



Ngā Poutama survey for consumers of mental health and addiction services, their families and whānau

Privacy impact assessment

August 2019

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Terminology notes

The term ‘consumer’ means people using mental health and addiction services. Other terms used by the health and disability sector include tāngata whaiora, patients, service users and clients. ‘Patient’ is also used specifically when referring to patient management systems.

1. Introduction

Purpose of the Ngā Poutama consumer, family and whānau survey

The Ngā Poutama survey is about enabling consumers, families and whānau to give their views and experience of mental health and addiction services in New Zealand. The survey results will be used to monitor and improve the quality and safety of services.

Growing evidence indicates that better experience, developing partnerships with consumers, and consumer and whānau-centred care are linked to improved health, clinical, financial, service and satisfaction outcomes.^{1,2}

The Health Quality & Safety Commission's (the Commission's) mental health and addiction quality improvement programme was established to improve the quality and safety of mental health and addiction services in New Zealand. Capturing, understanding and acting on consumer and whānau experiences is vital to quality improvement.

The Ngā Poutama consumer, family and whānau survey also complements the Ngā Poutama staff survey findings. Conducted in August 2018, this survey captured staff attitudes, beliefs and values of the quality and safety culture in mental health and addiction services. A subset of the questions (eg, whether staff agreed that their service treated consumers, families and whānau with respect) was also asked in the consumer, family and whānau survey to compare both perspectives.

The Ngā Poutama consumer, family and whānau survey monitors improvements in the mental health and addiction services. The 2019 survey will be used as a baseline and will be repeated in approximately two years' time.

Purpose of this report

This report addresses the impact that the Ngā Poutama survey and its reporting may have on individual privacy. It identifies potential risks in breaches of privacy and outlines how the risks are managed. It also describes the due diligence that has been carried out to assess and minimise potential areas of risk, along with compliance with privacy principles.

Currently all district health boards (DHBs), the Commission and the survey provider Mobius Research and Strategy Ltd (Mobius) have processes in place to ensure the privacy of personal information.

¹ Balik B, Conway J, Zipperer L, et al. 2011. *Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care*. IHI Innovation Series white paper. Cambridge, Massachusetts: Institute for Healthcare Improvement. URL: www.IHI.org (accessed April 2019).

²Agency for Healthcare Research and Quality. 2018. *Section 2: Why Improve Patient Experience?*. URL: <https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/2-why-improve/index.html> (accessed April 2019).

2. The Ngā Poutama consumer, family and whānau survey

Developing the survey

The survey was developed by the mental health and addiction quality improvement programme team, with input from its consumer advisory group, Māori advisory group and DHB working group. The mental health and addiction quality improvement programme is overseen by a leadership group, in communication with a stakeholder group. Both groups comprise a diverse range of leaders from the mental health and addiction sector.

Further information about the mental health and addiction quality improvement programme is available on the Commission's website at www.hqsc.govt.nz/our-programmes/mental-health-and-addiction-quality-improvement/programme.

The survey was developed using the following work streams.

- Establish the survey framework taking a co-designed, co-produced approach: defining what experience measures matter to consumers, families and whānau.
- Translate the survey framework into survey questions with robust cognitive testing to ensure the questions are simple and measure the intended concept.
- Establish the methodology to invite consumers, families and whānau to participate in the survey, with input from DHB representatives.
- Conduct the survey fieldwork.
- Analysis and reporting of results. Engage with DHBs and consumer groups on using the results to inform quality improvement initiatives.

Using personal information

The Privacy Commission defines 'personal information' as any information that can identify a living human being. The information does not have to be particularly sensitive or negative.

For the Ngā Poutama survey, 'personal information' means:

- participants' name and contact details, for example, postal address or email used to send invitations to participate in the survey
- the anonymous survey responses that includes some personal information (eg, demographic information)
- diagnoses, care details, treatment, experiences and so on that don't have identifying details but are specific enough that they can identify a person.

There are two processes to invite participants to do the survey: one for consumers and one for families and whānau.

Consumers

Each DHB extracts consumers' contact details from its patient management system. These are consumers discharged from inpatient or community-based mental health and addiction service within the survey's reference period. Consumers aged under 16 years are excluded, along with consumers who the DHB has lost to follow up.

The contact details are sent securely via SFTP to the national survey provider, Mobius. The contact details are then used to invite consumers to participate in the survey. The contact details are not used for any other purpose.

The survey is voluntary and all responses are anonymous. There is no link between the contact details held by Mobius and survey responses, which means the survey responses cannot be linked to identify an individual. Once the survey finishes, Mobius deletes all contact information from its database.

