobias”.*

Discussion

This scoping project first aimed to identify what wellbeing challenges children, young people, and families experienced when living with CHD across the North East and North Cumbria, and then secondly, aimed to determine the support individuals wished to receive from services to help with these specific challenges. For the first aim, a thorough scoping approach was implemented which led to the identification of 9 key wellbeing challenges: i) lack of facilities and support; ii) unfairly missing out (events/opportunities); iii) burden of travel and hospital appointments; iv) managing physical signs and symptoms; v) impact on family and family systems; vi) procedural anxiety and worries about the future; vii) adjustment to life with CHD; viii) social understanding; and ix) psychological difficulties. Further group concept mapping methodology revealed areas of high importance and low success within each of the nine-wellbeing challenges. These results are consistent with previous findings that found children and young people living with CHD are at risk of a range of long-term physical, neurodevelopmental, and psychosocial sequalae (Marelli et al., 2016; Marino et al., 2016; Sood et al., 2024; Simko & McGinnis, 2003; Ryan et al., 2019; Majnemer et al., 2006).

For the second aim, a focus group and idea generation task were implemented to explore how individuals would like support from services across the Network. A total of four themes were identified: i) education; ii) empowerment and person-centred care; iii) a point of contact within the team; and iv) adapting facilities. Specific ideas and thoughts were generated by participants of how they wished services were set up to support them across the Network and this led into a formal list of recommendations being created (Please see list on page 36 below).

Barriers and Gaps in Care

It is important to note that the data presented highlighted key barriers and gaps to care. One of the main barriers to promoting and providing psychological care is the lack of resource of psychological provision across the Network as highlighted in section *'Information Gathering and Relationship Building'*. As previously described, the below minimum level of psychology provision across the network leads to gaps in what can be offered by psychology directly to families and indirectly to healthcare teams to support psychological wellbeing, long waits for care, lack of psychology care to transition to, and inequity in access across the region. In addition to the gaps in psychology provision, other services and professional groups that offer psychosocial support are very limited e.g. family hub complex care coordinators, play-based support, and other support worker roles.

Another barrier to promoting good psychological care across the Network is resource limitation (i.e., the way that clinics are set up, their seating areas, and local facilities). Although this is not a direct problem that can be solved immediately, if there are hospital expansion plans or refurbishments, this data can help inform decision making and planning to accommodate the ideas and challenges children, young people and families have shared.

Finally, it is very important to note that a lack of funding in healthcare is a barrier to developing and providing services, resources, facilities and psychologically informed care for CHD across the Network.

In order to address these gaps and improve the wellbeing support offered to children, young people, and families, a list of proposed recommendations was co-developed alongside two models of care.

Model 1: Creating a Psychologically Informed Network

Figure 6. Creating a Psychologically Informed Network Around a Child Living With CHD.

As more people with CHD survive into adulthood, there is an increasing need to prioritise wellbeing and psychosocial care (Kovacs et al., 2022; Oster et al., 2013). To support this within the NENC-CHD Network, staff must feel equipped to address wellbeing challenges, making it essential that the wider system around the child is psychologically informed.

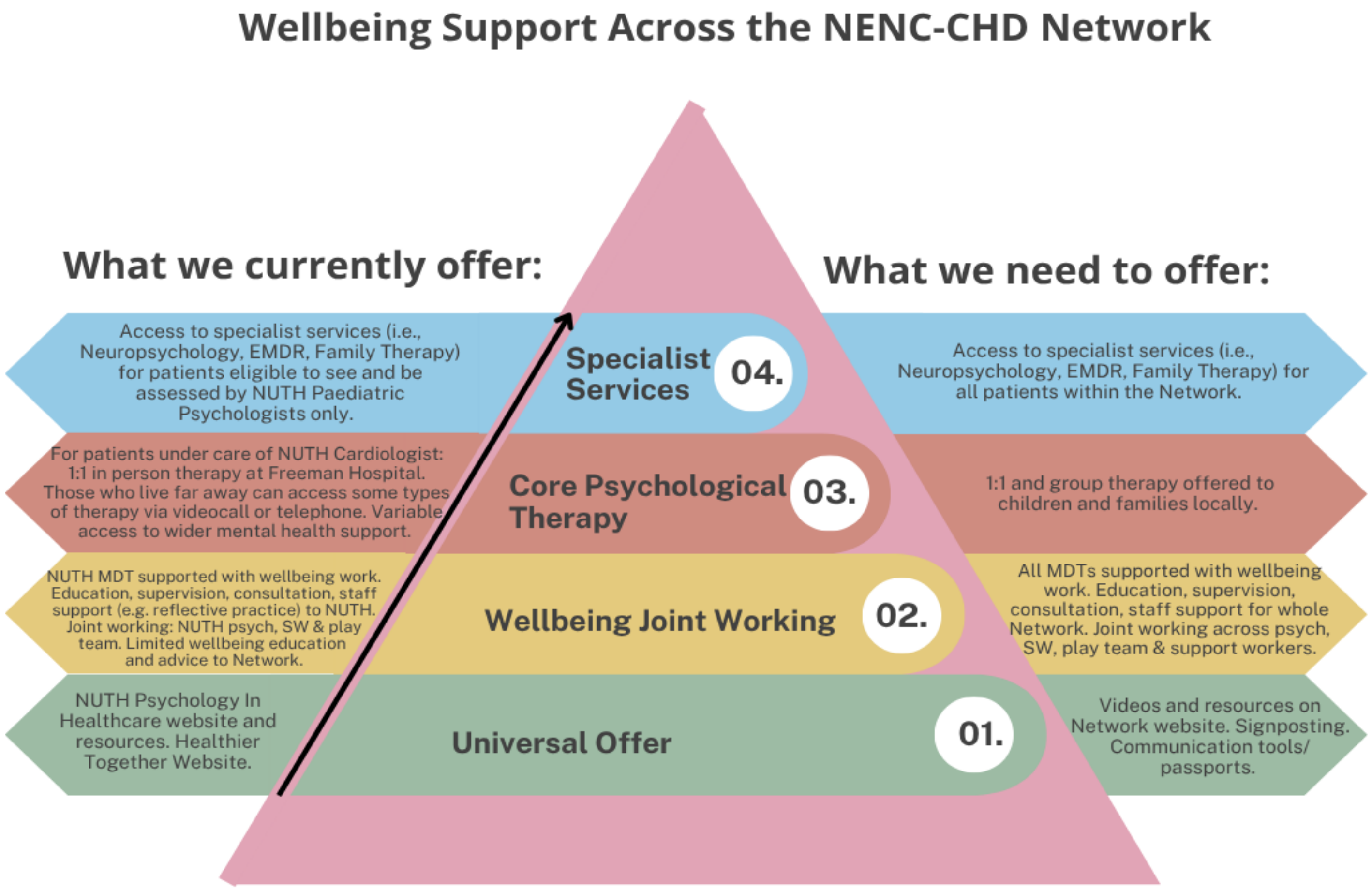
Figure 6 outlines a proposed pyramid model to achieve this. At its base, staff and key stakeholders across the Network are trained to be psychologically aware. The foundation step includes education and training to support informed-decision making – for example, around clinic environments and appointment planning.

The next level focuses on psychologically supporting staff teams themselves. Staff must feel safe, supported, and heard, to perform well. This is fostered through supervision, reflective practice, debriefing sessions, and cultivating a compassionate team culture.

Above this is the identification and assessment of wellbeing challenges in children, young people, and families. Tools and guidance will be provided to help staff communicate, refer, and signpost appropriately. This aligns with the tiered psychological care model shown in Figure 7 (the second model created which illustrates the proposed and current psychological care tiers, highlighting existing provision and areas for growth to ensure equitable support across the Network).

At the top of the pyramid is the extension of wellbeing support into the community and better integration of inpatient and outpatient care. This includes training for community groups and families.

Model 2: Psychological Tier Support Model



Access to specialist services (i.e., Neuropsychology, EMDR, Family Therapy) for patients eligible to see and be assessed by NUTH Paediatric Psychologists only.

Access to specialist services (i.e., Neuropsychology, EMDR, Family Therapy) for all patients within the Network.

For patients under care of NUTH Cardiologist: 1:1 in person therapy at Freeman Hospital. Those who live far away can access some types of therapy via videocall or telephone. Variable access to wider mental health support.

1:1 and group therapy offered to children and families locally.

NUTH MDT supported with wellbeing work. Education, supervision, consultation, staff support (e.g. reflective practice) to NUTH. Joint working: NUTH psych, SW & play team. Limited wellbeing education and advice to Network.

All MDTs supported with wellbeing work. Education, supervision, consultation, staff support for whole Network. Joint working across psych, SW, play team & support workers.

NUTH Psychology In Healthcare website and resources. Healthier Together Website.

Videos and resources on Network website. Signposting. Communication tools/ passports.

Figure 7. Tiered System to Psychological Provision.

Recommendations

Recommendations for Improving Psychosocial Care Across the North East and North Cumbria

Presented below is a list of recommendations following data collection and analysis with children, young people, families, and staff members across the Network to support individuals with the 9 clusters of identified wellbeing challenges. Please note that in many areas covered in the recommendations there has been some work done already by the Network team, hospital MDTs, and NHS trusts which can be built upon. The list below highlights who seems best placed to be responsible for driving and implementing the recommendations proposed. *(It is important to note that a large number of these developments require leadership and* *coordination by the small Network team who already hold a vast remit for service development. Therefore, these recommendations will need to be considered by the network team and a strategy developed for working on the recommendations that will have the greatest and swiftest impact).*

Psychology in Healthcare Psychology Team:

- To use the remaining CHUF project funding over the next 6 months to offer guidance to the Network in beginning to implement recommendations and support the development of key coproduced resources and education.
- To share information across the Network about a tiered model of psychological informed care. To also provide information for families to support their understanding of the tiered model and how they can access different types of support (please see Figure 7).
- To review the current use of limited psychological resources and staffing and consider whether there are opportunities to improve responsiveness, accessibility, and equity. Examples of changes that could be considered are calls to families prior to them waiting to be seen to offer immediate advice and resources, considering options for shorter but sooner care offers for certain difficulties.
- To highlight the risks associated with under-resourcing psychology at the Level 1 centre and advise that this should be included in the risk register for the cardiothoracic directorate.
- To continue to identify opportunities for securing funding for gaps in provision (e.g. transition and adult CHD psychology, pre-birth psychological care, sibling support, non-CHD cardiac care), and to bring resourcing in line with NHS England service specification and the national picture for psychology provision.
- To think about the use and implementation of group therapy, including exploring the possibility of a specific group for procedural anxiety.
- To think about possibilities for the use of technology within interventions offered (i.e., VR for procedural anxiety) and explore funding opportunities to enable this.

