



New Zealand patient experience survey programme refresh 2019/20

Contents

Document purpose	3
Background	3
Review of questionnaires	5
Stakeholder engagement	8
Literacy and English level analysis	9
Finalising the revised questionnaires	10
Patient review of questionnaire through cognitive pre-testing	10
Survey sampling and invitation methods	15

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Document purpose

This document describes the process the Health Quality & Safety Commission (the Commission) and its contracted provider, Ipsos, undertook in 2019/20 to review and refresh the New Zealand patient experience survey programme.

The purpose of the refresh was to check the surveys were working as well as possible and were meeting the needs of the sector.

The refresh included a review of both questionnaires, multiple rounds of stakeholder engagement and cognitive pre-testing in priority populations of both the questionnaires and the survey process.

Background

The Commission runs two national adult patient experience surveys: the adult inpatient experience survey (IPES) and the primary care patient experience survey (PCPES). Both surveys aim to improve the quality of health services in Aotearoa New Zealand by enabling patients to give feedback that can be used to monitor and improve the quality and safety of health services. The surveys provide consistent tools that can be used for national measures as well as local assessment and improvement.

The IPES has been running quarterly in all district health boards (DHBs) since 2014. A selection of adult patients (aged 15 years and over) who spend at least one night in hospital during each survey sample period are invited to take part.

The PCPES was first introduced in 2015 in a small number of pilot general practices, with gradual implementation beginning in 2016. The survey now runs in most general practices nationally every quarter. Adults aged 15 years and over who are enrolled with and seen by participating general practices are invited to take part.

In 2019, the Commission sought a request for proposals (RFP) from interested parties to undertake the ongoing quarterly data collection and reporting system services for the two surveys. The outcome of the RFP was a decision to move to a new survey provider, Ipsos. As part of the transition to the new provider, the Commission and Ipsos undertook a thorough review of the questionnaires and survey processes.

Framework for the refresh

The framework for the refresh process focused on improving survey participation by Māori and Pacific peoples. Specific activities were threaded through the process, including:

- cognitive pre-testing of the revised questions, with a focus on Māori and Pacific peoples
- testing the invitation wording
- testing the survey process (how patients are informed of the survey)
- reviewing and amending the sampling methodology
- translating the revised questionnaires into te reo Māori
- developing, testing and implementing a set of questions to measure patients' experience of culturally safe care.

The refresh included the following four elements.

1. Questionnaire review

This involved a scan of existing surveys, a literature review and a review of the questionnaire.

The survey scan explored other New Zealand and international surveys. This included checking the revised questions aligned with those in the New Zealand Health Survey where appropriate.

The literature review focused on updating knowledge since implementation of the existing surveys as opposed to a review that started from scratch.

The following considerations underpinned the questionnaire review process.

- Respondent burden: the questionnaire had to not place an onerous burden on those who completed it; it would be quick to complete and easy to answer the questions.
- Response rates: the questionnaire had to maximise the chance of people responding; questions were easy and safe for respondents to answer and there was a benefit for them in answering.
- Picker questions:¹ the IPES previously used the Picker question set, incurring a subscription cost that increased annually. We evaluated the benefit of this investment to decide whether it was still the best approach, and decided it was not.
- Stakeholder needs: we asked for feedback from stakeholders to find out if the surveys best meet their needs.
- Ability to drive change/improvements: the questionnaire results had to generate 'actionable' information for providers so they can make improvements based on patient experience.
- Consistency between surveys: the review aimed to result in the two surveys being more closely aligned where suitable and beneficial.
- The review considered the impact of the COVID-19 pandemic and resulting changes to health care delivery.
- The revised questionnaire would undergo a literacy and English level analysis.
- We would incorporate best practice (learnings from survey scans and literature reviews).
- 2. Stakeholder engagement

We conducted workshops around each survey to better understand stakeholders' needs and their use of and concerns about the existing questionnaires. We also gathered feedback from a broader stakeholder group through supplementary forms. All feedback fed into the questionnaire review.

This process helped to identify new question topics and areas to future-proof against changes in the health care system.

