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Abbreviations list

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<tr>
<th>Abbreviation</th>
<th>Meaning</th>
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<tr>
<td>Commission</td>
<td>Health Quality &amp; Safety Commission</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HIPC</td>
<td>Health Information Privacy Code 1994</td>
</tr>
<tr>
<td>IPIF</td>
<td>Integrated Performance and Incentive Framework</td>
</tr>
<tr>
<td>IPP</td>
<td>Information Privacy Principles</td>
</tr>
<tr>
<td>NES</td>
<td>National Enrolment Service</td>
</tr>
<tr>
<td>NHI</td>
<td>National Health Index</td>
</tr>
<tr>
<td>PES</td>
<td>Patient experience survey</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
</tr>
<tr>
<td>PMS</td>
<td>Patient Management System</td>
</tr>
<tr>
<td>SFTP</td>
<td>Secure file transfer protocol</td>
</tr>
<tr>
<td>SMS</td>
<td>Short message service (text)</td>
</tr>
<tr>
<td>VM</td>
<td>Virtual Machine</td>
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1. Introduction

1.1 Primary care patient experience survey
The Ministry of Health (MOH) and the Health Quality & Safety Commission (the Commission) are introducing patient experience measures for primary care using online patient surveys. The primary care patient experience survey, or PES, is being developed by the Commission to find out what patients’ experience in primary care is like and how their overall care is managed between their general practice, diagnostic services, specialists, other health professionals and or hospital staff. The information will be used to improve the quality of service delivery and patient safety.

The survey looks at a patient’s experience of the whole health care system using primary care as a window. It focuses on the coordination and integration of care, rather than just the last visit to a GP’s surgery.

The survey is modular; patients answer questions relevant to their experiences. For example questions on medication and chronic conditions will be answered only by patients for whom this is relevant.

Patient feedback is anonymous, voluntary and patients can choose to opt-out of the survey.

The PES will be adopted by all practices as part of the Primary Health Organisation (PHO) Services Agreement. However, there will be a phased roll out.

Who will be surveyed?
Patients who have received a consult from the primary care service provider they’re enrolled with during the previous quarter may receive a survey invitation. Children under 15 will not be surveyed.

How will patients be surveyed?
Survey invitations will be emailed or texted to patients through a national system that has been funded by the MOH for PHOs, practices and District Health Boards (DHBs). Patients will receive a website link and be asked to complete the survey in a set period of time. Their anonymous responses will be reported to practices and PHOs in real time via a secure online portal. Summarised information will be reported to DHBs, the Commission and the MOH the same way. The process is automated to minimise administrative burden to practices.

So we can meet tight timeframes and to minimise administration for PHOs and practices the PES will start with email and text invites only. After a number of survey rounds we will review
the need to use other methods to reach patients not being reached by email and text. This allows us to ensure additional methods of capturing feedback are specifically designed to meet the needs of patients not well represented in this first phase. Any new ways of capturing feedback will be put in place with the involvement of PHOs and practices, and this privacy assessment will be revisited.

**How often will patients be surveyed?**
The survey will be conducted nationally every three months. Patients won’t be asked to participate more than once every six months.

**When will the first survey be conducted?**
As part of the pilot phase test surveys will be conducted with a subset of patients in June, July and August 2015. In September 2015 the first live survey, in its final form, will be sent to patients enrolled only with the pilot PHOs. It will be reported in October. This cycle will be repeated every three months.

Once a minimum level of patient experience contact information is achieved in the National Enrolment Service (NES), patients from all PHOs can be invited to participate in the survey.

### 1.2 Why is the survey being introduced
Understanding patients’ experience is vital to improving patient safety and the quality of care. It helps us understand the quality of health and disability services. Currently New Zealand does not have a consistent national approach to collection, measurement and use of primary care patient experience information on a regular basis.

In particular by introducing a primary care PES we’ll improve our understanding of how New Zealanders experience the coordination of health care services.

The survey is part of the Integrated Performance and Incentive Framework (IPIF): a quality improvement framework developed by the health sector with support from the MOH. The goal of IPIF is that all New Zealanders can access the health services they need in order to be healthy. The PES is a key component of the IPIF framework.

One important way to create a better patient experience is through making better use of technology. Being able to capture, understand and act on patient experiences in a timely manner, is a vital contributor to improving health service delivery and also prioritising attention and resources.

Hospital patient experience measures are already in place. A selection of patients who spent at least one night in hospital are sent an invitation via email, text or post, inviting them to participate in the national inpatient survey on a quarterly basis. DHBs have the option of conducting the hospital survey weekly or fortnightly. Survey responses are anonymous unless patients choose to provide their contact details.

### 1.3 Purpose of this report
The following report will address the impact that the PES and reporting may have on individual privacy. It will identify where the potential areas of risk may be for breaches of privacy and outline the strategies that will be in place to mitigate the risk. At the same time,
the report will also indicate to stakeholders that due diligence has been carried out to assess and minimise potential areas of risk along with compliance with the information privacy principles (IPP).

Currently all DHBs, PHOs, the Commission and Cemplicity (the national survey system provider) have processes in place to ensure the privacy of health information. We take privacy seriously.

The ability to design system architecture which addresses actual or potential privacy concerns is dependent, to some extent, on early identification of privacy issues and where risks lie. With this in mind we have prepared this ‘interim' privacy assessment in the early phases of system development, sought feedback from the Office of the Privacy Commissioner and incorporated this feedback in the survey system design.

As the survey system design is finalised, tested and implemented this document will be updated and a final report published.

1.3 Assessment process
The assessment process will be:

- Draft preparation
- Reviewed draft prepared for feedback
- Feedback incorporated
- Independent review (Office of the Privacy Commissioner and legal)
- Feedback incorporated
- Interim report approved and distributed
- Final report prepared, approved and distributed once the project ‘goes live’

Draft versions of this document will be made available for stakeholders’ information and comment.

2. Description of the project and information flows

2.1 PES project
The PES project involves the following work to develop, test, and implement the survey:

- survey tool development, including cognitive testing and cultural appropriateness
- sampling method
- patient contact information - pilot PHOs, NES
- **privacy impact assessment**
- PHO Service Agreement process
- survey and reporting system
- communication and engagement with health care professionals and patients/consumers.
We refer to the current development and testing process as the pilot phase. Six PHOs have agreed to work with us through this phase: Procare Networks, National Hauora Coalition, Midland Health Network, Whanganui Regional Health Network, Compass Health and Pegasus Health.

**Survey development**
The draft PES is a tool we can now start testing in New Zealand. Six PHOs have agreed to work with us to test the survey. The survey received from Australia has been through an initial feedback process and revised to reflect the New Zealand health care environment.

Following the approach we used successfully in the hospital survey, this survey was tested with 15 focus groups across the six PHOs in April, May and June. The patient focus groups were asked:

- What does that question/instruction mean to you?
- Please tell me what it was asking in your own words?
- Thinking about your experience, would you be able to answer that question?
- How important/relevant is that question to you?
- If there is an important question missing, what is it?

Patients that participate in the focus groups are asked to participate, provided information on what's involved and provide their explicit permission to be contacted and participate.

The testing is an iterative process and we update and retest the survey as part of this process. The survey is revised for the focus groups feedback and then undergoes online cognitive testing, including health professional feedback. Finally, 15 patient interviews are conducted before the final survey is agreed.

**Patient contact and demographic information**
To be able to send the survey invitations through a national system and minimise costs and administrative burden we need patient information from the PHO (which is from the practices). This will be patient identifiable contact information and demographic information such as age, gender and ethnicity. No clinical information or information not directly needed for the purpose of the survey is required. Email and mobile phone contact information is important to be able to send the survey through an automated process.

**Long term solution**
In the long term we plan to use patient information from a single source, the NES. A patient preferences area will be added to practice management systems enabling practice staff to ask patients for their email and mobile contact information, and whether they wish to opt-out of the national survey.

