

Email address: bruce.keogh@nhs.net

30 August 2013

Dear John,

Thank you for the work that you have done to develop standards for adults with congenital heart disease. I am aware that you have been in this for the long haul and I want to assure you that your work remains vital for the new review.

I have asked Professor Deirdre Kelly who was leading the clinical work on how to implement the Safe and Sustainable model with her Clinical Implementation Advisory Group to oversee the process of bringing to a conclusion the work on additional standards for children's congenital heart services and I would be grateful if you would work with her to make a joint recommendation on a single combined set of standards.

I would like to take the opportunity to highlight three points that have been raised with us as important, and ask that in your work you take them into account:

Firstly, the scope of the new review – although yet to be finalised – is different from any previous work in that it is comprehensive and includes the whole patient pathway:

- Fetal diagnosis of congenital heart disease
- Pre-natal care (including care of women whose unborn child has suspected or confirmed congenital heart disease)
- Care for children and young people
- Transition from children's services to adult services
- Care for adults
- End of life care
- Care and support for families suffering bereavement

It is important therefore that the standards we set now, building on those developed by the Safe and Sustainable process, cover the whole pathway. I would be grateful if you would work with Tony Salmon who has been leading the group developing standards for children to ensure that there is a comprehensive and consistent set of standards covering the whole pathway. We are still considering the full scope of the review, including its relationship to other heart disease in children, ECMO and transplant services. If there is any expansion of scope this will be agreed by the

advisory group which I am establishing, and which you have been invited to join, so you will be able to consider whether this will require any further work on standards.

Secondly, I wanted to pick up on a concern that has been voiced by a number of people in the listening events that we have organised. It has been said on more than one occasion that some of the standards previously developed were 'fudged', that is to say that they took too much account of whether existing providers were already meeting them or would be able to meet them in the future. Examples would be the definition of and requirements for co-location. My colleague Bill McCarthy set out NHS England's position clearly in the paper discussed by our board on 18 July 2013. The aim of the new review is to ensure that services achieve the highest possible quality, within the available resources, now and for future generations. It is important therefore that the standards set out what is needed to achieve this. As we are seeking to improve services it is quite likely that there will be some standards that are very challenging for existing providers. It is important that the standards we set represent the ideal. If it transpires that one or more provider is unable to meet some of the standards this is a process that will be managed by commissioners and does not need to be taken into account in setting the standards. This may not have been stated so clearly at the time your group were developing the ACHD standards so I would be grateful if you would consider whether they are aligned with this approach, and if not what further work needs to be done.

Thirdly, NHS England has set out principles for the new review that include transparency and evidence. We have said that we will be clear about the nature and limitations of the available evidence and about any intention to rely on expert opinion in the absence of evidence. I would be grateful therefore if you could consider how this applies to the standards you have developed and advise me accordingly.

Finally, let me once again thank you, and through you those who have worked as part of your group, for the hard work that you have already put in and for your continued commitment to see the task through.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Bruce Keogh', with a horizontal line underneath.

Professor Sir Bruce Keogh
National Medical Director, NHS England

Cc: Dr Tony Salmon
Professor Deirdre Kelly