



The Children's Heart Federation is the UK's largest children's heart charity and an umbrella organisation representing 20 heart charities and support groups. CHF provides a voice to families and children who are born with heart conditions, as well as providing support, advice and grants.

### Question 1

**In your view, where is the health service falling short for children and young people, what is our weakest link and what can we do to improve things to make sure it makes a real difference to the lives of children and young people?**

#### **1. The need for earlier diagnosis of conditions**

Earlier diagnosis should be a major goal of the health system, not only is it of benefit to the patient and family, preventing unnecessary suffering, worry and damage, it also offers the potential to reduce costs to the health system.

Only around a third of instances of congenital heart disease (CoHD) are picked up before birth and whilst there are further newborn tests at 72 hours and 6-8 weeks where further instances of CHD are picked up, many still slip through the net.

There is often a lack of awareness by some medical staff particularly back in the community, at local hospitals and at GP surgeries of CoHD and other 'rare' conditions. There needs to be a joined up strategy for detecting CoHD early as long delays in diagnosis which have been reported by countless parents, cause stress, anxiety and needless suffering to the child and wider family. Late diagnosis also can cause untold damage to a young person's heart.

It's important that parents' and young peoples' concerns are taken seriously when talking to medical professionals. They should be seen as partners in diagnosing health problems in their children, as they often know their child best and are well placed to spot when something is wrong. Far too often CHF has heard parents say that despite raising concerns over their children's health with their GP or health professional, they were told not to worry rather than being taken seriously or advice given about what to be aware of when returning home.

CHD is the most common birth defect and as all health professionals who are to come into contact with children and young people should be educated to spot the key signs of a possible heart condition. CHF has recently launched a Think HEART campaign which gives 5 easy to spot signs to identify a possible heart problem. Simply, easy to understand information like this would be beneficial to parents and medical professionals to ensure that when children present with these symptoms that a heart problem is properly considered as a possible explanation. Empowering parents and patients should be the mission of the NHS. They should not be seen as passive but instead active partners in diagnosis, treatment and prevention. This campaign is a key example of how parents with the right information can work with medical professionals to aid earlier diagnosis. Medical professionals should not be afraid to provide patients and parents with more information.

The Newborn Infant Physical Examination Programme is a welcome improvement, offering the possibility for higher quality checks, carried out routinely across the country. CHF believe that NIPE, as demonstrated in the current pilot, offers the

potential to ensure higher quality newborn testing, reduce those who slip through the net and miss these vital checks. It also provides the ability to have fail safes, data sharing, audit and monitoring with comprehensive data available nationally for the first time. National programmes such as this should receive the necessary support, funding and leadership needed to ensure they are successfully implemented in hospitals across the country.

CHF support the integration of Pulse Oximetry testing into the Newborn Physical Examination Programme (NIPE). The test has shown very positive results in trials in the West Midlands, concerns over time and resources are shown to be largely unfounded and the test should be one part of the various key elements in early detection of heart conditions. Midwives should also be fully trained to administer this test in hospitals and the community. It is important that such advances in diagnosis are not continually delayed and implemented sporadically across the country.

## **2. Drive forward the highest quality services**

There have been great advancements in medical treatment for those with congenital heart conditions as with many other conditions, with this has come increased life expectancy, new treatments available and examples of top quality treatment. However, whilst the quality of treatment whilst good in some places, it is patchy and in many others quality is variable. This is why CHF support the Safe and Sustainable process which aims to ensure that all patients have access to the highest quality specialist surgical units. This offers the chance for larger units, round the clock care and reduced cancellations due to emergencies. It is essential that once the decision is made about which units should provide cardiac surgery; the required investment is made to bring these units up to the necessary high quality level which has been promised.

There needs to be improvements in the surgical training scheme and it needs to be ensured that there is ongoing professional development for all forms of medical professionals. Mentorship and appraisal should be a common feature of life for medical professionals ensuring that their skills continue to be refreshed and they are continually advancing.

Parents and young people find cancellations of procedures extremely frustrating and distressing. There should be significant efforts to minimise them as far as possible. Data about cancellations are easily to collect and should be publically available.

There needs to be better information for parents and young people about the range of support and facilities available at each hospital. Children and young people with long-term conditions like CoHD will often have to stay in hospital for long periods after procedures, or make frequent trips so the hospital can become a regular feature of life. Hospitals should make greater efforts to ensure visits and long stays are as easy and comfortable as possible as far too often they are unwelcoming, difficult to navigate and costly places to be. This includes the need to provide accommodation if overnight stays for parents whose children have to go in overnight, cheap or free parking facilities and subsidised food for those making regular or long visits with children. Hospitals should be welcoming places during some of the most difficult periods in families' lives, making efforts to reduce stress during already difficult times.

