

# Consultation response on 'Liberating the NHS' White Paper from Children's Heart Federation

## Vision

We welcome all the elements of the vision of an NHS laid out at 1.10, except for 'puts clinicians in the driving seat'. We contest the polarisation 'clinicians good, managers bad' advanced by this strategy. We support a competency-based approach to the National Health Service, giving professionals the opportunity to shine within their core skill set. We support participation between health service users, providers and planners in designing and delivering an excellent health system and believe that skilful managers can be better placed than clinicians to make strategic decisions about the health service because they have a greater degree of detachment. We have seen too many examples of vested interests/empire building from clinicians to trust that putting GPs in charge of commissioning is in the best interests of patients.

We welcome the continued close working between the Department of Health and the Department for Children [1.17] We look for the education and support needs of children with congenital heart disease to be recognised and met, so that these children can participate and be included on their own terms in learning activities. This will require a range of measures, including staffing with sufficient numbers of school and specialist nurses and providing orientation and training for educationalists in how to support these children to achieve their best – which third sector health and disability organisations should be involved in providing.

We welcome the commission on funding long-term care and support [1.8], noting the importance of recognising the specific needs of children and young people with a health condition, and the families that support them, as being distinct from the needs of older people with long term conditions.

We feel that there is a very real danger that this strategy is more likely to *reduce* productivity and efficiency rather than improve it [1.20], as the number of health bodies will actually proliferate and the fragmentation of the current system could be made worse, with higher costs and wastage due to loss of financial control and constraints on 'external organisations' providing support for commissioning [see box on page 29 and 4.21].

We would have greater confidence in the commitment to evidence-based policy-making if the evidence base for this strategy had been more convincingly presented and the initiative trailed in the conservative party manifesto [1.23]

## Primary Legislation

1.	Enabling the creation of a <b>Public Health Service</b> , with a lead role on public health evidence and analysis
1.1.	We are particularly concerned that all pregnant women should receive high quality antenatal screening to check for foetal heart abnormalities, that the Newborn and

	Infant Physical Examination programme should be strengthened and rolled out and that a routine healthcheck for adults with congenital heart conditions should be made available to the GUCH (grown up congenital heart) population, in order to minimise health risks from congenital heart disease.
2.	Transferring <b>local health improvement functions</b> to local authorities, with ring-fenced funding and accountability to the Secretary of State for Health
2.1	Congenital heart care and support needs to be treated as a set of specialised health and social care interventions/activities, commissioned and led by a specialised function rather than being part of a public health initiative.
3.	Placing the <b>Health and Social Care Information Centre</b> , currently a Special Health Authority, on a firmer statutory footing, with powers over other organisations in relation to information collection
3.1.	<ul style="list-style-type: none"> <li>• We applaud the move to drive towards greater transparency about outcomes and expect measures to be in place to ensure that the performance of children’s heart services – including comparisons between the performance of different treating units – are clear and understandable to the public. We note that some clinicians may choose not to treat rather than risk adverse statistics at their unit and we look for regulatory bodies to use powers to expose practices that deny patient care except on the best clinical grounds.</li> <li>• We look for a link between the Congenital Cardiac Audit Database (CCAD) and the commissioning process so that the information in CCAD informs commissioning decisions in relation to congenital heart surgery.</li> <li>• We look for a move to including morbidity data in CCAD, and being able to track the longitudinal history of interventions for congenital heart patients as soon as possible.</li> <li>• We look for the development and application of PROMS for children and young people and an effective tool to gather the views of parents about paediatric cardiac care across the national congenital cardiac service [2.7]</li> <li>• We propose a role for third sector congenital cardiac organisations to gather reports from parents and young service users after episodes of care to provide independent, qualitative evaluation data on the quality of service provision [2.8]</li> </ul> <p>We support the use of peer-performance data and high quality internal audit data and statistical analyses to improve understanding of the strengths and weaknesses of multidisciplinary team performance in paediatric cardiac care [2.9] – learning from the weaknesses exposed in the use of data by the Oxford John Radcliffe Unit exposed by the Inquiry Report (July 2010).</p>
3.2.	We would expect the Information Strategy to deliver marked improvements in communication between bodies involved in the treatment and care of children with a heart condition. At the moment, children’s notes are often not available at the time they are needed because record systems and information-sharing protocols and practices are inadequate.
4.	Enshrining <b>improvement in healthcare outcomes</b> as the central purpose of the NHS;
4.1.	We welcome the focus on healthcare outcomes, as parents of children with heart

