



Understanding Children's Heart Surgery Data: A Cross-Disciplinary Approach to Codevelop a Website

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Risk-adjusted survival statistics after children's heart surgery are published annually in the United Kingdom. Interpreting these statistics is difficult, and better resources about how to interpret survival data are needed. Here we describe how a multidisciplinary team of mathematicians, psychologists, and a charity worked with parents of heart surgery children and other users to codevelop online resources to present survival outcomes. Early and ongoing involvement of users was crucial and considerably changed the content, scope, and

look of the website, and the formal psychology experiments provided deeper insight. The website <http://childrensheartsurgery.info/> was launched in June 2016 to very positive reviews.

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Since 2000, all UK pediatric heart surgery centers have contributed data on every cardiac procedure to the National Congenital Heart Disease Audit (NCHDA) [1]. In 2013, the NCHDA began using the Partial Risk Adjustment in Surgery (PRAiS) risk model [2–4] to report risk-adjusted 30-day survival outcomes for participating hospitals. That triggered events resulting in the temporary suspension of surgery at one unit in 2013. The attending media scrutiny, impact on families, and public anger [5–9], alongside previous and more recent media coverage on children's heart surgery services [10–15], illustrate the need for resources to support appropriate interpretation of outcome data for families, journalists, clinicians, and decision makers. As part of a project to update the PRAiS risk model (see accompanying papers [16, 17]), we codeveloped an explanatory website aimed at these diverse public and professional audiences (<http://childrensheartsurgery.info/>). It was a multidisciplinary effort and was a transformative and valuable experience for the team (Table 1).

After its launch in June 2016, a *Lancet* editorial [18] commended the website: "Many more areas of medicine requiring risk communication should take this initiative as a long overdue and most welcome example." In *The Annals*, Jacobs and colleagues [19] have discussed the drive for public reporting in the United States and highlighted

the need for resources "that assist patients and families in correctly interpreting complex data." To encourage and help others to undertake similar ventures, here we describe our approach and the lessons we learned.

Overall Strategy

The final output was aimed at two audiences: (1) older patients and families of children who have had/will have heart surgery; and (2) other interested users, including press officers and policy advisors for medical charities or professional bodies, the media, medical communicators, hospital family liaison services, and patient advocates.

An initial draft of content was followed by a process of iterative web development in response to user feedback. We involved both groups of target users from the outset, convening four 1.5-hour workshops for each group over a year. We aimed for four to six participants per workshop, with none attending more than once to ensure a fresh perspective. Participants received only minimal details about the project and were not required to read anything in advance. Workshops began with a brief background presentation and by establishing appropriate consent and permissions (eg, recording). Next, participants were

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Table 1. Team Reflections on Codeveloping Website

<p>Christina Pagel (mathematician): “People really valued having access to this information, presented in a clear and balanced way. I learned that accessibly presenting abstract and difficult concepts takes a huge amount of effort and listening. For anyone embarking on a similar project, do not underestimate the time needed and go for it—it was an eye-opening experience.”</p>
<p>David Spiegelhalter (risk communicator; statistician): “This has been a humbling and invaluable experience. I thought I knew something about communicating statistics, but sitting listening to enthusiastic users struggling to understand concepts made me realize my inadequacy. If we want to genuinely communicate statistical evidence, I am now utterly convinced that users have to be involved from the very start.”</p>
<p>Tim Rakow (experimental psychologist): “Collaboration has been key to the success of this project. I believe we have developed something that should allow people to engage with what would otherwise be fairly opaque information.”</p>
<p>Emily Jesper (workshop facilitator, science communicator): “It was fantastic to feel that researchers involved in the project were so responsive to the user feedback and careful to consider how to sensitively communicate and not afraid to ask participants about issues they were stuck on. It highlighted why involving the audience early cannot be underestimated, and we urge other researchers to adopt this approach.”</p>

each given about 15 minutes to explore website material on a laptop (workshop 2 onward). It was made clear to parents that they were free to leave if they did not feel comfortable to continue. There then followed a facilitated discussion, the focus of which varied between workshops as described below. We tested understanding of concepts and plain language explanations in all workshops. We identified where a concept had not been explained clearly and concepts that were especially difficult to understand. Participants were invited to provide feedback remotely on future iterations of the site (all accepted), and we incorporated their feedback on the near-final web material.

At months 10 and months 12 to 15, we also shared web content with the UK Children’s Heart Federation,

specialists (including three pediatric cardiac surgeons, two cardiologists, two intensivists, and two data experts), and representatives of the NCHDA (including senior clinicians) and incorporated their feedback. Starting 7 months into the project, the psychology team (T.R., E.B.) used a mixed-methods approach to evaluate candidate components for the website. A summary of the strategy is shown in [Figure 1](#).

Evolution of the Site

Workshop Participants

We held four rounds of two workshops, involving 15 participants in the parent workshops and 22 participants in the other workshops. Two team members facilitated each workshop, and two to three others attended as observers.