3. Cognitive pre-testing of revised questionnaires

We conducted cognitive interviews to assess how patients understood and interpreted the questions and instructions. As part of the goal to improve participation and explore ways to

¹ The Picker Institute has developed and refined the principles of patient-centred care and the patient experience since the mid-1990s. The Picker Institute Principles of Patient-Centred Care ('Picker Principles') are used widely to develop measures of patient experience.

improve response rates, we deliberately focused testing on Māori and Pacific peoples, as well as youth and those in rural areas.

4. Review of the survey sample method

We reviewed the sampling methodology for both surveys and, along with the patient experience of care governance group, decided to over-sample Māori and Pacific peoples deliberately.

Implementing the revised questionnaires

The refresh work started before the COVID-19 pandemic in 2020 while we were transitioning the survey programme to Ipsos.

We had a pause in the quarterly programme in February 2020 as we moved to the new provider. Then, due to the uncertainty of COVID-19 and its impact on health services, we were also unable to run the May 2020 survey. Quarterly surveying started again in August 2020 with the revised questionnaires.

We analysed the survey responses after the August survey to confirm the questions performed as expected. This included checking for unusual responses and reading through respondents' feedback to see if they were raising any issues.

Both questionnaires were then translated into te reo Māori and respondents to the November 2020 survey round were able to respond using these options if they wished.

Comparing historic data

We recommend caution when comparing results from surveys that use the refreshed approach and the previous versions of the surveys, which ran up to the end of 2019. There are a number of reasons for this.

- For the IPES, the move away from the Picker question set meant a complete break in the time series (see below for more detail).
- In the previous version of the PCPES, patients were asked about their experience over the last 12 months, whereas in the refreshed survey they were asked about their most recent experience.
- The effect of COVID-19 on the health system (lockdown, and both people's responses and actual population health) meant there were disruptions to services during 2020, some of which continue.
- A new survey tool was adopted (a result of using a different provider).
- The change in sampling method, with its focus on increasing response rates, means a possible change in the results.

Review of questionnaires

Introduction and objectives

We took a pragmatic rather than academic approach when reviewing current best practice in patient experience surveys. This involved a survey scan and a literature review. The survey scan drew on international experience and also explored other New Zealand and international surveys. The literature review focused on updating knowledge since implementation of the existing survey rather a review that started from scratch.

We conducted workshops around each survey to better understand stakeholders' needs and use of and concerns about the existing questionnaire. We also gathered feedback from a broader stakeholder group through supplementary forms. All feedback fed into the review of the questionnaires.

The responses to the existing surveys were analysed; we looked specifically for comments from respondents, high levels of missing data or 'do not know' responses, and current results (eg, differentiation in the data). This included:

- desktop review, to identify questions that may not meet best-practice design principles or fit the information needs of the survey
- item non-response analysis, to identify any questions that respondents appeared to have greater difficulty answering or were less likely to answer
- item response analysis, to identify any questions that may be subject to ceiling effects (there being little to gain from questions that are almost always answered positively) or show little variation between groups or over time
- qualitative analysis of open-ended responses, to look for respondent feedback on survey questions and examples of question misinterpretation
- consideration of findings from previous Commission reviews (pilot study, cognitive interviews conducted in 2015 and the Sapere evaluation of the PCPES tool²)
- consideration of sector feedback we have received since the survey began.

The IPES questionnaire review followed on from an earlier review of the proprietary questionnaire used from 2014 to 2019. That review sought to answer two questions:

- 1. Is the Picker question set still the best approach?
- 2. If not, which option/s should be adopted?

The result of the review was a recommendation to move to a non-proprietary survey combining two to three validated international questionnaires. This would allow for greater flexibility and customisation, and potential benchmarking with Australia in the future.

Key actions

The questionnaire review process identified a set of improvements to the existing question sets, described below. All these changes were implemented as part of the refresh.

1. Adopt a core question set

Adopting a core question set to align more closely the IPES and PCPES questionnaires would help to focus on aspects of the experience that are common to all patient types and would be used in both questionnaires alongside questions specific to the experience (eg, primary care or inpatient). This approach would also provide a core set of questions to use across any new questionnaires, should the survey tool be expanded beyond primary care and inpatient experience.

2. Replace the cultural support question with a set of cultural safety measures

The existing cultural support question was identified as being difficult to interpret and use. It was agreed that a separate part of the questionnaire review process would involve

² See: <u>www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3283</u>.

developing, testing and implementing a set of questions that measure patients' experience of culturally safe care.