	conditions assert that safety and high clinical standards are their highest priorities.
4.2.	We support the proposed NICE quality standards and would draw the distinction, in developing care pathways for heart disease, between congenital heart conditions and coronary heart disease.
4.3.	We welcome the focus on research and advise the NHS to partner with voluntary sector support organisations to define and undertake research. We hope that the research remit will extend to social care topics related to medical conditions, such as non-clinical strategies that enable children with complex health conditions to achieve their full potential.
4.4.	We would expect Medical Education England to work closely with relevant third sector patient support organisations to identify and address gaps in the knowledge of healthcare professionals about the lived experience of having a health condition [4.33 and box on page 40].

5.	Making the <b>National Institute for Health and Clinical Excellence</b> a non-departmental public body, to define its role and functions, reform its processes, secure its independence, and extend its remit to social care;
5.1.	We welcome the link between quality standards for health and social care and look for this to be reflected in commissioning arrangements for children and young people with heart conditions. We feel it would be more appropriate for commissioning of the whole package of care related to a child's cardiac and related conditions (including educational support, psychological and social care) to be done by the same agency that commissions medical care, to ensure the child's holistic needs are met. Again, this is based on experience of parents of heart children that GPs and other primary care practitioners do not understand the detail and wider implications of paediatric cardiac conditions.

6.	Establishing the independent <b>NHS Commissioning Board</b> , accountable to the Secretary of State, paving the way for the abolition of SHAs. The NHS Commissioning Board will initially be established as a Special Health Authority; the Bill will convert it into an independent non-departmental public body;
6.1.	We are seriously concerned that abolishing the SHAs [4.13] will lead to dispersal of commissioning expertise needed to implement the Safe and Sustainable Children's Heart Surgery programme (implementation 2011 onwards). Any structural changes to commissioning arrangements must ensure a smooth and full transfer of commissioning knowledge related to this programme, in order to ensure that the consensus standards for future congenital heart services are implemented across England and Wales.
6.2.	We welcome the principle of 'no decision about me without me' and look for the NHS Commissioning Board [2.4] to facilitate the involvement of voluntary sector health organisations to play an advisory, advocacy and mediating role to 'level the playing field' in power between healthcare professionals and patients.
6.3.	We believe it is right to centralise national and regional commissioning for comparatively rare conditions [4.11] using the Specialised Services National Definitions Set [point 4. In box on page 32].
6.4.	The commitment to improved information provision and extending choice must recognise the dependency of parents of critically ill children on the healthcare professionals advising them. We would expect the information strategy to support

	<p>the deployment of staff with strong communications skills in discussions with parents and patients about risk and treatment options – this may involve a change in internal protocols about how information is shared with parents/patients (timing, format and who does the talking). We suggest that healthcare teams make greater use of the expertise of third sector health support organisations in improving communication with health service users.</p> <p>We welcome the principle of the single telephone number for urgent care with the understanding that those who field calls are well informed about services used by children and young people with a health defect and related conditions across the country. In an urgent situation, the telephone service must not introduce delays for callers with specialist/rare medical needs.</p> <p>As part of the process for extending choice, we would expect to see the extension of the Expert Patient, Carer and Parent initiatives which empower health service users to take control of their service use experience and health decisions.</p>
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7.	Placing <b>clear limits on the role of the Secretary of State</b> in relation to the NHS Commissioning Board, and local NHS organisations, thereby strengthening the NHS Constitution
	No comment

