HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

The health care experience of disabled people during COVID-19: Summary of findings from the COVID-19 patient experience survey

Te wheako tauwhiro hauora a te hunga hauā i te wā KOWHEORI-19: He whakarāpopototanga o ngā kitenga o te tiro whānui KOWHEORI-19

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Contents | Rārangi take

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Te Kāwanatanga o Aotearoa
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Document purpose | Te whāinga

This document summarises findings and key themes from responses from disabled people to the Health Quality & Safety Commission's COVID-19 patient experience survey.

The survey is an online survey of New Zealanders and part of the New Zealand patient experience survey programme, conducted by the Health Quality & Safety Commission with support from the Ministry of Health.

More information is available at: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/covid-19-patient-experience-survey.

The survey contributes important information to help us understand the health experiences of disabled people during the COVID-19 emergency. This better understanding will inform future emergency planning, as recommended by the Independent Monitoring Mechanism's report on the New Zealand Government's response to the COVID-19 emergency. More information is available at: www.ombudsman.parliament.nz/resources/making-disability-rights-real-pandemic.

For enquiries about this report: survey@hqsc.govt.nz.

Introduction | Kupu whakataki

The Health Quality & Safety Commission ran a COVID-19-specific patient experience survey in partnership with interested primary health organisations (PHOs) in June and July 2020.

The goal of the survey was to understand the impact of COVID-19 on people's experience of health care during and after the first COVID-19 lockdown (levels 3 and 4) and how health services could understand, learn and respond.

The experience of receiving health care for disabled people is likely to be different to that of other people, possibly even more so during a global pandemic and the associated lockdowns.

Information on disability was collected in the COVID-19 patient experience survey via two sets of questions: the Washington Group Short Set (WGSS);[1] and a question on whether respondents self-identify as being disabled (or having a disability).[2]

In the survey population, almost 1 in 5 (19.0 percent) were identified as having a disability using either criteria. Interestingly, only a third of this group were identified as having a disability by both criteria. This raises some questions about how precisely the WGSS definition of what constitutes having a disability maps to New Zealanders perceptions of the same.

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[1] See Appendix for question sets.

[2] See Appendix for question sets.

Table 1: Proportion of the New Zealand population classified as disabled, COVID-19 patient experience survey responses, 2020

Category	Proportion (%)	Number
Self-identified as disabled, but not included in WGSS criteria	6.0	1,281
Included in WGSS criteria, but did not self-identify as disabled[3]	6.4	1,351
Self-identified and included in WGSS criteria	5.5	1,166
Total identified as disabled using either criteria[4]	19.0	4,031
Neither self-identified nor included in WGSS criteria	81.0	17,238
Total[5]		**21,269**

To simplify reporting and comparison of responses, we created a 'derived variable',[6] combining those identified as being disabled through either question set. To confirm the suitability of this approach we consulted with subject-matter experts, including Stats NZ, the Human Rights Commission and the Office for Disability Issues. The Commission would like to thank the individuals from these organisations for their guidance.

The rationale for combining the two indicators is detailed in the disability methodology document.[7] Combining the two indicators, 19.0 percent of respondents were classified as being disabled.

- Almost a quarter (22.6 percent) of those aged 65 years and over were disabled, however this increased to more than half (50.8 percent) of those aged 85 years and over. By comparison, 12.4 percent of those aged under 35 years were disabled.
- At all ages, Māori were more likely to be disabled than the non-Māori, non-Pacific population surveyed (21.8 percent compared with 18.1 percent).
- In the survey population, disabled people were more likely to live in areas of high deprivation, with 20.5 percent of the disabled survey population living in deprivation quintile 5 (the highest level of deprivation), compared with just 12.6 percent of non-disabled people.

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[3] Those who did not self-identify as disabled included those who said they were not disabled and those who were unsure.

[4] This group contains those who answered at least one of the WGSS questions or self-identification question indicating that they were disabled.

[5] We have not included respondents who answered that they were not disabled according to the WGSS but did not respond to the self-identification question (1,891 respondents). This is because we cannot definitively confirm their disability status.

[6] A derived variable is one that is created by calculating a value from existing variables – in this instance, a 'yes' answer to either (or both) the WGSS questions or the self-identification question results in a result for the derived variable.

[7] See: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/4318.

