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Comorbidities and confusion: addressing COVID-19 vaccine access and information challenges

Katie Attwell, Leah Roberts, Christopher C Blyth

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CDI is produced by:

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Australian Government Department of Health and Aged Care

GPO Box 9848, (MDP 6)
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www.health.gov.au/cdi

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Comorbidities and confusion: addressing COVID-19 vaccine access and information challenges

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Abstract

Objective

Early in the coronavirus disease 2019 (COVID-19) pandemic, evidence emerged that individuals with chronic and immunocompromising conditions faced increased risk of severe infection, including death. The Australian Government and public health authorities prioritised these citizens' access to vaccines, including them in phase 1b of the rollout from 22 March 2021. Given the rapidly evolving knowledge and advice, we sought to understand what people with comorbidities understood about their eligibility, where they obtained information, and their experiences interfacing with the program.

Methods

Through the mixed methods project *Coronavax*, we conducted semi-structured in-depth interviews with eight West Australians aged under 60 who signed up to the study's webpage and declared comorbidities pertinent to serious COVID-19 complications. Interviews were conducted during January–April 2022, audio-recorded, transcribed in full, and analysed in NVivo 20 using inductive methods. We validated participants' accounts of state government actions with a representative in person and in writing.

Results

We identified access and informational barriers – and a lack of understanding – about vaccine eligibility amongst West Australians with comorbidities. Amid a rapidly changing landscape of knowledge with subsequent policy implications, this group received insufficient information for their needs for understanding their place in the immunisation program.

Conclusions

Fast-changing knowledge about vaccines creates communication challenges for government and health professionals. We identify an urgent need to develop, pilot, and evaluate strategies for providing vaccination information in routine and pandemic settings.

Keywords: COVID-19; chronic disease management; communication and marketing; epidemic; health policy

Introduction

Early in the coronavirus disease 2019 (COVID-19) pandemic, evidence emerged that individuals with comorbidities (including cardiorespiratory disease, kidney disease, obesity, and immunocompromising conditions) faced increased risk of severe infection and death.^{1,2} The Australian Government prioritised these citizens' access to vaccines, including them in phase 1b of the rollout from 22 March 2021.

Despite the urgency of vaccinating people with comorbidities, the pandemic disrupted access to routine care,³ potentially inhibiting people's ability to seek information and receive vaccines. Specifically, a lack of understanding about eligibility and barriers to access had the potential to impact vaccine uptake. Researchers have previously identified similar issues in existing comorbidity-based vaccination programs (e.g. influenza, pneumococcal).^{4,5}

Australia's COVID-19 vaccine rollout faced numerous challenges that affected almost all groups. In April 2021, with global concern about thrombosis with thrombocytopenia syndrome (TTS) following the AstraZeneca (Vaxzevria) vaccine, the Australian Technical Advisory Group on Immunisation (ATAGI) recommended that Pfizer (Comirnaty) was preferred for those younger than 50 years.⁶ This saw a major revision of the rollout,⁷ and limited supplies of Comirnaty until the third quarter of 2021 delayed younger people's access. By August 2021, supply constraints were easing and all Australians 16 years and over were eligible for vaccination.

