

## Research study

### The health of fathers of children with a life-limiting condition

#### Information for fathers

- We would like to invite you to take part in a research study to learn more about the health of fathers of children with a life-limiting condition. This includes all individuals who define themselves as the father or a child with a life-limiting condition including biological fathers, non-biological fathers, step-fathers, foster fathers and adoptive fathers.
- The study will collect information from fathers of children with a life-limiting condition and is being carried out by researchers at The Martin House Research Centre at the University of York  
  
(<https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/>)

#### Why is this research being carried out?

There are more children and young people living with medical conditions that may shorten their lives (life-limiting conditions). The parents of these children commonly provide and coordinate all of their child's care needs. The existing research on these parents focuses on mothers, meaning that we know less about fathers. This research study is important because

it will help us to understand the experiences of fathers and how their experiences might affect their own health. It will also help us to understand how fathers look after their own health and well-being. Understanding the impact on fathers' own health is important not only for fathers themselves but in ensuring that they feel able to care for their child.

### **Why have I been chosen, and do I have to take part?**

You have been identified as the father of a child with a life-limiting condition. Taking part is entirely your decision and whatever you decide will **not** affect the standard of care and support or other benefits you and your child receive.

### **What will happen if I decide to take part?**

The study is made up of 2 parts: a web-based survey and an interview with a researcher. If you take part in the study you will be asked to complete the survey first. You will then be asked if you would also like to take part in an interview. This is optional though.

### **The Survey**

The survey is web-based and you can do it in your own time. It will take around 20 minutes to complete. You will be provided with a web link to the survey. There will be a short section at the beginning to check that you are eligible and then you will be able to consent to take part. The main part of the survey will include questions relating to you, your family, your child's characteristics including their health condition, and your own physical and mental health, sleep and caregiving. If you decide that you are interested in taking part in the

interview as well as the survey, you will be able to provide your contact details at the end of the survey.

### **The interview**

This involves an interview with a researcher which we will use to gain more of an in-depth understanding of your experiences and health. This interview will last around 45-90 minutes. Once we have your details, we will contact you to arrange an interview and answer any questions that you may have. During the interview you will be asked to talk about your experiences as a father of a child with a life-limiting condition, your own physical and mental health and how you think your experiences have affected your health. You will also be asked about ways in which you look after your own health.

You can choose where the interview takes place and you can have someone with you if you would like. It can be face-to-face (depending on COVID-19 restrictions), over the phone or via video call e.g. Zoom. With your consent, the interview will be audio recorded so that we don't miss anything that you tell us.

### **Will my taking part be kept confidential?**

We will keep your survey responses and what you tell us in interview or during contact with the research team completely confidential, unless you tell us something that raises concerns that you or someone else is at serious risk of harm. If this happens, we would talk to you first

and the best thing to do. We will follow strict rules about confidentiality and all information will be stored in locked filing cabinets and in password-protected folders on computers.

### **What are the possible benefits and risks to me of taking part?**

By taking part in this study you could help others. Information collected from you and from other fathers could lead to a better understanding of the experiences and health of fathers of children with a life-limiting condition. It is possible that you may find it difficult to talk about or answer questions relating to your own health. If you find the survey or the interview distressing, please contact the research team and we can provide details of local organisations who can help. Taking part is voluntary and you can decide to withdraw from the study at any time.

### **Are there any expenses or payment for taking part in this study?**

If you have to travel in order to participate in the study, we will reimburse your travel costs.

### **If I want to take part, what do I need to do next?**

If you would like to take part in the survey, please follow the URL link below or scan the QR code where you can consent to the study and complete the survey.

[https://york.qualtrics.com/jfe/form/SV\\_7NVsrVKvBOXoTEq](https://york.qualtrics.com/jfe/form/SV_7NVsrVKvBOXoTEq)



If you would also like to take part in the interview, then you will be able to provide your contact details at the end of the survey and a researcher will contact you. Whether you take part in the survey, or both parts is completely your choice.

If you have any questions about either aspect of the study or about any of the statements on this form or the consent form please contact [mhrc@york.ac.uk](mailto:mhrc@york.ac.uk), 01904 328711.

### **What if I change my mind during the study?**

You can withdraw at any time and you do not need to give us a reason. We will keep the information we have already obtained from you. If we have your personal details we will keep them so that if you contact us again, we know that you have taken part. We will not use this information to contact you though.

### **What will you do with the information I provide?**

We will use the information you provide to describe the health of fathers of children with a life-limiting condition, and factors that influence this. Individuals from the University of York and regulatory organisations may look at your research records to check the accuracy of the research study. The only people at the University of York who will have access to information that identifies you will be the people that need to contact you or audit the data collection process. The people who analyse the data will not be able to identify you. If you choose not to provide your contact details (i.e. only take part in the survey and not the interview), all of your data will remain anonymous. We will write about the study in publication read by

researchers and care providers. We will present the findings at events and on websites. We may use the data to support other research in the future, and the data may be shared with other researchers in a way that you will not be identifiable. The information that we share with others will not identify you and will only be used for the purposes of health and social care research. It cannot be used to contact you and will not affect the care that you or your child receive. It will not be used to make decisions about future services available to you, such as insurance.

### **How long will the University of York keep my information?**

The University of York will keep identifiable information about you, including your signed consent form, for 3 years after the study has finished. We will also keep the information you share in the survey and the interview for at least 10 years from the end date of the study. Your interview data will be stored as an anonymised transcript of the audio recording. The audio recording will be deleted immediately after transcription and accuracy checks.

### **Who is responsible for keeping my information safe?**

The University of York is the sponsor this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The University of York is a publicly-funded organisation that conducts research to improve health, care and services. Research following UK Policy Framework for Health and Social Care Research is conducted to serve the interests of society as a whole. This means that the University of York is using the legal basis provided under the General Data Protection Regulation of a task in the public interest to use your personal data for this research. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information that we already obtained about you. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-participants/> or by contacting [dataprotection@york.ac.uk](mailto:dataprotection@york.ac.uk).

### **What will happen if the study stops earlier than expected?**

Should the research stop earlier than planned and you are affected in any way, we will tell you and explain why if we have your contact details.

**Thank you for the taking the time to read this information sheet. Please keep  
this copy.**

**Get in touch with the research team:**

**Victoria Fisher**

email. [mhrc@york.ac.uk](mailto:mhrc@york.ac.uk)

**Study funding and approvals:**

The University of York is the sponsor for this study.

The study is funded by the National Institute for Health Research (NIHR) (Academy) (Study Reference:18400).

The London- Bloomsbury Research Ethics Committee have approved this study (reference: 21/LO/0591)

**Who to contact if you have concerns about the study or wish to make a complaint:**

Lorna Fraser- Director of the Martin House Research Centre: email: [lorna.fraser@york.ac.uk](mailto:lorna.fraser@york.ac.uk) telephone: 01904321889

If you feel unhappy with the way your complaint was dealt with, please contact the research office at The University of York:

Michael Barber

Telephone: 01904 318693

Email: [michael.barber@york.ac.uk](mailto:michael.barber@york.ac.uk)

Address: Innovation Centre, Ron Cooke Hub, University of York, York, YO10 5GE

If you wish to raise a complaint on how we have handled your personal data, you can contact the University of York's Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO).

The University of York's Data Protection Officer can be contacted at [dataprotection@york.ac.uk](mailto:dataprotection@york.ac.uk)