**Understanding PRAiS risk model for mortality following heart surgery in children**

## User-testing workshop 3Held on Tuesday 6th October 2015 13:00 – 15:00

**14a Clerkenwell Green, London, EC1R 0DP**

***Report by Sense About Science***

**1. Introduction**

***1.1 The project***

PRAiS2 is a collaboration between University College London, King’s College London, University of Cambridge, Children’s Heart Federation and Sense About Science and has two primary aims. Firstly, to improve a **r**isk adjustment model for mortality data following children’s heart surgery. Secondly, the data from PRAiS2 will be presented as an online resource for families, the public and the media in order to facilitate appropriate interpretation of this published data. The content of this website will be developed with 8 user-testing workshops over 4 stages. At each stage, the website will be evaluated by 2 user-testing groups: interested users and parents of children with heart disease.

***1.2. User-testing aims***

This second stage user-testing workshop involved interested users. Its primary aim was to not only make the risk model plot publicly available but publicly *accessible* and understandable to a wide audience. It aimed to find out what information is (a) vital across the board to interpret the plot accurately, and (b) what is only necessary and useful for those who are going to be delving deeper, e.g. for professional use- so can be less instantly accessible on the website.

***1.3. This report***

This short report captures insights from the participants and presents suggestions for improving communication of the risk model and accessibility of the website to visitors. It also outlines other issues raised during user-testing. General feedback is first outlined, followed by specific feedback relating to each section of the website. Within each section, Sense About Science has made several recommendations based on our extensive experience of public engagement work. The contents of this report include:

1. Introduction

2. Attendees

3. Workshop materials

4. General observations

5. Introduction tab

6. Data tab

7. FAQs tab

8. Uses of the website

9. Further involvement

10. Appendices

**2. Attendees**

***2.1. Participants***

* Rob Finch, Managing Editor, NHS Choices & Behind the Headlines (RF)
* Grace Gottlieb, Policy Officer, Royal College of Surgeons (GG)
* Lauren Snaith, Senior Media & Campaigns Officer, Royal College of Paediatrics & Child Health (LS)
* Edward Parker, Voice of Young Science member & PhD student at Imperial College London (EP)

***2.2. Observers***

* Christina Pagel, Reader of Operational Research, University College London (CP)
* Martin Utley, Professor of Operational Research, University College London (MU)
* Mike Pearson, Educational Technologist, University of Cambridge (MP)
* Emily Blackshaw, Research Worker – DISCOVER Project, King's College London (EB)

***2.3. Facilitators***

* Emily Jesper, Assistant Director, Sense About Science (EJ)
* Joanne Thomas, Projects & Events Officer, Sense About Science (JT)

**3. Workshop materials**

As with the previous round of user-testing, participants had received only minimal details about the project and had not been required to prepare anything prior to the workshop. Participants joined us for a sandwich lunch, where they were introduced to the facilitators, observers, to Sense About Science and each other before JT gave a brief presentation on the background of the project and how the workshop would run.

Following the first round of user-testing with both interested users and parents of children with heart disease, all feedback was reviewed and incorporated into building the web resources. For the second round of user-testing, the online web tool was available and all content was therefore reviewed on laptops rather than paper.

Participants were given 10 minutes to explore the website unprompted. Each participant had a separate laptop, with the website preloaded to the introduction page (see Appendix A). MP explained that there were a few known bugs in the site which would be fixed. The website had three tabs available:

* Introduction tab (Appendix A)
* Data tab (Appendix B)
* Generic FAQs about the chart (Appendix C)

**4. General observations from participants**

After 10 minutes, participants were asked to provide general feedback and initial impressions. RF seemed impressed with the website functionality itself and commented how responsive it was to eg adjusting the size of the text. GG and EP both commented that they were very impressed with the website overall and only detailed points needed reviewing.

**5. Introduction tab**

The first points that participants raised were primarily about the introduction tab. LS liked the simple layout of the site, with its 3 clear tabs at the top. She felt the introductory text could be a bit shorter, ie half the current size and thought the *'what is this site for'* subsectionwould particularly benefit from being shortened. LS suggested having a click through to more detail about the project for those that were interested after a shorter initial introductory section would prevent detail being lost. LS confirmed she would prefer to click out to further details rather than scrolling down the page. RF agreed the text could be shorter and also raised suggestions of where improvements were needed; he noted that the first sentence in the *'What is this site for'* subsection did not answer the question. This section needs to say *who* the websiteis for and *how* to use it. LS agreed and felt JT’s presentation at the start of the workshop provided this missing information (ie that the site is for parents who have children going through some of the procedures being reported on).

GG also agreed this section should be shorter, and suggested using bullet points and/or more subheadings as a solution. She noted it was great to see the key caveats clearly covered (ie different hospitals should not be compared) and thought it was very important to have these prominently at the top. EP thought the final subsection of this tab *'How do we put survival rates into context'* was very well done, despite being potentially challenging. He thought the text here could be shortened, but really liked the pink stand-out box that starts 'IMPORTANT!'. RF suggested alternative titles for this subsection as it was unclear what context meant: eg *‘How can I use this data correctly?’*, *‘How are the survival rates put into context'* or *'I've heard Birmingham does harder cases, how do you account for this'*. He felt the *‘we’* in the current title was not the appropriate tone. MU also suggested an alternative title: *‘What if some hospitals do harder cases?’*

EP stated it was unclear why local charities were included in this subsection titled *'Which hospitals perform heart surgery in children*'. RF agreed and had expected the links to go through to data about those specific hospitals rather than the hospital websites themselves. He found this quite jarring. LS agreed it would be more useful for these to link to hospital data instead. Although the data tab contained links to specific hospital data, participants felt a link should also be included on this introductory page. MP agreed it would be technically possible to include this link. RF suggested it could be added on the right hand site of the webpage, or perhaps as a *'Find your trust/hospital'* map or button. LS agreed this information should be displayed elsewhere, and agreed a side bar was a potential solution.

