

## The Ocelot Study

### Information Sheet for children

#### What is a study?

A study is when people look at something to try and understand it better. They are done for lots of reasons and are very important.



#### Why is this study being done?

We want to try and help people who were born with OA/TOF by understanding more about what it is like to live with this condition.

#### Why have I been invited to join in?

You were born with OA/TOF and so you are the expert in what it is like to live with this!

#### Do I have to take part?

No! It is entirely up to you whether you take part or not, no-one will mind whatever you decide. If you don't take part, you will carry on being looked after by your medical team as normal.

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

We will ask you to fill in 2 surveys about what things are important to you living with OA/TOF.

You will answer the first survey and then we will look at what everyone has told us. We will then change the questions in the survey based on people's answers and send the second survey to you. You will be told what most people answered and we will ask if you still think the same as you did before (we will remind you of how you answered) or if you think something else now. It is fine to keep your answer the same and it is also fine to change your answer. It is completely up to you!



### It is very important that you complete BOTH surveys

The surveys will be sent to children, young people and adults all around the world to find out how people feel about living with repaired OA/TOF.

So that we can compare all the answers, the survey has to be the same for children and adults. This means you will likely need help from an adult in answering the questions as some of the words are a bit tricky– but we really want to hear what you think.

The Ocelot Study: Developing a lifelong core outcome set for the health outcomes for children and adults with congenital oesophageal atresia and /or tracheo-oesophageal fistula

### What do I need to take part?

You need access to an electronic device (laptop or computer are best) and need to have access to an email address to register for the study. (If your parents have also registered for the study to give their views, you will need a different e-mail address to the one they used).

### Will taking part help me?

We hope that you will enjoy taking part. The study may not help you directly, but some children like to take part as they are helping doctors and researchers to know more about their condition.

### Is there anything bad about taking part?

Sometimes thinking about the things that are important because of the way you were born can make you upset. If you get upset and don't want to carry on, that is okay just exit the survey

### Who are the people running the study?

The study is being run by a team of healthcare professionals and scientists from all over the world. It is led by Dr Rebecca Thursfield who is a doctor at Alder Hey Children's hospital in Liverpool.

### How do I take part?

If you have read and understood this information and would like to take part, you can sign up here: <https://delphimanager.liv.ac.uk/ocelot/>

### Where can I get more information?

If you have any questions or complaints, please contact the study team:

Telephone: 0151 252 5777 (ask for Dr Thursfield)

Email: [theoceletostudy@liverpool.ac.uk](mailto:theoceletostudy@liverpool.ac.uk)



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