Patient and Public Group - Consultation Workshop

12 May 2014

Attendees:

Mike Knapton, British Heart Foundation
Amy Smullen, British Heart Foundation
Rohini Simobodyal, Children’s Heart Federation
Christine Stringfellow, Down’s Heart Group
Nick de Naeyer, Evelina Children’s Heart Organisation
Robyn Lotto, KEEPTHEBEAT
Louise Hall, Little Hearts Matter
Claire Hennessey, Max Appeal!
Bob Ward, Save our Surgery
Caroline Mutton, The Brompton Fountain
John Richardson, The Somerville Foundation
Penny Allsop, NHS England
Claire McDonald, NHS England
John Holden, NHS England

Introduction

Claire McDonald introduced the session and identified the aims as being to:

- discuss consultation materials and methods;
- consider what good looks like; and
- consider what will promote good engagement.

Claire showed some slides that related to what the review team had heard already from the patient and public and clinicians’ groups.

John Holden provided an update on engagement activity highlighting:

- 9 children and young people events over the Easter holiday (engaged with around 100 children and young people and 60 relations and/or carers)
- The new review team is halfway through its visits to units
- Breakfast briefing for MPs and peers
- NHS England governance groups
- A webinar with local government and Healthwatch

John also noted the recent announcement by the National Screening Committee that it is setting up trials to look at pulse oximetry and welcomed this as an example of developing evidence-based practice. There was discussion about the reasons for piloting, given its relative inexpensiveness, but recognition that the test can lead to false positives and that the consequences of that can be significant.
John turned to the session and identified a desire to ensure that the consultation on standards for children and adults is the best it can be; the most effective it can be; where we give people what they expect; and where we make it possible for everyone to make it their own and to turn it into something relevant for them. He emphasised that the experts were in the group and he was keen to be guided by that expertise and to use it to extend the consultation conversations.

Members of the group then identified what they wanted to leave the session with:

- a better understanding of the process over the summer and engagement in that process;
- a sense that we are moving forward and making progress;
- a clearer understanding of how individual members of the group could motivate others to get involved where there is not the same motivator of fear and units closing as there had been in the past; and
- a consultation that promotes equitable services across the country and enables consultants to tell us what standards they would wish to work to.

The consultation needs to reflect the following:

- Be clear and simple
- Be easy to understand
- The standards need to be smart
- People don’t want a long complicated list
- People want to know how the standards differ from the status quo – if children’s services are already ok, what is the case for change?
- We need to have a clear understanding of what we want to achieve – need to say clearly what this is for – so that members of the group can explain the purpose when they are asked
- We are making decisions in 2014 for people who don’t know that they will have children with congenital heart disease – we need to show that we are planning for the future and make clear to them and to the wider population why this work helps
- Need to be clear about what we are proposing and how long it will take to happen

Engagement needs to be:

- Ongoing.
- And we need to maintain 2 way communications throughout the process.

**Consultation methods**

The group discussed:

- Benefits of video and radio
- The need to think about engagement with populations who cannot read and do not use the internet
• Importance of being culturally sensitive and using people who can be trusted to deliver messages – recognising that translation of materials is not always the issue; it may be literacy, so radio and video may be more appropriate
• We need to think about who we want to reach and how best to reach them, recognising that substantial numbers of families will not engage digitally
• The importance of getting a person’s interest quickly so that they can engage – maximum of 10 minutes to encourage someone

And then considered the audiences to try to identify who might be drawn to which approach. A list is attached at Annex A.

The group discussed some of the sensitive issues relating to responses:

• the risk of minority views being “crowded out”
• the suggestion that not all contributions were equal;
• concern that some respondents might use a prepared “script”
• concern that “knowledgeable” respondents would be given same consideration as others; and
• whether petitions are an appropriate response.

John’s view was that we want to encourage as many people as we can to respond - so he was relaxed about whether contributors chose to use their own words or to rely on crib sheets or prepared statements. However, we might well ask people to respond under certain headings and not just freestyle, otherwise analysis of the responses could be unmanageable.

**The purpose of the consultation**

John opened the discussion by explaining that we are consulting on a single coherent set of standards for children and adults which has been derived from three separate sets of standards. The single set of standards will underpin two service specifications: one for children and one for adults. The standards set out what an excellent service would be and are deliberately stretching. John stressed that the consultation is about national standards and not about service reconfiguration. If – in the light of refreshed capacity requirements, application of the standards, and the work on function and form - any significant local service change proposals were to result from this, John thought that it would probably require a separate consultation.

The group briefly discussed the nature of the standards and their evidence base, with some concern that the draft ScHARR report seems to indicate that there is no evidence to support a particular size of unit or model of working e.g. co-location.

John explained that the draft report is subject to quality assurance and the final report may differ in tone and emphasis from the draft. The final findings would need to be reflected in the consultation (whether or not they change the draft standards, the fact that we have looked at the literature is an important consideration).

The group were keen that the consultation needed to encourage professionals to say what they can and cannot deliver.
The group then discussed what messages the consultation needed to include (Annex B) and returned to methods of communication (Annex C).

**Events**

There was discussion about potentially holding (as a minimum) an engagement event in each area hosting a unit, and the need to consider afternoon and evening sessions. A note of caution was given that that format sounded like the one used for Safe and Sustainable, which could be presentationally controversial.

The group also talked about regional events, e.g. to see a video, and the need to reimburse travel expenses to ensure inclusiveness.

