Participant Information Sheet			
Study title:	**The New Zealand Cerebral Palsy Register** **Te Rēhita a Hōkai Nukurangi Aotearoa**		
Locality:	New Zealand	Ethics committee ref.:	**13/NTA/130**
Lead investigator:	Professor Susan Stott	Contact phone number:	**0212242298**

What is Te Rēhita a Hōkai Nukurangi Aotearoa or the NZ Cerebral Palsy Register?
The Register collects information about your child and their hōkai nukurangi or cerebral palsy (CP) as well as information about other people with CP in Aotearoa New Zealand. The information that is collected is confidential to the Register.

Why do we need the NZ Cerebral Palsy Register?
We know that CP is the most common cause of physical disability for children in Aotearoa New Zealand. We currently do not know how many people in Aotearoa New Zealand have CP and how CP affects people's everyday lives. The more people who join the Register, the more information we will have about people with CP in Aotearoa NZ. This information can help to seek further funding as well as guide and improve health services and future treatments for people with CP.

What are the aims of the NZ Cerebral Palsy Register?
The aim of the Register is to collect health information about:

- How many people have CP in Aotearoa New Zealand?
- How CP affects Māori and how are health outcomes for Māori with CP different from other groups?
- What can be changed to improve the future for people with CP and their whānau/families?

What are the benefits of the NZ Cerebral Palsy Register?
The Register is able to combine all the health information on people with CP in Aotearoa NZ, to help health services and disability groups to:

- Understand what living with CP means for different groups (such as Māori or people living in different parts of the country)
- Guide health planning staff, to make sure all people with CP can access the right health services when they are needed
- Promote research about CP so we can learn about what works in preventing and improving health for all people with CP in Aotearoa New Zealand
- Share important information with you and your whānau.

Who are the health professionals who run the Register?
The Register is based at Starship Children's Health, Auckland, led by Professor Susan Stott, Paediatric Orthopaedic Surgeon together with a team of health professionals from each DHB region in Aotearoa New Zealand. The Register team also includes Dr Anna Mackey and Alexandra Sorhage who are both based at Starship Hospital and work part-time for the Register. The Register team works closely with many health professionals from across all parts of the country.

How do you join the Register?

It is your choice whether your child with CP joins the Register. If you decide your child will not join the Register this will not affect the healthcare your child with CP receives in any way.

Step 1 – You get information about the Register

Because your child has CP, a health professional or someone on the Register team may have talked to you and/or arranged for you to be sent this Information Sheet about the Register.

Step 2 – You get ready to join the Register

Please read this Information Sheet and talk about it with your whānau/family.
Once the Register team knows you have the Information Sheet, the Register team waits for a four-week period before they add your information to the Register. This is called an ***"opt-out period"***.

Step 3 – Opting out

If you decide you do not want your child to join the Register you need to let the Register team know within four weeks of receiving this Information Sheet by doing **one** of these things:

- Complete the Opt Out form on the last page of this Information Sheet and send it to the Register team at NZCPR, C/o Paediatric Orthopaedics, Starship Children's Health, Private Bag 92024, Auckland 1142 **OR** scan and email the completed form to: nzcpregister@tewhatuora.govt.nz
- Email: Register Team *nzcpregister@tewhatuora.govt.nz* (Include name, date of birth; NHI of the person with CP)
- Text or phone: **0212242298** and leave a message including name, date of birth and NHI of the person with CP). Please note this call or text will incur a standard charge
- Ask your GP, paediatrician, physiotherapist, or occupational therapist to contact the Register team on your behalf to let the Register team know you do not want your child to join.

If you choose to 'opt-out', you do not have to give a reason and it will not affect the health care your child receives.

If you 'opt out' within the four-week period your child's information will not be added to the Register. You can decide that your child will join the Register at a later time.

Step 4 - Joining the Register

After a four-week period, the Register team or a health professional from your local DHB (who has been given special authority by the Register team) will go ahead and enter the CP related health information onto the Register. The CP health information is in your child's medical record and includes:

- birth history (place of birth, birth weight, gestational age, any relevant investigations or time spent in a special care unit)
- type of CP (including time of diagnosis, health services involved with your child at the time of diagnosis, including any brain images (Magnetic Resonance Images)

- functional abilities (classification scores for movement, eating and communication, and information relating to vision, speech, epilepsy, intellect).

The Register team may contact you or your local health professional if they need more information that cannot be found in your child's medical record. The team only collects information relating to your child's CP and we only collect this data once. However, if your child is under five years of age when they join the Register, the Register team will reconfirm your child's diagnosis and functional ability after their fifth birthday, to make sure nothing has changed in your child's early development. We do not go back into your child's medical records once your child has joined the Register and has passed their fifth birthday.
You will receive a confirmation letter, email or phone call once your child has joined the Register.

Can I complete my child's health information when they join the Register?
Yes, you can do this yourself by

1. Completing the online form on the Register portal https://nz.cpregister.com/ Click 'Become A Member' to create a username and password to login then complete your child's information.
2. Sending an online notification from the Register website: https://nzcpregister.co.nz/ . Follow the link to 'Join the Register', or click on 'Notify Us'.
3. Email the register (nzcpregister@tewhatuora.govt.nz) with your child's information. Please include their full name, date of birth, current suburb and NHI if known.

If you do not know all of the information you need to fill in, please contact the Register team and they can help you.

Can I change my mind after my child has joined the Register?
Yes, you can ask us to remove your child's information from the Register at any time. Your child's information will become "a silent record" which means the Register team:

- cannot view your child's information
- will not make contact with you or your child to advise you or your child of research projects
- will not use any of your child's information for reporting purposes.