    - Age is a strong predictor of disability, however, it does not explain why disabled people were more likely to live in high deprivation areas. Older people in the survey population were less likely to live in high deprivation areas (only 9.3 percent of those aged 75 years and over lived in deprivation quintile 5 areas, compared with 26.7 percent of those aged 75 years and over living in deprivation quintile 1). Māori were more likely to live in high deprivation areas compared with the non-Māori, non-Pacific population surveyed (24.3 percent of Māori respondents lived in deprivation quintile 5 compared with 9.9 percent of the non-Māori, non-Pacific population).
- Disabled people were more likely to have long-term conditions, with 94.8 percent of disabled people having at least one long-term condition compared with 73.1 percent of other people.
- Disabled people were also more likely to have multiple long-term conditions, with more than half of those with a disability saying they had three or more long-term conditions compared with a median of one for those without a disability.

Survey findings | Ngā kitenga o te tiro whānui

Access by disabled people to the health care they needed during lockdown

Disabled people clearly had a different experience of accessing health care during the COVID-19 lockdown compared with that of non-disabled people.

During alert levels 3 and 4, health care was considered an essential service, and therefore allowed to continue operating. However, some services were deprioritised, particularly in the secondary sector, and the way patients were encouraged to access health care changed. Official advice said the following about accessing health care:

> If you're concerned about any aspect of your health, call your GP. Your doctor may offer you a consultation by text, email, phone or video. This is to stop person-to-person contact. If, however, your doctor feels you need a consultation in person, they will organise this for you.
>
> You're allowed to travel during Alert Levels 3 and 4 to access medical support. You can drive to a medical centre or hospital. Just call first so you know what to do when you get there. For example, you may be asked to use a particular entrance, or to wait outside in your car until you're called. If you're sick you should avoid public transport when travelling to a medical appointment.[8]

We asked respondents about a number of ways they might usually access health care, and whether the lockdown kept them from accessing any of them. Disabled people were more likely, across all modes of health care, to report that lockdown affected their access.

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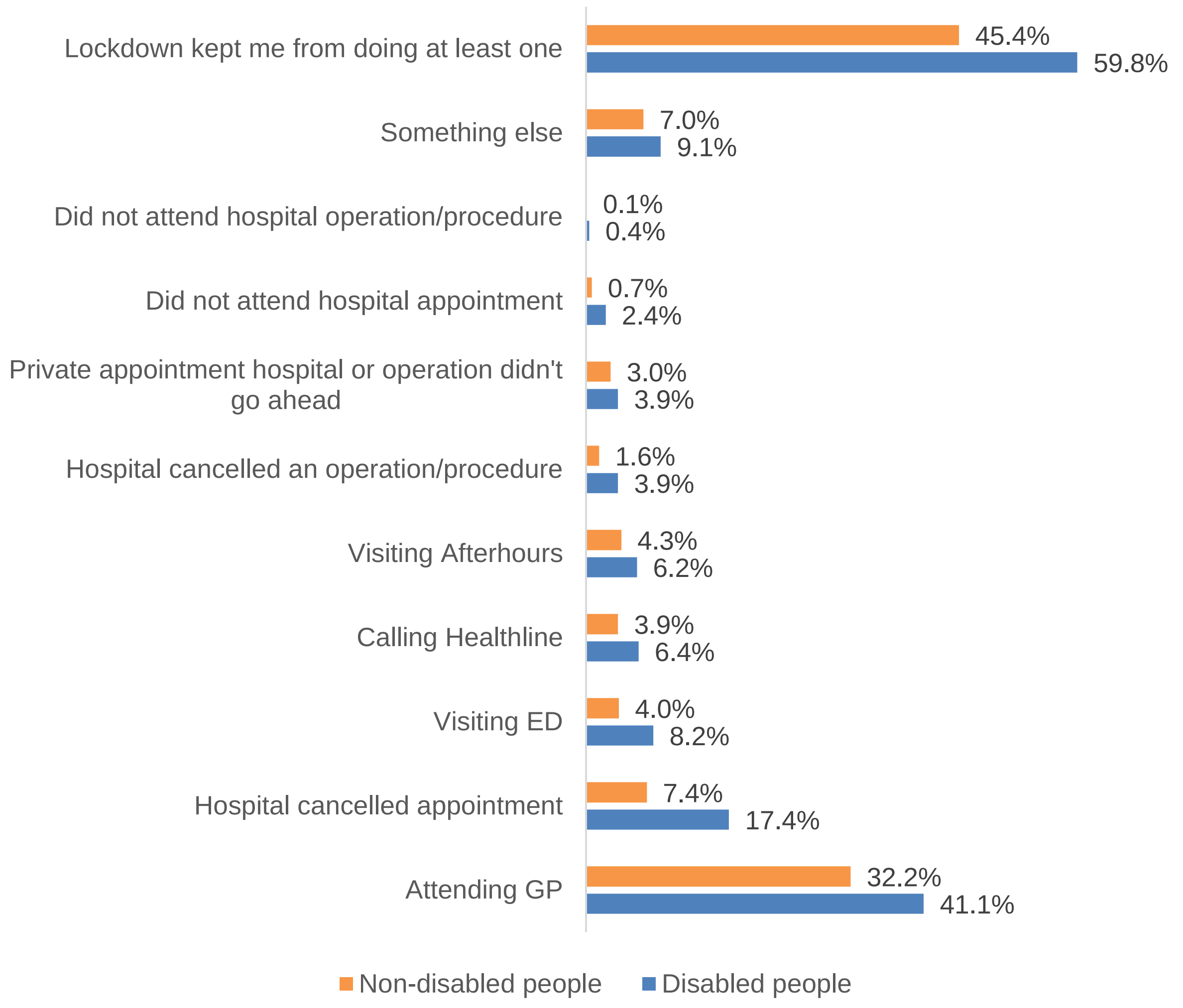
[8] Source: archived covid19.govt.nz website: https://web.archive.org/web/20200513091558mp_/https://covid19.govt.nz/individuals-and-households/health-and-wellbeing/how-to-access-healthcare/#health-services-at-alert-levels-3-and-4.