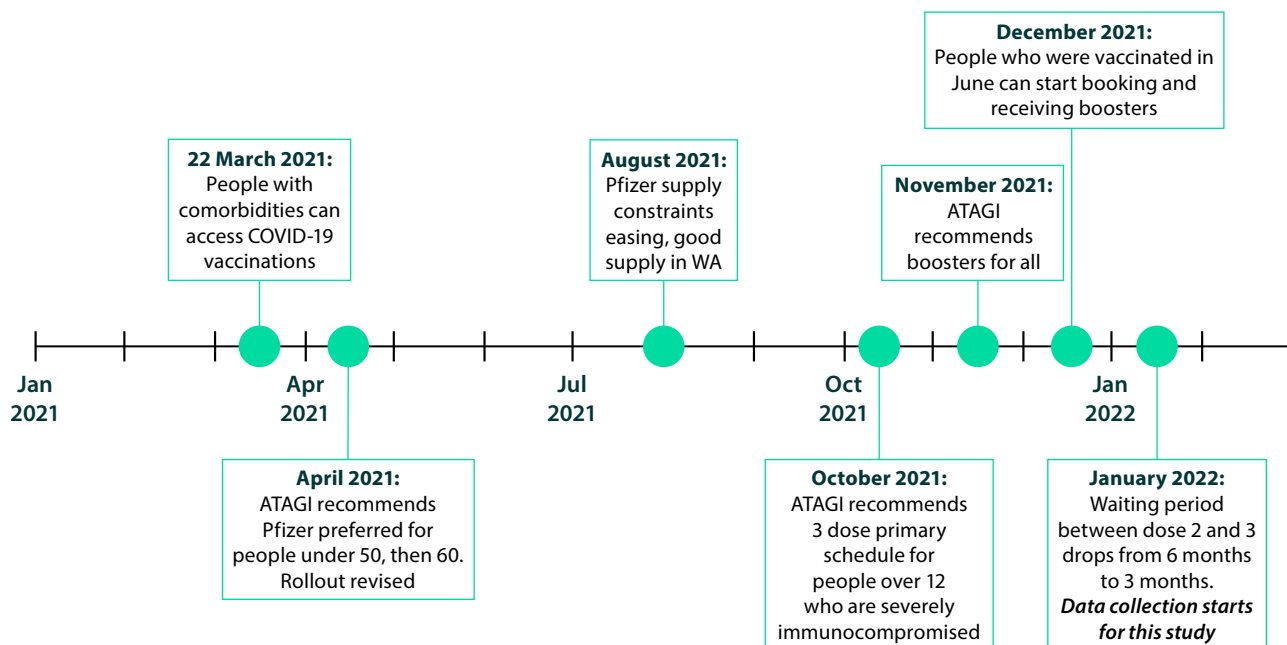
In October 2021, severely immunocompromised people aged 12 years and older were recommended a third primary dose to address suboptimal immune response to the two-dose schedule. ATAGI's statement about this third dose was published online; was disseminated to the states/territories, peak bodies, and providers; and was addressed in a statement from the Chief Medical Officer which was reported by mainstream media.⁸⁻¹⁰ There were no specific public communication campaigns advising individuals belonging to this group that they were eligible.

With evidence of waning protection from two-dose schedules, ATAGI recommended boosters in November 2021.ⁱ Priority group members who had already been vaccinated by June 2021 could book their boosters in December. In January 2022, when we started collecting data for this study, the waiting period after the second dose was reduced from six to three months, enabling rapid access for the wider population. Amid the public messaging about these booster doses, there was no formal targeting of people with comorbidities. Some jurisdictions were facing significant community transmission of the Omicron variant, and authorities likely wished to limit this by boosting as many people as possible, rather than by focusing on specific groups.

Given the rapidly evolving knowledge, advice, and technical challenges (see timeline, Figure 1), we sought to discern what people with comorbidities understood about eligibility, where they obtained information, and what were their experiences interfacing with the program. Understanding the knowledge and experiences of people with comorbidities can help governments to ascertain whether their vaccine programs and information are reaching the right people, and to identify areas for improvement.

i For clarity, we use the terminology of a two-dose or three-dose primary schedule (the latter for the severely immunocompromised) and 'boosters' for subsequent doses. However, from a health communication perspective, 'booster' language may imply that subsequent doses are less important.

Figure 1: Timeline of vaccine rollout pertinent to people with comorbidities



Methods

During the pandemic, we conducted a mixed methods research project called Coronavax: Preparing Community and Government. We undertook in-depth semi-structured qualitative interviews to explore the attitudes and experiences of Western Australia (WA) residents, grouped by age, occupation, and other important features, during the COVID-19 vaccination program. We translated findings to government partners whose experiences we also researched separately. An interdisciplinary team with expertise in vaccination social science and medicine designed and iteratively modified the community interview schedule over the life of the project to capture participants' experiences with, and attitudes towards, the vaccination program, broadly construed (see question guide in open access protocol).¹¹ We invited sign-ups for the Coronavax community research studies through the survey program REDCap from March 2021 using media promotion, word of mouth and snowballing.^{12,13} This particular study focused on adults with comorbidities who were aged under 60 (we had already interviewed older adults – some of whom also had comorbidities – for a separate Coronavax study).¹⁴ Interviews were conducted using video-conferencing software during January–April 2022, when all adults were eligible for boosters. Interviews were audio-recorded, transcribed in full, and analysed in NVivo 20 using inductive methods.

