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Freedom's Inquiry

I'm not sure if this might be outside the terms of reference for this inquiry, but would you be able to look into the gradual erosion of patient rights, especially in the area of data control (as part of our property rights), please? I've listed a few things below that I can think of offhand, but there seems to be a general trend towards sharing patient data more freely, and with less patient consent required, or at least, with it being much harder for patients to prevent it. Some examples:

- Constantly trying to push ehealth and telehealth onto patients, especially on an opt-out basis, which would result in many patients being given ehealth records without their knowledge or consent. This would also apply retrospectively, to information shared with doctors at a time when the patient believed it would be kept confidential.
- Some hospitals, such as the new Fiona Stanley Hospital in Perth, are switching to paperless systems, without much reference to patients having any choice in that, not even on an opt-out basis.
- The Health Department's policy encouraging the digitisation of patients' medical records, with a view to keeping them for extended periods of time, again without any reference to patient control over the process.

See: http://www.health.wa.gov.au/circularsnew/circular.cfm?Circ_ID=13184

- The Health Department also appears to be sending identified patient medical information to the state archives, according to their Patient Information Retention and Disposal Schedule as published here:

http://www.health.wa.gov.au/circularsnew/circular.cfm?Circ_ID=13185

Again, there's nothing in that document about patient consent, and the information sent does appear to be medically revealing, including full medical records in some cases, all of which it appears will be made public after 100 years. Do patients have any data control rights there, to ask that that not happen?

- Their use of the term 'metadata' is also concerning, when it includes patient names, as well as revealing medical information.
- Just in general, that patients have very little control over their medical records, how they're stored and shared, what gets recorded in them, or indeed, the ability to opt out of having them at all. Doctors claim that they own the physical copy of our medical records, but that we own the data, but if we truly owned that data, then shouldn't we have control over how, where and if it's recorded?
- Broad consent forms which don't allow for fine-grained control over privacy issues, or which don't make it obvious that patients have a choice. In particular, anything which involves putting medical information online should require specific consent and make it clear to the patient that they won't be denied treatment if they withhold that consent.
- Any attempt to restrict anonymous healthcare, for instance, by removing patients' ability to pay by cash. This would be one unintended consequence of the introduction of a cashless welfare card, and a valid reason for why money for discretionary spending should always be retained.
- The census includes an accompanying health survey which forces randomly selected participants to provide their medical information to the government, with no right to refuse. The data produced

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by this survey is unreliable anyway due to its non-consensual and non-anonymous nature.

- Similarly, medical notification requirements for driver's licences make no attempt to limit the amount of medical information requested by the government. They could, for instance, ask instead for a numerical score out of 100, to be calculated by a treating doctor, rather than requesting and storing the actual medical information.

- Reality shows being allowed to film patients without first getting consent, sometimes airing the footage with nothing but facial blurring to protect the patient's privacy. Especially in an emergency setting, patients should be able to seek medical treatment without having to worry about avoiding TV cameras.

- Likewise for reality shows following police officers or border security, the cameras could make the officers less approachable by people who need their help, and also the public humiliation element in these shows would constitute punishment before a fair trial. Cameras in courtrooms would have the same issues.

The above are just a few examples I can think of regarding the erosion of patient rights, particularly in the area of data control. With regards to the terms of reference for this inquiry, the best fit might be under property rights, due to our ownership rights over our data, and also retrospectivity, in that this increasing data sharing is also being applied to data gained at a time when patients assumed their information would be held securely, in an offline environment.

Thankyou for your consideration,

Emily Flinders.

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8