



Consumers Health
Forum **OF** Australia

SUBMISSION

**General Practice Data and Clinical
Decision Support – Issues Paper**

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*Submission on General Practice Data and
Decision Support Systems*

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interest of Australian healthcare consumers and those with an interest in healthcare consumer affairs. CHF works to achieve safe, quality, and timely health care for all Australians, supported by accessible health information systems. At the heart of CHF's policy agenda is consumer centred care with access to and delivery of clinically safe and high-quality health care as key areas of focus.

CHF agree with the importance of sharing and using health data in a safe and consistent way for the public good in the context of improving health services, developing health policies and priorities, and improving health outcomes.

In the context of CHF's commitment to quality improvement in health care we support and recognise the value of use of electronic clinical decision support (eCDS) systems in general practice. However, from a quality and safety perspective our response raises significant concerns on several issues and challenges in terms of the current state.

While CHF welcomes the opportunity to participate in this consultation the two separate topics of broader sharing of general practice data and eCDS and the issues surrounding each are of such significance and complexity, they warrant separate and extensive consultation.

The Issues Paper makes no reference to the National Digital Health Strategy and in particular the current consultations on the National Interoperability Plan. Addressing the issues and challenges raised in this consultation paper must ensure consistency with existing and proposed national data sharing policies, practices, oversight, governance, quality and safety, technical interoperability and privacy and security. As such it is essential that proposals arising from this consultation reflect these strategies in terms of objectives and alignment of proposed actions.

While CHF understands this is an initial consultation paper, we look forward to further consultation on these topics which we understand will be undertaken once firmer proposals on the way forward are developed.

CHF strongly suggests that the issue of broader sharing of General Practice Data and eCDS systems form separate future consultations.

Consumer Consultation

CHF consulted consumer members of its Primary Health Care, Safety and Quality and Digital Health Special Interest Groups on this issues paper. There was a unanimous view that the issues paper covered two significant topics compromised the consultation given each raised extensive and complex issues, many of which overlapped. Consumers also unanimously expressed their concern at the absence of any reference to shared decision making in relation to eCDS. The issues in this context for patients using NDIS support was highlighted. Overall, there was a specific concern about the lack of a consumer/patient

voice in terms of both broader general practice data sharing and the eCDS processes. We would hope that a more consumer/patient focus be incorporated in the consultations to follow.

In relation to broader data sharing of general practice data there was concern about the lack of attention to how data is handled within general practices. For rural and remote consumers this was a concern because of the turn-over of general practitioners and staff at practices and the lack of training or skills in the use of Practice Management Systems (PMS) and management of patient data. Some indicated a need for security breach alerts. They expressed a need for standards and training within practices that addressed issues related to patient health data management. Overall consumers indicated that the issues in this paper validated concerns around the safety and security of their health data.

The issue of practice data handling by Primary Health Care Networks (PHNs) was also raised noting that each PHN handles data differently and the absence of consistent standards.

While concerns with the wider use of general practice data and the use of eCDS data were significant all agreed that a national approach to standards in both technical compliance of systems, privacy and security and transparent principles and “rules” around sharing of all consumer/patient data was required to provide oversight and governance.

General Practice Data

Policy Objectives

Q.1 - Do you agree with the policy objectives outlined?

CHF supports the stated policy objectives in relation to the sharing of practice data. However, the proposals for use of aggregate general practice data for use at the national and regional level and potential linking to other health service data at Federal, State and Territories level, represents a significant change to current linkages of general practice data. At present PHNs provide Practice Incentive Payments (PIP) indicators to the Australian Institute for Health and Welfare (AIHW) and, with appropriate consents, PHNs may provide data to State/Territory, hospitals, and other health system data. However, it is our understanding that this data is only identifiable at the PHN level and not at individual practice or practitioner level.

Changes in this regard require regulatory changes but could potentially face resistance from GPs where the data may be identified at practice and even practitioner level. CHF would support sharing of aggregate data at the PHN level but not at practice or practitioner level.

Q. 2 - Are there other objectives Government should consider?

CHF considers it important that an additional objective should make a statement in relation to alignment with technical and non-technical elements of the National Electronic Health Interoperability Plan and the National Digital Health Strategy both of which are expected to be released in 2022 following extensive consultation, including with CHF.

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

While a range of benefits are not difficult to identify, a key barrier to realising the greatest value is the current inability to adequately link general practice data with data from other healthcare settings. This creates a gap in health data as consumers move across and between the health system, different providers, and healthcare settings.

For States and Territories, the clinical data has value in terms of enabling better health care planning, including significant future health infrastructure needs, hospitals, aged care facilities for example. With Australia's health funding model this would contribute to improved strategic health planning at the State/Territory level.

