



Could you help us improve the quality of services for congenital heart disease by sharing your experiences?

Congenital Heart Audit: Measuring Progress In Outcomes Nationally (CHAMPION)

What is the study about?

About 5,600 babies are born with Congenital Heart Disease every year in England. It is a complex, lifelong condition and many problems cannot be fully cured. Every year about 7,500 procedures are performed on children and 3,000 on adults. All hospitals submit data on each procedure that they undertake to a central NHS audit database. Currently, the NHS carefully monitors the proportion of people surviving at least 30 days following surgery for CHD. Survival is very high and we know that there are many other aspects of quality that the NHS could measure and report.

The NHS has commissioned a study to develop new ways for measuring quality of services for congenital heart disease services for both children and adults. This includes developing fair ways of measuring survival after surgery in adults and also developing ways of reporting longer term outcomes for people treated for CHD.

We believe it is crucial to try to measure what people living with CHD and their families think is most important to them. In this online forum, we hope to hear about your views about what should be measured and reported on quality of CHD services. We might not be able to measure everything yet, but we promise to listen to you and to measure we can. We will also capture what we can't yet to do so that the NHS can think about changing what new data should be routinely collected in the future.

We would like to invite you to join our Facebook discussion group and tell us about your experience of congenital heart disease services. The discussion group is being run by Little Hearts Matter and is part of the larger study (called CHAMPION) based at University College London.

What will happen if I join the discussion forum?

If you would like to join the discussion forum you will need to have a Facebook account. When you request to join the discussion forum you will be asked to give some basic information about yourself to help us understand better what people are telling us. Please complete the form at the bottom of the Champion Study research page - www.lhm.org.uk/news-and-events/current-research/champion-study/. If you are a member of Little Hearts Matter you will then be contacted by email to give you access to the group and you can begin posting in the discussion. There will be some specific questions posted for everyone to respond to but we would also be interested in just hearing any stories about your care that you would like to share.

The forum will open in the summer of 2020.

Who is the forum open to?

We would love to hear from parents and relatives of a young person with a single ventricle heart condition, also adults and teenagers living with half a working heart

It is possible that important views and comments could come from bereaved parents or relatives whose child did not recover from their treatment. As such, some discussions may touch upon sensitive issues for some families. If you are upset by any of the discussions on the forum and would like to talk to someone you can contact The Little Hearts Matter Team on 0121 4558982 who will offer you support.

How will the information be used?

The results of the larger study and important insights from these discussion groups will be published and shared with the NHS audit body and clinicians and academics through conferences and in academic journals. We will also produce a summary of the findings for sharing on the LHM website. You will not be identified in any report or publication. We may use direct quotes in an anonymised form when reporting the results of the study in publications and presentations.

Will my information be kept confidential?

The discussion forum is a closed group so only other forum members and staff from Little Hearts Matter will be able to identify you from your posts. Little Hearts Matter will be responsible for running the discussion forums and will remove all names from forum posts before sharing this information with the research team at University College London. The research team will not have any personal information about you other than the information you give when you sign up to the discussion (age, sex, location and role e.g. parent, relative, friend).

What if I change my mind and want to leave the discussion?

You can leave the discussion forum at any time. If you wish your posts to be removed from the forum and excluded from the study you can do this by contacting a forum administrator.

Who is organising and funding the research?

The study team is based at University College London. Great Ormond Street Hospital, Alder Hey Children's Hospital, University Hospitals Bristol, Leeds Teaching Hospital, Magdi Yacoub Institute, Barts Health NHS Trust, Royal Brompton and Harefield NHS Trust and, Newcastle University. Little Hearts Matter, the Children's Heart Federation and The Somerville Foundation are also collaborating in the study. The overall study has been funded by a grant from the National Institute of Health Research (ref no. PR-R20-0318-23001) and has been reviewed by NRES Committee North of Scotland – REC 1 (reference no.20/NS/0022).

Who can I contact if I want more information?

If you would like more information or would like to talk to someone about the study you can contact Suzie at Little Hearts Matter on 0121 455 8982 or email suzie@lhm.org.uk