*Sense About Science recommendations*

* Shorten all sections of introductory text
  + Experiment with using more bullet points or subheadings
  + Include option to click out to further information to ensure content is not lost (ie highlight relevant FAQs)
* Edit the first sentence of the *‘What is this site for?’* to include who it is for and how to use it (eg take content from JT’s introductory talk)
* Edit the title of the ‘How do we put survival rates into context’. Perhaps use RF’s suggestion *‘How can I use this data correctly?’*
* Replace table of charities with map with clickable links to more information about each of those hospital trusts and their associated charities.

**6. Data tab**

Participants were then prompted for feedback about the data tab.

***6.1.Chart***

***6.1.1. Dots & blue bars***

GG's first comments about this tab were that she liked the use of dots and blue bars. RF noted it was reassuring to see that observed survival data for all hospitals were within the extended predicted ranges. GG was confused about what the range meant and had wrongly interpreted the graph as showing mortality, rather than survival data. She noted this was probably because of her background at Royal College of Surgeons, where they use mortality data. RF suggested a way to avoid misinterpretation could be to have one end of the chart in green (ie good) and the other in red (bad). LS agreed colours could make it clearer, although she suggested avoiding red and use softer colours. GG thought this might exacerbate false alarm and noted that journalists are likely to pull out those hospitals with survival data in the lower section of the bar and perhaps turn these into a scare story.

When asked if using a positive frame of survival rather than mortality data was preferable on the site, GG agreed it was. RF also agreed and felt as survival rates were so high (ie 97%), this should be emphasised. He also said it should be made more clear that all hospitals observed data fell in the expected ranges. He suggested adding a green ‘OK’ button for all those within the expected range and a warning triangle for those outside it. CP was cautious about this idea and instead suggested a short summary at the bottom reading eg *“There is no evidence that any of these hospitals’ survival rates are meaningfully different from what is predicted”*. EP agreed this would be a great addition and RF added this would make it clearer to visitors.

*Sense About Science recommendations*

* Considerusing two colours (not red).
  + JT & EJ could user-test this at the next stage of user-testing or EB could run an experiment.
* Consider using green ‘OK’ button or other icon to show they are within the expected range
  + JT & EJ could user-test this at the next stage of user-testing or EB could run an experiment.
* MP add sentence at the bottom: “There is no evidence that any of these hospitals’ survival rate is meaningfully different from what is predicted”.

***6.1.2. Key***

Participants felt other aspects of the data needed clarification, and a key or illustrated example was mentioned numerous times as a potential solution.

For example, EP mentioned that although the introduction tab made it very clear that the risk model was comparing observed data with predicted, it was unclear which was which on the data tab. He suggested having a key with eg "[black dot] = observed survival" would make it much clearer, with a similar key to explain the range. RF agreed with this suggestion and felt the key should be clearly displayed on this page. GG also agreed and suggested a small box containing the key could be placed to the left of the Introduction tab at the top of the webpage. CP suggested the key could be in the title above the bars, to which EP agreed. For further clarification for visitors, RF also suggested there could be an annotated example (ie a screen shot) shown on the introduction page.

EP was unsure what the two different shades of the bars represented. EJ suggested reading the relevant FAQ (suggested edits to this FAQ can be found in Section 7 of this report). EP agreed this should be clear on the data tab too, and suggested having an example bar labelled up at the top of the data tab, as an extra header that would remain as the user scrolled down. Or alternatively, to add this detail to the key:

“[Light blue bar] = predicted range for this hospital“

“[Dark blue bar] = extended predicted range for this hospital”

EB also added this could be explained in the video animation voice over (see Section 6.1.6)

When asked if it was clear why the bars were different sizes, participants felt it was. GG noted it was explained well on the first page, and was due to a variety of factors. EP added it was mainly because of the number of surgeries. CP noted this was also covered in FAQ 10 & 11, yet RF thought it would be helpful to include this in a key on the chart too. When prompted about whether it was clear what action NICOR would take depending where a hospital’s observed data falls within the plot, participants felt it could be made clearer. Although this information can be found in FAQ 6, RF suggested this should also be added to the key eg for the white area “If the observed survival falls in this section ...... In these cases, NICOR would....”

MP asked participants if they would prefer the key to have a cancellable box, ie where the first time a visitor logs onto that webpage, they see it and can then choose to press 'x' to remove the box. However, GG and RF both felt that this wouldn't be a useful alternative; they would both prefer to have the key permanently visible as a reference point rather than a popup.

