Inquiry into Data Availability and Use
Productivity Commission
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RE: Submission on the Data Availability and Use Draft Report - 2016

Dear Productivity Commission

I welcome the opportunity to respond to the *Data Availability and Use* draft report which was recently released by the Productivity Commission. In writing this submission, I have drawn upon my experience as a social science researcher (workplace behaviours, motivation) and my interest in health literacy and patient empowerment.

Regards

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Productivity Commission: Data Availability and Use (Draft Report)

I have limited my feedback on the draft report to comments on health data.

Firstly, geographic information on the existing use of health services such as dental treatment (p.7) is not necessarily an indicator of demand. Many rural and regional locations have few, if any, dental practices, despite a demand, waiting list, and need for them. Private health insurance data (ADA, Draft Report, p.7) is not representative data - not all Australians have private health insurance, and those who do may increasingly quit due to rising fees and diminishing value for money.

On the other hand, Medicare data such the use of the Child Dental Benefit Schedule could be used for targeted dental education programs. There is also a lack of data on the number of Australians who cannot afford basic dental care.

Health Data Exemplifies the Problem

- **De-identified data from dental records**

De-identified data from dental records are under-utilised in Australia, most likely because records are held by separate private dental practices. However data from electronic dental records have multiple benefits and can generate new knowledge (Lui et al., 2013).

Underlying datasets from de-identified electronic dental data could be more widely used to determine: the association between oral health and diseases; the links between dental materials and health; and the long-term risks of exposure to x-rays used in dentistry.

Although deemed 'biocompatible'[1] and approved by the Therapeutic Goods Association (TGA), there is limited research on the release of Bisphenol A (BPA) from dental materials. Extant studies show that composite materials vary in their release of BPA (e.g. Tsitrou et al., 2014); that greater exposure to bisGMA-based dental composite restorations has been associated with impaired psychosocial function in children (Maserejian et al., 2012); that BPA exposure is associated with thyroid hormone disruption (Moriyama et al., 2002); and that BPA exposure is

[1] There is a need for further research on 'biocompatibility'. See Mousavinasab, S. M. (2011). Biocompatibility of composite resins. *Dental Research Journal*, 8(Suppl1), S21- S29.

associated with oxidative stress and inflammation in postmenopausal women (Yang et al., 2009). Olea et al. (1996) argue that the use of bis-GMA-based resins, particularly the use of sealants in children, contributes to exposure to xenoestrogens and should be re-evaluated.

There is clearly a need to increase our understanding of the wider systemic and psychosocial health effects of exposure to BPA from resin based dental materials. Despite growing public awareness around BPA, dentists largely select TGA approved materials based on their functionality and appearance (gloss, light transparency, wear). Given that more longitudinal studies are needed around the health implications of BPA and bisGMA – the current retention of dental records (7 years) is inadequate (and My Health Record may facilitate increased retention).

To provide fully informed consent, patients also need to know the true risks of a dental procedure. However in Australia, there is a lack of data on the prevalence of adverse events such as prolonged anaesthesia, dental needle injuries (e.g. see Sambrook & Goss, 2011), and tooth implant failures. To collect such data, My Health Record should be treated by dentists as a clinical record; noting adverse events.

My Health Record - Dental Records

Many Australians will have concerns around privacy, as well as a lack of confidence in the security of electronically controlled data, particularly following the 2016 Census. While patients may have concerns about medical records, some may want greater access to their dental records. There may be advantages to their *opt-in* use of My Health Record for keeping full dental records in one central location.

Advantages:

1. Storing dental x-rays in one location may help to minimise the risk of patient overexposure because practitioners may be alerted to “unnecessary duplicates” (CBO, 2008; Draft Report p.7). Some dental practices have purchased their own x-ray machine and x-rays are covered by private health insurance. Their overuse might arise when patients move to a new location or between dental practices.

2. Patients should know what dental materials have been used in their mouth. There is currently an inconsistency in dental records in relation to the absence/recording of materials used. Although deemed 'biocompatible' and approved by the TGA, research on the release of Bisphenol A (BPA) from dental materials is undeveloped. Further, a number of dental materials used in Australia have been recalled by the TGA since 2012[2] - showing the importance of the patient knowing (or asking their dentist) which materials were used.
3. Patients can add information such as allergies. Patients with rare diseases may benefit from this input. For example, in dentistry, several medicines should be used 'with caution' in patients with Myasthenia Gravis (Rai, 2007).

Concerns:

1. Many Australians have concerns around privacy and a lack of confidence in the security of electronically held data. Further security detail is needed on how My Health Record is "just like online banking" (Dept. Health, 2016).
2. If healthcare providers see each other's records[3], the patient's right to an impartial, independent second opinion is diminished. The *Data Availability and Use* draft report (p. 153) cites the ADA's comment that patient identity can be accessed via HICAPS by private health insurers.
3. If healthcare providers see each other's records, adverse events might not be recorded (patients could restrict this shared function).
4. Patient access to My Health Record may be inequitable: there are regional, socioeconomic, and demographic differences in internet access across Australia, including for Indigenous people and people aged over 65 (ABS, 2006). This shows that public access and assistance might be needed.

[2] Whether dentists regularly monitor and inform patients of these TGA dental recalls is unclear
[3] Patients can reportedly restrict this function (My Health Record brochure, Department Health, 2016)

My Health Record - Medical Records

Putting patients in control **?** (*Draft Report p.521*)

My Health Record will allow patients to add information on allergies, adverse reactions and personal health notes to their record. This patient input may enable patients with rare diseases to feel greater control over their healthcare; given that health practitioners can have little clinical experience with rare disease populations.

- Example: The Myasthenia Gravis (MG) patient

Myasthenia gravis (MG) is "a relatively rare neurological disease that is associated with a loss of acetylcholine receptors that initiate muscle contraction" (Vincent, 2002, p.797). A key issue for MG patient management is the avoidance of contraindicated medicines which can exacerbate the condition.

In the USA, fluoroquinolones carry **black box** warnings (high risk) to avoid in patients with MG - *but there are no such warnings in Australia*[4] - for exactly the same products.

MG patients may have had adverse reactions to, and be aware of these fluoroquinolone risks, and may note them on their My Health Record. Those patients can be prescribed *safer alternatives* for reasonably uncomplicated infections (Jones, Sorbello, & Boucher, 2011).

However, it remains to be tested whether health practitioners will take the MG patient's own My Health Record entries into account - or instead rely on TGA information, together with a 'one size fits all' approach to treatment. Patient medical alert bracelets can also be overlooked.

- While patients may have control over what goes on their My Health Record, and who can see it, they have less control over whether practitioners will use and apply patient-entered information in a 'shared-decision making' model of health-care.

[4] By the Therapeutic Goods Association

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