

# Participant Information Sheet

## 1. Study Title

Identifying experiences, attitudes and practices around limitation of treatment agreement (LOTA) decisions among paediatric professionals in the Yorkshire and Humber region.

# 2. Invitation

You are being invited to take part in this research project. Before you decide to do so, it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Thank you for reading this.

## 3. What is the project's purpose?

This study aims to investigate the opinion of paediatric health professionals, both doctors and nurses, in the Yorkshire and Humber region as to when it is appropriate to have a discussion regarding end of life decisions and limitation of treatment agreements in children with known life-limiting and life-threatening conditions.

# 4. Why have I been chosen?

You have been chosen as being a paediatric health professional you will have the knowledge about the end of life care decisions and limitation of treatment agreements (LOTA) in paediatric population.

### 5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be able to keep a copy of this information sheet and you should indicate your agreement to the online consent form. Your participation in this study is entirely voluntary. The survey is anonymous and the withdrawal of data will not be possible once all the responses have been submitted as we cannot identify the participant from an anonymous dataset.

## 6. What will happen to me if I take part?

You will be asked to complete a web-based questionnaire which we estimate will take you about 15 minutes.

### 7. What do I have to do?

Please answer the questions in the questionnaire. You will be presented with a clinical vignette followed by three sequential patient encounters. For each of the statements following a patient encounter, please indicate how much you agree or disagree to the statement by clicking the number that most closely corresponds to your opinion.

### 8. What are the possible disadvantages and risks of taking part?

Participating in the research is not anticipated to cause you any disadvantages.

## 9. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified or identifiable in any reports or publications. Data collected may be shared in an anonymised form. These anonymised data will not allow any individuals or their institutions to be identified or identifiable.

### 10. What will happen to the results of the research project?

This study is a part of my MSc Child Health from University of Leeds. You will not be identified in any report or publication.

### 11. Who has ethically reviewed the project?

This project has been ethically approved by the University of Leeds research ethics committee. The project has undergone School of Medicine Research Ethics Committee review, reference MREC 18-026, V2 and was approved on 6th March 2019.

## 12. Contacts for further information

Dr Muhammad Ali, Post CCT Fellow Paediatrics, West Yorkshire, mt15m2a@leeds.ac.uk Dr Fatemah Rajah, Embrace Transport Consultant, fatemah.rajah@sch.nhs.uk

Thank you for taking part in this research.