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## **How the focus groups and online forum contributed to the ongoing study to select, define and evaluate important complications after heart surgery in children**

### **Aim of the overall project**

Partly through sharing data and building an understanding of deaths following surgery, the teams caring for the 5000 children that undergo heart surgery in the UK per year have achieved notable improvements in survival rates. However, this surgery remains risky and at least 500 children per year experience “surgical morbidities” such as brain injury or serious infection within the breastbone. These events, some of which are potentially avoidable, can have major short and long-term impacts on a child’s health and development. At the moment it is not possible to estimate accurately the true scale of the impact of surgical morbidity on children and families, or of the considerable costs to the NHS. This is because there is little solid information on how often such events occur, which patients are most at risk and what the precise impacts are.

This general lack of good quality information disadvantages patients and carers as they cannot be fully informed about the chances of suffering these morbidities. Crucially, this lack of information also hampers clinical teams wanting to devise, target and evaluate initiatives to reduce surgical morbidity and improve further the safety and quality of the service delivered to patients. We want to rectify this. Our ambitious study will take place across 5 UK paediatric cardiac surgery centres and will involve surgeons, representatives from the Children’s Heart Federation, intensive care doctors, nurses, experts in clinical governance, data managers, psychologists, health economists, statisticians and other analysts.

### **The intended role of the focus groups and online forum**

The effects of post-operative morbidities on children and families go beyond the extra medical attention required to treat them, extending into the realm of patient experience and quality of life. Therefore the selection of the most important morbidities to evaluate needs to be made together with patient representatives, and consider patient reported outcomes as well as clinical outcomes. With the help of the Children’s Heart Federation, we ran 3 focus groups, each in a different UK city, to get the perspectives of patients and carers on which morbidities are most important to them. We also sought patient and family views via an online forum run by the CHF.

A group of experts including doctors, nurses and psychologists as well patient representatives met twice in 2014 to decide on a short list of morbidities that we will track over 18 months in each of the 5 Centres from the autumn of 2015 onwards. The concerns and thoughts raised in the focus groups and online forum fed directly into this selection process.

### **Morbidities identified as important by patients and families**

We had an amazing response from families in the focus groups and online forum who shared their stories, experiences and worries. Over 25 different morbidities were identified by families and those which they identified as being most concerning were brain damage, developmental delay and behavioural problems. Many families talked about ongoing problems with feeding as being particularly challenging, especially once their child was back home following surgery.

We also heard moving accounts of the impact on families in terms of stress, exhaustion, children’s behaviour (both the sick child and their siblings), financial pressures and family breakup. These were particularly marked for morbidities that had a longer lasting impact on the child (such as brain damage and longer term feeding problems).

Many parents also talked about the importance of communication between them and the clinical team caring for their child with some parents feeling that they left hospital unprepared to care for their child.



## Selection of morbidities to evaluate for 18 months from Autumn 2015

The concerns raised by patients and families fed directly into the expert panel which selected a shortlist of ten morbidities. The selection panel were:

*Members of the morbidity selection panel*

Name	Organisation	Role on the panel
Ms Rehana Ahmed	Independent	Family representative
Mr David Barron	Birmingham Children's Hospital	Heart surgeon
Dr Jane Cassidy	Birmingham Children's Hospital	Intensive care doctor
Dr Kate English	Leeds General Infirmary	Cardiologist
Dr Allan Goldman	Great Ormond Street Hospital	Intensive care doctor
Dr Helen Jepps	Bradford Royal Infirmary	Paediatrician
Ms Samantha Johnson	Evelina Children's Heart Organisation	Family representative
Dr Ravi Kumar	Royal Berkshire Hospital	Paediatrician
Ms Isobel Macleod	Royal Hospital for Sick Children, Glasgow	Intensive care nurse
Mr Andrew Parry	University Hospitals Bristol	Heart surgeon
Dr Samana Schwank	Children's Heart Federation	Family representative
Ms Emma Simmonds	Evelina London Children's Hospital	Clinical nurse specialist
Professor Tom Treasure	Independent	Chairperson
Mr Victor Tsang	Great Ormond Street Hospital	Heart surgeon
Professor Rob Tulloh	University Hospitals Bristol	Cardiologist
Dr Emma Twigg	Great Ormond Street Hospital	Clinical psychologist

In selecting the final ten morbidities, the panel took into account clinical severity, impact on families and feasibility of measurement within the scope of this project. Some things of concern to both families and clinical teams, such as developmental delay and post-traumatic stress, were not included in the final shortlist because we would not be able to identify these problems or measure their impact within the timescales of our study. However, feeding problems, brain damage and communication were all included with explicit recognition of their importance as reported by families in the focus groups and online forum. The final ten morbidities chosen were:



Morbidity	Notes
New permanent neurological injury	This is a measure of brain damage and was identified as the single most important morbidity by both families and clinicians.
Unplanned re-operation	This measures whether the child needed to have another unexpected operation shortly after their main operation. Parents raised this as a scary & worrying experience.
ECMO / mechanical support	This is a rare but serious complication when the child's heart needs intensive support to recover after surgery.
Necrotising enterocolitis (NEC)	Sometimes when the heart is not pumping blood very efficiently, parts of the child's bowel can be damaged due to lack of oxygen which causes this condition. It leads to problems feeding.
Vocal cord palsy	Sometimes a nerve in the larynx can be damaged during surgery which leads to a problem with the vocal cords. This condition can lead to problems feeding.
Problems feeding (excluding NEC or vocal cord palsy)	The selection panel recognised that many other factors can lead to longer term problems with feeding, and given what families were saying about its impact, they felt it was very important to measure how often it happens and what its impact is.
Near miss	This describes a collection of adverse events that can happen while the child recovers in intensive care. For instance, if the child has a cardiac arrest that would be considered as a near miss.
Acute kidney injury	Sometimes poor heart function can cause the kidneys to fail which in a subset of cases can lead to longer term problems for the child.
Poor communication between the clinical team and family	This was included following the reports from the focus groups and online forum. The selection panel felt it was important to understand the impact of this on the child and family and recognised that a family that felt unprepared to care for their child at home might lead to worse outcomes for that child.
Hospital acquired infection	This includes wound infections after surgery and also infections that can happen in the tubes connected to children in intensive care.

### Other concerns raised by families

Many families talked about the long term psychological stress for all members of the family and the lack of psychological support that was available for both children and parents in the longer term after surgery. Our study will measure quality of life, including measures of parents' anxiety and depression, for 6 months after surgery and so we will have a better idea of how common such stresses are in the short term.

We also intend to publish academic papers to share the concerns raised by families in the focus groups and online forum with the clinical community and NHS managers. This means that even though we cannot measure everything in our study, the many concerns raised by families will be shared and acknowledged. We hope that these will prompt other studies that can address these concerns directly in the future.

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### Department of Health Disclaimer:

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