The linking of general practice data, particularly at the "local" PHN level, combined with changes in demographic data, would also contribute to improved and better targeted national health policies and planning.

Access to a wider range of general practice data for health and clinical research would contribute to improved health outcomes, health policies, interventions and planning at both State/Territory and national level.

With the rapid progression to a more digitally connected health care system it is recognised that digital innovations can accelerate existing health care access inequities as well as create new barriers. General practice data could be used or designed to consistently track elements that can be identified as changes in health care access at a more "local" (PHN) level as a means of designing strategies focussed on reducing health access inequity.

There are gaps in the types of data that are collected. CHF supports the inclusion of patient-reported outcome measures (PROMS) to general practice data collection. PROMS are collected using validated tools or questionnaires and can complement traditional methods of clinical assessment, such as medical history and physical examination.

PROMS collection is encouraged in the 2020–25 National Health Reform Agreement to empower patients to be involved in their health care, improve care across the health system, and focus on outcomes that matter to patients.

"The patient is the most reliable reporter of their symptoms, function and health-related quality of life, and can provide a holistic viewpoint of the benefits and risks of treatments or the severity of their conditions. Including the patient's voice is critical for shared decision making and patient-centred care. (January 2022 MJA article

<https://www.mja.com.au/journal/2022/216/1/patient-reported-outcome-measures-proms-guide-clinical-care-recommendations-and>

Improved quality of general practice data it will ensure more accurate contribution to analysis of member country issues related to health undertaken by the World Health Organisation and the OECD both of which Australia is a member. These analyses include international comparisons of investment in health care with health outcomes and are important in monitoring and comparing health systems to allow member countries access to detailed data on positive international experience to identify options for improvement.

Some Issues with Current General Practice Data Arrangements

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

The PIP works well in terms of quality improvement. However, if endorsed digital innovations aimed at improving quality and safety and governed by national standards, are further developed, and integrated into PMS the need for specific PIPs would become increasingly unnecessary and ultimately lead to incentives related to use of broader digital health innovations rather than the current “narrow” approach to digital based incentives, secure messaging for example.

The collection of data by PHNs and shared back to practices within their “jurisdiction” has delivered positive outcomes in improving quality and efficiency arising from the ability of practices to compare their outcomes with their peers.

CHF supports the role of PHNS in supporting general practice quality improvement. PHNS play a pivotal role in delivering improvement strategies, provide leadership and as custodians of practice data. In that context CHF would support an ongoing and expanded role for PHNs in the collection of a broader but targeted set of data from general practice. PHNs remain a respected and trusted support by general practice overall which represents will be a key element in ensure general practice acceptance and participation in possible future changes to the collection and sharing of data.

A caveat is the necessary establishment of consistent data handling principles. regulation and rules at the PHN level and is discussed further in Q.5

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

In terms of PHN’s roles in collecting data there is a concern that there are no consistent standards for the handling of general practice data across PHNs. It appears there are varied approaches between PHNs which is unacceptable. In addition to a consistent set of regulations across handling, management and collection of general practice data PHN staff must be trained in these regulations and use of digital systems collecting and possibly sharing this data either back to practices or beyond PHNs. However, concerns exist around the sharing of this data beyond PHNs in the absence of any consistent

regulations that should be the basis of conditions of sharing outlined further in CHF's response,

Consumers are concerned about the absence of oversight related to the use of general practice data. The absence of a consistent and transparent regime which covers issues surrounding consent, use and purpose of data sharing, and privacy and security is of significant concern. This is particularly so, given the lack of adequate regulation and governance in the role of practice management system vendors in general practice data extraction combined with the lack of any oversight, rules, or regulations in relation to practice data once transferred out of general practice.

The quality of general practice data is currently affected by a range of non-clinical issues related the varied design of different practice management systems, the lack of technical and interoperability standards and the varied operation of data extraction tools. Of particular concern is that vendors can determine what data to extract from Practice Management Systems (PMS) and the format of that data.

CHF has concerns around the lack of clarity related to data flow, particularly in relation to objectives to broaden access to clinical data and future linkage of data across care settings and as such, addressing this issue will require strong alignment with the final National Health Interoperability Plan. In this context other factors such as common language and the ensuring clinical guidelines can be integrated into eCDS are essential. Again, an issue addressed as part of the role of an National Interoperability Plan, CHF agrees that in the absence of "high quality and standardised data, the ability of the health system to meet patient needs...could be compromised".

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

This question is somewhat premature in looking to a future state of data sharing beyond that which currently occurs. A meaningful response will ultimately depend on proposals arising from this consultation which we understand will be the subject of further consultation.

