

INTRODUCTION

Each year in the UK, approximately seven thousand children are born with a heart defect (congenital heart disease). Congenital heart disease covers a wide range of disorders from relatively minor (such as a small hole in the heart) to more severe conditions where a child's heart cannot function without medical intervention. About half of all children born with a heart defect will need heart surgery at some stage in their childhood. However, these operations are technically challenging to perform, and sometimes surgery carries substantial risks. Complex surgical procedures on extremely small hearts are among the most technically challenging in modern medicine. Understandably, patients, families, health professionals, and society in general are concerned to know that the outcomes of these procedures are being properly monitored, sometimes called quality assurance.

Survival to 30 days after heart surgery in children has been improving steadily over the last 20 years and now over 97% of children survive to at least one month after surgery. However, the risk of a poor outcome after surgery is very different for different heart defects and is also affected by other factors such as the age of the child and other health problems the child may also have. So when monitoring outcomes for hospitals we need to be sure we are taking into account how risky the procedures they are performing are as well as we can.

Since 2000, all UK specialist hospitals have contributed data on all procedures performed in children to the National Congenital Heart Disease Audit (NCHDA), one of the national audits managed by the National Institute of Cardiovascular Outcomes Research (NICOR). Each child's survival status is independently obtained from the Office of National Statistics (ONS) and NICOR has published survival statistics for each hospital for individual procedure categories online since 2007. Since 2013, NICOR has also published annual reports of survival outcomes across all operations performed on children with heart disease within each specialist hospital.

To monitor outcomes as fairly as possible, NICOR uses statistical methods to see whether outcomes from each hospital are in line with "what we would predict" after taking into account how risky the procedures were. So while monitoring outcomes by counting survivors in different centres seems straightforward, unfortunately it is not

that simple (whether in congenital audit or elsewhere). We want to help people explore what the published audit data actually means and how we can use the results.

TABLE HEADING

Below is a table of the results published by NICOR for 2010-2013.

For completeness and to aid interpretation, we have added some extra columns to the published table.

FIGURE HEADING

The graph shows a summary of how each specialist hospital's actual 30-day survival rate over 2010-2013 compared to the predicted survival. This graph matches that published by NICOR. Please see explanations below and FAQs to interpret this graph.

TABLE + FIGURE HEADING

This shows the table combined with the graph – the graph has been flipped on its side to show the same information next to the relevant information for each hospital.

Generic FAQs about the chart

Q1. Why do the plots have different coloured areas?

The outcomes of surgery can vary from one hospital to another for a number of reasons. One important reason is “chance factors” that affect outcomes that have nothing to do with the standard of care that is offered by a hospital and cause a hospital to have more or fewer survivors than predicted from the statistical method. This does NOT mean that we have observed a “genuine” difference. For example, we might observe that Hospital A has more survivors than predicted this year. If this is due to chance factors, then, next year, it is just as likely that A has fewer survivors than predicted. This is similar to flipping a coin 10 times – we would predict “5 heads” but would not be surprised to get 4 or 6 heads. We would not assume that getting 4 or 6 heads was because the coin was biased but would put it down to chance. But if we got no heads out of 10 flips, then we would start thinking the coin might be biased.

The different coloured regions on the graph show how likely it is that the differences between a hospital's actual outcomes and what was predicted are due to these chance factors, so that we do not draw "rash" conclusions.

Q2. What does it mean if a hospital falls inside the white area?

Congenital heart disease covers a wide range of disorders and the more serious and complex heart defects remain a significant cause of death in childhood.

In publishing the outcomes after surgery, we want to try to be "fair" to the clinical teams. So reporting of outcomes has to take account of (1) the many different diagnoses and additional health problems that patients can have, (2) the wide range of the surgical operations performed, and (3) differences in complexities of surgeries performed between hospitals. A statistical method is used to try to take these three issues into account to estimate a hospital's predicted survival percentage each year. To allow for the influence of "chance factors", we then estimate the range of survival percentage within which we predict each hospital's actual survival rate to be each year. This predicted range is the white area in the plot. If a hospital's results are inside the white area then this means that the actual survival is in line with what is predicted, given the complexity and number of surgeries that the hospital performed in that time period.

We would not expect any hospital's results to be *exactly* what is predicted by the statistical method (which would be like throwing exactly 50 heads in 100 flips of a coin!), which is why there is a predicted *range* (the white area). It would be misleading to rank hospitals by where they appear within the white area because the difference might be down to chance. Which is also why, if two hospitals are within the white area, it is not correct to say that one hospital's results are 'better' than another's. See also Q2 for more on how to interpret a hospital's position relative to the white area.

Q3. What does it mean if a hospital falls outside the white area?

