AUSTRALIAN MEDICAL ASSOCIATION
ABN 37 008 426 793
T I 61 2 6270 5400
F I 61 2 6270 5499
E I ama@ama.com.au
W I www.ama.com.au
39 Brisbane Ave Barton ACT 2600
PO Box 6090 Kingston ACT 2604

General practice data and electronic clinical decision support

AMA submission to the Department of Health – General practice data and electronic clinical decision support - Issues Paper

via: consultation hub

Introduction and context

1. Do you agree with the policy objectives outlined?

Yes. The AMA agrees with the following policy objectives:

- ensure general practice data is available into the future to support GPs, PHNs and other health system actors to carry out their respective roles and participate in continuous quality improvement at individual practice and regional, jurisdictional and national health system levels
- ensure any access to or sharing of general practice data is conducted safely and securely and that privacy continues to be protected, including through effective de-identification of personal information
- ensure that the safe, secure sharing of de-identified general practice data is not inhibited by systems or costs
- support continuous improvement in the quality and comparability of general practice data.

General practice data

The AMA's vision for general practice involves greater use of the data held within general practice. Such data can enhance the provision of care for patients, including improved patient outcomes, more equitable and individualised care, less duplication and gaps in care and support patient experience and involvement. Additionally, it can improve productivity, efficiency and experience for general practitioners and their staff and to provide an evidence base for care and services, and to drive quality care initiatives, both at the practice level but also across the health system and to facilitate well-informed and appropriately funded health policy. The AMA believes that greater access to general practice data will be key in emphasising, and enhancing understanding, about the role of general practice and the value of care GPs provide to their patients and more generally to the health system. This must inform improved funding reforms to better support and reward quality longitudinal, integrated and comprehensive care delivering improved patient outcomes.

It will be vital that analyses are informed by quality data. Ideally, the coding of clinical data should be automated. Until this is the case, the work must be remunerated via the development of incentives that support the clinical coding of patient data at the source point. Enhancing the value and meaningfulness of analytical outputs in informing health policies and initiatives that will enhance patient health care experiences and health outcomes.

Identifiability

Regarding the second objective, it must be remembered that de-identification of personal information is only one step in protecting patient privacy. Aggregation of any data made available outside of the general practice which supplied it is also required to minimise the risks of re-identification. The AMA supports the use of de-identified and aggregated data from practices to support population health planning, while maintaining data privacy.

Linkages

Data linkages across the primary, secondary and tertiary sectors must be enabled to reflect patient health care journeys and to identify gaps or barriers to care and their contribution to downstream costs. Similarly, such access to comprehensive health care data will highlight where there are efficiencies within the health system and should further inform support for the provision of quality care that delivers improved patient outcomes such as reduced morbidity and avoidable hospitalisations.

Accessibility

Any analytical findings must be contexualised, and it is therefore vital that practicing health professionals have input to any data analyses to ensure this. Findings must be used to guide improvements in care and care delivery, and not used punitively. Primary health practitioners should have ready and free access to data analyses to support quality improvement and innovations in care.

2. Are there other objectives Government should consider?

3. Are there other current or potential future benefits or uses of general practice data that should be considered?

Quality general practice data provides a good basis for predicting the impact to the health system of a health event, such as a pandemic, dust storm, particle distributing thunderstorm, or smoke pollution. It could also be utilised to facilitate warning notifications and response information to at-risk patient populations at a local level, as well as to local health facilities of the likely surge in services required in such an event. For example, the impact on asthma sufferers and likely care needs in the event of smoke pollution from a bushfire.

Also, it is important to ensure that general practice data is used for the public good and not to serve vested commercial interests. With the rise of vertical integration within the health sector, where a single corporate entity is the provider of health services across primary care, tertiary care, aged care and an insurer there is a strong motivation for access to general practice data to ultimately improve profit margins and corporate sustainability. Access to general practice data would afford an entity such as a private health insurer insight into the emerging health issues of its clientele and preventive services that could be provided proactively to improve health outcomes and reduce use of higher cost services over the longer term. While a positive example of how general practice data could support better health care, the risks of such access must also be considered and mitigated. Risks of particular concern being that practitioner's clinical autonomy regarding care pathways and services insured could be restricted, and patient's trust in the confidentiality of their health information may be undermined.