As the quality of data and the systems are improved to address the issues and challenges this will become clearer. It is expected that many of the proposed "solutions" will be addressed in the forthcoming draft of the National Interoperability Plan. A key factor relates to clarity around, consent and data privacy and security as a dependency for broader sharing for both practitioners and consumers. This becomes even more complex if the future objective is to share data across different care settings which raises issues of consistency in regulatory factors that may differ for non-GP health care settings that are under the jurisdiction of the State or Territory. This is particularly so in relation to issues such as consent and privacy where data is being shared within sections of State and Territory health systems such as hospitals, where laws/regulations related to data sharing, privacy, consent, and security may differ from those imposed on general practice. These are all issues under consideration within a National Interoperability Plan.

In terms of purposes for sharing CHF considers that clear and concise statement of “purposes” is essential and must be consistent and nationally applied.

Extensive research on consumers attitudes to sharing their health data consistently shows that there is a high level of willingness to share their data with and between their providers, with government and for not-for-profit research.

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

Presently PHNs can share general practice data with governments under certain consent provisions. However, there is no clarity around what these conditions are, the purpose for which the data is used and consent processes in an environment where there is no oversight or regulation. Of particular concern, is the absence of oversight, rules or regulations in relation to practice data once transferred out of general practice and then beyond PHNs.

It is difficult to respond to this question given the current lack of clarity on key issues and a proposal as to what entity should have oversight and has the capability for secure storage and sharing of data. An issue also raised in consultations around the National Interoperability Plan

Consumer support for sharing of their data is based on a level of trust and particularly in relation to the uses of their data.. Maintaining or increasing trust requires consumers to understand quite clearly how their information will be used, any exceptions to key purposes and are able to see tangible benefits, including the “common good”.

Outcomes from the 2017 Productivity Commission report Data Availability and Use identified consumer trust as a key issue, and that community trust and acceptance can be built through enhancement of consumer rights, genuine safeguards, transparency, and effective management of risk (Finding 4,2).

In terms of Privacy and Security CHF would recommend the approach taken in relation to use and protection of MBS and PBS data under the Australian Privacy Principles and the National Health (Privacy) Rules 2018. These have been enablers for an improved understanding of limits and concessions in relation to data linking, sharing and privacy protection measures. Given the extremely sensitive nature of primary care patient data it is essential that such an approach clearly outline the purposes, use limitations, exceptions and privacy and security measures to protect health data.

Other conditions, discussed in more detail in this response, include national oversight and regulation across the range of issues of concern.

Governments should not be permitted to access general practice clinical data to evaluate clinical decision making by individual practitioners or for overseeing MBS billing practices. Consequently, data should not be aggregated at the individual practitioner or practice level but only at the PHN level.

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

Currently general practice data does not provide a view of the overall patient journey linking key event or encounter data which occur within other health settings, such as specialist care and hospitals. Consequently, there exists a gap in general practice data where the patient is referred to secondary care and then referred back to primary care. This is a focus of the National Digital Health Strategy and National Interoperability Plan.

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

The quality of general practice data given the inability for it to incorporate or be linked with data from patient encounters across the healthcare system in the absence of interoperability between other care settings regardless of location.

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

Implementation of the current proposals related to the National Health Interoperability Plan and the current draft National Digital Health Strategy. Both are currently at different stages of completion. The final of the National Digital Health Strategy is expected to be released in the first half of 2022 following national consultation of the draft in the last quarter of 2021. Consultation on the National Health Interoperability Plan was also undertaken in the last quarter of 2021 and CHF are advised that a draft of the plan will be distribute for consultation shortly.

Examples Of Systems and Solutions Implemented Overseas

Q11 - Are these examples relevant to Australia?

In terms of the examples provided it is important to consider the health funding system. In that context the UK's health funding system is more akin to that of Australia whereas New Zealand's is a fund holding system. CHF is of the view that the UK examples are along the lines of what may be most suitable in the Australian context. We would support that an established marketplace which allows practices to select from "approved" supplier systems based on technology, data standards and capabilities that all practice management systems must meet. We understand that Medicare takes this approach permitting only those practices which use listed compliant systems to access its digital systems such as online MBS claiming.

In terms of managing health care data and research CHF believes the UK system is more appropriate. We would, however, argue that the role of collecting and aggregating practice data remains with PHN's. Further, that a centralised "agency" be responsible for the

collection of PHN's aggregated data, (and any amalgamation), storage, access to and use of primary health care data to ensure it is used as securely and efficiently as possible and in accordance with a nationally agreed set of privacy principles, linked to the National Health (Privacy) Rules 2018 as outlined in our response to Question 7

CHF's response to Question 16 is relevant to the above.

