

# Participant Information & Consent Form – All countries

<b>Study Title</b>	<b>COCOON Study – Continuing care in COvid-19 O</b> utbreak: A global survey of <b>N</b> ew and expectant parent experiences
<b>Short Title</b>	COCOON Global Survey
<b>HREC Number</b>	MML HREC 63526
<b>Principal Investigator</b>	Professor Vicki Flenady
<b>Coordinating Investigator</b>	Dr Siobhan Loughnan
<b>Location</b>	Mater Research, South Brisbane QLD Australia

## Part 1 Participant information

This survey is part of a global initiative to understand the challenges and concerns of parents who are pregnant or have recently given birth during the COVID-19 global pandemic outbreak (from 30<sup>th</sup> January 2020 on). We also want to understand the experiences of parents who have lost their baby since the outbreak, to whom we extend our sympathies. It is hoped that our research can help improve care for all families around the world.

This information sheet and consent form explains the study and what taking part involves. Knowing what is involved can help you decide if you want to participate. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether to take part or not, you might want to talk about it with a relative, friend or health worker.

If you decide to take part in this study, you will be asked to check a box below to indicate your consent. By checking YES, you agree that you:

- Understand what you have read.
- Consent to being involved in the study described.
- Consent to sharing your personal and health information as described.

### *1.1 What is the purpose of this study?*

The Stillbirth Centre of Research Excellence is coordinating a global research study on the psychosocial impact of COVID-19 pandemic outbreak on women and their partners who are pregnant or have recently given birth and accessing maternity care services during this time.

### *1.2 What does participation in this study involve?*

You are invited to take part in this survey if you are currently pregnant or have had your baby during the COVID-19 outbreak – from 30<sup>th</sup> January, 2020 onwards – or if your partner is currently pregnant or had your baby during the outbreak. **Both mothers and fathers/partners are welcome to participate. We also wish to invite parents who have experienced the loss of their baby during this time.**

**This survey consists of about 45 questions and should take approximately 20 mins to complete.** You will be asked to complete a survey about the care you received during and/or after your or your partner's pregnancy during the COVID-19 pandemic.

### ***1.3 What if I want to withdraw after starting the survey?***

Participation is voluntary and you are free to decide whether you would like to participate or not. If you do decide to participate but then change your mind before finishing the survey, simply close your web browser. You should be aware that any data collected up to the time of your withdrawal will form part of the study results. As the survey is completed anonymously, the researchers cannot identify you to be able to withdraw your answers. At the end of the survey there is the option to leave your contact details with us to participate in a follow-up survey. This will mean that your survey responses will no longer be anonymous. This is so we can link your two surveys together to see if there have been any changes over time. If you wish to withdraw from participating further, you can do this by contacting the research team via email – [stillbirthcre@mater.uq.edu.au](mailto:stillbirthcre@mater.uq.edu.au).

### ***1.4 What are the possible risks/benefits of participating?***

Please be aware that you may not receive any direct personal benefit from this research. However, your contribution will help improve our understanding of the effect of COVID-19 on pregnancy and postpartum care and how this can be addressed now, and for future outbreaks.

If at any time you feel worried or upset while answering the questions, you are encouraged to seek advice from your healthcare provider or reach out to the support organisations listed below.

## **Part 2 How the study is being conducted?**

### ***2.1 What will happen to information about the participant?***

By completing this survey, your responses will help us to understand the impact of COVID-19 outbreak on families and the types of support that may help at such a time. Your responses will help to identify where maternity care can be improved for parents during pregnancy and after they give birth during the current COVID-19 outbreak. It will also be useful to help in planning better responses if such outbreaks happen in the future.

The information you provide in the survey cannot be used to identify you. We do not ask you to provide your name or any other contact details as part of the survey. At the end of the survey, if you would like to receive a follow-up (second) survey in a few months' time, you can choose to leave your name and contact details so that we can send this to you. Please note, your responses will then no longer be anonymous. This is so we can link your surveys together to see if there have been any changes over time. Once the study has finished and we start analyzing the responses from this survey, all data will be grouped and results presented together (not individually).

