

Tēna koutou katoa

I am writing on behalf of the New Zealand COVID-19 in Pregnancy Registry team.

Firstly, a **BIG thank you** to you all for your hard work in submitting notifications and data collection forms over the last 18 months.

Secondly, I am writing to let you know that we are ending notifications to the Registry at this time. We have selected a final notification date 1<sup>st</sup> February 2022.

The team met last week and considered a number of issues to reach this decision. Our rationale includes:

- Omicron variant has a significantly different impact than previous variants and the vast majority of COVID in NZ is now Omicron.
- COVID is now a highly prevalent disease that is predominantly community based and only causes mild disease (even in pregnancy).
- Widespread vaccination and other preventative measures make COVID a significantly different disease to when the Registry started.
- Registries are designed for rare events/conditions, COVID is no longer rare or severe.
- The very high prevalence make it burdensome and challenging to succeed as a
  prospective registry with less women being likely to be seen/admitted whilst
  positive so providing information to allow opt-out may be more difficult, clinicians
  are very busy providing clinical care, the Registry remains an unfunded project so
  limited support for central Registry activity.
- Registries from other countries, with much higher numbers of COVID in pregnancy will provide more information on Omicron wave (+/- high vaccination rates).
- UK and Australian registries stopping notifications end of March (but remain available if new variants of concern arise).
- Issues relevant to New Zealand and equity remain important, including disease burden and vaccination for Māori and non-Māori. Review of Registry data to date will provide some information on this. Ongoing Registry use is unlikely to provide further information (more risk of bias with under-reporting in some communities

and data collected is too limited to answer questions that are better suited to alternative study design).

We considered the possibility of more selective reporting e.g. those admitted to hospital with COVID disease or ICU admissions only. However, we will still have low numbers by comparison to other countries and the level of work required to do this well and the impact on clinicians and the central team make this impractical and does not justify the output. However, we do plan to keep the Registry alive (ethics approval etc) and so if a new variant of concern arises in New Zealand early in its time course we can restart notifications and we will let you know if this is proposed.

We are **committed to obtaining the highest quality data possible for the Registry to date** and so once this Omicron wave is settling we will be in touch with each site to ensure we have captured as much data as possible, including retrospectively for any cases up to 1<sup>st</sup> February 2022.

One of the main aims of this project was to establish a central pregnancy registry that could not only work for COVID but also **other rare diseases/conditions in pregnancy for use in the future**. As you will know UKOSS has been running for many years and they were very quickly able to utilise their system to gain extremely helpful, almost real-time, information for COVID in pregnancy that has been used throughout the world (>17, 000 cases of COVID in pregnancy hospital admissions). We have had a few teething issues but are really pleased in how so many came together early (with support from all our professional colleges) to set up the Registry and for so many DHBs being willing to come on-board including nominations for local site contacts. We plan to **review the process we have used and improve it so we will have a system that can be activated quickly and support our understanding of new and rare diseases in the future.** 

Please feel free to share this information with your teams, we will also be making sure the message is circulated more widely.

So thank you again for all your work on the Registry to date. Please take a well-deserved break from notifications for now. We will be in touch soon about missing cases and data up to 1<sup>st</sup> February 2022.

Ngā mihi nui Katie

on behalf of the New Zealand COVID-19 in Pregnancy Registry team

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