*Sense About Science recommendations*

* MP to add key at the top (that remains visible when visitors scroll) to include:
  + "[Black dot] = observed survival"
  + “[Light blue bar] = predicted range for this hospital“
  + “[Dark blue bar] = extended predicted range for this hospital”
  + “[White area]: If the observed survival falls in this section, ...... In these cases, NICOR would....”
* MP to add annotated example of a data bar to introductory page

***6.1.3. Hover-overs***

GG noted she did not initially realise the bars had a hover-over which revealed explainer text. She thought this feature would be particularly difficult to find if viewing the website on a phone or tablet. RF hadn't realised the click function existed in the 10 minutes of exploring the site. LS found this feature worked fine and commented she preferred a hover-over rather than a click, as it appears immediately. GG and EP also both preferred a hover-over. GG suggested if the table was reduced in size, there may be room to add this extra information at the side of the webpage.

When asked if the availability of the double click function to bring up data about each individual hospital was clear, LS noted she had only found this by accident. MP suggested he could add this instruction as an *‘i’* hover-over in the *‘Hospital’* column. CP noted this could be added to a *‘tips’* section at the top. EP felt again the illustrated example at the top of the page with instructions about how to interact with the table could be beneficial, although it may make the webpage cluttered so should be tested. He suggested again the key might be a simpler way of illustrating this. EB added that including this in the animation would be beneficial (Section 6.1.6). When asked about the text in the hover-overs, RF and LS both felt that the box and accompanying text were clear.

*Sense About Science recommendations*

* MP add the instruction of double clicking as a ‘*i*’ hover-over in the *Hospital* column

***6.1.4. X Axis:*** ***Labels & layout***

RF noted the title *‘Observed survival with predicted range’* should be moved further down the title bar to be nearer the numbers, ie without the functionality slider in between. However, EP disagreed and noted that it was more important to read the title before seeing the slider bar. He felt the current layout and presentation was very clear. EP noted the graph labelling was also clear, but that he would be interested to see alternatives. LS also felt the x axis was fine in its current form, however she noted that an alternative would be to have the slider across the bottom, perhaps a more expected position. However GG disagreed as it would make this function harder to find.

When MP suggested a button (eg scroll based) alternative to the slider, GG and LS both felt the current slider was preferable. RF noted he liked the sound of the buttons and would like to see them. All participants agreed it would be good to compare the two as it was hard to visualise the suggestion.

*Sense About Science recommendations*

* MP keep x axis title & slider in current position
  + JT & EJ to ask for further feedback at next stage of user-testing
* MP to develop scroll-based button as alternative to slider
  + Suggest EB test these two options for preference

***6.1.5 Slider function & default view***

Participants were prompted for their comments about where the default slider function should be: full range (0-100% survival) vs full detail (zoomed in on the 94-100% survival rates). The default setting currently on the website is full detail.

Participants felt it was clear enough that the slider function was available. Overall, all participants agreed they preferred the full detail view and that this should be the default. GG felt it was unnecessary to show the full range as all hospitals fit well into the full detail view. However, participants did like the full range view option. EP noted it was great how this view clearly emphasised how all survival rates are so high and similar. RF agreed this view makes it more obvious that all hospitals are so similar and added if there wasn’t a *‘0’* present, visitors might think someone is trying to ‘fudge’ the data. However he noted the full range did distort some of the results, eg it made Great Ormond St's observed survival black dot appear out of the predicted range. Because of this, RF felt although a useful view to give people, it could be misleading. RF noted for clarification the graph could fade out at 94% to make the zoom out function more obvious.

*Sense About Science recommendations*

* MP to keep full detail slider as default view but add fade out on left hand side to emphasise presence of slider function.

***6.1.6.Chart states: animation***

EJ asked participants for their thoughts about the chart states function at the bottom of the data tab. MP explained the idea is to build a video animation based on these chart states with a spoken narrative (by CP) over the top to appear as visitors arrive at the site. GG thought an animation would be very helpful for visitors and would reduce misinterpretation, particularly if it explained eg *“If you see a dot here..., this means....”*. EP agreed, and suggested illustrating *“This is what it would look like if eg one is failing, but as you can see none of them are outside the range.”*

*Sense About Science recommendations*

* Create video animation which includes explanation of:
  + The difference between dark & light blue bars
  + The different actions NICOR take depending where the dot falls
    - eg *“if you see a dot here.....”*
    - *“This is what it would look like if eg one is failing, but as you can see none of them are outside the range.”*
  + Why bars are different sizes for different hospitals
  + Explanation of click & hover functions
  + Explanation of slider function

***6.1.6.1. Sequence of states***

EJ prompted participants to consider which order these chart states should take in the animation.

EP noted the preference may vary from person to person, but felt it should first establish the predicted range (chart state #4) and then move to state #3 to show the observed survival (dot). GG and LS both agreed with this order and stressed it was important to see the dots last, as this provided the background information. Neither LS or GG felt strongly about using the inner or outer predicted range (ie either state #5 or #4 would work). RF’s preference differed; he would start with chart state #5, showing the inner prediction range first, then progress to chart state #2 (observed survival) followed by adding the extended prediction range (chart #3). EP followed that RF’s could also work.

RF asked the other participants if one of the hospitals fell below the expected range, would they feel the narrative should be changed. GG noted in this scenario, a visitor would “go woah” regardless of the order of the animation so it probably would not matter.

