

PARTICIPANT INFORMATION SHEET

Young children with Hokai Nukurangi - Cerebral Palsy, does Physiotherapy intervention match whānau expectation: A National Survey

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Purpose of the Study

I am looking to determine if physiotherapy intervention provided to children with a diagnosis of Cerebral Palsy (CP) matches the needs and expectations of their whānau who care for them. I hope that the study could inform and where needed improve the delivery of physiotherapy intervention in Aotearoa New Zealand. Listening and communicating with whānau is important to identify areas of strength and to make improvements in the delivery of healthcare services.

Eligibility

- Parent or primary caregiver of child with a diagnosis of CP
- Aged between 3 and 18
- Living within Aotearoa New Zealand
- Receiving or has received Physiotherapy intervention.

Involvement

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, between the ages of 3-18, are currently living in Aotearoa New Zealand and receive or have received Physiotherapy intervention. If you choose to take part in this survey, you will be asked to share your views and experiences on the Physiotherapy your child receives.

After giving informed consent, you will then be directed to begin the online survey. This will include a mixture of tick boxes, rating scales and open-ended questions.

I will first ask you some background information such as age, ethnicity, gender, your child's diagnosis of CP, and what part of the country you reside. Following this, the survey you will be asked to answer questions relating to the following topics, that are structured around a Māori model of health, Te Whare Tapa Wha. Using this model will enable me to gain a holistic understanding of the needs of your child and your whānau.

Section 1 – Taha Tinana. The capacity for physical growth and development.

How Cerebral Palsy affects and impacts your child? What are their physical needs? What physiotherapy intervention your child receives or has received.

Section 2 – Taha Whānau. The capacity to belong and to share as part of a wider system. Is your child's therapy able to be incorporated into home? Are you included in decision making for your child?

Section 3 – Taha Hinengaro. The capacity to think and feel. What is enjoyment for your child and how do they interact with the world? Are you able to communicate or express concerns with your physiotherapist?

Section 4 – Taha Wairua. The capacity for faith, beliefs and identity.

Is cultural identity and spiritual identity acknowledged as important?

This will align with the Māori health model of Te Whare Tapa Wha whereby to achieve Hauora or optimum health and wellbeing these four cornerstones must be fulfilled.

The survey will take approximately 15-20 mins and the study will run for approximately 6 months.

Possible Benefits and Risks

The importance of the therapeutic alliance between health professional and health consumer is key to healthcare and service delivery.

There is potential risk of emotional distress. If you feel at any time the questions raise concerns of the provision of healthcare for your child, you are welcome to contact any member of the research team. We hope that we would be able to provide you with organisations that can be of assistance.

Participation

Your participation is voluntary, and we urge you to seek advice of those that you trust if you are unsure of your participation. You have the right to not answer questions if you choose. Any data collected cannot be identified to any individual. We also welcome any questions or concerns you may have and can contact us at any time. All contributions and responses will at all times remain confidential.

Withdrawal

You may withdraw your consent to participate at any time, you do not need to give a reason for your decision, and any responses attached to your assigned code will be destroyed. This can take place up to pressing the submission button following this your data cannot be identified and we are unable to remove your responses.

Privacy

As stated previously no information provided will identify any individual participant. All data collected will only be accessible to the research team, who are 1 student researcher and 2 research supervisors.

Research Results

The data collected will be used to write an honours report outlining the thoughts and perceptions of whanau of a child with CP who receive physiotherapy intervention. Further use of research results through journal publication, conference presentation or further research is possible. You and your child will not be identified in any future publication or presentation. Anonymity and confidentiality will be strictly adhered with any reporting of data.

Accessibility

You may request a summary of research findings and results by contacting any member of the research team.

Further Enquiries

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