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

ELECTRONIC CLINICAL DECISION SUPPORT (ECDS)

ECDS for GPS At the Point Of Care

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

The requesting diagnostic services referral function, which was altered on the advice of some diagnostic providers is a positive change and endorsed by the RCPA. This shifted from a simple test referral to a system in eCDS which at the point of requesting responded "why". Following response, the system then asked questions whether this was for diagnosis, screening, or monitoring. The response was subsequently linked to clinical guidelines. However, not all eCDS have incorporated this function. While this has had a likely impact on workflow it represents a significant quality and safety improvement. Unfortunately, not all eCDS systems incorporate this function and vary in integration of clinical guidelines.

There is a question as to how shared decision making can be incorporated into eCDS.

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

Shared decision making is not related to eCDs or other technology but is about the consultation. How digital health can contribute to ensuring shared decision making is difficult. While clinical guidelines, even when included in the eCDS, related shared decision making may be accessible there are limited options for an active driver of use. Alerts in eCDS are an identified issue in terms of impacting on the consultation. However, if unnecessary alerts can be eliminated, in consultation with general practice, alerts practitioners identify as essential, and the at which point they occur, could be incorporated to encourage shared decision making. For example, if the condition offers choices in types of diagnostics. an alert to discuss options with the patient such as MRI versus CT based on radiation load. Whether options are covered by MBS or not this

information should be shared with patients where a choice in diagnostic procedure will deliver the clinical information required.

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

The adoption of SNOWMED by pathology providers and currently evolving with radiology providers represent a positive step and should be encouraged across all providers and possibly included as a compliance measure in future potential “preferred provider” arrangements.

The Current Regulatory Framework For ECDS

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

CHF's view is governance and oversight should be at the Federal Government level and this was supported in CHF's consumer consultation. This ensures that regulatory issues, particularly safety, quality, privacy, security etc can be, developed at a national level and thus ensure consistency across all jurisdictions and care settings. Options could include the National Digital Health Agency or the Department of Health, or a combination of the Therapeutic Goods Administration (TGA), or Medicare and another Federal entity. Further the issues to be addressed must ensure consistency with other existing and proposed data sharing policies, practices, and legislation at national level, in line with a regulatory framework for other aspects of digital health. This includes alignment with strategies aimed at progressing the National Digital Health Strategy and the National Health Interoperability Plan both of which require a national approach across all jurisdictions.

The potential role of the TGA is complicated by the variability between eCDSs which determines their varying status in relation to classification as a “medical device” and thus oversight in terms of TGA regulation of software-based medical devices. Further TGA regulations ensure therapeutic goods are safe to use, i.e. they will not cause harm if used as intended. Therapeutic goods providers must prove the “risks” are low and do not need to prove any “benefit”.

In terms of the issues and challenges raised it is difficult to see how the TGA regulations in relation to Medical Devices can address the Issues and Challenges (page 17) identified in this paper.

Medicare is included in our thinking given their extensive and positive role in managing security and privacy of health data. This includes requirements that only endorsed/compliant software systems may be used by practices to interact with Medicare systems. In this context Medicare established a list of compliant system providers from which practices may select. It also demonstrates a strong and accepted

compliance regime with system vendors and illustrates how compliance can drive vendors.

CHF's response to Question 7 is relevant to the above.

Potential Benefits of ECDS Use Across the Health Care Ecosystem

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

While CHF would agree with the range of potential benefits outlined in the paper the realisation of these benefits is dependent on use and the quality of the source of information extracted by eCDS and their alignment with general practice workflow.

Given the variation in GP use of eCDS it would seem difficult to assess benefits in terms of health outcomes, improvements in the safety and quality of care, efficiency, and decreased operational costs for GPs and the health system more broadly. Addressing numerous issues outlined as Issues and Challenges are likely to improve level of use.

The overall view in international research indicates that eCDS contribute to improved quality and safety and improved outcomes. However, research is based on different eCDS systems in a range of care settings and often related to a particular clinical issue. In the end clinical judgement which is outside the eCDS is the determining factor. However, improvements in "questioning" in eCDS systems such as "why" are you referring to this diagnostic procedure and for what purposes may lead to a better understanding of benefits in an environment where there is consistency across eCDS.

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

The important challenge is to increase use of eCDS by general practice. In this context the inconsistencies across various eCDS systems create a lack of trust on the part of GPs, particularly in relation to the quality and currency of information and the fact that clinical guidelines are not integrated into eCDS.