Towards the end of the workshop, CP offered her thoughts about the order of animation:

* Start on chart state #1 (just dots) to explain that you can’t draw conclusions from this alone
* Then remove #1 dots and show chart state #4 or #5 to explain that each hospital has a predicted range (and explain on the voiceover that the inner and outer predicted bars are different colours to represent that the audit body (NICOR) would respond differently to these two outcomes.)
* Then show #3 (observed survival) to show how each hospital is compared to its range
* Conclude with illustrative data eg *“This is what would happen if the observed survival is here....”*

When participants were asked their thoughts on CP’s suggested order, they all felt this made sense.

*Sense About Science recommendations*

* Create animation & voice over which most fairly represents the information (the order CP recommends)
  + Suggest EB to test
  + JT & EJ to test at next user-testing stage

***6.1.6.2. Sample data vs actual data?***

MP asked whether sample data or actual data should be used in the video animation. LS would prefer sample data eg hosp A, B, C, D, due to its anonymity whereas actual data could look like a particular hospital was being promoted. Other participants agreed.

*Sense About Science recommendations*

* MP to include sample data in animation

***6.1.7.Themes***

GG was confused by the themes. MP explained it was to evaluate participant’s preference of different bar colours. GG, EP and RF all raised a preference for blue, with RF commenting it was a ‘sympathetic’ colour. RF asked the reason for these colour option, MP explained they were currently default.

MP asked if participants had a preference whether the inner bar should be darker or lighter than the outer bar. GG preferred lighter colour on the inner predicted range, particularly as most dots are found in the middle, so the colour contrast is enhanced. RF agreed it looks better visually with the lighter colour on the inner bar, however he noted that he would have more confidence in the data with the bolder colour on the inner bar. He suggested the colour could fade out towards the edge of the outer bar. CP agreed with this suggestion from a statistical perspective commenting that if it is viewed as a probability, the colour should fade out at the edges as the observed survival data are less likely to be in the outer bars. Participants all agreed they had no concerns about having a darker colour for the inner bar.

*Sense About Science recommendations*

* Suggest EB tests different colour options including:
  + Colour of bars
  + Darker shade on inner or outer bar
  + Colour fade out at edges of the outer bars
* EJ & JT to test at next stage of user-testing

***6.2. Tables***

When participants were prompted for feedback on the tables and whether column titles were clear, all agreed they were. However, they felt having a separate column for hospital code was unnecessary. LS suggested the first column should instead be “Hospital (hospital code)”. RF suggested instead of hospital code, the table could include location as parents were more likely to search by this. RF and LS both liked the idea of a map to illustrate locations.

RF felt it wasn’t clear why only ‘*Number of Operations’* was orderable. EJ noted it had been deliberate not to enable ‘*Number of Deaths’, ‘Number of Survivors’* or *‘Observed Survival Rate’* to be orderable to avoid comparisons being made. Participants felt it would be useful to add this reason why we decided not to add this function, perhaps as an *‘i’*. EP felt the current *‘i’* hover-overs were useful, excluding *‘The hospital name’*, which he felt was unnecessary and should be removed. GG thought a link to the NICOR report should be added to this page, particularly as it is mentioned in the *‘Hospital Code’* hover-over.

*Sense About Science recommendations*

* Consider merging *Hospital* and *Hospital Code* column and add details of location: eg *Hospital, Location (Hospital code)*
* Remove *hospital name ‘i’*
* Add information to *‘i’* of each columnexplaining why ‘*Number of Deaths’, ‘Number of Survivors’* or *‘Observed Survival Rate’* are not orderable
* Add a link to the NICOR report on the data tab; CP, MP, JT & EJ can discuss where

*Table layout*

MP noted that the table currently fills the whole screen and asked participants for their thoughts on making the table smaller and embedding it in a page with surrounding material. LS felt the current layout was clear and removing the hospital code column would provide more space. GG felt it would be helpful to see the smaller alternative and to test it in future workshops.

When MP asked how important it is to see all hospitals in one table, participants had mixed views. LS liked it and mentioned it made it very easy to compare, particularly useful for journalists to have all the information in one place. However GG noted that the content is based around why you shouldn’t compare hospitals, yet here they are lined up in one table. RF noted from a journalist’s perspective, comparing was the only reason to visit the site.

*Sense About Science recommendations*

* MP to experiment with reducing table size & embedding it with surrounding text
  + EB to test this
  + EJ & JT to test with further user-testing

**7. FAQs tab**

The participants were also asked for comments about the FAQs tab. RF noted in his role at NHS Choices, the preference is to avoid FAQs. Instead, they have a separate page for every answer, so when people google a particular question they can immediately find that answer. RF suggested an alternative for this website could be to link out to further details from the introduction tab. He also added that because of the current layout of the FAQs in narrow boxes, it makes each look quite long and daunting. GG and LS agreed the layout could be improved by removing the three columns. They felt the current format was distracting and difficult to read, particularly as the FAQs were different lengths and the chronology looked messy. LS suggested using dropdown or a concertina; RF agreed using sequential dropdown would make navigation neater. GG suggested having a list (ie index) of all FAQs at the top of the page with links that take you to each FAQ. Other participants liked this idea.

The participants all felt there were no unnecessary FAQs, and GG thought they were all good questions. However, RF mentioned starting this section with terminology was confusing and the order of the FAQs could be improved. EP noted that the FAQs are usually the ‘debris’ at the end which people don’t read, whereas in this case, the FAQs are key to really understanding the data. EP suggested ‘*Understanding the Data*’ could be an alternative and more substantial title. RF agreed and noted the order of the three tabs could be switched to reflect this, ie have data as the 3rd tab (far right) and place FAQs in the middle. CP agreed putting FAQs before the data tab implies the visitor should be reading this section before looking at the data, and could be called ‘*Making Sense of the data’*. GG and LS both felt it didn’t matter where the data tab was located, and EP agreed it was more a matter of the labelling.