The NES project will have completed its work to be able to capture the patient contact information by July. However, NES will have a phased uptake as patient management system vendors complete the required changes by June, and practices adopt the new software. As soon as the new software is installed in a practice a 'qualifying event' for a patient will become a trigger for the new information to feed through, along with new enrolments or re-confirmation of enrolment.
The phased uptake means email and mobile information will only populate in the NES as practices enter new enrolments, refresh enrolments, or a patient is specifically asked for their patient preferences information. It will take some time for enough information to be available from this single source.

Further down the track we will explore auto-populating the patient preference fields from existing mobile and email contacts in practices PMS to reduce practice administration, however this will not be the case for now and this privacy assessment will be revised if this occurs.

**Testing and Interim solution**
To enable us to complete the system design and testing we need to source patient information directly from the practices that have agreed to be involved in the testing via the PHOs. The practices consent to extract the data will be sought per Appendix 1 and we will test multiple means of notifying patients of the use of their information through the testing process.

Once testing is completed and the survey system is ready to be implemented a phased roll out will occur due to the timing of the NES rollout above. In the interim we propose to source patient information directly from the pilot PHOs for all their practices that are able to participate. We are currently working through steps to progress this, including ensuring practices and patients are adequately informed about the new survey and have a range of information readily available to them.

**Communication and engagement**
Pilot phase updates and resources will be shared with the wider sector including the proposed survey tool, cognitive testing reports, privacy impact assessments, information for patients and practices, a methodology and procedures document, and how to access the online patient experience reporting system (available at practice level).

There’ll be a steady flow of project updates to PHOs, DHBs and other people involved in the primary care sector. PHOs will need to forward these within their networks to ensure practitioners are fully informed.

A methodology and procedures document will be prepared as part of the project. The PES will be shown in Appendix 1 of that document.

**Patient notification**
The public will need to be notified about the project at key stages and through a range of means. No single method will ensure all patients likely to receive a survey are fully informed. We need to test a range of methods.

During the testing phase we will communicate with the PHOs and practices involved in the testing the importance of patient notification (although this is something they are well aware of). A patient flyer has been prepared for the test practices (see Appendix 2) that will need to be displayed to assist with notifying patients about the project. We will encourage practices to start routinely asking your patients’ for email address and mobile phone contact information, and mention the new national survey while doing so.
Practices are advised it’s important to ask for individual rather than family contacts to ensure patients’ privacy (the system provider will however ensure only one patient receives an invitation per email or mobile contact).

The Commission can also assist with local media releases, community notices etc. We know from past experience with the inpatient survey that people notice these and they increase survey response rates.

An important part of the testing phase is testing means of notifying and informing patients – what works/doesn’t work and what practices, PHOs and DHBs find useful. The final privacy assessment will incorporate the testing results and updated information.

The Commission will use strategic national media releases to inform the wider public about the survey. These will be distributed to DHB and PHO communication managers for local releases through the media, websites etc and will be ongoing throughout the life time of the survey.

### 2.2 Benefits

The PES provides the following benefits:

- A means for patients across the country to provide feedback on their health experience
- an automated, low administration, fully funded tool for general practice, PHOs and DHBs
- being able to capture, understand and act on patient experiences in a timely manner
- a good indicator of the quality of health services, with patient experience positively correlated to processes of care for prevention, disease management, and with adherence to medical advice and treatment plans
- a nationally consistent model of patient experience indicators, with general application across the health system and the ability for PHOs to benchmark patient experience results at practice and PHO level
- the ability to compare NZ data with overseas results
- can be incorporated with any existing local patient experience surveys
- integrating the lessons from patient experiences in a quality improvement programme increases the chances of service improvement
- collecting real time information
- continuous measuring and reporting
- benchmarking
- PHOs, practices and DHBs can login to monitor real-time updates to the dashboard reports that can be viewed relative to other PHOs results
- patients needing contact can be triaged and attended to as soon as possible by an appropriate staff member.
2.3 Indicative survey process\(^1\) - testing

HQSC, pilot PHOs, & test practices communicate the test survey through a range of methods (also being tested)

Enrolled patient has a consultation during a set sample period for each of the test survey rounds

Patient data extracted from test practices only, in accordance with rules on set date 9 days after sample period end

Extract uploaded via secure FTP to national survey provider (as close to day extracted from practices as possible)

Survey emailed or text, using practice logo/contact details, to all patients with a mobile or email contact in the extract, the same day as received from the PHO

During this time responses can be viewed updating “live” on the dashboard

Reminder sent to patients 7 days later

Survey closes after 14 days

Un-weighted reports available immediately.

\(^1\) This process and timing is yet to be piloted and may change.
2.4 Indicative survey process² - interim solution

HQSC, PHOs, DHBs & practices communicate the new survey through a range of methods.

Enrolled patient has a consultation during a set sample period each quarter.

Using the current quarterly register process & timing, pilot PHOs extract patient data from as many of their practices as possible, in accordance with the survey rules.

Extract uploaded via secure FTP to national survey provider (as close to day extracted from practices as possible).

Survey emailed or text, using practice logo/contact details, to a sample of patients with a mobile or email contact in the extract, the same day as received from the PHO.

During this time responses can be viewed updating “live” on the dashboard.

Reminder sent to patients 7 days later.

Survey closes after 21 days.

Un-weighted reports available immediately.
Weighted reports available 14 days after the survey closes.

² This process and timing is yet to be piloted and may change.
2.5 Indicative survey process\(^3\) - final (NES) solution

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<thead>
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<td>Enrolled patient has a ‘qualifying event’ during a set sample period each quarter</td>
</tr>
<tr>
<td>Patient data extracted in accordance with survey rules from NES on set date after sample period end</td>
</tr>
<tr>
<td>Extract uploaded via secure FTP to national survey provider (as close to day extracted from practices as possible)</td>
</tr>
<tr>
<td>Survey emailed or text, using practice logo/contact details, to a sample of patients with a mobile or email contact in the extract, the same day as received from the NES</td>
</tr>
<tr>
<td>Reminder sent to patients 7 days later</td>
</tr>
<tr>
<td>Survey closes after 21 days</td>
</tr>
<tr>
<td>Un-weighted reports available immediately. Weighted reports available 14 days after the survey closes.</td>
</tr>
</tbody>
</table>

\(^3\) This process and timing is yet to be piloted and may change.
2.6 National survey and reporting system

Cemplicity Limited has been contracted to provide the national survey and reporting system. The system will be part of the Connected Health Network no later than the completion of the pilot phase. The ‘system’ describes the end-to-end process to source patient information, send survey invitations, receive and store patient responses (anonymously), and provide real time reporting to appropriate people.

We will work with the pilot PHOs and their lead DHBs to test the final survey from the cognitive testing process. It will be tested within Cemplicity’s online survey and reporting system. The test will involve sending the survey to patients, adapting the online reporting tools and other system features for primary care.

In order to participate, PHOs, practices and DHBs will be provided with licences to access this funded patient experience system. No additional IT investment is required for PHOs and practices to participate in the core national survey. Only email access and an internet browser are required.

It is the same system currently being used for the national hospital survey in DHBs.

A key requirement of the system is to seek and report patient feedback through electronic means enabling real-time updates to the dashboard reports. This means minimal administration for PHOs and practices, higher quality, more timely data through minimal intervention, no postal delays, and immediate report updates. Patients requesting contact can be triaged and attended to as soon as possible by an appropriate staff member.

The system allows more frequent surveying – weekly or fortnightly if required. This allows for a continuous flow of data which is much more valuable for improvement purposes than a quarterly “temperature check”.

The survey procedures also accommodate mailed surveys, but PHOs or practices would need to administer these themselves.

A key requirement is the provision of patient email addresses and mobile phone contact information.

