Medical Software Industry Association Submission – Productivity Commission Report

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MSIA President – Emma Hossack

(07) 3292 0250 president@msia.com.au

MSIA Executive Officer – Jessica Abbey

eo@msia.com.au

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1 Executive Summary - MSIA Profile

The Medical Software Industry Association (MSIA) represents interests of the medical software providers across the spectrum of health care with 100% representation of those providing pharmacy services. The vision of this Association which represents the sector that enable efficiencies and transformation of health services is to enable vibrant and innovative software organisations to achieve better health outcomes for all Australians. The MSIA is a valuable stakeholder in Australian healthcare, and is frequently invited to submit its responses and offer suggestions in regard to initiatives such MyHealth Record, PBS Online, DHS Online PBS Authorities and the AMT to name just a few.

The MSIA has negotiated a range of important changes with government and other stakeholders having built a considerable profile with Commonwealth and jurisdictional Health Departments as the clearing house of communication between these organisations and the healthcare software providers. It is in the interests of further improving the use and efficacy of the data which our members work with on behalf of their clients, that this submission is made.

2 Overview of the MSIA Position on the Availability of Data

2.1 Critical Importance of Health

The MSIA is pleased to have the opportunity to table this submission. The ability to access and use data is possibly no more important than in healthcare where decisions depend on access to the right information at the right time in the right format. Mining companies have claimed that "Data is the mine of the future"[1] which underscores its financial value, but in healthcare data has the ability not only to enable transformational research and efficiencies, but to save lives. The examples given on pages 15-16 of the report are cognisant of the critical importance of the health sector in respect of this report. It is the area in which there are manifest inefficiencies, and death through iatrogenic cause of incorrect or insufficient information can be improved through the systems created by our members. President Obama called eHealth the low hanging fruit, and whilst all has not gone to plan in the United States, there is no doubt that improved protocols and frameworks for appropriate access and sharing of health information could have profound improvements on healthcare in Australia.

[1] Sam Walsh – Former CEO Rio Tinto
http://www.austmine.com.au/News/articleType/ArticleView/articleId/2298/Rio-Tintos-Mine-of-the-Future-Interview-with-Andrew-Harding

2.2 National Data Custodian

The prospect of a National Data Custodian, with a role similar to that of Dame Fiona Caldicott is most welcome.[2] The improvements in data access and health outcomes as a result of the creation of this role in healthcare in the UK have been significant making it a model to emulate. There are however significant risks to not getting the settings right or meeting the community attitudes to privacy and thus undermining trust[3]. In some sectors, like financial services there may be choices for consumers. In health if there is a requirement that certain information will be mandatorily collected and retained, it leaves the consumer with a binary choice e.g. the parent of a sick child is unlikely to argue their rights if the care of their child could be jeopardized. Likewise, in respect of research and oversight of what information is used by who, it is important to avoid the '…supervision of the sheep by the wolves, for the benefit of the wolves and a means for business to establish a pretence of regulations in order to hold off actual regulation.' [4]

2.3 Community Attitude and Trust

The OAIC *Community Attitude to Privacy Survey*[5] found that 90% of Australians trust health organisations, 74% trust financial institutions and 69% trust government entities. This puts the health carers in an enviable position, but it also means that the expectations are very high in this area[6]. MSIA members have been managing this trust for decades with a very high record and no notable breaches or loss of trust. The outcomes of breaches outlined on page 18 can be devastating and so finding the balance between individual controls, access to data in the national interest, increasing the usefulness of data and creating a culture of openness must be carefully considered with an emphasis on public consultation. Respect for the data collection and use principles embedded in the Australian Privacy Principles is key. As we saw recently with the failure of Medicare to effectively deidentify large data sets, the area is of great public interest and concern. The complexities of deidentification and reidentification

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[2] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF

[3] https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2881787

[4] Roger Clarke, 'Privacy as a Means of Engendering Trust in Cyberspace Commerce' University of New South Wales Law Journal 24(1) 2001 290, 295.: http://www.rogerclarke.com/DV/eTrust.html

[5] https://www.oaic.gov.au/images/documents/privacy/privacy-resources/privacy-reports/2013-community-attitudes-to-privacy-survey-report.pdf

cannot be under estimated[7], and failure to get the settings right will impact on providers, and on the systems which our members provide. This is critical.

2.4 Looking Forward

Together with our colleagues in the medical field it is something which we are confident can be achieved and we look forward to being a part of the work resulting from this responsible and forward thinking report. Our comments on the findings and recommendations follow.

3 Response to Draft Findings and Recommendations

Draft Finding 3.2 – The members of the MSIA are actively involved with data integration projects across Australia. Some impediments include lack of early consultation and appropriate scope as well as a lack of harmonised privacy and security settings. It is not always the legislation, sometimes it is the culture.

Draft Finding 3.3 – There is a reluctance to share reports in the area of health. For example, a large amount of the privacy Impact Assessment by Minter Ellison on the MyHR was redacted. This does little for public trust or confidence. The culture of openness and transparency espoused by the Report is welcome. There are many instances where lack of this has reduced efficiency and innovation and possibly undermined trust.

Draft Recommendation 3.1 – Agree and the MSIA would like to be a part of the discussion in respect of the improvements possible in the health sector.

Draft Recommendation 3.2 – Agree and the MSIA currently has members working in the area of research who navigate many of the issues and could provide learnings for the Commission.

Draft Recommendation 5.1 – Agree – uncertainty over reidentification and deidentification as seen in the recent debate involving Dr Khaled El Eman and Dr Vanessa Teague is evidence of this.[8]

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[7] : http://www.itnews.com.au/news/is-data-de-identification-a-myth-441572?eid=1&edate=20161117&utm_source=20161117_AM&utm_medium=newsletter&utm_campaign=daily_newsletter

[8] http://www.itnews.com.au/news/is-data-de-identification-a-myth-441572?eid=1&edate=20161117&utm_source=20161117_AM&utm_medium=newsletter&utm_campaign=daily_newsletter

Draft Recommendation 5.2 – Agree – there needs to be a robust framework to ensure Dr. Clarke's concerns above do not jeopardise the value proposition.

Draft Recommendation 5.3 – Data liking can compromise the collection and consent principles. These are key to healthcare. Great care and community consultation will be required and the MSIA will be happy to inform the discussion.

Draft Recommendation 6.2 – The use of APIs is common in the medical software industry. It would be good to have more parameters to ensure the openness of data and ability for individuals to manage their healthcare more effectively. There are issues of IP as well as cultural concerns which can impede the use of APIs.

Draft Recommendation 7.1 – Agree, the MSIA has seen many examples where private sectors could have performed tasks more effectively on behalf of Australian health consumers and tax payers.

Draft Recommendation 9.2 – A meaningful choice by consumers can only be made if there is transparency and education about the data set. For example, in respect of the MyHR, it is not well known that the default access settings enable *any* health practitioner in Australia to access a patient's record.

Conclusion

The MSIA looks forward to the final report and welcomes any further requests for information.

Yours Sincerely,

Emma Hossack
BA (Hons), LLB, LLM

PRESIDENT

E: ehossack@extensia.com.au
M: 0411 478 799 **P**: (07) 3292 0250
S: ehossack_extensia.com.au
W: **MSIA.com.au**

CEO, Extensia
Chair Strategy ANZ,
International Association of Privacy Professionals