

## **Note of meeting with national charities and patient groups, 16 July 2013**

In his introduction Bill McCarthy emphasised that NHS England wanted to achieve a lasting solution for every family in England who needs these services. This review should not be seen as a competition to find winners and losers; the aim was to get the best quality of care within the available resource, now and in the future. Quality included outcomes, safety, and patient experience. John Holden outlined the board paper due to be considered on 18 July.

In discussion the following points were made:

- NHS England had the legal responsibility for commissioning specialised services including those for CHD. The government gave NHS England a mandate which set out a series of objectives. As an independent body, at arm's length from government, NHS England had a Board which approved its key decisions. Of course, these decisions could be challenged through normal processes, including judicial review and Oversight and Scrutiny Committees, so it was essential that NHS England engaged properly with all stakeholders, including local government, throughout the new process.
- concern was raised about the blog which had attracted comment – some of it “potentially libellous” - from those critical of CHF's involvement. Some attendees felt that the comments were given added weight because they appeared on an NHS blog. NHS England wanted to talk to all stakeholders, national and local, and would not rule out any group. This did not imply special access or influence for any organisation or individual. Every stakeholder had a right to expect to be heard and for their views to be taken into account – including those who sometimes had difficulty being heard. Some of those present felt that the “ease with which bullying and harassing comments could be posted on blogs” made it difficult for parents to express different views
- the process would be transparent and accountable. Assumptions would be made explicit – there would be no “back-room deals” or pre-determined outcomes
- good engagement meant being able to shape decisions before they were made, not comment on them afterwards. One source of concern was the knock-on effect of decisions regarding CHD which might affect the viability of other services. How was the work on CHD going to link in to the wider work on specialised service commissioning?
- patient groups (national and local) would want the opportunity to co-design both the process of engagement and the idea of what a really good service looks like – they were the experts on what it felt like to be on the receiving end of the service. Where people had legitimate concerns about some aspect of service change (for example the transport implications) this did not mean change was impossible, but any solution must explicitly address those concerns and come up with some practical and useful ways to address them if there was to be any chance of stakeholders accepting a solution which was not their first choice.
- national organisations felt they were able to provide a national perspective, which was different from the perspective of local groups linked to a particular unit

- attendees quoted Bruce Keogh who (on another topic) had previously described some NHS organisations as “trapped in mediocrity”. What was NHS England’s ambition for CHD services – was it excellence? Or are we happy with adequate? There should also be an ambition to “reduce injustice”. As the single national commissioner, NHS England wanted a single national consistent service, not a patchwork of variable quality. People want an excellent, world class service, and NHS England shared this ambition – mediocre was not acceptable.
- delay was a problem in itself affecting service viability, recruitment, retention, training and so on. Major change would take time to implement even if an agreed plan could be delivered quickly. Where there were problems in quality of care, these needed to be addressed promptly through the appropriate interventions, without waiting for reconfiguration to be the vehicle for “managing out” problems.
- there were concerns about patient safety now, for example where there were instances of occasional practice. This was a serious issue of clinical governance for Trust boards to address, and of concern to the whole system, not just one or two organisations. CQC had a key role to regulate against essential levels of safety and quality. As commissioner, NHS England would not hesitate to act if there were concerns about patient safety.
- would NHS England re-work all the standards? Was everything “up for grabs”? It would be helpful for stakeholders to know exactly what was considered to be fixed. As far as possible NHS England would build on the platform of work already delivered on standards and networks, recognising that some issues needed further clarification (eg the meaning of “co-location”) and that adults’ and children’s standards must be consistent if there is to be a single service for the whole patient pathway.
- attendees noted that co-location is very important for people with an underlying condition such as 22q11.2 deletion
- NHS England would not rule out “setting the bar even higher” if that were in the best interests of patients now and in the future.
- at the same time, it would be important to do as much as possible in the interim – before the completion of the new review – to help stabilise and support improvement in current provision (for example what work on networks and standards could be implemented sooner)? NHS England recognised the desirability of supporting immediate improvement where possible, and would be considering the options and would want to bring forward proposals, but would need to manage risks of legal and other challenge by ensuring wide engagement.
- as a new organisation, and the sole national commissioner of national services, NHS England had an opportunity not open to its predecessor bodies. JCPCT had not been given the option to look at children’s and adults’ CHD services together. NHS England had to consider not just the viability of services now but resilience for the future.
- attendees were interested in the most effective means of communicating and engaging with NHS England. The problem to be solved was big and complex. One suggestion was that as well as providing updates, the blog (or another medium) should address a series of different topics in more detail to stimulate debate
- who were the stakeholders and what were their interests? NHS England would draw up an engagement plan. One observation was that surgery must be seen as a

national issue – relatively small numbers, finite expert resource, of interest to the whole population wherever they lived; whereas ongoing support (which is the vast majority of clinical contact time for most patients) might be seen as more of a regional issue with more local solutions.

- there was a balance to be struck between getting to an optimal model as quickly as possible (to help stabilise a fragile service) versus a sufficiently thorough engagement exercise, which could not be rushed.
- the Board paper was welcomed for recognising (in para 15) that this was not just an issue about the location of surgical centres, but about delivering a whole service for the whole population, from ante natal testing through children and young people, transition to adults and end of life care. The Board paper was also welcomed because the new aim was to look at more than just surgical outcomes.
- it would be essential for NHS England to consider the whole pathway of care – for most patients there would be a small number of highly significant surgical interventions, compared with much more extensive and enduring contact with local cardiology services. This in turn meant that the focus on transport /retrieval was understandable but related principally to the surgical events, which were infrequent, rather than on-going care (“commuting” to cardiology appointments) which was regular. These are very different issues. So – put crudely – focusing on travel times as a main determinant of location of surgical centres could be a “red herring”
- however, there were examples where even short journeys proved problematic, for example where patients had to return home on the tube after heart surgery. A complete solution would need to recognise that whatever the journey time, patients and their families needed reassurance about the very practical difficulties which confronted families at a time of huge stress and worry. In the context of travel this included simple but significant issues like car parking.
- there were already examples which NHS England should consider where surgery had ceased at a centre but a new pattern had been established whereby patients travelled to the next nearest centre for their surgery - for example following the cessation of surgery at Cardiff patients now typically travelled to Bristol for surgery
- there was concern that the previous process had been derailed, and a plea for statements of commitment from NHS England that there would be strenuous efforts to see this process through for the benefit of all patients now and in the future – in the full realisation that this may be fraught with conflicting interests and opinions.
- NHS England were challenged for not being sufficiently “passionate about the issues”. But there had been no lack of passion in the previous process which had been unable, despite best endeavours, to deliver a lasting solution.
- NHS England was therefore totally committed to achieve a workable solution but would do so with rigour, honesty and transparency building on clinically relevant standards once these had been assured and it was clear that the adult/child alignment was correct.
- monitoring and evaluation of the implementation of the review would be improved if a congenital heart disease register can be established. It would also avoid ‘lost to follow-ups’ in transition and movement of adults.