Figure 1: Responses to question 'Thinking of how you would have normally accessed health care before lockdown, did the alert level 3 and 4 lockdown keep you from doing any of the following?'



A total of 59.8 percent of disabled people reported they were not able to access health care during alert level 3 and 4 as they usually would compared with 45.4 percent of non-disabled people.

- Nearly one in five disabled people had a hospital appointment cancelled (17.4 percent) compared with 7.4 percent of other people.
- A total of 41.1 percent of disabled people were unable to access their general practitioner (GP) as usual compared with 32.2 percent of other people.
- A total of 8.2 percent of disabled people said they had avoided the emergency department when they usually would have attended, double the rate of the non-disabled population (4.0 percent).

It is important to note that while people may not have been able to access their GP as they usually would, they may have accessed them through alternative methods (for example telehealth – video or phone consultations).

Overall, disabled people were more likely not to seek health care as they usually would during the level 3 and 4 lockdown due to the fear of contracting COVID-19; 29.5 percent of disabled people cited this as a reason compared with 21.3 percent of other people. While older people are more likely to be disabled, a smaller proportion of those aged 65 years and over (20.0 percent) cited concern about contracting COVID-19 as a reason for not accessing health care as normal; this compares with those aged under 65 years of age (25.1 percent). This indicates that what we saw in the disabled population was not an age effect.

- Disabled people were less likely to delay or avoid seeking care because they perceived the health concern to not be urgent (31.9 percent of disabled people compared with 41.6 percent of other people).
- Alert level restrictions were the main reason for both groups for not accessing health care as they usually would, but disabled people were more likely to cite this as a reason (48.1 percent of disabled people compared with 42.5 percent of other people).
- When people were unable to access health care as they usually would, we asked them what they did instead.
  - The most common action for both disabled people and others was to have a phone or video appointment (51.7 percent of disabled people and 46.4 percent of other people).
  - About a quarter of patients waited to access health care, although disabled patients were more likely to delay care (27.0 percent) than other people (24.0 percent).