For statistical purposes the Register team keeps information relating to your child's type of CP only.
To get your child's information removed you need to

- Either tick the last box on the Opt Out form on the last page of this Information Sheet and send it to Register team at NZCPR, c/o Paediatric Orthopaedics, Starship Children's Health, Private Bag 92024, Auckland 1142 **OR** scan and email the form to: nzcpregister@tewhatuora.govt.nz
- Or email nzcpregister@tewhatuora.govt.nz (include name, date of birth and NHI of the person with CP)

What happens when my child turns 16?

We will contact any young person with CP when they turn 16 years of age to make sure that the young person is happy to continue to have their health information stored on the Register. Where the young person does not have "capacity" to make this decision, the young person's parent or legal guardian can make this decision.

How does the Register team protect the information on the Register?

We respect the fact that the information you give us is private to your child and strictly confidential. Your child's information and the information of others will be stored using greatest care and the most up to date security. The information is hosted online by an Australian company which specialises in keeping health information very secure including data from the CP Registers of other countries. This Australian company meets the high standards for data security set by the Ministry of Health and Department of Internal Affairs.

In addition, the Register team has consulted with Te Mana Raraunga (Māori Data Sovereignty Network) to make sure the Register protects and safeguards any Māori data held by the Register.

Your child's personal information is only able to be seen by the Register Team including one health professional from your local region who has been given special authority by the Register Team to add data to the Register or check the records held by the Register for that region only.

The Register team checks all the information on the Register on a regular basis to make sure the information is complete and correct.

No one else can access your child's information without going through a process. For example, a health professional or researcher wanting to use or access any of the information on the Register for research purposes will:

- need to get approval from the New Zealand Health and Disability Ethics Committee and the researcher's relevant Te Whatu Ora region
- have their research project reviewed by the Register's Governance Committee**.** The Governance Committee is a group of health professionals and people with CP which checks all requests to access the information on the Register for research purposes. This is another way the Register makes sure the information is kept secure.

If you need any more information on how we work to protect information on the Register please contact the Register team.

What else do I need to know about the Register?

- The plan is that the Register will continue indefinitely.
- Every three years the Register publishes a very short report about people in Aotearoa New Zealand with CP. This report is published at the same time as reports from other countries such as Australia, Sri Lanka and Bangladesh. These other reports help the Register team see how Aotearoa New Zealand is progressing in relation to other countries. All data in the Aotearoa New Zealand report is anonymous.
- This proposal has received ethical approval from the NZ Health and Disability Ethics Committee (HDEC 13/NTA/130).

Who should I contact for more information or if I have questions about the Register?
Register team: Anna Mackey or Alexandra Sorhage, Starship Children's Health: text or phone 0212242298 **OR** Email: nzcpregister@tewhatuora.govt.nz

If you want to talk to someone who is not involved with the Register, you can contact an independent health and disability advocate on:
Phone: 0800 555 050 Fax: 0800 2 SUPPORT (0800 2787 7678) Email: advocacy@advocacy.org.nz

For Māori whānau who require cultural support, talk to your whānau first.
Or you may contact your local Māori health Support Service. The contact details for the Māori health Support Services are on page 6.

If you have any questions or complaints about the Register, contact the Register team or you can also contact the Health and Disability Ethics Committee that approved this study on: Phone 0800 400 569 (Ministry of Health general enquiries), Email: hdecs@health.govt.nz

Opt Out Form New Zealand Cerebral Palsy Register (the Register)

(Please tick one or all of these options which apply to you or your child)
◯ I would like to opt-out of having my child's information entered onto the Register
◯ I do not wish to be contacted about taking part in relevant research studies
◯ (**For silent records)** I would like to remove an existing record from the Register.
Signature: _____ Date: ____/____/_____
Name of person signing _____
Relationship to person with CP_____
Name of person with CP _____
Date of birth of person with CP _____
NHI of person with CP: _____

Māori health Support Services

District	*Contact details*
Northland	Te Poutokomanawa (Māori Health Service) Phone: (09) 430 4101 ext. 3239
Waitemata and Auckland	He Kamaka Waiora (Māori Health Team) Phone: 09 486 8324 ext 2324 Ian Kaihe-Wetting, Service Manager - Te Kaahui Ora Maori Health CMH
Counties Manukau	Phone: (09)276 0138
Waikato	Te Puna Oranga Phone: (07) 8398899 ext 97528
Lakes	Te Aka Matua Kaupapa Maori Service (Lakes Māori Health Team) Phone: (07) 349 9009 (extension 8829, or 8806)
Bay of plenty	Te Pou Kōkiri (Regional Maori Health Service), Tauranga Hospital Phone: 07 579 8560 or 07 306 0999 (extension 4640)
Taranaki	Tui Ora - Community and Cultural Services 0800 TUI ORA / 0800 884 672
Capital and Coast / Hutt Valley	Whanau Care Services whanaucareservices@huttvalleydhb.org.nz or whanaucareservices@ccdhb.org.nz
Hawke's Bay	Te Wāhanga Hauora Māori Health Services Phone: (06) 878 8109 (extension 5779), (06) 878 1654 or 0800 333 671
Canterbury / West Coast	Canterbury Māori Health Services He Waka Tapu Phone: (03)373- 8150 or 0800 HEWAKA
Nelson Marlborough	Pou Manaaki Services: 03 546 1800 Nelson Hospital: 022 011 3376 or 022 012 2955 Wairau Hospital: 022 013 2732 or 027 246 0470
Otago / Southland	Southland hospital: Te Tuhinga Tahi - Diane Parata Nāhi, Māori registered nurse 027 575 1128, Lisa Whatuira, kaiāwhina 027 328 0403, or Sonny Tonihi, kaiāwhina 0272971730 Dunedin hospital: Te Ara Hauora 03 474 0999 extension 58649
Other districts	Please contact the NZ Cerebral Palsy Register for assistance