3. Review the modules

For the IPES, this included replacing the topic approach to the survey (eg, surgery, communication) to one that follows the patient journey. This would align more closely with the way a patient naturally assesses an experience, and with best practice as reflected in the literature review and survey scan.

For the PCPES, there were several areas where better definition of which experience to include would improve responses. For example, in the medication section, it was not clear what constituted a regular medication and the inclusion of non-prescribed vitamins made subsequent questions more difficult to answer.

In the PCPES the 'other health care professionals' and 'specialist' sections were removed because it was not possible to determine which providers the answers related to. This inability to assign results and lack of a mechanism to either identify the provider or provide them with the feedback meant responses could not be used for quality improvement purposes.

4. Overall domain scores

The use of domain scores was discussed. Two key issues were: i) these have been stable over time and it has been difficult to see any improvement on them quarter by quarter; and ii) the score itself does not necessarily highlight where improvement is needed. This was particularly the case when the domain score was a composite of many questions.

We agreed the concept of domains remained a useful lens through which to review the results and domains should continue in some form. However, domain scores would no longer be a key focus of reporting.

5. Open-ended question approach

We agreed to add to both surveys two constant, open-ended (free text) questions near the end of the questionnaire to ask: i) what could have been improved; and ii) what went well. The benefit of this approach was that specific information for improvement (what went wrong) and aspects that are working well would be automatically classified for data users.

A third floating question was suggested for future consideration. This could be used to understand one closed question in more detail. The question selected might be an area of focus for providers or an aspect that requires more detail to understand how it could be improved.

6. Questionnaire feedback

We agreed to add an open-ended question at the end of every survey to seek feedback from respondents on the questionnaire itself. This provides important information on their survey experience such as questions they struggled to answer, survey length and any technical difficulties. Note that respondents can access an 0800 helpdesk, which is likely to address technical issues such as logging into and completing the survey. The questionnaire feedback will not be reported on but will be monitored closely by Ipsos and shared with the Commission.

7. Continuous questionnaire improvement

An annual review of the questionnaires to ensure they remain fit for purpose was recommended.

8. Align with Stats NZ demographic questions

In the update, we needed to ensure questions on gender and ethnicity aligned with wording from updated Stats NZ statistical standards. Sexual orientation would be aligned once the new statistical standards are released.

9. Readability and accessibility

We agreed to apply a test against an academic word list to ensure the questionnaires are appropriate for people with low levels of literacy.

The questionnaire software tool will use best practice in accessibility for those with vision and mobility difficulties. This will align with the Commission's commitment to working towards meeting the Accessibility Charter.

10. Other changes

- In the PCPES, we agreed to change the timeframe from experience in the last 12 months to experience in the most recent visit. Asking about experience in last 12 months can lead to difficulties when experiences have varied greatly; respondents have changed practices within that time; or respondents do not have one GP or nurse they usually see. This approach would be more consistent with the question wording and response options, which tend to frame a single experience. This change would also allow the addition of a question to differentiate which type of health care professional the most recent visit was with (eg, usual doctor, other doctor, nurse, mental health professional) and to not combine GP and nurse in the one question.
- The questions were updated to allow for changes since the survey was developed in 2015. For example, COVID-19 led to a large increase in the use of video and phone consultations; these were added as an appointment option. Questions to gauge awareness and use of patient portals were also added.
- Populations of interest questions to identify different population groups were added. These included disability status (added August 2019) and sexual orientation.

Stakeholder engagement

We engaged with stakeholders at multiple points in the review process. The stakeholder workshops described above were attended by more than 75 stakeholders from DHBs, primary health organisations (PHOs), general practice, the Ministry of Health, Stats NZ and others. Additional feedback was collected via a supplementary feedback form or was shared directly.

We held a second set of workshops to gather more feedback on the revised questionnaires and clarify specific question areas where more consultation was needed.

Literacy and English level analysis

The surveys were developed with the aim of reaching a wide audience with varying levels of English literacy. We undertook a vocabulary and readability review in comparison with English proficiency evaluation standards.

Readability

A variety of tested reading-level formulas were used to understand whether respondents would have difficulty reading the surveys. Each method measured different criteria based on vocabulary, sentence length and complexity. The results of these tests showed the surveys are around Year 9 reading level (see Tables 1 and 2).