2.6.1 Information flows and system access

Step 1: PHO’s send extract information to Cemplicity (pre-Connected Health)

The PHOs each connect via a SFTP client to the SFTP server that is housed within its own dedicated virtual machine (VM) within the Datacom application server environment. This SFTP server is secured via individual IP addresses within each of the PHOs and is only open through the firewall on the SFTP port. All other traffic is denied.

On connection, each of the PHOs uploads their extract for the period. This extract is a csv file in accordance with Appendix 3.

During the period the surveys are run an integration application takes this csv file, converts the data to the appropriate format, and stores it inside MS SQL Server. The csv file is then
deleted. In the event a PHO wishes to mail surveys to patients, a new file is put back on the SFTP server for the PHOs to download which contains the mail sample contact details.

Once this data is transformed, invitations can then be sent to the patients via email and SMS.

*Step 1a: PHO’s or NES send extract information to Cemplicity via Connected Health Network*

The PHOs/NES each connect via a SFTP client via the Connected Health Network to Cemplicity’s server. This SFTP connection is further secured via an explicit IP address provided by the PHO/NES and is only open through the firewall on the SFTP port. All other traffic is denied.

On connection, each of the PHOs or NES uploads their extract for the period. This extract is a csv file in accordance with Appendix 3.

Once the extract is uploaded Cemplicity will connect via a SFTP using the same process as above (explicit IP addresses on Port 22) to its own dedicated virtual machine (VM) within the Datacom environment.

During the period the surveys are run an integration application takes this csv file once it is in the Datacom environment, converts the data to the appropriate format, and stores it inside a MS SQL Server behind a Datacom secured network connection. The csv file is then deleted.

Once this data is transformed, invitations can then be sent to the patients via email and SMS.

*Step 2: Invitations are sent from the application servers to patients*

On sending of invitations a 36 character GUID is created that is used to link the patient’s experience responses to the non-clinical background data provided in the file. For SMS invitations a code is given which links to this same 36 character GUID.

The patients receive the invitation via SMS or email and then complete the survey via any web based browser, mobile phone, tablet (or through a mailed/paper process which is then input online by PHOs once received).

Email invitations are all sent from feedback@myexperience.health.nz with their practices logo (if available) and contact information.

Eligibility for a .health.nz domain name is restricted to organisations who deliver health services through registered practitioners. The myexperience.health.nz address is used as a trusted source of correspondence for recipients.

SMS invitations are sent from the number 2333 with the practice name.

On clicking on the link in the invitation, the URL https://se.myexperience.health.nz?u=<GUID> will take patients through the firewall over port
80 and into the application server environment. Ultimately patients answers will be stored in the database on clicking the submit button.

Patients that receive an invitation via a non-smartphone (or in the mail) can go to [www.myexperience.health.nz](http://www.myexperience.health.nz) and enter their unique code to complete their survey.

Note: There is no external access directly to the database servers; these are routed through internal IP addresses.

The SFTP server and the application VMs are separate machines.

**Step 3: Report Users Access Data**

The third step involves users at individual practices, PHOs, DHBs, the Commission and the Ministry of Health accessing the reporting portal via a 256 bit encrypted https link. These users are authenticated via a login that utilizes a unique key / SALT algorithm. On gaining access to the portal they are routed to the report application server which displays aggregated data pulled from SQL Server.

Cookies are used sparingly within the reporting application (but not the survey application accessed by patients responding) and these are limited to standard settings like group by or sort order. The users’ preferences are remembered via the cookie. If these preferences don’t exist the application simply defaults to the global setting. Cemplicity also uses a cookie for authentication purposes when users log on. Cemplicity does not record behaviour specific information outside of these standard preferences.

**Step 4: Tidy Up**

Cemplicity runs scheduled clean up tasks that delete invitation information at agreed times after a period closes. Patient contact information is only retained in the system for as long as needed to send the survey invitation and reminders. All reportable data is therefore anonymous.

The information flows are shown in [Diagram 1](#).

### 2.6.2 System management

The successful performance of the national survey and reporting system is dependent on adequate and appropriate oversight and relationship management and on adequate and appropriate review of the services performed.

A system management group will be established to provide oversight for the national system.

The group’s role is to:

- review and monitor the working relationship;
- review the progress and completion of projects; and
- prioritise and approve change requests and new services.

Membership may consist of, but is not limited to:
• System provider's representative(s);
• Commission’s representative;
• IPIF programme representative;
• PHO/practice representatives;
• DHB representative.

Other members can be co-opted onto the group as the group sees necessary.

Decisions on any significant changes or development will be sought from the IPIF programme governance.
### 2.6.3 Stakeholder access

The systems online reporting portal can be tailored to the appropriate user access rights. This is accessed through an internet browser. The following access to data reported by the system is proposed:

<table>
<thead>
<tr>
<th>Information</th>
<th>Data level</th>
<th>Patient</th>
<th>Practice</th>
<th>PHO</th>
<th>DHB</th>
<th>System provider</th>
<th>National</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient data file</td>
<td>Individual</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Survey responses</td>
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<td>✓</td>
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<td></td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>only if patient requests contact &amp; approves access to copy of survey</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard reports</td>
<td>Practice level</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<td>PHO level</td>
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<td></td>
<td>DHB level</td>
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<tr>
<td>Patient comments</td>
<td>Individual (anon) - practice level</td>
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<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Note 1 – this is an automated process however the system provider’s staff may need to check data files when dealing with errors.
2.6.3.1 Customisation – what a user sees

Within the portals it is possible to define the reports and administrative functions available to a user:

1. In the report menu
2. Across the filters that are available
3. Administrative functions:
   a. User Management
   b. Moderation Capabilities

2.6.3.2 Quarterly Process – proposed access rights

Practices and PHOs

- All users have access rights that allow them to login and view the dashboard and all available reports.
- PHO users can see the reports at practice level for all practices in the PHO and PHO, DHB and national aggregated reports.
- Practice users can see the reports at practice level for their practice and PHO, DHB and national aggregated reports.
- The initial user set up is auto published by the system provider. Once the survey is live each PHO will be provided administrator access to be able to maintain their PHO and practice users through a secure user interface.

DHBs, Commission, and MOH

- All users have access rights that allow them to login and view the dashboard and all available reports.
- Users can see PHO, DHB and national aggregated reports.
- The user set up is auto published and managed centrally by the system provider.

2.6.4 Security Measures

The MyExperience portal is secured via 256bit encryption SSL certificate. All logins are run through a SALT / HASH algorithm. No passwords are kept in native format anywhere within the system. All login attempts are encrypted and then passed through the algorithm to see if they match the hash held at database level. On gaining access, all logins and login attempts are recorded with the following information:

- Date and Time of login attempt
- Username of login attempt
- Login attempt response
- UserGUID if succeeded
- User Agent used
- User IP address
Within the reporting section of the portal there is no ability to insert data as it is read only. All administrative facilities, for example moderation, user management, have logging against them as well which allow a view of the administrator who has authorised data changes.

**Patient data**

Within the background data of the portal we have a key that allows the linking back of data to an original data file. There is another security process in place to avoid identification:

- Anyone asking for identification of a respondent is denied in writing.
- If further requests are made, this would be escalated to the Commission.  

**Security Testing**

Cemplicity use Insomnia for security and penetration testing on a regular basis. Independent audits can be conducted by the Commission at any time under contract.

### 2.6.5 Online Reports

All users have the same report view when they login in to the system, subject to access restrictions.

The reports are able to be filtered (drop down box selection) for:

- date ranges
- age bands (so reduce patient identification)
- gender
- ethnicity
- practice
- PHO
- DHB

Users will also be able to download reports in formats such as PDF, image and csv/excel for easy internal reporting.

During testing we will need to ascertain what combination of filters can be used at once to ensure reported data does not become so granular that patients are identifiable.