The feedback from the workshops and psychology experiments fundamentally influenced and changed almost every aspect of the website. Here we concentrate on two major themes: the development of the key messages, and the data display.

Starting Web Material Development

The initial focus was on explaining the key table and graphic in the public NCHDA annual report ([Figs 2 and 3](#)) [1]. The vertical axis in [Figure 3](#) is the ratio of actual survival to predicted survival from the PRAiS risk model. If this value is greater (less) than 1, then survival at that hospital was higher (lower) than predicted. The white area gives the 95% prediction interval for this ratio—essentially the range within which we expect hospital outcomes to lie.

Members of the project team (C.P., D.S., M.P., E.J.) discussed potential content of the web material and plans for the first workshops. Fresh to the material, our web programmer (M.P.) suggested that by rotating the chart ([Fig 3](#)) through 90 degrees, it could become another column on the corresponding table ([Fig 2](#)), which might make the relationship between the table

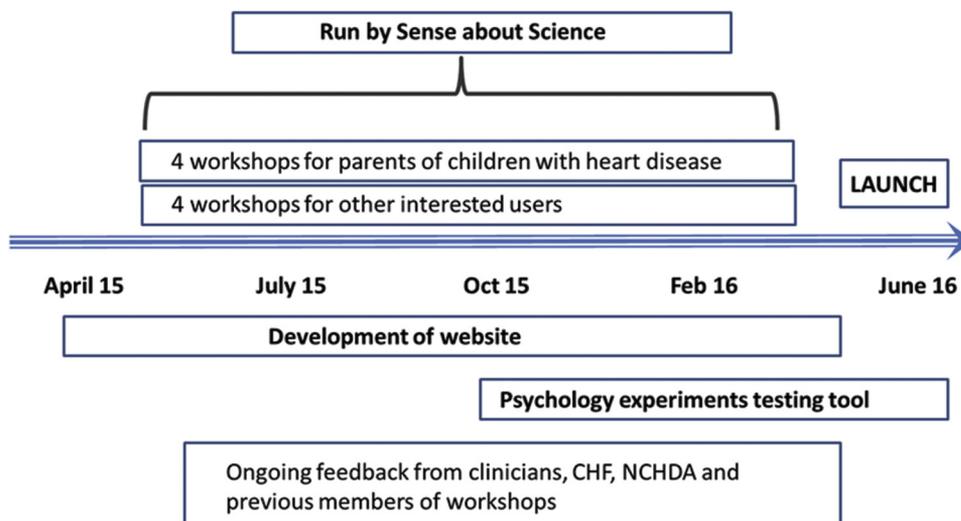


Fig 1. Summary of the development plan for the website. (CHF = Children’s Heart Federation; NCHDA = National Congenital Heart Disease Audit.)

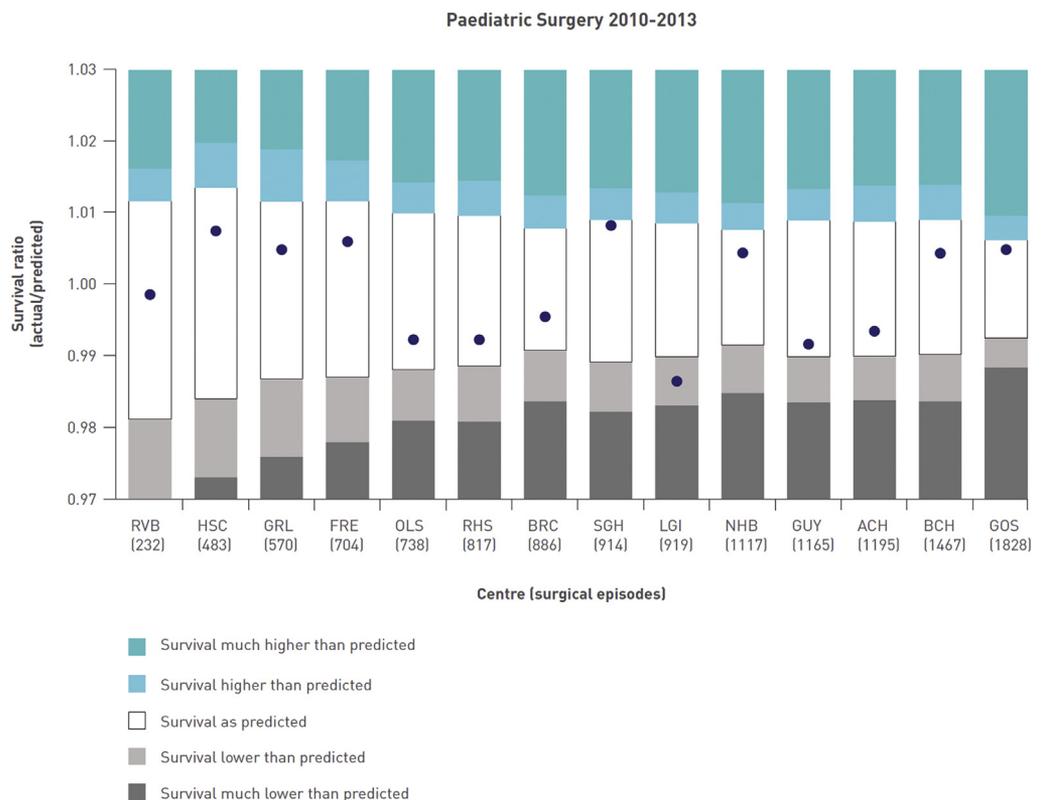
Code	Unit	Surgical Episodes	Actual Survival	Predicted Survival	Actual/ Predicted Survival Ratio
RVB	Belfast, Royal Victoria Hospital	232	98.3%	98.4%	0.999
HSC	London, Harley Street Clinic	483	97.9%	97.2%	1.007
GRL	Leicester, Glenfield Hospital	570	97.9%	97.4%	1.005
FRE	Newcastle, Freeman Hospital	704	97.7%	97.1%	1.006
OLS	Dublin, Our Lady's Children's Hospital	738	97.0%	97.8%	0.992
RHS	Glasgow, Royal Hospital for Sick Children	817	96.8%	97.6%	0.992
BRC	Bristol Royal Hospital For Children	886	97.6%	98.1%	0.995
SGH	Southampton, Wessex Cardiothoracic Centre	914	98.5%	97.7%	1.008
LGI	Leeds General Infirmary	919	96.5%	97.8%	0.987
NHB	London, Royal Brompton Hospital	1117	98.4%	98.0%	1.004
GUY	London, Evelina Children's Hospital	1165	96.4%	97.2%	0.992
ACH	Liverpool, Alder Hey Hospital	1195	96.7%	97.3%	0.993
BCH	Birmingham Children's Hospital	1467	97.0%	96.6%	1.004
GOS	London, Great Ormond Street Hospital for Children	1828	98.2%	97.8%	1.005

