

Summary Participant Information sheet

V1.0_Aproved_10.08.23

A Cluster Randomised Controlled Trial of Early Positive Approaches to Support (E-PAtS) for families of young children with intellectual disability.

Dr Nick Gore

We invite you to take part in a research study.

- You are being invited to take part in a research study. Before you decide, it is important to understand why the research is being done and what it would involve for you.
- Please take the time to read the following information carefully. You can talk to others (e.g., family and friends) about the study before you decide whether to take part. You can talk to researchers about the study to find out more (contacts are provided at the end of this document).
- You are free to decide whether or not to take part in this study. If you choose not to take part, this will not affect your current support.
- Ask us if there is anything you are not clear about.

What is the study about?

- We have developed a family caregiver support programme for parent/caregivers of young children (no younger than 18 months, and not yet 6 years of age) with additional developmental needs (sometimes referred to as intellectual disability, developmental delay or learning disability).
- The programme is called Early Positive Approaches to Support (E-PAtS). We want to find out if E-PAtS helps to improve the wellbeing of parents/caregivers of children with additional developmental needs. As well as supporting parent to look after their wellbeing, E-PAtS covers practical strategies to support child development and behaviour, and how to access services.
- In E-PAtS, parent/caregivers (adult family members who support a child with additional developmental needs) are supported in a group by a trained family caregiver and professional over 8 sessions (2.5 hours each including time for a break).
- This study is a randomised study, which means that a computer will randomly assign participants by chance to groups that either receive the E-PAtS now or groups that receive just their current usual supports (and then E-PAtS 12 months later).
- You will also be asked to complete questionnaires at three different times over a period of 12-months, whether you receive E-PAtS now or 12 months later. These questionnaires may take around 40 minutes to complete.

Why have I been approached?

- You have been invited to take part in this study as you are a parent/caregiver of a child with additional developmental needs (no younger than 18 months and not yet 6 years of age).
- We would also like to invite a second parent/caregiver from your family to take part. They will have a choice as to whether to attend the E-PAtS sessions with you or not.
- If you feel they would be willing to take part, we would like to request their contact details and we will contact them separately to invite them to also take part.

Confidentiality & General Data Protection Requirements (GDPR)

- Everyone involved in this study will keep your data safe and secure. We will follow all privacy rules and data protection regulations, as required by law.
- The main participant information sheet tells you more about this.

Who has reviewed the study?

- The study has been approved by the Tizard Centre Ethics Committee

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact either of the following people (both of whom will be able to help you)::

Janine Bates (Study Manager) E-PAtSTrial@cardiff.ac.uk, Tel: 02920687616
Nick Gore (Chief Investigator) LSSJEarlySupportRCT@kent.ac.uk

Thank you for taking the time to read this Summary Participant Information Sheet