

**SENATE STANDING COMMITTEE ON
COMMUNITY AFFAIRS**

**Healthcare Identifiers Bill 2010 and
Healthcare Identifiers (Consequential
Amendments) Bill 2010**

SUBMISSION

SUBMISSION NUMBER: 3

SUBMITTER

Adam Johnston

**Submission: Healthcare Identifiers Bill 2010 and Healthcare Identifiers
(Consequential Amendments) Bill 2010**

Dear Sir,

I really must wonder about the bona fides of the Government's "consultation" process prior to the establishment of this Senate inquiry, because my assessment of the initial Bill regarding healthcare identifiers is that it is little changed from the prior version.

In this submission, let me highlight Clause 4 of the principal Bill. For the Government on the one hand to say in sub-paragraph (1) that the Act will bind the Crown, yet in sub-paragraph (2) absolve itself of all liability, is curious indeed. If the Government is convinced e-health is such an advance, why will it not accept the legal responsibility for the program it is implementing? Should health information be disclosed inappropriately, the Government (or its principal agent, Medicare Australia) must not be allowed to legislatively excuse itself from responsibility.

Furthermore, I am sceptical about claims that electronic records necessarily reduce errors. Computers can be just as full of erroneous information as paper files, because at some point a fallible human being has to enter the data into the machine. Indeed, with the rise of cyber crime, hacking and computer viruses, might the electronic record be seen, one day, as more fragile and vulnerable than the paper record? This may be perverse, but does not seem improbable. After all, it is the computer (and not the paper filing cabinet) that needs an IT department to keep it going.

This does not mean I am opposed to the wide use of computers per se, but when these machines are dealing with something as intimate as my medical records, there is cause for pause and reflection.

It is noteworthy that this submission has to be with the Senate by early March, yet I was only advised of the inquiry today (as a stakeholder) by the e-Health Branch of the Health Department via email. This suggests two serious pieces of legislation will receive limited scrutiny. That is both unfortunate in terms of health policy and health outcomes for individuals. I am sure there are some people (particularly from isolated communities) who could benefit from the technology. However, I will neither use nor provide to my doctors, specialists or other health professionals any health identifier I

am assigned. This is because I have little confidence in the legislation, its design or the claim it will reduce medical errors.

I recommend that the Senate reject the legislation, unless there are very substantial amendments. These proposed amendments were outlined in my submissions to the consultation process; here recorded as Appendices 1 and 2. I stand by the argument in these documents.

Furthermore, as someone confined to a wheelchair by disability with a greater than average reliance on health services, you might expect me to embrace this reform. However, as the documents following will show, there is reassurance from dusty files in archives, as opposed to readily retrieved electronic records. The latter is more easily open to abuse, unless patients hold a degree of enforceable 'ownership' over their medical records. Yet, in neither Bill is a 'healthcare recipient' given this authority. Rather, we must rely on service operators and healthcare providers. Should we fear our records have been misused, a complaint to the Privacy Commissioner can be made; however, it is unlikely that an individual would ever be able to amass sufficient evidence to launch a criminal prosecution. And as stated, the Commonwealth has legislatively excused itself of legal responsibility and liability.

Governments often talk about the need for 'patient centred care' and 'better outcomes for patients'. This proposal is not about that; it ascribes individuals yet another number, and in the name of an (alleged) reduction in medical errors, says we should accept the ready transfer of personal medical data between healthcare providers. Yet, at no stage does this legislation give a 'healthcare recipient' the ability to act as 'gatekeeper' of their own data. The identifiers are created and stored by others and individuals are expected to accept that the operation of ethics committees, Medicare Australia and the Privacy Commissioner will be sufficient.

As you may be able to tell, this is of little comfort.

Yours faithfully,

Adam Johnston

26 February 2010

Appendix 1

First submission to the eHealth Taskforce

(Healthcare Identifiers and Privacy Submission 002 - Adam Johnston)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-002>

Healthcare Identifiers and Privacy Submission
Primary and Ambulatory Care Division (MDP 1)
Department of Health and Ageing
GPO Box 9848
CANBERRA ACT 2601

Dear Sir,

Q1. Do you agree that the functions to be conferred on the Medicare CEO are sufficient?