The first and second author collaborated on the coding iteratively, with frequent discussions, bringing in the senior author (a medical expert) for clinical expertise. During this process we decided to focus on emblematic narratives of two participants that demonstrated challenges and complexity with the rollout (see Boxes 1 and 2). We validated state government actions that our participants described (e.g. the process of collecting data from and sending letters to people with comorbidities about the vaccination program) with a representative in person and in writing. Further study design and methods for the Coronavax study are published elsewhere.¹¹ Ethical approval was provided via the Child and Adolescent Health Services Human Research Ethics Committee (RGS0000004457). Participants received a \$20 gift voucher.

For this study exploring access and knowledge of eligibility, we reviewed comorbidities that participants declared to make sure that they were eligible for early vaccination in Group 1b. Eight participants qualified for inclusion and are the focus of this article. We analyse their answers to questions about which doses they received, how they obtained information about eligibility, and how they interfaced with the vaccination system. Separate data regarding attitudes towards COVID-19 disease and vaccination from the wider group of 18 participants who declared comorbidities has been published elsewhere.¹⁵

Table 1: Participants' vaccine doses and reports of advice

Pseudonym	Age	Sex	Comorbidity	Vaccination timing and doses	Vaccine advice
Anna	24	F	high blood pressure, obesity	Two doses from June 2021 (sought dose in April 2021 but faced supply problems), boosted December 2021	No medical interaction
Boris	33	M	severe asthma	Two doses from August 2021 (access issues: could not get time off work for earlier booking), boosted January 2022	Dealt with GP
Liz	46	F	Type 1 diabetes	Two doses from March 2021, boosted January 2022	Dealt with specialist
Dawn	59	F	severe asthma	Two doses from May 2021, boosted January 2022	Dealt with GP and medical or research professionals in social network
Jess	22	F	auto-immune condition	Two doses from August 2021 (access delays despite belief she was in 1b), third dose in January 2022, booster unscheduled	Dealt with specialist and research professionals in social network
Gillian	23	F	Type 1 diabetes	Two doses from September 2021 (delay due to hesitancy and procrastination), boosted January 2022	No specialist interaction; utilised forums for people with diabetes
Redgum	21	M	MADD ^a	Two doses from September 2021 (delay due to belief of low risk of disease, GP's preference to wait for Comirnaty, and Comirnaty shortages), boosted January 2022	Dealt with specialist (opportunistically) and family
Polly	55	F	Type 2 diabetes	Two doses from April 2021, booster date uncertain	No medical interaction other than workplace (in healthcare)

^a MADD: multiple acyl-CoA dehydrogenase deficiency (rare genetic disease).

Results

Participant characteristics

Eight participants with pertinent comorbidities were included (six female and two male), aged 21 to 55 years. Participants had seven different comorbidities, with some reporting more than one. All had received three COVID-19 vaccines. Table 1 includes participants' ages, comorbidities, and self-reported dates of vaccine doses.

Challenges with accessing vaccines and information about eligibility

Some participants described issues accessing vaccines. Anna (hypertension, obesity) sought her first dose in April 2021 but had to wait until June following the program changes. "WA... *didn't allow*" people of her age group to access AstraZeneca (Vaxzevria) so she "*had to wait until there was stock of Pfizer.*"

Table 1 reports how participants obtained information about their vaccine eligibility. Discussing vaccination with a medical professional was one key mechanism. Some spoke with specialists, sometimes opportunistically at existing appointments (Box 1). Others benefited from prompt engagement by their general practitioner (GP). Dawn (severe asthma) praised active outreach for herself and her husband, who had a history of heart failure. "*Our doctor said, 'You need to come in and get it done,' and so he literally booked us in. The minute they started opening it up to take appointments, he had us in there.*" Participants also spoke to family, friends, and co-workers (including those with medical expertise). Some sought or received no medical help, such as Gillian (Box 2), who "*didn't want to spend the money on getting an appointment*" and Anna (hypertension, obesity), whose "*strategy has just been: try not to get [COVID], basically.*" Jess (autoimmune condition) received the third dose recommendation for the severely immunocompromised, but not in a straightforward or timely fashion (Box 1).

What participants' comorbidities meant for accessing information and, in some cases, for additional doses was sometimes unclear to them, their families, social networks, and even healthcare providers. This information gap is highlighted by two diabetics living together who, secondary to their different understandings of their risk, received different instructions (Box 2).

