We are looking to explore the current health service delivery to people with cerebral palsy from both the perspective of the people with cerebral palsy and their whānau, and the clinicians working in this area. We would like your help with identifying the current issues in early diagnosis and management of cerebral palsy by finding out about your preferences through workshops. The purpose of the workshops are to help come up with solutions to improve access to healthcare and service delivery around the diagnosis and early management of cerebral palsy in New Zealand.

We will be holding up to four workshops including different groups of people, you only need to attend one, or two, if you wish. In the first ('discovery') workshop/s, you will be invited to explore with other participants and share your experiences, opinions and ideas about the diagnosis of cerebral palsy in New Zealand and the journey through healthcare from thereon.

In the second ('prototyping') workshop/s, should you wish to attend, you will explore alongside other participants the sort of information you would like in an education resource, how the information should be presented, and together create potential solutions that are useful, helpful and appropriate for people with cerebral palsy, families/whānau, and clinicians.

This information sheet will help you decide if you’d like to take part in our project. It sets out why we are doing the project, what taking part would involve, and what will happen after the project ends. A member of the project team will go through this information with you and answer any questions you may have. You do not have to decide today whether or not to take part in this workshop. Before you decide, you may want to talk about the project with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in the workshop(s), you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

**What is the purpose of the study?**

The purpose of the workshops is to help come up with solutions to improve access to healthcare and service delivery around the diagnosis and early management of cerebral palsy in New Zealand.

We would like to design solutions with you so we can better understand how we can best improve the experience of persons with cerebral palsy and their families, and those of the healthcare workers in this area. This will help us make sure that information about diagnosis and early healthcare is given in a way that best suits those who are affected by these experiences, and contributes positively to the overall healthcare received by individuals in our care.
What will my participation in the study involve?

You have been invited to take part in this project as you are either a family member/caregiver of a child with a diagnosis of cerebral palsy, or a health care provider working with children under the age of five years with (or who may be at risk of) cerebral palsy in New Zealand.

If you choose to take part in the workshop(s), you will be asked to share your views and experiences on the diagnosis of cerebral palsy and the early (up to 5 years of age) health care management of children with cerebral palsy in New Zealand.

This will take place as a group discussion with about 6 to 12 other people, which will last up to 2 hours per workshop. You will have an option to choose to attend only the first (‘discovery’) workshop, or both the ‘discovery’ and ‘prototyping’ workshops. The workshop(s) will take place either in the hospital or at the University of Auckland, or at a convenient location nearby at a time to be decided. Free parking will be available for you to use if you need this. You are welcome to have a support person attend with you if you wish. If you identify as Māori, you can also access Māori cultural support services by letting one of the people on the project know or by contacting the Māori health support person at the end of this form. In order to make sure we can accurately remember the views of the group we will be video recording the workshop.

During the first, ‘discovery’ workshop, if you are a family member / caregiver of a child with cerebral palsy, you will be invited to share your experiences and opinions regarding the care you / your child received. If you are a health care provider, we will ask you about the care you provide working with young children with (or who may be at risk of) cerebral palsy. In the second, ‘prototyping’ workshop, as a group, we will ask you all to help co-design what you would like healthcare in cerebral palsy to look like in the future. This will help us understand whether the current healthcare relating to service delivery, referral, and diagnosis experience in New Zealand needs to be improved and what changes need to be made. We will ask you some background information about yourself such as age, ethnicity, whether English is your usual language of conversation, and, where relevant your child’s diagnosis of cerebral palsy or your professional qualifications and role.

What are the possible benefits and risks of this study?

This study is the first of its kind and we hope that the information gathered will help to improve access to healthcare and service delivery around the diagnosis and early management of cerebral palsy in New Zealand. If you like, you can receive a summary of the results when the project is completed.

Some refreshments will be provided during the workshop and you will be offered a $40 petrol / grocery voucher to thank you for your time and to help with transport costs. Families requiring child care during the workshops will be offered an $80 voucher for reimbursement for their time.

If you have any questions or concerns, or if you become distressed during the workshop that you wish to discuss with someone who is not involved with the workshop, feel free to let the workshop facilitator know. They will take a note of these and refer you to an appropriate staff member who may be able to help.

What are my rights?

Whether or not you take part is your choice. If you don’t want to take part, you don’t have to give a reason, and it won’t affect the care you receive, your relationship with members of the research team, or your professional role.
To respect the privacy of others involved in the discussions, it is important that you do not share what other people have said at the workshop with people who are not involved in this project.

Your views will be combined with those of other participants to work out how best to create solutions for people with cerebral palsy, families/whānau, and health service providers. The information will be summarised in a written report. All contributions will remain anonymous and none of the material in the results will personally identify you.

**WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?**

If you do want to take part now, but change your mind later, you can pull out of the project at any time – before, during or following the workshop. You do not need to give a reason for withdrawing. If you take part in the workshop, your contribution to the group will not be able to be separated from that of other participants and the information collected about you (prior to your withdrawal) will continue to be used.