This is a difficult question and so the answer is a bit long!

First, it is important to remember that the size of the white boxes and the position of each hospital's point depends on assuming that the statistical method and the data

used to apply it are both perfect. They are in fact not perfect (but as good as we can currently get them) and so, in a way, the white area is our best estimate of where each hospital's outcome would be, based on previous national data.

So, a single hospital falling outside the white area is in some way "unexpected" and the national audit body want to understand what has happened. However, a hospital can still fall outside the white area just through chance factors (see Q1 above).

If we were looking only at one hospital, there is a 5% (1 in 20) probability that it will fall out of the white area just by chance (with a 1 in 40 probability of being below the white and a 1 in 40 probability of being above).

However, if we are looking at all 14 hospitals at once there's actually a 50% probability (10 in 20) that at least one hospital will fall outside the white area just by chance! This is similar to the difference between flipping one coin and flipping many: if I only flip one coin there is a 50% probability that I'll get one head whereas if I flipped, say, the four coins in a row the probability of me getting at least one head in the four throws goes up to 94%.

So, on average, we'd anticipate half of NICOR's annual reports to have at least one centre outside the white area, either above or below, by chance alone. This is why it is important not to overreact when a hospital is outside the white area.

That said we do want to know whether there could be another reason for a hospital to have fallen out of the white area which could include: poorer data quality; unusual patients that are less well accounted for by the statistical prediction method or something not going quite right in the pathway of care. This is why, when a hospital falls outside the white area, the hospital and the national audit body examine the data and their clinical processes in more detail to try see if there's anything to worry about (if the hospital is below the white – see also Q5) or if there's something the other hospitals can learn (if the hospital is above the white).

Q4. What does it mean if a hospital falls in the dark area?

If we were looking only at one hospital, there is a 1 in 500 probability that it will fall in the dark area just by chance (with a 1 in 1000 probability of being in the dark grey area and a 1 in 1000 probability of being in the dark blue area).

If we are looking at all 14 hospitals at once there's still a low probability (1 in 30) that at least one hospital will fall in the dark area just by chance.

Q5. What happens if Hospital X is outside the white area with worse than predicted survival?

A hospital can have an outcome that is outside the white area for many reasons (see answer to Q3 above). One cause for this finding is that the data submitted is of poor quality. The first step undertaken by the NCHDA is to check whether this is the case and published results have been through a quality control process with the hospital in question to ensure, as far as possible, that this is not the case. A further reason may be that some of the patients are unusual with more complex or rarer health problems, and that these are less well accounted for by the statistical prediction method. It could also just be due to chance factors. The final reason the NCHDA consider is that there is a potential problem in the pathway of care and it is important to either rule this out or start to improve care if the national audit body decides that this is the reason.

If a hospital is outside the white area with worse than predicted survival, the National Congenital Heart Disease Audit Steering Committee which includes the Presidents of the Society of Cardiothoracic Surgeons and the British Congenital Cardiac Association is notified. The Committee in turn notifies the Medical Director and the lead doctor for congenital heart disease at the hospital in question and a detailed examination of the hospital's results takes place. There are established and published procedures involving the Royal College of Surgeons and/or the Care Quality Commission which can be put into action if the detailed assessment raises concerns about care [*link to national guidelines about to be published*].

The report on individual instances like this would then be published online by the national audit body, alongside the relevant NHDA Annual Report.

Q6. Which hospital should I go to?

You can use the national audit data to see how the different hospitals are doing compared to what is predicted from the statistical model (see answer to Q2) for a particular time period. You can also use the national audit website to explore how

many operations of each type a hospital does and survival outcomes for each of these. However, this cannot, in itself, tell you which hospital you should go to and does not provide proof that one hospital is “better” than any other, and remember that outcomes will vary from year to year through chance factors.

When considering which hospital, there are many factors to take into account, including how well the clinical team know your child and their medical history, any particular medical issues that your child has (for instance, some hospitals specialise in treating children with a particular problem) and how far the hospital is from your home.

You should discuss your child’s care with their specialist cardiologist to determine what the best treatment option is for your child.

Q7. What about my child?

The published data cannot tell you about the risk for your child specifically– this will depend on other factors that are not necessarily captured in the national data. Your child’s specialist cardiologist and/or cardiac surgeon will be able to discuss this with you.

Q8. Is hospital X safe?

The safety or otherwise of a hospital cannot be determined from these data alone.

If the annual audit highlights any potential cause for concern, the National Congenital Heart Disease Audit Steering Committee is notified. The committee in turn, notifies the Medical Director and the relevant doctors at the hospital in question, and a detailed examination of the hospital’s results takes place. There are established procedures involving the Royal College of Surgeons and/or the Care Quality Commission which can be put into action if the detailed assessment raises concerns about the results. The report on individual instances like this is then published online by the national audit body.

