



## Who is carrying out the study?

The Early Moves study is an ORIGINS subproject being led by Professor Jane Valentine (Perth Children's Hospital) and Professor Catherine Elliott (Curtin University).

## Ethical information

The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact Joondalup Health Campus Executive Office on (08) 9400 9404. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

## Questions?

If you would like further information about these additional assessments, please do not hesitate to contact Caroline Alexander by phone or email:

**0434 938 571 | [earlymoves@health.wa.gov.au](mailto:earlymoves@health.wa.gov.au)**



**early moves**

**Invitation for additional assessments and data linkage**

Thank you for participating in the Early Moves project. Your participation to date has been incredibly valuable. By completing the developmental assessment at 2-years, we hope to learn how to identify babies at risk of learning difficulties at a very young age, so we can, in the future, make sure they get intervention to offer them the best start to life.

This information booklet contains information about additional assessments and data linkage you are invited to participate in, so we can better understand some other important issues.



**Perth Children's Hospital** | **Curtin University** | **THE ORIGINS PROJECT** | **TELETHON KIDS INSTITUTE** | **Joondalup Health Campus**

**Implementing partners**

**Government of Western Australia** | **Department of Health** | **National Health and Medical Research Council** | **Perth Children's Hospital** | **St John of God** | **Murdoch Children's Research Institute** | **UNSW** | **mater research**

**Funding partners**

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## Why do we want additional information?

Collecting additional information about the development of the children in Early Moves will help us understand if a baby's early movements can predict other common disorders too. We would also like to understand the financial and personal impact in the early years for those with a child with developmental disorders compared to those developing typically. Understanding these costs is an important step as we work towards improving supports for families.

We are now inviting families participating in Early Moves to complete some brief questionnaires to give us some more important information about their child's general health and development. This will take approximately 20 minutes to complete. We are also asking your permission to access your child's health and medical information that is held by the WA Department of Health and Services Australia.

### DO I HAVE TO TAKE PART?

You do not have to consent to any or all of the additional measures or data access included here. Your decision to take part in the additional measures described here will not impact your participation in Early Moves or ORIGINS. Even if you consent to take part and change your mind, that is OK and you can withdraw at any time without giving a reason. If you do withdraw, the information we have already collected may still be used.

### WHAT ABOUT MY PRIVACY?

The information we collect and about you and your child is kept strictly confidential and stored securely at Perth Children's Hospital. No identifying information will be stored with your study data or data accessed from external databases. Your information is only accessed by authorised Early Moves researchers for the purposes of the Early Moves project.

## What additional assessments are involved?

- **Screening for early signs of Autism Spectrum Disorder (ASD)**

You will be asked to complete a short questionnaire about your child. If your response indicates concerns about your child's social and communication development, we will talk through these in a short interview. If a higher risk of ASD is identified we will do a full diagnostic assessment and refer your child to appropriate services to ensure you and your child get the best support.

- **A questionnaire on Carer Quality of Life**

This brief questionnaire asks about your experience caring for your child and the impact on your quality of life, helping us understand the personal impact of raising a child with and without developmental disorders.

- **Complete a Health Resource Use Questionnaire**

We may contact you with some follow-up questions about your use of private health services and external care for your child, helping us understand the financial impact of raising a child with and without developmental disorders.

- **Parent Report of Children's Abilities**

We may contact you via telephone to ask some questions about your child's thinking and language skills. This should take 10-15 minutes.

## What additional information about my child will be accessed?

The Department of Health collects important health and medical information about the patients accessing services and the care provided to them. So we can understand more about your child's health and development in their first 6 years, and the financial impact of this, we require data from these databases:

- **Medicare and Pharmaceutical Benefits Scheme claims** (information on your child's doctor visits and the associated costs [Medicare] and prescription medications you have filled for your child [Pharmaceutical Benefits Scheme])
- **Midwives Notification System** (health and medical information about the pregnancy, labour and birth of your child)
- **WA Register of Developmental Abnormalities** (if applicable, any diagnosis of a developmental anomaly your child has received)
- **Emergency Department (ED) Data System** (when and why your child visited the ED and the care they were provided)
- **Hospital Morbidity Data System** (when and why your child was admitted to hospital, and the care provided to your child)
- **Child Development Services (CDS) Database** (if applicable, any referrals your child has had to child development services, as well as clinical contacts including assessments and treatments)