A survey response rate report is included so that practices and PHOs can easily analyse the response rate. This also enables us to analyse the response rates across different collection methods.

A sample of the DHB inpatient survey reports are shown in Appendix 5. The PES reports will be appended in the final report.

### 2.6.6 Quantitative and Qualitative Analysis

The national provider will provide a survey data file to PHOs and the Commission so that further analysis can be performed. The PES data file is not currently available as the survey

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4 Note patients would only be able to be identified during the timeframe that their identifiable data was retained in the system.
is yet to be finalised. An example survey data file is shown in Appendix 4 and is a fair reflection of what the file would look like. Test survey data will be analysed to ensure the data fields provided do not enable the data to reveal who a patient is. A number of the fields shown in the appendix may need to be removed in discussion with the pilot PHOs to ensure this.

The rows in the file returned to PHOs will be in order of patient responses received, not in the same order as the patient data exported by PHOs or NES to the national provider. This will further ensure patient responses are anonymous.

PHOs will be able to further analyse or report the PES information as they choose for internal purposes to improve patients' experience. The patient comment boxes will be of particular interest to practices and PHOs. This information is viewable in the comments reports where practices and PHOs are able to filter, view word clouds and search on particular terms. Further qualitative analysis can be undertaken by the PHOs using the data extract provided.

The Commission will use the survey data file primarily to prepare the quarterly weighted reports. It will also take a long term view of the information and perform analysis as required to look at differential response, response rates and identify national trends that may suggest changes to the survey tool.

3. Privacy Impact Analysis

The following section will address the twelve rules in the Health Information Privacy Code 1994 (HIPC). It will outline how the Commission will address each of the rules from a risk perspective and the strategy for containment.

Rule 1: Purpose of Collection of Health Information

All health professionals providing services to patients collect information and record that information in their patient management system (PMS). This record is to meet legal requirements of the health professional to describe and support the management of the patient’s healthcare. Use of the information will be in line with the Health Information Privacy Statement shown in Appendix 6 that all patients sight on enrolment with a PHO.

Impact from this project:

This project 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.

The project does add fields specifically related to patient experience survey participation to the PHO enrolment form and PMS. This enables patients to be advised about the survey, provide their contact details and gives them the choice to opt-out of the survey if they wish.

The project does encourage an increase in patient email address and mobile phone contact information collection. Practices are asked to record individual rather than family contacts to
ensure patients’ privacy. The survey provider will ensure the survey is not sent via the same mobile or email contact to more than one individual. The email survey invitation includes an unsubscribe option.

PHOs and practices will be encouraged to put up notices about the survey in practices, on community noticeboards, websites and use local media releases with the Commissions support.

Practices and PHOs public notices and ‘your rights’ brochures should also include similar information re use of patient information for monitoring of quality etc. The Commission will encourage adding a statement about the PES to these notices to increase the uptake and awareness of this by both patients and staff.

Rule 2: Source of Health Information

In almost all situations health information is collected directly from the patient or the patient’s representative by the health professional or health team member. This can be collected via face to face, phone or electronically. At times information will be forwarded to the general practice team by other health professionals that are providing care to the patient and it is expected that those professionals will be collecting the information using the same or similar process as indicated by the Health Information Privacy Code, 1994 (HIPC). This information, once received, will be recorded in the PMS.

Impact from this project:

For the purposes of the PES survey the non-clinical health information required to send the survey and report the results is collected by the practice directly from the patient and either provided to:

1) the PHO who then sends the data to Cemplicity through a SFTP or
2) captured online by the NES who will then provide a quarterly file for all PHOs to Cemplicity through a SFTP.

PHOs through their privacy statements advise patients their contact information may be used for health planning purposes and to keep them safe. Their enrolment process will also be updated to specifically request information for the PES.

The non-clinical information provided by the PHO or NES will not be used in a form in which the individual concerned is identified other than to send a survey invite and reminder; will be used for statistical and research purposes in an aggregated form and will not be published in a form that could reasonably be expected to identify the individual concerned.

Rule 3: Collection of Health Information from Individual

At present all the information collected from the individual is contained in practices PMS. Patients are provided with a privacy statement that outlines how their health information is collected, stored and used. The privacy statement is quite broad and does not specifically mention the national survey. This information is readily available at all practices.

Impact from this project:
The project does require practices to advise patients their information may be used for survey purposes and add information specifically related to Patient experience survey participation to the PHO enrolment form and PMS. This enables patients to be advised about the survey, provide their contact details and gives them the choice to opt-out of the survey if they wish.

The PES does include an ‘unsubscribe’ option so that patients can automatically exclude themselves from receiving future survey invitations via the system provider.

**Rule 4: Manner of collection of Health Information**
Practices collect health information in a lawful manner with consideration of patients. At present all practices have processes in place for the collection of health information from both a clinical and business perspective.

*Impact from this project:*

This project will have no impact on the current processes in place.

**Rule 5: Storage and Security of Health Information**
At present in general practice all health information is generally stored electronically in their PMS. Security measures are in place to ensure all information is safeguarded from unauthorised access or disclosure as required per the relevant legislation.

*Impact from this project:*

This project will have an impact on the sharing of information in relation to the provision of services to patients to enable patient feedback to practices, PHOs and DHBs in a nationally consistent manner. Non-clinical patient information as described in Appendix 3 is provided to the PHOs national system provider through the secure processes described in section 2.6.1.

All responses to the survey are anonymous unless responders choose to provide their contact details because they wish to talk to someone at the practice or PHO.

Each survey sent has a unique ID that enables line-by-line analysis of responses. When the patient data extract is imported to the national system, a number is assigned to each line of information. The national survey and reporting process does not require patient identifiable information from the data extract to be held in the database. Initially it is needed to enable email and text correspondence to be addressed but once each survey link is closed (three weeks after email and text surveys are sent), all identifiable information sourced from the data extract is deleted from the system.

Note that demographic information such as age, gender, and ethnicity is retained.

The national system provider is required to host the database within New Zealand and strict privacy and security protocols are maintained and described in the Agreement. They are also part of the Connected Health Network.

The system provider must meet their obligations of privacy and confidentiality under the following legislation:
• Privacy Act 1993
• The Health Information Privacy Code 1994; and
• The Health Act 1956

in their performance of their obligations under their Agreement at all times during the Term of the Agreement.

Rule 6: Access to personal health information
At present if patients wish to have access to their health information at their general practice they would put forward a request to the practice either verbally or in writing. The information may be provided face to face or in the form of printed notes from the electronic PMS.

Information can be withheld under certain circumstances in line with the rules of the Health Information Privacy Code 1994.

Impact from this project:
This project will have no impact on the access and processes.

Rule 7: Correction of Health Information
At present any request for the correction of a patient’s health information would be recorded in the PMS. This request would generally come from the patient viewing their own health records either by face to face viewing of the electronic records or by sighting a printout of the health information.

Impact from this project:
This project will have no impact on this rule.

Rule 8: Accuracy of Health Information to be checked before use
At present all health providers are tasked to ensure that all reasonable steps are taken to record information in a patient’s health record in an accurate manner. However any information collected from the patient is reliant on the patient providing all relevant information at the time.

At times the provider may share relevant aspects of the patient information to other health professionals and are required to ensure the information is up to date and complete.

Impact from this project:
This project would have no impact on this rule.

Rule 9: Retention of Health Information
Currently practices hold health information that has been collected in the PMS. This information is held in the active form while the patient is accessing services, but is marked inactive when the patient ceases to access services whether this is by transferring to another practice or if the patient is deceased.

Impact from this project:
This project will have no impact on this rule as it applies to practices and PHOs. The health information that is collected is still stored in the patient management system. The non-clinical information provided for the survey purposes is retained as follows:

- Patient identifiable information is removed from the survey system provider’s database once each survey period closes.
- Anonymous, but unique, date, demographic, HPI-O ID (practice and PHO), PHO ID and DHB ID information will be retained in the survey system provider’s database for as long as the survey reporting is required.

