



Australian Government

Department of Health

PIP Eligible Data Set Data Governance Framework

Acknowledgement

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Introduction

Context

The Practice Incentives Program (PIP) Quality Improvement (QI) Incentive Data Governance Framework for the PIP Eligible Data Set is a principles-based document that broadly articulates the roles and responsibilities of all data custodians involved in the content, collection, use, access, aggregation, privacy and security of the PIP Eligible Data Set.

The Department of Health is responsible for oversight and enforcement of this Framework and recognises that data is a strategic asset of national significance. The Framework is consistent with overarching government strategies, frameworks, and legislation, including the Council of Australian Governments' endorsed National Digital Health Strategy, the My Health Record secondary use of data framework, and the *Privacy Act 1988*.

Quality Improvement

Quality improvement is foundational to contemporary high performing primary care. It has the potential to influence and improve uptake of evidence-based practices for better patient outcomes, better system performance, and better professional development. It incorporates a team based approach, peer review, reflective practice, best practice, and data analysis. Ideally, quality in contemporary primary care settings is known and understood by those working in primary care teams, transparent to patients and funders alike, and rewarded.

PIP QI Incentive

The PIP QI Incentive is a payment to general practices for activities that support continuous quality improvement in patient outcomes and the delivery of best practice care. The PIP QI Incentive represents a move away from process focussed funding towards outcome focussed funding.

The PIP QI Incentive is a mechanism for undertaking continuous quality improvement through the collection and review of uniform, nationally consistent, general practice data, against ten key Improvement Measures that contribute to local, regional and national health outcomes. General practices commit to implementing quality improvement plans that support them in their role of managing their patients' health. Improvements in digital maturity, data cleansing, clinical coding, and the seven attributes of quality health records underpin the PIP QI Incentive.

Data collected through the PIP QI Incentive has the potential to benefit patients directly. For example, Improvement Measures allow the practice to understand what proportion of their patients may benefit from preventative treatments, or may need recall to ensure effective management of a specified chronic disease, such as diabetes. This can help delay progression of the condition, improve quality of life, increase life expectancy, and decrease the need for high cost interventions. By using the PIP Eligible Data Set as a common baseline PIP QI aims to drive quality improvement, and to provide clear guidance to general practices and general practitioners that elect to participate in the incentive.

PIP Eligible Data Set

The PIP Eligible Data Set supports the implementation, management and ongoing development of the PIP QI Incentive. The PIP Eligible Data Set demonstrates general practice improvement in quality of care and patient outcomes across key health priority areas. It also informs regional health planning and service delivery, and national health policy.

The PIP Eligible Data Set is only the specified Improvement Measures de-identified data set provided by a general practice as part of their participation in the PIP QI Incentive payment. Any other data shared by a general practice with a third party is outside the scope of this Framework.

Principles

The PIP Eligible Data Set Data Governance Framework is a principles based document that articulates the five broad principles and responsibilities that underpin the governance of the PIP Eligible Data Set:

1. Privacy
2. Content
3. Collection, use and access
4. Aggregation
5. Security

Data Custodians

Context

The PIP Eligible Data Set Data Governance Framework governs the data custodians involved in aggregating the data into the PIP Eligible Data Set at local, regional and national level. The PIP Eligible Data Set is comprised of data extracted on specified quality Improvement Measures from participating general practices' clinical information systems. The de-identified data is analysed at both regional and national levels to inform broader public health policy, planning and service delivery.

Rationale

Simple, clear rules and guidance on the specific roles and responsibilities for data content, collection, use, access, aggregation, privacy, security, and data ownership for local, regional and national data custodians of the PIP Eligible Data Set.

Details

PIP Eligible Data Set – Local Data Custodians

DESCRIPTION: Participating general practices control collection, use, access, privacy and security of data at the general practice level and are designated local data custodians.

ROLE: Ensure the accuracy and completeness of the data contained in their clinical information systems and use it to improve the quality of patient care and outcomes.