Some issues with current general practice data arrangements

4. What aspects of the current system in relation to general practice data work well?

The Quality Improvement Incentive under the Practice Incentive Program has helped ensure that data from over 5700 participating practices across the nation is available to help assess and inform quality improvement.

5. What aspects of the current process in relation to general practice data are of concern?

<u>My Health Record</u>

The sharing of patient clinical information with the My Health Record (MyHR) remains a "clunky" exercise for general practitioners and there is no direct incentive to support GPs for time spent currently populating or reviewing the record. The impact this has on the population of the My Health Record is reflected in data which indicates that only 20% of Australians have had a Shared Health Summary (SHS) uploaded to their record.

The MyHR is yet to fulfill its potential. Further evolving the MyHR so that engagement with it is seamless for practitioners and the information within actively supports them with caring for the patient is essential. Ideally the use of the MyHR would not disrupt the clinical flow of care but instead support it. Ensuring the MyHR adds value to practitioners in caring for the patients will ensure, without the need for incentives, its comprehensive usage. The AMA is happy to further discuss with the ADHA how the functionality of the MyHR could be improved.

<u>Privacy and Consent</u>

As the discussion paper identifies there continues to be a lack of clarity regarding privacy and consent requirements. GPs safeguard the trust that their patients place in them and thus it is vital that:

- the risks of shared de-identified patient data being re-identified are minimised,
- explicit patient consent is required for the sharing of health information relevant to the patient's care with existing or future members of the patient's multidisciplinary health care team, and

- practitioners understand what data is being extracted, who it is to be shared with, and how it is to be utilised, and what accountability measures are in place in the event of breach of the terms of use, all of which are articulated in data sharing agreements.

6. *What general practice data should be shared, with whom and for what purposes?*

The AMA considers that the disclosure and linkage of general practice data must be limited to initiatives that exclusively aim to improve the health and health care of patients. Such initiatives would include health research, health policy analysis, health service program development and delivery, best practice health care, public health initiatives and the identification of unmet health service demand. Only the data that is relevant for these purposes should be shared and could include clinical diagnosis, types of services accessed, rates of service utilisation, risk factors, clinical indicators, current prescribed medications, vaccinations, allergies, and immunity status.

7. *Under which conditions should governments have access to aggregate general practice data?*

Governments should have access to aggregate general practice data to understand the health of the nation, preventive and comprehensiveness of care provided, prevalence of disease and multimorbidity, assess access equity, service utilisation and unmet needs, and to inform health policy and funding initiatives that will deliver better patient outcomes and appropriately funded and cost-effective care.

8. *Are there any issues not covered above that impact on ongoing access to general practice data?*

Patients, GPs and general practices need to trust that appropriate governance measures are in place to ensure personal information is protected and that their data is used to enhance patient care and the public good.

Use of general practice data to facilitate cost cutting, such as occurred with the 2011-12 Federal Budget when Bettering the Evaluation and Care of Health (BEACH) data was used to justify cuts to the scheduled fee for GP Mental Health Treatment Plan items, is one way that ongoing access to general practice data could be threatened.

Ongoing access to general practice data is influenced by relevant legislation, which can largely differ between jurisdictions and also at the Commonwealth – State level. Some examples include regulation pertaining to the period of retention of medical records and access to medical records of deceased patients. Therefore, the AMA argues that there is a requirement for broader coordination and harmonisation of legislative instruments, in particular when it comes to data availability and access, as well as interoperability requirements between jurisdictions. This will require broader Federal coordination and should be complemented by the implementation of the National Digital Health Blueprint.

Finally, the AMA is aware that the Attorney General Department is currently undertaking a review of the Privacy Act 1988*. The outcomes of the said review may have effect and influence the developments around the access to general practice data. Specifically, the amended Act

may have implications for the privacy aspects of the aggregate general practice data use and patient consent.