Disabled people were more likely to have used a telehealth option

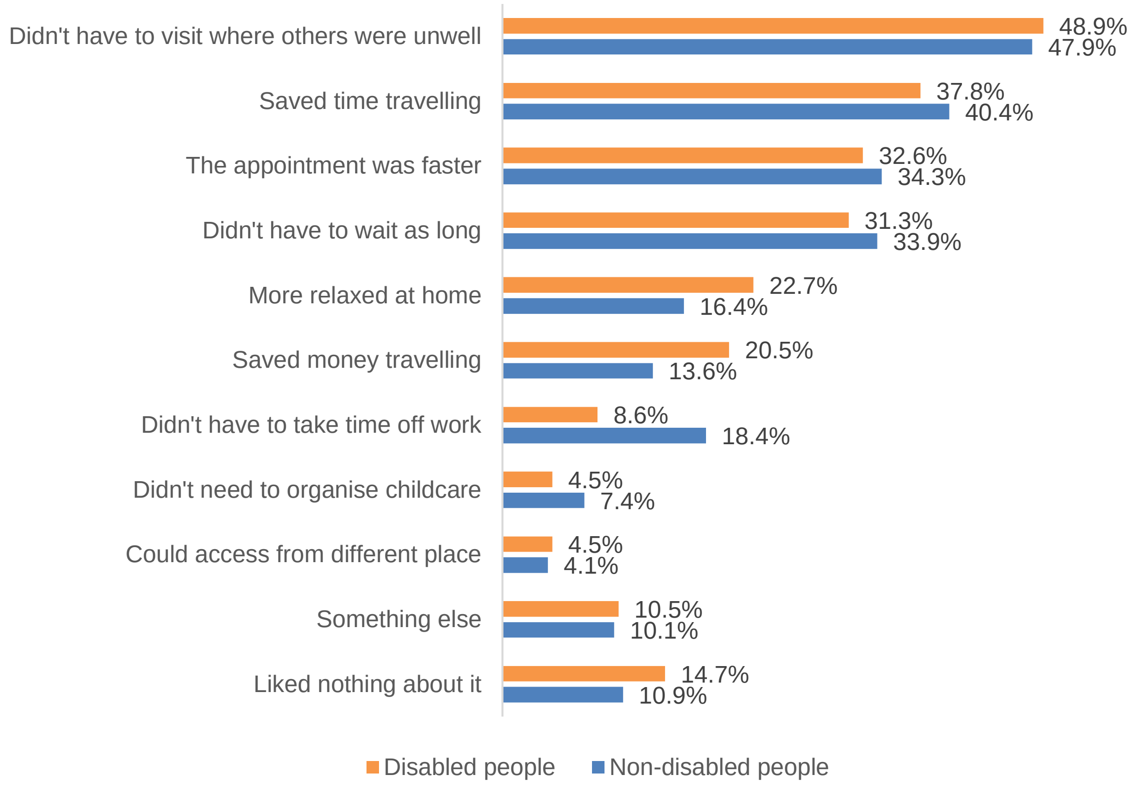
In the survey we asked patients what type of appointment (in person, phone, video) was their most recent appointment with their GP. Disabled people were more likely to have taken up the option of a phone appointment compared with other people (46.0 percent compared with 41.7 percent). This likely reflects that disabled people reported they were not able to access their GP as usual during the level 3 and 4 lockdown, although even before the pandemic, disabled people were more likely to use a telehealth option with their GP (11.3 percent compared with 7.4 percent of other people).

Telehealth options must work for disabled patients. The disabled community is a diverse group, and for some telehealth options may help improve access, whereas for others telehealth may be a barrier to accessing care.

Some disabled patients noted that mobility issues meant telehealth services improved access.

> ‘Each time I rang was to make an appointment for my monthly meds and found the doctor was doing these normal monthly things by phone, then emailing my script to my pharmacy, and they both couriered them to me, also the second time the pharmacist delivered them personally. I felt it was a great service as I'm quite disabled so the not having to go out was great as well as, I felt, safer. The fact you still spoke with your GP personally over the phone made it just great, and I also thought made a lot of sense.’
>
> ‘It's is physically difficult for me to get in and out of car (twice each) and walk a distance around doctors practice and chemist.’
>
> ‘Doctor very late. Comfortable at home warm and could do chores. Very boring frustrating in waiting room. Also it's a huge effort to go there due to disability mobility issues.’

Figure 2: Responses to question 'What did you like about having a GP appointment by video call/over the telephone?'



Not having to visit somewhere where other patients may be unwell was the top reported reason for why patients liked a telehealth appointment for both disabled and other patients (48.9 percent and 47.9 percent, respectively).