While you cannot use these data to determine the safety of a hospital, you can use the data to see how the different hospitals are doing compared to what is predicted from the statistical method (see answers to Q2 & Q3) over a set time period. You can

also use the national audit website to explore how many operations of each type a hospital performs each year, and to find out 30-day survival outcomes for most types of operation. However this cannot, in itself, tell you which hospital you should go to and does not provide proof that one hospital is “better” than any other. Remember too that outcomes will vary from year to year by chance. Although most operations are reported, rare and relatively uncommon operations are not reported separately due to the very small numbers involved and you should speak to your child’s specialist cardiologist for more information on the exact operation being proposed if you cannot find it on the website.

Q9. How reliable is the data?

The data comes from the National Institute for Cardiovascular Outcomes Research (UCL NICOR) which collects national data for the National Heart Disease Audits. All hospitals performing heart surgery in children have to submit their data in a standard format to NICOR and hospitals are independently audited each year as part of a data validation process (to check the quality of the data submitted).

So, the data is of high quality but no large scale datasets are ever perfect and it is inevitable that a few records will not be 100% accurate. However, this dataset is among the highest quality in the world for children’s heart surgery.

Q10. What are the limitations of the data?

Apart from occasional inaccuracies in the data, there are other limits to what the data can tell us about surgery outcomes. There are risk factors not routinely collected (for instance the size or relative severity of a child’s heart defect) which means these cannot be accounted for in our statistical prediction method. Different hospitals might also record the same heart condition slightly differently and this might affect the survival percentage predicted for these hospitals.

These data are also snapshots in time of what happened at each specialist hospital. A particularly challenging patient mix one year (in ways not accounted for in our prediction) or a run of very bad luck could cause a very good hospital to have worse outcomes than predicted. So we need to be careful about reading too much into any single time period.

Q11. Is it all just about survival at 30 days?

No. This data only looks at what happens shortly after surgery. These data cannot tell us about longer term (e.g. 90 day, 1 year or 5 year) survival, or other outcomes such as post-surgery complication rates or the impact of surgery on the child or their family.

Neither can it tell us about how or why a hospital achieved the recorded results, so it cannot, by itself, tell us whether one hospital offers better or worse quality care than any other. These data cannot tell you what the results are likely to be next year. It also cannot tell us anything about what happens to children who never get operated on for whatever reason, since data on these children is not currently submitted to national audit.

Q12. What is statistical risk adjustment and why is it used?

Currently, about 3500 children under the age of 16 have heart surgery each year in the United Kingdom and Republic of Ireland and overall 97% of children survive to at least 30 days after surgery. However, congenital heart disease covers a wide range of disorders, from relatively minor to more severe conditions and complex heart defects remain an important cause of childhood mortality.

In publishing the outcomes after surgery, we want to try to be “fair” to the clinical teams whose outcomes are being reported. To do this, the reporting of outcomes should take account of the many different diagnoses and additional health problems that patients can have, the wide range of the procedures performed and differences in complexities of procedures performed between hospitals. Taking account of such different features is called “risk adjustment”. For example, a hospital that treats difficult cases is not expected to have the same percentage survival as a hospital that does not get so many difficult cases referred to it. If both hospitals offer the same standard of care, we would expect a lower survival percentage at the hospital that sees more of the difficult cases. By adjusting for the known risks in the patients that a hospital treats, the statistical method can be used to predict a survival percentage for each hospital.

Q11. What is the risk adjustment method used by National Audit?

The National Audit body uses a risk adjustment method developed by researchers at Great Ormond Street Hospital and University College London called PRAiS (Partial

Risk Adjustment in Surgery). The underlying methodology of this method is published in the academic literature [[link](#)] if you are interested in learning more details.

Q12. Are there any limitations to risk adjustment?

Yes there are. Risk adjustment allows for fairer comparisons to be made between hospitals but it still cannot make it completely fair. It is always 'partial' and there will always be important risk factors that are not routinely recorded and so cannot be captured by risk adjustment methods. Risk adjustment methods are developed and calibrated on historical data (typically at least a year out of date) and cannot necessarily adjust or account for future changes to the way data is collected (for instance more complete data) or new methods of surgical or medical management.

Q13. Why do the hospitals that do more operations have narrower white ranges?

If a hospital does not carry out many operations, then a run of good or bad luck ("chance factors") can have a large impact on their overall survival rate, and so we need more leeway between actual and predicted survival in order to rule out the influence of chance factors. The white ranges get narrower as the hospitals do more operations.