Fig 2. Table of outcomes taken from the National Congenital Heart Disease Audit 2010–2013 report [1] accompanying Figure 3.

and the graphic more transparent (Fig 4). We therefore decided to present participants in the first round of workshops with the following: introductory text; NCHDA table of results (Fig 2); NCHDA results graphic

(Fig 3); combined version of the table and graphic (Fig 4); some basic explanatory text for the graphic; and draft answers to example “frequently asked questions” (FAQ).

Fig 3. Example of the key National Institute for Cardiovascular Outcomes Research output, taken from the 2010–2013 annual report [1]. Medical center codes are defined in Figure 2. (Green bars = survival much higher than predicted; blue-green = survival higher than predicted; white = survival as predicted; light gray = survival lower than predicted; dark gray = survival much lower than predicted.)



Unit	Code	Operations	Deaths	Mortality (%)	Survivors	Survival (%)	Predicted (%)	Actual/Predicted	Actual (Dot) On Predicted (Bands)
Belfast, Royal Victoria Hospital	RVB	232	4	1.7%	228	98.3%	98.4%	0.999	
London, Harley Street Clinic	HSC	483	10	2.1%	473	97.9%	97.2%	1.008	
Leicester, Glenfield Hospital	GRL	570	12	2.1%	558	97.9%	97.4%	1.005	
Newcastle, Freeman Hospital	FRE	704	16	2.3%	688	97.7%	97.1%	1.006	
Dublin, Our Lady's Children's Hospital	OLS	738	22	3%	716	97.0%	97.8%	0.992	
Glasgow, Royal Hospital for Sick	RHS	817	26	3.2%	791	96.8%	97.6%	0.992	
Bristol Royal Hospital for Children	BRC	886	21	2.4%	865	97.6%	98.1%	0.995	
Southampton, Wessex	SGH	914	14	1.5%	900	98.5%	97.7%	1.008	
Leeds General Infirmary	LGI	919	32	3.5%	887	96.5%	97.8%	0.987	
London, Royal Brompton Hospital	NHB	1117	18	1.6%	1099	98.4%	98.0%	1.004	
London, Evelina Children's Hospital	GUY	1165	42	3.6%	1123	96.4%	97.2%	0.992	
Liverpool, Alder Hey Hospital	ACH	1195	39	3.3%	1156	96.7%	97.3%	0.994	
Birmingham Children's Hospital	BCH	1467	44	3%	1423	97.0%	96.6%	1.004	
London, Great Ormond Street	GOS	1828	33	1.8%	1795	98.2%	97.8%	1.004	

Fig 4. New horizontal display of the graphic alongside the table content. (Green bars = survival much higher than predicted; blue-green = survival higher than predicted; white = survival as predicted; light gray = survival lower than predicted; dark gray = survival much lower than predicted.)