NENC Network Team:

Education:

- To offer staff within school's education on CHD for developing awareness. Look at how to access schools and the possibility of CHD being discussed in schools during assembly. Education to remove the stereotype that heart conditions are something you get 'when old' within schools.
- To offer parent group education. Provide parent education session on: a) supporting my child with neurodiversity and additional needs whilst living with CHD; and b) supporting my child with anxiety (and the link to experiencing physical symptoms).
- To offer professionals' education on: a) neurodiversity and anxiety when coming to hospital; b) procedural anxiety (including how to implement the procedural anxiety workbook); c) talking about wellbeing challenges; and d) the impact of trauma (including the trauma associated with surgery processes and delays).

To develop co-produced information and resources:

- Resources on *'coming to clinic'* and *'coming to the ward',* including to support those patients with additional needs (network wide).
- A communication tool to empower children, young people and families to communicate in clinic appointments (ask questions and talk about things that are important to them).
- A tool/s for families to complete to share important information about their child with healthcare teams when they attend hospital e.g. Hospital Passport/ All About Me book (templates available for whole Network). To draw on resources that have already been created by families within this area (incl. 'Tommys Stars Passport').
- Online booklet on understanding and managing wellbeing challenges.
- Peer support stories shared through developing videos with a focus on promoting living well with CHD and how individuals overcame wellbeing challenges.
- Facilitated peer support groups for parents and for children and young people.
- Peer support videos on preparing for surgeries and procedures, including what has helped and how they have managed, in order to help support others. These are to be aimed at parents and children/young people.
- A transition guide for the move into adult services (applicable to whole Network). As part of this explore developing videos of children/families who have gone through the transition process and them sharing their accounts of what helped with transition. To develop videos tours of adult clinic spaces across the region to help with the transition process. Explore the possibility of the videos including a young person asking a familiar paediatric nurse/ doctor questions and being met by the adult team.
- A Network wide transition event for families and young people to share information, to support conversations, and contribute to service development.
- After reviewing existing materials available, sharing or developing booklets/comics/videos for young people that explains their heart condition.
- A template information sheet that can be placed in clinics across the Network that included information about key professionals and how to contact for advice or support. To think about presenting this in different ways (i.e., paper, QR codes, website).
- An accessible App for children and families to use with all the information and resources available. Apps are available for offering support to families with other long-term conditions, so this could be a future development for consideration by the National CHD network.

Website development:

- Resources on procedural anxiety including videos of coming to hospital to have a CT scan/MRI scan.
- Information on what CHD is and what is involved when coming to clinic.
- Transition area on website providing education to children and parents across the Network. For this to include FAQ's and signposting to who to contact if need more information or have further questions.
- Neurodevelopmental conditions area to support and signposting for adults and children.
- Information to support families and young people with medical jargon

- A FAQ area for parents/carers and children.
- Information for families to support travel to hospital for appointments (i.e., options for parking, claiming back costs of travel).
- A page on network website that would be maintained by network with up-to-date information on sources of support as shown in Figure 2.

Other areas:

- To identify whether opportunities exist for funding before writing a case of need for a Network Psychologist, with support from NUTH Psychologists.
- To support locality clinical leads with highlighting the gaps in health psychology provision for patients in their area, linking with local health psychology teams to establish the provision that would be required to meet this need, and recording risk of harm associated with lack of provision on risk registers.
- To support locality clinical leads with highlighting the gaps in play-based support provision for patients in their area (inpatient and outpatients), linking with local play specialists/nursery nurses to establish the provision that would be required to meet this need, and recording risk of harm associated with lack of provision on risk registers.
- To explore the possibility of funding for community support worker roles across the Network (i.e., youth worker, peer support worker, family support worker).
- Given that the role of social work has changed, and the provision offered to families across the region has significantly reduced just recently, to explore the new role of Family Hub Complex Coordinators, and support any potential gaps across the region in provision for children, young people, and families.
- To link with cardiac nurse specialists on exploring the scope and limits of their role and exploring support roles for advice that may be helpful.
- To explore the possibility of a support line for patients (point of contact to signpost and support non-clinical questions) and whether this could be supported by charity funding/hosted within a charity.
- To ensure that information about where and how to access clinical and non-clinical information and support is made easily accessible for children, young people and families.
- Using a tiered model to further develop psychologically informed care across the network (see Figure 7). A network psychologist is needed to fully realise these plans, and additional staffing across the network to give more equity of access across hospitals and increase support in communities. There are steps that can be taken even prior to further investment though to improve the offer to families across the region.
- Consider in discussion with whole Network how we can support children and families with shared care and those involved with multiple teams. This should include what information children and families would want to share across teams and with others and empowering them to share information/ letters themselves with schools. This may also involve drawing on resources that have already been created by children and families such as, ‘Tommys Stars Passport’.

- Discussion across hospitals about how we can share information with schools about wellbeing needs of children with CHD, including considering the potential for using school health care plans for highlighting emotional wellbeing needs alongside physical health needs.
- To continue to promote events for children and families as hosted by the Network, including events to meet others as well as events to learn (i.e., CPR training).
- To promote best practice guidance (e.g. NICE quality standard: Transition from children's to adults' services, 2024) for transitional care to hospital teams and offer support and advice on implementing this.
- To continue to support seeking feedback of experiences of services from children and families across the Network. To explore how to capture this in a meaningful way across the Network and communicate back to children and families what actions have followed in response to feedback.
- To link with National CHD Network to identify whether we can work jointly across regions on any of these needs or share resources.
- To consider as a whole Network how NHS provision across the Network, that has been focused predominantly around inpatient care and hospital visits, could turn its focus more to support patients and family's wellbeing needs out of hospital. This would include considering where we can provide support closer to home.
- The project team to feedback the list of recommendations to children, young people, and families across the Network to gather their views and ideas. Thinking creatively about how to do this to encourage a large audience.
- To create a subgroup within the Networks PPPG (parent and patient participation group) for wellbeing. This group of people will be involved in going through all of the recommendations in co-development and collaboration on tasks.

Level 1 & 3 Hospitals:

- Discussion about how patients can contact healthcare teams for advice, considering scope and limits of cardiac liaison nurses' role (led by cardiac liaison nurses) and whether support worker roles could be helpful? (increasing accessibility to advice).
- Lead clinician to seek advice from EDI Teams about improving accessibility of care. To ensure that we are asking patients and parents about accessibility needs when they first come into service (i.e., additional needs/communication adaptations /neurodiversity).
- Consideration by outpatient clinic teams about how families may need to use clinic space flexibility due to neurodiversity and anxiety/trauma (e.g., separate waiting space and/or buzzer call back to return to clinic system).
- As a whole MDT to consider the possibility of wider appointment times for hospital appointments (i.e., evening and weekend appointments).
- Responsibility of the MDT to share website/resources to the children and families in their locality once launched.

- To address any issues with appointment letters to ensure that appointment letters are sent to children and families in advance to allow them to give notice and take time off work/school.
- To explore whether there are opportunities to provide MDT care and support to families closer to home.
- Clinical leads to review best practice advice for transitional care (e.g. NICE quality standard: Transition from children's to adults' services, 2024) and identify areas for service improvement. The network team can be contacted for advice and support with this.
- Identifying any gaps in availability of play-based support and associated roles (e.g., clown doctors) and the additional provision required to meet the needs of patients. Explore whether there are opportunities for funding. Informing the Network of any inequity across the region.
- Clinical leads to highlight the gap in psychology provision for patients in their area and link with local health psychology teams to establish the provision that would be required to meet this need.
- It is acknowledged that the current financial climate in the NHS and changes to NHS structures make it challenging to identify sources of funding. If no opportunities exist for pursuing funding at this time, clinical leads should record this on clinical risk registers detailing the risk of emotional and physical harm to patients. Please ask the network team if you require advice with this.

Charities (including CHUF):

- To consider financially supporting the production of emotional wellbeing resources, patient videos, and education packages that will be developed by the Network.
- To consider supporting additional wellbeing activities (e.g., complementary therapies, yoga, hand massages, calm down kits) for patients and carers across the Network. Some of these would be appropriate for an inpatient setting and others for in the community.
- To support children with feelings of anxiety when in hospital/clinic by providing fidget toys and distracting activities (i.e., drawing, colouring that is age appropriate).
- To explore the possibility, in partnership with NHS health teams, of a non-clinical support line for patients (point of contact to signpost and support questions). Consider if this could be supported by charity funding or hosted within charity.
- To explore the possibilities, in partnership with NHS health teams, of how charity funding could be used to extend or enhance psychosocial care provision in a "joined up" way with core NHS psychology and support services.

Healthcare teams: the network team and partner charities are working already to try to overcome some of the challenges identified. We hope that these recommendations support the whole system as a guide in your efforts for where to focus energies in order to make changes that patients and families tell us will make a difference.

Strengths and Opportunities

During the course of conducting this scoping project strengths and opportunities have shone out that should be highlighted alongside the gaps and barriers that have been previously highlighted.

There is great willingness from healthcare teams across the region to support the psychological wellbeing of patients and families that they care for. Professionals have spoken with passion about how important it is to support psychological wellbeing in providing physical health care, both in terms of improving physical health outcomes and improving quality of life. There is also recognition that this makes economic sense for the NHS due to reduction in costs elsewhere.

