

Child Information Sheet

TRANSMIT: A multifaceted knowledge TRANslation Strategy iMproving function in children and youth with cerebral palsy

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1. What is this study about?

When you have cerebral palsy (CP) it is hard to know which treatments will help you. We made a mobile app to help kids with CP and their families. This app is called cpThrive. It can help find the treatments that might work best for you. cpThrive has information and video clips. This study checks if cpThrive is helpful to kids with CP and their families. It also looks at whether using the app changes the things you can do.

2. Can I join?

You can be part of this study if you are under 18 and have CP. Your parents or carers also need to be involved.

3. What will I do?

If you say yes, you will get the cpThrive app for one year. With help from your parents, you will:

- Get cpThrive on your phone or tablet
- Read a page called 'child assent form' and say yes
- Give your age and NDIS number* (if you have one) and where you live
- Pick three goals for what you want to do
- Say how you do on each goal
- Every two or three months say how you are going on your goals
- It takes 5 minutes each time
- You can change your goals at any time

We will use your NDIS number to compare your information to others in the NDIS who are not using the app. This will help us to see if the app is helping people to reach their goals.

What the app does

cpThrive has lots of treatments to pick from. You can put in details about yourself and what you want to improve on. It tells you all about the treatments, who can use them and how much you need. All the details come from up-to-date research.

4. Can I stop using it?

Yes. It is your choice. You can stop any time you want to. It won't affect your care at all. You can even keep using the app once the study has stopped or you have stopped using it.

5. Are there any risks?

The app doesn't physically hurt you because it is just on your mobile. Sometimes, it may make you worry or feel sad. Maybe you will read about a treatment you had when you were younger that doesn't work. Maybe you will see a video and feel sad. It's important to talk to your parents or carers about this if it happens.

6. How much is it?

It's free to be part of the study. You need a phone or tablet to use the app on. You also need internet as well to make it work.

7. Will it help?

We don't know if it will help or not. This is why we want to do the study. You can access the treatments that may help you. You can also help us make the app better.

8. Your information is safe

- We will not write your name on test results
- We will not know who you are by looking at your NDIS number
- A number is used instead of your name and only the study team can see details
- The information is kept safe at the University of Sydney
- We keep your information until you are 25 years old
- We will ask you before using your details for any other studies
- If we talk about the study, we will not use your name

We will ask your parents to check a privacy policy in the app. Sometimes we may use other companies to help us make the app better. All of the details stay in Australia.

9. The results

We will share the study in books and talks. No names will be used in these books or talks. No one will know it was you in the study. We can send you the group results if you would like that. Just let your parents know.

10. What to do if I am worried?

If you feel sad or worried about anything you see on the app, you can talk to your parents, carers or your Doctor. Your parents can also contact a leader of the study:

Dr Maria Mc Namara, Cerebral Palsy Alliance Research Institute, The University of Sydney.

Email: mmcnamara@cerebralpalsy.org.au

Phone: 0438129511

Some other phone numbers that can help you are:

- Kids Helpline (1800 55 1800)

- Beyond Blue (1300 224 636)
- Headspace (1800 650 890)
- People with Disability Australia: <https://pwd.org.au/get-help/>
- Disability Gateway: <https://www.disabilitygateway.gov.au/health-wellbeing/mental-health>.
- Ask Izzy: <https://askizzy.org.au/>

11. How to ask questions

You can talk to your parents or to one of the researchers:

Dr Maria Mc Namara

Cerebral Palsy Alliance Research Institute, The University of Sydney.

Email: mmcnamara@cerebralpalsy.org.au

Phone: 0438129511

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12. What if I am not happy with the study?

You can tell your parents about how you feel. If they want to complain they can contact the ethics office:

Research Ethics office

Email: SCHN-Ethics@health.nsw.gov.au

Phone: 02 7825 1253

Or they can contact the Office of the Australian Information Commissioner:

Website: www.oaic.gov.au

Telephone: 1300 363 992

Email: enquiries@oaic.gov.au

Mail: GPO Box 5218, Sydney NSW 2001