

Participant Information Sheet

Having a child with single ventricle Congenital Heart Disease: Parental experience of role and identity

My name is Shannon Dandy and I am a trainee clinical psychologist. I am conducting this research as a student in the Doctorate in Clinical Psychology Programme at Lancaster University, Lancaster, United Kingdom. Thank you for taking the time to read this information sheet. **If, at the end of reading the information, you would like to take part or would like further information, please contact me at s.dandy@lancaster.ac.uk. Please note that this email address is not monitored at all times.**

What is the study about?

The purpose of this study is to interview parents of children aged 16 years or under with single ventricle Congenital Heart Disease who have had their completed Fontan surgery. Previous research has recognised the unique experiences parents have when their child has single ventricle Congenital Heart Disease and has suggested that there may be an impact on how parents understand their own identity and roles. However, no study has yet considered this in detail. Therefore, the current study is looking to address this gap and provide a platform for parents to speak about their experiences.

Why have I been approached?

You have been approached because the study is looking to hear about the experiences of people who have a child aged 16 years or under with single ventricle Congenital Heart Disease who had their completed Fontan surgery at least six months ago.

Are there any requirements to taking part?

Yes. To take part, you should:

- Have a child aged 16 years or under with single ventricle Congenital Heart Disease, who had their completed Fontan surgery at least 6 months ago.
- Live in the UK.
- Be able to understand and speak English. The reason for this is that there is limited funding for the research and, therefore, it is not possible to fund translation or interpretation services.
- Be available to take part in an interview during working hours (Monday – Friday, 9am-5pm).

If your child is currently in hospital or has had a heart transplant it will not be possible to take part in this research. This is because these are unique experiences that will not be able to be fully explored by the current study.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part and you are under no obligation to do so.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview with me which will last for approximately one to one and a half hours. The interview will take place at a time that suits you, between the hours of 9am-5pm from Monday to Friday. Interviews will be audio recorded and carried out remotely. It is recommended that interviews take place via Microsoft Teams and information on how to access and use this software will be supplied prior to the interview, via email. However, if you have a preference for telephone or other videoconferencing software then this would be considered. Please note that the security of interviews completed via telephone or other videoconferencing software cannot be guaranteed due to the nature of the platforms.

During the interview, you will be asked about your experiences of parenting a child with single ventricle Congenital Heart Disease. These experiences will be unique to you, but specific questions will include asking about your journey with your child, your perception of your parental roles, your sense of identity and your psychological wellbeing.

If you do not answer the telephone or video call at the specified time of the interview, the researcher will try to call you twice more, after 5 and 10 minutes. If all calls go unanswered, the researcher will assume that you no longer wish to take part and will not persist in trying to contact you.

Can I change my mind?

Yes. You can choose to withdraw from the study at any time before or during the interview without giving any reason. Once the interview has been completed, you will be able to withdraw your data for up to two weeks after the interview. You can withdraw from the study by contacting me directly via email. After this time, the data will begin to be anonymised, transcribed, analysed and incorporated into themes. As a result, it will not be possible to identify and withdraw the data.

Will my data be identifiable?

Any personal data that you provide will be kept confidentially and separately from your interview responses. The audio recording of your interview will be typed and made anonymous by removing any identifying information, including your name and your child's name. The interview will not ask you to state your child's hospital of treatment, but if this is mentioned during conversation then it will be removed from the typed transcript. Anonymised direct quotations from your interview may be used in the write-up of the study, but a pseudonym (false name) will be used so your name will not be attached to them. All reasonable steps will be taken to protect your anonymity.

The data collected for this study will be stored securely. Only the lead researcher, Shannon Dandy, will have access to participant interviews, which will be stored electronically on a secure drive. The research supervisors, Dr Craig Murray and Dr Anja Wittkowski, will have access to anonymised interview transcripts. Audio recordings of interviews will be deleted

once they have been transcribed. At the end of the study, electronic copies of anonymised interview transcripts will be kept securely for 10 years at Lancaster University, in line with university policy. Audio recordings of you providing verbal consent will be kept securely and separately for the same 10-year period. At the end of this period, the anonymised transcripts and audio recordings of verbal consent will be deleted.

There are some limits to confidentiality; specifically, if something is said in the interview that makes me think that you, or someone else, may be at risk of harm then I will have to break confidentiality and speak to another member of staff or other relevant agencies about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis paper that will be assessed as part of my Doctorate in Clinical Psychology qualification. It may be decided to submit the report to a peer-reviewed journal which, if published, would be accessible via the internet. You will be offered a summary of the research findings have been written, to see how your input contributed to the findings. When, or if, direct quotes from your interview are used in the report or publication, this will be anonymised.

For more information on how Lancaster University processes personal data for research purposes and your data rights, please visit our webpage:

www.lancaster.ac.uk/research/data-protection

Are there any risks?

There are no risks anticipated with participating in this study. However, I am aware that having a child with single ventricle Congenital Heart Disease can be a challenging experience and it may be upsetting to talk about these experiences. Therefore, if you experience any distress during or following participation in the study you are encouraged to let me know. In addition, you will be provided with a debrief sheet that will provide contact details for resources that you could access for support.

Are there any benefits to taking part?

There are no direct benefits to you for taking part. However, it is hoped that findings from the research might help healthcare professionals working with children with single ventricle Congenital Heart Disease to better understand parents' experiences.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you would like to participate in this research or have any further questions, please contact the main researcher on the details below. However, please note that the email is not monitored at all times.

Shannon Dandy
Doctorate in Clinical Psychology
Lancaster University, Lancaster
LA1 4YG
Email: s.dandy@lancaster.ac.uk

You can also contact the main research supervisor if you wish to:

Dr Craig Murray
Doctorate in Clinical Psychology
Lancaster University, Lancaster
LA1 4YG
Email: c.murray@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith
Research Director
Doctorate in Clinical Psychology
Lancaster University, Lancaster
LA1 4YG
Email: ian.smith@lancaster.ac.uk

If you wish to speak to someone outside of the Doctorate in Clinical Psychology Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine (Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

As part of the interview, you may choose to talk about things that are difficult or upsetting for you and cause distress. These feelings may go away within a few minutes, hours or days. However, should you continue to feel distress, either as a result of taking part or in the future, please contact your GP. The following sources of support may also be useful:

- Your child's Cardiology team (sometimes there is also a Clinical Psychologist who works within the Cardiology team who may be able to offer support).
- Little Hearts Matter: A national charity supporting children with single ventricle Congenital Heart Disease and their families
 - 0121 455 8982



- Lhm.org.uk
- Children's Heart Federation: A national charity for children with heart conditions and their families
 - 0300 561 0065
 - Chfed.org.uk
- Other sources of emotional support may also be helpful, for example the Samaritan's Helpline: 116 123