Workshop Round 1, Month 3

DATA DISPLAY. Mathematicians (D.S., C.P.) were both familiar with the way NCHDA presented the hospital outcomes (Fig 3). However, the value of the workshops became immediately apparent. Some workshop participants were drawn to the color regions in Figure 3 and interpreted it as a bar chart, which gave the (incorrect) impression that the hospitals on the horizontal axis are ranked by increasing survival. After discussion with participants, we decided to make the prediction interval colored and the outermost areas white, to focus attention on the dot and its predicted range. In both workshops, participants unanimously preferred the combined display (Fig 4), so we adopted it.

The workshops demonstrated that ratios are hard to understand and easy to misinterpret. The mathematicians (D.S., C.P.) spent considerable time in both workshops explaining what the ratio of actual to predicted survival represented and why it was used instead of raw survival (we note this ratio is also used in the United States [19]). The ratio is preferred by the NCHDA because every hospital has the same expected value of 1, which gives the graph in Figure 3 a common center line. As discussion progressed, the mathematicians emphasized that hospitals should not be compared directly with each other using their raw survival rates and that the key feature is whether the “dot” on the graph (representing the hospital) is within its predicted range. Discussing this aspect

later, we realized that emphasizing that hospitals should only be compared with their own predictions made it confusing to then transform hospital results to a ratio whose main benefit is to allow comparison between hospitals. We also realized that providing the exact predicted survival was inconsistent with emphasizing that the predicted range was the important feature. We therefore decided to present actual survival for each hospital within its predicted range of survival, and not to provide the exact predicted survival rate.

PREDICTED SURVIVAL. Predicted survival created much discussion—participants asked when and how predictions were made. For instance, some people assumed that the hospital predicted its survival rates after knowing its actual survival, or that (analogous to predictions of poor performance in sports or education) hospitals with lower predictions were “worse.” We had tried to avoid using detail about the risk adjustment method in our explanations, instead using language such as “predicted survival (%) is the percentage of operations where the child would survive at least 30 days after their operation estimated using previous national data about children similar to those cared for at that hospital.” That proved unhelpful, because different people interpreted this very differently. Parents in particular wanted to know more about how the survival was predicted. We realized that we would have to explain risk adjustment “up front” and learn how people interpreted the terms “predicted” or “expected.”

UNDERSTANDING PUBLISHED CHILDREN'S HEART SURGERY OUTCOMES

[Intro](#) [Data](#) [FAQs](#)

UNDERSTANDING PUBLISHED CHILDREN'S HEART SURGERY OUTCOMES

What is this site for?

The main outcome measure that the NHS uses to monitor children's heart surgery in the UK is the *30-day survival rate*. This is the percentage of operations where the child survived at least 30 days after their heart surgery (e.g. 100% would mean that every child survived). Every year or two there are some articles in the press about children's heart surgery in the UK. Often, these articles compare one hospital to another or suggest that a hospital has more deaths than it "should have".

- Where do journalists get these numbers from?
- What do they mean by "should have"?
- How valid are these sorts of comparisons?
- What do survival rates actually tell you?

Our website will help you explore what survival rates **can** and **can't** tell you: for instance, if one hospital has a higher survival rate than another it **does not mean** that one hospital must be better than the other. We hope that this website will let everyone can see and understand how the NHS monitors children's heart surgery.

This site cannot help parents make decisions about their child's treatment. If you are concerned about your child's treatment plan **please speak with your child's cardiologist or surgeon.** You can also access the support available from national charities such as the [Children's Heart Federation](#) or [Little Hearts Matter](#) or local charities for your specialist children's hospital (see below). These guides on [speaking to your child's surgeon](#) or [seeking a second opinion](#), written by the Children's Heart Federation, might also be helpful.

We know that there is much more to children's heart surgery than survival to 30 days after surgery, such as much longer term survival and quality of life after surgery. Although this information is not routinely available at the moment, we are actively researching how to collect, interpret and publish this data (more in the FAQs).

Which hospitals perform heart surgery in children?

What can published survival rates tell you without extra information?

Currently, about 3500 children under the age of 16 have heart surgery each year in the United Kingdom and Republic of Ireland. Overall, the survival rate is 97%, telling us that the UK has very high survival rates for this difficult speciality.

However, heart disease in children covers a wide range of disorders, from relatively minor to more severe conditions. The different conditions mean that different surgeries can carry very different risks for children. There are also other factors that make some surgeries riskier than others. For instance, some children also have other health problems or are very small which can make surgery more risky.

Some hospitals specialise in certain conditions, meaning that some hospitals tend to operate on children with a lower chance of survival. It would be unfair to then expect all hospitals to have the same survival rates each year. Circumstances also change from year to year, so that one year a hospital might see many more very complex cases than the year before. Therefore, we expect any hospital's survival rate to vary over time.