*Sense About Science recommendations*

* Layout changes to FAQs:
  + Remove columns to ensure clear, chronological layout
  + Add concertina or index list
  + Update the title of FAQ section to *‘Understanding the data’*
    - EJ & JT to ask for feedback at next stage of user-testing
  + Keep current order of tabs (ie FAQs as third)

***Specific FAQ comments***

***Terminology***

In the first stage of user-testing, participants discussed the language around probability. Participants in this second user-testing stage were therefore asked for their thoughts on the use of the term ‘chance factors’ throughout the content.

EP thought the current language and explanation was good. GG felt although this is a complex concept to explain, the website does this as well as possible. EP mentioned it could be made more prominent that a hospital’s observed survival rate could fall out of the predicted range by chance. He thought this was the hardest nuance to draw out and so could perhaps be stressed in the animation. Participants discussed whether there should be more statistical information on this page and MP thought perhaps a simulation with 100 popup dots could be added. However, when JT asked whether participants felt a link to external resources would be preferable, all agreed. Useful resources were mentioned and noted for website development (eg David Spiegelhalter and MP’s work on *Understanding Uncertainty*, and Sense About Science’s public guide, [*Making Sense of Statistics*](http://www.senseaboutscience.org/resources.php/1/making-sense-of-statistics)).

*Sense About Science recommendations*

* Include links to further statistical information
* EJ, JT, CP, DS & MP to suggest resources

***Question 3:***

RF felt the order of FAQs was not correct, ie Q3 should not be about the National Audit body NICOR as few would be interested in this. CP noted that including NICOR near the top of this section was because the risk model is based on NICOR’s data and they are the body who carry out data quality checking. RF added that this FAQ should therefore read *“Where is this data from?* to reflect the question that a user might ask. MU and CP both agreed.

RF suggested that Q12 could perhaps be added to this FAQ to reduce the number. GG also suggested Q13 might fit here. CP felt that Q12 and Q13 respond more to Q4, but agreed that the current order was not optimal and encouraged more feedback about what would be best.

*Sense About Science recommendations*

* Edit title of third FAQ to *“Where is this data from?*
* EJ, JT & CP to develop order of FAQs before next stage of user-testing

***Question 6:***

Participants felt this FAQ was particularly important and RF thought it should have a more direct title, eg *“If a hospital falls out of its range, is it bad?”* GG added that using *“its range”* is too vague, and should instead read *“its predicted range”*. GG also suggested this question should be split up. RF agreed and suggested:

1. *“What does it mean if a hospital falls outside its predicted range?”*

2. “*What does audit body do if a hospital falls outside its predicted range?”*

*Sense About Science recommendations*

* Divide this question into 2 as RF suggests
* JT & EJ to particularly focus on this question in the next stage of user-testing

***Question 11:***

GG commented that it seemed Q11 originally came after Q8 and the answer did not make sense: it started with ‘no’. MP mentioned he had already corrected this. RF thought this question should be softened, particularly the heading. As it discusses survival and quality of life, he felt the tone might not be appropriate for a parent reading it.

*Sense About Science recommendations*

* To test tone of this FAQ in line with RF’s comments

**8. Uses of this website**

***8.1. Users***

Participants were interested in who the intended users of this website were. LS asked if parents were the primary user. RF suggested parents of children who have had heart surgery, particularly those who had died or who were putting forward a legal case, might be especially interested in this information. When asked what parents would want to know when they come to the site, LS suggested it would simply be whether the hospital their child is at is within the predicted range.

EJ noted some researchers might also use the website. RF also mentioned he could imagine politicians being interested in this data, and particularly because it is children’s heart surgery, they might want it to be even more certain and have higher survival rates than other data of this type. CP added that all data is made publicly available by NICOR, and given news coverage this data has received in the past, it is clear that journalists have already been using it. EJ noted that once this website is launched, data on the users can be collated.

EP mentioned that the tool could also be very useful for his role in teaching medical students about statistics. Whilst he noted this was not a primary aim or priority for this project, the simplicity of the website in explaining key statistical concepts eg variation, confidence intervals etc, could be a great learning tool, and indicative of the questions patients might ask them.

*Sense About Science recommendations*

* Consider how information on users can be captured once website is launched.

***8.2. Potential avenues for misinterpretation***

When asked how other users might use this data, participants agreed it would be to compare hospitals, particularly by journalists. LS noted that although it was clear from the current content that comparisons should not be made, journalists would pick out the ‘best’ and ‘worst’ survival data. RF agreed, commenting he could imagine a headline reading *“The worst hospital is...”*. LS thought making the introduction page more concise might make this caution much clearer and should be brought out as one of the 3 key points of the site. RF asked if there should be a *“do’s and don’ts”* section on the website to try to avoid this. He noted it would be very easy for a journalist to come up with their own stats ie calculate the mortality rate from the number of operations and number of deaths. RF also noted some journalists might be sceptical of the data, ie, they might think hospitals with survival data above the predicted range might be lying. GG agreed, from her experience working on surgeons outcomes data, she found people became very sceptical of surgeons who had outcomes above the expected range.