The second- and third-rated reasons for liking a telehealth appointment were the same for disabled and other patients; the appointment saved them time because they didn't need to travel (37.8 percent of disabled patients and 40.4 percent of other patients) and the appointment itself was faster (32.6 percent and 34.3 percent). There was no statistically significant difference between the proportions of disabled and other patients saying they liked their telehealth appointment for any of these top three reasons.

There was no pre-prescribed option to allow patients to report that they liked the ability to have the consultation remotely due to mobility issues, however a number of comments, like those above, indicated that telehealth could help patients who may otherwise find it difficult to access health care providers.

While many disabled patients liked having a telehealth appointment for various reasons, more disabled patients than other patients indicated they liked nothing about the telehealth appointment (14.7 percent compared with 10.9 percent). The diversity of the disabled community needs to be taken into consideration when implementing telehealth to improve access for this population group.

When asked what, if anything, they didn't like about their telehealth appointment, disabled patients were more likely to report having difficulty communicating with their GP.

> ‘I have to use hearing aids and I find it easier face-to-face as I must lip read a bit and have facial feedback that I have understood when responding to a question.’
>
> ‘I have Parkinson's and it's very hard to understand me when my meds are not working so a face-to-face appointment would have been better.’
>
> ‘I'm hard of hearing so it was awkward having to ask my GP to repeat himself.’

Disabled patients were more likely to report they didn’t like that they:

- couldn’t show their physical symptoms (37.4 percent versus 33.6 percent for non-disabled people)
- found it more difficult to explain themselves compared with when they had an in-person appointment (31.8 percent vs 25.0 percent)
- found it harder to hear or understand their GP than when they had an in-person appointment (12.9 percent (more than one in ten) vs 7.6 percent).

Disabled people were common adopters of virtual (phone or video) appointments during the lockdown period. The needs of disabled people are slightly different to those of other people, therefore it is vital that health providers understand what would improve access to general practices or health clinics for this population group, whether it be virtual appointments or something else.

The top five things disabled patients wanted to see their health clinics/GPs offer in the future were:

- same-day appointments for urgent problems (93.6 percent)
- having prescriptions faxed to their pharmacy (91.7 percent)
- accessing test results through a secure online portal (87.3 percent)
- ordering prescriptions online (81.3 percent)
- accessing notes through a secure online portal (78.7 percent).

Despite the higher take-up of virtual appointments, disabled people were no more likely to say that phone appointments should be offered in the future (73.2 percent compared with 72.7 percent of other people). They were also less likely to want to see video appointments continue beyond the pandemic (41.9 percent compared with 46.9 percent of other people).

The ability for disabled people to see their GP the same or next working day varies by district health board

We also explored how quickly people who were able to access their GP via all appointment types were seen. Around half (49.2 percent) of disabled people were able to be seen the same or next working day compared with 55.0 percent of other people. Although the difference between the two groups is not particularly large, given the higher health needs of the disabled population, it may mean there was unmet need for timely health care appointments.

If we compare district health boards (DHBs) with high proportions of disabled people with those with low, there are differences in how quickly patients in general are able to be seen. In the three DHBs with the lowest proportions of disabled people (Waitematā, Capital &

