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Privacy
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19 August 2014

Meeting Outcomes

Friday 15 August 2014, 1.30 pm onwards, Expo Centre cafe, Melbourne.

Attendees: Paul Madden (DoH), Linda Powell (DoH), Juanita Fernando (APF)

❖ THE MEETING

You seemed to “hear” the frustrations experienced by stakeholders, including civil society advocates, the legal community and health privacy specialists, with regard to:

1. The various PCEHR (Personally Controlled Electronic Health Record) models that have spawned since the Howard years, with no learning evidently carried over from one to another
2. Health authorities’ “cherry picking” findings from PIA’s and other audits and reports of the PCEHR for implementation
3. The lack of transparent information as to these reports and why findings are “cherry picked” for implementation
4. The insecure nature of most computers utilised for patient care across the health sector, pointless PiP (Practice Incentives Program) programs etc.,
5. The professional limitations of those working on the PCEHR in the public domain
6. Batch files for the IHI based on Medicare numbers, which are less than 70% accurate; of those that are accurate, 99.9% have gone onto to devise a functional IHI
7. Registration assistants selecting sick patients at the point of care or unemployed migrants from Centrelink that don't speak English well to register for a PCEHR, without ever populating the record
8. The damage to trust experienced by several patients' re PID consent overrides and government management of their information
9. The mystery of the “Heathelink opt out” trial program closure in NSW.
10. The proliferation of digital silos of patient information that have emerged which, depending on patient consent, may feed into the PCEHR- eHealth has fostered this proliferation. How will this matter be addressed?

❖ THE “DOING END”

Reflecting on contemporaneous notes from the meeting, several related questions about the “doing end” of the PCEHR system have emerged that I hope you can clarify.

1. There is no consistent definition used for the PCEHR and no clarity between the terms “PCEHR”, “EMR” (Electronic Medical Record) and “EHR (Electronic Health Record)” as borne out by the discussion last week. How is the PCEHR defined?
2. There is no business case or plans for the PCEHR implementation in the public domain. The community including doctors, industry, patients and other stakeholders do not want to witness another rushed implementation of the PCEHR for political reasons, as seemed to have occurred during the previous decade. Yet iteration after iteration is currently being considered without supporting evidence. Even DoH comments on the health benefits of a PCEHR are minimal and often confusing or “facts” are misleading.
3. Where have the clinical safety reports that were funded by government money been published? A PCEHR system will only work if there is community trust in national e-health implementations. The findings of clinical safety audits are not helpful if these are not transparently available.



4. Patients may elect NOT to upload information about medications and illnesses to the PCEHR or not to authorise views of these for some health workers. Thus the record will not be reliable for treatment even if a health worker knows this patient's IHI (the actual record may be blank). What warning will be provided to health workers so this is understood?
5. Many patients that report to A&E are unable to identify themselves, so even if the patient has an IHI linked to a medical record, staff are unaware of this and the record may be blank or partially populated in any case.
6. Precisely where, in legislation supporting the PCEHR, is access to the health records database secured from Centrelink, PBS and other government agencies? The PCEHR shares a my.gov logon with these other government databases and stakeholders have no understanding of how this arrangement functions in practise- do you have a config plan I can study?
7. GPs will not receive funding from Medicare to populate the PCEHR. Neither will the patient be required to provide any co-payment to populate the record. So if my sole purposes for seeing a GP is to populate the record, and he/she cannot claim the consultation from Medicare and neither will the patient pay... who will?
8. Stakeholders are unclear about private health insurer's roles re managing private/public PCEHR system arrangements into the future.
9. Standing consent will be a problem if the patient does not wish this automatically uploaded to their PCEHR - what contingency measures are in place for those citizens who join, quit and re-join the PCEHR at a later stage? I can see all kinds of problems re standing consent, not the least of which will be default values embedded in hospital administration and medical software.
10. Recent publications in Pulse IT (http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=2016:consumer-study-shows-pcehr-too-hard-to-sign-up-for&catid=16:australian-ehealth&Itemid=327&utm_source=Pulse%2BIT+-+eNewsletter) suggest most people are unable to sign up to the PCEHR. Will people be able to "opt out" a great deal more easily than the flawed registration process indicates?
11. How will the DoH ensure that an "opt-out" national PCEHR registration system will not result in more than 20 million empty medical records similar to the registration assistant experience where Australians have already decided they do not wish to participate in the system?
12. Why won't the IHI become a default Australia card?

❖ TANGENTIAL ISSUES

1. Is there a business case in existence for the PCEHR as it is presently implemented and what does it say?
2. Can the PCEHR actually be optimised to be useful to both clinicians and consumers? How might this occur?
3. What is the evidence foundation on which the PCEHR is based?
4. What research exists specifically on its effectiveness and value and safety for stakeholders?
5. What does the evidence garnered from confidential safety reports and other sources indicate regarding PCEHR iterations that are safe and useful for citizens (both the community and clinicians)?
6. Why are the plans for an update for the PCEHR not being considered in the context of an updated National E-Health Strategy - which seems yet to be completed?