Parent/Guardian 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?

In Australia, there are many treatment options for children with cerebral palsy (CP). It can be hard for families to know which treatments to choose. We have developed a mobile app for people with CP and their families, called cpThrive. cpThrive will help families make decisions about which treatments might be most helpful, based on a child and family's priorities. cpThrive will have information on over 120 treatment options and includes a decision support tool to assist you in finding the most helpful treatments. Videos showing real-life examples of treatments will also be included.

The aim of this study is to explore whether the cpThrive app helps families to find interventions that are most suitable for their child with CP. We also want to understand if using the cpThrive app leads to better function.

After the study, the cpThrive app will be freely available to everyone.

2. Why am I being asked to participate?

You are being asked to participate in this study as you are the parent/caregiver of a child with cerebral palsy aged 0 up to 17 years.

3. What will the study involve?

If you consent to being involved, you will be given access to the cpThrive app for 12 months. Participation will involve:

- Downloading the 'cpThrive' app on your phone or device
- Reading the participant information sheet and if you would like to, signing the consent form

- You will be prompted to enter your email address in the app when you first sign up and a name for each significant person you add. The name can be anything you like e.g. a nickname, and doesn't have to be a real name if you would prefer not to put this in the app.
- Providing your child's age, NDIS number (if they have one) and the postcode you live in. We will use your child's NDIS number to compare their information to other NDIS participants who are not using the app. This will help us to see if the app is helping people to reach their goals. Your child's NDIS number will be used by the NDIA to link it with information that they will provide to the researchers such as:
    - Age, background, gender, language spoken at home, and other demographic information
    - Payments
    - Outcomes
    - Experience of the Scheme and Access
    - Plan Supports and Packages
    - Providers
    - Early childhood pathway data
- Providing three of your child's current goals in the cpThrive app, and rating your child's current performance on these goals, on a scale of 1 to 10. You will be asked to rate the goals at the beginning, then every 3 months during the project. This will take approximately 5 minutes. You can change and update the goals at any time.
- You will use the cpThrive app to explore which treatments are most suitable for your child and your family.

At the end of the study, we might ask if you would like to give feedback through an interview. If you agree, you will complete a separate consent form.

What is the cpThrive app?

The cpThrive app has information on over 120 treatment options. This includes allied health treatments that might be provided by a physiotherapist, speech pathologist or occupational therapist. It also includes medications, surgery options and alternative and complementary treatments.

cpThrive provides information about what the treatment is, who the treatment is for, where the treatment is done and how much of the treatment is needed. It also includes how effective the treatment is, based on current research.

cpThrive includes a decision support tool, that enables you to select the current goals/priorities of your child, provide information about your child's age and abilities, and use this information to find treatments that are likely to be most helpful.

4. Can we withdraw once started?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. If you decide not to participate or to withdraw, it will not affect the support or health services you are currently accessing. Whatever your decision, it will not affect your relationship with the staff who you work with. If you withdraw, you can decide whether you wish your information to be destroyed or used.

You can continue to use the app even after you withdraw or the study finishes.

5. Are there any risks?

The risks involved in participating in this study are very low and every effort has been taken to develop family friendly materials. Despite this, you may come across sensitive questions in the cpThrive app about your child's function, which could cause distress. There is also a small chance that knowing more about treatments could cause distress, for example if you had previously engaged in a treatment that the research shows can cause harm.

6. Are there any costs?

There are no costs associated with participating in this study. In order to participate, you will need to have access to a phone or device on which to download and use the cpThrive app. You will also need to have internet access or data to use the cpThrive app.

7. Are there any benefits?

We do not know whether there will be benefits to participating in this study. This is because we do not yet know whether the cpThrive app is helpful for people with CP and their families. By participating in this study, you may have access to more information about helpful treatments. Participating will also contribute to improving the cpThrive app for yourself and others to use in future.

8. What will happen to information that is collected?

Confidentiality

- All data will be stored without your child's name attached to it.
- The researchers will provide NDIS numbers of study participants to the NDIA. No other information will be given to the NDIA. The NDIA will link the NDIS numbers of study participants to the NDIS data collected by them. The NDIA will then give the researchers a data set containing data for every NDIS participant aged 0-17 with CP in Australia. Having this dataset will allow the researchers to compare outcomes for those who are using cpThrive with those who are not. This is how we can tell whether cpThrive is helping people. There will be no names in the data provided to the researchers by the NDIA.
- The researchers will use a special Study ID number, to identify each child in the study. Their NDIS number will then be removed from the dataset. This Study ID number will be linked to your child's NDIS number, but the linking file will be kept confidential, stored separately in a secure highly protected location at The University of Sydney. This will only be available to a small number of the research team. This file will only be accessed if absolutely necessary e.g. if you decide to withdraw from the study at a later date.
- Only a small number of the research team will have access to your child's information. This information is labelled 're-identifiable' as there is some small chance that your child's NDIS number could be used to identify them. However, this is very unlikely, and every effort will be taken to ensure this does not happen.

- The cpThrive app will collect data that you provide into a secure electronic database hosted by Miroma Project Factory, the software development company who created and maintain the app, on Amazon Web Services. This data will be transferred securely to The University of Sydney's highly protected SharePoint and Research Data Store, meeting the highest security standards.
- Data will be stored securely until your child reaches the age of 25, in case they wish to view the study data. The data available will be combined group data from everyone involved in the study. Your child's data will not be stored in a way that can be identified. Should you or your child wish to access data, you can contact the research team via the contact details on the following page.
- If you choose to provide us with your email address at the end of the study, your data may be used in future research projects. We will seek ethics approval for those projects and will ask you before we use your data in any future research.
- If we give talks or write about the results of this project, we will not be able to use any names or identifying details.
- You will not receive access to your personal results because all your child's details will be anonymous, and no one will be able to identify your child. The results from the group study may be published in easy-to-read formats such as on social media or in scientific journals. You may also ask to receive the group results from the study by selecting that option on the consent form.
- There is a privacy policy within the app that you will be prompted to review and agree to. We may use other companies to make changes to the features and functions of the app in the future. To do this, cpThrive may disclose your information to overseas recipients. These third party services may include: Google Firebase Authentication, OneSignal, SendGrid, & Jotform. No NDIS numbers or data will leave Australia.

9. Will I be told the results of the study?

We plan to publish the study results in medical journals and present the results at conferences. In any publication or presentation, information about you will be anonymous and your child will not be identified. Group results of the study will be provided to you. You can provide your email address on the consent form to let us know you would like to receive the results.

10. What if I experience distress or need emotional support?

If you become distressed and you would like to talk to someone, please contact your GP, your healthcare professional or someone from the research team:

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

Email: mmcnamara@cerebralpalsy.org.au **Phone:** 0438129511

You may also wish to contact:

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. What if I would like further information?

When you have read this information, the following researcher will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact:

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

Email: mmcnamara@cerebralpalsy.org.au **Phone:** 0438129511

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12. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The Sydney Children's Hospitals Network Project No: 2025/ETH01321 according to the *National Statement on Ethical Conduct in Human Research (2023).*

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the ethics office:

Research Ethics office
Email: SCHN-Ethics@health.nsw.gov.au
Phone: 02-7825 1253

If you have a privacy complaint in relation to the use of your data, you should contact the Office of the Australian Information Commissioner. You will be able to lodge a complaint with them.

Website: www.oaic.gov.au
Telephone: 1300 363 992
Email: enquiries@oaic.gov.au
Mail: GPO Box 5218, Sydney NSW 2001

This information sheet is for you to keep

Parent / Guardian Withdrawal of Consent Form

Project Title: TRANSMIT: A multifaceted knowledge TRANslation Strategy iMprovIng funcTion in children and youth with cerebral palsy

I wish to WITHDRAW my child from the study effective from the date below. My child's NDIS ID number is ____________________ (this is needed to ensure the data we withdraw belongs to your child). I request that the study handles the information they have collected about my child in the following way (choose one option):

☐ DESTROY all information collected about my child to date so it can no longer be used for research

☐ RETAIN all information collected about my child to date so it can continue to be used for research

I understand that:

1. no further information about my child will be collected for the study from the withdrawal date;
2. information about my child that has already been analysed and/or included in a publication by the study, may not be able to be destroyed; and
3. choosing to withdraw my child from the study will not affect my child's access to Health Services or Government benefits.
4. We will not be contacted to use this data for any future research purposes.

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Signature **Date**

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Please print full name

This form should be forwarded by email to: Dr Maria Mc Namara, mmcnamara@cerebralpalsy.org.au

Alternatively, forms can be posted to: Dr Maria Mc Namara, Cerebral Palsy Alliance Research Institute, Brain and Mind Centre, Unit 53, 66-70 Parramatta Road, Camperdown, NSW 2050