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**Privacy Legislation
in New
South Wales
Response to the “An
Evaluation of the
Healthelink Electronic
Records Pilot” report by
KPMG for NSW Health
December 2008**

17 December 2008

The Hon. Nicola Roxon MP
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Minister,

RE: Report- An Evaluation of the Healthelink Records Pilot

I am writing in my capacity as Chair of the Health Sub Committee of the Australian Privacy Foundation (APF).

We recently noted a summary evaluation report published on the Healthelink website (<http://www.healthelink.nsw.gov.au/>). There are several flaws in the summary, review attached, that can only be rectified by public and open access to the full data set. Hence, I write to ask that the relevant information be placed in the public domain.

We believe that access to the full dataset collected by KPMG for NSW Health, even if aggregated, is vital information from the privacy advocacy perspective. It is also pertinent to Australian national e-health efforts. As the report itself acknowledges, “... this is the largest shared electronic health record pilot to occur in Australia to date [p7].” We therefore request your support in asking that the full dataset is published in the public domain.

Yours faithfully

Juanita Fernando
Chair
Health Sub Committee

Board Member, Australian Privacy Foundation



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The Hon. John Della Paolona, BA MLC
Level 30 Governor Macquarie Tower,
1 Farrer Place,
Sydney NSW 2000

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RE: Report- An Evaluation of the Healthelink Records Pilot

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We note the summary report published on the Healthelink website (<http://www.healthelink.nsw.gov.au/>). There are several flaws in the summary, review attached, that can only be rectified by public and open access to the full data set. Hence, I write to ask that the relevant information be placed in the public domain.

We believe that access to the full dataset collected by KPMG, even if aggregated, is vital information from the privacy advocacy perspective. As the report itself acknowledges, "... this is the largest shared electronic health record pilot to occur in Australia to date [p7]." We therefore ask that the full dataset is published on the NSW Health website to facilitate a consumer-based review of the project.

Yours faithfully

Juanita Fernando
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Privacy Legislation in New South Wales

Response to the “An Evaluation of the Healthelink Electronic Records Pilot” report by KPMG for NSW Health December 2008

The Australian Privacy Foundation (APF) is disappointed by the “An evaluation of the Healthelink Electronic Health Records Pilot” report recently released by NSW Health [1]. The report suggests that the evaluation suffers from several methodological weaknesses and lacks adequate information in at least six areas. Firstly, the report does not provide sufficient information about the approach used to analyse research data. Secondly, the terms of reference are extremely limited. Third, it defines and uses the generic word ‘patient’ in confusing ways. Fourth, the report recommends an incremental approach to extending Healthelink beyond the current postcodes based on doubtful, if not spurious, evidence as to consent [1: Section 6.1]. Fifth, the Healthelink evaluation examines the trial from the viewpoint of health authorities and researchers rather than that of patients and clinicians. Finally, “Section 6 Considerations for future developments” is based on potentially questionable evidence that is not accessible in the public domain. Yet the poor quality evaluation underpins a range of considerations for future developments, which will affect the lives of the citizens in NSW, not to mention other Australian patients. The work is poorly presented and so undermines confidence on any subsequent action taken as a result of the evaluation. Consequently, this work will address each of the criticisms in turn.

1. The research approach

The research approach used for this evaluation is, at the very least, shoddy. There is no meaningful information as to the selection of participants for the study. Were all participants over 65 years of age or under 15 years of age? Did both cohorts share some characteristics? Was the evaluation sample representative of both cohorts? How many participants, in both cohorts, suffer from chronic illness and were their responses any different to other participants? How many of each group of participants were interviewed for qualitative work and how many of each cohort for quantitative work? Did the evaluation depend on key informants? If so, who were they and how did they contribute to the research? How were participants recruited for each part of the evaluation and what were they told about it? Data analysis that is not supported by an understanding of participant demographics and purposive qualities has no meaning at all.

There is no information about the research instruments used for the qualitative and quantitative aspects of the work [1: p.5,]. Researchers across all disciplines work to an acceptable, basic standard whereby a sample of the research instrument/instruments is/are provided for analytical purposes. The research tool/s must be provided before any scientist, let alone the APF, will accept the accuracy or meaningfulness of study findings presented in the report.

The report refers to consultation with consumer groups, although none are named [1: p.5,]. The APF, the primary national consumer group association dedicated to protecting the privacy rights of Australians, was not asked to provide any feedback about the trial at all. Why doesn't the report name the consumer groups from whom feedback was sought? In short, the evaluation report effectively asks Australians to 'trust' the NSW government yet again, as is the case with plans for national Shared Electronic Health Records (SEHR) and Unique Healthcare Identifiers (UHI) [2].

2. Terms of reference

The terms of reference for the study are extremely constrained. The purpose of the evaluation was to assess the acceptability, usability and viability of Healthelink [1: p5]. The study may have provided some very useful and interesting findings, especially as this is the largest shared electronic health record pilot to occur in Australia to date [1: p7]. Instead, as noted earlier, patient experiences are not contextualised in any significant way. The evaluation excludes information about the cost of establishing and operating Healthelink in both private and public practices [1: p5, p10]. Patients that did not opt-out of Healthelink within 30 days of commencement were treated as if they had consented to participate in the entire trial [1: p8]. Only a limited number of uncategorised health service providers, with selected and unnamed patient information systems, were permitted to contribute data to the trial [1: p6]. Thus, the terms of reference wasted the chance to collect and report useful data.

