Meeting with local authorities hosting congenital heart disease specialist units and associated Healthwatch organisations

8 January 2014

Introduction

Upper tier local authorities which host specialist congenital cardiology centres, and associated local Healthwatch organisations, met representatives of NHS England to discuss the new review of congenital heart disease. Lincolnshire County Council was also invited to the meeting. While not hosting a specialist service, Lincolnshire was one of the authorities that referred Safe and Sustainable to the Secretary of State for Health. A list of those invited and those who attended this meeting is attached at Annex A at the end of this report. The purpose of the meeting was for the review team to provide an update on their work, to establish a dialogue and to seek advice on how best to engage with local government more widely in the future.

Presentations

John Holden welcomed participants to the meeting and emphasised the importance of their contribution to ongoing thinking. He gave an update on the review but emphasised that the update should not contain surprises/new material. He noted that the aim was to build on work done to date where that was valuable. In those areas that were controversial or perhaps not fully worked through in the previous work, the new review would take a fresh look. John identified the different strands of work:

- alignment of three different sets of standards dealing with any ambiguity and ensuring that they reflect the model of optimum care;
- analysis using latest data focusing in the first instance on specialist inpatient care and later on other aspects of the congenital heart disease (CHD) service and other interdependent services;
- using the analysis to enable modelling of functions and form to meet capacity requirements;
- commissioning and change model – looking at how NHS England will commission for change ensuring that service specifications translate into practical improvements for patients;
- making sure that information about the performance of congenital heart services is provided in a way that is understandable and timely; and
- early diagnosis with better and less variable ante-natal and neo-natal detection rates.

John emphasised that the new review team are committed to making the process as open as possible. He highlighted the potential tension between pace and inclusivity. While some people would like the new review to complete its work rapidly, there is a need to ensure that there is engagement. He also noted that the timescale set for this work would need to take account of a number of factors including local Government elections. John presented the latest thinking on the timing of the consultation on standards which is likely to be late Spring 2014.

Michael Wilson then presented feedback to date from groups representing patients and public, clinicians and providers. He drew out some of the key messages being raised across groups and explained how the new review was responding.

There were opportunities during and after the presentations for questions and answers. We note these below.

Questions and answers

The review and timing

Q. If this is a new process, how can you justify importing work from the previous (i.e. Safe and Sustainable) process – as referred to in Professor Grant's letter to the Secretary of State for Health dated 31 July 2013?

A. We have made a judgement that to start from the beginning again would cause very significant delay and be very demoralising for those clinicians and others who gave up so much time to support the development of standards. But we are not taking previous work without questioning it. We have taken the Safe and Sustainable standards and looked at them afresh. Our medical director Bruce Keogh has reminded the standards groups of the need to identify best practice, rather than best fit with current provision. The standards groups are now working to finalise standards that cover the whole life course. This will form the basis of a consultation this year.

Q. What is the timetable for the new review?

A. By June 2014 we will have put in place many of the building blocks for the new arrangements but we will not have finished by then. Specifically, work will be well advanced on the standards, but we will not have got to the stage where we are specifying providers – and, depending on our findings on capacity requirements and the commissioning process selected, we may never do so. By the end of the year we hope to have an agreed specification which will inform future commissioning. We understand the need to work at

pace, but this cannot be at the expense of taking the time to get things right or the need for inclusivity.

Q. Are the new review team aware of the need to respect the restricted period of local Government elections in May 2014?

A. Yes. We do not intend to consult on this particular set of service specifications during the restricted period.

Q. Is the new review team adequately resourced?

A. We are taking steps to make sure that the review has the resources required. We have always recognised that this is an important piece of work but we need to increase our capacity to deliver at a pace that respects the need for widespread engagement at every stage of this process.

Q. Can the new review team be as open as possible on timing so that local stakeholders can plan effectively?

A. We understand that sharing information about timetable will help everyone to plan more effectively. There has been a broad consensus that the review needs to have the work on standards at its core. We have developed a reasonably detailed timeline for this work which we have shared today. The timetable for other parts of our work programme, for example, describing the form and functions of the future system will become more apparent as we move forward. Some of the work on the other objectives can be undertaken in parallel with the work on standards, but some will, necessarily, need to wait until the standards have been signed off.