RESPONSIBILITIES: All general practices have sensitive, personal information and health information about patients contained in their clinical information system and/or paper filing system. General practitioners have existing professional and legal obligations to ensure the information contained in their patient files is current, accurate, securely stored, and confidential. Accredited general practices also obtain specific patient consent for transferring health information to third parties for quality improvement and clinical audit activities. These responsibilities do not change for general practices participating in the PIP QI Incentive.

Participating PIP QI Incentive general practices have the opportunity to receive assurance that any arrangements they enter into with data extraction companies or regional data custodians are sufficient to continue to comply with their existing privacy and security obligations. They also continue to ensure security updates and/or patches issued by their clinical information system provider, or by their data extraction provider are installed.

PIP Eligible Data Set – Regional Data Custodians

DESCRIPTION: Primary Health Networks (PHNs) aggregate and control collection, use, access, privacy and security of data at the regional level and are designated regional data custodians.

ROLE: Extract and analyse the PIP Eligible Data Set to support participating general practices implement quality improvement activities.

RESPONSIBILITIES: Regional data custodians are responsible for ensuring robust data extraction of the Improvement Measures that form the PIP Eligible Data Set from general practices participating in the PIP QI Incentive. They also ensure prompt installation of all security updates or patches in their information technology systems. They set up user accounts, manage and monitor access, and ensure audit trails by unique user identification are available. They execute licenses and contracts with data extraction companies that are current and fit for purpose with all necessary security and privacy safeguards in place. They extract and analyse the PIP Eligible Data Set to support practices implement quality improvement activities.

PIP Eligible Data Set – National Data Custodian

DESCRIPTION: A yet to be determined national provider aggregates and controls collection, use, access, privacy and security of data at the national level and is the designated national data custodian of the PIP Eligible Data Set.

ROLE: Analyse the PIP Eligible Data Set for population health planning, policy development, program management, disease burden analysis, and relevant trends.

RESPONSIBILITIES: The national data custodian is responsible for managing the use, disclosure and protection of source data, any access requests and associated ethics processes, periodic evaluation and review to assess whether the use of the data is meeting the intended health related benefits. The national data custodian is also responsible for the maintenance of infrastructure necessary for ensuring data security, including secure servers and remote access protocols.

Principle 1 – Privacy – Protection of the privacy of individuals is maximised

Context

Collection, use and access of the PIP Eligible Data Set must comply with all relevant overarching legal requirements to ensure the privacy of individual patients.

Rationale

Australians expect strong safeguards to ensure their health information is safe and secure, that the privacy of their health information is respected, and their rights protected. All healthcare providers in Australia have professional and legal obligations to protect their patients' health information. The PIP QI Incentive is safeguarding privacy by only using a specified, limited, de-identified data set, and by obtaining evidence of the assurance process before, during and after de-identification.

Details

Personal information is protected by law. All local, regional and national data custodians have current privacy notices and privacy policies consistent with the *Privacy Act 1988*, and relevant state or territory legislation.

Privacy of individual patients

The protection of patient privacy is paramount. No personally identifying information of any patient is provided as part of the PIP Eligible Data set to regional data custodians or the national data custodian. The PIP Eligible Data Set is not linked to other data sets if such linkage could reasonably result in the data being re-identified.

Privacy of participating general practices and general practitioners

Regional data custodians collect identifying information of general practitioners and general practices participating in the PIP QI Incentive. This identifying information is not part of the PIP Eligible Data Set. It is collected to administer the PIP QI Incentive: to analyse the data, create quality improvement plans, assign the quality improvement plan to the correct general practitioner and/or general practice, and to confirm eligibility of the general practice to receive the PIP QI Incentive payment. The provision of identifying information to the Department of Health and the Department of Human Services occurs to administer the program, including program compliance, statistics and research, policy development, payment of the incentive, and accountability for the expenditure of Commonwealth funds.

Local Data Custodians protection of privacy

General practices use robust data extraction tools that de-identify patient information so they can confidently share that information with third parties. Practice culture combined with digital systems enable them to meet their existing obligations to keep their patients' health information secure and private, and they know that any de-identified health data shared is to improve patient outcomes.