The NENC-CHD Network team have long championed support for psychological wellbeing for children, young people and families. They lead with good practice in how co-collaboration transforms improvement projects and leads to more meaningful outcomes and outputs for families. Their leadership will be instrumental in supporting the whole network to take the next steps with acting on recommendations.

The children and young people living with CHD and their families have given their time and ideas generously to this project. This shows their enthusiasm for helping to shape services that they need, and their optimism, in the face of the barriers and economic challenges, that we can make a difference. We have a huge opportunity to work in partnership as health teams, and as a Network, with families as we look to make changes that will support good psychological health in CHD across the region.

Conclusion

This scoping report has identified what the wellbeing challenges are for children, young people, and families living with CHD across the NENC-CHD Network. As part of this, gaps and barriers to care were identified and compared against national service specifications. It appears that there are strengths and opportunities within the Network to support the wellbeing of children, young people, and families. The scoping project also provided a list of specific recommendations of how to support these challenges as identified by the children, families and staff members. These recommendations provide the Network with the opportunity to move from challenges to change when supporting wellbeing.

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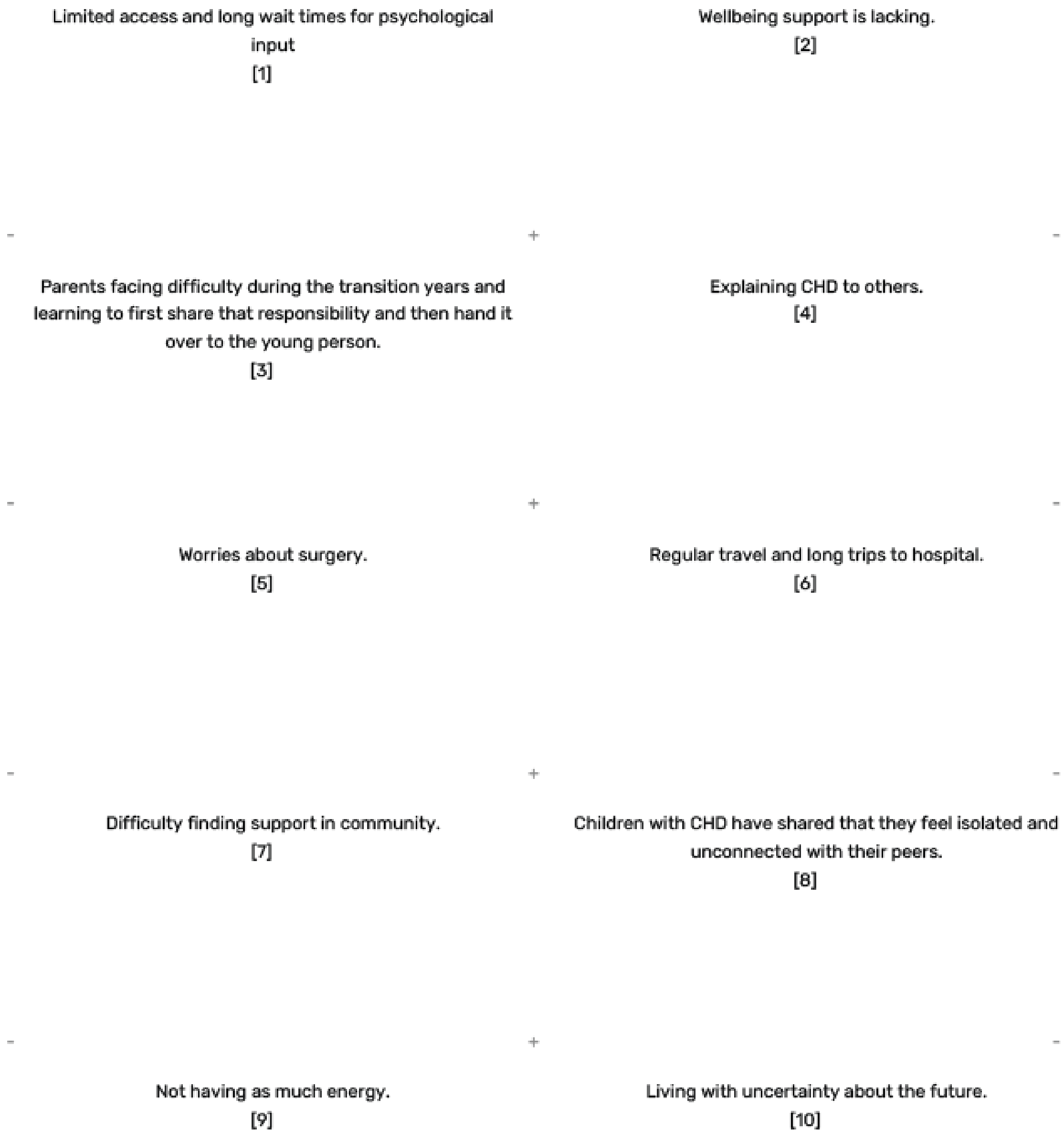
Appendix

Appendix A: Sorting Cards



Limited access and long wait times for psychological input
[1]

Wellbeing support is lacking.
[2]

Parents facing difficulty during the transition years and learning to first share that responsibility and then hand it over to the young person.
[3]

Explaining CHD to others.
[4]

Worries about surgery.
[5]

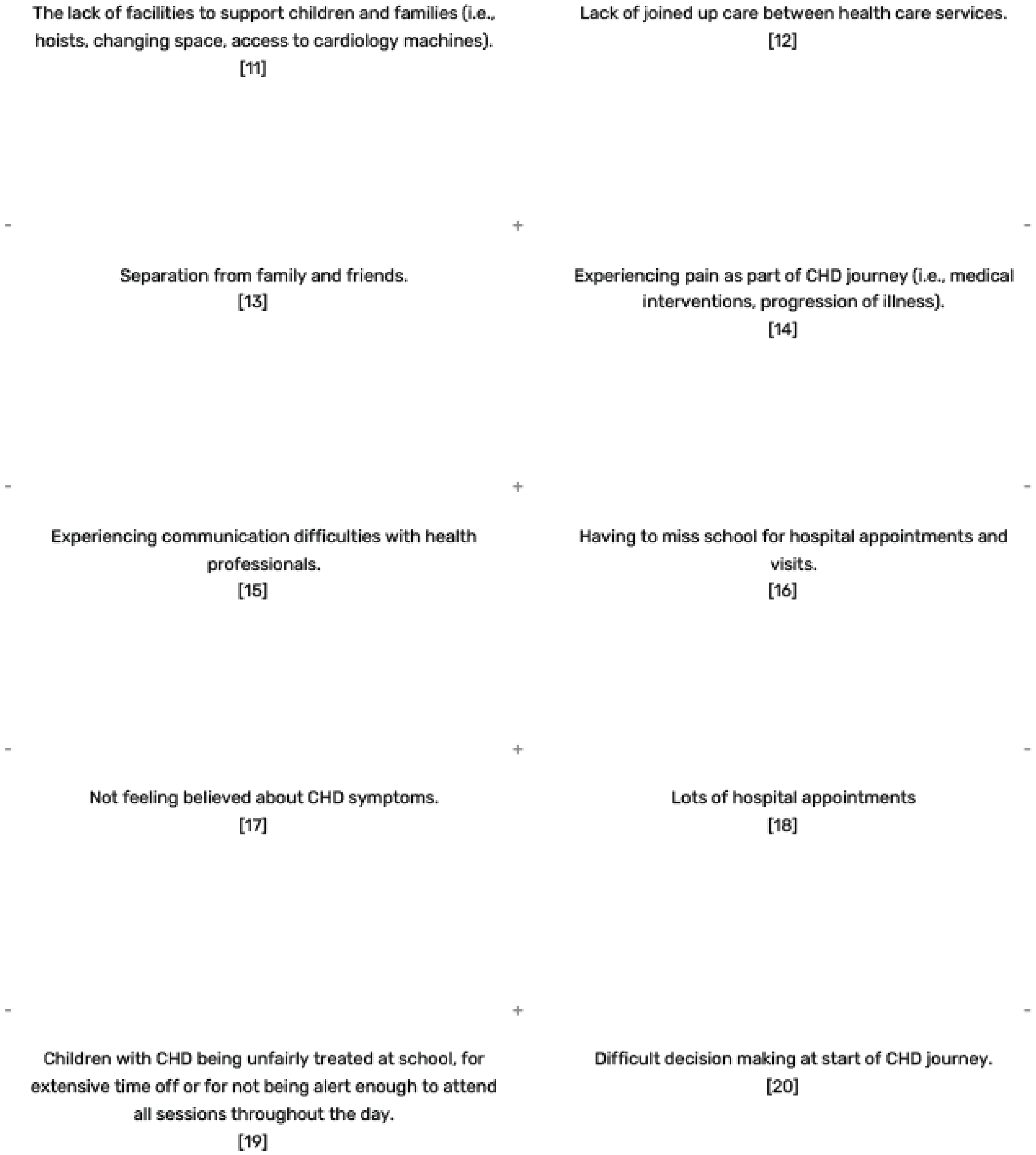
Regular travel and long trips to hospital.
[6]

Difficulty finding support in community.
[7]

Children with CHD have shared that they feel isolated and unconnected with their peers.
[8]

Not having as much energy.
[9]

Living with uncertainty about the future.
[10]



The lack of facilities to support children and families (i.e., hoists, changing space, access to cardiology machines).
[11]

Lack of joined up care between health care services.
[12]

\- + -

Separation from family and friends.
[13]

Experiencing pain as part of CHD journey (i.e., medical interventions, progression of illness).
[14]

\- + -

Experiencing communication difficulties with health professionals.
[15]

Having to miss school for hospital appointments and visits.
[16]