CP asked participants if they think website being available in 2013 (when release of NICOR data led to Leeds Children’s Unit being temporarily closed), would have made a difference. RF felt the quality of media reporting has been creeping up slowly over the last few years and perhaps having something clear to point to may have helped.

*Sense About Science recommendations*

* CP to ensure introductory text emphasises that data should not be compared. [NB. This should be helped by MP adding *‘i’* on data tab about why this cannot be ordered.]

**9. Further involvement**

Participants all agreed to continued involvement in this project by reviewing and sending feedback at further development stages. They were also very interested to know when the final website was being launched and what the dissemination plan would be once finished. EJ explained Sense About Science's role in this: sharing a press release with journalists and media outlets, and disseminating the resource to relevant networks, eg to health information organisations, scientific & medical organisations, charities and civil organisations.

RF was very interested in discussing working with his organisation, NHS Choices, to highlight and promote this website, eg to link to it from their web pages on heart surgery, which receive 10,000s web hits each year. RF has put EJ & JT in touch with his colleagues to develop this strategy.

Participants were also interested in how often the website would be updated with new data. CP explained that this would be once a year, when NICOR publish their report. CP added the current website was based on 2011-14 data. All participants felt it was very important to make this transparent on the data tab, and LS suggested this could be added at the top by the results table eg *“This data is from 2011-14”.* LS added the site could have an alert eg *“when is the new data coming out”*, where people could sign-up if they were interested. While RF was not convinced many users would be interested in this, he felt explicitly stating that the data is annually refreshed would be reassuring, and useful for journalists to know that it is current.

*Sense About Science recommendations*

* MP to add eg *“This data is updated annually. The data displayed in this chart is from 2011-14”* to data tab
* EJ & JT to involve participants in future development stages
* EJ & JT to work with NHS Choices on dissemination plan

**10. Appendices**

***10.1. Appendix A: Introduction***

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**](http://www.chfed.org.uk/documents/2012/11/second-opinion-factsheet.pdf) or [**Little Hearts Matter**](http://www.lhm.org.uk/) or local charities for your specialist children’s hospital (see below). These guides on [speaking to your child’s surgeon](http://www.chfed.org.uk/documents/2015/02/talking-to-doctors-pdf-factsheet.pdf) or [seeking a second opinion](http://www.chfed.org.uk/documents/2012/11/second-opinion-factsheet.pdf), 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?

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).

The hospitals are listed below alongside links to their local family charities. (CAN WE PUT IN A MAP?)

| **WHERE** | **LOCAL CHARITIES** |
| --- | --- |
| **ENGLAND** |  |
| [Birmingham Children’s Hospital](http://www.bch.nhs.uk/content/heart-unit) | [Young at Heart](http://www.youngatheart.org.uk/)[Birmingham Children’s Hospital Charity](http://www.bch.org.uk/letusplay?utm_source=Trust%20web%20ad&utm_medium=web&utm_campaign=donate) |
| [Bristol Royal Hospital for Children](http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/the-paediatric-cardiac-service/) | [Heart Families South West](http://www.heartfamilies.org.uk/)[South West Children’s Heart Circle](http://www.heartcircle.org/) |
| [Leeds General Infirmary](http://www.leedsth.nhs.uk/a-z-of-services/childrens-cardiology/) | [The Childrens Heart Surgery Fund](http://chsf.org.uk/) |
| [Leicester, Glenfield Hospital](http://www.leicestershospitals.nhs.uk/aboutus/leicester-hospitals-charity/childrens-heart-unit/) | [Heart Link](http://www.heartlink-glenfield.org.uk/) |
| [Liverpool, Alder Hey Hospital](http://www.alderhey.nhs.uk/departments/cardiac/) | [Alder Hey Charity](http://www.alderheycharity.org/) |
| [London, Evelina London Children&#39;s Hospital](http://www.evelinalondon.nhs.uk/our-services/hospital/heart-services/overview.aspx) | [ECHO – Evelina Children’s Heart Organisation](http://www.echo-evelina.org.uk/) |
| [London, Great Ormond Street Hospital for Children](http://www.gosh.nhs.uk/medical-information/clinical-specialties/cardiothoracic-surgery-information-parents-and-visitors) | [Great Ormond Street Hospital Charity](http://www.gosh.org/) |
| [London, Harley Street Clinic](http://theharleystreetclinic.co.uk/cardiac/congenital-heart-care)(Private) |  |
| [London, Royal Brompton Hospital](http://www.rbht.nhs.uk/about/our-work/brompton/) | [The Brompton Fountain](http://www.thebromptonfountain.org.uk/) |
| [Newcastle, Freeman Hospital](http://www.newcastle-hospitals.org.uk/services/cardiothoracic_services_childrens-heart-unit.aspx) | [Newcastle Children’s Heart Unit Fund](http://www.newcastle-hospitals.org.uk/services/cardiothoracic_services_childrens-heart-unit_childrens-heart-unit-fund-chuf.aspx) |
| [Southampton, Wessex Cardiothoracic Centre](http://www.uhs.nhs.uk/OurServices/Childhealth/Childrenscongenitalcardiacservices/Childrenscongenitalcardiacservices.aspx)(Southampton Children’s Hospital) | [Families of Ocean Ward](http://www.oceanward.co.uk/) |
| **NORTHERN IRELAND** |  |
| [Belfast, Royal Victoria Hospital](http://belfasttrust-cardiacsurgery.hscni.net/about-cardiac-surgery/location/) | [Children’s Heartbeat Trust](http://www.childrensheartbeattrust.org/) |
| **SCOTLAND** |  |
| [Glasgow, Royal Hospital for Children](http://www.nhsggc.org.uk/locations/hospitals/the-royal-hospital-for-children-glasgow/) | [The Scottish Association for Children with Heart Disorders (SACHD)](http://www.youngheart.info/) |
| **IRELAND** |  |
| [Dublin, Our Lady&#39;s Children&#39;s Hospital](http://www.heartchildren.ie/our-lady%E2%80%99s-children%E2%80%99s-hospital-crumlin) | [Heart Children Ireland](http://www.heartchildren.ie/our-lady%E2%80%99s-children%E2%80%99s-hospital-crumlin) |