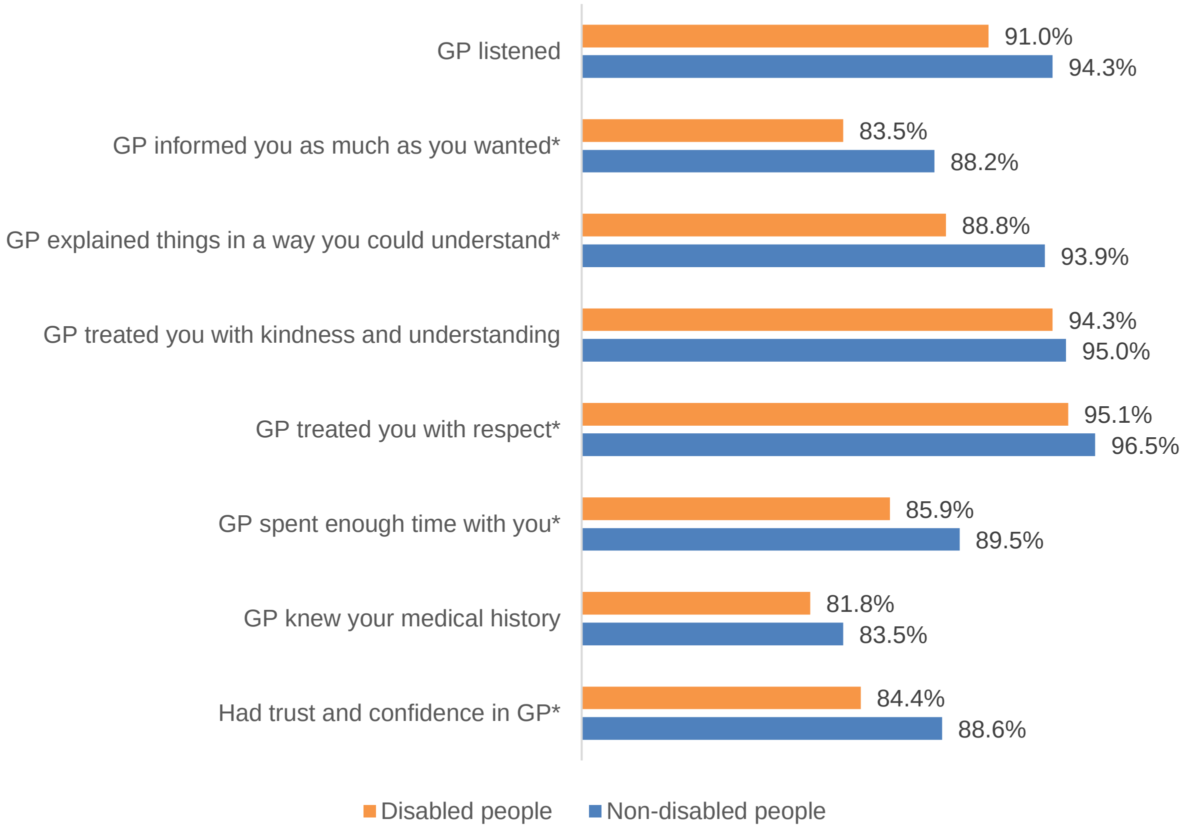
Coast and Auckland),[9] 55.2 percent of patients were able to be seen the same or next working day. This compares with just 34.4 percent of all patients in Whanganui, Northland and Tairāwhiti (the three DHBs with the highest proportion of disabled people).

Disabled patients, overall, reported having a poorer experience

Disabled patients were more likely to have a regular GP, and were more likely to have seen them during their latest visit. However, they reported a poorer experience across the majority of the experience types we asked about. In general, the number of disabled patients agreeing ‘Yes, definitely’ to each of the statements was high, however the difference between disabled people and non-disabled people highlights that the experience for disabled patients could have been improved.

The COVID-19 survey followed the experience of the patients who had a primary care appointment during or after the level 3 lockdown. Patients were asked questions about their experience with the GP they saw on their most recent visit.

Figure 3: Patient experience measures for disabled and other patients, percentage responding ‘Yes, definitely’



* Percentage of disabled people responding ‘Yes, definitely’ is significantly lower than the percentage of non-disabled people responding ‘Yes, definitely’.

There are some differences in the experiences of those with disabilities and those without during the period since level 3. Disabled people were less likely to feel that their GP informed them as much as they wanted about their condition, treatment or care; they were

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[9] Five DHBs had a proportion of the population with lower rates of disability than the overall survey population, however only Waitematā, Capital & Coast and Auckland were significantly lower.

also less likely to feel that the GP spent sufficient time with them and that the GP explained things to them in a way they could understand.

Disabled people were also less likely to say they had trust and confidence in their GP, compared with other people.

Disabled people reported, in general, having a poorer experience with their GP during their last appointment, despite being more likely to have a regular GP.

Disabled people were no more likely than non-disabled people to report their GP knew their medical history, however they were less likely to report that they had trust and confidence in their GP.

Disabled people were less likely to feel their GP involved them in decision-making about treatment and care compared with the non-disabled people surveyed. Involving patients in decisions about treatment and care is vital to provide safe and inclusive care, especially for a group more likely to have multiple long-term conditions.