Video and any electronic data collected from this study will be password-protected in a secure electronic drive, and hard copy data will be in locked storage. The information we collect in this study will be kept under secure conditions with The University of Auckland until at least 10 years, and then it will be destroyed.

The results of this research may be presented at conferences and published in professional journals. You and your child will not be identified in any results that are published or presented. Data generated from this study may be made available for use in future research, however anonymity and confidentiality will remain.

**Who do I contact for more information or if I have concerns?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Sian Williams.
CaPTuRE Project research officer, University of Auckland
Phone: +64 9 923 6929
Email: sian.williams@auckland.ac.nz

CaPTuRE: Cerebral Palsy - Translating Research on Early identification

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<tr>
<th>Dr Sian Williams</th>
<th>Prof Susan Stott</th>
<th>Dr Anna Mackey</th>
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<tr>
<td>Post-Doctoral Fellow</td>
<td>Starship Children's Health</td>
<td>NZ Cerebral Palsy Register</td>
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<td>Australasian Cerebral Palsy Clinical Trials Network</td>
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<td><a href="mailto:sian.williams@auckland.ac.nz">sian.williams@auckland.ac.nz</a></td>
<td><a href="mailto:s_stott@auckland.ac.nz">s_stott@auckland.ac.nz</a></td>
<td><a href="mailto:AMackey@adhb.govt.nz">AMackey@adhb.govt.nz</a></td>
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<tr>
<th>Ms Amy Hogan</th>
<th>Dr. Malcolm Battin</th>
<th>Alexandra Sorhage</th>
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<td>Disability Advocate</td>
<td>Neonatologist</td>
<td>NZ Cerebral Palsy Register</td>
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<td>Cerebral Palsy Society</td>
<td>Starship Children's Health</td>
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<td><a href="mailto:amy@cpsociety.org.nz">amy@cpsociety.org.nz</a></td>
<td><a href="mailto:Malcolmb@adhb.govt.nz">Malcolmb@adhb.govt.nz</a></td>
<td><a href="mailto:ASorhage@adhb.govt.nz">ASorhage@adhb.govt.nz</a></td>
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<tr>
<th>Dr Collette Muir</th>
<th>Dr. Nichola Wilson</th>
<th>Dr Corrine Jordan Watson</th>
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<tr>
<td>Paediatrician</td>
<td>Orthopaedic surgeon</td>
<td>Advanced Paediatric Physiotherapy Practitioner</td>
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If you want to talk to someone who isn’t involved with the study, you can contact an independent health and disability advocate on:
For Maori Health support please contact:
For support, talk to your whānau in the first instance. Alternatively you may contact the
administrator for He Kamaka Waiora Māori Health Team on 09 486 8324 ext 2324.

If you have any questions or complaints about the study, you may contact the Auckland and
Waitematā District Health Boards’ Māori Research Committee or Māori Research Advisor by
phoning 09 486 8920 ext 3204

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:

- **Phone:** 0800 4 ETHICS
- **Email:** hdecs@moh.govt.nz

**Thank you** for reading this and considering participating.
Consent Form

The cerebral palsy diagnosis experience and ensuing clinical pathways:
using a co-design approach to improve the healthcare journey

• I have read, or have had read to me in my first language, and understand the Participant Information Sheet.
• I have been given sufficient time to consider whether or not to participate in this study.
• I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.
• I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.
• I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time (before, during or after the workshop) without the need for explanation, and without this affecting my / my child’s medical care.
• If I take part in the workshop and decide to withdraw from the workshop, I understand that my contribution to the workshop up to the point of my withdrawal cannot be separated from other participants and the information collected about me may continue to be used.
• I consent to the research staff collecting my views through discussion in the workshop, including information about my understanding of my / my child’s health condition, service provision and medicines.
• I agree to the workshop being video-recorded.
• I understand that, due to the nature of the workshop, confidentiality cannot be guaranteed. However, participants are expected to respect the confidentiality of the others attending the workshop by agreeing not to disclose anything discussed in it.
• I understand that no material, which could identify me personally, will be used in any reports arising from this study.
• I know who to contact if I have any questions about the project.
• I understand my responsibilities as a workshop participant.
• I wish to receive a summary of the results from the project □ No □ Yes □

Address or email address I would like invitations for future workshops or the results summary to be sent to (please write) ____________________________________________________________

Declaration by participant: I consent to take part in this project.

Participant’s name: ___________________________  Signature: ___________________________  Date: ___________________________

Declaration by member of research team: I have given a verbal explanation of the research project to the participant, and have answered the participant’s questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher’s name: ___________________________  Signature: ___________________________  Date: ___________________________
Consent Form (Healthcare Provider)

The cerebral palsy diagnosis experience and ensuing clinical pathways: using a co-design approach to improve the healthcare journey

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Researcher’s name:

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