8.	Giving <b>local authorities new functions</b> to increase the local democratic legitimacy in relation to the local strategies for NHS commissioning, and support integration and partnership working across social care, the NHS and public health
	No comment

9.	Establishing a statutory framework for a <b>comprehensive system of GP consortia</b> , paving the way for the abolition of PCTs;
9.1.	<ul style="list-style-type: none"> <li>• We contest the view that general practice is the ‘medical home’ for children and young people with congenital heart conditions [1.6] and that ‘primary care professionals coordinate all the services that patients receive’ [4.3] In making health choices for heart children, parents frequently bypass GP services because they find that many GPs have an inadequate understanding of congenital heart disease (CoHD) – understandably, since a GP may only see one or two cases of CoHD during their working life.</li> <li>• Lack of understanding of CoHD is also widespread within accident and emergency services.</li> <li>• Parents also report lack of understanding within other primary care services – especially health visitor and dietician services for infants.</li> </ul> <p>Commissioning arrangements must ensure care and referral pathways that enable congenital heart patients to receive the right treatment in a smooth and timely way. We look to the strengthening of local, community services, including the expansion of the network of paediatricians with expertise in cardiology and community-based specialised congenital cardiac support nurses, as indicated in standards for Safe and Sustainable Children’s Heart Services. We recommend ‘open access’ to specialist support for children and young people with heart conditions to specialist support services as even ‘routine care’ can have complications for children with complex health needs.</p>

9.2.	We are very concerned that the loss of PCTs [4.16] will have a negative impact on prescribing vital medicine for congenital heart patients, as experience shows that GPs sometimes manage their prescribing budgets in a way that discriminates against patients with legitimate but high cost pharmaceutical needs. We expect that any new arrangements will preserve and improve prescribing effectiveness for congenital heart patients. We particularly urge that the new arrangements will assist with balancing safety and availability of off label medication [3.22-3.23]
9.3.	We are concerned that some patients groups, especially those whose treatment is expensive will be unattractive prospects to providers [4.26 and point 4 in box on page 46] and that vulnerable patient groups have less access to treatment because providers will 'cherry pick' patients.
10.	Establishing <b>HealthWatch</b> as a statutory part of the Care Quality Commission to champion services users and carers across health and social care, and turning Local Involvement Networks into local HealthWatch;
10.	We welcome developments that strengthen the voice of patients [2.24] and encourage the commitment of funds to develop and provide training for lay people and service users to act as 'critical friends' to the NHS. We look for true independence for consumer champion bodies, with an ability to set their own agenda and have the capacity not to be driven by the priorities of other agencies, including local authorities that may commission their services. Local health watch must be resourced to have infrastructure support (e.g. secretariat functions) to be able to get on with the business of being consumer champions.
10.	Health Watch must be able to champion the needs not just of neighbourhoods (geographically-defined communities) but also geographically-dispersed communities of interest, joined by a shared (comparatively rare) health condition [2.25]
10.	We would look for 'more teeth' for Local Health Watch than merely 'recommending' poor services are investigated.
11.	Reforming the <b>foundation trust</b> model, removing restrictions and enabling new governance arrangements, increasing transparency in their functions, repealing foundation trust deauthorisation and enabling the abolition of the NHS trust model
	No comment
12.	Strengthening the role of the <b>Care Quality Commission</b> as an effective quality inspectorate
	We would welcome this and encourage Care Quality Commission to work with experienced third sector organisations to develop its inspection practices
13.	Developing <b>Monitor</b> into the economic regulator for health and social care, including provisions for special administration
	No comment
14.	Associated with these changes, reducing the number of <b>arm's-length bodies</b> in the health sector, and amending their roles and functions
	No comment