Box 1: Jess's experience

Jess (autoimmune condition) sought a booster once eligibility opened, but access was complicated by communications about the three-course primary dose. In December 2021, during a routine consultation, Jess's rheumatologist advised that she could receive a booster dose two months after her previous vaccination, which was in late August 2021. (Jess was being recommended a *third dose*, not a *booster*.) Jess showed her pharmacist her prescription, and the pharmacist confirmed she could be vaccinated immediately. Jess wanted Moderna (Spikevax) and booked the vaccine for a week later, but then received a letter from WA Health directing her to book her third dose on the government website. The WA Government only had Pfizer (Comirnaty), and Jess believed she was being directed to this brand, so she cancelled her Moderna appointment, leading to a longer wait to access a Pfizer appointment. "*I'm still not a hundred percent sure whether that was my third dose or my booster,*" Jess explained. She compared her Healthy WA vaccination online booking account with that of a friend to see how different doses were recorded. "*I would assume that I'll be able to get my booster in a couple of months, but I still feel kind of in the dark about that.*"

Box 2: Gillian's experience

Gillian and her partner were young people with diabetes. When they booked vaccines on the state government website, he ticked that he was immunocompromised, but Gillian did not. "*There's been a lot of confusion about whether we're immune compromised, because it's an autoimmune disease ... but then we're not on immunosuppressants.*" As a result of classifying themselves differently (and in his case, incorrectly), Gillian's partner was invited for a third dose, whereas Gillian was not. WA Health wrote to everybody who ticked that they were immunocompromised, believing this would activate eligible people for third doses or boosters.

Participants' suggestions for improvements

When asked how they might be better informed about vaccine access and eligibility, Jess (autoimmune condition) suggested push notifications to inform people of their eligibility in real-time, like dental check-up reminders. Others highlighted the need for more information on eligibility from providers, governments, and peak bodies, including more targeted communication for people with specific comorbidities.

Discussion

We identified access and informational barriers, and a lack of understanding about eligibility, amongst our sample of West Australians with comorbidities. Amid a rapidly changing landscape, this group received insufficient information to understand their place in the immunisation program. Lacking clarity about doses and eligibility – and in some cases facing supply constraints or other barriers – some could not easily identify whether they possessed a pertinent comorbidity to promptly access the appropriate doses.ⁱⁱ

Despite government efforts to educate providers and develop resources for providers and the public,¹⁶ our results reflect the challenges in ensuring that this eligibility information reached potential vaccine recipients. Our participants' experiences indicate a lack of clarity around whether recommendations and knowledge of category awareness should be oriented towards *providers* (who push information out to patients) or the *public* (who receive or seek out information for themselves or family and friends). Traditionally, vaccine information and advice for risk-based programs have been directed to providers. However, during COVID-19, the urgent need to disseminate (frequently changing) advice demonstrated that both approaches were required.

To augment provider knowledge and awareness, public communications could target individuals with comorbidities directly. Our results demonstrate the WA Health Department's employment of this strategy. They invited self-identification of comorbidities when people signed up to the vaccination portal and later sent letters to those who ticked the box.

However, a longer-term strategy for shifting to public communications directly with individuals about vaccine eligibility within Australia's risk-based program would require significant community education. Ideally, education would start with a person's diagnosis with a serious condition.

Complementing this, peak bodies for diseases could disseminate risk information regarding vaccine-preventable disease, as suggested by participants. In fact, many peak bodies did disseminate information,^{17,18} but this messaging strategy can pose challenges without further consideration and investment. Not all peak bodies have wide reach, and frequent vaccine messaging may compete with other communications. Solutions may include government prepared co-badged resources that peak bodies can forward to consumers, helping to build upon the credibility and trustworthiness of these organisations. Analyses of COVID-19 vaccination communication campaigns in the United States demonstrate the importance of additional strategic health communication criteria – including the messaging being easy to understand and actionable – and that the use of intermediaries (like peak bodies) requires materials that are 'end user ready'.¹⁹

A separate but parallel strategy could involve innovating systems to deliver more targeted outreach by treating professionals, either GPs or specialists, who have access to high quality and evolving eligibility information, who provide effective recommendations associated with uptake of other comorbidity-based vaccine programs,⁵ and who are often experienced in recall and reminders, which have been shown to be effective in increasing immunisation coverage.²⁰ Dawn and her husband benefited from this kind of care from their GP. However, there are challenges here too. Significant barriers remain to engaging with healthcare, including a lack of face-to-face appointments, out-of-pocket costs, lack of a regular GP, and the cost of accessing specialists. Some of our participants avoided seeing their medical professionals outside of scheduled appointments due to the expense. On the provider side, capacity and resourcing constraints remain, with previous research finding barriers including provider reticence and skillset deficiencies.⁴ There may also be a disconnect between disciplines about who is responsible for vaccine advice.²¹

ii The lead author discovered that she should have been vaccinated in group 1b (instead of with the general population in August 2021) only whilst writing this article.

