

# Practice Incentive Program Quality Improvement Incentive Data Privacy and Security Review

Summary and Recommendations

### Overview

The Department of Health commissioned a Data Privacy and Security Review of data collected through the Practice Incentive Program (PIP) Quality Improvement (QI) Incentive and the processes by which it is held and transferred by data custodians (**the Review**). The Review was initiated in response to concerns that had been raised by a number of stakeholder groups regarding the security of general practice data being collected and analysed by Primary Health Networks (**PHNs**) and the Australian Institute of Health and Welfare (**AIHW**).

The Review found that despite differences in the way the data is collected from general practice by PHNs, data security controls to protect de-identified data from misuse, interference and loss were appropriate. A total of 14 recommendations were made to further strengthen data protection.

## **Background**

The PIP QI Incentive is a payment made to general practices that undertake quality improvement activities to improve patient care. It requires participating general practices (**local data custodians**) to share a minimum set of de-identified, patient data (**PIP Eligible Data Set**) with their local PHN (**regional data custodians**). The data collected is used by PHNs to work in partnership with general practices to support ongoing quality improvement activities. The data also contributes to service planning and identification of population health needs. De-identified data aggregated at the PHN level will be shared with the AIHW (**national data custodian**) for national level analysis and research.

### **Approach**

Stakeholders participating in the Review included all PHNs, data extraction tool vendors and clinical information system vendors. Engagement was through a series of meetings, teleconferences and online questionnaires. The Review focused on a number of areas directly related to the a) physical and digital data storage, access and contractual protections for security and b) privacy policies relating to the collection and sharing of the PIP Eligible Data Set. Independent technical validation and auditing of the data extraction and reporting process was not in scope for the Review.

### **Findings**

The Review found that whilst there is variability in the way the PIP Eligible Data Set is collected from general practices and transferred to the PHNs, the data security controls currently in place during the data collection, use and storage processes are appropriate to protect de-identified data from misuse, interference and loss.

Further, the Review identified that variability between PHNs is largely in the data extraction tool used and the format and level of aggregation of the data that is being transferred. It is the prerogative of PHNs and participating general practices to negotiate agreements on the provision of data, with certain types of arrangements being more privacy-positive and carrying a lower risk of unauthorised disclosure.

The requirement by the *Privacy Act 1988* is that the de-identification efforts account for and minimise the risk of re-identification. The stakeholders consulted in this Review indicated that data is being de-identified prior to leaving the general practice.

### **Outcome and next steps**

The implementation of the PIP QI Incentive has increased awareness among all stakeholders of data privacy and security issues. This increased awareness has presented an opportunity to implement best practice approaches around the collection of general practice data more generally.

The Review has made 14 recommendations to the Department of Health for further strengthening the PIP QI Incentive around the sharing of the PIP Eligible Data Set with respect to data privacy and security. These include strategic, data set and operational recommendations. The Department is committed to addressing all of the recommendations outlined in the Review.

# **PIP QI Data Privacy and Security Review- Recommendations**

No.	Recommendation	Current Status	Department of Health's response to recommendation
1	The Department of Health perform a review into the extraction of wider population health data sets and other data sets from general practices to PHNs, and how this data is handled and used by data extraction vendors, PHNs and Commonwealth agencies.	Action required	The Department is currently considering the potential need for a regulatory impact statement process to assess regulatory options to improve, privacy, security and interoperability arrangements for general practice and/or broader health data.
2	From its early stages, any changed or new program that addresses the collection or use of patient or practice data involve a broader collaboration between the Department of Health, general practices, PHNs, data extraction tool vendors and clinical information system vendors.	Continuing	The Department will continue to engage with relevant stakeholders on programs, which collect patient or practice data.
3	Targeted information campaigns and information resources be provided well in advance to address any anticipated concerns of both general practices and patients ahead of the implementation of any new or changed data collection program.	Continuing	The Department will continue to provide relevant stakeholders the opportunity to comment on proposed resources to ensure queries and concerns are addressed prior to public release. The Department will work to improve lead times for public release of resources and material to support sector readiness.
4	That planning and budgeting for any programs involving the collection of data account for the high resource and effort cost associated with the implementation of data privacy and security best practice controls.	Continuing	The Department will continue to monitor the costs and regulatory burdens associated with implementing data privacy principles and security best practice controls. This will be assessed through ongoing engagement with relevant stakeholders required to implement these measures.
5	To support consistency in privacy and security maturity across PHNs, opportunities for ongoing inter-PHN collaboration to share knowledge and practices be identified.	Actioned	PHNs have a number of established networks for collaboration in data privacy and security, such as the PHN Data Steering Group and state based data governance committees.  This will be bolstered by the Government's \$10 million investment in a PHN National Data Storage and Analysis Solution (NDSAS).  In addition, the Department has established a PHN PIP QI working group and SharePoint site to facilitate collaboration and the sharing of knowledge across regions. The working group provides PHNs with direct access to the Departmental PIP QI staff ensuring timely support.
6	PHNs be provided with an optional standard contract which includes the data privacy and security controls expected in contractual arrangements and other agreements with third-party providers. This should be supported by the facilitation of collaboration and knowledge sharing between PHNs, particularly in the area of contract management.	Actioned	The Department has developed a model data sharing agreement which has been co-designed with PHNs, the PIP Advisory Group (PIPAG) and its Data Governance Sub Committee.  The model data sharing agreement sets out model terms and conditions for the creation and submission of the PIP Eligible Data Set.
7	Guidance be provided on the level of security controls that are expected around the direct reporting of the PIP Eligible Data Set and that vendors are supported in the development of interfaces which ensure that data privacy and security is maintained.	Actioned	The Department engaged Doll Martin Associates Pty Ltd. to develop clear and concise resources for the PIP Eligible Data Set submission requirements. These resources have been finalised and will assist in providing clarity around privacy and security requirements for the data set by articulating the type of data required by general practice to PHNs and emphasising deidentification and suppression requirements.  The Department will also continue to work with the PIPAG Data Governance Sub-Committee to ensure that the PIP Eligible Data Set Data Governance Framework provides sufficient guidance on security and privacy arrangements.  The Department has also developed a time limited PHN Data Working Group to assist software vendors and PHNs in understanding PIP QI data requirements including those relating to data privacy and security.
8	A detailed specification on the reporting, data aggregation and manipulation requirements of the national data custodian be developed and provided to PHNs expeditiously to inform planning and change management.	In progress	The Department has established a Regional and National Data Custodian SharePoint site to enable collaboration between the Australian Institute of Health Welfare (AIHW) and the PHNs on specific data sharing requirements. The AIHW is working directly with a number of PHNs to develop and test data shells and mechanisms for the exchange of data including supporting data sharing agreements
9	An independent testing and validation of the data extraction process through data extraction tools be performed to review effectiveness of security controls and processes, including the deidentification of data.	Action required	As noted under Recommendation 1, the Department is currently considering the potential need for a regulatory impact statement process to assess regulatory options to improve, privacy, security and interoperability arrangements for general practice and/or broader health data. The RIS will address independent testing and validation of data from differing extraction tools.