This means that we **cannot** use survival rates to compare hospitals to each other, or to look at one hospital from one year to the next, **without** putting the survival rates into the context of how complex the cases were. In other words, if a hospital's 30-day survival rate is lower this year than last year, it does **not** necessarily mean that things have got worse. Likewise, as we have already stressed elsewhere, if one hospital has a higher survival rate than another hospital it does **not** necessarily mean that one hospital is better than the other.

How do we put survival rates into context?

Every individual is unique and may respond differently to treatment (surgery, drugs, postoperative care).

Our research has shown that there are some consistent factors that hospitals routinely collect information about that do affect a child's chance of survival. These things include:

- the age and weight of the child (other things being equal, the bigger and stronger a child is, the safer the surgery is);
- what problem in the heart the surgery is trying to fix (some hearts have more complex defects than others);
- other health problems a child might have (e.g. a genetic syndrome);
- the complexity of the surgical procedure.

Knowing these factors for each patient, allows us to identify types of patient who are at greater or lesser risk even though we cannot predict exactly how a particular individual will respond.

We use what is called a "statistical model" to combine what we know about these aspects for the children a hospital has treated over any given time period (e.g. 3 years). This mathematical combination results in a **predicted** overall proportion of survivors for **that specific hospital**. We would expect the survival rate actually achieved in that hospital to be not too far away from this prediction and so we finally calculate a **predicted range** for that specific hospital. If that hospital's actual survival rate is within that predicted range, its results are in line with what we expect.

IMPORTANT! The predicted range depends on the types of patients treated at that hospital over that time period – so each hospital will have a different predicted range and its predicted range will vary from year to year!

That is why we only compare a hospital's survival rate to its predicted range (from the independent statistical model) and not to survival rates at other hospitals.

Fig 5. Our first attempt at the introduction page (showing just the top and the bottom of the page).