\- + -

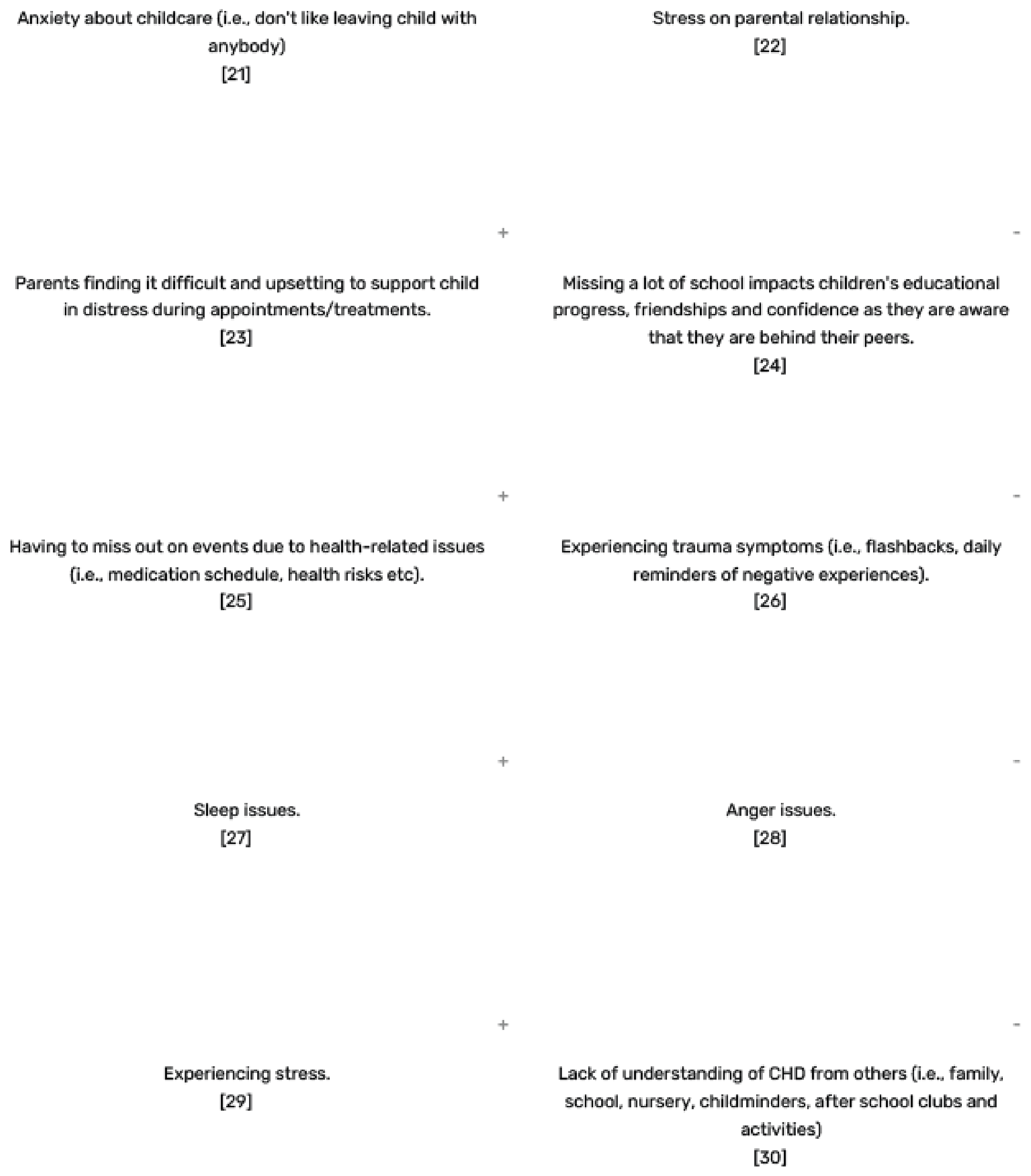
Not feeling believed about CHD symptoms.
[17]

Lots of hospital appointments
[18]

\- + -

Children with CHD being unfairly treated at school, for extensive time off or for not being alert enough to attend all sessions throughout the day.
[19]

Difficult decision making at start of CHD journey.
[20]



Anxiety about childcare (i.e., don't like leaving child with anybody)
[21]

Stress on parental relationship.
[22]

+

Parents finding it difficult and upsetting to support child in distress during appointments/treatments.
[23]

-

Missing a lot of school impacts children's educational progress, friendships and confidence as they are aware that they are behind their peers.
[24]

+

Having to miss out on events due to health-related issues (i.e., medication schedule, health risks etc).
[25]

-

Experiencing trauma symptoms (i.e., flashbacks, daily reminders of negative experiences).
[26]

+

Sleep issues.
[27]

-

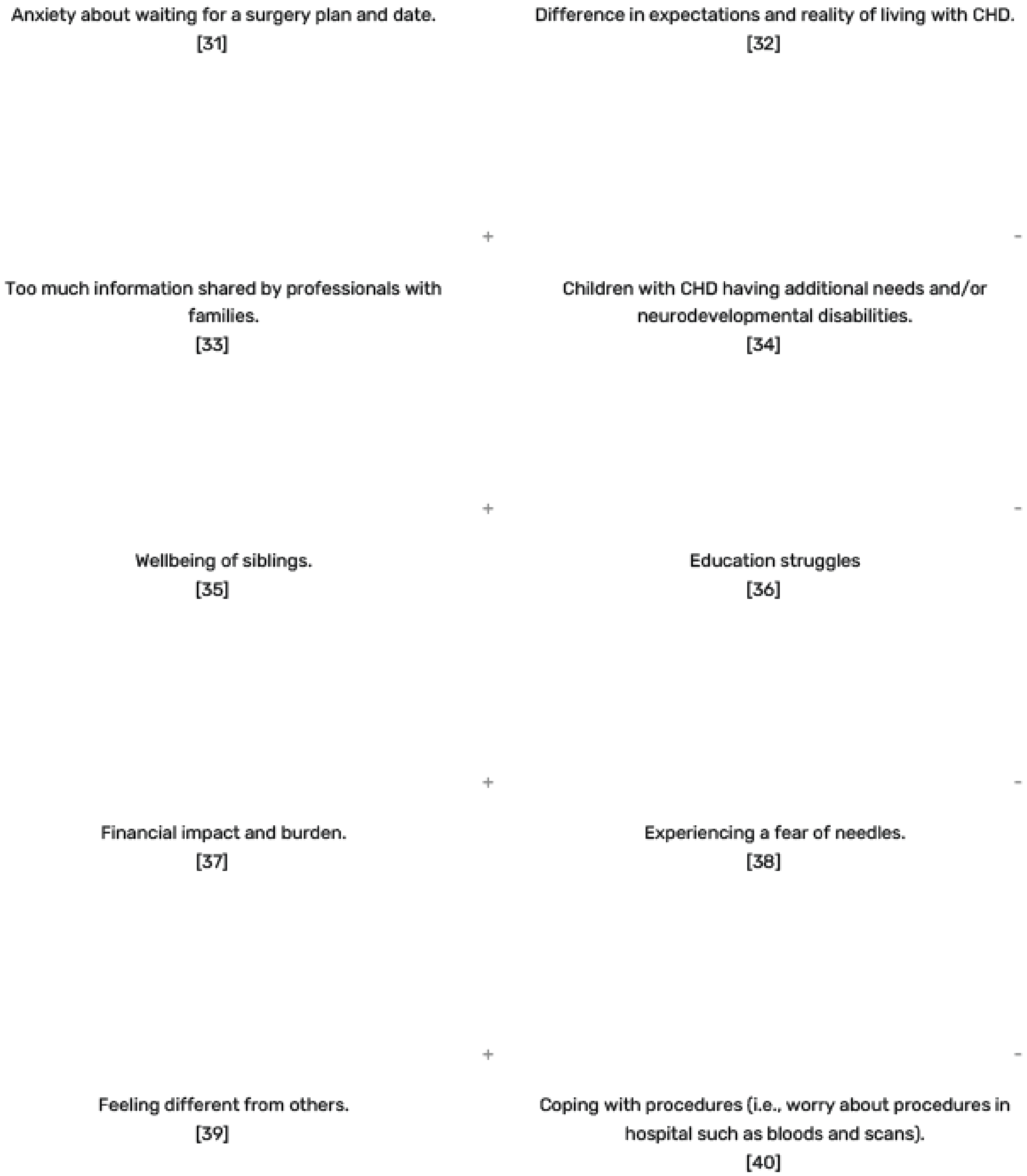
Anger issues.
[28]

+

Experiencing stress.
[29]

-

Lack of understanding of CHD from others (i.e., family, school, nursery, childminders, after school clubs and activities)
[30]



Anxiety about waiting for a surgery plan and date.
[31]

Difference in expectations and reality of living with CHD.
[32]

Too much information shared by professionals with families.
[33]

Children with CHD having additional needs and/or neurodevelopmental disabilities.
[34]

Wellbeing of siblings.
[35]