Statistics	PCPES	IPES
Number of sentences	966	354
Words per sentence	5.3	5.8
Characters per word	4.7	4.6
Percentage of difficult words (estimated)	15%	15%

Table 1: Summary statistics of survey texts

Table 2: Reading level tests, summary scores

Reading-level tests	PCPES	IPES
Flesch reading ease score (plain text = 60+)	72.1	70.5
Gunning Fog scale (5 = readable, 10 = hard, 15 = difficult, 20 = very difficult)	8.2	8.1
Flesch–Kincaid grade level (average student in which year/grade)	4.5	4.9
SMOG (Simple Measure of Gobbledygook) grade (# years of education)	8.3	8.4
Dale–Chall score ($4 = 4^{th}$ grade, $9+$ = college)	8.1	7.3
Fry readability grade level (average syllables/average sentences)	3	4

Vocabulary

The complexity of vocabulary used within the surveys was also reviewed using a core vocabulary list of approximately 2,800 words that represents the most important words for learners. The New General Service List (NGSL) can be used to categorise the percentage of words in a text that fit within this list. An ideal target is for 95 percent of vocabulary to be on the general list.

Table 3 shows that both surveys met the 95 percent criteria and, importantly, the 95 percent goal was achieved in the first 1,000 words, meaning the text is fairly basic.

Word lists percentages ³	PCPES	IPES
NGSL – first 1,000 words	92%	91%
NGSL – second 1,000 words	4%	4%
NGSL – next general word lists	0.7%	1%
NAWL (new academic word list) – academic words	0.8%	0.8%
Off-list words	3%	3%

Table 3: Percentage of survey text in vocabulary lists

Sentence structure and syntax

The sentence structure was also reviewed to simplify complex sentences.

Finalising the revised questionnaires

Once we had finalised the revised questionnaires, we shared them with stakeholders to get their feedback. They were also compared with ongoing Ministry of Health and other initiatives such as Cornerstone and Healthcare Homes to check that necessary patient experience measures were still included.

Patient review of questionnaire through cognitive pre-testing

The revised questionnaires underwent full cognitive pre-testing to assess how patients understood and interpreted the questions and instructions. The aim was to find out from patients if:

- the survey instructions and questions were easy to understand
- the questions were relevant
- the surveys enabled them to talk about what they thought was important
- any important questions were missing
- there were any completion barriers or triggers this information would help us to look at ways to improve response rates.

As part of the goal to improve participation and explore ways to increase response rates, we took a deliberate approach to focusing testing in Māori and Pacific peoples, youth and rural.

There were 19 interviews conducted between 4 March and 20 March 2020 in Hawke's Bay and the Auckland region.

³ Lexetutor – Corpus Vocabulary Tool – see: <u>www.lextutor.ca/cgi-bin/vp/comp/output.pl</u>.

Approach to interviews

Interviews were carried out at locations suitable to the respondent, eg, their home, office or a location provided by Ipsos. Respondents received a koha in recognition for their time.

We took a 'thought-aloud' approach⁴ to question review with participants as they completed the questionnaire. Areas of interest were discussed further after an initial unaided response to the questionnaire. This was followed by a discussion of communication and invitation options, and strategies for better engaging with various communities represented by the participants.

Participants

Participants were recruited from lists provided by DHBs and practices in Auckland and Hawke's Bay to take part in 1.5-hour interviews with an Ipsos interviewer. They were asked by their DHBs or practices to take part in an interview with Ipsos. Participation was voluntary, and patients were informed that Ipsos would be carrying out the interviews before their details were shared with Ipsos for scheduling interviews. The process of recruiting and conducting the interviews followed Ipsos' standard processes to ensure respondent privacy and protection under the Research Association New Zealand Code of Practice. Interested participants were offered a secure neutral location to conduct the interview or to choose a location based on their own comfort level.

In addition, Māori and Pacific advisors from Pegasus PHO, Counties Manakau DHB, Waitematā DHB, Hawke's Bay Consumer Council, Hawke's Bay DHB, Whanganui DHB, Taranaki DHB and Auckland DHB were invited to provide feedback on the questionnaires.

Below is the breakdown of participants in the cognitive testing interviews (Table 4). The rising threat of COVID-19 did impact stakeholders' ability to take part and meant there were a few missed targets, especially among Pacific peoples in primary care and rural patients. In addition, two of the final primary care interviews were postponed to a later date.