**Rule 10: Limits on the use of Health Information**

Currently health information in practices and PHOs is obtained in line with the Information Privacy Principles (IPPs) and the set guidelines as to the use of that information. Generally all health information is stored in the PMS. Patients are given a PHO enrolment form which outlines the use of the health information when enrolling with the practice. The practice team and privacy officer within the practice are then the guardians of the information and are tasked with ensuring the information is used according to the IPPs.

*Impact from this project:*

This project will have an impact on the use of non-clinical information; however patients will be advised and explicitly asked for their contact information to be able to send the survey invitation for the long term NES solution. They will also be able to opt out of the use of their information for this purpose.

For testing purposes and the interim solution we will need to use different methods to notify patients that email and mobile contact information they may have provided may be used to send them a survey invitation.

**Rule 11: Limits on disclosure of Health Information**

Currently health information held in general practice is disclosed to other health professionals involved in the care of the patients. Patients are currently aware that health information would be disclosed from time to time as required, but this would generally occur via phone conversations between clinicians or the use of a referral letter.

*Impact from this project:*

This project will have an impact on the disclosure of non-clinical information; however patients will be advised and explicitly asked for their contact information to be able to send the survey invitation.

If the national system provider receives an Official Information Act (OIA) request they are required under their agreement to refer this to the Commission or PHO(s).

If the Commission receives an OIA request this will be referred to the PHO(s) for response where this relates to PHO(s) data.

The Commission will only ever disclose PHO level aggregate survey results.
Rule 12: Unique Identifiers
Currently practices and PHOs use the National Health Index number (NHI) as the unique identifier for patients.

Impact from this project:
This project will have an impact on this rule as the national survey and reporting system will assign a unique identifier to each survey response, which is unrelated to NHI. This is to enable survey responses to be anonymous unless the patient asks to be contacted by the practice or PHO and explicitly gives their permission for their survey response to be viewed by the practice or PHO.
4. Privacy risk assessment

The risks of the project are summarised as follows:

<table>
<thead>
<tr>
<th>Risk Description</th>
<th>Risk Source</th>
<th>Probability</th>
<th>Impact</th>
<th>Rating</th>
<th>Mitigation Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failing to comply with the letter or spirit of the Act</td>
<td>Commission, MDH, PHO, system provider</td>
<td>Unlikely</td>
<td>Critical</td>
<td>Moderate</td>
<td>Draft PIA is prepared early in the project to enable feedback from stakeholders, OPC, legal review and any issues addressed during the system development.</td>
</tr>
<tr>
<td>Stimulating public outcry as a result of a perceived loss of privacy or failure to meet expectations</td>
<td>Public</td>
<td>Unlikely</td>
<td>Critical</td>
<td>Moderate</td>
<td>Communication at a range of levels, through a range of means to all stakeholders, including the public.</td>
</tr>
<tr>
<td>Loss of credibility if people feel that the project has not adequately considered or addressed privacy concerns</td>
<td>All stakeholders</td>
<td>Possible</td>
<td>Marginal</td>
<td>Moderate</td>
<td>Draft PIA is prepared early in the project to enable feedback from stakeholders, OPC, legal review and any issues addressed during the system development.</td>
</tr>
<tr>
<td>Underestimating privacy requirements with the result that systems need to be redesigned</td>
<td>Commission, system provider</td>
<td>Unlikely</td>
<td>Marginal</td>
<td>Low</td>
<td>Communication at a range of levels, through a range of means to all stakeholders, including the public.</td>
</tr>
<tr>
<td>A patient is surprised to have received the survey</td>
<td>Patient</td>
<td>Possible</td>
<td>Marginal</td>
<td>Moderate</td>
<td>Communication at a range of levels, through a range of means to all stakeholders, including the public. Patients are specifically asked by the practice for their PES preferences.</td>
</tr>
<tr>
<td>A patient feels uncomfortable responding to the survey due to privacy concerns</td>
<td>Patient</td>
<td>Possible</td>
<td>Negligible</td>
<td>Low</td>
<td>Communication at a range of levels, through a range of means to all stakeholders, including the public. Patients are specifically asked by the practice for their PES preferences. Patients that are uncomfortable can opt-out of the survey or unsubscribe from future emails.</td>
</tr>
<tr>
<td>Practices feel uncomfortable providing patient contact details due to privacy concerns</td>
<td>Practices, PHOs</td>
<td>Likely</td>
<td>Marginal</td>
<td>High</td>
<td>Communication at a range of levels, through a range of means to all stakeholders, including the public. Ensure practices understand that patients are to be asked their PES preferences.</td>
</tr>
<tr>
<td>Inappropriate system access - internal users</td>
<td>Practices, PHOs, DHBs, MOH, Commission</td>
<td>Unlikely</td>
<td>Critical</td>
<td>Moderate</td>
<td>System access is set in accordance with the final PIA. Organisations ensure only appropriate persons have login access. In either event no individually identifiable information can be viewed unless the patient has provided their explicit consent.</td>
</tr>
<tr>
<td>Inappropriate system access - external party</td>
<td>Public (hacker)</td>
<td>Rare</td>
<td>Critical</td>
<td>Moderate</td>
<td>Our system provider is contractually required to maintain tight security protocols. Data must be housed in NZ and infrastructure is supplied by one of the governments IaaS providers, Datacom. The system provider is also approved to be part of the Connected Health Network.</td>
</tr>
</tbody>
</table>

5. Privacy enhancing measures

Privacy measures will be enhanced through:

5.1 Communications plan

A communications plan will be developed and implemented to ensure patients and health professionals are aware of the PES project. A range of documentation has already
been prepared as part of this with communications targeted to provide information that’s most important to the different stakeholders.

5.2 Patient Consent
Processes will be put in place to notify patients that their contact information may be used to invite them to complete a national patient experience survey. We will need to use multiple methods to achieve widespread notification rather than rely on practice notices and verbal advice. The opportunity will be given to patients to opt-out of receiving the survey. Completing the survey is voluntary; patients can ignore and delete the survey invitation. Patients can also ‘unsubscribe’ from receiving survey emails in the future.

5.3 Education Plan
All health professionals that will have access to the PES reporting portal will be provided detailed training materials for the use of this tool. Training material will explicitly cover privacy requirements to reinforce the HIPC.

5.4 System management
A system management group will be established to provide oversight for the national system. Any risks or issues will be reported through this group. System changes will be discussed and agreed through this group. The IPIF governance group will be updated by the Commission as needed.

The system management group will have terms of reference which articulates the role and purpose of the group.

6. Compliance mechanisms
This interim privacy impact assessment has been prepared early in the project, where we have enough known information to describe the proposed project but still have a substantial portion of the project to be communicated, developed and agreed.

As the project ‘goes live’ this privacy impact assessment will be revisited and a final report prepared.

The system management group provides a mechanism to log and periodically review (no less than every 6 months) any issues, risks, and complaints.

Annual review process
There will be an annual review process where stakeholders will be invited to complete a survey on the PES and provide their feedback. This feedback will be collated and reviewed by the system management group. The Commission will revisit the Methodology and Procedures document and the Privacy Impact Assessment as part of the annual review to ensure any relevant changes are recorded.

Contractual requirements - Audit and inspection
Under its contract with the system provider Cemplicity the Commission can every 12 months audit, review and validate the performance of the Project, including the performance of the system provider and other contractors.
Appendix 1: Consent to extract patient data

[16 June 2015]

Attention: GPs and Practice Managers

Action: Consent to extract patient data

PRIMARY CARE PATIENT EXPERIENCE SURVEY

We are seeking your consent to extract data that will be used in an anonymous way to support an important national project. The Ministry of Health (MOH) and the Health Quality & Safety Commission (the Commission) are introducing patient experience measures for primary care using online patient surveys. The primary care patient experience survey is being developed by the Commission to find out what patients’ experience in primary care is like and how their overall care is managed between their general practice, diagnostic services, specialists, and or hospital staff. The information will be used to improve the quality of service delivery and patient safety. The Commission is also working with the RNZCGP with a view to the survey contributing to the Foundation standard and Cornerstone standard requirements.