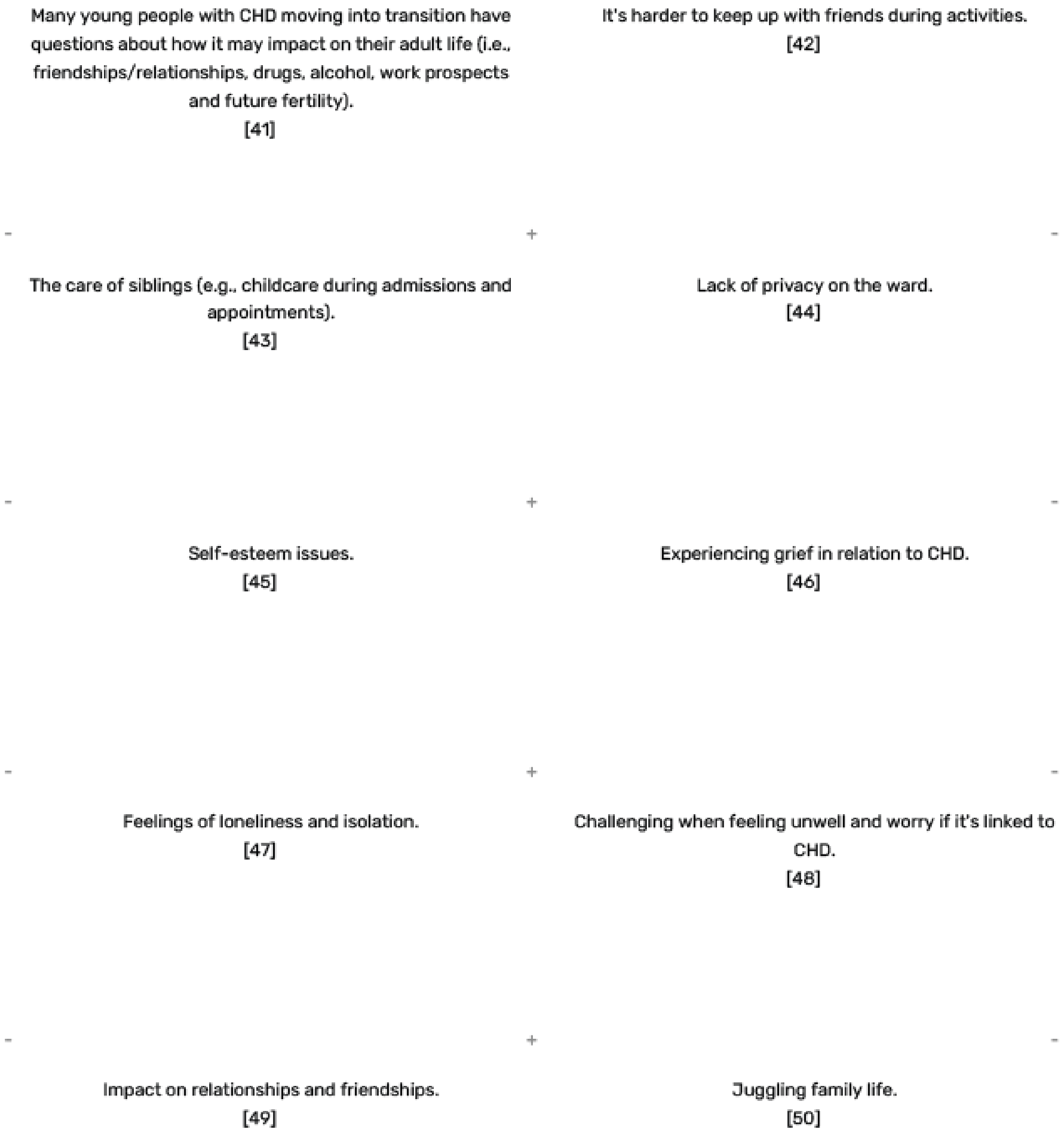
Education struggles
[36]

Financial impact and burden.
[37]

Experiencing a fear of needles.
[38]

Feeling different from others.
[39]

Coping with procedures (i.e., worry about procedures in hospital such as bloods and scans).
[40]



Many young people with CHD moving into transition have questions about how it may impact on their adult life (i.e., friendships/relationships, drugs, alcohol, work prospects and future fertility).
[41]

It's harder to keep up with friends during activities.
[42]

The care of siblings (e.g., childcare during admissions and appointments).
[43]

Lack of privacy on the ward.
[44]

Self-esteem issues.
[45]

Experiencing grief in relation to CHD.
[46]

Feelings of loneliness and isolation.
[47]

Challenging when feeling unwell and worry if it's linked to CHD.
[48]

Impact on relationships and friendships.
[49]

Juggling family life.
[50]

Limitations on physical activity, missing out on sports and PE.
[51]

Body image issues.
[52]

Finding it very hard to explain to what is wrong with their heart in a way that they and others understand.
[53]

Children and families with CHD must do many things that their peers without CHD do not have to do (e.g. attend clinic, take medication, have surgery).
[54]

Being embarrassed about scar/not wanting anyone to see the scar
[55]

The effects of CHD on other aspects of health.
[56]

Having to miss out on opportunities (e.g. social opportunities/ school trips and residentials).
[57]

Challenges eating.
[58]

Taking time off work to attend hospital appointments.
[59]

Finding it difficult to understand CHD conditions.
[60]

Hospitals can be scary places for children.
[61]

Worry about the future.
[62]

\- +
\-

Feelings of shame around your illness.
[63]

Experiencing anxiety.
[64]

\- +
\-

Trying to adjust to a 'new' normal
[65]

Managing physical symptoms of CHD (i.e., breathlessness, difficulties walking)
[66]

\- +
\-

Learning to accept that the care and treatment for CHD is life long and the reality of needing further intervention and surgery throughout their lives.
[67]

Too little information shared by professionals with families.
[68]

\- +
\-

Parents may struggle with change in their own identity (i.e., challenges of integrating roles of parent, carer, worker, and individual).
[69]

Appendix B: Rating Sheets

Wellbeing Challenges in CHD: Scoping Report

How successfully do you think these issues are being met?

On a scale of 1 to 5 Please mark the circle that best describes how successfully each statement is currently being met

Example

Please mark your answer with an "X".

1. Limited access and long wait times for psychological input

1	2	3	4	5
○	○	⊗	○	○

1. Limited access and long wait times for psychological input

1	2	3	4	5
○	○	○	○	○

2. Wellbeing support is lacking.

1	2	3	4	5
○	○	○	○	○

3. Parents facing difficulty during the transition years and learning to first share that responsibility and then hand it over to the young person.

1	2	3	4	5
○	○	○	○	○

4. Explaining CHD to others.

1	2	3	4	5

○ ○ ○ ○ ○

5. Worries about surgery.

1 2 3 4 5

○ ○ ○ ○ ○

6. Regular travel and long trips to hospital.

1 2 3 4 5

○ ○ ○ ○ ○

7. Difficulty finding support in community.

1 2 3 4 5

○ ○ ○ ○ ○

8. Children with CHD have shared that they feel isolated and unconnected with their peers.

1 2 3 4 5

○ ○ ○ ○ ○

9. Not having as much energy.

1 2 3 4 5

○ ○ ○ ○ ○

10. Living with uncertainty about the future.

1 2 3 4 5

○ ○ ○ ○ ○

11. The lack of facilities to support children and families (i.e., hoists, changing space, access to cardiology machines).

1 2 3 4 5

○ ○ ○ ○ ○

12. Lack of joined up care between health care services.

1 2 3 4 5

○ ○ ○ ○ ○

13. Separation from family and friends.

1	2	3	4	5
○	○	○	○	○

14. Experiencing pain as part of CHD journey (i.e., medical interventions, progression of illness).

1	2	3	4	5
○	○	○	○	○

15. Experiencing communication difficulties with health professionals.

1	2	3	4	5
○	○	○	○	○

16. Having to miss school for hospital appointments and visits.

1	2	3	4	5
○	○	○	○	○

17. Not feeling believed about CHD symptoms.

1	2	3	4	5
○	○	○	○	○

18. Lots of hospital appointments

1	2	3	4	5
○	○	○	○	○

19. Children with CHD being unfairly treated at school, for extensive time off or for not being alert enough to attend all sessions throughout the day.

1	2	3	4	5
○	○	○	○	○

20. Difficult decision making at start of CHD journey.

1	2	3	4	5
○	○	○	○	○

21. Anxiety about childcare (i.e., don't like leaving child with anybody)

1	2	3	4	5

○	○	○	○	○

22. Stress on parental relationship.

1	2	3	4	5
○	○	○	○	○

23. Parents finding it difficult and upsetting to support child in distress during appointments/treatments.

1	2	3	4	5
○	○	○	○	○

24. Missing a lot of school impacts children's educational progress, friendships and confidence as they are aware that they are behind their peers.

1	2	3	4	5
○	○	○	○	○

25. Having to miss out on events due to health-related issues (i.e., medication schedule, health risks etc).

1	2	3	4	5
○	○	○	○	○

26. Experiencing trauma symptoms (i.e., flashbacks, daily reminders of negative experiences).

1	2	3	4	5
○	○	○	○	○

27. Sleep issues.

1	2	3	4	5
○	○	○	○	○

28. Anger issues.

1	2	3	4	5
○	○	○	○	○

29. Experiencing stress.

1	2	3	4	5

○	○	○	○	○

30. Lack of understanding of CHD from others (i.e., family, school, nursery, childminders, after school clubs and activities)

1	2	3	4	5
○	○	○	○	○

31. Anxiety about waiting for a surgery plan and date.

1	2	3	4	5
○	○	○	○	○

32. Difference in expectations and reality of living with CHD.

1	2	3	4	5
○	○	○	○	○

33. Too much information shared by professionals with families.

1	2	3	4	5
○	○	○	○	○

34. Children with CHD having additional needs and/or neurodevelopmental disabilities.

1	2	3	4	5
○	○	○	○	○

35. Wellbeing of siblings.

1	2	3	4	5
○	○	○	○	○

36. Education struggles

1	2	3	4	5
○	○	○	○	○

37. Financial impact and burden.

1	2	3	4	5
○	○	○	○	○

38. Experiencing a fear of needles.

1	2	3	4	5
○	○	○	○	○

39. Feeling different from others.

1	2	3	4	5
○	○	○	○	○

40. Coping with procedures (i.e., worry about procedures in hospital such as bloods and scans).

1	2	3	4	5
○	○	○	○	○

41. Many young people with CHD moving into transition have questions about how it may impact on their adult life (i.e., friendships/relationships, drugs, alcohol, work prospects and future fertility).

