

Reflections on conducting research with healthcare users in a pandemic lockdown

Fiona Imlach

ABSTRACT

The COVID-19 lockdown period created both challenges and opportunities to undertake research. Research was facilitated by flexibility from funders and team members, support from networks and stakeholders and the willingness of individuals to participate. We could learn from the experience of lockdown research by improving institutional support for research processes and dissemination, investing in a nationwide online panel for public good research and ensuring that a planned database of health research can collect and monitor research proposals in times of rapid change and uncertainty.

For most of us, the COVID-19 pandemic and lockdown is and was an unforeseen and unprecedented experience. It changed the way we worked, shopped and engaged with each other. It also changed the way we did research.

On 29 February 2020, the first case of COVID-19 was confirmed in Aotearoa/New Zealand. At that time, I was writing an ethics application for a research project to explore how service users experienced primary healthcare delivered by practices adopting the Health Care Home (HCH) model in Wellington as part of a Health Research Council programme grant.

Our research team submitted an application to the University Human Ethics Committee (HEC) on 12 March 2020, the day after the World Health Organization declared that there was, in fact, a pandemic. The public health calamity became apparent over the next few weeks, with travellers to New Zealand required to self-isolate for 14 days—and a \$12.1 billion COVID-19 business package announced. By 19 March, borders and ports were closed to all but the country's citizens and their dependents and our research team had our first (online) conversation about whether or how to

continue with our extant project. During the next week, we were introduced to the new pandemic Alert Levels, and moved rapidly from Level 2, through Level 3 to Level 4 at midnight of 25 March, the equivalent of a nationwide lockdown.

It was now obvious that our research could not be conducted as intended, as it needed the assistance of primary care providers to recruit service users for in-person interviews. I withdrew our ethics committee application. The next day, a university directive was issued which provided guidelines for all organisations doing research: "There is an ethical imperative to ensure that you do not put others at risk of infection through your research. If your proposed project involves face-to-face interviews or focus groups you must either adopt other methods for data collection or delay the research."¹ Also at the time, primary care staff were undertaking a massive change in service delivery from in-person to 'tele-health' (remote consultations by telephone, video, email, etc) wherever possible, as required by the shift to Alert Levels 3 and 4. They were also managing the fear of exposing themselves and others to a virus that was yet poorly understood. This

milieu of stress and uncertainty meant that a research project based in primary care that had no direct relationship to the COVID-19 event was at best inopportune (and at worst, unacceptable). Seeking service users' views on healthcare in HCH practices was rendered an irrelevant question, as healthcare delivery was completely upended by the crisis. Implementing services which were considered staples in HCH practices, such as telephone triage and consultations, patient portals and email contacts, became a priority in the lockdown, where telehealth became mandatory as a first port of call, almost overnight.

In this context, our only option was to pivot, and swiftly. Our research team had wanted to explore service users' experiences of HCH—the obvious corollary was to shift to exploring their experience of healthcare in the pandemic, particularly the lockdown period. Essentially, a nationwide change programme had been forced upon general practice, after years of inconsistency in embracing new technologies and new ways of engaging healthcare service users to fit the people-centred direction of the New Zealand Health Strategy.² We expected that many researchers would be looking at these changes from the perspective of clinicians, but the consumer's voice was in danger of being overlooked. The Health Quality and Safety Commission runs a regular survey that records patient experiences of primary care,³ but through unfortunate timing, this was in abeyance due to a change of research provider and a review of the content, so would not be in the field during lockdown. The New Zealand Health Survey, which also collects detailed information about patients and their experiences of healthcare, was on hold during this period, since it was administered in-person. It was replaced by a weekly telephone survey from 30 March.⁴ This focused on health and wellbeing and included some questions on access to healthcare but did not ask in detail about experiences of telehealth.

This seemed to be a gap. Would people like the new telehealth approaches or not? Did telehealth meet their needs or not? Would the exposure to telehealth during lockdown mean they wanted these types of services in the future? When did they work

well, and for whom, and when did they not work, and why?

