Consumers Health Forum of Australia

SUBMISSION

DOHAC – General Practice data and electronic clinical decision support

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Introduction

Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in healthcare consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care.
CHF appreciates the opportunity to provide a submission to the Department of Health and Aged Care on their General Practice Data and Electronic Clinical Decision Support impact statement.

CHF previously submitted a response to the issues paper on GP Data and electronic clinical decision support. We acknowledge that many of the concerns raised were addressed, but believe that much of the body of our previous feedback is still relevant. Our concerns surrounding security, data quality, and shared decision making persist, and several of the options presented are not suitable, based on those concerns.

Principles of design

Following on from unpublished research involving over two thousand consumers, CHF has developed principles of design which we believe secondary-use data projects should adhere to. As follows:

- A thorough and dynamic approach to consent, empowering consumers with regards to the use of their data, including systems for review and re-establishment of consent
- An opt-in, not opt-out system, requiring active consent and engagement on the part of the consumer
- Consumers should have the choice to be notified regarding requests for access to their data, including which requests were granted, and the outcomes of the data usage.
- These should be accompanied by efforts to increase health literacy and literacy surrounding data usage in order for consumers to be able to take ownership of their data.
- Effective de-identification must be practiced, and consumer data safety must not be compromised

A firm commitment to consumer co-design is paramount. Whenever decisions are being made that impact consumers, it is vital that consumers are consulted at each stage in order to determine the best path forward. It is also important when decisions regarding consumer data are being made that consumers are more than just their data. Their safety and their consent matter. The safety of consumer data is an issue that has been extensively examined by CHF, and the findings have consistently shown that as a general rule, consumers are amenable to the sharing of their data for non-commercial health and research projects[1], while not generally amenable to the use of their data for commercial purposes. In line with this, active and informed consent are another key tenet of our principles of design. The following points and direction have been developed with these principles in mind.

[1] CHF, 2018, *Engaging consumers in their health data journey*

Issues

CHF agrees with the problem statement provided. The current system is not adequate and presents a wide range of issues for consumers and providers both, and the Department of Health and Aged Care has correctly identified these issues, in line with the concerns of consumers.

Accessibility of information

It is vital when performing a consumer consultation that information is presented in an accessible, easy to read manner. The impact statement document is not presented in such a way. While acknowledging the inherent complexities of the issue at hand, and the intricacies involved in developing a model for eCDS and data sharing, the position of CHF is that this was not created with consumer consultation in mind. As this is a development with significant potential ramifications for consumers, this system should not be developed without substantial consumer input, to a level that is impossible with the impact statement as provided. The length, depth of information, and large number of discussion questions pose a large burden on any consumer that could be involved in the consultation. A more thorough and accessible consumer consultation must take place. It is also worth noting that the consolidation of several issues into one impact statement has the potential to obfuscate issues, and makes the process of consultation significantly more convoluted and difficult to present clearly.

Shared decision making

CHF notes that the concept of shared decision making is touched upon only once in the entire document, and that there are no guidelines on how shared decision making regarding patient specific data will be undertaken. Shared decision making, and the ownership of health information by consumers is one of the core tenets of CHF and has been repeatedly raised by consumers as a priority. In order for this program to be in line with the needs of consumers, there must be a greater emphasis on shared decision making as a core part of this process. Our research has indicated that patients are generally happy for their health information to be used to support health initiatives and research, so increasing the level of consumer ownership over their data shouldn't have a significant impact on non-commercial use. It is worth noting also that there are consumer demographics which are likely to be more cautious about their data, such as those with mental health conditions or other stigmatised health issues, and that losing agency over their data may make members of those demographics reluctant to seek treatment whatsoever.

Co-design

While co-design with practitioners, industry stakeholders, and clinical guideline developers is mentioned several times, direct co-design with consumers is not mentioned. CHF notes that consumers are listed as one of twelve different subdivisions of stakeholders, but there is little mention of how involved consumers would be in any part of the process. The term "co-design

with stakeholders" must be clarified in order to accurately reflect the level of consumer involvement in the design process.

Informed and Dynamic Consent

In line with our principles of design, informed consent is a vital aspect of any development involving consumer data. Consent is alluded to numerous times throughout the document, but there is not enough of an emphasis on the development of a dynamic consent process for use of consumer data. Consumer consent should be gained in a manner which does not subject the consumer to immediate pressure to provide consent, without adequate opportunity to revoke or alter the terms of their consent. A dynamic consent process, in which consumers are made aware of the use of their data in an ongoing manner, is optimal.

Which option?

Option 1: Retain the Status Quo

CHF does not support Option 1. The Department of Health and Aged Care has done an excellent job of identifying problems with the current model of GP Data sharing and eCDS, and the concerns raised echo the concerns of health consumers and CHF. It is clear that reform is needed . The priorities of consumers on these issues are both safety and quality of service, and one of the most important ways these can be assured are by providing a consistent standard of service that the status quo cannot deliver.

Option 2: Facilitate Stakeholder-led Regulation

CHF does not generally support voluntary, opt-in self-regulatory models. This is particularly true when the body of stakeholders from which the regulators are drawn is ill-defined. Should a stakeholder-led regulatory body be formed in order to oversee GP data and eCDS conduct, consumers must have a voice on that panel. Consumer representatives must have equal representation to any other stakeholder body, and they must be remunerated for their time. CHF would recommend that CHF-nominated consumer representatives are used for this, in a similar manner to the CHF and CHOICE nominated representatives present on the Pharmaceutical Benefits Advisory Committee.

The optimal use-case for Option 2 is as a stepping-stone from which to transition to Option 4. It is less powerful as a stand-alone option, and offers consumers less in the way of protection.

Option 3: Establish incentive-based compliance

Option 3 presents a voluntary model, emphasising the use of incentives to encourage compliance. This is not a model that CHF supports. It does not guarantee security or consistency of safety and service quality for consumers, and it presents rewarding providers for doing simple due diligence, rather than ensuring that responsible best practice is legislated and regulated.

Option 4: Introduce legislation and establish a new regulatory scheme

While acknowledging the complexities inherent to the establishment of regulatory schemes, CHF recommends this option. The establishment of a regulatory scheme, backed by legislation, is the surest way to ensure the safety and efficacy of these systems, and to ensure adequate consumer representation and protection. Whether a transition directly to this model or a stepped approach moving towards it is used, it is the position of CHF that this should be the final goal of any move towards reform in this area. It is also the position of CHF that should this approach be taken, there must be significant consumer input at each stage of the transition into this model.

Conclusion

While a number of issues have been found with the presentation of the paper, CHF strongly supports the development of a legislatively-backed regulatory scheme protecting both the safety and standard of care in the use of GP Data and electronic clinical decision support. CHF would welcome involvement in the nomination and organisation of consumer representation in the future developmental stages of this legislation and expects that consumer voices will be involved in whatever option is chosen.