1	2	3	4	5
○	○	○	○	○

42. It's harder to keep up with friends during activities.

1	2	3	4	5
○	○	○	○	○

43. The care of siblings (e.g., childcare during admissions and appointments).

1	2	3	4	5
○	○	○	○	○

44. Lack of privacy on the ward.

1	2	3	4	5
○	○	○	○	○

45. Self-esteem issues.

1	2	3	4	5
○	○	○	○	○

46. Experiencing grief in relation to CHD.

1	2	3	4	5

○ ○ ○ ○ ○

47. Feelings of loneliness and isolation.

1 2 3 4 5

○ ○ ○ ○ ○

48. Challenging when feeling unwell and worry if it's linked to CHD.

1 2 3 4 5

○ ○ ○ ○ ○

49. Impact on relationships and friendships.

1 2 3 4 5

○ ○ ○ ○ ○

50. Juggling family life.

1 2 3 4 5

○ ○ ○ ○ ○

51. Limitations on physical activity, missing out on sports and PE.

1 2 3 4 5

○ ○ ○ ○ ○

52. Body image issues.

1 2 3 4 5

○ ○ ○ ○ ○

53. Finding it very hard to explain to what is wrong with their heart in a way that they and others understand.

1 2 3 4 5

○ ○ ○ ○ ○

54. Children and families with CHD must do many things that their peers without CHD do not have to do (e.g. attend clinic, take medication, have surgery).

1 2 3 4 5

○ ○ ○ ○ ○

---

55. Being embarrassed about scar/not wanting anyone to see the scar

1 2 3 4 5

○ ○ ○ ○ ○

---

56. The effects of CHD on other aspects of health.

1 2 3 4 5

○ ○ ○ ○ ○

---

57. Having to miss out on opportunities (e.g. social opportunities/ school trips and residentials).

1 2 3 4 5

○ ○ ○ ○ ○

---

58. Challenges eating.

1 2 3 4 5

○ ○ ○ ○ ○

---

59. Taking time off work to attend hospital appointments.

1 2 3 4 5

○ ○ ○ ○ ○

---

60. Finding it difficult to understand CHD conditions.

1 2 3 4 5

○ ○ ○ ○ ○

---

61. Hospitals can be scary places for children.

1 2 3 4 5

○ ○ ○ ○ ○

---

62. Worry about the future.

1 2 3 4 5

○ ○ ○ ○ ○

---

63. Feelings of shame around your illness.

1	2	3	4	5
○	○	○	○	○

---

64. Experiencing anxiety.

1	2	3	4	5
○	○	○	○	○

---

65. Trying to adjust to a 'new' normal

1	2	3	4	5
○	○	○	○	○

---

66. Managing physical symptoms of CHD (i.e., breathlessness, difficulties walking)

1	2	3	4	5
○	○	○	○	○

---

67. Learning to accept that the care and treatment for CHD is life long and the reality of needing further intervention and surgery throughout their lives.

1	2	3	4	5
○	○	○	○	○

---

68. Too little information shared by professionals with families.

1	2	3	4	5
○	○	○	○	○

---

69. Parents may struggle with change in their own identity (i.e., challenges of integrating roles of parent, carer, worker, and individual).

1	2	3	4	5
○	○	○	○	○

How important is this issue to you?

On a scale of 1 to 5   Please mark the circle that best describes how important each statement is to you

Example

Please mark your answer with an "X".

1. Limited access and long wait times for psychological input

1	2	3	4	5
○	○	⊗	○	○

1. Limited access and long wait times for psychological input

1	2	3	4	5
○	○	○	○	○

2. Wellbeing support is lacking.

1	2	3	4	5
○	○	○	○	○

3. Parents facing difficulty during the transition years and learning to first share that responsibility and then hand it over to the young person.

1	2	3	4	5
○	○	○	○	○

4. Explaining CHD to others.

1	2	3	4	5

○	○	○	○	○

5. Worries about surgery.

1	2	3	4	5
○	○	○	○	○

6. Regular travel and long trips to hospital.

1	2	3	4	5
○	○	○	○	○

7. Difficulty finding support in community.

1	2	3	4	5
○	○	○	○	○

8. Children with CHD have shared that they feel isolated and unconnected with their peers.

1	2	3	4	5
○	○	○	○	○

9. Not having as much energy.

1	2	3	4	5
○	○	○	○	○

10. Living with uncertainty about the future.

1	2	3	4	5
○	○	○	○	○

11. The lack of facilities to support children and families (i.e., hoists, changing space, access to cardiology machines).

1	2	3	4	5
○	○	○	○	○

12. Lack of joined up care between health care services.

1	2	3	4	5
○	○	○	○	○

13. Separation from family and friends.

1	2	3	4	5
○	○	○	○	○

14. Experiencing pain as part of CHD journey (i.e., medical interventions, progression of illness).

1	2	3	4	5
○	○	○	○	○

15. Experiencing communication difficulties with health professionals.

1	2	3	4	5
○	○	○	○	○

16. Having to miss school for hospital appointments and visits.

1	2	3	4	5
○	○	○	○	○

17. Not feeling believed about CHD symptoms.

1	2	3	4	5
○	○	○	○	○

18. Lots of hospital appointments

1	2	3	4	5
○	○	○	○	○

19. Children with CHD being unfairly treated at school, for extensive time off or for not being alert enough to attend all sessions throughout the day.

1	2	3	4	5
○	○	○	○	○

20. Difficult decision making at start of CHD journey.

1	2	3	4	5
○	○	○	○	○

21. Anxiety about childcare (i.e., don't like leaving child with anybody)

1	2	3	4	5

○ ○ ○ ○ ○

22. Stress on parental relationship.

1 2 3 4 5

○ ○ ○ ○ ○

23. Parents finding it difficult and upsetting to support child in distress during appointments/treatments.

1 2 3 4 5

○ ○ ○ ○ ○

24. Missing a lot of school impacts children's educational progress, friendships and confidence as they are aware that they are behind their peers.

1 2 3 4 5

○ ○ ○ ○ ○

25. Having to miss out on events due to health-related issues (i.e., medication schedule, health risks etc).

1 2 3 4 5

○ ○ ○ ○ ○

26. Experiencing trauma symptoms (i.e., flashbacks, daily reminders of negative experiences).

1 2 3 4 5

○ ○ ○ ○ ○

27. Sleep issues.

1 2 3 4 5

○ ○ ○ ○ ○

28. Anger issues.

1 2 3 4 5

○ ○ ○ ○ ○

29. Experiencing stress.

1 2 3 4 5

○ ○ ○ ○ ○

30. Lack of understanding of CHD from others (i.e., family, school, nursery, childminders, after school clubs and activities)

1	2	3	4	5
○	○	○	○	○

31. Anxiety about waiting for a surgery plan and date.

1	2	3	4	5
○	○	○	○	○

32. Difference in expectations and reality of living with CHD.

1	2	3	4	5
○	○	○	○	○

33. Too much information shared by professionals with families.

1	2	3	4	5
○	○	○	○	○

34. Children with CHD having additional needs and/or neurodevelopmental disabilities.

1	2	3	4	5
○	○	○	○	○

35. Wellbeing of siblings.

1	2	3	4	5
○	○	○	○	○

36. Education struggles

1	2	3	4	5
○	○	○	○	○

37. Financial impact and burden.

1	2	3	4	5
○	○	○	○	○

38. Experiencing a fear of needles.

1	2	3	4	5
○	○	○	○	○

39. Feeling different from others.

1	2	3	4	5
○	○	○	○	○

40. Coping with procedures (i.e., worry about procedures in hospital such as bloods and scans).

1	2	3	4	5
○	○	○	○	○

41. Many young people with CHD moving into transition have questions about how it may impact on their adult life (i.e., friendships/relationships, drugs, alcohol, work prospects and future fertility).

1	2	3	4	5
○	○	○	○	○

42. It's harder to keep up with friends during activities.

1	2	3	4	5
○	○	○	○	○

43. The care of siblings (e.g., childcare during admissions and appointments).

1	2	3	4	5
○	○	○	○	○

44. Lack of privacy on the ward.

1	2	3	4	5
○	○	○	○	○

45. Self-esteem issues.

1	2	3	4	5
○	○	○	○	○

46. Experiencing grief in relation to CHD.

1	2	3	4	5

○ ○ ○ ○ ○

47. Feelings of loneliness and isolation.

1	2	3	4	5
○	○	○	○	○

48. Challenging when feeling unwell and worry if it's linked to CHD.

1	2	3	4	5
○	○	○	○	○

49. Impact on relationships and friendships.

1	2	3	4	5
○	○	○	○	○

50. Juggling family life.

1	2	3	4	5
○	○	○	○	○

51. Limitations on physical activity, missing out on sports and PE.

1	2	3	4	5
○	○	○	○	○

52. Body image issues.

1	2	3	4	5
○	○	○	○	○

53. Finding it very hard to explain to what is wrong with their heart in a way that they and others understand.

1	2	3	4	5
○	○	○	○	○

54. Children and families with CHD must do many things that their peers without CHD do not have to do (e.g. attend clinic, take medication, have surgery).

1 2 3 4 5

○ ○ ○ ○ ○

55. Being embarrassed about scar/not wanting anyone to see the scar

1	2	3	4	5
○	○	○	○	○

56. The effects of CHD on other aspects of health.

1	2	3	4	5
○	○	○	○	○

57. Having to miss out on opportunities (e.g. social opportunities/ school trips and residentials).

1	2	3	4	5
○	○	○	○	○

58. Challenges eating.

1	2	3	4	5
○	○	○	○	○

59. Taking time off work to attend hospital appointments.

1	2	3	4	5
○	○	○	○	○

60. Finding it difficult to understand CHD conditions.

1	2	3	4	5
○	○	○	○	○

61. Hospitals can be scary places for children.

1	2	3	4	5
○	○	○	○	○

62. Worry about the future.

1	2	3	4	5
○	○	○	○	○

63. Feelings of shame around your illness.

1	2	3	4	5
○	○	○	○	○

64. Experiencing anxiety.

1	2	3	4	5
○	○	○	○	○

65. Trying to adjust to a 'new' normal

1	2	3	4	5
○	○	○	○	○

66. Managing physical symptoms of CHD (i.e., breathlessness, difficulties walking)

1	2	3	4	5
○	○	○	○	○

67. Learning to accept that the care and treatment for CHD is life long and the reality of needing further intervention and surgery throughout their lives.