Participants sought ‘push’ notifications to advise them of their dose eligibility. For existing and future risk-based comorbidity vaccination programs, these push notifications could be implemented at practice level. However, only government systems could attain universal reach. Yet at this level, networks are not yet set up to recognise and reach individuals with comorbidities, even with electronic health records, due to data compatibility and privacy issues. One potential strategy is to include a comorbidity ‘flag’ on the Australian Immunisation Register.⁴ However, not all people access regular medical care, providers would need incentivising to keep the Register up to date, comorbidities and therapies change over time, and people would need to be happy to provide their medical information to governments. Multiple strategies are likely needed to reach populations with comorbidities, but WA’s attempts to collect comorbidity data at vaccine sign-up were a promising start.

The COVID-19 pandemic exemplified an ongoing shift from vaccination as a paediatric concern to a whole-of-life issue that poses continuing challenges, particularly for comorbid populations.⁴ The National Immunisation Program funds influenza, pneumococcal and meningococcal vaccines for individuals with comorbidities, yet these programs are less effective than “age-based” programs because they require interpretation by consumers or providers. Healthcare access issues affect these programs too, with recent calls to enhance vaccine delivery in underutilised hospital and pharmacy settings.^{4,5,22} It is also difficult to quantify the success of such campaigns, given challenges in determining the number of people eligible for them.⁴

There are limitations to our small study, most notably that we would have found further diverse experiences of knowledge and systemic interface within a larger sample. We might have been able to include more health conditions and to better capture the experiences of people in regional areas. Our results cannot be generalised to other people with comorbidities in WA or other states. Nevertheless, we were able to capture the experiences of an important population at a crucial time in the vaccine rollout.

Conclusion

Fast-changing knowledge about vaccines creates communication challenges for government and health professionals, as we found in this study of knowledge about access and eligibility amongst people with comorbidities during the COVID-19 vaccine rollout. We identify an urgent need to develop, pilot, and evaluate strategies for providing vaccination information to people with comorbidities in routine and pandemic settings. Those responsible for our public health systems must learn whether the greatest impact and efficacy lies in enhancing the capacities of providers (e.g. at practice level, including ‘push’ systems there), or in educating and directly activating the public. The best strategy will need to consider the speed of communications, accuracy and reach, as well as the need for regular programmatic updates during pandemics. Successful strategies can be applied to risk-based groups for influenza, pneumococcal, meningococcal, and future vaccinations. Knowledge and strategy gaps identified here highlight the ongoing need for social science research to inform government programs and strategies.

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Data availability

The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

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Author details

A/Prof. Katie Attwell¹

Miss Leah Roberts²

Prof. Christopher C Blyth³

1. Associate Professor, VaxPol Lab, School of Social Sciences, The University of Western Australia, Perth, Australia.

Honorary Fellow, Wesfarmers Centre of Vaccines and Infectious Diseases, Telethon Kids Institute, Perth, Western Australia, Australia.

2. PhD Candidate, School of Population and Global Health, The University of Western Australia, Perth, Australia.

3. Professor, UWA Medical School, The University of Western Australia, Perth, Australia.

Director, Wesfarmers Centre for Vaccines and Infectious Diseases, Telethon Kids Institute, Perth Children's Hospital, Hospital Avenue, Nedlands, Perth, Western Australia, Australia.

Clinical Microbiologist, Department of Microbiology, PathWest Laboratory Medicine, QEII Medical Centre, Nedlands, Perth, Western Australia, Australia.

Corresponding author

A/Prof. Katie Attwell

Address: M259, The University of Western Australia, 35 Stirling Highway, Crawley, Perth, Western Australia, Australia, 6009

Phone: +61 8 6488 3472

Email: katie.attwell@uwa.edu.au

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