* https://www.ag.gov.au/integrity/consultations/review-privacy-act-1988

9. What is the single, most pressing issue facing ongoing access to general practice data?

Lack of software interoperability is a key concern and negatively impacts the potential of technology in streamlining the collection and sharing of general practice data. Interoperability is crucial to reducing system inefficiencies, administrative burdens and enabling information sharing and communication between care team members and across health sectors.

Software providers should be required to adhere to a minimum set of standards and licencing requirements that provide for:

- systems interoperability,
- key data connections across platforms enabling single entry updates – for example if a GP records an immunisation in their clinical record it is automatically fed to AIR and the MHR, or if a patient has an X-ray performed at a public hospital the record of it, including report and image are directly imported to the nominated GP's clinical record for that patient,
- imbedded coding technology that captures key aspects of clinical care such as diagnosis and interventions, and maps to approved clinical terminologies such as SNOMED CT® AU1 and the Australian Medicines Terminology (AMT) ~~embedded~~,
- integrated access to systems such as MHR, the Australian Immunisation Register, Prescription Exchange Services and future pathology and diagnostic imaging exchanges services, and
- streamlined data transfers and record replication when switching software provider.

The AMA supports the development of clinical software and systems that is able to undertake effective, valid and meaningful clinical coding of patient data within medical practitioners' usual documentation processes and methods.

The AMA supports the importance of clinical coding of patient data at the clinical, practice, community and population levels. This includes in informing patient care, care planning, coordination and provision, quality improvement, community and population outcomes, health care need and improving health equity.

10. What upcoming developments may impact the flow of general practice data?

The flow of general practice data could be enhanced if:

- clinical data uploads to the MyHR are automated, or failing that GPs must paid the full cost of manually uploading it (facilitated via a Service Incentive Payment (SIP)),
- clinical coding was automated, or failing that SIPs to support clinical coding were introduced,
- clinical and practice management software providers are required to meet minimum standards of system interoperability to facilitate streamlined two-way transfer of key clinical data for example: to and from clinical register's (ie AIR and screening registries),

My HR, and members of the patient's health care team (medical and allied) (including hospital discharge summaries, and care plans)

The PIP eHealth Incentive (aka ePIP) is currently being reviewed. The flow of general practice data could be enhanced or stalled depending on how the incentive is modified. The AMA has advised the reviewing consultants against modifications to the incentive that would entail frequent increases to and arbitrary setting of benchmarks. This would leave GPs disillusioned with the incentive and discourage rather than encourage participation in the incentive and in uploading clinical information to the MyHR. The AMA having also advised that until key data can be automatically uploaded to the MyHR introducing a Service Incentive Payment (SIP) would further support GPs with the administrative task of uploading a Shared Health Summary (SHS) to a patient's MyHR.

Furthermore, the AMA would support clinical software providers being required to ensure their software easily and effectively enables clinical coding which can be mapped against a nationally recognised disease classification or terminology system.

The AMA understands that the API Gateway (Health Information Exchange) will simplify information sharing between care settings. The Gateway aiming to support the integration of health data from multiple sources, such as vaccination and screening registries, aged care facilities, and state/territory health systems, into clinical information systems. This integration should support secure and streamlined access to relevant clinical information as needed for the delivery of timely and appropriate patient care in general practice and across the health sector.

While the discussion paper primarily focusses on the flow of general practice data out of the practice, the flow of data into the practice must also be considered. It is vital that there is a two-way flow of data from and to general practice if inefficiencies within the health system are to be minimised and systems maximised to support GPs in caring for their patients. For example, if key clinical information from a patient's MyHR, such as immunisations performed elsewhere and tests undertaken along with their results were automatically downloaded to the patient's nominated GP's clinical record, GP's would have the information they need at hand for directing the pathway of care for that patient. Inefficiencies such as duplicate testing and practitioner time spent exiting the clinical record to log in and review the MyHR during a consultation could be avoided.

Other developments and initiatives currently undertaken at the Commonwealth level that may influence the flow of general practice data in the future include:

- review of the Privacy Act 1988, as stated previously, in particular the privacy aspect of data sharing and patient consent to data sharing.
- development of the National Healthcare Interoperability Plan, that should lead to improved data exchange and collection, storage and analysis.
- development of the National Digital Health Blueprint that should outline a vision for digital health in Australia and support a nationally consistent approach to accelerate harmonisation of relevant legislation across jurisdictions.