1	2	3	4	5
○	○	○	○	○

68. Too little information shared by professionals with families.

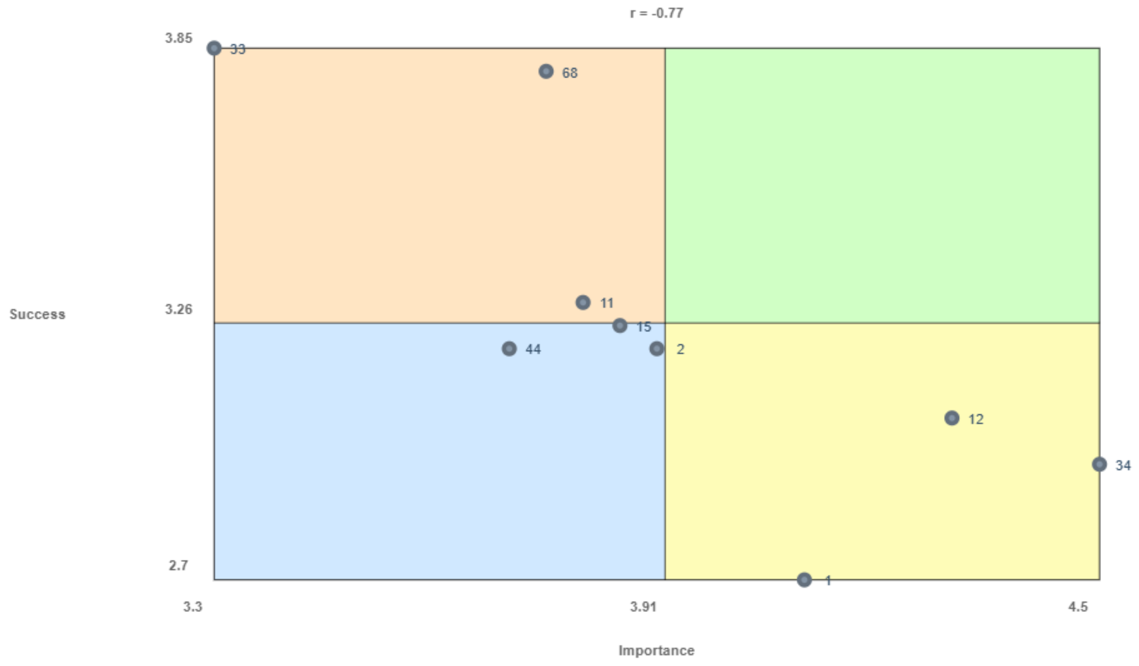
1	2	3	4	5
○	○	○	○	○

69. Parents may struggle with change in their own identity (i.e., challenges of integrating roles of parent, carer, worker, and individual).

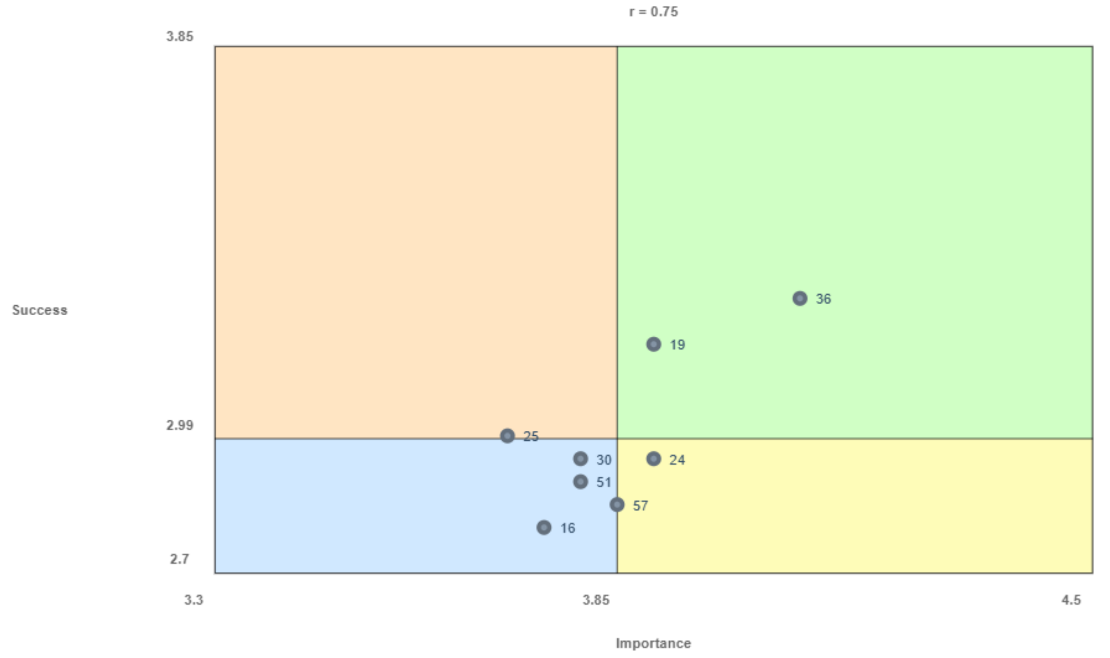
1	2	3	4	5
○	○	○	○	○

Appendix C: Go-Zone Maps

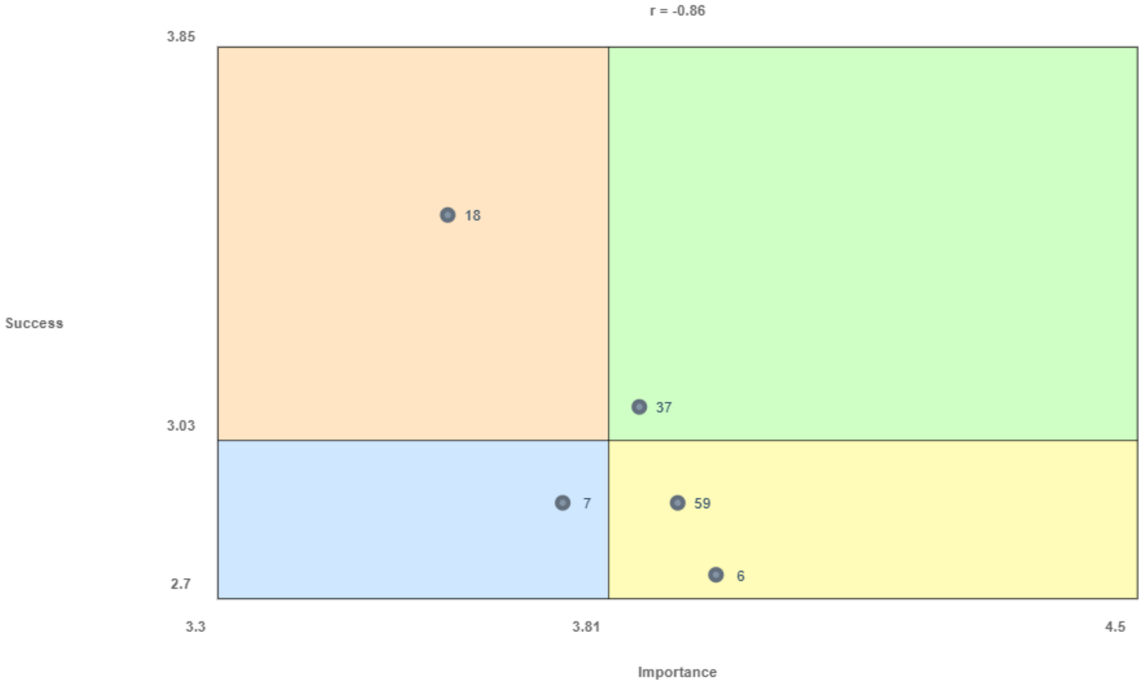
Cluster 1: Lack of Facilities and Support



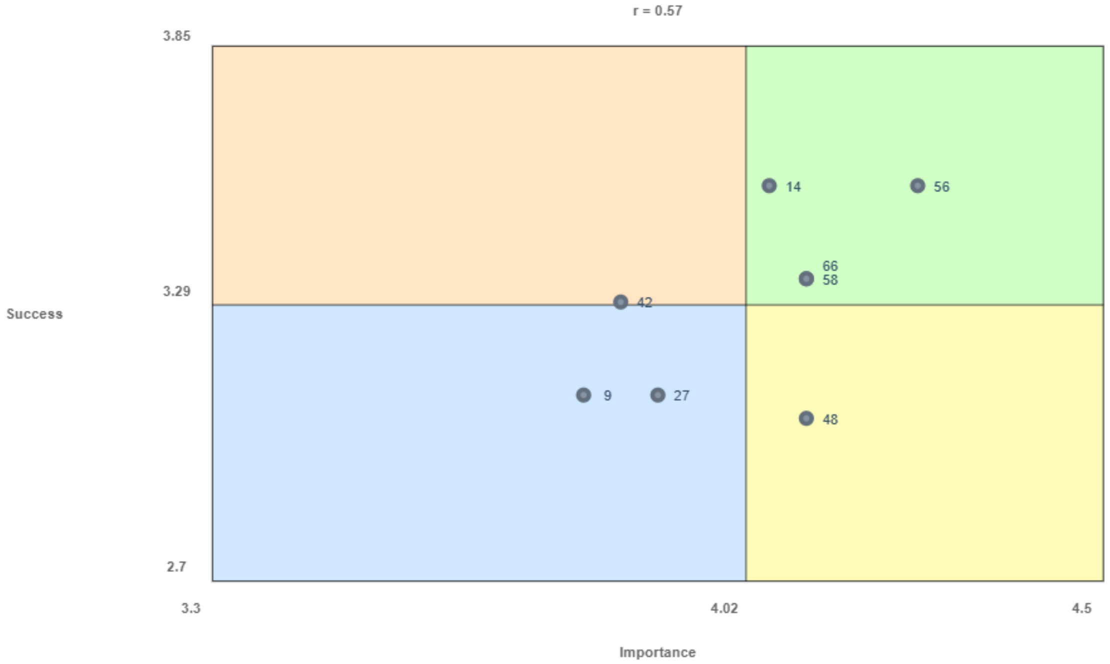
Cluster 2: Unfairly Missing Out (events/opportunities)



