

London South Bank University: Heart Siblings Research



A message from Lizzie Bichard at London South Bank University about their Heart Siblings research & how ECHO members can get involved:

Dear ECHO families,

My name is Lizzie Bichard and I am a PhD student at London South Bank University (LSBU). I am an intensive care nurse by background and have previous experience caring for children with congenital heart disease (CHD) and their families.

It was great to meet some of you at the [ECHO wellbeing day](#) at Kent life on 26th October. During the wellbeing day I shared some of the results from the PPIE (patient, public involvement and engagement) activity from August 2017. Some of you also shared your contact details and offered to be part of an advisory group for a project we are planning now.

The history of our links with ECHO and our interest in sibling research started when we reviewed available research focusing on siblings of children with CHD. We didn't find much and what we did find was outdated, included very few people (small sample size) or it wasn't very thorough. We have sent a literature review out for publication and once it has been accepted; we can share it with you.

After we did this, we thought it would be most useful to meet with parents and siblings of children with CHD and find out about their experiences. This is when we met some families at ECHO HQ in August 2017. We split siblings and parents into three groups and used some games with the younger children to find out what they thought about the impact. We recorded these sessions and then made notes on what things were being talked about a lot. This helped us to have some ideas about the project we are planning now. We are also writing a report for ECHO about the PPIE project and this will be available soon and we can share it with you.

The project we are planning now is the research that will be part of my PhD. I'm hoping it will provide families with information on how siblings can be supported to reduce the negative impact of having a sibling with CHD. We want to know what is difficult, but we also want to know the positives so that we can understand why some children find it harder than others and what things help children cope with the difficult bits.

Some families kindly gave me their details at the wellbeing day, but I would like to extend the invitation out to any families who would like to be involved but were not around on the wellbeing day. I would like to invite you to be part of an advisory group.

Get involved:

If this is something which sounds interesting and you would like to get involved or have further information please email Elizabeth (Lizzie) Bichard: bichare2@lsbu.ac.uk



FAQ

What is an advisory group?

Being a member of an advisory group for a research project means that your thoughts and opinions about things relating to the project will help to shape its development. Your influence will improve the quality of the research.

Why do you want me to be involved?

I have lots of experience working with children in different settings, but I don't have a sibling or any member of my family who has CHD. I'm also not a parent so it important for me to undertake a research project which is going to be specific and ask questions which are important to the people it affects.

What questions might I be asked?

Some examples might be: Does this information sheet make sense? What do you think about the wording? Are the terms used too complicated for a younger sibling to understand? How should I recruit siblings to research? Where might siblings like to be interviewed?

What if I don't have time?

Being part of an advisory group does require some time to respond to questions or review a document. However, I understand that everyone has busy lives, sometimes life is hectic and at other times things are a little more relaxed. I also understand that you might agree to take part and change your mind. All of this is fine, there is no pressure and if you feel like there is too much of an expectation please do let me know.

How long will I have to review the things you send?

I will usually allow a week to review things, if longer is needed and there are no deadlines then this might be possible. If you need more time, please let me know. I will send out a date when it would be helpful to have replies returned and if I don't receive one, I will assume that you don't have time now and that is fine.

What will I be asked to do?

I would like to send you some ideas about the project, what I plan to do and why, some information leaflets or consent forms and see if they make sense. It would be helpful if I could email/send things for you to look over and you can either send me a few thoughts or we can arrange a time to chat over the phone to go through things.

What if I disagree with something you've written, or I don't like the information sheets?

This is important to me and I want to hear the negative comments. I appreciate that its difficult to say you don't like things but, if you don't like it then its likely that others won't either and then I might not get enough people to take part. The ultimate goal is to get information from siblings about the impact having a brother/sister with CHD has on their lives. It's a difficult thing to talk about and I want families and the siblings to feel happy and comfortable enough to share things. Please feel free and open to tell me exactly what you think.

What if I have no experience with research?

You don't need to have any experience with research or even anything academic, you are the experts on what it's like to have a child with CHD in the family and this is what I need help with. Together we can make a great project which encourages people to share their stories and help the general population, health services, teachers and other families understand more about what sibling's face and what makes them strong and unique.

You don't listen to what I'm saying!

I will always take on board any comments you send but it has to be realistic within the scope of the project. This study currently has no funding available and it's only one researcher (me!) trying to get all the information. I have three years on the project, and I will try and get the best quality information so that I can share it with those who need to read it. In the research world there are lots of rules and regulations which are important to follow. They keep researchers and people safe and make sure that my research causes no harm or distress to anyone. I must have approval from the university, ethical committees, hospital and charities to do this research and they have rules that I must follow. Sometimes something you suggest might not be possible and I will explain why but please don't think I haven't taken this on board.

Why can't we make this project bigger?

Time, funding and expertise are all important factors and we have to be realistic and make sure that the research we produce is real, honest and trustworthy and that the results will give information to all families of children with CHD not just those taking part. It might be really disappointing when some siblings are excluded (because of age, situation, language, health problems etc) but there will always be a reason. It also doesn't mean that we can't keep looking at this important area and plan further research in this area. It's important, I'm passionate about it and I really hope we do!

What if I change my mind?

A quick email, no reason required will do the job. No pressure

What might I get out of this?

Being involved in an advisory group for a project will hopefully empower you and your family to influence changes for future families who will experience something similar. If we have more information to support siblings in the future, we hope this will give them strength and resilience to conquer the difficult things and give parents, teachers and health professionals information on how best to support them. We also hope that in the future we can provide siblings with more formal support, services which are just for them. This being said, it may not be right for your family depending on your situation, this is understood and respected.

To take part in advisory group may also help with some professional skills, confidence and knowledge and can look good on your CV if you are interested in any work with children, healthcare or research related work in the future.

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective and more credible”

PROFESSOR DAME SALLY DAVIES - CHIEF MEDICAL OFFICER