⁴ In a 'thought-aloud' approach, participants are asked to say in words what they are thinking about when they are reading and answering questions. For example, this could mean explaining different examples they are drawing on, how they are counting things, whether they are struggling to recall time periods or feeling uncomfortable about answering a question.

Group	Target	Participants	
		PCPES	IPES
Total interviews completed		8	11
Hard targets: ⁵			
Māori	4	7	7
Pacific peoples	4	1	5
Asian	1	1	1
Other	1	2	1
Youth (15–24)	3	1	4
Rural	2	-	1
Hawke's Bay	5	8	5
Auckland (with a focus on South Auckland)	5	-	6
Soft targets:		·	
English as a second/foreign language	2	1	2
(PCPES only) In past 12 months:			
has been prescribed medication	2	2	-
has got a test or x-ray	2	2	-
has visited emergency department	2	1	-
has stayed overnight in a hospital	2	1	-
(PCPES only) Currently has a long-term condition	2	5	-
(IPES only) Had an operation or procedure	2	-	8

Table 4: Summary of participants included in cognitive testing interviews

Results

Most participants were from Māori or Pacific communities. Overall, the questionnaires were well received by patients who took part in the cognitive pre-testing. Most participants felt that the questionnaires asked about all relevant aspects of their hospital or primary health care experience.

Improving response rates and encouraging participation

Participants made suggestions about how best to reach them and members of their community.

- Add a personalised connection on the survey invitation:
 - Have the invitation come from the doctors and nurses with whom patients have already built trust.
 - In primary care, have the doctor note the upcoming invitation during survey week.
 - \circ Have a print version available, particularly for older participants.

⁵ Total ethnicity was used for this measure; if a participant had multiple ethnicities these were all recorded.

- Have pop-ups on popular health-related websites and in social media as an invitation to take part.
- Use invitation messaging that was generic but inclusive (using hello/kia ora/talofa lava).
- Provide free data to complete the survey.
- Have incentives to take part, such as small cash rewards, discounts at the chemist, entering a draw for a bigger prize and entrance to a community event.
- Several participants noted they would like a face-to-face approach where they could ask for clarification and which was more personalised; this was particularly the case for older people. One suggestion was for community leaders, social workers or someone they know and trust to complete the questionnaire with them. Ipsos has provided an 0800 number to provide support for people completing the survey.
- Survey length was discussed. The ability to answer a shorter version was suggested as an option, while for others the length and depth of questions worked well. One participant suggested offering a five-minute version that then allowed respondents to continue to more questions if they wished.
- The language of the survey was discussed with each participant. While most were happy to complete it in English, they noted others in their community might prefer a translated version (especially older groups). One Asian participant who spoke English as a second language noted that email and online response options were easier for people with a lack of confidence in oral English to complete.

Communications - the email and text invitation

Participants in the review were given the email and text invitations and asked to give feedback.

Features participants liked in the email were:

- including their local DHB or practice logo this was important to build trust with the legitimacy of the invitation
- for inpatient participants, since the invitation was coming from the DHB there was more urgency to read it carefully and respond.

Aspects of the email invitation to consider improving were:

- ensure the invitation is not too long or wordy
- add information on how the results would be used. Participants valued assurance that results are used to improve services.

The content of the email invitation was considered helpful, even though not all participants read it all but might just confirm the purpose and then click on the link.

With the text message, some participants were concerned about identifying the source and verifying the legitimacy of the sender. Timing the text to directly follow the email invite and referencing further information would add credibility.

Older participants were less likely to be using email and text messages actively for communication.

Scale and response options

Different respondents had preferences for different scales. The most popular was a fourpoint scale ranging from completely to not at all, however since there was nothing in pretesting that indicated respondents struggled with the response options given to them in the three-point scale, the latter was retained.

Participants identified improvements to the visual presentation of the response options for both surveys to make them easier to view.

Resulting changes

Following the initial interviews, the following changes were made to the IPES questionnaire.

