

Heart surgery and impact on mental health among new national priorities for congenital heart disease research

- *Patients, parents, charities and healthcare professionals agree key focuses for future research and innovation for disease affecting around half a million people in UK*
- *Priorities will be used to drive a national strategy, focusing research efforts on the most important issues, to be launched early next year*

Children and adults have said that improving outcomes of heart surgery and how congenital heart disease impacts on mental health should be among the top priorities for future research.

Published today in [Open Heart](#), a team of UK patients, parents and healthcare professionals worked with the James Lind Alliance in a national priority setting partnership to determine a set of focuses for research into congenital heart disease (CHD) which affects 1 in 100 children and an estimated more than 250,000 adults in the UK.

Among the priorities identified for future research in children and adults were improving the outcomes of heart surgery for CHD and the impact of CHD on mental health, recognising the significant psychological effect of diagnosis and life-long management of the disease.

Funded by the George Davies Charitable Trust, more than 500 people responded to the initial survey and following a prioritisation survey and two workshops, two top 10 lists of key priorities for research into child/antenatal CHD, and adult CHD were agreed.

Other areas of focus include research to enable less invasive interventions, improve CHD screening before and after birth, using new technologies and innovation to personalise care and better outcomes, and improve quality of life for children and adults living with CHD.

Mr Nigel Drury, Clinician Scientist at the University of Birmingham and Consultant in Paediatric Cardiac Surgery at Birmingham Children's Hospital, and lead author of the study said:

“Working with parents, patients, and the healthcare workers who care for them, we have identified the research areas that are key to advancing the management of congenital heart disease from before birth through to adulthood.

“The Top 10 lists cover a wide range of issues that impact on those with CHD, looking beyond early survival to encompass more holistic outcomes such as quality of life and reducing the burden of living with CHD. Identifying national priorities for research provides a platform to answer the questions that matter most, and we are finalising a national strategy on how to address them.”

Transforming collaborative research

As well as publishing the priorities for research, the paper outlines how the new national strategy to address the priorities will be taken forward, with endorsement from national charity and professional organisation partners.

The strategy, which will be launched early next year, will see the development of a new network in the UK and Ireland for studies across multiple sites, focusing on clinical trials that have the potential to change clinical practice in CHD.

Other initiatives include the setting up of a national CHD patient and public involvement group made up of patient, parent, and charity members, who will actively contribute to the development, conduct and reporting of research.

Rajwant Kaur Singh, CEO of the Children’s Heart Federation said:

“The Children’s Heart Federation (CHF) is fully aware of the importance of listening to the needs and concerns of children with heart conditions and those who care for them, to better enable them to grow to live independent and fulfilled adult lives. We were therefore enthusiastic to be involved in this valuable research from the outset, with our Trustees, staff team and patient and parent members participating throughout. Looking forward, we are keen to ensure the priorities are given adequate attention to enable the best possible outcomes and quality of life for children born with heart conditions.”

Kate Nash from Somerville Heart Foundation said:

"As the UK's national charity for people born with a heart condition, Somerville Heart Foundation welcomes this research illuminating mental health for those born with a heart condition, and the need for further research in this area, as well as reinforcing how important we know heart surgery outcomes are. We congratulate Nigel Drury and the whole team." --

The priority areas in full:

Children	Adults
1. How can damage to organs (eg, heart, brain, lung, kidney, bowel) during heart surgery in children with CHD be minimised to reduce complications, especially in those who require multiple operations?	1. How can less invasive interventions be performed for CHD with the same outcomes as open-heart surgery?
2. How can prenatal and postnatal screening strategies (eg, scans, pulse oximetry, novel techniques) be improved to achieve greater accuracy, avoid late diagnosis and reduce complications from CHD?	2. How can the longevity of the Fontan circulation be prolonged and the impact of complications (eg, liver, protein-losing enteropathy, renal, endocrine, fertility) be reduced?
3. What are the effects of CHD, low oxygen saturations and interventions on brain development and behavioural outcomes, and how can these be improved?	3. What is the impact of living with CHD on mental health in adults and how can this be improved through access to psychological support and other therapies?
4. How can the frequency or need for reoperations be reduced for people with CHD (eg, improved valve/conduit longevity or that grow with the patient)?	4. How can technology be used to deliver personalised care and improve outcomes of those with CHD (eg, artificial intelligence, 3D printing, genomics, stem cells, organ regeneration)?
5. How can technology be used to deliver personalised care and improve outcomes in CHD (eg, artificial intelligence, 3D printing, genomics, stem cells, organ regeneration)?	5. What are the risks and limitations associated with pregnancy, childbirth and motherhood for women with CHD, and what information and support is available?
6. What is the impact of living with CHD on mental health in children and how can this	6. What are the best treatment strategies for heart failure in adults with CHD, in

be improved through access to psychological support and other therapies?	particular those with a systemic right ventricle?
7. What is the impact of living with CHD on quality of life in children and how can this be improved?	7. How can the management of arrhythmias, including sudden cardiac death, in adults with CHD be improved?
8. How can less invasive interventions be performed for CHD with the same outcomes as open-heart surgery?	8. How can the indications, timing of referral and outcomes of transplantation and long-term mechanical support in adults with CHD be improved?
9. How can the longevity of the Fontan circulation be prolonged and the impact of complications (eg, liver, protein-losing enteropathy, renal, endocrine, fertility) be reduced?	9. What is the impact of living with CHD on quality of life in adults and how can this be improved?
10. What are the long-term outcomes and life expectancy of children born with CHD?	10. How can the frequency or need for reoperations be reduced for people with CHD (eg, improved valve/conduit longevity or that grow with the patient)?

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For media enquiries please contact Tim Mayo, Press Office, University of Birmingham, tel: +44 (0)7920 405040: email: t.mayo@bham.ac.uk

Notes to editor:

- The [University of Birmingham](https://www.birmingham.ac.uk) is ranked amongst the world's top 100 institutions. Its work brings people from across the world to Birmingham, including researchers, teachers and more than 6,500 international students from over 150 countries.
- The University of Birmingham is a founding member of Birmingham Health Partners (BHP), a strategic alliance which transcends organisational boundaries to rapidly translate healthcare research findings into new diagnostics, drugs and devices for patients. Birmingham Health Partners is a strategic alliance between seven organisations who collaborate to bring healthcare innovations through to clinical application:
 - University of Birmingham
 - University Hospitals Birmingham NHS Foundation Trust
 - Birmingham Women's and Children's Hospitals NHS Foundation Trust
 - Aston University
 - The Royal Orthopaedic Hospital NHS Foundation Trust
 - Sandwell and West Birmingham Hospitals NHS Trust
 - West Midlands Academic Health Science Network

About The Children's Heart Federation

The Children's Heart Federation (CHF) is the leading national charity championing children with heart conditions. CHF is dedicated in empowering these children, their families, and carers.

Our vision is that all children with heart conditions have their medical and social needs met so they can live the fullest life possible. Our mission is to provide recognition, research, and resources to support those affected by children's heart conditions. We work collaboratively with individuals and organisations to inform, inspire and improve the lives of children with congenital and acquired heart disease.

About Somerville Heart Foundation

Somerville Heart Foundation is the only UK-wide charity supporting adults and young people as they transfer to adult services, with all forms of Adult Congenital Heart Disease.

The charity was set up in 1993 by Professor Jane Somerville who recognised the need for a charity for this new and rapidly growing set of survivors.

It is estimated there are over 250,000 people in the UK who have survived into adulthood, with now more adults having the condition than children as around 90% now survive as opposed to 15% during the 1950s and 1960s.

We are here to support people born with a heart condition so they can lead as fulfilled lives as possible, as well as campaigning to make sure the health services are there for them.