Parents and young people value the provision of specialise nurses however their availability and roles vary greatly. Access to Children's Cardiac Nurse Specialists (formally Cardiac Liaison Nurses) greatly improves the quality of care and support.

There is a need to strengthen their roles, ensure they are available in the community, and have a standard job description and services parents and young people can expect from CCNSs. Overall specialist nurses are a great addition to medical teams, and provide much needed support, care and advice that parents and young people value. Efforts should be made to ensure that they remain condition-specific and available to all.

### **3. Ensuring that the pathways of care are clearly defined**

Across all ages of treatment it is important to have clear care pathways; for antenatal care and scans, for children or adults with CoHD. Clear, well drawn, easy to understand pathways, will ensure consistent care across the country as well as enabling patients to best understand their treatment, what to expect and how to hold to account their healthcare providers. Far too often the routes patients must follow are a complex mystery and access to certain services as well as timelines seems arbitrary. Patients and young people want to have clear indications of what length of time they can and should be able to expect before treatment with clear routes to access services.

### **4. Ensuring fully integrated care across all sectors**

There is a need to ensure that referral pathways are robust and that primary and secondary care fully integrated with one another. Not only is it important to ensure there is joined up care between different sections of the health system but also other sectors and agencies. Whether it is social care, the education sector or the DWP parents and young people want agencies to better communicate with one another rather than operating as separate silos and work together rather than seemingly provide continual barriers to support and treatment.

#### **Question 2**

**With so many different parts of the health system in place, what do they need to focus on and improve to make sure they each work together to deliver the best possible health service for children and young people ?**

#### **1. A better managed transition between child and adult services**

The transition between childhood and adulthood is a difficult time for any young person, let alone those with an ongoing medical condition. These difficulties are often compounded further by the movement between child and adult services in the health system. The problems with transition are well documented and discussed.

A successfully managed transition process clearly needs to look at the whole family. Children's needs and wishes will often vary, as will the level of involvement of their parents in their care. This needs to be taken into account and a one-size fits all approach to transition will not be suitable for young people with long-term and complex conditions. Clearly many parents will want, and often need, to remain involved in their child's care. Therefore considerations should be made about how this is facilitated and communicated with parents during transition.

Young people tell us that they want to be involved in the transitional arrangements and this process should be a discussion rather than simply being informed by letter than their care is now changing. It is vital that during this crucial phase, young people do not fall out of the system. Those with long-term conditions like CoHD will need to have their condition carefully monitored for life, and whilst young people should be

empowered to manage their conditions, they will need and require the ongoing support of the health system.

## **2. Better communication with young people and families**

It is important to ensure that medical professionals who deal with young people are able to effectively communicate with them. Parents and young people want medical professionals to have a clear and often better understanding of their child's condition and treatment options.

Parents and young people value key workers or care coordinators. They tell us that they want a single, trusted, named and contactable source. When communicating with parents and young people about treatment and diagnosis having a named individual who is contactable is essential to help deal with questions or concerns. Letters should be given to parents after verbal explanations of treatment, referrals and diagnosis so that parents and young people can take them with them for reference later. All communications should be written in simple, plain language.

It is important that all communications to young people are worded in the correct manner with due consideration for young people with learning difficulties. Many children with CoHD also have some form of learning difficulty or developmental problem, it is essential that this is considered at all times in the health system, during planning, delivery and evaluation of services. Where patient experience are being assessed such as through Patient Reported Experience Measures (PREMs) or people with learning patient voice is being encouraged, consideration should always be given as how to specifically involved young difficulties, simply providing documents in larger print or simpler language does not equate to proper engagement and personal one-to-one outreach may be necessary to ensure these patients experiences are fully taken into account and their voices are heard.

## **3. A stronger role for the voices of young people and families**

Young people and their families must be at the centre of their care and at a suitable age be involved in decisions about services. Parents and young peoples should be involved in planning services. Local Healthwatches as well as Health and Wellbeing Boards should be inclusive of children's voices as well as parents.

Parents tell us often that they are not given or told of their right to second opinions. It is essential that parents and young people are given information about external bodies of support and information who can offer independence advice and guidance. Parents and young people should be made aware and given a real choice about what hospital, what treatment and what clinician is involved in their care.

