



**Australian
Privacy
Foundation**

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8 November 2010

Mr P. Fleming
CEO, National E-Health Transition Authority Limited

Dear Mr Fleming

Re: Personally Controlled Electronic Health Record (PCEHR)

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. The APF has sought to communicate privacy concerns to NEHTA on many occasions in the past.

We have sought, and continue to seek, to play our part in the development of a national framework for patient-controlled EHR, including privacy and personal information security protections. To gain acceptance, the framework needs to reflect the interests of the stakeholders, and, most critically, of the people whose data it is intended that the records contain.

Over the last five years, your organisation has held various events, but not as part of a coherent process. The contributions have not been cumulative, there has been no carry-through on outcomes from the events, and the previous senior staff-member was side-lined and left in frustration. The lack of a coherent process is all the more surprising in view of frequent statements by NEHTA staff that privacy concerns are a serious impediment to progress in eHealth.

Partly stimulated by this very disappointing experience, the APF has prepared the attached Policy Statement, which identifies the key characteristics of an effective consultation process.

The APF has now been invited to attend PCEHR Roundtables. We welcome the opportunity for engagement. We note that one of the three Aims of the Roundtables is "to obtain feedback from participants, explore options, answer questions, note comments, concerns and recommendations". Yet we've also been told that "the roundtables are not part of the formal consultation process".

This creates the impression that your organisation intends to once again avoid carry-through of information from meetings. This prevents a cumulative approach to understanding and commitment, and inevitably leads to negative perceptions by advocates and severe criticisms in the media.

Would you please confirm your organisation's commitment to a methodical and cumulative approach to engagement with privacy advocacy organisations, in line with the attached description.

Yours sincerely

Roger Clarke
Chair, for the Board of the Australian Privacy Foundation
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Policy re Consultations

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The APF comprises professionals who have background in a wide variety of professions, industries and technologies. They bring their expertise to bear on proposals and issues by gathering evidence, drawing evidence-based conclusions, and providing verbal and written submissions. Moreover, APF members generally perform this work *pro bono*, as volunteers, in the public interest. Organisations that listen, and use the information provided, achieve high returns on their investment.

The APF participates in consultations with proponents of projects that have potentially negative privacy impacts. Where possible, it also works with proponents of privacy protective measures, including laws, codes, organisational measures, business processes, system design features and privacy enhancing technologies (PETs).

The APF undertakes consultations with organisations of many kinds. These include corporations (e.g. Google), industry and professional associations (e.g. Communications Alliance, Universities Australia, Media Alliance), oversight agencies (e.g. the Australian Privacy Commissioner), government agencies in all jurisdictions (e.g. the Office of Transport Security, the Commonwealth Attorney-General's Department, Centrelink, Queensland Transport, Penrith City Council) and multi-governmental organisations (e.g. the National eHealth Transition Authority – NEHTA).

However, in order to commit the time, effort and opportunity-cost involved in participating in consultations, APF members expect that the organisation sponsoring the project will be committed, and that the process will be effective. Unfortunately, that has not always been the case.

This Policy Statement identifies the key features of effective consultations, and aspects that undermine them.

Positive Indicators of Effective Consultations

Initiation

- Initiation by the sponsoring organisation
- Evidence of executive commitment to identify and address privacy concerns
- Active effort by the sponsoring organisation to identify, and gain the involvement of, the relevant privacy advocacy organisations

Conduct

- Provision to privacy advocacy organisations of sufficiently comprehensive and clear information about the proposal, in advance of meetings
- Provision of verbal briefings to supplement the previously-distributed information
- A practical approach to any [confidentiality](#) and security issues
- Facilitation of interactions among stakeholders in order to identify concerns, clarify issues, define problems, and come up with ways to avoid or at least mitigate negative privacy impacts
- Documentation of the outcomes of consultations
- Progressive development of an 'issues register' to record problems and their potential and agreed solutions
- Progressive development of a 'privacy design features paper', showing which features are intended to avoid or mitigate which privacy issues

Results

- Outcomes that demonstrate accommodation of the perspectives of the consultees, e.g. assimilation of impact avoidance and impact mitigation measures into subsequent rounds of documentation, and into design and implementation activities
- Specific commitments to avoidance and mitigation measures as part of the design
- Control mechanisms to ensure carry-through on the commitments

Negative Indicators

- Communication-avoidance behaviours, such as non-response to communications, slow responses or vague responses that fail to address the questions asked
- Engagement-avoidance behaviours, such as the absence of key staff from meetings, and the use of consultants not only as facilitators and advisors but also as a shield between the organisation and the consultees
- Unwillingness to provide travel expenses and *per diems* to ensure that the appropriate people can participate in events

- Stage-managed meetings that are dominated by briefings and 'talking at' participants and that limit the air-time for participants to enquire, discuss and suggest
- Defensive behaviours, such as unrealistic or excessive approaches to [confidentiality](#) or security issues, ill-justified denial of information, or the ruling of relevant aspects of the matter to be off the agenda
- Commitment-avoidance behaviours, such as statements to the effect that the organisation reserves the right to cancel the process or ignore the outcomes, or that staff present at meetings do not have the authority to bind the organisation
- Inadequate follow-up to meetings
- Absence of effort to sustain corporate memory through the process, e.g. through staff-turnover without strong handover/takeover procedures
- Inadequate follow-through on commitments made

APF thanks its site-sponsor:



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