No. I do not think that this sufficient; whatever mechanisms the CEO of Medicare (the CEO) designs, they should be tabled in Parliament and subjected to scrutiny (possibly with reference to a Regulations and Ordinances Committee of the House and/or Senate). Additionally, a particular concern is that under the current model, the CEO will have responsibility for:

“...developing and maintaining mechanisms for users to access their own records and correct or update details...”¹

These mechanisms should be legislatively enshrined, if not in the principal Act, then in the subordinate legislation. Furthermore, the legislation should prescribe that it is the patient (or their nominated guardian, if they are incapacitated) who has a proprietary interest in the health record or records. Doctors, other health care professionals and providers (be they public entities or private corporations) should be identified as trustees. Misuse or improper use of a health record should result in joint liability for damage between a service provider *and* their employee, the latter losing the protection of “agency” should their act or omission have resulted in the unwarranted disclosure.

Making healthcare workers personally liable in the collection and disclosure of information is the appropriate place to set the standard. Additionally, as a healthcare consumer with what in “medical jargon” is described as “co-morbidities”, I am not content to leave management of my many health records to the CEO, the AHMRC, the ALRC, the Privacy Commissioner, a research ethics committee or anyone else. These bodies may be distantly accountable to me through legislation or regulation, but as a consumer I am unlikely to have contact with them, nor a capacity to influence what they may or may not do with my records.

Nor am I pleased that this legislation is going to exist alongside the current “hotch potch” of State and Territory laws; this will make it all but impossible for all but

¹ Healthcare identifiers and privacy: Discussion paper on proposals for legislative support, Issued by the Australian Health Ministers’ Advisory Council, July 2009, p.22
[http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-ehealth-consultation/\\$File/Typeset%20discussion%20paper%20-%20public%20release%20version%20070709.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-ehealth-consultation/$File/Typeset%20discussion%20paper%20-%20public%20release%20version%20070709.pdf)

the most determined to seek redress, as a complaint is passed between agencies, or gets bogged down in a question of whether a matter falls with the State or Commonwealth jurisdiction.² There should be a one-stop shop approach which makes things clear for consumers and health professionals alike, while “covering the field” from a jurisprudential perspective.

Further, I am concerned that this is not an “opt in” process; all Australians will get a health identification number whether we want one or not, with the current Medicare card seen as inadequate because “they are not unique (family members are often on the same card)...identification of individuals receiving healthcare services.”³ This shows just how specific the information held is going to be.

I am not happy with this, partly because the claim that computerised access to health care information necessarily leads to better outcomes does not stack up. At some point, a human being (with all our attendant fallibilities) has to enter data into the machine. An incorrectly spelt, outdated or falsified name or address can easily enter a computer, with no-one being any the wiser, least of all the computer, for perhaps a very long time. We should pause to remember that the computer is little more than an electronic filing cabinet and not an oracle. I noted these concerns in a submission to the ALRC’s review of privacy legislation highlighting well publicised, cases of fraud, data misuse and instances where computer systems that perhaps should have been linked were not, and of data that could not be matched.⁴

Again, just because a new piece of technology or computer software comes along does not mean government, industry or the public are obliged to use it (or to try and create a use or reason to implement it). Equally, as patients/health service recipients, we need to accept that our doctors and other carers are human; they will make mistakes, but most should not lead to a fatality. I am not convinced that a computerised record will necessarily lead to such a reduction in adverse incidents that I would be prepared to commit my entire medical history to computer. Indeed, if this were ever to happen I would insist on holding proprietary rights over the information.

² I note that the Productivity Commission has recently been investigating mutual recognition schemes. Providing a submission to that inquiry, I argued that “the moment any State Government launches a new program in the social services, business regulation or some other area of activity which has the potential to impact on an equivalent interstate initiative, the relevant legislation, explanatory memorandum, regulations or guidelines should specify how reciprocity or mutual recognition arrangements will work. These points should be considered *before* a measure is introduced, in an attempt to avoid costly amendment or duplication of regulations post facto”. See http://www.pc.gov.au/_data/assets/pdf_file/0011/84494/subdr58.pdf I would advise similar uniformity in this matter, which is why I would take “the one stop shop” approach.

