

## **PARTICIPANT INFORMATION SHEET**

### **Co-producing training resources about the experience of receiving a prenatal diagnosis of a fetal anomaly.**

You are invited to take part in a study about people's experiences and feelings when they find out during pregnancy that their baby has a difference in their health, development or genetics. This study will help health and allied health professionals learn how to support people who receive this kind of news, and it will create stories that will be used in training for these professionals.

The study is being led by Pieta Shakes from James Cook University, and it's being done in partnership with Through the Unexpected. The study is funded by The Liptember Foundation.

If you decide to take part, you can choose to be a **Participant** or a **Participant Researcher**.

If you choose to be a **Participant**, you will be asked to take part in a group discussion with other parents and the researcher. This discussion will take about 2.5 hours, and it will be recorded. You will also be asked to give feedback on the discussion and stories by email. You will be paid for your time and expertise, up to 5.5 hours at \$40.09 per hour, either with an ABN or through gift cards.

If you choose to be a **Participant Researcher**, you will be asked to join the research team, complete some training, help run a group discussion, analyse the findings, and help write the stories. This will take about 32 hours, and you will be paid for your time and expertise, at \$40.09 per hour which will require you to have an ABN. You can also co-author publications and help share the study's findings, if you choose to.

Participation in this study is voluntary, and you can stop at any time. If you take part the study, you may experience some discomfort or mild distress. You will be given support contact information and encouraged to monitor your well-being throughout the study. As the group discussion includes other people, we can't be sure that you won't know the other people or that they will keep everything confidential.

Metropolitan based participants will be reimbursed up to \$35 for travel and parking costs to attend the group and regional, rural and remote participants will be reimbursed up to \$500. You will need to send through the receipts to claim the reimbursements.

Your contact details will be kept confidential. The data from the study will be used in research publications and reports, as well as in training created by Through the Unexpected. You will not be identified in any publications unless you are a Participant Researcher and choose to be identified as a co-author.

If you know someone who might be interested in taking part, please share this information with them.

If you have any questions, please contact Pieta Shakes or Dr. Tracey Ahern.

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Human Research Ethics Approval Number: H9049

*If you have any concerns regarding the ethical conduct of the study, please contact:  
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