Regional Data Custodians protection of privacy

Regional data custodians ensure that an individual's privacy is protected in the process of preparing, supplying and receiving de-identified data from local data custodians to the PIP Eligible Data Set. Proven methods reduce the risk of breaching an individual's privacy to very low levels. This is formalised in data sharing and licensing agreements with general practices and with data extraction companies. Regional data custodians have data governance committees to oversee their data governance frameworks, data policies, data procedures, data guidelines, and risk management plans that include specifications for audit trails, the notification and management of data breaches, and disaster recovery plans.

National Data Custodian protection of privacy

The national data custodian ensures privacy policies and privacy notices comply with all relevant legislation. No identifying information is provided to the national data custodian.

Note: Regional data custodians or the national data custodian cannot re-identify the PIP Eligible Data Set.

Resources

- [Privacy Act 1988](#) and Australian Privacy Principles for APP entities: specifically APP 10, 11, 12 and 13
- Privacy fact sheets [49](#) and [50](#) – Office of the Australian Information Commissioner
- State and Territory privacy laws
- [Guidelines approved under Section 95A of the Privacy Act 1988](#) – National Health and Medical Research Council, 2014

Principle 2 – Content – PIP Eligible Data Set is clearly defined

Context

The PIP Eligible Data Set aims to support quality improvement by providing a consistent method of benchmarking and tracking improvement in patient quality of care and outcomes. The PIP Eligible Data Set is designed to aid local, regional and national primary care quality improvement.

Rationale

To ensure national consistency the PIP Eligible Data Set has clear specifications with defined terminology and clear rules for the calculation of each PIP Quality Improvement Measure.

Details

The Improvement Measures are:

1. Proportion of patients with diabetes with a current HbA1c result
2. Proportion of patients with a smoking status
3. Proportion of patients with a weight classification
4. Proportion of patients aged 65 and over who were immunised against influenza
5. Proportion of patients with diabetes who were immunised against influenza
6. Proportion of patients with COPD who were immunised against influenza
7. Proportion of patients with an alcohol consumption status
8. Proportion of patients with the necessary risk factors assessed to enable CVD assessment
9. Proportion of female patients with an up-to-date cervical screening
10. Proportion of patients with diabetes with a blood pressure result

Specifications

Each Improvement Measure that forms part of the PIP Eligible Data Set is consistently and precisely specified. Any future Improvement Measures will be specified the same way.

The PIP Eligible Data Set specifications promote consistent data analysis and interpretation:

- definition
- rationale
- computation description, including method of calculation, numerator and denominator
- computation
- numerator data element and source
- numerator data source attributes: data source, frequency, data custodian
- denominator data element and source
- denominator data source attributes: data source, frequency, data custodian
- interpretation
- disaggregation data
- disaggregation data elements
- aggregation data
- aggregation data elements
- references.

Resources

- PIP QI Guidelines, 2018
- PIP QI Data Specifications, 2018
- [Privacy Act 1988](#)
- [Standards for General Practice 5th edition](#) – Royal Australian College of General Practitioners
- Impact of Digital Health on the Safety and Quality of Health Care, Australian Commission on Safety and Quality Care in Health Care, 2018
- [Practice level indicators of safety and quality for primary health care](#) specification – Australian Commission on Safety and Quality Care in Health Care, 2012

Principle 3 – Collection, Use and Access – PIP Eligible Data Set management is consistent

Context

The PIP Eligible Data Set is a national data asset. Collection, use and access to the PIP Eligible Data Set is consistently and transparently managed throughout Australia.

Rationale

The PIP Eligible Data Set provides the foundation for a national data set for primary care quality improvement.

Details

The PIP Eligible Data Set supports the implementation, management and ongoing development of the PIP QI Incentive. De-identified data in key areas of patient quality of care and outcomes are analysed to inform quality improvement plans. Future iterations will respond to emerging evidence on areas of high need.

Collection

A significant proportion of general practices exchange de-identified healthcare data from their clinical information system with third parties via secure third party data extraction tools. Data extraction and transfer occurs under data sharing and licensing agreements between third parties and general practices, using robust data extraction tools. Regional data custodians only collect the PIP Eligible Data Set from general practices that participate in the PIP QI Incentive payment.

The Department of Health requires that:

- Contemporary de-identification methods and techniques are appropriately applied before any data is collected and made accessible to regional data custodians.
- No patient identified personal or health information is removed or stored externally from the general practice's clinical information system.