Our PHO is one of six PHOs participating in the pilot work to develop the survey.

We are asking for you to indicate your consent to provide non-clinical patient data to the project team. [Insert PHO name] will, with your consent, extract data from your PMS and make it available through a secure transfer process to Cemplicity who is the Commission’s contracted survey system provider. You can consent by completing the fax back form on the following page or via email to [insert contact name].

Click here (or paste and copy into your browser): http://bit.ly/1QMZ7m3 to see the draft survey.

What do you need to do?
We will provide you with a poster that will need to be displayed to assist with notifying patients about the project. It would also help if you start routinely asking your patients’ for email address and mobile phone contact information, and mention the new national survey while doing so. Individual rather than family contacts are important to ensure patients’ privacy (the system provider will however ensure only one patient receives an invitation per email or mobile contact).

We also need practice contact details and a logo file (if you have one) for the survey invitation so we can personalise the survey to appear as if it came from you.

How will patients be surveyed?
Survey invitations will be emailed or texted to a sample of enrolled patients. Patients will receive a website link and be asked to complete the survey in a set period of time.

Who will be surveyed when?
Enrolled patients who have received a consult in your practice during the following periods shown in the table below will receive a survey invitation if they have provided a mobile or email contact. Children under 15 will not be surveyed.
<table>
<thead>
<tr>
<th>Sample period</th>
<th>Survey sent</th>
<th>Survey closes</th>
</tr>
</thead>
<tbody>
<tr>
<td>22 – 26 June</td>
<td>8 July</td>
<td>22 July</td>
</tr>
<tr>
<td>29 – 3 July</td>
<td>15 July</td>
<td>29 July</td>
</tr>
<tr>
<td>13 – 17 July</td>
<td>29 July</td>
<td>12 August</td>
</tr>
</tbody>
</table>

**How will the feedback be reported?**
Patients’ anonymous responses will be reported to you and your PHO in real time via a secure online portal (the system provider, Cemplicity, will be in touch to give you access to this during July). Summarised information will be available to the Commission project team. The process is automated to minimise administrative burden to practices.

If a patient requests contact with you as their service provider or with their PHO you will also be notified via the online reporting process.

All patient identifiable information is deleted from the system when the survey period closes.

There will be a range of customisable reports enabling you to interpret the feedback for your specific general practice together with comparisons against other practices in your PHO network or against all the general practices participating in the testing.

As a test practice you will have the opportunity to contribute to the final system design, appearance and usefulness of the reporting.

**What data do we need to extract?**
The list of the data fields specifically required for this patient experience survey is:

<table>
<thead>
<tr>
<th>Data Field</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHI Number</td>
</tr>
<tr>
<td>Title / Prefix</td>
</tr>
<tr>
<td>First Given Name</td>
</tr>
<tr>
<td>First Preferred Name</td>
</tr>
<tr>
<td>Family Name</td>
</tr>
<tr>
<td>Address line 1</td>
</tr>
<tr>
<td>Address line 2</td>
</tr>
<tr>
<td>Suburb</td>
</tr>
<tr>
<td>City</td>
</tr>
<tr>
<td>Post code</td>
</tr>
<tr>
<td>Mobile phone</td>
</tr>
<tr>
<td>Email address</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Date of birth</td>
</tr>
<tr>
<td>Date of last consultation</td>
</tr>
<tr>
<td>(Date of invoice)</td>
</tr>
<tr>
<td>Ethnicity 1</td>
</tr>
<tr>
<td>Ethnicity 2</td>
</tr>
<tr>
<td>Ethnicity 3</td>
</tr>
<tr>
<td>HPI-O (practice)</td>
</tr>
<tr>
<td>HPI-O (PHO)</td>
</tr>
<tr>
<td>PHO Org ID</td>
</tr>
<tr>
<td>DHB of domicile (patient)</td>
</tr>
</tbody>
</table>
We understand that some of these fields may be blank, but an important part of our testing process is to understand what is or isn’t available in your PMS, and how this affects the survey process.

**Privacy**
We will apply all the same high standard of privacy safeguards and policies as we usually do with all data and its use. We will act to protect individuals privacy at all times.

A privacy impact assessment has been conducted for the project and a copy is available here [link to this document] along with the Office of the Privacy Commissioner’s comments.

**Additional information**

**Contacts**
If you have any further questions regarding the project, the data or extraction please contact [name] at [PHO name] on [phone] or by email [email address].

You can also contact Tania Simmons, the Commission’s project manager on 06 374 2868 or by email tania.simmons@hqsc.govt.nz.
Patient Experience Survey Fax Back

(Please write practice name and mark your preference)

*Practice Name: ________________________________*

Data Extract: National patient experience survey

☐ AGREE

We agree to our data being used to send a patient survey and report anonymous results for the national survey.

☐ UNSURE or UNDECIDED

We are unsure or are undecided as to whether to agree or not to our data being used for this project. We would like to discuss it further.

Name of Contact in Practice: ________________________________

*We will contact you to arrange a time to discuss further at your convenience*

☐ DO NOT AGREE

We do not agree to our data being used to send a patient survey and report anonymous results for the national project.

Please Fax Back by [date] to:
[name]
on
[fax number]
Appendix 2: Patient flyer example

You may be asked to help test a new national patient survey.

The Health Quality & Safety Commission and your general practice are working together to develop a new online national patient experience survey.

The survey aims to find out what your experience with health care is like and how your overall care is managed.

Your practice or medical centre is participating in the survey’s testing process. This process is about ensuring we are asking you the right questions in a way that everyone can easily understand.

You may receive an invitation to complete the survey online.

You privacy will be protected at all times through the process.

Taking part is voluntary. You can choose to say yes or no. Your responses will be anonymous.

The survey is a way for you to help improve care and access to health services in local communities across New Zealand.

Talk to your doctor or nurse if you have any questions.

newzealand.govt.nz  www.hqsc.govt.nz
Appendix 3: Draft Patient experience – import file

This document describes the rules surrounding the data extract and resulting file format required for importing patients information from practices/PHOs into the national system’s data warehouse.

Data extract rules

Each PHO extracts the patient data for importing into the PES data warehouse (for sending survey invites, reminders and generating dashboard reports), in accordance with the survey timetable.

The patient extract should include all patient consults that satisfy the following rules:

1. Frequency – [period to be determined] each quarter according to the survey timetable.
2. Date Range:
   Patients with a qualifying event that falls within the xx day period from <day> 00:01 to <day> 23:59.
3. The extract file should exclude any patients if they have been previously included in an extract file supplied in the last 12 weeks. (This rule needs to be turned off if an extract is being regenerated as noted above) Exclude these patients using NHI prior to FTP upload.
4. Only include people aged 15 and over – [Consultation date] – [Date of birth] >= 15 years.
5. Include all records even if no email address or mobile number. (In future we may limit to those records containing an email address or mobile number.)
6. All deceased patients as at the date the extract is run should be excluded from the extract (Note: do not exclude based on the extract date range)
7. Each patient should only appear once in the extract file – PHO to check for and remove duplicates.
8. Only the patient’s most recent qualifying event within the extraction period should be included.