There will also be promotional material about the survey. It is given out through networks and other channels. This process does not use personal information.

Families and whānau

The process for family and whānau differs to that to invite consumers to participate in the survey. There is no appropriate list of family and whānau contacts. Instead the survey is promoted through networks and where consumers pass on the survey to their family and whānau member. There are no collected or retained contact details for family and whānau.

For both consumers and families and whānau who choose to participate in the survey, the survey response includes experience responses, along with demographic information (eg, sex, ethnicity) and mental health and addiction service use (eg, name of DHB, type of service). No name, date of birth, address or any other contact details are collected in the survey response.

Survey responses are reported in aggregate form for quality improvement purposes. Responses are not be published in a way that could reasonably be expected to identify an individual.

The diagram on the following page shows the survey process.

Survey process



Information flows

The following steps outline the information flows.

Step 1: DHBs send consumers' contact details to Mobius

DHBs extract consumers' contact details from their patient management systems, including name, email address (if available), phone number (if available), postal address, ethnicity, whether an inpatient or using community services, date of discharge and DHB name.

The data is password protected and securely sent to Mobius. DHBs connect via a secure file transfer protocol (SFTP).

Mobius receives the password by text or phone. DHBs upload the data as a csv file.

Mobius converts the data to an appropriate format and stores it on their secure system. The csv file is then deleted.

Step 2: Invitations are sent to consumers

Consumers receive an invitation to participate in the survey via email, text or post. They complete the survey online or fill in a hard copy (which is then input online).

Invitations that are emailed are sent from Mobius with the Health Quality & Safety Commission logo and contact information for Mobius.

Text invitations are sent from a text distribution platform.

Step 3: Postal invitations

In cases of a consumer having no email or mobile phone number, a consumer may be posted a survey invitation. To post the survey invitations, Mobius will share consumer postal addresses onto an approved mailing house.

Step 4: Delete contact details

Consumers' contact details are only retained in Mobius' system for as long as needed to send out survey invitation and reminders. When the survey finishes, all contact details are deleted. Mobius' laptop drive is reformatted at the end of the project. No data is backed up or kept on a cloud-based server.

Step 5: Data clean and analysis

The survey responses are analysed to check for any duplication, inconsistencies and omissions. The final anonymous survey data set is then shared with the Commission via a password-protected file. The password is sent separately by text or phone.

Step 6: Redacting qualitative information

The survey includes mainly closed-ended questions (eg, experience measures rated on a Likert scale of strongly agree through to strongly disagree). This data is anonymous.

There are two additional open-ended questions where consumers, families and whānau can write in comment boxes. There are reminders to not include any details that would identify them (eg, names) in the comment boxes. The Commission reviews every open-ended question to ensure no identifiable details are included. If so, they are redacted (removed).

Step 7: Reporting results

The Commission reports the closed-ended survey results in aggregate form, not individual details. The results are published on the Commission website and shared with DHBs and consumer, family and whānau groups.

Redacted responses to the open-ended questions will be shared with DHBs. This is only the redacted open-ended response and no other detailed survey data (eg, demographic details) is shared with DHBs to maintain the anonymity of the responses. This qualitative information will be of particular interest to DHBs to hear about experiences in consumers, family and whānau 'own words'.

3. Privacy impact analysis

This privacy impact analysis outlines how personal information is managed for the Ngā Poutama consumer, family and whānau survey. The Commission, Mobius and DHBs all take privacy seriously.

There are two parts to the collection of personal information.

1. Using personal information to invite consumers to participate (contact details).
2. Collecting anonymous personal information (survey responses).

Both apply to consumers, but only the second part applies to family and whānau. This is because, as noted in the previous section, contact details aren't used for family and whānau.

Principle 1: Purpose for collection of personal information

Using personal information to invite consumers to participate in the survey

Personal information is used for the purpose of monitoring quality of services.

Mobius uses personal contact details provided by DHBs. Personal contact details are only be used to contact consumers to invite them to participate in the survey and there is no link, at any time, between contact details and survey responses.

Collecting anonymous personal information in survey responses

Identifiable personal information, for example, name, date of birth or address is not collected in the survey responses. There is simply no need for this information.

Survey responses are anonymous. Other personal information collected in the survey include responses to using mental health and addiction services, type of mental health and addiction service used and demographics. This personal information is reported in aggregate form for quality improvement purposes. It is not published in a form that could reasonably be expected to identify the individual.

Principle 2: Source of personal information

DHBs collect contact details directly from the consumer, or the consumer's representative, when they are admitted and they record that information in their patient management system.

This record is to meet legal requirements of the health professional to describe and support the management of the consumer's health care.