Disabled people were also less likely to report their individual and/or cultural needs being met during their most recent appointment (89.5 percent compared with 93.2 percent of other people).[10] Some disabled people noted that they felt that their diverse needs were not taken into account. Some mentioned that GPs did not necessarily treat them holistically. Below are some comments reflecting how disabled patients felt their individual and/or cultural needs could have been better met.

> ‘I have recently arrived from Australia seven months returning due to the loss of three family members in 2019. I have not been asked any questions by the GP about my medical history on a personal level and in a way that I felt like a person and not just a client.’
>
> ‘Again, the pills are the only thing a doctor does, no consideration for more hands-on helpful information or referrals.’
>
> ‘By getting to know myself.’

Picking up prescriptions from the pharmacy became more difficult for disabled people

Ensuring patients can get the medication they need is a key part of appropriate health care access. In the COVID-19 survey we asked how patients had found getting medication from their GP and from the pharmacy compared with before the pandemic.

On the whole, it appears that, for most disabled patients (90.4 percent), getting prescriptions from their doctor was easier or ‘about the same’ as before, while getting medication from the pharmacy became significantly more challenging; just over two in every ten disabled patients (22.3 percent) reported getting medicine from the pharmacy was harder than before.

When asked why it was harder for them to obtain medicines since the COVID-19 pandemic compared with before, some disabled people noted the social distancing required at pharmacies and a reluctance to travel due to fears of catching COVID-19. However, the vast majority cited the availability of medicine in one-month supply, in contrast to the usual three-month supply.

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[10] This figure excludes people who said they did not have any individual or cultural needs.

> ‘Can only get one month at a time instead of three months – probably due to supply – but means exposing myself more to obtain what I require.’
>
> ‘I would normally only have to pick main medicines every three months now it is monthly.’

While we understand the need for medicines to be limited to one-month supplies, the impact this will have on disabled people, and other vulnerable populations more likely to find frequent visits to the pharmacy difficult, is concerning.

Conclusion | Kupu whakakapi

Disabled people are more likely to report that they found barriers to accessing care during the lockdown period. This may reflect more regular usage of health services, but is still a result that emphasises how in times of system stress, people with greater needs can be doubly disadvantaged.

While telehealth options flourished during this period, and some disabled people found they met their health care needs, for others this alternative did not meet these needs. Telehealth is not a ‘silver bullet’ for increasing access. Nevertheless accessing health care through a telehealth option worked well for a substantial proportion of disabled people due to the mobility issues they faced. For this group, the rapid switch to telehealth, and the ongoing willingness of the primary care sector to continue with the flexible approach used during the lockdown, may mean the reduction of some barriers to accessing care and an increase in comfortable access to care.

Despite being more likely to have a regular GP, during the lockdown disabled patients generally reported having a poorer experience with their GP. This is concerning given they are more likely to have multiple long-term conditions.

Next steps | Mahi mō mua

This is the first time the Commission has reported on the experiences of disabled people in the patient experience survey. It is unclear from the data whether the worse experiences were specific to the COVID-19 period or are part of more systemic and ongoing concerns. We shall replicate this analysis with post-COVID period data to answer this question.

In future analyses we also will investigate the experience of disabled people with different types of disability, acknowledging that disabled people have diverse needs.

Within the Commission’s patient experience survey programme we will:

- continue to investigate disabled people as a population subgroup
- ensure disabled people are consistently included within the populations of interest who experience inequities in access, use and experience of health care services
- continue to investigate those inequities as experienced by disabled people.

We encourage all health services and practices to consider how they can best partner with disabled people to design services that are more accessible and result in better experiences for disabled people.

Appendix: Question sets | Āpitihanga: Huinga pātai

Washington Group Short Set

The WGSS question set includes:

- Do you have difficulty seeing, even if wearing glasses?
- Do you have difficulty hearing, even if using a hearing aid?
- Do you have difficulty walking or climbing steps?
- Do you have difficulty remembering or concentrating?
- Do you have difficulty washing all over or dressing?
- Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Answer options: No – no difficulty, Yes – some difficulty, Yes – a lot of difficulty, Cannot do at all).

If respondents answer ‘Yes – a lot of difficulty’ or ‘Cannot do at all’ to one or more of these questions, they are classified as having a disability under the WGSS.

Self-identification

The self-identification question was: Do you think of yourself as disabled (or as having a disability)?

Answer options: Yes, No, Unsure.