



Dr Aaron Bell and Professor David Anderson Evelina London Children's Hospital St Thomas's Hospital Westminster Bridge Rd London SE1 7EH National Institute for Cardiovascular Outcomes and Research 3rd Floor, 170 Tottenham Court Rd London. W1T 7HA T: 0203 108 3928 E: enquiries-nicor@ucl.ac.uk W: www.ucl.ac.uk/nicor

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Dear Dr Bell and Professor Anderson

Many thanks for your response to the 2012-15 NICOR data that showed a higher than expected early mortality for the Norwood procedure, for the second year running. It is very important to acknowledge that this was an 'alert (i.e. green flag)' rather than an 'alarm (red flag)' and we recognise this in our response, although noting that this has now occurred in consecutive years for the same procedure. We understand that this reflects, at least in part, the lag period inherent in reporting 3 yearly cohorts (itself necessary due to the relatively small numbers of patients undergoing individual congenital cardiology procedures).

The report gives a further detailed, open and clear account of the outcomes after the Norwood procedure, on the whole for the initial treatment of hypoplastic left heart syndrome (HLHS), and the change of clinical practice which began over a year ago. In fact these wide-ranging and sensible changes to clinical practice and governance arrangements were begun prior to our notification to you about your outlier status for the 2011-14 cohort of patients after this procedure. In particular you have again highlighted appropriately the importance of internal surveillance with regular reviews of practice and outcomes. Although HLHS is recognised as being a relatively very high risk condition with a significant probability that changes in mortality occurring entirely by chance, we have not been provided with a detailed case by case breakdown as last year, and have therefore assumed that the risk profile of the patients in the 2014-15 cohort has not changed materially. We also note the drop in external referrals to ELCH and the shift towards a hybrid pathway for the majority of HLHS patients.

There is *no evidence, therefore, to suggest that any further action needs to be taken*, however, we recommend that if your internal surveillance suggests no improvement in outcomes for the 2013-17 cohort, then this should be used as a trigger to invite an external review of your practice in this regard.

With respect to the coding issues highlighted and improving the accuracy of the procedures reported, there will be further changes with respect to the 2013-17 NCHDA analyses to address this, including the incorporation of a new reporting category for HLHS hybrid strategy procedures.

We understand that your report is already designed to be posted on the NCHDA NICOR website to provide better context for this 'alert' line outcome. We shall go ahead with this linkage as part of our

2012-15 Annual Report due for publication in the next few weeks (exact date of publication not yet finalised).

Please contact us if you have any further questions, or concerns. We must again emphasise the importance of maintaining close surveillance of the real-time outcomes for all congenital heart conditions in the interim before the next annual report.

Yours sincerely,

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Rodney Franklin, Clinical Lead National Congenital Heart Disease Audit, NICOR

Alan Magu

Alan Magee, BCCA President-elect

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Tim Graham, SCTS President