Examples of systems and solutions implemented overseas

The AMA notes the proposed implementation of General Practice Data for Planning and Research system in the UK as part of the National Health Service (NHS) and the concerns, primarily around the administrative burden and privacy that have seen it delayed until the following criteria are met*:

1. the ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded
2. the backlog of opt-outs has been fully cleared
3. a Trusted Research Environment has been developed and implemented in NHS Digital
4. patients have been made more aware of the scheme through a campaign of engagement and communication

* https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice

11. Are these examples relevant to Australia?

Yes. Currently, many general practices in Australia share their practice data with their Primary Health Network as part of initiatives to support continuous quality improvement, the management of patient populations and to better inform primary health care policy development and health care decision making at local, regional and national levels. Some of the requirements for the implementation of General Practice Data for Planning and Research system in the UK have already been implemented in Australia – such as allowing patients to opt-out of the MyHR and deleting the shared data if they do.

12. What other examples might inform the secure future for general practice data in Australia?

Targeted communication about the plan for sharing general practice data will be fundamental to ensuring the flow of general practice data. Communications must be clear and concise. Communications at a minimum must cover what type of data is shared, what that data is used for, and what protections are in place to protect patient/practitioner privacy and guard against misuse of the data. Failure to put in place an effective communication strategy covering the abovementioned aspects will jeopardise trust across the community and health profession in data sharing.

Electronic clinical decision support for GPs at the point of care

13. What aspects of the current system in relation to eCDS work well?

The AMA considers Clinical Decision Support (CDS) systems to be useful tools to alert, educate and inform clinicians of current best practice, at the point of care. Such tools may also prompt

specific actions in relation to patient care such as recommending appropriate diagnostic tests, medications, referrals or treatment options.

14. What aspects of the current process in relation to eCDS are of concern?

The AMA would not support the use of any eCDS where the basis of the recommendation could not be traced back to the relevant clinical guideline or clinical inputs. General practitioners understand their patients and their skill, and experience with differential diagnosis cannot be substituted. The AMA would not support the use of any eCDS system where the clinical autonomy of the medical practitioner was not maintained. Clinical guidelines are usually condition specific and thus recommendations within an eCDS system may not fully account for the specifics of a patient's condition particularly if there are multimorbidities. For example, a recommendation to support best practice diabetic care may suggest actions that would be counterproductive to managing the patient's depression. Similarly, recommendations for stroke management may be unnecessary or have an adverse impact on patient quality of life if the patient is elderly and frail or suffering a terminal disease.

Over-ride mechanisms within the eCDS will be essential to ensure clinical autonomy is retained. Any use of an over-ride should be supported by a recorded reason utilising a drop down menu. Use of over-rides could then be analysed to identify:

- if improvements to the eCDS are required; or
- if a practitioner's behaviour requires further explanation or investigation.

Ideally the use of eCDS's should provide a good balance of flexibility, oversight and clinician responsibility.

Furthermore, there is a risk that assessing and rewarding adherence to eCDS recommendations without a full account of all the clinical factors could effectively erode practitioners' autonomy and adversely impact patient outcomes.

15. What upcoming developments may impact eCDS functionality and integration into clinical workflows?

Improving the use of clinical coding within general practice would enhance eCDS functionality. Putting incentives in place to support uptake of clinical coding would enhance the accuracy and usefulness of eCDS. Ensuring the interoperability of eCDS so they can seamlessly be integrated into any clinical software would be fundamental if their usage is to become part of the clinical workflow.

As was envisaged by the Diagnostic Medicine Clinical Committee of the MBS Review Taskforce eCDS could be used as a gateway mechanism to enable GPs to request additional investigations under Medicare, without the need for specialist referral.