File format

The file received from the PHO needs to meet the following:

- All column headings must be provided as the first line and must match the Field name specified in the table below.
- Where required, use ‘0d0a’ as a record terminator. ‘0’ is a zero.
- The extract file must be named using the following convention: e.g. PROCARE_PE_From_yyyymmdd_To_yyyymmdd.csv
- Codes as opposed to descriptions will be used in columns wherever possible.
- DateTime values should be provided using yyyyMMdd hh:mm:ss
- When fields have embedded commas, commas need to be placed inside double quotes as per the following example:

```
“Nick”,"1 Story Road, Otahuhu", 21, 33,"This is a comment, with a comma"
```

In the example above, the fields with embedded commas are enclosed in double quotes as per normal CSV rules. This then renders 5 columns for the comma delimited row. If there is an embedded double quote in the field then it can be escaped by preceding it with another double quote as per the specification.

<table>
<thead>
<tr>
<th>Field</th>
<th>Data Type</th>
<th>Mandatory Value</th>
<th>Allowed Options (If Restricted)</th>
<th>Example Data</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHI Number</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>-</td>
<td>CHB2702</td>
<td></td>
</tr>
<tr>
<td>Title / Prefix</td>
<td>Text</td>
<td>-</td>
<td>-</td>
<td>Mrs</td>
<td></td>
</tr>
<tr>
<td>First Given Name</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>-</td>
<td>Jennifer</td>
<td></td>
</tr>
<tr>
<td>First Preferred Name</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td>Jenny</td>
<td></td>
</tr>
<tr>
<td>Family Name</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>-</td>
<td>Smith</td>
<td></td>
</tr>
<tr>
<td>Address line 1</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>-</td>
<td>1 Story Street</td>
<td></td>
</tr>
<tr>
<td>Address line 2</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td>Timaru RD1</td>
<td></td>
</tr>
<tr>
<td>Suburb</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td>Waitahora</td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>-</td>
<td>Dannevirke</td>
<td></td>
</tr>
<tr>
<td>Post code</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td>0931</td>
<td></td>
</tr>
<tr>
<td>Mobile phone</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td>0279876543</td>
<td></td>
</tr>
<tr>
<td>Email address</td>
<td>Alphanumeric</td>
<td>-</td>
<td>-</td>
<td><a href="mailto:david@gmail.com">david@gmail.com</a></td>
<td></td>
</tr>
<tr>
<td>Field</td>
<td>Data Type</td>
<td>Mandatory Value</td>
<td>Allowed Options (If Restricted)</td>
<td>Example Data</td>
<td>Comment</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------</td>
<td>-----------------</td>
<td>---------------------------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Date</td>
<td>✓</td>
<td></td>
<td>19900615</td>
<td>The patient’s date of birth</td>
</tr>
<tr>
<td>Date of qualifying event</td>
<td>Date</td>
<td>✓</td>
<td></td>
<td>20110816</td>
<td>Otherwise known as ‘Date of last consultation’ and often the ‘Date of invoice’ field is used</td>
</tr>
<tr>
<td>HPI-O (practice)</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>F2N084-H</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPI-O (PHO)</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>F2N084-H</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHO Org ID</td>
<td>Alphanumeric</td>
<td>✓</td>
<td>794645</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Field</td>
<td>Data Type</td>
<td>Mandatory Value</td>
<td>Allowed Options (If Restricted)</td>
<td>Example Data</td>
<td>Comment</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>---------------------------------</td>
<td>---------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>DHB of domicile (patient)</strong></td>
<td>Integer</td>
<td>-</td>
<td>DHB Area codes</td>
<td>123 or 011</td>
<td>DHB that the patient is domiciled in (This is an optional field to be provided if easily available) See DHB codes below.</td>
</tr>
<tr>
<td><strong>Practice DHB</strong></td>
<td>Integer</td>
<td>✓</td>
<td>DHB Area codes</td>
<td>123 or 011</td>
<td>DHB the practice is physically located in. See DHB codes below.</td>
</tr>
<tr>
<td><strong>Lead/PHO DHB</strong></td>
<td>Integer</td>
<td>✓</td>
<td>DHB Area codes</td>
<td>123 or 011</td>
<td>DHB the PHO holds a contract with. See DHB codes below.</td>
</tr>
</tbody>
</table>

**DHB Codes**

<table>
<thead>
<tr>
<th>DHB Code</th>
<th>DHB Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>011</td>
<td>Northland</td>
</tr>
<tr>
<td>021</td>
<td>Waitemata</td>
</tr>
<tr>
<td>022</td>
<td>Auckland</td>
</tr>
<tr>
<td>023</td>
<td>Counties Manukau</td>
</tr>
<tr>
<td>031</td>
<td>Waikato</td>
</tr>
<tr>
<td>042</td>
<td>Lakes</td>
</tr>
<tr>
<td>047</td>
<td>Bay of Plenty</td>
</tr>
<tr>
<td>051</td>
<td>Tairawhiti</td>
</tr>
<tr>
<td>071</td>
<td>Taranaki</td>
</tr>
<tr>
<td>061</td>
<td>Hawke's Bay</td>
</tr>
<tr>
<td>081</td>
<td>Midcentral</td>
</tr>
<tr>
<td>082</td>
<td>Whanganui</td>
</tr>
<tr>
<td>091</td>
<td>Capital and Coast</td>
</tr>
<tr>
<td>092</td>
<td>Hutt</td>
</tr>
<tr>
<td>093</td>
<td>Wairarapa</td>
</tr>
<tr>
<td>101</td>
<td>Nelson Marlborough</td>
</tr>
<tr>
<td>111</td>
<td>West Coast</td>
</tr>
<tr>
<td>121</td>
<td>Canterbury</td>
</tr>
<tr>
<td>123</td>
<td>South Canterbury</td>
</tr>
<tr>
<td>160</td>
<td>Southern</td>
</tr>
</tbody>
</table>
Appendix 4: Survey data file – still under development

Test survey data will be analysed to ensure the data fields provided do not enable the data to reveal who a patient is. A number of the fields above will need to be removed in discussion with the pilot PHOs to ensure this.

The rows in the file returned to PHOs will be in order of patient responses received, not in the same order as the patient data exported by PHOs or NES to the national provider. This will further ensure patient responses are anonymous.

The survey response file sent to PHOs or the Commission is expected to meet the following:

The file received from the system provider needs to meet the following:

- All column headings must be provided as the first line and must match the Field name specified in the table below.
- Where required, use ‘0d0a’ as a record terminator. ‘0’ is a zero.
- The extract file must be named using the following convention: e.g. PROCARE_PE_From_yyyymmdd_To_yyyymmdd.csv
- Codes as opposed to descriptions will be used in columns wherever possible.
- DateTime values should be provided using yyyyMMdd hh:mm:ss
- When fields have embedded commas, commas need to be placed inside double quotes as per the following example:

  “Nick”,”1 Story Road, Otahuhu”, 21, 33,”This is a comment, with a comma"

In the example above, the fields with embedded commas are enclosed in double quotes as per normal CSV rules. This then renders 5 columns for the comma delimited row. If there is an embedded double quote in the field then it can be escaped by preceding it with another double quote as per the specification.

