The COVID-19 Infection in Pregnancy in New Zealand Registry

INFORMATION SHEET

Principal Investigators:

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Contact/more info: 021 0831 4824   covid19@auckland.ac.nz   www.liggins.auckland.ac.nz/covid19

What is the COVID-19 in Pregnancy New Zealand Registry? COVID-19 is an illness caused by a new coronavirus that most commonly affects the lungs and airways. We have limited information on how this infection may affect pregnant women and newborn babies. We have developed a registry to collection information about all women in New Zealand who are pregnant, or have recently been pregnant, and have been diagnosed with COVID-19. We will collect information about each woman's health, obstetric history, current pregnancy, birth and the health of the newborn baby up to 6 weeks after birth. The Registry will help us understand how many women get COVID-19 in pregnancy and the effect this has on pregnancy and the newborn baby. This will help us provide better care for pregnant women and their babies.

What does this mean for you? As you have had COVID-19 in pregnancy or soon after, we will include your information in the Registry unless you specifically tell us not to. The information we need to know is already collected by your midwife or doctor and they will pass this information to us. There are no additional visits or tests needed and *there is nothing extra that you need to do*.

What happens to the information collected? Your information is stored securely by The University of Auckland and only a very few people are able to look at it. Information that can identify you is stored separately from other information in the Registry. Your information is coded and Registry data is stored only under this code (called your Registry ID number). When reports are written and published about the Registry information is put together and it is not possible to identify any one person. No unauthorised people will be able to see any information held in the Registry.

Use of data by others. Data from the Registry may be combined with international work. Access to the Registry data is limited to researchers who demonstrate their scientific need and ability to protect your rights as described above. Any research request must obtain the agreement of the Registry management team as well as a research ethics committee before starting. Your identifying information will not be released to any external parties or researchers. As our knowledge of COVID-19 grows, new research projects may be developed. You may be contacted by your own doctor or midwife in the future regarding new research. Taking part in any future research will be voluntary, i.e. your choice.

Who do I contact for more information? If you would like to see your and your baby's information or you have any questions about the Registry, please contact the investigators at covid19@auckland.ac.nz or via phone 021 0831 4824.

Who do I contact if I do not want my or my baby's information to be included? To 'opt-out' of having information included, please notify the investigators: 021 0831 4824 or covid19@auckland.ac.nz. All information collected about you and your baby up until that time will be removed and no further information will be added.

Reports from this research will be shared on our webpage and with Te Rōpū Whakakaupapa Urutā (the National Māori Pandemic Group) and Tumu Whakarae (the National DHB Māori General Managers Group) for dissemination to DHB Māori Directorates. If you require Māori cultural support, talk to your whānau in the first instance. Alternatively, you may contact Dr Kasey Tawhara, Māori researcher, at covid19@auckland.ac.nz or via phone 021 0831 4824.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:
Freephone: 0800 555 050, Freefax: 0800 2 SUPPORT (0800 2787 7678), Email: advocacy@advocacy.org.nz
You can also contact the health and disability ethics committee (HDEC) that approved this study on:
Phone: 0800 4 ETHICS   Email: hdecs@health.govt.nz

Approval. This study has been reviewed and received ethical approval from the Northern B Health and Disability Ethics Committee, reference 20/NTB/81.

THE COVID-19 IN PREGNANCY REGISTRY

1. YOUR INFORMATION INTO THE REGISTRY

Information about you and your pregnancy will be provided by your midwife/doctor at the time of COVID-19 diagnosis and after your pregnancy has ended. **No input is required from you**, all the information used is already gathered about you and your pregnancy/baby.

YOUR IDENTIFYING DETAILS WILL INCLUDE

- Your name
- Your NHI
- Your date of birth
- Your address

OTHER INFORMATION ABOUT YOU WILL INCLUDE

- Your pregnancy
- Your medical history
- Your birth
- Your baby

2. THE REGISTRY

IDENTIFICATION DATABASE

This includes your identifying details linked to a Registry ID number.

This information will be held securely. It will not be directly linked to the information database.

ACCESS LINKING EACH DATABASE IS TIGHTLY CONTROLLED AND ONLY USED TO COMPLETE INFORMATION COLLECTION

INFORMATION DATABASE

This includes all other information collected about you. Information is stored under your Registry ID number.

Only researchers have access to this for analysis and reporting.

It does not identify individuals.

3. LOOKING AT THE NUMBERS

Information collected from the registry **information database** will be grouped together and used for analysis and public reports.

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