

Key Principles and Rationale

The Intention of the AGPA to assist a smooth rollout of the QI-PIP program and to ensure that the data collection and storage systems that are in place are of an appropriate standard to protect our colleagues, our patients and the sector to enable good QI initiatives using data whilst ensuring the confidentiality of patient information and commercially sensitive Practice data.

The Alliance recommends the following principles be adopted and incorporated into the QI-PIP program:

- **A privacy impact assessment should be undertaken.**
- **A data governance framework must be established prior to the release of any aggregate data sets to third parties, as has been established with the My Health Record.**
- **Further consideration be given to avoiding the inherent risk of data collection by 31 PHNs in favour of a single, trusted, national data repository. AGPA is of the view that the Australian Institute of Health and Welfare (as a trusted and respected organisation) has the capability to be that repository, potentially through its integrated “Health care quality and performance” arm.**
- **Patients should be provided with transparent advice regarding the data collection process and their ability to opt out.**
- **All patient data be sufficiently de-identified at transmission from the Practice to ensure there is minimal risk of re-identification.**
- **A single national sign-up contract for General Practice uploads to this data repository.**
- **The only data elements uploaded to the national repository are the 10 agreed QI PIP requirements represented as ratios rather than atomic data. The QI PIP Eligible Data Set should consist only of 10 ratios, each of which reports the proportion of the Practice’s patients who meet the criterion in each of the 10 measures.**
- **Individual practice and Doctors’ personal and demographic data must be de-identified and MBS data must be excluded from the collection.**
- **Practices must be provided with competitively neutral choices regarding the upload tools available including the option for direct upload from native clinical software.**
- **Data should be made available to PHNs and other interested parties via a secondary use framework.**
- **Commercialisation of the uploaded QI PIP data sets must be prohibited under law.**

A rationale and some links are attached for information.

Recommendation Rationale

Quality improvement is a key component of high-quality general practice and underpins the continuing evolution of general practice.

Consequently AGPA is of the view that practices which are eligible for the QI – PIP should only enrol into that program once they have carefully reviewed the requirements and associated contractual obligations and that Practices should be fully aware of the benefits and risks and establish mechanisms to manage and mitigate those risks accordingly.

Practice Owners and Directors must also consider their personal liability and exposure particularly in relation to the Privacy Act and its associated provisions. Where in doubt it may be prudent to seek advice from the provider’s Medical Indemnity Provider

The only appropriate use of the PIP Eligible Data Set is for quality improvement. This should not provide a methodology for infiltration into General Practices by the primary-care networks or

indeed government for any other purposes including compliance with the Medicare Benefits Schedule or used as a mechanism for performance management.

AGPA expects all arrangements for the governance of the QI PIP Eligible Data Set to have been made acceptable to the profession prior to the first release of any data sets to third parties.

Given that the process may expose commercially sensitive and patient sensitive data AGPA also calls upon the government to undertake a privacy impact assessment. This is especially of concern when using third party extraction tools and proving these data to organisations without established data management, governance and ethical processes.

General practices should be informed that they have a clear and unfettered choice of how they extract the QI PIP Eligible Data Set from their clinical and administrative databases. They should be informed that currently this can be done in the following ways:

- By purchasing their own licences for commercially available data extraction tools and using that tool to provide the data set via a practice controlled upload.
- Use their own in-house or contracted technical skills to develop a stand-alone query and extraction process from their clinical and administrative databases for the data required for the QI PIP Eligible Data Set.
- Enter into a contract with their Primary Health Care Network (PHN) for a subsidised licence for a commercially available data extraction tool, in exchange for permitting the PHN to perform the extraction of the QI PIP Eligible Data Set and to upload it to the PHN. AGPA believes that many of the contracts that practices have with PHNs for the extraction and uploading of data do not limit the data to just that required for the QI PIP Eligible Data Set, and advises practices to review any current contract with their PHN which was signed before 1 August 2019. AGPA points to the statement from the RACGP on 2 August 2019 <https://www1.racgp.org.au/newsgp/professional/gps-urged-to-show-caution-when-joining-pip-qi> .

AGPA also understands that several key vendors of clinical software packages are currently working to add embedded capability within their own software for practices to have the ability to generate, view and upload the QI PIP Eligible Data Set. This will be under the explicit control of the practice and will consequently obviate the need to use any separate data extraction tool (whether self-funded or subsidised under a contract with the PHN). **AGPA believes that this is the preferred mechanism for data upload as it creates a clear and transparent mechanism for QI PIP data upload which is controlled by the practice and is cost neutral.**

Should a practice choose to enter into a contract with a (PHN) to use the tools that are being advised or provided by that network, the contract must be clear about what is being agreed, what information is being collected and sent, what is being collected and not sent, and what will happen to the data that is collected.

Measures to protect the integrity of the data whilst in the hands of the PHN must be clearly defined and responsibility taken by the curating receiving organisation. **The requirement for Practices to indemnify PHNs is unacceptable.**

Practices have ownership of and must maintain the integrity of their own data and control of what is extracted and transmitted from their systems. In particular de-identified data must be confirmed as being de-identified and patients must have the opportunity to opt out of the process.

The case for the involvement of the PHNs as direct data extractors has not been made. AGPA reiterates a preference for a single trusted national data repository. Furthermore, AGPA understands that some PHNs have expressed legitimate concerns about being required to undertake this role.

In this context AGPA insists that for the sake of transparency and the avoidance of any perception of conflict of interest that the composition of the PIP Advisory Group and any relationships of the members of that Group to PHNs must be publicly disclosed.

If the data were entrusted to a single trusted agency such as the Australian Institute of Health and Welfare then data collected at a national level could be aggregated and fed back to PHNs and anybody else in the community in a readable format that is both clear and concise. Concerns about compliance by being the receiver of information can be obviated by ensuring that the transmission log is kept and sent to the receiving agency and that that agency sending back a transmission of receipt is all that is required and incurs no logical expectation of entering into compliance processes.

We maintain that key management of issues such as ethical guidance and ethical approval of processes, data integrity and all elements of data governance are best achieved at a national level by an organisation that has a track record and is trusted by the public, health professionals all jurisdictions. For example, data for the national KPIs for the Aboriginal and Torres Strait Islander community currently is transmitted directly from Aboriginal Community Controlled Health Services to the Commonwealth without an intermediary.

Successful QI using data projects:

<https://aspren.dmac.adelaide.edu.au/>

<https://www.nps.org.au/medicine-insight>

<https://improve.org.au/services/apcc/>

<https://www.cprd.com/>

Highlighted issues of concern:

<https://www.nature.com/articles/s41467-019-10933-3>

<https://www.theguardian.com/technology/2019/jul/23/anonymised-data-never-be-anonymous-enough-study-finds>

<https://www.upguard.com/breaches/data-leak-neoclinical-australia-new-zealand>