DHBs tell consumers how the information they provide is used. DHBs will already have a statement in their registration/admission form that is similar to this:

GENERAL PRIVACY STATEMENT

We collect your health information to provide you with appropriate care, to plan for and fund health services, to carry out teaching and to monitor quality. We share this information with other health care providers and agencies involved in your care. We treat your information as confidential and ensure that it is kept secure and only accessed by authorised persons. You have a right to request access to your records and to request correction of the information. Information may be supplied to family, support people or other agencies if you give us your permission or disclosure is authorised by law.

This statement covers the collection of the consumer's contact details to use for surveys that monitor quality.

For the small number of DHBs that do not use a general privacy statement within mental health and addiction services, the Health Information Privacy Code (HIPC) is overarching. The HIPC specifies disclosure of personal information to a third party for purposes like this survey are one of the permitted exceptions under Rule 11 of the HIPC, under clauses 2(h) and 2(c).

The Ngā Poutama survey does not change the current purpose of collecting health information, or the way health information is collected, recorded or used in the patient management system by health professionals.

To mitigate the risk that consumers may not be aware that their contact details may be shared to third parties, there are additional measures taken.

- Advertising and reminders before and during the survey period (eg, additional posters, flyers and reminders from health professionals) with information about using consumer personal information for monitoring quality.
- Reminding consumers they can opt-out from sharing their personal information (where this is possible, to implement in patient management systems).

Principle 3: Collection of information from subject

Consumers' contact details are collected from the individual and kept in DHBs' patient management systems. Consumers are given a privacy statement that outlines how their health information is collected, stored and used (see Principle 2 for a generic example). This information is readily available at all DHBs.

The steps outlined in Principle 2 also apply where consumers can opt-out from sharing their contact details (where this is possible to implement in DHB patient management systems).

Completing the survey is entirely voluntary. The survey clearly outlines that the survey is voluntary and that choosing to not participate does not have any negative impact on a consumer's mental health and addiction treatment. The survey also outlines why the survey is being conducted and how the results are used.

Principle 4: Manner of collection of personal information

DHBs collect health information in a lawful manner with consideration of consumers. All DHBs have processes in place for collecting health information from a clinical and business perspective.

The survey is conducted with strong ethical principles. Participating in the survey is voluntary with participants giving informed consent for using the data for the outlined purposes. Only consumers, families and whānau aged 16 years or over are invited to participate in the survey.

Principle 5: Storage and security of personal information

DHB storage and security of personal information

Health information in DHBs is either stored electronically in their patient management systems or paper patient files. There are security measures to ensure all information is safeguarded from unauthorised access or disclosure, as required by the relevant legislation.

Contact details used for the survey are sent to Mobius through a secure SFTP.

Mobius storage and security of personal information

Contact details are only used by Mobius to post, email or text an invitation to participate in the survey. When the survey has finished, all contact information is deleted from the system.

Mobius must host its database in New Zealand and strict privacy and security protocols are maintained and described in their contract agreement with the Commission. They are required to meet their obligations of privacy and confidentiality under the following legislation:

- Privacy Act 1993
- Health Information Privacy Code 1994
- Health Act 1956

Mobius has been delivering research, evaluation and consultation services in the public and private sectors for 20 years. Mobius receives multiple customer, client and stakeholder contact data sets each month from a range of clients – with the largest of these to date having been in excess of 250,000 unique contacts (from the Ministry of Business, Innovation and Employment).

Mobius takes the utmost care with all confidential information and has never had a data (or any other security) breach. This is a result of not only complying with Research Association of New Zealand guidelines to manage contact data but also by applying the principles and processes of ISO 20252:2019.

As an approved all-of-government provider, Mobius' data-related practices are also informed by Department of Internal Affairs guidelines and recommended processes (including risk minimisation and mitigation actions). Mobius has no staff other than two owners and directors.

Contact details received from DHBs are stored on a single secure laptop accessible only to the project administrator. For this project, the laptop is:

- only kept at Mobius' secure office and is password protected
- encrypted using Apple's FileVault2 XYS-AES-128 encryptions with a 256-bit key
- not used for any other purpose other than this project.

Not only is the contact data deleted once it's used, the laptop's drive is reformatted at the end of the project.

No data is backed up to or kept on a cloud-based server.

Commission storage and security of personal information

Only the survey responses are provided to the Commission. The Commission does not receive contact details at any time.

All responses to the survey are anonymous. As noted in Principle 1, the survey information has responses to experience measures, demographic information and limited mental health and addiction service use data. This information is provided to the Commission.

Information is only used to inform and monitor the quality of DHB mental health and addiction services at aggregate level. It is not used for any other purpose.