There was an understanding that it would not be possible logistically for the national team to run or fund a large number of “town hall meetings”. The group considered alternative ways to ensure geographic spread including planned national and local events being organised by others (including the Somerville Conference and World Heart Day). Support from the review team could either be by way of a resource pack (standard presentation for all meetings) or by attending some but not all. The group noted that if there were to be local events, it would be important to engage with local groups first and ensure that all groups were invited.

John said he would consider how best to work with colleagues in Area Teams to ensure local reach and at the same time asked the group for their thoughts (see box below).

**Resources**

Members of the group asked the new CHD review team to provide a point of contact during consultation for questions that they could not answer locally, and to prepare a resource pack that they can use when talking to others. There was also some discussion about the possible role of area teams in supporting local engagement and with the press. A suggestion for the media was to provide case studies.

**Consultation response**

John was asked what would happen at the end of the consultation. There would be a report setting out what we had asked, what we had heard and how we had responded to what we heard and what (if anything) we could say about what this means for services. He advised that the findings would feed into the final standards and service specifications.

John estimated that the process the new CHD review team is following will mean that there will be a 12 week consultation, then time to consider responses, prepare an analysis, and complete governance in order to finalise the standards and specifications (perhaps another 12 weeks). There would need to be a 6 month notice period that commissioners would need to serve to providers before services could be commissioned against the new specification. This would mean the new standards and specifications could not be
contractually enforced before July 2015 at the earliest. In practice the process may take significantly longer; but at the same time, the standards are widely known and anecdotally we can see that providers are already considering the proposals to determine how they can respond to the challenge to improve services for CHD patients

John asked this group (and will extend the same request to all engagement and advisory groups) for advice on:

- How to sequence activity during the consultation period – for example when would be the best time to hold any events; and
- The groups’ expectations of the national team before and during the process – how could NHS England support local efforts to make this an effective consultation

And invited everyone to come up with

offers and suggestions of what we can do collectively and locally. NHS England could consider how it could support events organised by others (including materials, attendance etc.) organised by others.
Who – i.e. which audiences are we trying to reach?

THESE ARE THE PROPOSALS FROM PATIENT AND PUBLIC ATTENDEES AT THE MEETING AND NOT A DEFINITIVE NHS ENGLAND POSITION...

- Children and young people with CHD
- Adults with CHD
- Black, Asian and Minority Ethnic (BAME) communities - faith and cultural groups - Ethnic Minority health group
- Individual units - the institutions and the people within
- Representative organisations - local and national
- Parents - bereaved also
- Local government
  - Education system
  - Health and Wellbeing Boards
  - Social Services
  - Special Education Needs (SEN) groups together in Sept
- Assembly members
- MPs and Peers - their constituents
- Healthwatch - local and national
- Clinicians and NHS employees
- Research scientists
- Health Education England
- Those for who this is not relevant - general public - value for money may be possible concern
- Patient and Public Involvement Groups
- NHS England Patient and Public Voice links and groups and its audiences
What - i.e. what things must the consultation cover?

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- The group felt strongly that the consultation document must begin with a restatement of the “case for change”. Their suggestions on this included:
  - We are consulting because we want things to make sense, we want a single set of standards, we are looking for continuous improvement that is being managed, not perfection.
  - We want to have value for money (VFM) and the best possible outcomes.
  - We need to recognise that there is an opportunity cost for other cardio treatment.
  - We need standards to enable commissioning and to improve services.
  - We need to ensure that we have the same standards for adults as we have for children.
  - We need processes because complex children become complex adults.
  - We recognise that all units are safe but there is variation in practice.

- Standards across the tiers - some are excellent - all should be.

- Need to ensure that we portray sub-specialisation in a way that is not a criticism – all units cover a broad range of services, but clinicians need to recognise where their competence ends and where they need another operator to come in or when to refer to another unit.

- Explain the knotty issues - numbers/subspecialisation/experience and professional expectations and attitudes of clinicians.
How – i.e. which methods of communication should be used?

THESE ARE THE PROPOSALS FROM PATIENT AND PUBLIC ATTENDEES AT THE MEETING AND NOT A DEFINITIVE NHS ENGLAND POSITION...

- Facebook (firm favourite from some) with regular and intermittent users
- On line forums
- GP surgeries (e.g. literature drops or TV displays)
- Social media - You Tube etc
- This can be done with support from the central team
- Have a National Face/Voice/Message for the campaign - debate about how local the interpretation/delivery should be and whether a local face can be divisive
- 10 minutes proposed as optimum time for video
- local discussions prompting different viewpoints
- nationals approach with ability for local introduction
- Possibility of a non partisan celebrity being used that all could agree with and would provide a national face (suggestions included national famous TV figures)
- Easy read with details as extra as the standard approach
- Look at the Schools Foods Standards as a complicated set of standards that was honed down to A4 sheet on a tea towel  http://www.schoolfoodplan.com/2-standards/
- Made culturally relevant for different audiences, for example an oral translation by a native speaker or asking ethnic minority health group to participate
- Animation – using the “cartoon” techniques which the Kings Fund have used to explain e.g. NHS reforms
- Video from parents or young people explaining the consultation
- Question around each standard
- Core Scripts - to work with local groups
- Standard set of words (“core script”) - possibly pre consultation, to “warm people up”
- Link to KHIDMAH events - Robyn Lotto has passed details to Claire