

## CELLOS Study: Delphi Survey Information Sheet for Children and Young People 12-15 Years Old

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### Why are you doing this study?

Doctors want to know the best way to fix kids' leg problems. They use research to decide which surgery is the best for kids who need an operation on their legs. This is surgery from their hips to their feet. We want to make the research better. Most studies only look at how the leg moves after surgery. They forget to measure other things which are important to kids. Other things they could measure are if kids can play sports better after surgery, or if they can sleep longer.

The CELLOS study wants to make this better. We want to find out what's really important for kids who get non-emergency leg surgery. We're making a list of all the things that other studies have measured before. We also talked to doctors, kids, and their parents to learn more. Now, we want you to help us decide what's most important.

We made a survey to vote on what researchers should measure. You will be asked to fill in different versions of this survey, up to four times. If you want to, you might get invited to two online workshops. In these workshops, we'll talk about what we found in the survey. Your thoughts will help doctors choose the best surgery for kids' legs, from their hips to their feet.

### Why have I been invited?

We are asking you to take part because you are between 8 and 25 years old. Also, you have had surgery to your leg, or you will have surgery to your leg soon.

This study will include up to four surveys. After the survey, some people will join together online in a workshop to talk about the survey results. We will ask about 150 people to fill in the surveys. We will ask about 25 people to take part in the online workshops.

### What will happen if I take part?

Once you finish reading this, you'll decide if you want to join. You'll sign a form to say you are happy to be part of this. Then, you'll do the first survey. We'll ask about some questions about you. Then we'll ask you to vote on what you think researchers should measure after kids get non-emergency leg surgery. You can vote on what's important and add things we might have missed. It will take about 15 minutes.

After the first survey, we'll look at how everyone voted. If everyone agrees on an outcome, we'll keep it. If people suggest outcomes we missed, we'll add them. Then we'll ask you to fill the survey again. We'll do this up to four times, or until everyone agrees. If you miss a round, we'll remind you.

After the survey, there will be two online workshops with about 25 people. The first workshop will talk about what's most important to measure after surgery. The second workshop will talk about how the researchers can measure. These workshops will be on Microsoft Teams. They'll be recorded with audio and video.

Before the workshop there will be an online 'Meet and Greet'. You can meet other children and parents taking part. You can talk about how the workshop will run and ask any questions. You can choose if you want to come or not. After the workshop there will be another online chat. At this you can talk about how the workshop went. Again, you can choose if you want to come or not. After the workshop you will also be sent a form. The form will ask about how you found the workshop.

If you are interested in joining a workshop, let your parent or carer know. If you want to, then you might be invited to these workshops. We email your parent or guardian if you are invited.

### **Do I have to join in?**

No, it is up to you! We will ask you to sign a form to say that you agree to take part. This is called an assent form.

### **What are the advantages and disadvantages of taking part?**

Joining in will not help you, but it might help kids in the future. If you complete four rounds of the survey, it will take about one hour of your time. If you are invited to take part in a workshop, these will take about four hours.

### **Will I get anything for taking part?**

If you take part a workshop, you and your parent or carer will be offered a £75 gift voucher. This is a thank you for taking part.

### **Will anybody know I am taking part?**

We will keep your information private. This means we will only tell those who have a need or right to know that you are taking part. This will include the research team, people helping with the research and your parent/guardian. Other than these people, we will only share information without your name.

### **What happens if I don't want to take part in the study anymore?**

Tell your parent/guardian or the people carrying out the research that you don't want to take part. You don't have to give a reason. No one will be annoyed with you. It is your choice.

You can also ask the researchers to delete your information from the survey. You can do this up to one week after the survey closes. If you want to delete your information, your parent or carer can let the researcher know. If you take part in a workshop, we will not be able to delete your information. This is because you will be talking with other people, so we will not be able to delete just your information.

## **What happens to the results of the study?**

What we find out will become a book for a degree at the University of Oxford. We want to tell researchers the results of this study. This will make sure they measure the right things in future research studies. To tell researchers the results, we'll write articles, do presentations and make an information pack for researchers. We'll also make an animated video. If you would like to see the video or read about what we find out, ask your parent or guardian. They can find the results on our X(Twitter) page @CELLOSstudy.

We would like to use quotes from you in the results we share. The quote will be published under a pseudonym (fake name). Every effort will be made to maintain your confidentiality.

## **What will happen to my data?**

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the sponsor for this study. It is the data controller and is responsible for looking after your information and using it properly. We will be using information from you in order to undertake this study and will use the minimum personally identifiable information possible.

We will store any research documents with personal information, such as consent forms, securely at the University of Oxford for five years after the end of the study as part of the research record. We will keep any other identifiable information for a maximum of three months after the study has finished. This will include your contact details.

We will run the survey on a secure online survey platform. We will store the results online until the end of this study. Once the study is finished, we will download the results and erase them from the online survey platform. The results will be anonymised when they are downloaded.

The workshops will be audio and video recorded using Microsoft Teams. The video file will be saved on the secure University of Oxford network drive in a password protected file, where only the research team can access it. It will be kept for five years along with the research data. A backup recording will be made with an encrypted digital recorder. This will be kept only until the video recording is checked.

For the workshops, we will use a company to help run it. If anybody needs a translator, we will use a company who does translations. Before the workshop, both companies will sign a contract to say that they will keep what you said secret.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at <https://compliance.web.ox.ac.uk/individual-rights>

You can find out more about how we use your information by contacting [CELLOS.study@ndorms.ox.ac.uk](mailto:CELLOS.study@ndorms.ox.ac.uk)

### **Who has reviewed the study?**

Before any research involving people can start, it has to be checked. A Research Ethics Committee makes sure that it is OK for the research to go ahead. This study has been checked by Harrow Research Ethics Committee (reference 24/PR/0719)