³ Healthcare identifiers and privacy, op. cit., p.15

⁴ See Appendix 1, particularly pages 4-7

In my view, this would be the only way patients could gain meaningful leverage over researchers and others, who have been given exemptions to make secondary use of our information.⁵ “The public interest” is an ill-defined phrase to excuse or explain secondary uses, which while it may be justified in some cases, should not necessarily prevent people financially gaining from their records. Concerns have increasingly been raised about the ownership and control of DNA,⁶ and individuals should not have to suffer the indignity of losing control of their health records as well as their genes. Nor should we lose the ability to seek a return from researchers; again, in the case of genes and tissue samples, we have seen how the public have lost out as researchers have patented that which many patients/research participants gave freely.⁷ Individuals should not be duped again and lose property rights, nor the economic value of their medical records, like we have already lost so much of our DNA. I would prefer to see the legislation prescribe that specific, informed consent must be gained for secondary uses, because as stated earlier the “public interest” is an ill-defined phrase, which could all too readily be used to transfer information without a patient’s knowledge or consent. As a form of protection, the Government should add a clause to the legislation that states the phrase “public interest” shall be read narrowly and that there shall be a presumption against release.

The diagram on page 27 of the discussion paper shows that there are a number of databases and information flows in the proposed system. It is of concern, not only that there are a number of databases and information flows, but that Medicare Australia is only recorded as the ‘initial’ provider of the Healthcare Identifiers Service.⁸ Should the service be out-sourced to a private sector provider, it is essential that individuals exercise some significant level of control and/or ownership of their records, as discussed above. In this respect, it is noteworthy that the discussion paper cites a 2008 ‘Government Insights Issues Paper’ sponsored by BEA/Oracle.⁹ There is nothing wrong with private sector involvement in this proposal, however, this is a key motivation for my calling for patients to have ownership rights.

Q21. Do you think participation agreements are an appropriate mechanism for setting out the responsibilities of the parties involved (i.e. healthcare provider organisations and the HI Service Operator)?

⁵ See Healthcare identifiers and privacy, op. cit., p.30

⁶ For example see <http://www.scribepublications.com.au/book/genecartels> I have also expressed by own concerns to IP Australia at <http://www.acip.gov.au/expusubs/Adam%20Johnston.pdf>

⁷ Some research participants have fortunately showed themselves far more shrewd than others – see Taking the Least of You, By REBECCA SKLOOT, Published: April 16, 2006 (New York Times) <http://www.nytimes.com/2006/04/16/magazine/16tissue.html?ei=507>

⁸ See Healthcare identifiers and privacy, op. cit., p.27

⁹ See *ibid.*, p.16 (footnote 13) Also see <http://www.oracle.com/welcome/index.html?origref=http://www.oracle.com/us/corporate/index.htm> for information on BEA/Oracle

No. I have never been a supporter of agreements or Memorandums of Understanding (MoUs). From my own experience when job seeking, MoUs between employers and agents are not enforceable, least of all by the job seeker, who isn't even a party to the arrangement. It was a frustration of mine that I would be obliged to go to meetings about jobs which may not ultimately exist; agents and Centrelink could potentially take action against me for non-compliance, but I had no equivalent authority to ensure MoUs were fulfilled.¹⁰ 'Participation agreements' fill me with similar misgivings. This is why I again emphasise my desire for patients to have real ownership and control over their records – and that this must be clearly stated in the legislation.

Q33. Do you agree that the consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes?

I certainly do agree with this. Preferably however, the reforms I have proposed will make direct marketing so difficult that it will not be attempted.¹¹

In summary, given its current form, I would not use or disclose a Health Identifier to any health worker or related service provider. Additionally, one is far from convinced that this proposal will solve problems – it may just create a bigger one.

Yours faithfully,

Adam Johnston

July 21, 2009

¹⁰ See my submission to the ATFS Secretariat at http://taxreview.treasury.gov.au/content/submissions/pre_14_november_2008/Adam_Johnston.pdf particularly pages 6 - 8 (Adobe numbering)

¹¹ Also see Appendix 1, op. cit., pp. 1-2

Appendix 2

Second Submission to e-Health Taskforce

[http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/\\$FILE/010_Adam%20Johnston%20pt1_31-12-09.doc](http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/$FILE/010_Adam%20Johnston%20pt1_31-12-09.doc).

31/12/09 – Adam Johnston

e-Health Branch
Department of Health and Ageing

Dear Sir,

I have read the Exposure Draft of the Bill with great concern. Firstly, as a person with co-morbidities and high needs through disability, I note that nowhere in the legislation is there a section allowing individuals the choice of “opting out” of the e-health process. If we want any health care from a provider, we will have to accept the creation of a record. The e-health Branch should consider whether a refusal to submit information for the creation of an e-health record is equivalent to a refusal of treatment (or, would in effect cause the same outcome).