The current regulatory framework for eCDS

16. What do you think is the appropriate level of Australian Government involvement in the governance/oversight of eCDS?

There should be an eCDS licensing system whereby the Government and the profession develops specifications and standards to maximise effective interoperability and utility, and maintains ongoing intellectual property rights and control of the system. The AMA would be happy to be involved along with the relevant colleges, associations and societies in conjunction with Government to progress the development of a non-mandatory or acceptable eCDS system.

Some benefits, issues and challenges with eCDS design and use

17. What do you see as the benefits of eCDS use for shared decision making at point of care?

They can help support patient safety and improved patient outcomes by reducing medication errors due to drug to drug interactions, enhancing clinical management through best practice alerts, and reducing patient and health system cost by reducing duplication of diagnostic testing and identification of cost-effective treatment options.

18. What do you see as the issues/challenges of eCDS design and use and what are the associated impacts?

These are outlined well in RT Sutton et al's *Overview of Clinical Decision Support Systems* at https://www.nature.com/articles/s41746-020-0221-y.pdf

19. Do you have any suggestions as to potential next steps to address any identified issues and challenges?

As above.

Some opportunities

20. Are there other levers the Government should consider introducing?

Interoperability between different systems will be the key to success of implementation of electronic clinical decision support into the future, if the ultimate goal is to use the eCDS systems across multiple settings and patient populations. Development and implementation of the National Healthcare Interoperability Plan will be a step in the right direction. In the AMA view, interoperability should extend beyond accessibility and discoverability of information, to the ambition of creating more efficient and effective ways of providing health care and supporting the clinicians who are at the forefront of care. An interoperable system should aim to support the clinicians and reduce their workload, which is also the goal of eCDS. This is important as the poorly designed, inefficient and ineffective electronic health records can increase workload, and that would be the opposite of what eCDS should be aiming to achieve.

Secondly, adequate coding systems will have to be put in place. As the consultation paper notes, quality of data that can be used for eCDS in Australia varies due to variations in data entry. Therefore, a nationally agreed consistency of data entry will have to be put in place, to include many different aspects from clinical practice, such as diagnoses, procedures, observations, or drugs. Each of these concepts should be translated into a set of clinical codes also known as a clinical code set, so that they can subsequently be extracted and used by relevant clinical decision support systems.

Thirdly, additional resources and thought will have to be put towards strengthening privacy of data used in eCDS in Australia. As noted above, the AMA is aware of the ongoing review of the Privacy Act 1988, which will affect the developments in the healthcare space as well. The AMA argues that strengthening of privacy should not further complicate the compliance requirements for medical professionals nor impose additional work but should be set up in such a way that provides them with the confidence that the systems they are using are protecting their patients' data and the information available to them.

Along with strengthening the privacy protections, there will have to be additional resources put towards ensuring cybersecurity in the healthcare space. According to the latest report published by the Office of the Australian Information Commissioner, healthcare providers are the most common target of all data breaches, majority of which happens through malicious criminal cyber-attacks [i], and this trend has been consistent since the Commissioner started publishing the reports on data breeches [ii].

Finally, the Government should consider additional leavers to strengthen compliance requirements for clinical software vendors. The Australian health digital landscape has numerous clinical software providers. Introduction of interoperability standards [iii] will go some way to ensure unification of information across the sector, but there should also be more stringent requirements put on vendors to comply and implement the standards.

i https://www.oaic.gov.au/__data/assets/pdf_file/0013/2803/oaic-notifiable-data-breaches-report-jan-june-2021.pdf
ii https://www.oaic.gov.au/privacy/notifiable-data-breaches/notifiable-data-breaches-statistics
iii https://www.digitalhealth.gov.au/sites/default/files/2020-12/Standards_Development_Model_v1.1_2020.pdf

21. What impact might different levers have?

As outlined above.

22. Which of these levers of change should be further explored and why?

The AMA argues that all of the above listed levers – interoperability, strengthened data privacy, improved cybersecurity and improved compliance by clinical software vendors – should not be just explored but implemented in the short term to facilitate and enable adequate use of eCDS in Australia.

23. What specific options might be considered?

As listed above.

18 FEBRUARY 2022

Contact

Michelle Grybaitis
Senior Policy Adviser
General Practice Section
Ph: (02) 6270 5496
mgrybaitis@ama.com.au]