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## Participant Information Sheet

**Project title:** The Preschool Autism Therapy (PATH) Study: An adaptive randomised-controlled trial of communication interventions for young children with a diagnosis of autism spectrum disorder

### **Name of Researchers:**

This study is led by Professor Andrew Whitehouse and is run through the CliniKids Autism Research Team at the Telethon Kids Institute. This project is associated with the University of Western Australia as it involves the research project of a PhD student (Sarah Pillar).

### **Invitation:**

You are invited to participate in a project of the CliniKids Autism Research Team. You have been invited to take part in this project because you are the parent/caregiver of a preschool child with a diagnosis of autism.

### **Aim of the Study (What is the project about?)**

Children with autism often have delays in their communication and social skills and been shown to benefit from participation in therapies to improve these skills. PACT (Paediatric Autism Communication Therapy) and JASPER (Joint Attention Symbolic Play and Engagement Regulation Therapy) are therapies that target the improvement of communication and social skills in children with a diagnosis of Autism. However, we don't know whether PACT or JASPER is more effective, or whether PACT is better for some children while JASPER is better for others. This research will compare the outcomes of children who receive PACT and with the outcomes of children who receive JASPER to help us understand which therapy is best for which children. The study will also help us understand how long should we expect improvement from a therapy to take and is that improvement increased when the child is given that therapy more frequently.

### **Voluntary Participation and Withdrawal from the Study**

Participation in this study is completely voluntary. You are free to withdraw from the study at any time, without giving an explanation. If you withdraw, we will delete all the data you have already provided, unless you provide us with permission to retain it. If you withdraw it will not influence the care your child receives nor impact your relationship with anyone within the CliniKids Autism Research Team.



### What does participation involve?

The study involves receiving 24 weeks of either PACT or JASPER intervention, divided into two 12 week blocks. We are conducting what is called a ‘randomised trial’, which means that we are trying to compare these interventions, by randomly allocating children to receive either PACT or JASPER therapy. This means you will not choose which therapy your child will receive. The time commitment for participation in these interventions is as follows:

	PACT	JASPER
Block 1: Weeks 1 - 12	One 90 minute appointments <u>per fortnight</u> with daily home practice (20-30 minutes per day).	Two 45 minute appointments <u>per week</u> (no home practice required).
Block 2: Weeks 13 - 24	Depending on how the child is responding to the intervention, they will receive either: 1) One 90 minute appointments <u>per fortnight</u> with daily home practice (20-30 minutes per day). 2) One 90 minute appointments <u>per week</u> with daily home practice (20-30 minutes per day).	Depending on how the child is responding to the intervention, they will receive either: 1) Two 45 minute appointments <u>per week</u> (no home practice required). 2) Three 45 minute appointments <u>per week</u> (no home practice required).
<b>TOTAL time commitment to therapy over the duration of the project:</b>	Up to 4 hours and 15 minutes per week over 24 weeks	Up to 2 hours and 15 minutes per week over 24 weeks

Both PACT and JASPER intervention have been shown in previous research studies to support children with their development of social-communication skills. However, the therapies look quite different in practice. All therapy sessions are held at the CliniKids clinic in SUBIACO (free on-site parking available).

### What does PACT Therapy look like?

In PACT Therapy, the intervention is mediated by the parent. This means that the trained therapist does **not** work directly with the child, but rather, spends time supporting the parent to use therapeutic strategies with their child. The parent and therapist watch videos of the parent and child playing together. The therapist supports the parent to reflect on what strategies work well and which strategies are less helpful. Together they decide on goals for what strategies the parent should use. These strategies are reviewed throughout the intervention as the child’s social-communication skills develop.

### What does JASPER Therapy look like?

In JASPER Therapy, the intervention is mediated by the therapist. This means that a trained therapist works directly with the child. The therapist and child engage in a range of play based routines and the therapist uses modeling and teaching strategies to embed learning targets within the play routines.



At three timepoints during the study you will also be asked to attend an assessment session, where your child will complete developmental assessments and you will complete questionnaires. The time commitment for participation in these assessment sessions are as follows:

	When?	How long does it take?
Assessment 1: <i>Study Entry Assessment</i>	Before starting PACT or JASPER intervention	2.5 hours
Assessment 2: 24 weeks <i>End of Therapy Assessment</i>	After your child has received 24 weeks of PACT or JASPER	2.5 hours
Assessment 3: 52 weeks <i>One Year Follow-up</i>	One year after completing 'Assessment 1'	2.5 hours
<b>TOTAL time commitment to assessment over the duration of the project:</b>		7.5 hours

Therapy sessions and assessment sessions will be video recorded and electronically stored, to ensure the quality of the therapies are maintained and to help with the scoring of behavioural assessments.

### Your privacy

Your participation in this study and any information you provide will be treated in a confidential manner. Information from this project will be published but your name and identifying details will not be used in any publication arising out of the research without your consent. The data will be kept in a non-identifiable format, in a password protected computer on a secure server. All data shall be retained for a minimum of 7 years after project completion or publication, or the children have reached 25 years of age (whichever is the later) and then destroyed.

### Possible Benefits

Your child will receive 24 weeks of either PACT or JASPER therapy (free of charge) from which your child may benefit by developing improved communication and social skills. Your child's progress will also be closely monitored through regular assessments and we can provide you with information regarding their skill development. We will use the information we collect to publish scientific papers, which you will be offered access to read. We will communicate our findings to the broader public through scientific and community presentations. The findings may benefit the broader autism community by helping clinicians and families to make more informed choices about which interventions best support children with autism to develop communication and social skills.



### **Possible Risks and Risk Management Plan**

Both PACT and JASPER have been previously studied and shown to be safe and acceptable to children and their families. Based on current scientific evidence we have no reason to believe your child will be disadvantaged by receiving one of these therapies over the other.

In the event that any concerns are identified for you (such as increased stress) or your child, you may contact the Project Manager (Sarah Pillar) at any time and we will promptly address this and refer you to the appropriate services if required.

### **Contacts**

If you would like to participate or discuss any aspect of this study please feel free to contact Sarah Pillar on Ph 6319 1832 or via email [PathStudy@telethonkids.org.au](mailto:PathStudy@telethonkids.org.au)

Sincerely,

Professor Andrew Whitehouse

Chief Investigator

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Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to [humanethics@uwa.edu.au](mailto:humanethics@uwa.edu.au). All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.