Survey information is held in the Commission's secure data storage area and stored in locked folders that can be accessed only by appropriate team members. The Commission is hosted by Revera (Spark) and is on an all-of-government infrastructure as a service contract (IaaS) with database storage on New Zealand servers, located within its purpose-built data centres, behind Commission-dedicated firewalls.

These contracts are overseen by the Department of Internal Affairs and providers are required to meet security standards to join the all-of-government panel. Revera provides regular security patching for the Commission. All staff have unique logins and database server access is separated and restricted to authorised staff.

Principle 6: Access to personal information

Consumers are entitled to access their health information that is held at their DHB. They put forward a request to the DHB either verbally or in writing. The information may be provided face-to-face or they may be given printed notes from the patient management system. Information can be withheld under certain circumstances, in line with the rules of the Health Information Privacy Code 1994.

Responses to the survey cannot be accessed by an individual, since the survey is anonymous and there is no way to link a survey response back to an individual. This is made clear to respondents in the covering instructions to the survey.

Principle 7: Correction of personal information

Requests to correct health information are recorded in the DHB's patient management system.

The survey also provides an opportunity to check and correct consumers' contact information. Mobius identifies invalid mobile phone numbers, email addresses or incorrect postal addresses and provides DHBs with error reports to assist DHBs meet their obligations under Principle 8. It includes the number of duplicated contact details.

Principle 8: Accuracy, etc, of personal information to be checked before use

DHBs are tasked to ensure that all reasonable steps are taken to accurately record information in a consumer's health record. However, information collected from the consumer is reliant on the consumer or their representative to provide relevant and correct information at the time.

The Commission asked DHBs to improve the collection of consumers' email addresses to allow DHBs to get greater numbers of email addresses before the survey started, and make any necessary changes in patient management systems.

Principle 9: Agency not to keep personal information for longer than necessary

DHBs hold health information that has been collected in patient management systems or archived in accordance with the Public Records Act 2005.

Contact details that are provided to Mobius is removed from the database when the survey ends.

Anonymous responses to the survey are kept for as long as the survey reporting is required (and then in accordance with the Public Records Act 2005).

Principle 10: Limits on use of personal information

When consumers are admitted, they should be advised that health information, including their information, may be used to monitor quality (as part of the general privacy statement).

Monitoring quality applies to the survey. Additional steps outlined in principle 2 are taken to mitigate the risk that consumers are not aware their personal information is used for this purpose.

Principle 11: Limits on disclosure of personal information

If Mobius receives an Official Information Act (OIA) request, they are to refer this to the Commission or relevant DHB.

If the Commission receives an OIA request this will be referred to the relevant DHB for a response, where it relates to a DHB's data.

The Commission will only ever disclose non-identifiable aggregate survey results, with the exception of the redacted open-ended survey responses sent to DHBs for the purposes of quality improvement.

Principle 12: Unique identifiers

The survey does not assign unique identifiers to survey responses.

| | | Impact | | | | |
|-------------|-------------|---------|--------|----------|--------|---------|
| | | Trivial | Minor | Moderate | Major | Extreme |
| Probability | Rare | Low | Low | Low | Medium | Medium |
| | Unlikely | Low | Low | Medium | Medium | Medium |
| | Moderate | Low | Medium | Medium | Medium | High |
| | Likely | Medium | Medium | Medium | High | High |
| | Very likely | Medium | Medium | High | High | High |

4. Privacy risk assessment

The privacy risks of the programme are summarised below.

| Risk description | Risk source | Probability | Impact on project | Rating | Mitigation strategy |
|--|-----------------------------------|-------------|-------------------|--------|---|
| People who share contact details with the consumer (eg, family members at the same address or work contacts with shared email address) find out the consumer used mental health and addiction services due to survey invitation. | Consumer networks | Likely | Major | High | The invitation to the survey (email, text or letter) does not reference mental health and addiction services. It will describe that this is a survey to understand their recent experience of using DHB services. Only once the respondent enters the survey, will it reference mental health and addiction services. Emails, texts and letters are addressed to the named consumer (eg, Dear John). The survey provider searches email addresses and removes clear situations of people having joint or family emails. This includes using keywords such as 'family', 'and', and 'whānau'. |
| Loss of credibility of the Commission if people feel that the survey process has not adequately considered or addressed privacy concerns. | All stakeholders | Moderate | Moderate | Medium | Privacy implications are considered early on and get feedback from stakeholders, Office of the Privacy Commissioner and DHBs, and any issues are addressed. There is a public-facing privacy summary and this PIA available before the survey starts. |
| DHBs feel uncomfortable providing consumer contact details due to privacy concerns. | Commission, survey provider, DHBs | Likely | Major | High | Privacy implications were considered early on and discussed with quality and risk managers, staff in the quality improvement network, patient experience managers and the survey methodology working group (comprising DHB representatives). |
| A consumer is surprised to have received the survey. | Consumer | Likely | Minor | Medium | Communication about the survey, to all stakeholders, including the public, and promotion through posters, handing out flyers on discharge and other promotion. DHBs ensure consumers receive information about how their health information is used, and the Commission will request DHBs give consumers an additional reminder in the month before the survey starts. |
| A family and whānau member is surprised to have received the survey. | Family and whānau | Unlikely | Minor | Low | Communication about the survey to all stakeholders, including the public, and promotion through posters and other advertising in advance. Commission advertises the survey through suitable networks (eg, Supporting Families). |

