



The Children's Heart Federation is the UK's largest children's heart charity and an umbrella organisation representing 23 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.

## **Children's Heart Federation response to the Consultation - Liberating the NHS: 'no decision about me, without me'**

### **Overview**

The Children's Heart Federation (CHF) feels that it is important that parents right to choice and to a shared-role in decision making about treatment options is available at all stages of the care pathway.

With advances in treatment and technology meaning that those with congenital heart disease (CHD) are surviving well in to adulthood, and the patient population is expanding, it is essential that CHD, like many other rare conditions are viewed correctly as long-term conditions, with all that this involves. Patients with CHD and where appropriate their parents or carer must therefore be involved right across their life-course in the management of their condition and decision making.

The case for shared-decision making is clear with improvements in treatment adherence and use of prescribed medication. When patients are not actively engaged in decisions about medication for example there are cases, of which CHF is directly aware, where there are misunderstandings about whether the medication is a one off, or part of ongoing treatment leading to misuse or failure to continue using the necessary medications, resulting in deterioration in health or serious medical complications. Similarly greater patient involvement leads to improved health behaviours and gives parents and patients the ability to use services more appropriately reducing costs<sup>1</sup>.

With regards to the suggestion that urgent and emergency care will not be included in the shared-decision making model, it is essential that the definition of what constitutes urgent and emergency care is clearly outlined. Whilst much care is urgent, there can often still rightly be a role for shared-decision making, with parents and patients playing an active role in care choices.

### **Are the proposals set out in this document realistic and achievable?**

CHF welcomes the focus and potential promised by the 'no decision about me, without me' agenda, however there is a clear need to identify how this can realistically be realised. This is clearly a significant task and requires more than simple tick-boxes approaches or standard questions. To truly realise shared decision making in the NHS there will need to be cultural change, amongst clinicians and also amongst patients. As The Health Foundation outlines there is a need for a change 'in philosophy, in culture and in the roles of patients and professionals'<sup>2</sup>. The process should be entrenched throughout the health service to become a key part of all clinical consultations.

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<sup>1</sup> National Voices, 2012, *National Voices' Response to the Consultation* p.4

<sup>2</sup> The Health Foundation, Feb 2012, *Leading the way to shared decision making* p.4

The document in 7.16 highlights correctly the need to involve the Royal Colleges and other associations of medical professionals. However the proposals and suggestions about better education and training are far too limited. Professional development and greater focus during the training of medical professionals about how to facilitate and manage shared-decision making are needed. Clearly to ensure that this is successful there needs to be close working with the professional colleges and associations and leadership from them demonstrating that they recognise and value the role of shared-decision making in the health service. CHF agrees with a number of elements of the National Voices contributions about the need for communication skills to be valued as part of professional development. These include the need to understand how to elicit patient and parents views about treatment, the ability to ensure that parents have adequately understood the treatment options rather than simply to overload parents and patients, at often very difficult period in their life, with complex medical information and to work out what level of involvement patients and parents want in their care<sup>3</sup>.

In section 2.9 in the model for shared-decision making it is stated that 'sometimes people may not value sharing in decisions and making choices', whilst this may be the case, this must not be allowed to create complacency about encouraging individuals to be involved in decisions. Whilst it may be the case that some patients and parents are initially more difficult to engage, lack information, and the inclination to be involved in decisions, this should not prevent engagement and encouragement.

CHF would welcome further clarification generally about what shared decision making involves, what patients and parents can expect and what are their rights. This is essential to ensure proper accountability if these are not provided. Whilst it is welcome that it is again stressed that since 2008 patients have the right to choose from any clinically appropriate provider, and that PCTs had duties to publicise and promote patients entitlement to choice, there is a need for yet more transparency about what choices and options are available. Far too often parents are told they cannot access a second-opinion or referral when they may want them, and rather than being encouraged to explore choices, or talked through the process, such options are dismissed out of hand, and parents in difficult circumstances are put off pursuing such legitimate options.

We were slightly disappointed that whilst there is some discussion of the ability for patients and parents to ask for a second opinion, there is no more robust statement about this issue or the right for a patient to seek a second opinion should they feel it necessary. This is certainly disappointing.

## **Looking at the proposals collectively, are there any specific areas that we have not recognised appropriately in the consultation document?**

### **1. The need for better communication with young people and families**

An area which does not receive sufficient weight or attention in the document is how to enable those with learning delays and difficulties to be involved in shared-decision making. It is important to ensure that medical professionals who deal with young people and those with learning difficulties are able to effectively communicate with

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<sup>3</sup> National Voices, 2012, *National Voices' Response to the Consultation* p.11

them. Parents and young people want medical professionals to have a clear and often better understanding of their child's condition and treatment options.

When communicating with parents and young people about treatment options 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 CHD 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.

Patients and their carers different capabilities need to be considered carefully and may mean that some individuals require more time with professionals before making decisions, and also more time on their own, with the support of families, carers or third sector organisations to work through the possible options for their care before making a truly informed and chosen decision.

Parents and young people, particularly with learning difficulties, value key workers or care coordinators. They tell us that they want a single, trusted, named and contactable source that they can discuss their care options with and find out how they can navigate the health system.