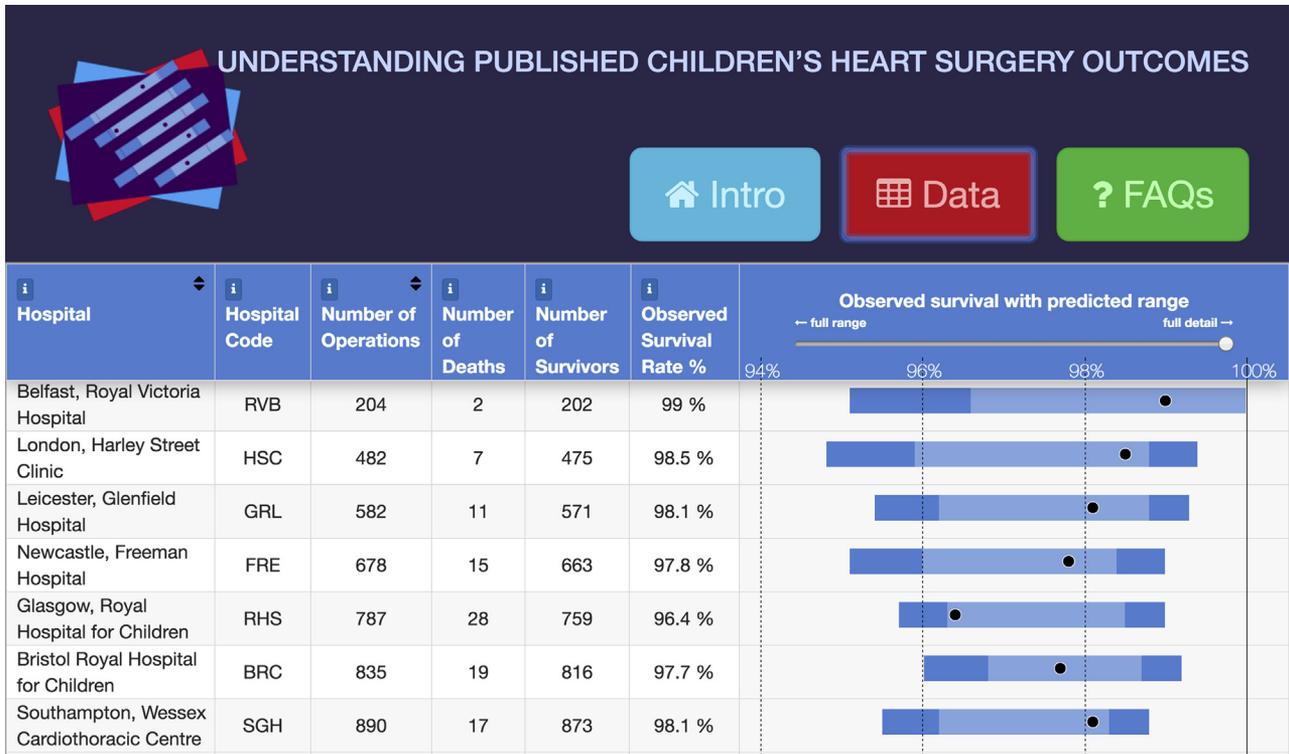


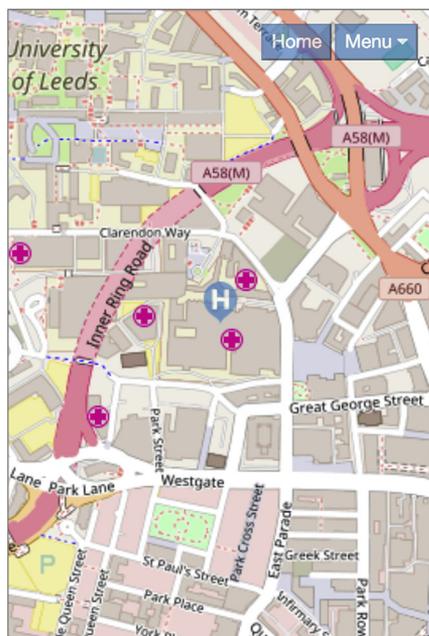
Fig 6. Our first attempt at the data page.

Mapped Data for 2011-2014

There are fourteen hospitals in the UK and Ireland that perform heart surgery in children (here a child means someone under the age of 16).

This data is updated annually and covers the last three years. The survival data in this map is from 2011-14

To see all hospitals together [visit the data page](#).



Leeds General Infirmary

Observed survival with predicted range



The hospital performed **976 operations**.

After 30 days there were **953 survivors** and **23 deaths** had been recorded.

The observed 30 day survival rate was **97.6%**.

There is no evidence that the hospital's survival rate is meaningfully different from what is predicted

Further web information

- [Leeds General Infirmary](#)
- [The Childrens Heart Surgery Fund](#)

Fig 7. The mapped data tab showing the display for a specific hospital.

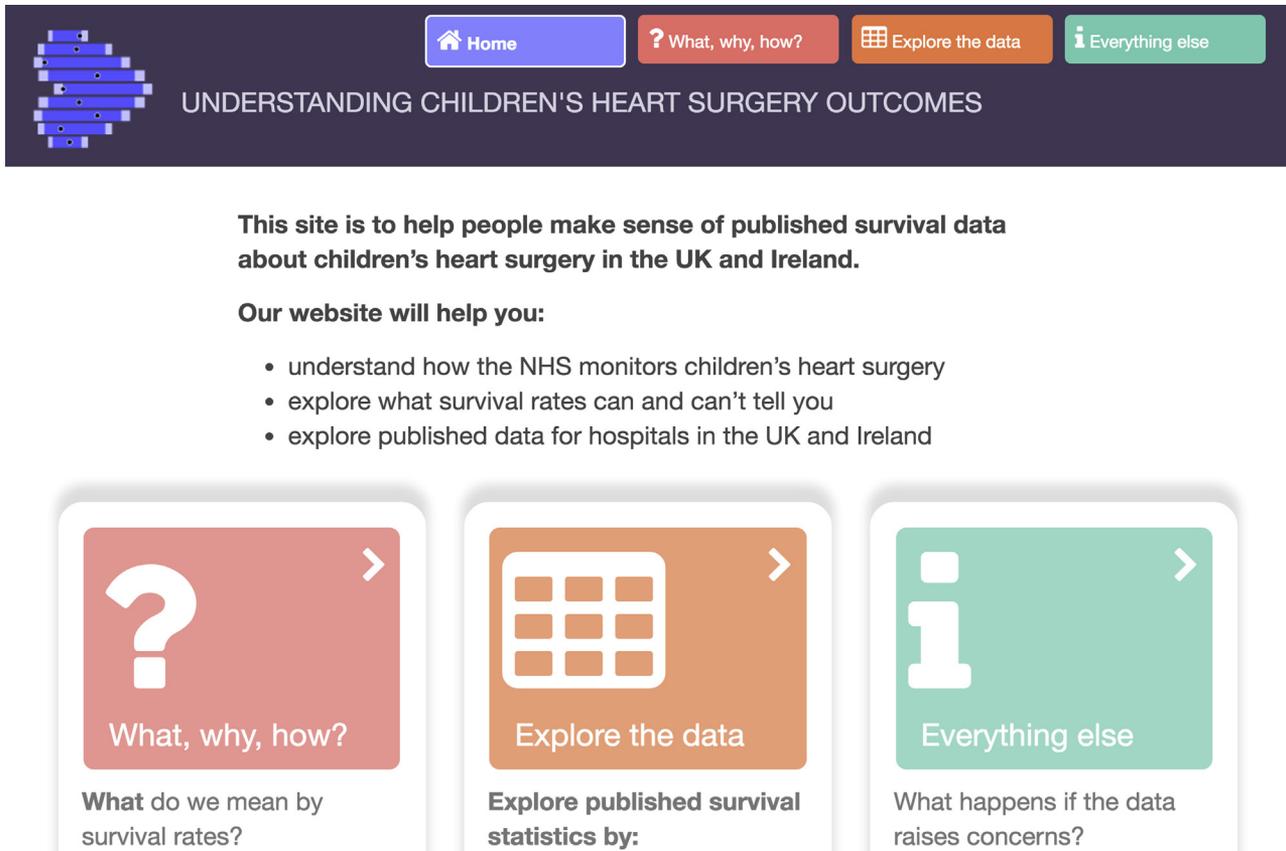


Fig 8. The new, simpler home page developed for the third set of workshops. This is its final version from the live website.

