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

Methodology for disability reporting – COVID-19 patient experience survey

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Contents

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This document is available on the Health Quality & Safety Commission's website:
www.hqsc.govt.nz

Document purpose

This document outlines the methodology used by the Health Quality & Safety Commission in analysing data relating to responses to the COVID-19 patient experience survey[1] from disabled people.

For more information: survey@hqsc.govt.nz.

Introduction

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

The Health Quality & Safety Commission sought to understand the experience of disabled people during the COVID-19 lockdown via the COVID-19 patient experience survey. The survey findings are intended to help health care providers provide disabled people with the care they need.

The *New Zealand Disability Strategy 2016–2026*[2] defines disabled people as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis.'

In the COVID-19 patient experience survey, respondents were asked two sets of questions to understand whether they were disabled: the Washington Group Short Set (WGSS) and a self-identification question.

The WGSS measures a respondent's ability to carry out six activities:

- seeing
- hearing
- walking or climbing steps
- remembering or concentrating
- washing all over and dressing
- communicating in a respondent's usual language.

Respondents to the survey were asked to rate whether they had no difficulty doing the activity, some difficulty, a lot of difficulty or they could not do it at all. Difficulty (or inability to do it at all) would 'in an unaccommodating environment [would] place an individual at risk of restricted social participation'. If a respondent indicated they could not do or would have a lot of difficulty doing one or more of the activities, they were classified as having a disability according to the WGSS. This may or may not differ from how the person identified.

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[1] The COVID-19 patient experience survey is an online survey of New Zealanders, designed to understand experiences of health care during the COVID-19 pandemic. It is part of the New Zealand patient experience survey programme, conducted by the Health Quality & Safety Commission with support from the Ministry of Health. URL: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/covid-19-patient-experience-survey.

[2] Office for Disability Issues. 2016. *New Zealand Disability Strategy 2016–2026*. Wellington: Office for Disability Issues. URL: www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf.

The WGSS has received some criticism because it does not necessarily identify all people with a disability; in particular it may exclude people with developmental disabilities.[3]

The self-identification question for disability in the survey was, ‘Do you think of yourself as disabled (or as having a disability)? Yes; No; Unsure. The inclusion of this question allowed us to capture a different measure of the disabled population, particularly given the potential deficits in the WGSS.

The WGSS and the self-identification question ask different things of respondents, so we would not necessarily anticipate that all those who qualified under the WGSS would self-identify, and vice versa.

What the data tells us

The survey was sent to adults aged 15 and over who were enrolled with a primary health organisation. In total, around 26,000 people responded. Of those, we have disability information for about 21,000 people, of which 19 percent either met the WGSS criteria or self-identified as disabled (see Table 1).

Two samples of patients were surveyed; those who had a contact with their GP in the first two weeks of Level 3 lockdown (28 April–11 May 2020), and those who were enrolled with a GP but did not have a contact.

The proportions of the population surveyed who were classified as disabled under the WGSS and who self-identified as disabled were relatively similar, but only about one-third of those who were identified under either criteria were captured in both (Table 1).

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[4]	6.4	1,351
Self-identified and included in WGSS criteria	5.5	1,166
Total identified as disabled using either criteria[5]	19.0	4,031
Neither self-identified nor included in WGSS criteria	81.0	17,238
Total[6]		**21,269**

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[3] Institute of Epidemiology & Health Care. 2019. Which one to use?: The Washington Group Questions or The Model Disability Survey. London: UCL. URL: www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-or-model-disability-survey-0.

[4] Those who do not self-identify as disabled include those who say they are not disabled, and those who are unsure.

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

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

The proportions in Table 1 are lower than those captured in some other surveys. The New Zealand Disability Survey (2013)[7] reported that 24 percent of respondents identified as disabled. It is likely that disabled people are under-represented in the COVID-19 survey responses, however, the intention of the survey, and subsequent analysis, was not to measure the size of the disabled population but to understand how their experience of health care during the COVID-19 lockdown period differed from that of the non-disabled population.

Reporting on disability status

To simplify reporting and comparison between disabled and non-disabled populations, we created a 'derived variable',[8] combining those identified as being disabled through either question. To confirm the suitability of this approach we consulted with subject-matter experts, including Stats NZ, the Human Rights Commission (HRC) and the Office for Disability Issues.

The HRC carried out a survey on attitudes of New Zealanders towards disabled people. While the results of this study are yet to be published, the HRC took a similar analytic approach in combining the two metrics, so that anyone who was classified under the WGSS or had self-identified as being disabled was classified as disabled. The HRC carried out analysis using this derived variable, and where there were differences between the WGSS-defined and self-identified populations, these were highlighted in the analysis.

The HRC's approach was developed in conjunction with a research advisory group comprising three disabled people, of whom two are researchers.

The Office for Disability Issues was comfortable with our proposed approach of combining the two groups (as HRC had done). It did highlight that, by combining the two question sets, we lose the ability to compare the results with other surveys. We are comfortable with this because we are not currently looking at comparative studies. If we wish to compare nationally or internationally in the future, the derived variable can be disaggregated.

We also approached Statistics NZ to discuss how we might proceed with the disability analysis. It cautioned us about combining the two questions because they measure different concepts of disability. Statistics NZ recommended the use of the WGSS because it is considered the most useful for policy purposes.