This is a very serious outcome, but in my mind the refusal to provide information for an electronic record cannot be deemed equivalent to a refusal of treatment. It was therefore somewhat reassuring to read in the Frequently Asked Questions (FAQ) brochure for individuals the statement that:

“...If your health provider is unable to obtain your IHI from the HI Service, or your IHI is not available for any reason, you will not be refused treatment...”¹

However, might people think seriously twice and thrice about seeking treatment in the first instance? As related in the Appendix to my previous submission, many institutions from banks to universities are withdrawing service options and, requiring their clients, customers or students to both access and provide information by exclusively electronic means. While these institutions assure you that their on-line/electronic service portals are ‘safe and secure’, given that these assurances often come with the qualifier ‘please keep your anti-virus software up to date’, one is left with little comfort. In any event, why should we be obliged to carry yet another administrative number around in our wallet, to access another electronic record?

Equally, while e-health might be an advance, it is not necessarily an improvement. Go into any general practitioner’s office, a medical centre or hospital and you will find multiple computer work stations. In many respects, e-health is already here and, while it might be seen as financially inefficient to maintain some paper records and other non-electronic means of identifying people, I remain to be convinced that we all must be forcibly ‘transitioned’ into a new system. Let doctors, patients and hospital administrations decide if and when they can afford (and will get maximum benefit from) an e-health system.²

¹ National E-Health Transition Authority, *Setting foundations for e-health with healthcare identifiers, FAQs for Individuals*, p.4 available at <http://www.nehta.gov.au/connecting-australia/healthcare-identifiers> (www.nehta.gov.au)

² From the analog telephone system to the analog television and radio signal, to light bulbs and a national broadband scheme, governments of all persuasions have never hesitated to tell us what technology they are

Furthermore, where humans are involved, errors will always occur, regardless of whether we have a paper or electronic system. People are fallible and, while systems can (and should) be put in place to guard against this, nothing is foolproof. As such, I do not believe the Exposure Draft represents so much of an advance that I am ready to embrace it and have all or most of my records stored electronically. As stated in my prior submission, some formal statement about patients holding a proprietary interest in their records would be an essential element for me to change my view.

Furthermore, the Exposure Draft leaves much to be written in subordinate legislation. While Regulations will be tabled in Parliament, unless a parliamentarian moves a disallowance motion, the Regulations will come into force without much scrutiny. However, health records are potentially of great personal significance to individuals and their families and, while appreciating that the Minister is required to conduct a review in three years³ I would much prefer a more open and transparent review structure.

A Joint Parliamentary Committee should be established in order to examine the appropriateness of any Regulations made, or subsequently amended. All parties concerned, including the Privacy Commissioner, service operators and any Ethics Committee⁴ which has approved research under Clause 15 of the Exposure Draft should be required to report to the Committee.⁵ The Ministerial Council should also be compelled by the legislation to table records of its proceedings before the Committee; although I appreciate that for constitutional reasons it is probably not possible to require

going to shut down on our behalf, nor how much the replacement will cost us, either individually or collectively. Rarely however, have governments stopped to ask whether we want or need these things (or whether we are willing to pay for them, particularly when official cost estimates and the actual price can leave a large public debt that taxpayers have to meet). There appears to be a marked reluctance on the part of governments to leave many decisions to consumers. From my perspective for example, my old analog mobile phone worked just fine, where the digital phone transmission is notable for all the 'dead spots' even in Sydney. And as for the digital TV – you can put the kettle on while waiting for it to 'boot up'!

³ Exposure Draft, clause 23

⁴ These committees are constituted by universities and other institutions. But I wonder how publicly accountability many of these bodies are; they assess proposals via their own internal guidelines and perhaps (as appropriate) guidelines issued by bodies like the National Health and Medical Research Council (NHMRC). The critical consideration here is that guidelines are non-binding and can be used as a way to bypass more formal scrutiny. Yet it is largely "guidelines" that academic ethics committees use to assess the appropriateness of the research applications which come before them, as well as the progress and conduct of researchers currently working in an institution. However, if guidelines are non-binding, why should any research institution be able to 'enforce' them via the provision or denial of facilities to a researcher? Equally, why should someone acquiesce to an arbitrary set of 'technically' unenforceable rules simply because another party or committee in authority calls them "ethical guidelines"? (For a discussion of this point, refer to Appendix 1, pp. 10 – 30. The paper was prompted by a media report in 2007 that Sydney University had, in order to acquire land to build a medical research facility, agreed with the landholder St John's College to prohibit stem cell research at the new complex. As a supporter of the research and someone with a disability, I was appalled that an Australian tertiary institution would ever allow its researchers to be shackled by religious authorities. From this point on, I have had serious reservations about leaving matters in the hands of ethics committees or University Councils and, in particular, their preparedness to distinguish between 'ethics' and 'religious dogma')

⁵ While it is preferable that all hearings were held in public, the Committee will face situations where 'in-camera' hearings may be necessary.