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 that 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:

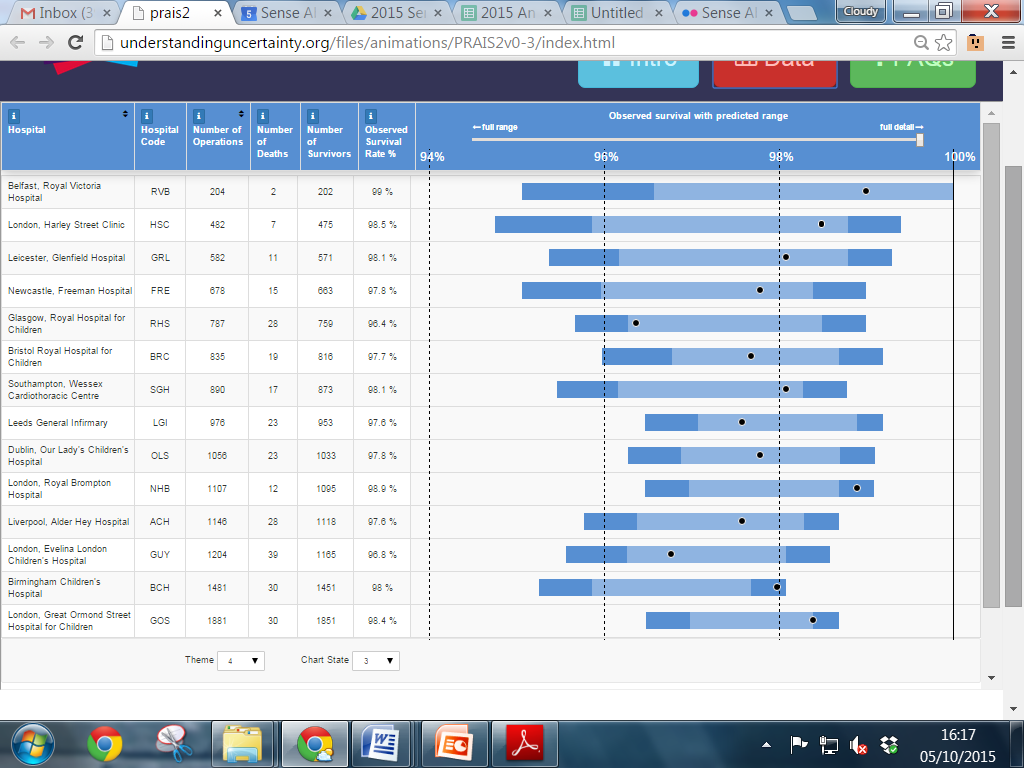
* the age and weight of the child (other things being equal, the bigger and stronger a child is, the safer the surgery is);
* what problem in the heart the surgery is trying to fix (some hearts have more complex defects than others);
* other health problems a child might have (e.g. a genetic syndrome);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

***10.2. Appendix B: Data***

***10.3. Appendix C: Generic FAQs about the chart***

Terminology

**Survival rate**

The percentage of operations where the child survived at least 30 days after their operation.

**Chance factors**

It is impossible to predict precisely what is going to happen in an individual operation.  This is partly due to the inevitable inability to predict the future with certainty – all people are physically unique and will react slightly differently to medicines, anaesthetic, surgery and no heart problem is exactly the same as another. Our inability to predict precisely is also partly because there are factors that we suspect may influence the outcome but cannot be included in the statistical method either because these factors are difficult to define or no routine data on them is collected. Together, we call these all &#39;chance factors&#39;.

**Q1. Why do some children need heart surgery?**

Each year in the UK, about 7000 babies are born with a heart defect (called congenital heart disease). Congenital heart disease covers a wide range of problems from the relatively minor (such as a small hole in the heart) to more severe conditions where a child needs specialist hospital care. About half of all children born with a heart defect will need heart surgery at some stage in their childhood. Children can also develop problems with their heart as they grow up (for instance, through an infection) and also require hospital care (called acquired heart disease).

**Q2. Why are survival rates monitored and published?**

In the 1990s, there were found to be problems with the standard of care for children having heart surgery at the Bristol Royal Infirmary with the proportion of children who died after surgery at Bristol being much higher than in other UK hospitals. The formal inquiry into the what happened ([The Bristol Inquiry 2001](http://webarchive.nationalarchives.gov.uk/20090811143745/http:/www.bristol-inquiry.org.uk/final_report/the_report.pdf)) led to a number of changes, including a new compulsory national reporting system so that the proportion of children surviving to 30 days after surgery for all hospitals were published every year. Results that appear unusual compared to the rest of the UK are then checked further by the national audit body (NICOR).