- Procedure was changed to operation or surgery. (For example, 'During your visit in hospital, did you have a procedure?' was changed to 'During your visit in hospital, did you have an operation or surgery?')
- The family/whānau 'helping' question was removed to focus on family/whānau inclusion in discussions. ('Did hospital staff talk with you about whether you would have the help you needed when you left the hospital?' was changed to 'Did hospital staff include your family/whānau or someone close to you in discussions about planning for your care after your stay?')
- The religious or spiritual support question was removed. ('Were you able to get religious or spiritual support if you wanted it?')
- The body tissue question was removed pending cultural safety review. ('Were you able to decide what you wanted to do with any body tissue (organs, blood, hair etc...) that was removed, if any?')
- The staff 'communicating with each other' question was replaced with a 'conflicting information' question. ('As far as you could tell, did the staff involved in your care communicate with each other about your treatment?' was replaced with 'Were you given conflicting information by different doctors or staff involved in your care, eg, one would tell you one thing and then another would tell you something different?')
- The introduction to the 'overall evaluation' question was revised. ('The next questions are about your overall view of your latest hospital visit. Please think about all the aspects of your visit including those we have covered in the questions above and any other aspects that are important to you.')

Changes to the PCPES included the following.

- The introduction was updated to remind respondents to reflect on doctors and nurses at a specific practice.
- The introduction to the 'overall evaluation' question was revised. ('The next questions are about your overall view of your latest experience with your GP/nurse clinic. Please think about all the aspects of experience stay including those we have covered in the questions above and any other aspects that are important to you.')
- The wording for the access barriers question was revised. (The question 'In the last 12 months, was there a time when you had a medical problem but did not visit a GP or nurse because of cost?' was removed and different cost barriers (appointment too expensive; owed money to the general practice or medical centre) were added to the list of reasons why someone did not attend in the last 12 months.)

- 'Don't know' was removed from the wrong medicine being provided question. ('In the last 12 months, have you been given the wrong medicine or wrong dose by someone from [PRACTICE NAME] or a pharmacist (outside of hospital)?' Answer options yes/no.)
- Family/whānau involvement was removed in the long-term condition planning question.
 ('In the last 12 months has your doctor(s) or specialist(s) included your family/whānau or someone close to you in discussions about your care or treatment for your condition(s)?')

Future suggestions to consider

In the IPES, patients are asked the respect, kindness and understanding, and trust questions about their doctors, nurses and other members of their health care team. Asking three questions per aspect of care may be burdensome. To shorten the survey, it may be worth asking once each about respect, kindness and understanding, and trust, then clarifying which health care team member role it applies if the answer is a 'no'. Most participants had consistent answers across each of these questions and were happy to respond to each of them.

Survey sampling and invitation methods

Improving participation by Māori and Pacific patients

The Commission ran a COVID-19-specific patient experience survey in partnership with interested PHOs in June 2020. To improve participation by Māori and Pacific patients in that survey we:

- tested the content and style of the survey invitation with Māori and Pacific patients as part of the national survey review and applied those learnings to the COVID-19 survey
- tested different invitation modes to see which increased response rates most (eg, pair email invite with SMS reminder, offer SMS to those with no email contact)
- amended the sample to over-sample Māori and Pacific patients deliberately.

The impact of amending the sample framework meant that, while in November 2019 Māori received 10 percent of the survey invitations, in the COVID-19 survey, 27 percent of invitations were sent to Māori.

PCPES

The approach to the PCPES is to get as many responses as possible among all eligible contactable patients. Applying the findings from the COVID-19 survey, the sampling method has been changed to oversample Māori and Pacific patients deliberately.

IPES

Each DHB is responsible for extracting patient data that forms the survey sample. Up to the end of 2019, invitations were sent to a random sample of 400 patients per DHB. As part of the survey refresh, the limit on the number of invitations sent each quarter per DHB was removed.

DHBs were also encouraged to ensure the patient sample provided contains a representative sample of Māori and Pacific peoples. We recommend DHBs monitor the percentage of invitations sent each quarter by ethnicity and take proactive steps to improve the collection of patient contact details.

Survey invitation method – improving participation

A further learning from the COVID-19 survey was that pairing an email and a text invitation improves response rates in Māori and Pacific peoples.

This approach was tested in the PCPES in November 2020 and resulted in a response rate for Māori and Pacific peoples that was comparable with non-Māori, non-Pacific. For the IPES, DHBs are encouraged to include both email and cellphone details for the Māori and Pacific patients in their sample.

The paired approach will continue to be used.