



Submission: General practice data and electronic clinical decision support

The George Institute for Global Health welcomes the opportunity to make this submission in response to the 'General practice data and electronic clinical decision support' Issues Paper.

We believe primary health care should be at the heart of the Australian health system. It needs to be of high value, integrated, equitable and patient-centred. It should be readily available and accessible for people across their life course, responding to acute needs at critical life stages and proactive in the intervening periods to promote health and well-being.

The George Institute strongly believes, as the Issues Paper states, recent challenges have reinforced the importance of primary health care in Australia.

Introduction and context

1. Do you agree with the policy objectives outlined?

Yes, The George Institute agrees with the policy objectives of the 'General practice data and electronic clinical decision support' Issues Paper.

2. Are there other objectives Government should consider?

The George Institute recommends the Australian Government consider the following objectives:

- Implementing a data structure that is easily extractable and compatible for the long-term future, especially in relation to automated processes, notably artificial intelligence (AI) and machine learning.
- Data sharing should be encouraged, and not be onerous, in primary care. It should be further embraced with apps, while maintaining strict adherence to the Australian Privacy Principles.
- Data should be shared with a patient control standard, including a detailed explanation to consumers of an opt-out versus opt-in approach.
- Universal electronic medical records (EMR) data standards that are adopted by all software vendors to allow for more robust sharing.
- Data extraction should be easy to do and done in a format that is consistent regardless of the software system and extraction tool being used.

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

The George Institute recommends that patient access to their own health data will improve active engagement in their own healthcare. This will further ensure improved personalized care, patient experience and care coordination.

Some issues with current general practice data arrangements

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

The George Institute believes general practice data works well in most formats, particularly in it being extractable using automated processes.

Currently, some data can be shared. We believe there is an opportunity for data to be more optimally used for quality improvement (QI) in primary healthcare, and there are missed opportunities to improve primary health care performance and foster a learning health system.

A major gap in current primary health care data is the lack of a whole system view of the patient journey. Consequently, primary care providers have little ability to look at the care provided to their patients in hospital, specialist, allied health and aged care sectors and identify areas for improvement.

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

The George Institute is concerned with the current lack of patient consent. This is currently implied, rather than actual.

We have long-term and ongoing concerns around data security and data governance. We note and appreciate the Issues Paper detailing these concerns.

As you are currently aware, individual primary care practices maintain their own security of data, meaning there are several variables between all stakeholders. We agree on the need for balancing the benefits with the risks of enhanced data access and sharing. This is an important consideration for all health data but particularly is an issue with general practices which remain largely managed by small businesses around the country with variable information technology infrastructure.

In relation to data governance, The George Institute supports the National Data Governance Framework across Primary Health Networks (PHN), and encourage this be promoted to increase its awareness and understanding.

As mentioned above, we are concerned about the lack of data linkage between, for example, including but not limited to hospitals, specialists, aged care facilities and social services.

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

The George Institute recommends only explicitly patient consented de-identified data should be shared. General practice needs to be supported to provide adequate information to support patients making informed decisions on these matters and patients need to have the ability to regular review their decisions and alter their preferences if desired.

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

The George Institute recommends only explicitly patient consented de-identified data should be shared and accessed by governments to aggregate general practice data. In the context of research, we recommend usual processes be adhered to and that any request to waiver consent is reviewed and approved by a Human Research Ethics Committee.

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

N/A.

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

The George Institute believes data governance is the most pressing issue facing ongoing access to general practice data.

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

The [NSW Government's Lumos program](#) is an exemplar where ethics committee approved linked patient data across primary care and hospital sectors has been achieved at scale.

Examples of systems and solutions implemented overseas

11. Are these examples relevant to Australia?

Yes, New Zealand and the United Kingdom (UK) have similar patient management systems (PMS) to Australia. The difference is that PMS selection in Australia is managed by individual GP practices, as opposed to being coordinated by a centralized body.