No.	Recommendation	Current Status	Department of Health's response to recommendation
10	PIP Eligible Data Set regional and national data custodians review their archiving and data disposal requirements and seek where possible to dispose of the PIP Eligible Data Set where it is no longer being used for its intended purposes. The requirement to dispose of the PIP Eligible Data Set once it is no longer needed to fulfil a contractual obligation should be included in contractual arrangements with third-party vendors.	Action required	The Department will develop PIP QI archiving and disposal requirements in consultation with the PIPAG and its Data Governance Sub-Committee.
11	In order to avoid uncertainty, it is recommended that the Department and the AIHW provide detailed specifications for the PIP Eligible Data Set in one document, which includes definitions for Improvement Measures and their denominators and numerators, and how each of these measures should be disaggregated when they are reported, for example, by which specific age groups, sex groups, gender groups etc. This information should be made available to all stakeholders in the PIP QI process.	Actioned	The Department engaged Doll Martin Associates Pty Ltd. to develop clear and concise resources for the PIP Eligible Data Set submission requirements. These resources, developed in collaboration with the AIHW and the Department, PHNs and the Software Providers have been finalised and are as follows:  - PIP QI Data Specifications - PIP QI Code Mapping - PIP QI Technical Specifications (version 2) - PIP QI User Guide  These documents clarify how each measure is calculated and will provide in-depth information for clinical information system providers and clear information for practices.  The documents have been endorsed by the PIPAG and its Data Governance Sub-Committee and subsequently released to key stakeholders.
12	The Department of Health and the national data custodian review and publish the purposes for requiring disaggregation by ethnicity and sexual orientation, considering their status as sensitive information and the associated risks associated with disclosing this information.	Actioned	The Department in consultation with PIPAG and PIPAG DGSC reviewed the requirement for disaggregation by ethnicity and sexual orientation. Noting the sensitivity of this information and the associated risks both ethnicity and sexual orientation have been removed.
13	PHNs currently collecting person-level data as a part of PIP QI reporting review and confirm that they have considered the enhanced security controls which mitigate the greater risk of reidentification associated with small and granular data sets.	In progress	As noted under Recommendation 11, the Department engaged Doll Martin Associates Pty Ltd. to develop materials which further clarify the data format and requirements pertaining to the PIP Eligible Data Set. The Department will also continue to work with the PIPAG Data Governance Sub-Committee on ensuring all data custodians are aware of their responsibilities.
14	PHNs, the Department of Health and the national data custodian should review and clarify the requirements for the format of reporting, to remove the confusion regarding aggregated versus person level reporting.	In progress	As noted under Recommendation 11, the Department engaged Doll Martin Associates Pty Ltd. to develop materials which further clarify the data requirements pertaining to the PIP Eligible Data Set.  Materials include:  - PIP QI Data Specifications - PIP QI Code Mapping - PIP QI Technical Specifications (version 2) - PIP QI User Guide  The Department will also work closely with PHNs and Software Providers through the PHN Data Working to ensure there is a clear understanding of the data requirements for PIP QI.

Current Status	Definition
In progress	Work on this recommendation has already commenced
Actioned	The recommendation has already been actioned and implemented
Action required	The Department will undertake steps to address the recommendation
Continuing	The Department will continue its work in key areas to support the successful implementation of PIP QI