Patient and Public Group Meeting

Friday 13 June 2014
Elizabeth Fry Suite, Friends House, Euston Road, London

1. Introduction

The Chair opened the meeting and welcomed the group. Apologies were noted from Lois Brown, Bob Ward, Penny Green, Jon Arnold, Caroline Mutton and Maura Gillespie.

There was some debate about the running order, which was resolved.

2. Engagement meetings

A request was made to look at planned timing and location of these Patient and Public Engagement and Advisory Group meetings, to enable more local patient and parent representatives to attend. This was said to be a specific problem for those in the north of the country, due to the expense and time commitments involved. John Holden confirmed that the review team was willing to accommodate the wishes of the group, but that when this had been raised previously, there was a general consensus that meetings in London were generally the best compromise for all because of good transport links. Where it had become apparent that some groups missed out, NHS England tried to address this in other ways. It was also relevant to note that there had been a visit to every specialist unit in the country during April-June 2014, with explicit opportunities to meet patients and families, and a further nine regional events for children and young people in April. The review team was also expecting to hold four regional events during the period of consultation on draft standards, and to support other local engagement events through provision of materials etc. A specific suggestion was made to use technology (for example: internet-based 'WebEx' meetings) to overcome this issue, and a discussion followed about the merits of face-to-face and virtual meetings. The review team agreed to consider this further.

3. Stakeholder concerns

It was suggested that the review team "does not respond" to what it is told by stakeholders. John Holden said he did not accept this; the review had tried hard to accommodate the views of stakeholders both in terms of the way the review was conducted and in terms of its content, not least the extensive 'pre-consultation engagement' on draft standards.

It was also suggested that the forthcoming consultation on ‘aspirational standards’ would result in lobbying from groups who would look at the draft standards and infer the outcome of the review for their local unit, and would campaign along partisan lines rather than in the best interests of all patients: should NHS England therefore limit the consultation in some way to manage this risk? John Holden acknowledged that some respondents may well focus on what they think will be most/least favourable to their local unit, but felt that this was a legitimate response to a public consultation. It was not a justification for limiting the field of consultees. NHS England wanted the widest possible response, and would critically evaluate responses for their potential to improve outcomes for patients, using the same sort of process that had been applied to the development of standards, e.g. expert clinical review with stakeholder engagement, and formal governance to sign off any changes.

4. Update on progress

John Holden gave an update on the review’s progress since the last patient and public meeting which took place on 27 March 2014. He outlined various activities including the Trust visits led by Professor Deirdre Kelly, and the children and young people’s events that took place over the Easter break. John explained briefly the process of assurance and governance that the review team had to follow in order to publish standards for consultation. It was imperative to comply with these requirements, to demonstrate that due process had been followed, but there were inevitably risks of delay associated with an assurance process whose outcome could not be guaranteed. John also noted that any work completed by the review team would need to align with other work on specialised services.

Following John’s update a discussion ensured on affordability – would the affordability assessment alter the standards before they went to consultation? John’s strong view was that the consultation must set out standards which described an excellent service, but the subsequent implementation of those standards, once agreed, would need to take full account of any affordability constraints with an effective approach to live within budget.

Discussion of the ‘equality assessment’ triggered a question about how geography and the distribution of services would affect patients’ and families’ right to equality. The group wanted reassurance that travel implications and hospital transport services would be considered within the review process.

Attendees asked about the May 2015 General Election and whether this would impact on the process. The response was that the current project timetable permitted the service specifications to be agreed by the end of March 2015, i.e. before the restricted period when significant announcements were not possible. However it was also pointed out that NHS England had the legal responsibility to commission this service. Whilst close co-operation with the Department of Health was helpful in managing political concerns and enabling Ministers to account for NHS England's work, the Board of NHS England was independent and did not need agreement or "permission" from Ministers to proceed. It was NHS England's intention to finalise the specifications before the restricted period but this would not be rushed to meet an election deadline. The Chair noted that some of these issues were beyond the scope of the review and belonged in more generic areas of NHS policy.

5. Learning from engagement

Michael Wilson outlined some of the learning from the Trust visits, not least how differently each centre works. Claire McDonald gave a brief overview of what we were told from the children and young people's events held across the country.

There was a discussion about some of the key items reported such as patient choice, transition, networking and networks, interdependencies, number of surgeries per surgeon and surgeons per unit.

6. Quality

It was reported that relationships were still strained between units/clinicians, and some attendees expressed continuing concerns about the appropriateness of referrals. NHS England noted that 1. networked care - e.g. as described in the standards, especially between specialist centres - facilitated peer review and benchmarking, which could help to shine a light on practices within and between units; and 2. the transition dashboard was now in use as a quality monitoring tool, with regular situation report phone calls between commissioning teams etc.