Note: No data leaves the general practice without the practice's permission.

Use

The PIP Eligible Data Set aims to:

1. improve the quality of care and patient outcomes
2. improve the capacity for general practices to benchmark their activities against peers on an agreed set of improvement measures;
3. provide nationally consistent, comparable data against specified quality improvement measures to create regional and national health data sets;
4. contribute to service planning and population health mapping at different levels including, PHN boundaries, local health districts, jurisdictional boundaries, and national; and
5. confirm participant eligibility for the receipt of Commonwealth funding under the PIP QI incentive.

Prohibited Use

The PIP Eligible Data Set is prohibited from being commercialised by any data custodians.

Note: The patient information within the PIP Eligible Data Set remains de-identified at regional and national levels. The only data custodian with access to identified information is the local data custodian (participating general practice).

Access

The national data custodian manages applications to access the PIP Eligible Data Set. In summary, applications must comply with any guidance issued, be made in writing to the national data custodian, be published on a searchable register, and only be for one of the five uses described above. Assessment includes trusted users and the Five Safes Framework for effective use of sensitive data.

Resources

- [Framework to guide the secondary use of My Health Record system data](#) – Department of Health, 2018
- [Australian Code for the Responsible Conduct of Research](#) – National Health and Medical Research Council, 2018
- [National Safety and Quality Health Service Standards, Second Edition](#) – Australian Commission on Safety and Quality Care in Health Care, 2017

Principle 4 – Aggregation – PIP Eligible Data Set is managed according to clear protocols

Context

The PIP Eligible Data Set is aggregated at regional and national levels, and disaggregated where relevant. This aids public health policy, planning, service delivery, and trend analysis. Data sharing agreements, data storage and security policies, and data custodians support aggregation and disaggregation.

Rationale

Governments, PHNs, researchers, scientists, and the health informatics community may access the de-identified data in the PIP Eligible Data Set for research to help deliver insights on health trends and deliver population health improvements. The national data custodian will determine exact arrangements.

Details

Aggregation, disaggregation and linkage of the PIP Eligible Data Set at various geographic, demographic and clinical levels will be permitted. Permissions for all data custodians will be established in line with suppression rules determined by the national data custodian. The PIP Eligible Data Set will not be linked to other data sets if such linkage could reasonably result in the PIP Eligible Data Set being re-identified.

Table 1: Aggregation and disaggregation permissions

Group	Type	Local Data Custodian	Regional Data Custodian	National Data Custodian
Geographic level	Local practice	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
	Suburb	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
	Post code	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	ABS Postal area	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	District		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Region		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	PHN Boundary		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Modified Monash Model		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Rural, Remote & Metropolitan Areas		<input checked="" type="checkbox"/>	
	SA1		<input checked="" type="checkbox"/>	
	SA2		<input checked="" type="checkbox"/>	
	SA3		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Jurisdiction			<input checked="" type="checkbox"/>
	National			<input checked="" type="checkbox"/>
Demographics	Sex	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Gender	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Age (five year brackets)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Ethnicity	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	ATSI status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Relationship status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Sexual orientation	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Clinical	Type 1 Diabetes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Type 2 Diabetes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	COPD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Weight classification	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Smoking status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Cervical screening status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Influenza immunisation status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Resources

- [Standards for General Practice 5th edition](#) – Royal Australian College of General Practitioners
- [Australian Code for the Responsible Conduct of Research](#) – National Health and Medical Research Council, 2018
- [Ethical considerations in quality assurance and evaluation activities](#) – National Health and Medical Research Council, 2014

Principle 5 – Security – PIP Eligible Data Set confidentiality, integrity, and availability is maintained

Context

Collection, transfer, access and storage of the PIP Eligible Data Set is undertaken in a secure manner to maintain the three pillars of security: confidentiality, integrity, and availability.

Rationale

General practitioners have existing professional obligations and legal requirements to keep their patients' health information secure and private. Strong security and risk management frameworks that protect sensitive information while also enabling the safe and efficient sharing of information are vital. They are essential to building trust and enabling quality improvement activities. General practitioners need confidence in the security of the digital systems that enable them to share de-identified patient information with third parties. They also need assurances that the PIP Eligible Data Set is used appropriately to help them improve patient outcomes.