Q. What is the likelihood that future work on commissioning / reconfigurations will be stopped because of the General Election in 2015?

A. We are not working in a vacuum and we need to take into account a range of factors nationally and locally, including elections. However, NHS England's Board is clear about its responsibility to improve outcomes for patients and this will always be at the heart of its work and the decisions it takes.

Scope

Q. Will National Institute for Cardiovascular Outcomes Research (NICOR) be looking at a range of determinants that impact congenital heart disease?

A. Yes, we have asked NICOR to undertake a new assessment for us on what the data is telling us and what factors influence outcomes. We have made it clear that we need to know where the data is and isn't showing there are correlations in relation to outcomes; and where it is not conclusive either way. We are also commissioning, separately, an evidence review which will look at determinants.

Q. Should we be encouraging pre-conception counselling in those social and community groups particularly affected with CHD?

A. We will consider this in relation to what we find out about the impact of different determinants.

Q. Will the new review team be looking at population forecasts?

A. Yes, we plan to look at this when we are considering future capacity. We will also look at other variables including changes in survival rates and advances in clinical practice.

Communication and engagement

Q. Most of the communication to date seems to have been aimed at health professionals. How is the new review team going to communicate with children and young people; parents and carers?

A. The new review team has set up an independently chaired Patient and Public group comprising a range of charities, support groups and umbrella bodies. We have ensured that all areas with congenital heart disease specialist units are represented. We are planning an engagement event with children and young people and also looking at what we can do to better connect with Black and Minority Ethnic (BAME) groups. In addition to that, John Holden's blog is aimed at a general audience.

Q. How are the new review team going to ensure that Health and Wellbeing Boards and Oversight and Scrutiny Committees understand that the scope of the review covers adults as well as children?

A. We are looking at how we communicate and what other methods over and above the blog we can use. We are working with the Local Government Association, Healthwatch and the Centre for Public Scrutiny to ensure that the relevant boards and committees are aware of the review process.

Q. Will the new review team be including Health and Wellbeing Boards in their thinking on governance of their work?

A. We recognise the important role Health and Wellbeing Boards play and have started to engage with them. Representatives are here today. We are looking at how we can best engage with Health and Wellbeing Boards in a manner that is appropriate to the review, and would welcome any suggestions local authorities might have.

Q. Is the new review team going to work directly with Oversight and Scrutiny Committees (OSCs)?

A. We recognise the important role OSCs play both in helping us to understand the issues from a local perspective, and in mitigating the risk of future challenge. We have already attended four different joint OSCs. We are looking at how we can best engage with OSCs in a manner that is appropriate to the review fair to all interested parties, and would welcome any suggestions local authorities might have. We are in discussion with the Centre for Public Scrutiny to help us to ensure that scrutiny committees are aware of the review.

Q. There have been concerns expressed about the earlier work: that the membership of influential groups was not representative of the country as a whole, and was skewed towards London and the South. How will the new review avoid the same problems?

A. We have ensured that doctors and managers from every hospital providing specialist congenital heart disease services have been invited to our engagement and advisory groups. In the case of the Clinical Advisory Panel, it is true to say that members, in particular from the Royal Colleges, tend to be from the South. But we need to remember that they are present as representatives of their Colleges and not their places of work, and that they

were typically elected to their position by College members. We are satisfied that we have taken appropriate steps to manage any risk of in-built bias.

Q. The last review found conflicts of interest. We need openness this time.

A. We have agreed a robust process for dealing with potential conflicts of interest and will in due course publish a register. We want to work in an environment of openness and will continue to ensure that we make publicly available notes of meetings and so on.

Q. Are you getting advice from geneticists?

A. In the work we are undertaking on early diagnosis we are speaking to specialists but, so far, not geneticists.

Q. Are you getting primary care input?

A. We are not speaking specifically to primary care providers. At the moment, the major part of our work focuses on the standards for hospital settings, not primary care.