Attendees asked about progress on work promised at a previous engagement meeting (from colleagues at the Care Quality Commission (CQC) and NHS England's medical team) on guidelines of how to escalate worries/concerns about referral practices etc.

Action: The review team said they would chase up this piece of work and share any updates.

A suggestion was made that the use of PREMs (patient reported experience measures) be encouraged as a means of comparison. (The Children's Heart Federation and Heartline families have co-created PREMs for heart valve patients and this could offer potential for patients with congenital heart disease).

7. Activity

John Holden updated attendees on the activity analysis work led by Joanna Glenwright. Further information was shared on analysis and the different drivers of change with regards to data. There was then a discussion about what the group thought might be leading to increases in activity other than population change - it was decided that the members of the group would reflect on this and comment in their own time.

Action: The review team would share Ms Glenwright's handout.

The group discussed the progress report and findings from ScHARR (the University of Sheffield's School of Health and Related Research, who are conducting the literature review). Michael Wilson gave a very brief overview of the very latest conclusions from the National Institute for Cardiovascular Outcomes Research (NICOR), about the relationship between outcomes and other factors; although they have not yet published their findings Michael was able to share the headlines of a summary that he had been given in order to write a paper for the Clinical Advisory Panel.

8. Standards and specification

Michael Wilson outlined the differences between the standards and service specification.

A question was asked about the standards and which will have priority and which will impact on whether a service is commissioned or not. It was clarified by the team that no one standard would be weighted more important than another, but that it was clear that some standards were easier to achieve, many of the standards are aspirational and clearly some will be more challenging for units than others.

Michael went on to note that during consultation we would be asking stakeholders which standards they believe to be most important so if in the future standards need to be weighted to align with the budget then this could be informed by knowledge of the level of importance for stakeholders.

9. Consultation and responses

Finally there was a discussion on how responses to consultation would be weighted, and whether more importance would be given to more knowledgeable contributors. It was noted that this issue was discussed at length at the Patient and Public Workshop on 12 May 2014 and the conclusion was that responses would not be weighted.

Michael Wilson went on to explain the review team’s approach to consultation and what needed to be done before consultation. He described the different documents and materials likely to be available for consultation.

John Holden reminded the group of the plenary meeting on 25 July 2014 and requested that any issues the group would like raising at the meeting be sent in advance to the review team.

Peter Weissberg thanked everyone for their participation and closed the meeting.

Question posed to Michael Wilson, Programme Director by Jon Arnold, Tiny Tickers (via email):

Had I been able to attend, I would have asked a question about how the work on improving detection rates will be brought into the work on standards and service specifications.

As part of the Clinical Reference Group, I've already had the opportunity to input on the draft standards. Obviously, the focus of these is from the point of detection onwards, so my question is how the work on detection will dovetail with these standards and form part of the public consultation.

Response from Michael Wilson:

A. The standards and specifications being developed by the review are for CHD services. They will cover the fetal pathway from the point that an anomaly is suspected and the mother is referred to specialist fetal services for confirmation. The initial detection or suspicion of a problem usually happens during the 18-20 week scan which is part of routine maternity services, commissioned by clinical commissioning groups (CCGs) against their own specifications. As this cannot be addressed through the CHD standards, we have set up a separate work stream to focus on improving early detection. It seems likely that the main issues, which are thought to relate to training, workforce and the absence of a national anomaly register, will be best addressed by working with other NHS partners (especially Health Education England and Public Health England) so that it is our initial approach. We will also work with CCGs on any helpful refinements to their commissioning approach once we have clear proposals.

Action Log:

Date:	**Action:**
13 June 2014	Follow up from previous meeting the work with CQC – guidelines on who you can talk to, to escalate worries.
13 June 2014	Send out Joanna Glenwright's handout so Patient and Public Group can share what they believe are the drivers of change re: data/activity analysis – along with slides and minutes.

Patient and Public Group Meeting Attendees

Friday 13 June 2014

Name	Organisation
Professor Peter Weissberg (Chair)	**British Heart Foundation**
Amy Smullen	**British Heart Foundation**
Anne Keatley-Clarke	**Children's Heart Federation (CHF)**
Rohini Simbodyal	**Children's Heart Federation (CHF)**
Sharon Coyle	**Children's Heart Surgery Fund**
Christine Stringfellow	**Down's Heart Group**
Nick de Naeyer	**Evelina Children's Heart Organisation (ECHO)**
Hazel Greig Midlane	**Heartline Families**
Adam Tansey	**KEEPTHEBEAT**
Suzie Hutchinson	**Little Hearts Matter**
Julie Wootton	**Max Appeal!**
Claire Hennessey	**Max Appeal!**
John Richardson	**The Somerville Foundation**
Caroline Langridge	**Young Hearts**

NHS England Representatives

Name	Organisation
Michael Wilson	**NHS England**
John Holden	**NHS England**
Claire McDonald	**NHS England**
Jennie Smith	**NHS England**