Participant Information Sheet
PART 2

Title of Project: 'The effect of an Admission Support Plan on improving the hospital admission experience of children and young people with developmental disabilities, communication difficulties and challenging behaviours.'

Lead researcher: Dr Elizabeth Keeling **Study Site: Starship Children's Hospital**

Email: ekeeling@adhb.govt.nz **Phone: 021760576**

Ethics committee ref.: xxxxxxxx

You are invited to take part in a study which aims to test whether an admission support plan that caregivers complete about their child's developmental, communication or behavioural needs, can improve the hospital admission experience for children and their families.

This information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation involves, what the benefits are, and what happens after the study ends.

Please read this information carefully and let us know if you have any questions. You may want to talk about the study with family, whānau, friends, or other healthcare providers. Please feel free to do this.

If you agree to take part in this study, you will be asked to sign the consent form on the last page of this document. You will be given a copy of the information sheet and consent form to keep.

This document is 4 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

Voluntary Participation and Withdrawal From This Study

Participation in this study is completely voluntary. 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 your child receives. If you do want to take part now, but change your mind later, you can pull out of the study at any time by contacting the research team.

What is the purpose of the study?

Previous research has shown that admissions to hospital for children with developmental, communication and behavioural difficulties can be stressful for the children and their families.

The overall aim of this research is to develop an Admission Support Plan (ASP) that parents or caregivers complete, which will help staff understand their child's unique developmental, communication or behavioural needs. We are interested to know whether using the ASP improves the hospital admission experience for children and young people with developmental difficulties, and their families.

How is the study designed?

The study is designed in 3 parts: You are invited to take part in **Part 2** of the study.

Part 1: participants are invited to answer a short survey about their child's most recent admission to Starship Children's Hospital.

Part 2: participants will be invited to help co-design the Admission Support Plan (ASP) which will give hospital staff important information about a child or young person's communication and behavioural needs to assist in their future admissions.

Part 3: participants will be asked to complete the Admission Support Plan (ASP) at the beginning of their child's hospital admission to be used by hospital staff. Families who have used the ASP will be invited to answer a short survey about their child's admission shortly after discharge from hospital. Staff members who have used the ASP will also be invited to complete a short survey about whether they found it useful.

Who can take part in the study?

You have been asked to participate because your family member has a developmental disability and/or a communication or behavioural difficulty (such as Autism Spectrum Disorder, ADHD or cerebral palsy) and you have experience of hospital admission at Starship Children's Hospital, or you are an advocate within the developmental disability sector, or through your role at Starship Children's Hospital, you have contact with, or care for patients with these challenges.

What will my participation in the study involve?

You are invited to take part in **Part 2** of the study.

You will be invited to take part in a co-design workshop to help design an Admission Support Plan (ASP) which will give hospital staff important information about a child, to assist in future hospital admissions. The group will be asked to meet 2 times to discuss the design of the ASP. These workshops will be conducted in person and/or via Zoom and recorded for design and editing purposes.

What are the possible risks of this study?

We do not anticipate any risks of you taking part in this study. However, should you have any concerns, please contact us using the information supplied below.

Will you receive any reimbursement for your involvement in the study?

You will receive a small gift voucher/koha of $20 in appreciation for the time you have spent taking part in this study and support for the costs of parking when attending co-design workshops in person. Kai will be provided for any face-to-face meetings.

What will happen to my information?

Only we will have access to your/your child's identifiable information (any data that could identify you e.g. date of birth).

To make sure your personal information is kept confidential, information that identifies you will not be included in any reports or publications we generate. All storage will comply with local data security guidelines.

The results of the study will be published or presented, but not in a form that would reasonably be expected to identify you. If you have any questions about the collection and use of information about you, please discuss this with us.

Can I find out the results of the study?

It is anticipated that the results of this study should be available in 2022. If you wish to receive a copy of the study results, please provide the researchers with a valid email address.

Who is funding the study?

This study has been made possible by the Starship Foundation who have funded the salary of the principal researcher, Dr Elizabeth Keeling. Dr Hiran Thabrew's time is being funded by the University of Auckland and Dr Jin Russell's time is being funded by Auckland District Health Board. Any additional funding has been granted by the Auckland DHB Charitable Trust (A+ Trust).

Who has approved the study?

Approved by the Auckland Health Research Ethics Committee on [date] for three years. Reference number [xxxx].

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 the principal researcher or study supervisor below:

Principal researcher: Dr Elizabeth Keeling
Email: ekeeling@adhb.govt.nz
Phone: 021760576

Study supervisor: Dr Hiran Thabrew
Email: h.thabrew@auckland.ac.nz

Head of Department: Prof Sally Merry
Email: s.merry@auckland.ac.nz

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324, or contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext 3204 to discuss any questions or complaints about the study.

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

TE TOKA TUMAI
Auckland DHB

Starship
Child Health

Consent Form

Title of Project: ‘The effect of an Admission Support Plan on improving the hospital admission experience of children and young people with developmental disabilities, communication difficulties and challenging behaviours.’

Please tick to indicate you consent to the following

I have read, or have had read to me, in my first language, and I 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 Participant 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 without this affecting my child’s medical care.		
I consent to the research staff collecting and processing my/my child’s information, including information about my child’s health.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I know who to contact if I have any questions about the study in general.		
I understand what participating in this study involves.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

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

Participant name:

Participant email:

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:

Approved by the Auckland Health Research Ethics Committee on [date] for three years. Reference number [xxxx].