| | | | | | |
|--|-----------------------------|----------|----------|--------|--|
| A consumer feels uncomfortable responding to the survey due to privacy concerns. | Consumer | Likely | Minor | Medium | The survey is voluntary. Consumers who are uncomfortable can opt-out of sharing contact details in advance (where existing DHB systems support this). Also, consumers who receive a survey invitation may ignore it without consequence. This will be clear in the survey invitation and other communications. This privacy impact assessment is publicly available. |
| A family and whānau feels uncomfortable responding to the survey due to privacy concerns, | Family and whānau | Moderate | Minor | Medium | The survey is voluntary. Family and whānau who receive a survey invitation may ignore the invitation anonymously without any consequence of service delivery to their family member. This will be clear in the survey invitation and other communications. This privacy impact assessment is publicly available. |
| Inappropriate system access by an internal users. | Survey provider, Commission | Rare | Major | Medium | The Commission will not receive or have access to the contact details of consumers. The survey provider has strict requirements under their contract with the Commission on safeguarding contact details. The survey provider is a very small team. The survey response data set is anonymous. It will be stored on Commission systems in secure folders with only authorised staff access. |
| Inappropriate system access by an external party. | Public (hacker) | Rare | Extreme | Medium | The survey provider is contractually required to maintain tight security protocols. Data must be hosted in New Zealand. |
| Public outcry (negative media coverage or public commentary) of a perceived breach of privacy or failure to mitigate risks adequately. | Public | Unlikely | Moderate | Medium | There is communication to DHBs and consumer networks. This privacy impact assessment is publicly available, along with a summary version for greater accessibility. |

5. Privacy-enhancing measures

Privacy measures will be enhanced through the following measures.

Communications plan

A communications plan has been implemented to ensure consumers, families and whānau and DHBs are aware of the Ngā Poutama survey. Documentation will be targeted to different audiences and provide important information to the different stakeholders.

Consumer, family and whānau notifications

Processes are in place to notify consumers that their information may be used to monitor quality. The Commission worked with DHBs prior to the survey to introduce:

- advertising during the survey (eg, posters and reminders from health professionals) with similar information about using patient information to monitor quality
- flyers for DHB staff to hand out to consumers on discharge, and their family and whānau member if they attended the discharge appointment. The flyer provides information that they will soon be contacted to participate in the survey
- DHBs enabling consumers to opt-out of sharing their contact information for participating in the survey (where this is possible, to implement in DHB patient management systems).

Survey invitation

Attention has been given to how consumers, families and whānau are invited to participate in the survey to minimise the risk the survey invitation could disclose use of mental health and addiction services to other parties. The following privacy-enhancing measures have been implemented in the survey methodology.

Email and text invitations

The email or text invitation has no reference to mental health and addiction services. The wording requests participation in a survey about recent experience of DHB services. The email and text invitations have the consumer's name (eg, Dear John).

Postal invitations

Invitations are posted directly to the consumer, not to the general household. It is illegal to open another person's mail. The survey invitation letter does not reference mental health and addiction services (rather, broader DHB services).

Completing the survey

Once a respondent has been invited to participate in the survey, they can complete the survey:

- online (expected to be the most common way)
- by requesting a paper copy of the survey and returning in a pre-paid envelope
- by requesting a telephone interview
- by requesting a face-to-face interview (where this is possible/feasible).

Only once the respondent starts the survey, does it say it's about recent use of mental health and addiction services. It is very unlikely someone who is not the named consumer will take the next step to complete a survey that was addressed to them.

The online version of the survey will use the secure communication protocol of https.

If they do request a paper copy of the survey, the return address will not be a mental health and addiction service, but rather that of the survey provider, Mobius.

Publishing this privacy impact assessment

This privacy impact assessment is published on the Commission website, www.hqsc.govt.nz along with a summary to enable greater accessibility and transparency.