Participant Information Leaflet

Name of Study:

Clinicians' perspectives of current and future service provision for children and young people with cerebral palsy in Ireland

Site	**Trinity College Dublin**
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	**PI: Denise McDonald Consultant Paediatrician and Associate Academic Professor in Cerebral Palsy, School of Medicine, Trinity College Dublin** **Co-Investigator: Michelle Spirtos Associate Professor, Occupational Therapy, School of Medicine, Trinity College Dublin** **Co-Investigator: Ciara Dinneny, Research Assistant, Paediatrics, School of Medicine, Trinity College Dublin**
Study Organiser/ Sponsor (if applicable)	**Sponsored through ELEVATE research project (co-funded by Research Ireland and Cerebral Palsy Foundation)**
Data Controllers	**Trinity College Dublin**
Data Protection Officer	**Data Protection Officer** **Secretary's Office** **Trinity College Dublin** **Dublin 2**

You are being invited to take part in a research study that is being led by Professor Denise McDonald at Trinity College Dublin. Before you decide whether or not you wish to take part, please read this information sheet carefully. Ask Denise McDonald any questions. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your colleagues.

PART 1 -THE STUDY

Why is this study being done?

- We are doing this study to understand the resources available around the country to children and young people with cerebral palsy (CP). It aims to understand how clinicians experience the provision of care, including their own confidence in their skills and training, their access to support, and the availability of pathways to specialist and tertiary services when required.

Why have I been invited to take part?

- You have been invited to take part as a clinician working with children and young people with disability, specifically cerebral palsy.
- We are hoping to survey over 100 clinicians across CDNTs.
- The survey aims to gain an understanding of services across Ireland, acknowledging variations in population and resources.

Do I have to take part? Can I withdraw?

- Participation in this survey is **voluntary.**
- The survey is **anonymous**, meaning your identity will not be known to researchers
- A decision not to participate will have **no adverse consequences**
- You can choose not to complete the survey at any time, but once you have submitted the survey your answers cannot be withdrawn as the survey is anonymous.

What happens if I change my mind?

You can change your mind at any time as you complete the survey. However, once the survey is submitted by you there is no way of returning it to you as submission is anonymous.

How will the study be carried out?

This survey is online. Completion should not take more than 15 minutes. It can be completed at any time of the day most convenient to you.
We hope to reach as many clinicians as possible, across all areas of the country. The survey will be available to complete for 4 weeks.
We are interested in your experience of delivering services to children and young people, and your access to training and specialist support. We would like to understand how services vary across the country, including examples of good practice, and gaps and barriers to success.

What will happen to me if I decide to take part?

If you decide to take part, you will complete the survey online anonymously and submit your responses to the research team. It should not take longer than 15 minutes to complete.

You will not be asked for any contact details or personal identifiers.

What will happen to the Data?

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The data from the survey will be analysed and published in print and online.
We expect the data will provide information that warrants further enquiry. If this is the case, this will be subject to a further research study as a separate application and invitation to participate.

Are there any benefits to taking part in this research?

Taking part in this survey will not directly benefit you. However, the information from the survey may help us better understand the challenges and opportunities for service provision to children and young people with cerebral palsy, and the factors that could improve clinician and family experience. Your participation could contribute to improved care.

Are there any risks to me or others if I take part?

There is no risk to you in taking part in this survey. It is anonymous; you will not be identified to the researchers. There is no risk to others as the survey is intended to gather information about clinician's experience of delivering services, with no intention of gaining knowledge of individuals. It is hoped the survey will gather useful information that may contribute to service advancement.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The results of the survey will be analysed and reported in medical/scientific journals and disclosed at medical/scientific conferences.

PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

No personal data will be used as part of the survey. We ask that you do not include any identifiable information in the open-ended comments sections. If this is included, it will be deleted prior to analysis.

What will happen to my personal data?

No personal data will be gathered.

Will my personal data be kept confidential? How will my data be kept safe?

No personal data will be gathered

What is the lawful basis to use my personal data?

No personal data will be gathered

What are my rights?

You are entitled to discontinue completing the survey at any time. Once the survey has been submitted it cannot be withdrawn as the study has been completed through an anonymous online survey.

PART 3 – COSTS, FUNDING AND APPROVAL

Has this study been approved by a research ethics committee?

This study has been approved by Trinity College Dublin School of Medicine Research Ethics Committee (REC), Avista REC, Enable Ireland Research, Ethics and Quality Committee, St. Michaels House REC and Central Remedial Clinic REC.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is being completed with funding from the ELEVATE project, which is co-funded by Research Ireland and the Cerebral Palsy Foundation.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study.

PART 4 – FUTURE RESEARCH

Will my personal data and/or biological material be used in future studies? (May not apply)

Does not apply – anonymous survey

PART 5 – FURTHER INFORMATION

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- *Principal Investigator:* Professor Denise McDonald mcdonadg@tcd.ie
- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.*

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

You cannot be contacted again in relation to this study as it is anonymised and the researchers will not have access to your contact details.

We expect the data will provide information that warrants further enquiry. If this is the case, this will be subject to a further research study as a separate application and invitation to participate.