As a result of these conversations, we decided to assess the two groups, identifying where their characteristics and responses to questions in the survey differed or were similar, so we could understand whether combining the two groups was appropriate. It was our preference to respect those who identified as disabled but did not meet the narrow, functional definition of disability contained within the WGSS.

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[7] www.stats.govt.nz/information-releases/disability-survey-2013

[8] 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) WGSS or self-identification questions results in a result for the derived variable.

Differences and similarities – WGSS and self-identified disability

We assessed all responses to the experience questions for statistically significant[9] differences between the two groups; the discussion below focuses largely on those findings.

Demographics of the two groups

- More people were identified as being disabled via the WGSS than the self-identification question in the following age groups:
    - 15–24 years: 12.6 percent WGSS vs 5.5 percent self-identified
    - 25–34 years: 8.0 percent WGSS vs 5.9 percent self-identified
    - 75–84 years: 18.1 percent WGCC vs 16.4 percent self-identified.
- Slightly more people who self-identified as disabled had a long-term condition compared with those classified as disabled according to the WGSS (97.2 percent self-identified vs 94.1 percent WGSS).
- When responding to a question about COVID vulnerability, slightly more of those who self-identified as disabled said they were COVID vulnerable compared with the WGSS group (68.9 percent self-identified vs 64.9 percent WGSS).
- There were no significant differences in the proportion of respondents living in high deprivation areas between the two groups.

Tables 2–4 outline the proportion of each of the disability and non-disability populations by age group, ethnicity and gender.

Table 2: Proportion of COVID-19 patient experience survey responses, by age group and disability identification, 2020

Disability identification	**Age group (years) (%)**					
	15–24	**25–44**	**45–64**	**65–74**	**75–84**	**85+**
WGSS	12.6	7.6	10.9	11.7	18.1	35.7
Self-identified	5.5	6.6	11.6	11.0	16.4	33.2
Disabled derived variable	14.5	12.2	18.3	18.3	27.1	50.8
Not disabled	85.5	87.8	81.7	81.7	72.9	49.3

Table 3: Proportion of COVID-19 patient experience survey responses, by ethnicity and disability identification, 2020

Disability identification	**Ethnicity (%)**			
	Māori	**Pacific peoples**	**Asian**	**European/other**
WGSS	13.6	11.8	7.4	11.7
Self-identified	12.8	8.6	5.0	11.7
Disabled derived variable	21.8	18.0	10.4	18.5
Not disabled	78.2	82.0	89.6	81.5

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[9] Two-tailed test at 95 percent confidence interval was used, with the exception of comparing the two groups' demographics, where one- and two-tailed testing was used.

Table 4: Proportion of COVID-19 patient experience survey responses, by gender and disability identification, 2020

Disability identification	Gender (%)	
	Male	Female
WGSS	12.9	11.4
Self-identified	12.2	11.0
Disabled derived variable	20.1	18.0
Not disabled	79.9	82.0

Table 5 shows statistically significant differences in responses to questions in the COVID-19 patient experience survey by people classified as disabled according to the WGSS and who self-identified as disabled. The percentages for the non-disabled population are shown for comparison, along with an indication of whether those response rates are significantly different to those of the WGSS and/or self-identified population.

Table 5: Differences in responses to COVID-19 patient experience survey, by question and response option and disability identification, 2020

Question and response option (if applicable)	Disability identification (%)		
	WGSS	Self-identified	Non-disabled
Q2. Why did you not do what you would have usually done (accessed health care as they usually would have)? It was too expensive	6.4	4.2	2.0
Q5. Since New Zealand moved to alert level 3 (on Tuesday 28 April), how have you had an appointment with a GP from your GP/health clinic, for your own health? Phone appointment	57.7	61.4	53.5*
Q12. Was this appointment with your usual GP? Yes	80.1	85.2	78.9**SI
Q18. Were you confident that the GP knew enough about your medical history? Yes, definitely	79.5	82.8	83.5**WGSS
Q23. Did the GP involve you as much as you wanted to be in making decisions about your treatment and care? Yes, definitely	82.0	86.0	89.0*
Q26. Overall, do you feel the quality of the treatment and care you received was: Poor	2.3	1.3	0.8**WGSS
* Significant difference between both WGSS and self-identified populations and non-disabled population. **SI Significant difference between self-identified and non-disabled population. **WGSS Significant difference between WGSS and non-disabled population.			

Conclusion and approach

While there were some differences between the two WGSS and self-identified groups, there was no clear indication that we should analyse their results separately. In fact, there was close similarity across the vast majority of responses, which lends weight to the approach of analysing the two groups as one.

The similarity of the two groups, in regards to their demographics and responses to experience questions, indicates they had similar experiences of accessing health care. By combining the results of the two groups we can almost double the number of responses, which allows for more robust analysis.

In the reporting we will combine the two groups, unless there are differences between them (as outlined above), in which case we will analyse them separately. For one of the questions above (Q26. Overall quality of the treatment), only one response option showed a significant difference, and the absolute difference was small. We would not typically analyse the ‘poor’ response option by itself, so in this instance we will not analyse the two groups separately, however, we will note the difference.