Ministers to attend Committee hearings; though they could be invited. The Committee should table an Annual Report to Parliament, as well as others as it sees fit. The Committee should also have a general discretion to table any or all of the reports it receives.

The Review proposed by the Draft should also be conducted by the Parliamentary Committee, so that it is independent of the Government and the Minister. Again, while appreciating that Privacy Impact Statements have been prepared,⁶ I still hold a fear of my health details ending up on-line for all to see, or otherwise in the wrong hands whatever precautions may be put in place. Once information has leaked, the 'damage has been done' and there is only so much restitution/damages will achieve. Furthermore, complaining to either the Privacy Commissioner or seeking legal redress can be long, intimidating and sometimes costly processes.

Meanwhile the National Electronic Health Transition Authority's (NEHTA's) website would appear to suggest the e-health identifier technology is already being rolled out.⁷ And while the e-health messaging capacity is to be commended for the way it can potentially help people in isolated communities' access medical care, the question of whether similar technology should be applied unilaterally and universally is another matter. To that, I would say no.

The attached Appendix is a submission I gave to the recently concluded Human Rights Consultation. Its relevance to this process is this; in my view, government has become too big and intrudes into many areas of life where it is not invited, wanted nor required. An e-health record and number for each individual Australian is a frightening example of just how big and how prescriptive government has become. As a person with a disability I specifically related to the Human Rights Inquiry instances where one felt case managed by government officials to within an inch of my sanity.⁸ The document also asked whether human rights were best protected by government giving active rights guarantees, or rather guaranteeing to stay out of people's lives as much as possible. My conclusion was that personal liberty and individual rights were best protected in the latter scenario, highlighting the comments of UK scholar A. C. Grayling.⁹

This does not mean there is not a place for e-government. However, the wisdom of using it with regard to such personal and intimate details is highly questionable. To underline this point, the research into e-government appears far more focused on administrative disputes and decision-making, with the objection of reducing processing to a series of on-line templates available to the public. Individuals would complete templates and a decision (sometimes made by computer) would be entered on the basis of the data provided. This would also reduce the need for individuals to make direct contact with

⁶ See *Release of the Healthcare Identifier Service Privacy Impact Assessments*, available at <http://www.nehta.gov.au/connecting-australia/privacy/pias>

⁷ See, for example, *NEHTA Latest News - Northern Territory pushes the button on new e-health messaging system*, 15 December 2009, available at <http://www.nehta.gov.au/media-centre/nehta-news>

⁸ See Appendix 1, pp. 2-3

⁹ See *ibid.*, p.7 and the quotation noting that the highest duty of any government is to protect individual liberty

officials¹⁰ and, while this might have advantages in a purely administrative context, when it comes to the treatment of people's health and their health records, I think entirely different considerations are applicable.

Firstly, I am sceptical that having e-health records will necessarily reduce identification or other medical errors or misadventures. Go to any government or private sector office and look at their data management systems. Ultimately, the electronic filing cabinet (the computer) has many of the same problems as the old version standing in the corner of the room. Misspelt names and addresses, multiple entries for the same person, differing levels of familiarity and conformity with data entry protocols between staff and, undetected errors or false information accepted (perhaps inadvertently) as correct. Add to these familiar problems the modern day scourges' of any IT network; viruses, spam mail and hackers.

For all of the above reasons, I recommend caution in proceeding with this e-health initiative. In particular:

1. Individuals should be able to 'opt out' of the electronic health identification system
2. A Joint Parliamentary Committee should be established to monitor the legislation, review all regulations thoroughly and produce (at least) an Annual Report to Parliament
3. The Joint Parliamentary Committee should conduct the three year review of the legislation, so that this is seen to be independent of both the Minister and Government
4. The Joint Parliamentary Committee should be able to examine the proceedings of any relevant Ethics Committee. It should also be the direct recipient of reports from the Privacy Commissioner and service operators/providers.
5. The Joint Parliamentary Committee should have access to the proceedings of the Ministerial Council, and invite Ministers to attend Committee hearings, even if it cannot constitutionally compel their attendance

Yours faithfully,

Adam Johnston
December 31, 2009

¹⁰ See *ibid.*, pp. 6-7