Workshop Round 2, Months 8 to 10

By the second “interested user” workshop, we had developed three draft web pages: an introduction page (Fig 5), a data page (Fig 6), and an FAQ page. The introduction page stated explicitly that the risk adjustment method was objective (based only on patient characteristics), and that raw survival rates should not be compared between hospitals. For the data page, in addition to the changes identified from the first round of workshops, we included additional information available on clicking on a single hospital and by using “hover-overs.”

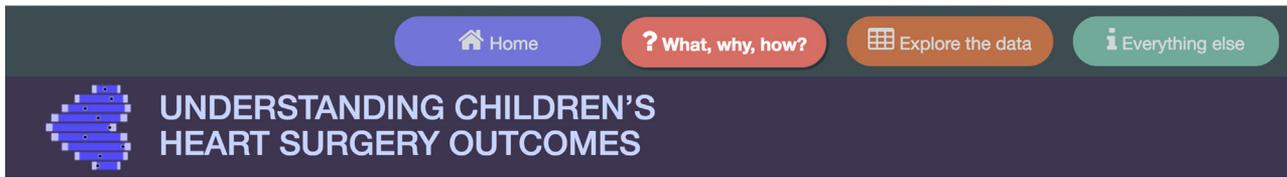
SECOND INTERESTED-USER WORKSHOP (MONTH 8). Feedback was generally positive, with participants endorsing the site design, data display, and warnings against comparing hospitals by survival rates, but they suggested that these warnings should be more prominent. Participants were reassured that all hospitals had high survival rates, and they suggested that this be emphasized. Most important, one participant commented that we emphasize that you should not compare hospitals and then present them in a table that invites comparison. The ensuing discussion prompted us to add a data view showing data individually by hospital.

SECOND PARENT WORKSHOP (MONTH 10). By this time, we had incorporated much of the feedback from the second interested-user workshop. Participants still wanted us to

be clearer about what background information was absolutely essential, and we discussed adding a “key points” section to the introduction.

We created a new “mapped data” page that allowed users to explore hospitals individually (Fig 7). We also provided links to the hospital website and any associated charity. There was still a separate page with the tabled data, as in Figure 6. The parents suggested that adding some explanation, plus links to relevant FAQs, alongside the individual hospital data displays would help.

FIRST SET OF PSYCHOLOGY EXPERIMENTS (MONTHS 10 AND 11). Three mixed-methods experiments explored how people understood and evaluated the prediction intervals and made subsequent judgments about hospitals, comparing the survival-ratio plot used in the National Institute for Cardiovascular Outcomes Research (NICOR) report (Fig 3) [20] against the percentage-survival plot from the website (Fig 6). The findings confirmed our decision to use percentage-survival plots instead of ratio plots (eg, accuracy of understanding for the outcome scale was 71% for the percentage plot compared with 41% for the ratio plot), but highlighted two key messages that we needed to emphasize even more: (1) comparing hospitals’ survival rates to other hospitals’ survival rates or predicted ranges is inappropriate; and (2) the predicted range is based on an objective statistical formula and only reflects the hospital’s case mix.



What, why, how?

This site is to help people make sense of the [published survival statistics](#) about children's heart surgery.

Key points

- If one hospital has a higher survival rate than another hospital it does not mean that it is better than the other
- The predicted range is calculated by a formula and depends **only** on the children treated at that hospital. A **lower** predicted range means a hospital treated children with **more complex** medical problems.
- A hospital's survival rate should only be compared to its predicted range. It is not valid to compare survival rates between hospitals.
- The 30-day survival rate for all UK hospitals is very high.

WHAT do we mean by survival statistics?

The NHS monitors children's heart surgery in the UK by reviewing each hospital's 30-day survival rate. This is the percentage of operations where the child survived at least 30 days after their heart surgery.

Approximately 3500 children under the age of 16 have heart surgery each year in the United Kingdom and Republic of Ireland.

WHY can survival rate data be difficult to interpret?

Fig 9. The new "What, why, how" page developed for the third set of workshops.

The experiments and workshops also emphasized the importance of consistency in using (or implying) terms such as "luck," "chance," "risk," "uncertainty," and "probability." We decided always to refer to predicted risk as "predicted chance of survival"; the placement of the survival dot in relation to its predicted range as "strong/some/no evidence that chances of survival at that hospital were different to that predicted using the formula"; and inherent uncertainty in outcome as "unforeseeable factors."