## **2. A role for the voices of young people and their families**

As outlined above when dealing with those with complex physical and mental health needs, and those with learning difficulties, the role of parents and carers must be recognised. CHF are particularly concerned that carers and parents of young people and adults with learning difficulties and delays are recognised as key partners in the care of their loved ones. Shared-decisions making can be better fostered for these individuals with the support of their next-of-kin and carer, who should not be excluded from the decision making process as is sometimes the case, but instead they must be included, sensitively where necessary, to support the individual making decisions about their care.

CHF are also concerned that with smaller patient populations, dealing with often specialised services Local HealthWatch may not be suitable or the right device to ensure that complaints are dealt with suitably with sufficient weight. It remains uncertain what HealthWatch England's role will be and CHF would like to see further clarification about its role and what powers it will have over such areas as ensuring patient's concerns are dealt with adequately. With small patient groups (such as those with CHD), often in large care networks, sometimes travelling for specialist treatment to other regions, it is important that there is suitable provision for such groups to have adequate redress and a means to ensure their rights for choice and the ability to be involved in shared-decision making are achieved and monitored.

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

To enable parents to have real choice, there is a clear need for them to be provided with more reliable and available data about the quality of services and outcomes. As pointed out by the Health Foundation patients need to make choices based on

'informed preferences' as well as personal preferences<sup>4</sup>. It is clear that if improvements are to be made then good quality data is needed on which services and care options 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). Where patient experiences are being assessed, such as through Patient Reported Experience Measures (PREMs) or 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.

Data should always be presented using simple language ensuring that it is as accessible as possible. The Central Cardiac Audit Database (CCAD) for instances, which is an information resource supposedly for parents, is often 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 CHD also value other indicators such as the rate of cancellations of surgical procedures and the facilities on offer at units, such as accommodation.

#### **4. Medication**

A further area on which CHF feels there was not appropriate consideration is that of medication. We would be interested to see whether shared-decision making will extend to the area of the prescription of medication. CHF feels strongly that it should and that patients should be involved more in decision-making about which drugs they can access as part of the care package for their long-term condition.

### **Have we identified the right means of making sure that patients will have an opportunity to make shared decisions, to be more involved in decision about their care across the majority of NHS funded services?**

#### **1. Better informed decision makers**

We welcome the recognition on the consultation document about the need for information to support shared decision-making. Ensuring that parents and patients have access to a wide range of information and support to make decisions is essential to realise the potential of the shared-decision making agenda.

Individuals need help to navigate services and support – whilst the document has correctly pointed out the need for information and identified various forms and sources, not enough stress has been put on the role of third sector providers and forms of support.

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<sup>4</sup> The Health Foundation, Feb 2012, *Leading the way to shared decision making* p.5

We welcome overall the aims of the Government's Information Strategy and its inclusion in these documents (7.19). CHF feels that the Informational Strategy works directly alongside the 'no decision about me, without me' agenda. Providing patients and parents with access to their GP records, patient and treatment information online, providing a one-stop portal for condition and treatment information as well as links to support groups and charities must be seen as a key part of enabling patients and parents to realise their role in making decisions about their care. CHF also agree about the need for this information to be benchmarked with a reliable level of quality. We feel that the Information Standard accreditation is a suitable device for delivering this level of certainty about quality.

## **2. Greater promotion of self-management**

CHF were interested to read about the stress placed in section 3.12 on personalised care planning and the benefits of telecare technology and other electronic equipment. Indeed many parents and patients would welcome the option to self-monitor or manage their condition, however often this option is not properly explored with many patients and parents. This can be for a number of reasons, service inertia, resistance to paying upfront costs (despite long-term savings) and also the tendency of some professionals to seek to retain tighter oversight and control of treatment.

Unfortunately the health service is often too slow to adopt such beneficial technologies, and in some places resistant to offering patients and parents the choice about whether they could use such devices to enable more independent home-care. 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.

As National Voices have rightly pointed out, 'the most important element of choice and control for individuals is in relation to how they live with their health status and conditions, and decide on the course of care and treatment that is right for them'<sup>5</sup>. Parents and patients want a choice over what treatment to have as much as where they have treatment and therefore greater efforts should be made to ensure such methods of self-monitoring and management are realisable.

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.

**Do you feel that these proposals go far enough and fast enough in extending choice and making 'no decision about me, without me' a reality?**

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<sup>5</sup> National Voices, 2012, *National Voices' Response to the Consultation* p.2

## **Conclusion**

The benefits of shared decision making are clear. Handing greater say to patients and involving them in their treatment improves the quality of healthcare they receive objectively, as well as improving their satisfaction with care as well as delivering cost savings<sup>6</sup>.

There does need to be further clarity over the scope of these changes and what they will really mean for patients and parents. Certainly however CHF feels that many patients and parents do want and deserve to be more involved in decision-making about their care.

To enable them to do so is key and there needs to be better training for medical professionals, information, support and data available for patients and parents on which they can make decisions about their care. Empowering patients must not be about merely tick-box activity or slogans but must be about a wider cultural and behavioural change in the health service.

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<sup>6</sup> The Health Foundation, Feb 2012, Leading the way to shared decision making p.5