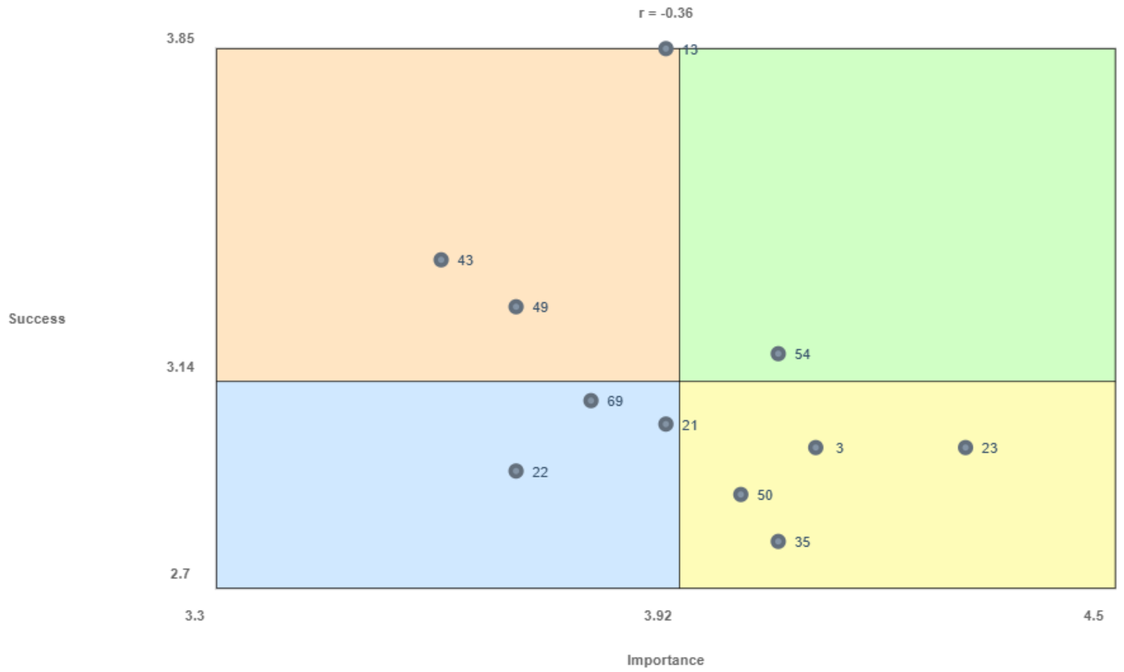
Cluster 3: Burden of Travel and Hospital Appointments



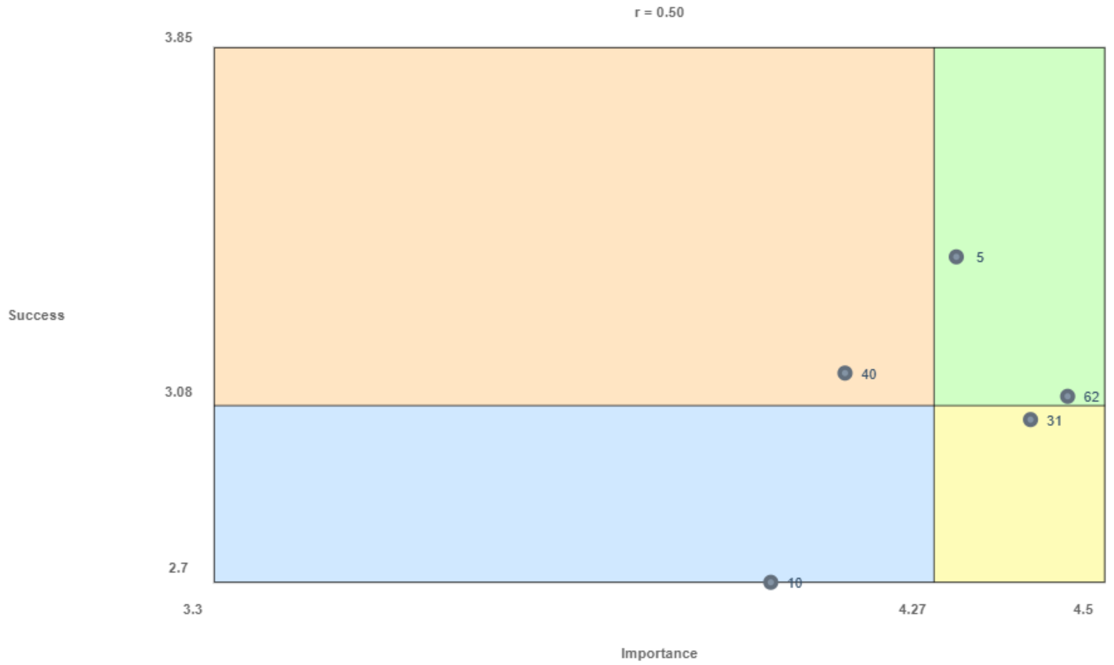
Cluster 4: Managing Physical Signs and Symptoms



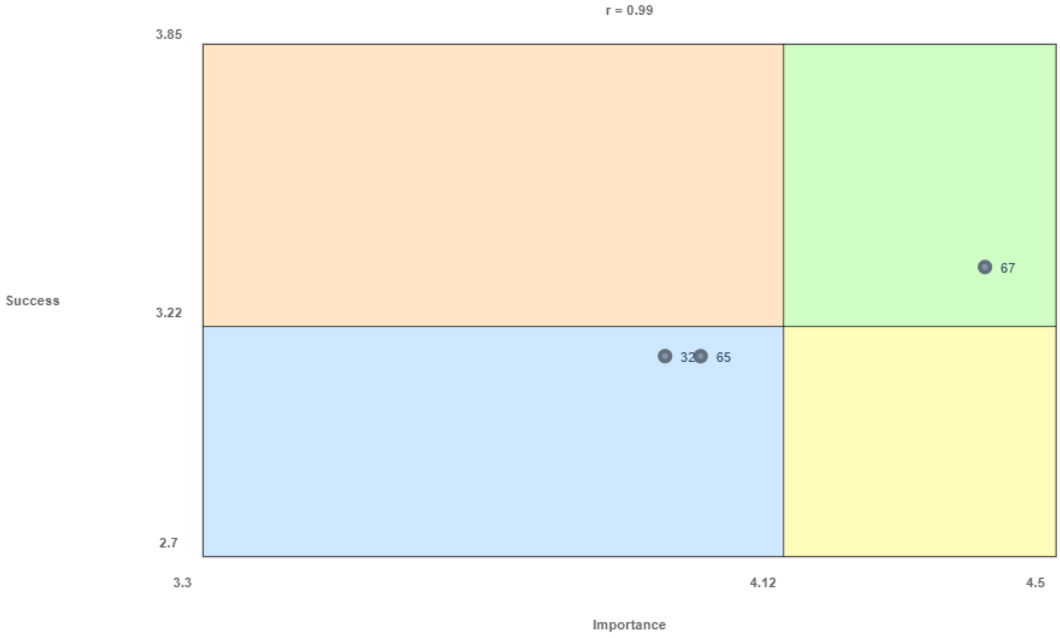
Cluster 5: Impact on Family and Family System



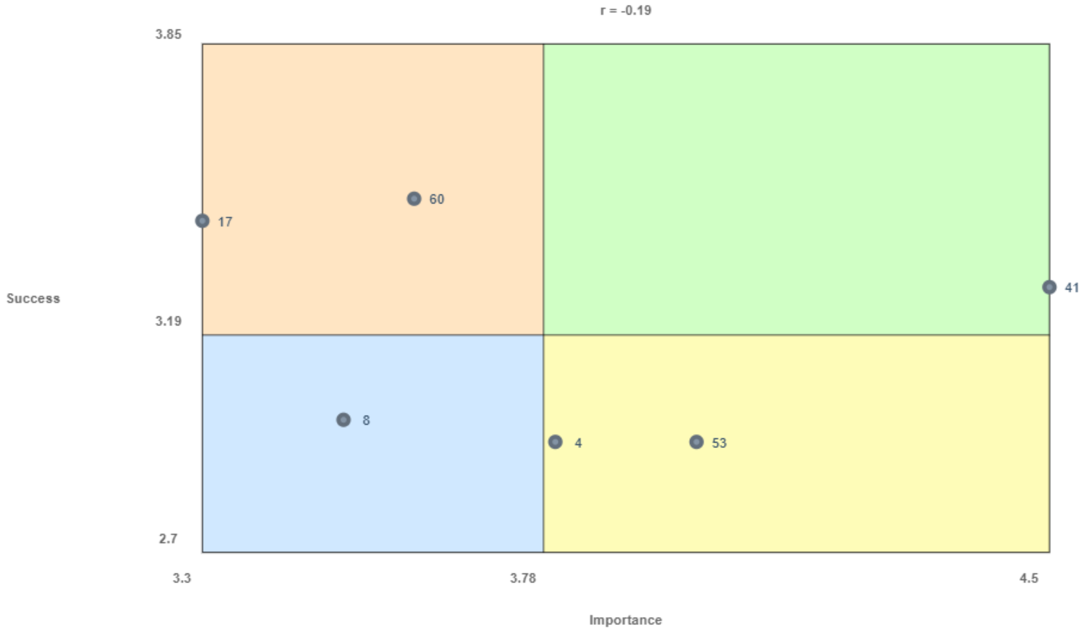
Cluster 6: Procedural Anxiety and Worries About the Future



Cluster 7: Adjustment to Life with CHD



Cluster 8: Social Understanding



Cluster 9: Psychological Difficulties