## **4. The promotion of self-management for children and young people**

The growing focus of the healthcare reforms on the importance of patient self-management and a shift to 'telecare' and 'telehealth' is very welcome. This implementation of these advances in practice however is patchy. Parents and young people who would benefit from the provision of INR/Coagu Chek machines for example are prevented from realising these benefits as currently the relatively inexpensive machine are unavailable on the NHS. A modest initial outlay would greatly improve these children's lives, allowing them to go to school, prevent long frequent trips to hospital and enabling them to experience more of a normal

childhood. It would also ensure that parents could seek more regular employment not having to take their children as frequently to the hospital, this on top of the undoubted savings to the health service by greatly reduced appointments and reduced staffing time needed to monitor Warfarin levels in patients.

Patients must be involved in their care. Self-management of individuals' conditions must be a priority, allowing maximum independence. Currently the NHS does not do all it can to ensure that patients are supported to live independent lives. Instead some practices can reinforce dependence. Focus on care close to home where possible and self-management of their condition must be a priority for all patients including those with cardiovascular conditions.

## **5. Improved data collection and clearer measures of service quality**

Data about the quality of services and outcomes is lacking and sparse. It is clear that if improvements are to be made, meaningful choice an option for parents and young people, then good quality data is needed on which services can be judged.

There should be greater measurement of satisfaction for young people with the services they use and it should be ensured that questionnaires are available for parents and young people to give views about the quality of the service they received to feed into Patient Reported Outcome Measures (PROMS).

The Central Cardiac Audit Database (CCAD) for instances, which is an information resource supposedly for parents, is hard to navigate, unfriendly to patients and most find it almost impossible to use adequately. It takes a great deal of time for data to be made available for use online and is limited to simply mortality based measures. Parents and patients want and deserve and more rounded and adequate analysis of care quality on which to base their decision about treatment options. They particularly want to see measures of quality based on morbidity. In determining the quality of care, parents of children with CoHD also value other indicators such as the rate of cancellations of surgical procedures and the facilities on offer at units, such as accommodation.

In all NHS data collection and reporting operations, there should be lay representatives involved on steering and monitoring groups. Data should always be presented using simple language ensuring that it is as accessible as possible.

### **Question 3**

**The NHS and Public Health Outcomes Frameworks both propose key areas of focus: making sure everyone lives healthy lives for longer, addressing inequalities, enhancing quality of life for people with long term conditions, helping people recover from ill health or following an injury, ensuring people have a positive experience of care, treating and caring for people in a safe environment and protecting them from harm. (Details of the current outcomes specific to children and young people within these frameworks are at <http://healthandcare.dh.gov.uk/outcomes-frameworks/> )**

**Are these the right priority areas in relation to children and young people's health outcomes? Is there anything missing.**

To drive improvements in service quality and ensure proper accountability of commissioning, there needs to be greater responsibility on the health service and

commissioning groups to gather data specific to children and young people with long-term conditions.

CHF recommend the following outcomes are monitored:

**Domain 1:**

- Early diagnosis of children and young people with a heart condition
- All children and young people to have access to specialists trained to work with young people

**Domain 2:**

- Children and young people have access to available equipment necessary to self-manage their conditions at home
- Reducing cancelled surgical procedures for young people in hospital
- Self-reported wellbeing of children and young people with long-term health conditions
- Reported levels of satisfaction with services from young people and children
- Those diagnosed with congenital heart problems and other long-term conditions are provided with information about support groups and charities that can provide further support.

**Key public health outcomes for children and young people must be relevant and specific to disabled children and young people. Currently the outcomes frameworks do not give enough weight and attention to young people and children with long-term health conditions. CHF feel that measures such as pupil absence, measures of those who are not in education, employment and training and a number of others should have specific secondary measures for those with long-term conditions.**

Excluding children and young people generally from other measures could have serious effects on the level of priority and attention given to children and young people. This may lead to resources in the health system being diverted away from areas which matter to them and risks marginalising the needs, care and concerns of children and young people and those with long-term conditions.

**Question 4**

**Is there anything else you'd like to tell us?**

It is important that the Children and Young People's Health Outcomes Strategy leads to long term change in the health system, putting children and young people at the very centre of care. Healthwatch should have a clear focus on children, all commissioning groups should have a strategy for children and young people and a children and young people's senate should be established.

It is essential that parents are continually considered and listened to when looking at the care of children and young people. Another key area of focus must be about the level of information given to parents and young people about independent sources of advice and support, and third sector groups. Those with long-term conditions need

and value the support and advice these groups can offer, and it is essential to improving the holistic care of children and young people with long-term conditions.