3. The 'patient'

The Healthelink evaluation report uses the generic word 'patient' in perplexing ways. For instance, 'patient' is defined as patients who were 65 years of age and older and the guardians of patients who were 15 years or younger at the time of enrolment [1: Footnote 2, p.5]. At the same time, we conjecture that the terms 'all patient groups' and 'a critical mass of patients' are used in some places to refer to patients more generically than as defined in the preceding sentence. The evaluation also refers to 'patients' in its closing paragraphs and, based on the context, is evidently referring to all patients in NSW or all Australian patients [1: p25, p27]. The final section of the report returns to use the word 'patient' as defined by the researcher/s [1: p28]. Assuming the confused application of the word is not a deliberate effort to conflate the findings of the research in such a way as to apply recommendations to all Australians, the various uses of the word contributes to the overall poor quality of the paper.

4. Extending Healthelink and consent

Notwithstanding questionable evidence, the report suggests that NSW Health should pursue an incremental approach to extending Healthelink beyond the select few postcodes studied for the trial [1: P24]. The approach would override patient consent mechanisms as this trial did in order to “create the opportunity for NSW Health to test those aspects of Healthelink that have not been fully explored “given its current scope

and configuration” [1:p24]. The APF opposes any effort to use patients as experimental subjects without their consent.

The “opt-out” approach to patient involvement for consent is among the clearest example of function-creep that the APF can cite. The Healthlink trial commenced as “opt-in” and when NSW Health was dissatisfied with the low number of participants enrolled in the trial, it was changed to “opt-out” [1: pp11, 12, 7]. The opt-out framework is heralded as a significant contribution to informing national e-health reforms [1:p2]. The report concludes that because few patients opted out of Healthlink within the 30 day period the evaluation permitted, that strong support for the lack of a consent model exists. Yet few opted-in either [1: p3].

There are several explanations as to the low numbers of patients opting out of the system, a few of which are documented in the report. Some participants may feel apathetic about e-health as either opt-in or opt-out systems simply because they are healthy, may not have consulted a clinician while the trials were running or did not have a good command of English [1: p15]. Perhaps it was time consuming and labour intensive to opt-out from the trial? Some patients will still not understand that their records were included in the trial [1:p15]. While patients with chronic illnesses may have benefitted from the trial this does not necessarily apply to all Australians, especially since most participants had relationships with a single clinician [1: p5; 3]. If trial participants unequivocally support the consent model, as is claimed in the report, then where is the evidence and why extend the range of eligible patients without their consent [1:pp11, 15]? In short, NSW Health is making unsubstantiated claims and, notably, refuses to place the evidence (even if aggregated) in the public domain for a thorough review by scientists, patients, clinicians and other commentators.

5. Who benefits?

On reflection of the paper, the APF explored who might benefit from the Healthlink evaluation. The stated purpose of the evaluation approach was to “inform the NSW Health state-wide rollout of Healthlink “with regard to “the acceptability, useability and viability of the model” [1: p2]. The paper also claims the trial was rolled out “in response to a need” that is “regarded as critical [1: p2].” To whom and to what need or needs does the report refer? Where is evidence supporting the idea that all patients or clinicians will benefit from the trial? Certainly other studies, using solid research methodologies and providing raw research data, presents different, more interesting perspectives of contextual e-health frameworks [3, 4].The APF view is that Healthlink proponents include bureaucrats, researchers, auditors and NSW Health rather than the majority of patients or clinicians.

6. Validity

The Healthlink paper disregards data validity concerns. The paper extrapolates from unscientific, potentially dubious research, to identify a range of areas for future development. For instance, one area earmarked for such development concerns governance, particularly the protection of patient privacy and confidentiality [1: pp. 24, 25]. This means that patients were compulsorily enrolled into a pilot program authorised by government health authorities without adequate protection of their private and sensitive contact, identification and health information. Thus, NSW Health are prepared to use experimental subjects without protecting their natural human right to dignity and respect [6].

The evaluation report also proposes extending Healthelink system access to multiple source of information not readily available to some clinicians during the trial, such as General Practitioner information systems, and implementing dynamic health information systems that would automate real time health record updates. [1: p4, 26]. It does not identify how this might be achieved. The paper recommends enabling the continuation of Healthelink using the same opt-out, lack of consent, model [1: p25]. At the same time, health authorities have identified “trust” as the key to introducing a viable national electronic health record in the future [5]. The APF is unsurprised when citizens express confusion and a lack of trust in national e-health frameworks.

7. Conclusion

The NSW Health report of the pilot lacks a great deal of pertinent information. The opt-out nature of the Healthelink trial and lack of data supporting the evaluation are excellent examples of why many Australian patients simply do not trust the government, especially in matters concerning their health records. In short, the paper is worthless due to the overwhelming lack of evidence that allegedly supports the efficiency propaganda outlined in the Healthelink evaluation. The scheme is funded by tax payers for the benefit of patients in NSW. If useful data has been collected, why is it not in the public domain? The APF, while supporting the application of technology to improve patient health outcomes more generally, questions report findings and is dismayed by the paucity of verifiable and reliable information it contains.

8. References

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