Workshop Round 3, Month 11

We focused on updating the site to be intuitive to navigate, to repeat key messages, to provide sufficient detail, and to have a simpler home page (Fig 8). The introduction content was moved to a new page ("What, why, how?") with a key points section at the top (Fig 9). Workshop feedback was now very positive, but nonetheless, participants suggested new content, wording revisions, and layout changes.

SECOND SET OF PSYCHOLOGY EXPERIMENTS (MONTH 12). An experiment found that if people viewed hospitals individually rather than alongside other hospitals, their interpretations of a hospital's outcomes seemed more reliant on the prediction interval (and less reliant on other hospitals' outcomes). We therefore promoted the individual hospital view over the combined table/graph. We retained the combined view for transparency and its similarity to the NCHDA report presentation. However, we added text to emphasize that hospitals should not be compared with each other on survival rate. Further details of methods and data for the first two rounds of psychology experiments are currently under review in a separate publication.

Workshop Round 4, Month 13

With the web content and navigation nearly finalized, the project team concentrated on two explanatory animations. We worked with an external animation company but changed their usual development process by allowing

Key points

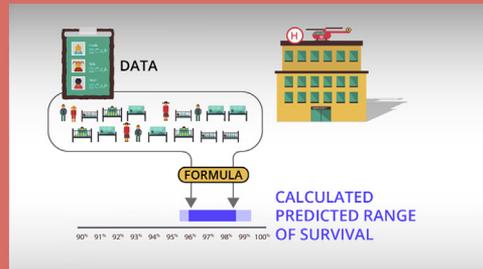
The 30-day survival rate after children's heart surgery is very high for all hospitals in the UK and Ireland, and is among the best in the world.



A higher survival rate does not imply a better hospital.



A hospital's predicted range of survival, calculated by a formula, depends on the particular children treated at that hospital. So a hospital treating children with more complex medical problems will have a lower predicted range.



A hospital's survival rate should only be compared to its own predicted range. It is not valid to directly compare survival rates between hospitals.

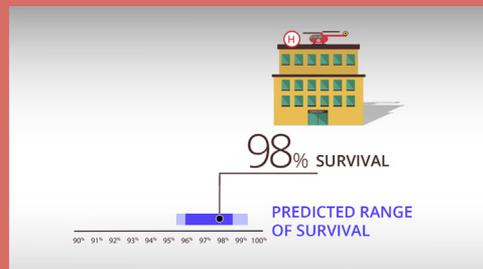


Fig 10. Final set of “Key points” at the top of the “What, why, how” webpage.

time for user feedback at a relatively advanced stage of animation development. In detailed discussions, the parent participants suggested moving key sections from one draft animation (explaining the predicted range) to the other (explaining the data display) and then layering the placement of the animations within the site. That led us to substantially rework the storyboards and scripts.

Finalizing Website Months 14 and 15 and Evaluation

The workshops showed that the key points at the top of the “What/why/how” section were extremely valuable

and should be prominent. We therefore illustrated the key points section of “What/why/how” (Fig 10) with images from the animations.

To determine whether the website provided “added value” over and above the NCHDA report [20], a small-scale randomized control trial compared people’s ability to answer questions about the audit data and their interpretation when they used either the NCHDA report only, or the website only, or both the report and website together. Results showed that the website improves comprehension and understanding of the data, raising scores for these

components by 0.75 and 1.25 standard deviations, respectively (see [Appendix](#)). The website offers three particular advantages over the report: it improves comprehension of the data plot; provides clearer information about the audit process triggered for outliers; and explains how often the survival rate will fall outside the predicted range by chance.

Lessons Learned and Summary

We set out to develop material to explain a single graph, but as we engaged with users, they helped us to develop messages about high survival rates, statistical methods, and avoiding inappropriate comparisons. By listening, we clearly communicated these messages and improved our presentation of the data. This early and continuous user engagement was vital, with each workshop improving and shaping the website. The multidisciplinary, multi-sector nature of our team was crucial to implementing this input (see also online articles from the perspective of a parent participant [21], Sense about Science [22, 23], and the mathematicians [24, 25]). The website “<http://childrenshearturgery.info/>” was launched on June 21, 2016. It was very well received and quickly endorsed by major stakeholders (charities, clinical specialists, national audit, National Health Service Choices, Royal Colleges, leading medical journals) [18, 26–30].

Building this website took considerable resources, including funding, people, and time. It was extremely helpful to have an external partner guide the stakeholder involvement and act as neutral facilitators at the workshops. For the technical web development, responsiveness and speed in changing the web material was important, requiring a technical strategy for reworking the website outside the norm for website development. Despite allowing ourselves 15 months, we were pressed for time—mainly because we underestimated the demands of implementing multiple iterations of feedback. For difficult topics such as survival outcomes, the parent workshops [21] in particular were humbling and vital for the team to understand the emotional aspect of the data for parents and inform development of sensitive communication. To summarize, there is no substitute for genuine co-production.

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