Until 2013, NICOR only published survival rates for certain types of procedure because there was not a good way of putting overall survival rates into context (see above). But recent [research](https://www.ucl.ac.uk/operational-research/AnalysisTools/PRAiS)has made this possible, and since 2013 NICOR has been publishing overall survival rates along with the “predicted range” for survival using the statistical model (see above). The calculation of the predicted range uses the same statistical method for all hospitals and is calculated without knowing what the survival rate at a hospital actually was.

The UK now has one of the strongest monitoring programmes in the world. Also,since reporting started, [survival rates have been improving](http://www.bbc.co.uk/news/health-32162803) and now**over97% of children survive to at least one month after surgery**.

**Q3. What does the national audit body do?**

[NICOR](http://www.ucl.ac.uk/nicor/patients)(The National Institute for Cardiovascular Outcomes Research) collects data and produces analysis to enable hospitals and healthcare improvement bodies to monitor and improve the quality of care and outcomes of children who need heart surgery. Data on every surgery or intervention performed on a child for heart problems is submitted to NICOR every 3 months, and each hospital undergoes independent checks of the quality of their submitted data.

NICOR tracks the survival of these children by linking to the national register of deaths using NHS number and also from hospital records. Each year, NICOR publishes a report of survival over the previous 3 years for each hospital in the UK and Ireland. It reports the proportion of children surviving for about 40 common surgical procedures and, since 2013, also overall survival for each hospital.

If a hospital’s survival outcomes are below a certain threshold, NICOR and the hospital together examine the data and the individual cases to understand whether any further action needs to be taken. In extreme cases, a hospital might stop doing surgery while action is taken to improve the service. You can read more this process on [NICOR’s patient information pages](https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Information%20for%20Patients?Opendocument) and in our FAQ section. In this website, we explain how survival statistics are used to support this decision making.

**Q4. Why is a different survival range predicted for each hospital?**

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.

If a hospital’s results are inside its range 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. Comparing only to each hospital’s predicted range helps to ensure that we do not draw unjustified conclusions about small differences between observe and predicted survival or between one hospital’s survival rate and another hospital’s survival rate.

**Q5. Why do the hospitals that do more operations have narrower ranges?**

If a hospital does not carry out many operations, then chance factors can have a large impact on their overall survival rate, and so we need to allow more leeway between observed and predicted survival in order to rule out the influence of chance factors. The ranges get narrower as the hospitals do more operations.

**Q6. What does it mean if a hospital falls *outside* its range?**

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

Firstly, the size of the range and the position of each hospital’s dot 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 predicted range is just our best estimate of where each hospital’s survival rate would be.

So, a single hospital falling outside its range is “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 its range just by chance (with a 1 in 40 probability of being on a particular side).

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 its range 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 its range, either above or below, by chance alone.

Considering now the “extended predicted range”, 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. This is why a hospital’s observed survival rate falling outside the extended predicted range is considered strong evidence that the chances of a patient surviving at that hospital are different to what is predicted.

We do want to know whether there could be a reason for a hospital to have fallen out of its range. One reason could be that the data submitted is of poor quality. The first step undertaken by NICOR 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 are not well accounted for by the statistical model. It could also just be due to chance factors. The final reason NICOR considers 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. This is why, particularly **when a hospital falls outside its range**, 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 or if there’s something the other hospitals can learn.

The safety or otherwise of a hospital **cannot** be determined from survival data alone. If a hospital actual survival is below the predicted range, the[National Congenital Heart Disease Audit Steering Committee](https://www.ucl.ac.uk/nicor/audits/congenital/governance)is notified. The Committee in turn notifies the Medical Director and the lead doctor for congenital heart disease at that hospital and a detailed examination of the hospital’s results takes place. There are established and [published procedures](https://www.gov.uk/government/publications/detection-and-management-of-outliers-guidance-prepared-by-national-clinical-audit-advisory-group) 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.

The report on individual instances like this would then be published online by the national audit body, alongside the relevant NHCDA Annual Report. **[link to a hospital-specific report if relevant]** . Such reports for previous years can be found on the NICOR publications website.

**Q7. 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 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 his or her 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.

**Q8. Can the published data tell me about the risks for my child?**

No, 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.

**Q9. How reliable are the data?**

The data come 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. All hospitals are independently audited each year as part of a data validation process (to check the quality of the data submitted).

So, the data are of high quality. While no large dataset is perfect (e.g., it is inevitable that a few records will not be 100% accurate), this dataset is among the most detailed and complete 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 number of particularly challenging patients one year (in ways not accounted for in our prediction) or a run of chance factors 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 What about survival after 30 days? And quality of life?**

No. This data set 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. There is a lot of [active research](http://www.gosh.nhs.uk/medical-information/clinical-specialties/cardiothoracic-surgery-information-parents-and-visitors/research/complications-after-heart-surgery-children)going right now (due to finish around 2018) investigating how to capture, interpret and publish longer term survival and complication rates so hopefully this information will be available in the next 5 years.

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 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](https://www.ucl.ac.uk/operational-research/AnalysisTools/PRAiS) if you are interested in learning more details.

**Q13. 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 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.