With the introduction of other digital health innovations available to general practice, such as input and access to My Health Record a key barrier to increasing adoption has been the failure to integrate use into clinical workflows. The consultation with the patient is a critical activity in this regard and any aspect of a digital system that interrupts the key component of GP care will impact on decisions related to use.

The vast number of highly problematic technical inconsistencies across eCDS systems represent a significant barrier to integration into the broader health system. Addressing

these inconsistencies will require alignment with Australia's Digital Health Plan and ultimately the National Interoperability Plan.

However, integration into the broader health system is likely to be negatively impacted by the lack of endorsed guidelines and/or standards developed for eCDS design, manufacture or use, a poor level of oversight and governance, and inconsistencies with broader national digital health initiatives

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

CHF has significant concern that there are "...no endorsed guidelines or standards specifically developed for eCDS design, manufacture or use within Australia". The variability between eCDS software design, including the varying quality and currency of information in eCDS, creates serious concern about safety and quality. Further, that software providers can select what is extracted from PMS is of concern in relation to privacy and security of practice and patient data. Given eCDS extract patient information from the eDCS this concern is heightened by the lack of transparency related to privacy and security, the lack of clarity about who has rights to the data once it leaves the general practice systems and the lack of transparency related to data usage expectations and authority.

CHF is of the view that addressing the above issues must be a priority. In that regard, as we note elsewhere, there is an urgent need to develop eCDS standards for which compliance is required for use in general practice. In addition, the identification of or establishment of a national oversight body and measures to ensure general practices only use compliant software.

Further, that issues around privacy and security, including determination of rights, including use, of general practice data are addressed and oversight in this regard is established.

Some Opportunities (Levers)

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

As noted, there is currently a significant issue with linking general practice data with data in other health care settings across the health system – importantly with specialist and hospital care and settings. This is relevant for general practice data broadly but also for eDCS which extract data from the PMS.

Improving linkages through digital health systems in the hospital system will be the subject of Commonwealth, State/Territory cooperation in relation to national digital health policies and plans. For specialists, however, there are few if any current levers that will have any impact on their participation in digital health transformation. In this regard CHF would support consideration of linking uptake and use of specific, mature,

technically viable, safe, and secure digital health innovations aimed at improving the safety and quality of care, with specialist accreditation.

In terms of providers of eCDS and other associated clinical software, establish an “approved provider” system based on compliance with a consistent set of endorsed standards for which a relevant government body has responsibility for oversight. Link accreditation to adoption of only an approved provider.

Q.21 - What impact might different levers have?

Awareness, Education and Training – improved understanding of the policy objectives is essential for acceptance. For consumers, understanding the policy objectives goes to the critical and proven need for clear statement of purpose to achieve acceptance. This will contribute to any relevant consent processes.

Digital Literacy is critical for both providers and consumers as digital and mobile health applications are increasingly being integrated into healthcare.

Co-designed value propositions for the sharing of general practice data are essential for a clear understanding of the overall objectives and broad acceptance, particularly for consumers.

Guidance – CHF considers this set of levers as highly important in supporting providers to align practices with the policy objectives. It would appear to also relate to improving provider digital literacy.

Incentives – CHF would consider the introduction of incentives to software companies/manufacturers to co-design eCDS products with practitioners as the incentive with the highest value in terms of outcome. Co-design would ensure product is designed to align with practice workflows, meets practitioners needs leading to increased acceptance, uptake and use.

Voluntary Standards and Guidelines. if the development of technical standards for eCDS addresses the range of inconsistencies and barriers to use outlined in this paper this lever will have a positive impact on quality and safety and on uptake and use.

Regulatory Actions - A lever linked to accreditation will become more important as health system digital interoperability progresses over time. If safety and quality are embedded into all aspects of digital health, specific quality improvement levers are likely to be less important as driving use of these innovations becomes the aim.

Linking use of an “approved provider” or compliant software will impact on the trust of general practice in eCDS and contribute to and uptake. Further, as changes occur in relation to the development of standards under the oversight of a specific body, this will create a driver for clinical software companies to comply

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

Awareness and Training, Guidance and Regulatory actions. As to why, see response to Question 21

Q.23 - What specific options might be considered?

Awareness and Training

Communications to stakeholders on the benefits of sharing general practice data, importance of standardisation and consent, the use of benefits of eCDS in primary health care settings.

Training to support end user digital literacy

Guidance

Co -designed guidance and resources for stakeholders to support general practice data-related activities.

Regulatory Actions

Establish a regulatory framework for how data should be used and shared.

Government undertakes a process to select compliant software vendors which stakeholders must select from.

Leverage general practice requirements to require the use of compliant software.