If you would like to access the findings from this global research study, please visit our website [www.stillbirthcre.org.au](http://www.stillbirthcre.org.au) to stay updated, or contact the research team via email on [stillbirthcre@mater.uq.edu.au](mailto:stillbirthcre@mater.uq.edu.au)

### ***2.2 Who has reviewed the study?***

The COCOON Global collaboration is coordinated by the Centre of Research Excellence in Stillbirth (Stillbirth CRE) based at the Mater Research Institute in Brisbane, Australia. All research in Australia involving humans is reviewed by an independent Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the appropriate HREC and the project will be

carried out according to Australia's *National Statement on Ethical Conduct in Human Research*. This statement has been developed to protect the interests of people who agree to participate in human research studies. This ethics review to all participants that complete this study as all data will be collected and stored by the Stillbirth CRE based at Mater Research Institute in Australia.

### **2.3 Further information and who to contact**

Once you have read this information, you are welcome to contact the research team if you would like any further information regarding this study or if you have any concerns related to your involvement in the study.

**Contact name:** Prof Vicki Flenady  
**Position:** Chief Investigator  
**Email:** [vicki.flenady@mater.uq.edu.au](mailto:vicki.flenady@mater.uq.edu.au)

**Contact name:** Dr Siobhan Loughnan  
**Position:** Coordinating Investigator  
**Email:** [Siobhan.Loughnan@mater.uq.edu.au](mailto:Siobhan.Loughnan@mater.uq.edu.au)

### **2.4 Concerns**

This study has been reviewed and approved by the Mater Misericordiae Ltd Human Research Ethics Committee (HREC/MML/58633 (V2)). Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Liaison Officer or Chairperson, Human Research Ethics Committee, Mater Misericordiae Ltd Level 2 Aubigny Place, Raymond Terrace South Brisbane 4101 Australia, or telephone (07) 3163 1585 or email: [research.ethics@mater.uq.edu.au](mailto:research.ethics@mater.uq.edu.au)

### **2.5 Global Support Services**

- If you are currently experiencing symptoms or are concerned about contact with a possible COVID-19 case, or for further information regarding the rapidly changing COVID-19 situation, please visit the World Health Organization (WHO) for more information and support: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen>
- For information and resources to support your mental health during this time, please visit the World Health Organization: <https://www.who.int/news-room/campaigns/connecting-the-world-to-combat-coronavirus/healthyathome/healthyathome---mental-health>
- For mental health and maternal health support, please visit:
  - Postpartum Support International - <https://www.postpartum.net>
  - World Health Organization - [https://www.who.int/health-topics/maternal-health#tab=tab\\_1](https://www.who.int/health-topics/maternal-health#tab=tab_1)
- For crisis support and suicide prevention support and information, please visit the International Association for Suicide Prevention - [https://www.iasp.info/resources/Crisis\\_Centres/](https://www.iasp.info/resources/Crisis_Centres/)
- For grief and bereavement support following the loss of your baby, please visit:
  - International Stillbirth Alliance - <https://www.stillbirthalliance.org>
  - World Health Organization - <https://www.who.int/news-room/spotlight/why-we-need-to-talk-about-losing-a-baby>

**Thank you for taking the time to consider this study. If you wish to take part in this study, please continue to the consent form on-screen.**

## Participant Online Consent – All countries

<b>Study Title</b>	<b>COCOON Study – Continuing care in COvid-19 Outbreak: A global survey of New and expectant parent experiences</b>
<b>Short Title</b>	COCOON Global Survey
<b>Project Sponsor</b>	Mater Misericordiae Ltd.
<b>Protocol Number</b>	1.0
<b>Principal Investigator</b>	Professor Vicki Flenady
<b>Coordinating Investigator</b>	Dr Siobhan Loughnan
<b>Investigator Contact</b>	0408 175 296
<b>Location</b>	Mater Research, South Brisbane QLD Australia

### Declaration by Participant

- I have read the Participant Information Sheet.
- I am an adult aged 18 years of age or older
- I understand the purposes, procedures and risks of the research described in the project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.
- I understand that the research project will be carried out according to the principles in Australia's National Health & Medical Research Council Statement on Ethical Conduct in Human Research.

Please check the box below to indicate your consent to participate in this research study:

Yes, I consent

**If you do not wish to participate in this study, please close your web browser now.  
Thank you.**