After a Zoom research team meeting on 24 March, this new project commenced and an online survey of healthcare service users about their experiences of telehealth, health and wellbeing during lockdown was developed, to be supplemented with in-depth interviews. The next steps were as follows:

- 1 April: First draft of an ethics application sent to the research team
- 2 April: Ethics application, survey questionnaire and associated documents submitted (under extremity) for consideration at University HEC meeting on 7 April
- 6 April: Social media posts drafted and plans on how to disseminate the survey developed
- 15 April: Received review and comments from University HEC
- 16 April: Submitted revised ethics application
- 17 April: Received approval for the project from University HEC
- 20 April: Online survey went 'live' and dissemination activities began
- 4 May: First in-depth qualitative interview completed
- 13 May: Online survey closed, as Aotearoa moved down to Alert Level 2 (1,010 usable responses)
- 28 May: Final in-depth qualitative interview completed (38 in total with 6 Māori and 3 Pacific participants)

It was a whirlwind experience. In the span of two months, we went from research project conception to completion of data collection, which in normal circumstances might take twice as long. There were some critical elements that enabled this to happen.

Flexibility from the research funders

This was a Health Research Council (HRC) funded project. The HRC were exceptionally accommodating about the change in focus of our project, demonstrating both their appreciation of the extraordinary circumstances and the value of relevant research in such circumstances.

Flexibility from the research team

The team adopted and adapted rapidly to the change in focus and we were also able to co-opt others from our wider research group to help with elements we had not expected in our previous project (such as survey data analysis).

Support from our networks and communities

Given the physical distancing and 'stay at home' constraints, we had to use online methods to reach out to survey participants. We used 'snowball recruitment', starting with personal and professional contacts and social media platforms, a method that had reported success during COVID-19.⁵ Many organisations and individuals went out of their way to disseminate the survey, even when I approached them cold, with no pre-existing connection. I do not even know who to thank for helping us achieve our target of 1,000 survey responses.

Telecommunications

With the restrictions on in-person meetings, more conversations with research team members happened on the phone (and by Zoom), which was more efficient than email. We conducted our participant interviews mostly by Zoom, with a few by telephone. While not typical practice for in-depth qualitative interviews, and for some researchers initially an unfamiliar and awkward method, this quickly became normal and comfortable. As a researcher in lockdown, the Zoom interviews provided a welcome means of meeting and talking to new people and feeling connected to society, a sentiment echoed by many participants. Other researchers have also found that online interviews can be a comfortable, safe and convenient way to engage with participants, even on a sensitive topic.⁶

Willing participants

We could not have completed this research without the contribution of the survey and interview participants, who generously gave us their time and openly shared their stories and experiences. The research team was overwhelmed with the number of people (436) who gave us their contact details to follow up after the survey with an interview. Researchers were warmly welcomed by participants into their worlds with notably little social

warm-up needed to start the interview.

With little prompting, participants opened up about deeply personal and stressful health and social experiences. Participants visually showed researchers aspects of their lives and lockdown activities through the webcams and followed up with messages.

Alongside the positives, however, there were things that could be done better, the next time we are confronted with an unprecedented disruption to our research, at a research institutional level and at a national level. At the institutional level, my experience was that institutions varied in their responses to COVID-19 and the lockdown and this inconsistency highlighted areas that could be improved in the future.

Ethics Committee processes

On 25 March, the Health and Disability Ethics Committees issued emergency ethical review standard operating procedures, outlining the intent for COVID-19-related (or affected) research to have an expedited five-day review, by a committee that was established on 5 April. The University HEC, however, did not follow this precedent or respond to requests for flexibility or increased timeliness in reviewing research projects that were related to COVID-19. Only by pure luck and dogged drafting was I able to submit our ethics application to meet the deadline for the pre-set HEC meeting. If I had missed this deadline, and had to wait another two to three weeks for the next meeting, I would have lost the moment. I appreciated the prompt acceptance of our revision of the application, but it was a significant, and potentially avoidable, cause of stress that the University HEC did not consider expediting their processes in a time of crisis, when the timeframe for undertaking this research was precariously narrow.

Institutional support for research dissemination

Members of the research team were affiliated with several universities across Aotearoa. One university disseminated the survey widely through their social media platforms and communication networks but another university provided very little support for dissemination. Which begs the question, if a university will not use its connections to promote research, who

will? Similarly, despite having a university communications and marketing team, I was unable to find anyone to help with designing a social media advertisement for our research. With no experience and without even having a Facebook account, I undertook a self-directed crash course on Facebook posts, which might have been a pleasant learning experience if I hadn't also been pulling together an ethics application under duress.

At a national level, the ability to conduct flexible and robust research, both in times of disruption and in usual circumstances, could be improved in several ways.