<table>
<thead>
<tr>
<th>Field</th>
<th>Data Type</th>
<th>Mandatory Value</th>
<th>Allowed Options (If Restricted)</th>
<th>Example Data</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID</td>
<td>Text</td>
<td>✓</td>
<td>-</td>
<td>Q1396, Q2001, Q3229</td>
<td>A unique ID for each survey is to be allocated. This should identify the quarter it relates to and is numbered 001-400.</td>
</tr>
<tr>
<td>Field</td>
<td>Data Type</td>
<td>Mandatory Value</td>
<td>Allowed Options (If Restricted)</td>
<td>Example Data</td>
<td>Comment</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>---------------------------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Age Group</strong></td>
<td>Integer</td>
<td>✓</td>
<td>15 – 24, 25 – 44, 45 – 64, 65 – 74, 75 – 84, 85+</td>
<td>15 - 24</td>
<td>This is the patient’s age on admission. Age groups are proposed to ensure patients remain anonymous.</td>
</tr>
<tr>
<td><strong>Survey period</strong></td>
<td>Date</td>
<td>✓</td>
<td></td>
<td>F012014</td>
<td>The naming of the survey period may be amended but there will need to be a unique name for each fortnight.</td>
</tr>
<tr>
<td>HPI-O (practice)</td>
<td>Alphanumeric</td>
<td>✓</td>
<td></td>
<td>F2N084-H</td>
<td></td>
</tr>
<tr>
<td>HPI-O (PHO)</td>
<td>Alphanumeric</td>
<td>✓</td>
<td></td>
<td>F2N084-H</td>
<td></td>
</tr>
<tr>
<td>PHO Org ID</td>
<td>Alphanumeric</td>
<td>✓</td>
<td></td>
<td>794645</td>
<td></td>
</tr>
<tr>
<td><strong>DHB of domicile (patient)</strong></td>
<td>Integer</td>
<td>-</td>
<td>DHB Area codes</td>
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<td>DHB that the patient is domiciled in (This is an optional field to be provided if easily available) See DHB codes below.</td>
</tr>
<tr>
<td><strong>Practice DHB</strong></td>
<td>Integer</td>
<td>✓</td>
<td>DHB Area codes</td>
<td>123 or 011</td>
<td>DHB the practice is physically located in. See DHB codes below.</td>
</tr>
<tr>
<td>Field</td>
<td>Data Type</td>
<td>Mandatory Value</td>
<td>Allowed Options (If Restricted)</td>
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</tr>
<tr>
<td>---------------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>---------------------------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Lead/PHO DHB</td>
<td>Integer</td>
<td>✓</td>
<td>DHB Area codes</td>
<td>123 or 011</td>
<td>DHB the PHO holds a contract with. See DHB codes below.</td>
</tr>
<tr>
<td>Behalf Yes or No</td>
<td>Text</td>
<td>✓</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Why on behalf</td>
<td>Text</td>
<td>✓ (if yes)</td>
<td>Free text field</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1</td>
<td>Integer</td>
<td>✓</td>
<td>1,2,3,4</td>
<td></td>
<td>1 = first option in list</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 = second option in list, etc</td>
</tr>
<tr>
<td>Q2</td>
<td>Integer</td>
<td>✓</td>
<td>1,2,3,4</td>
<td></td>
<td>1 = first option in list</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 = second option in list, etc</td>
</tr>
<tr>
<td>Q3</td>
<td>Integer</td>
<td>✓</td>
<td>1,2,3,4</td>
<td></td>
<td>1 = first option in list</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 = second option in list, etc</td>
</tr>
<tr>
<td>Etc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6: Health Information Privacy Statement

Health Information Privacy Statement

Purpose for Collection

Your health information is collected so we can provide you with quality care.

We also collect your health information to:

- Keep you and others safe
- Plan and fund health services
- Carry out authorised research
- Train healthcare professionals
- Prepare and publish statistics

Some examples of ways your health information can be used are:

- Your Primary Health Organisation (PHO)\(^5\) uses your information for clinical and administrative purposes, including obtaining subsidised funding for you.

- Your DHB uses your information to provide treatment and care. It may also use your information for planning and funding purposes.

- The Ministry of Health uses your demographic information to give you a National Health Index (NHI) number.\(^6\) The NHI helps to identify you when you use health services.

- The Ministry of Health holds some health information in national collections\(^7\) which helps it measure how well health services are delivered and to plan and fund future health services.

- From time to time auditors may conduct financial audits\(^8\) of your health practitioner. These auditors may review your records and may contact you to check that you received those services.

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\(^5\) Primary health organisations (PHOs) are funded by district health boards to support the provision of essential primary health care services through general practices to those people who are enrolled with the PHO. For more information see [http://www.health.govt.nz/our-work/primary-health-care/about-primary-health-organisations](http://www.health.govt.nz/our-work/primary-health-care/about-primary-health-organisations)

\(^6\) Demographic information includes name, address, date and place of birth and ethnicity. For more information about the National Health Index and your National Health Index number, see [http://www.health.govt.nz/our-work/health-identity/national-health-index](http://www.health.govt.nz/our-work/health-identity/national-health-index).

\(^7\) Information on the collections, what they hold and what the data can be used for can be found at [http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections](http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections)

\(^8\) A financial audit is an accounting process used in business. It uses an independent body to examine a business or organisation’s financial transactions and statements. The ultimate purpose of this form of auditing is to present an accurate account of an organisation’s financial business transactions. The practice is used to make sure that the organisation is trading financially fairly, and also that the accounts it is presenting to the public and/or to the shareholders are accurate and justified.
• From time to time a clinical audit\textsuperscript{9} may be conducted by a qualified health practitioner to review the appropriateness of services provided to you. If the audit involves checking on health matters, an appropriately qualified health practitioner will view the health records.

• When you choose to enrol in a health programme, relevant information may be shared with the health agency managing the programme.

Confidentiality and Information Sharing

Your privacy and the confidentiality of your information is our concern.

• Anything you say to your health practitioner may be included in your notes.

• Your health information will be shared with others involved in your healthcare, and with other agencies with your consent, or if authorised by law.

• You can choose not to share your health information in certain circumstances.

• Not sharing this information may affect the quality of care you receive.

• You have the right to know where your information is kept, who has access rights, and who has viewed or changed your information.

• Your information will be kept securely to prevent unauthorised access.

Quality

We undertake to keep your information accurate, up-to-date and relevant as is necessary for the purposes of treatment and care.

Access and Change

You have the right to access and correct your health information:

• You have the right to see and to request a copy of information about you. You do not have to give a reason for requesting that information. You may be required to provide proof of your identity. If you request a second copy of that information within 12 months, you may have to pay an administration fee for it\textsuperscript{10}.

• You may ask for health information about you to be corrected and you can expect staff to provide you with reasonable assistance. It may be that the healthcare provider chooses not to change that information. If that happens you can have a note added to your file if the change is not made\textsuperscript{11}.

Research

Your health information may be used in research approved by an ethics committee or when it has been anonymised.

\textsuperscript{9} A clinical audit is a process that has been defined as "a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change" (Ghosh R., ed; \textit{Clinical Audit for Doctors}. Nottingham: Developmedica, 2009. (ISBN 978-1-9068390-1-7 - "www.nice.org.uk": \textit{Principles of Best Practice in Clinical Audit 2002}. Retrieved Aug 2010.) The key component of clinical audit is that performance is reviewed (or \textit{audited}) to ensure that what \textit{should} be done is \textit{being} done, and if not it provides a framework to enable improvements to be made.

\textsuperscript{10} See Rule 6 Health Information Privacy Code 1994

\textsuperscript{11} See Rule 7 Health Information Privacy Code 1994
• If the research is to be published and may directly or indirectly lead to your being identified, this can only be done if the researcher has previously obtained your consent and the research has received ethics approval.
• If your health information is used for research or statistical purposes but is not published, or if it is published in a way that does not identify you, then the law currently does not require that you consent to this.¹²

Complaints

It is OK to complain – your complaints help ensure information is secure and trusted. Talk to your healthcare provider or freephone the Office of the Privacy Commissioner on 0800 803 909.


For further information regarding health information and research, a copy of the Health and Disability Committee’s Standard Operating procedures can be found at http://ethics.health.govt.nz/operating-procedures

If you have any concerns or questions, talk to your healthcare provider or freephone the Office of the Privacy Commissioner on 0800 803 909.

¹² Rule 11(2)(c) of the Health Information Privacy Code 1994 states the following in regard to research:

11 (2) Compliance with sub rule 1 (b) [authorisation by the individual – ed] is not necessary if the health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and that –
(c) The information –
(i) is to be used in a form in which the individual concerned is not identified; or
(ii) is to be used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; or
(iii) is to be used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned.