

SUPPLEMENTARY INFORMATION

Supplementary file 1. Participant Information Statement

Supplementary file 2. Patient Consent Form.



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KeE (Key-eLearning-Early Diagnosis): A study of eLearning for physician early diagnosis of cerebral palsy.

PARTICIPANT INFORMATION STATEMENT

What is the purpose of this study?

The purpose of this study is to identify all children with a diagnosis of cerebral palsy or high-risk of cerebral palsy as early as possible. This will help families to access the early intervention supports and services they will need to help their child achieve the best outcomes.

This study aims to evaluate online training to support doctors to diagnose cerebral palsy early, communicate diagnostic information to families and provide early intervention supports.

To evaluate the training, we are asking your doctor questions about your child and the timing of their diagnosis of cerebral palsy. We are also asking your doctor about referrals made to state and territory Cerebral Palsy Registers and access requests made to the National Disability Insurance Scheme (NDIS) for your child. This information helps to measure changes in the age of diagnosis across Australia and the supports that families receive.

What are the Cerebral Palsy Registers?

The Cerebral Palsy Registers in each state or territory are a confidential research database of information about people with cerebral palsy. The Australian Cerebral Palsy Register consolidates information from the state and territory registers in a de-identified way and provides a national picture of cerebral palsy. Information collected about each person with cerebral palsy includes birth details and the type of cerebral palsy.

Registration in the Cerebral Palsy Register is voluntary. If you would like to have your details included on the Cerebral Palsy Register, you are asked to provide written consent.

What is the National Disability Insurance Scheme (NDIS)?

The NDIS provides support for eligible children with a diagnosis of cerebral palsy or high-risk of cerebral palsy, their families and their carers. The NDIS is a world-first social and economic reform agenda, supporting people with disability to live an ordinary life in an inclusive community. Data is collected on all access requests made to the NDIS and on demographics and outcomes for all participants in the scheme.

The Chief Investigator of the study is Professor Iona Novak, The University of Sydney. Other members of the research team include A/Pof Karen Scott, The University of Sydney and Professor Roslyn Boyd, The University of Queensland. The study will be conducted by Ms Lynda McNamara,

PhD Student, University of Sydney Children's Hospital Westmead Clinical School. Lynda McNamara is in receipt of NHMRC Postgraduate Scholarship funding and The Australasian Cerebral Palsy Clinical Trials Network PhD Top-Up Scholarship to complete this project. The Cerebral Palsy Alliance has funded the development costs of the eLearning development for this project. The research team are also working with the National Disability Insurance Agency (NDIA) on this research project. There are no conflicts of interest nor financial benefits to be declared by researchers or the institutions involved.

What will the study involve for me?

If you choose to participate in this study, you will be asked to enter your name and electronic signature and your child's full name and date of birth into an online consent form.

If an access request for your child has been made to the NDIS, the NDIA will provide this research group with the age of your child at the time of access request and information about your child's access and eligibility. This data will enable the research team to measure the real-world impact of your doctor's training.

If your child is eligible for the NDIS, information will be provided to this research group about your child's plan budget. This information helps the research group measure early intervention supports received after a diagnosis of cerebral palsy has been provided to families.

You will also be asked for your consent to the sharing of information with the Cerebral Palsy Register in your state or territory.

How much of my time will the study take?

It is anticipated this study will take you 10 minutes to read the information about the Cerebral Palsy Register and the NDIS, and complete the online survey.

Do I have to be in the study? Can I withdraw from the study once I've started?

Participation in this study is voluntary.

Your decision to participate will in no way affect your current or future relationship with your health professionals or the services or funding that you receive.

Participation in the Cerebral Palsy Register is voluntary. Consent to participate can be withdrawn at any time. You can also choose to discontinue receiving any further information from the Cerebral Palsy Register at any point in the future.

Submitting your completed REDCap survey confirms your consent to participate.

Are there any costs or risks associated with being in the study?

Apart from your time, there are no anticipated costs or risks associated with your participation.

Are there any benefits associated with being in the study?

Your participation and time are valued. No guarantee, however, is provided that you will receive any other direct or individual benefit from participating in the study or participating in the Australian Cerebral Palsy Register or consenting to share information with the National Disability Insurance Scheme.

There is neither payment made for joining the Cerebral Palsy Register nor any therapy services received from the Cerebral Palsy Register in your state or territory or the Australian Cerebral Palsy Register. By participating in this study and the Cerebral Palsy Register in your state or territory, you are helping with research into cerebral palsy that will enable planning for service provision needs in Australia.

Consenting to being part of this research does not affect any decisions made by the NDIS. Your participation in this study does not affect the supports that your child will receive.

You will receive a downloadable gift voucher to the value of \$50 after completing the consent form.

What will happen to information about me that is collected during the study?

The consent process for this study will be completed via an online survey which is securely stored by The University of Sydney. This information is only for the purposes outlined in this Participant Information Statement unless otherwise authorised by you.

By participating, you agree to the collection of personal information about you and your infant and the transfer of this information to the Cerebral Palsy Register in your state or territory. Your information will be stored securely by The University of Sydney and the Cerebral Palsy Register in your state or territory.

By participating you agree to the researchers having access to data collected by the NDIS about your child, if an access request has been made. No information collected in this study will be stored by the NDIS. Information about your child received from the NDIS will be stored securely by The University of Sydney.

Your identity and information will be kept strictly confidential, except as required by law.

It will not be possible to personally identify you through the publication of the results of this study.

Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

What if I would like further information about the study?

Lynda McNamara will be available to answer any questions you may have:

- **Telephone:** +61 2 9975 8061
- **Email:** lmcn0957@uni.sydney.edu.au

Will I be told the results of the study?

If you would like the results of this study distributed to you via email, you will be asked to enter your email address into the survey.

What if I have a complaint or any concerns about the study?

The study has been reviewed by The University of Sydney's Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the University using the details outlined below. Please quote the study title and protocol number 2021/386.

The Manager, Ethics Administration, The University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep.

Supplementary file 2. Patient Consent Form.

KeE (Key-eLearning-Early Diagnosis): A study of eLearning for physician early diagnosis of cerebral palsy

The purpose of this study is to help doctors identify all children with a diagnosis of cerebral palsy or high-risk of cerebral palsy as early as possible so that families can access early intervention they need to achieve the best outcomes.

This study aims to evaluate online training to support doctors to diagnose cerebral palsy early.

To evaluate the training, we are asking your doctor questions about your child and the timing of their diagnosis of cerebral palsy. We are also asking your doctor about referrals made to the state and territory Cerebral Palsy Registers and access requests made to the National Disability Insurance Scheme (NDIS). This information helps to measure changes in the age of diagnosis across Australia and the supports that families receive.

What are the Cerebral Palsy Registers?

The Cerebral Palsy Registers in each state or territory are a confidential research database of information about people with cerebral palsy. The Australian Cerebral Palsy Register consolidates information from the state and territory registers in a de-identified way and provides a national picture of cerebral palsy. Information collected about each person with cerebral palsy includes birth details and the type of cerebral palsy.

The registers aim to: 1) monitor trends of cerebral palsy; 2) gain further understanding about the causes of cerebral palsy; 3) develop and evaluate preventative strategies; and 4) assist in planning services for people who have cerebral palsy.

Registration in the state and territory Cerebral Palsy Registers is voluntary. If you would like to have your details included in your state or territory Cerebral Palsy Register, you are asked to provide written consent.

This is an invitation to you to consent to the inclusion of your child on the Cerebral Palsy Register in your state or territory.

We respect your privacy. Only information that you consent to will be used in this study. This consent form outlines exactly what you are consenting to.

The information that you provide in this survey is strictly confidential. It will only be seen by researchers in this study and the organisations that you choose to share your information with.

What is the National Disability Insurance Scheme (NDIS)?

The (NDIS) provides support for eligible children with a diagnosis of cerebral palsy or high-risk of cerebral palsy, their families and their carers. The NDIS is a world-first social and economic reform agenda, supporting people with disability to live an ordinary life in an inclusive community. Data is collected on all access requests made to the NDIS and on demographics and outcomes for all participants in the scheme. Health professionals provide supporting information to the NDIS that describes diagnostic information about your child.

If you choose to participate in this study, you will be asked to enter your name and electronic signature and your child's full name and date of birth into this online consent form.