Reconfiguration

Q. Will there be an opportunity for discussion about how services will be delivered locally and regionally?

A. The consultation which we are currently planning will focus on national standards and not on reconfiguration. The standards will set a consistent national expectation for patients, wherever they live. But we expect that there may be different regional and local approaches to how the standards are achieved.

Q. Might there be scope for services to be grouped together differently and to have centres of excellence?

A. NHS England is consulting on specialised services and how they might be delivered. The new review team will ensure that we link with the wider strategic programme.

Q. What are you going to do about access?

A. We have heard different views on access. Some people have said that they would be willing to travel as far as it takes to get the best service; others have said that they want the service as near as possible. What we want to ensure is that, wherever someone lives, they have access to an excellent service which is resilient to events. And that wherever that service is, patients and families are getting the support they need when they use the service.

Q. Will it be possible for people to choose where they are treated?

A. We have affirmed that patient choice still applies and we will make that clear in the standards.

Q. Will NHS England want to commission sub-nationally and if so could this be done for example through the 4 regional teams that cover the country?

A. We are considering the best approach for commissioning, and there may be a number of potential approaches, but the specification for services will be the same across the whole country.

Q. Previous reviews have fallen because there has been inadequate local engagement. If there is a consultation on reconfiguration, local bodies (including Oversight and Scrutiny Committees) and residents need to know the rationale

A. We agree. We are keen to work with local authorities to ensure that this happens.

Q. Will it be possible to have early engagement before consultation on any reconfiguration plans so that local government scrutiny can be mobilised?

A. We recognise the importance of local scrutiny and are keen at all stages to ensure that it is fully involved. We hope that local authorities here today will be able to help us to this end.

Attendees

Organisation	Name	Position
Birmingham City Council	Cllr Susan Barnett	Chair of the Health and Adult Social Care Overview & Scrutiny Committee.
Cambridgeshire County Council	Jane Belman	Scrutiny and Improvement Officer
Cambridgeshire County Council	Cllr Kevin Reynolds	Member of Adults Wellbeing and Health Overview and Scrutiny Committee
Leeds City Council	Steven Courtney	Principal Scrutiny Advisor to the Leeds Health Scrutiny Board
Leeds City Council	Cllr John Illingworth	Chair of Health Scrutiny at Leeds City Council
Leeds City Council	Cllr Lisa Mulherin	Executive Member for Health & Wellbeing
Leicester City Council	Cllr Michael Cooke	Chair of Health and Wellbeing Scrutiny Commission
Leicestershire County Council	Cllr Ernie White	Chair of the Health and Wellbeing Board
Lincolnshire County Council	Simon Evans	Health Scrutiny Committee
Lincolnshire County Council	Cllr Christine Talbot	Chairman Health Scrutiny Committee
Manchester City Council	Ged Devereux	Senior Strategy Manager, Public Health
Oxfordshire County Council	Claire Phillips	Senior Policy and Performance Officer
Southampton City Council	Cllr. Paul Lewzey	Back Bench member of the Health and Wellbeing Board
Southampton City Council	Jessica North	Senior Communications Officer, Public Health
Southampton City Council	Cllr Dave Shields	Cabinet member for Health also Chair of the Health & Wellbeing Board
Westminster City Council	Mark Ewbank	Scrutiny Officer

Healthwatch Birmingham	Paul Devlin	Chief Executive Officer
Healthwatch England	Shona Johnstone	Public Policy and Partnerships Manager
Healthwatch Leeds	Pat Newdall	Healthwatch officer
Healthwatch Leicester	David Barsby	Policy and Partnership Officer
Healthwatch Leicestershire	Eric Charlesworth	LLR representative on the UHL Board and the East Leicestershire and Rutland Clinical Commissioning Group
Healthwatch Liverpool	Edwin Morgan	Chair
Healthwatch Manchester	Neil Walbran	Chief Officer
Healthwatch Oxfordshire	Larry Sanders	Chairman
NHS England	Penny Allsop	Project Manager
NHS England	John Holden	Director of System Policy
NHS England	Claire McDonald	Engagement Advisor
NHS England	Jennie Smith	Project Co-ordinator
NHS England	Michael Wilson	Programme Director