Improving risk adjustment in the PRAiS (Partial Risk Adjustment in Surgery) model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes

Christina Pagel,1* Libby Rogers,1 Katherine Brown,2 Gareth Ambler,3 David Anderson,4 David Barron,5 Emily Blackshaw,6 Sonya Crowe,1 Kate English,7 Rodney Franklin,8 Emily Jesper,9 Laura Meagher,10 Mike Pearson,11 Tim Rakow,6 Marta Salamonowicz,12 David Spiegelhalter,11 John Stickley,5 Joanne Thomas,9 Shane Tibby,4 Victor Tsang,2 Martin Utley1 and Thomas Witter4

1Clinical Operational Research Unit, University College London, London, UK
2Cardiac, Critical Care and Respiratory Division, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK
3Department of Statistical Science, University College London, London, UK
4Cardiology and Critical Care, Evelina London Children’s Hospital, Guy’s and St Thomas’ NHS Foundation Trust, London, UK
5Cardiothoracic Surgery, Birmingham Children’s Hospital, Birmingham, UK
6Department of Psychology, King’s College London, London, UK
7Cardiology, Leeds Teaching Hospitals NHS Trust, Leeds, UK
8Paediatric Cardiology, Royal Brompton & Harefield NHS Foundation Trust, London, UK
9Sense about Science, London, UK
10Technology Development Group, Dairsie, UK
11Statistical Laboratory, Centre for Mathematical Sciences, University of Cambridge, Cambridge, UK
12Children’s Heart Federation, Witham, UK

*Corresponding author c.pagel@ucl.ac.uk
Declared competing interests of authors: Christina Pagel, Sonya Crowe and Martin Utley report personal fees from University College London Consultants, outside the submitted work, from royalties from the sale of the original PRAiS software in 2013. No fees were received for work in this project. Rodney Franklin reports that he is Clinical Lead of the National Congenital Heart Disease Audit (NCHDA) within the National Institute of Cardiovascular Outcomes Research. Katherine Brown reports grants from Great Ormond Street Hospital Children’s Charity (grant number V1498) and the National Institute for Health Research (for Health Services and Delivery Research programme projects 10/2002/29 [Brown KL, Wray J, Knowles RL, Crowe S, Tregay J, Ridout D, et al. Infant deaths in the UK community following successful cardiac surgery: building the evidence base for optimal surveillance, a mixed-methods study. Health Serv Deliv Res 2016;4(19); and 12/5005/06 [under way]] outside the submitted work. Katherine Brown also sits on the steering committee of the NCHDA.

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Plain English summary

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Plain English summary

The risk of death for children undergoing heart surgery depends on their heart condition, the operation they have, their age and weight, and whether or not they have other health problems (called comorbidities). Previously, we developed a formula using these risk factors to estimate the chance of death within 30 days of surgery. The formula was used by the national audit body, contributing to the suspension of surgery at one unit in 2013 and the emotive media coverage surrounding this.

We aimed to:

1. improve the risk prediction formula by incorporating more information about comorbidities
2. develop online material to help people to understand how the NHS monitors children’s heart surgery.

For aim 1, the analysts worked with a clinical expert panel to incorporate more comorbidity information, using national data from 2009 to 2014, leading to a better formula. The national audit body and hospitals are now using this updated formula to monitor survival rates.

For aim 2, we wrote first drafts of the web content in May 2015. Over the following year, we held four sets of two workshops (one workshop with parents of children who had undergone heart surgery and one workshop with other potential users, such as press officers) to codevelop the website content. The workshop participants drove the development of the website’s key messages, as well as the language, layout and data presentation. As the website evolved, we carried out formal tests to see if one way of explaining the concepts worked better than another.

The website (http://childrensheartsurgery.info/) was launched in June 2016; it was very well received and was endorsed by charities, clinicians and the audit body.
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