Researcher collaboration for online research panels

The pandemic starkly highlighted the need for a way to access a representative sample of New Zealanders online. COMPASS and the Public Policy Institute have been investigating a nationwide probabilistic online panel for years, that academics and government researchers could access for 'public good' research.⁷ The only other alternative is the commercial online panels (eg, Colmar Brunton), but these are convenience samples, often lack adequate representation of Pacific peoples especially, and of Māori, and are expensive to use. My research group could not afford to use one of these panels, and had to resort to the social media dissemination strategy, which has its own biases. If there was ever a time to commit to funding a representative online panel that could be accessed rapidly for socially beneficially research, it is now.

Health research database

At the time of lockdown, there was limited information about what research was being

undertaken or planned with respect to COVID-19 or the response to the pandemic. Subsequently, a collection of such research projects was started, and is now online.⁸ This demonstrates what is possible, in a relatively short timeframe, when there is an urgent need for co-ordination and collaboration in research and funding. A regularly updated repository of all types of health research would also help avoid duplication and encourage collaboration and would be a useful way to map out existing health research, gaps and opportunities. The New Zealand Research Information System,⁹ which is an online hub about research and innovation being developed over the next four years by the Ministry of Business, Innovation and Employment, may be able to fill this gap and provide critical information for our next health emergency. This new system will need to be rigorously tested and evaluated to ensure it is fit for this purpose.¹⁰

From a research perspective, the pandemic provided both an obstruction to existing research and an opportunity for new research. What did I learn from this experience? It was all about whether people could work together, putting aside differences and unnecessary rules. Some people and organisations rise to the occasion with prescience and agility. People you don't even know, but who believe in the value of your work and the ultimate benefit for Aotearoa and the primary care system, will come forward to help you. There are changes we can make now, that will make doing research during a pandemic, a lockdown or a similar crisis much easier next time. And even if we keep COVID-19 beaten, there will be a next time.

Competing interests:

Nil.

Acknowledgements:

This research is part of a programme funded by the New Zealand Health Research Council (Enhancing Primary Health Care Services to Improve Health in Aotearoa/New Zealand), 18/667. Many thanks to members of the research team for reviewing this article and to the survey and interview participants.

Author information:

Fiona Imlach, Senior Research Fellow, Health Services Research Centre, Victoria University of Wellington, Wellington.

Corresponding author:

Fiona Imlach, Senior Research Fellow, Health Services Research Centre, Victoria University of Wellington, PO Box 600, Wellington 6140.
fiona.imlach@vuw.ac.nz

URL:

www.nzma.org.nz/journal-articles/reflections-on-conducting-research-with-healthcare-users-in-a-pandemic-lockdown

REFERENCES:

- Otago University. Human Ethics Committee: Important notice regarding face-to-face participant research. 24/3/2020, cited July 2020. Available from: <http://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html>
- Minister of Health. New Zealand Health Strategy: Future direction. Wellington: Ministry of Health, 2016.
- Health Quality & Safety Commission New Zealand. Primary Care Patient Experience. 2020, cited July 2020. Available from: <http://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/primary-care-patient-experience/>
- Ministry of Health. COVID-19 Health and Wellbeing Survey. 2020, cited July 2020. Available from: [http://www.health.govt.nz/our-work/diseases-and-conditions/](http://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-novel-coronavirus-resources-and-tools/covid-19-health-and-wellbeing-survey)
- Brauer M, Brossard D, DiPrete Brown L, Ho P, Schwakopf J. COVID-19 Coronavirus and Social Distancing Survey Results. Internal Report. Wisconsin: University of Wisconsin–Madison, 2020. Available from: <http://psych.wisc.edu/Brauer/BrauerLab/wp-content/uploads/2020/03/COVID-report-for-UW.pdf>
- Dodds S, Hess AC. Adapting research methodology during COVID-19: lessons for transformative service research. *Journal of Service Management*. 2020; ahead-of-print.
- Greaves L. An Investigation into the Feasibility of an Online National Probability Panel Study in New Zealand. Auckland: University of Auckland, 2017.
- Ministry of Business Innovation and Employment. COVID-19 research database. Edition. Wellington: Ministry of Business, Innovation and Employment, 2020, cited July 2020. Available from: <http://www.mbie.govt.nz/science-and-technology/science-and-innovation/research-and-data/nzris/covid-19-research-database/>
- Ministry of Business Innovation and Employment. New Zealand Research Information System. Wellington: Ministry of Business, Innovation and Employment, 2020, cited July 2020. Available from: <http://www.mbie.govt.nz/science-and-technology/science-and-innovation/research-and-data/nzris/>
- Ministry of Business Innovation and Employment & Ministry of Health. New Zealand Health Research Strategy 2017-2027. Wellington: Ministry of Business, Innovation and Employment & Ministry of Health, 2017.