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

The George Institute recommends the Wales' Secure Anonymised Information Linkage (SAIL) databank, the Canadian Primary Health Information Network, the UK General Practice Data for Planning and Research (GPDPR), the UK Clinical Practice Research Datalink (CPRD) and the OpenNotes movement in the United States.

The George Institute notes in May 2019, the New Zealand National Primary Care Data Service was delayed due to funding issues. According to [Heath Information New Zealand, Specifically](#), as the total cost was expected to be approximately \$10 million over five years, a business case process was required.

The George Institute notes in July 2021, the UK Government halted its controversial GP data sharing scheme. As outlined by [Healthcare IT News](#), it was to be resumed once the following conditions were met:

- The ability to delete data already collected prior to a person choosing to opt out;
- The backlog of existing opt outs being fully cleared;
- The development of a "trusted research environment"; and
- Greater patient awareness of the scheme.

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 George Institute believes the current system in relation to electronic clinical decision support (eCDS) systems in primary health care works reasonably well in providing drug dosage recommendations, alerts for drug Interactions and contraindications, and drug disease adverse outcomes.

However, there is potential for much greater use of decision support in other areas. The use of standardized medical codes could make integration of eCDS with PMS more seamless. For example, SNOMED CT and ATC.

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

The George Institute believes eCDS drug alerts could optimize other data in the clinical record and could be automated. For example, alerts could be generated based on a patient's kidney function and other pathology results.

We also believe preventive health screening alerts are not comprehensive and can be improved. For example, there is currently no mammogram alert in many PMSs.

We have conducted extensive research on clinical management algorithms for chronic diseases and demonstrated their effectiveness in improving primary care performance. Despite their promise, such strategies are difficult to scale in a non-research setting. We believe greater government support should be provided to take promising decision support research and implement this at scale.

We believe data input structures into PMS are not always in an easily extractable format and can be improved to ensure reliable data are provided to any eCDS. For example, data from My Health Record is held in static forms and cannot easily be imported into primary care records.

Finally, we believe there are a lack of guidelines around eCDS. We note the recent guidance from the Therapeutics Goods Administration (TGA) around software as a medical device, however, many eCDS tools will not fall into this definition and greater standards are required for unregulated software.

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

N/A.

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?

The George Institute believes there is appropriate governance in terms of the regulation of eCDS by the TGA. However, this needs to be supplemented with greater support to eCDS that falls outside of the definition of software as a medical device. This could address concerns around the quality of eCDS tools based on clinical management guidelines.

Some 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?

The George Institute believes there are benefits of eCDs use for shared decision making at point of care.

This includes an increase in patient:

- Quality of care: such as guidelines for treatment and recommendations for ongoing care and drug dosage;
- Safety: such as timely information to help inform decisions;
- Health outcomes: such as suggestions for possible investigations and diagnoses that match a patient's symptoms, as well as drug dosage recommendations and alerts for drug interactions and drug disease adverse outcomes;
- Efficiency and cost: such as timely and best practice treatment, and improved use of the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS); and
- Communication: such as populating clinical details in pathology or radiology requests.

The benefits of eCDs reduce errors in medication that could lead to adverse events. This helps keep people safe and healthy.

Some opportunities

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

The George Institute recommends the following core principles should be adhered to when mitigated challenges and associated impacts. eCDS systems should be:

- Not obtrusive to providers or patients;
- Not impact workflows in a significant way;
- Easily integrated with clinical information systems (CIS) while not slowing down day to day functions;
- Easily validated and updated;
- Based on an agreed set of minimal standards/ guidelines; and
- Support patient centered care and enhanced patient experience of care.

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

The George Institute recommends a user centered design process for eCDs development engaging both consumers and providers in their development.

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

The George Institute recommends funding support for practices that use eCDS aligning potentially with the Quality Improvement Practice Incentives Program (PIP).

21. What impact might different levers have?

N/A.

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

N/A.

23. What specific options might be considered?

N/A.