Details

Storage of the PIP Eligible Data Set meets the requirements for health data stored in Australia as determined by the Australian Digital Health Agency, and data custodians will comply with the best practice guides when issued in 2019. Regional data custodians monitor changes in technology and data science to anticipate new confidentiality and integrity threats. They use this knowledge to inform their security and risk approach.

Data custodians and data extraction companies detail who is responsible for which aspects of confidentiality, integrity and availability, including but not limited to, transfer protocols, secure delivery, access authentication, audit trails, and management of data breaches. Data custodians consider strategies to mitigate cyber security incidents, including the applicability of the Essential Eight.

Confidentiality is maintained with appropriate controls

- Data custodians implement role based access controls based on specified business needs
- Data custodians identify, mitigate and accept risks
- Data custodians encrypt sensitive data at rest and in transit

Integrity is maintained during data extraction, transfer and storage

- Data custodians and data extraction companies control access to the data at all times
- Data custodians maintain logs of all access, change, and transit of data
- Transfer of PIP Eligible Data Sets from local data custodians to regional and national data custodians meets the data storage specifications of the Australian Digital Health Agency

Availability is maintained through appropriate governance and contingency planning

- Dedicated servers for data warehouses with appropriate back-ups and disaster recovery plans
- Regional data custodians have data governance committees, frameworks, policies, guidelines
- Identified data within the PIP Eligible Data Set is not removed or stored externally from the general practice's clinical information system

Resources

- [Information Security Guide for small healthcare businesses](#) – Australian Digital Health Agency
- [Guide to securing personal information](#) – Office of the Australian Information Commissioner
- [Essential Eight Explained](#) – Australian Cyber Security Centre
- [Stay Smart Online Small business guide](#) – Australian Cyber Security Centre
- [Computer Information Security Standards](#) – 2nd edition RACGP

Next steps

Context

Data governance is more than a Framework. It is a system of rights and accountabilities that are supported by a range of processes and documents. These will be developed by the Department of Health, regional data custodians and the national data custodian to augment the Framework.

Rationale

It is important to ensure that the Framework and supporting documents align with developments in Australia's approach to data including integrating authorities, accredited data authorities, assessment of national interest data sets, and any new legislation such as the proposed Data Sharing and Release Act, and guidance issued by the National Data Commissioner. It is also important to ensure that once the national data custodian is appointed the Framework maps seamlessly without conflict into the organisational framework and any governing legislation of the national data custodian, noting the move from a paradigm that restricts access to data to one, which authorises sharing and release when appropriate data safeguards are in place.

Details

Local Data Custodians

Participating general practices will need to enter into data sharing agreements for the PIP Eligible Data Set with their local PHN.

Regional Data Custodians

Supporting elements should build off best practice guidance and standards on data availability and use, and any existing data governance arrangements such as data governance boards or appropriate advisory committees, ethics committees, and any other governance structures in place. Documentation may include:

- Data custodian level data governance framework including data management concepts, data acquisition, data backup and restore capabilities, data integrity, data quality management, data archiving, return and destruction
- Data governance committee terms of reference including membership and scope
- Data governance policy, guidelines or procedures that provides direction on how data is managed and what sanctions exist for breaches
- Data management plan specifying scope, program monitoring, roles and responsibilities, access and analysis
- Data request access process, documentation and supporting forms

National Data Custodian

The national data custodian will manage applications to access the PIP Eligible Data Set. The national data custodian will need to issue guidance material to those seeking to access the data set that explains the application process, the assessment criteria including trusted users, the Five Safes, and advises that applications will be published on a publically searchable register.

Documentation may include:

- Data request access process, documentation and supporting forms

Resources

- [Data availability and use](#) – Productivity Commission Inquiry Report
- [The Australian Government's response to the Productivity Commission Data Availability and Use Inquiry](#) – Department of Prime Minister and Cabinet
- [New Australian Government Data Sharing and Release Legislation – Issues Paper for Consultation](#) – Department of Prime Minister and Cabinet