If an access request for your child has been made to the NDIS, the National Disability Insurance Agency will provide this research group with the age of your child at the time of access request and information about your child's access and eligibility. This data will enable the research team to measure the real-world impact of your doctor's training.

If your child is eligible for the NDIS, information will be provided to this research group about your child's plan budget. This information helps the research group measure early intervention supports received after a diagnosis of cerebral palsy has been provided to families.

Consenting to being part of this research does not affect any decisions made by the NDIS. Your participation in this study does not affect the supports that your child will receive.

If you have any questions about this study you can contact Lynda McNamara:

Telephone: +61 2 9975 8061

Email: lmcn0957@uni.sydney.edu.au

Please complete the consent form below.

Thank you.

PART A – Information on Parent or Guardian.

1. I have read the Participant Information Statement

☐ Yes

☐ No

2. I understand that participation in this study involves my doctor sharing information about my child with the research team.

☐ Yes

☐ No

3. I understand that participation in this study involves sharing of information about my child to my state or territory Cerebral Palsy Register.

☐ Yes

☐ No

4. I understand that my child's information will be stored securely by The University of Sydney and the Cerebral Palsy Register in my state or territory.

☐ Yes

☐ No

5. I understand that participation in this study involves the sharing of my child's full name and date of birth with the NDIS so the NDIA can provide data on my child to the research team if an access request has been made to or my child is eligible for the NDIS.

☐ Yes

☐ No

6. I understand the NDIA will providing this research group with information about my child's eligibility to the NDIS, if an access request has been made.

☐ Yes

☐ No

7. I understand the NDIA will provide this research group with information about my child's plan budget, if my child is eligible for the scheme.

☐ Yes

☐ No

8. I understand that no information collected in this study will be stored by the NDIS.

☐ Yes

☐ No

Please answer the following questions as parent or guardian of your child with cerebral palsy.

1.

Please enter your surname.

2. Please enter your first names.

3. Please enter your postcode

PART B – Information on your child

Please answer the following questions about your child who has received a diagnosis of cerebral palsy or high-risk of cerebral palsy.

1. Please enter your child's surname.

2. Please enter your child's first names.

3. Please enter your child's date of birth.

PART C – Consent to sharing information with the Cerebral Palsy Register in your state or territory.

Registration in the Cerebral Palsy Register in your state or territory is voluntary. If you would like to have your details included on the Cerebral Palsy register in your state or territory you are asked to provide written consent.

Your details cannot be included in the register until a signed consent form is received by your state or territory.

The following questions relate to your consent to participate in the Cerebral Palsy Register in your state or territory.

There are different levels of consent on the register. You can choose your contribution and select your level of consent by responding Yes or No to the statements below.

If, in the future, you change your mind about participating in the register, you can withdraw your consent and your name will be removed from the register.

You can also choose to discontinue receiving information from the Cerebral Palsy Register in your state or territory at any point in the future.

This will not disadvantage you or your child in any way or affect the services that you are receiving.

Please tick Yes or No to the following statements about consent to the Cerebral Palsy Register in your state

or territory.

1. I consent to the collection, recording and storage of information on my state or territory Cerebral Palsy Register. This may involve consulting birth and current medical records.

☐ Yes

☐ No

2. I consent to the transfer of de-identified information to the Australian Cerebral Palsy Register.

☐ Yes

☐ No

3. I consent to receiving information from the Cerebral Palsy Register in my state or territory in the form of newsletters and invitations to participate in research projects.

☐ Yes

☐ No

4. I consent to health professionals that I nominate being contacted to assist in completing and verifying Cerebral Palsy Register information.

☐ Yes

☐ No

5. Please provide the name (s) of any health professional involved with your child that you would like to nominate to be contacted by the Cerebral Palsy Register in my state or territory.

Please sign this form electronically in the space provided.

Please provide the name of your doctor that notified you of your child's diagnosis and provided you with the information about this study. This allows us to notify your doctor that you have completed this consent form.

If you would like the results of this study to be sent to you via email, please enter your email address in the space provided.

Thank you for your participation in this study.

If you have any questions or would like more information please contact Lynda McNamara:

Telephone: +61 2 9975 8061

Email: lmcn0957@uni.sydney.edu.au