



**Australian  
Privacy  
Foundation**

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<http://www.privacy.org.au/>

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5 August 2010

Commissioner Timothy Pilgrim  
Office of the Privacy Commissioner  
Level 8 Piccadilly Tower  
133 Castlereagh Street  
Sydney NSW 2000  
GPO Box 5218  
Sydney NSW 2001

Dear Commissioner Pilgrim

**Re: Application for a Public Interest Determination on the collection and/or use of contact details for a patient's genetic relatives**

I thank your Office for affording me the opportunity provide this submission on the draft Public Interest Determination (PID) concerning the collection or (secondary) use of the contact details of a patient's genetic relative, to inform the relative about the patient's genetic information for the relative's own health. I have attached a copy of my response to your initial enquiry of August 2009 because the fundamental views expressed then remain valid.

My comments on this application, including on the necessity for, and the possible scope and nature of a PID, are outlined below.

**I. “ ... my Office has not received any complaints ...”**

I note that your Office has not received any complaints concerning the operation of the temporary PID. As the literature demonstrates, predictive genetic test results “may induce a sense of fatalism, the belief that little can be done to reduce the risk” [1]. Decision stories and patients' context vary considerably and the loss of certainty of not-knowing of genetic information may markedly affect subsequent patient action [2]. Genetic relatives can decide they have no control over the inevitable posed by receipt of genetic information and believe no significant benefit will result in reporting their concern over privacy threats to the Office of the Australian Privacy Commissioner. The lack of complaints is not generalisable evidence in support of the PID.

**II. Potential for the proposed act or practice to harm the interests of individuals.**

The predictive value of genetic illness in patients varies widely. Yet we know that many relatives suffer from false positive notions of the inevitability of suffering when receiving news of potential genetic links to a relative’s illness. These notions may lead to predictive genetic testing by relatives.

However, the outcomes of testing for single gene disorders are indecisive and testing for multi-factorial disorders are even less reliable. Test results are by no means certain. Nonetheless, asymptomatic genetic relatives are under a statutory duty of disclosure to report the family history of a genetic condition to insurers [3].

The literature shows there are no legal impediments to insurers sharing the genetic family information or selling it to other parties. Anecdotal evidence of “genetic discrimination” of these relatives is beginning to emerge [3, 4]. The tests may foster the development of a “genetic underclass” of Australians who are rejected by insurers [3].

The genetically-linked illness suffered by a family relative is, as noted, by no means predictive. Physician tests of the patient may signal that a disease will probably manifest in relatives at some time in the future but cannot foretell the timing or the severity of onset for that individual. Yet the emotional state, self-perception and social wellbeing of affected relatives may be irretrievably damaged by such disclosures [1, 2, 4]. Genetic links by no means conclusively establish that a family member will in fact develop a relative’s condition.

### **III. The extent to which the proposed act or practice is inconsistent with an individual's reasonable expectation of privacy.**

There is no evidence the proposed PID has considered risks to the patient or their genetic relatives from using their information. Neither is consideration of cases where people are advised of information they do not want to know, patients whose interests are damaged, advice which is wrong, or in effect useless. What of the individual’s rights not to be burdened with the knowledge of their likely death from certain causes, if nothing can be done?

Finally, research conducted by the School of Population Health at the University of Melbourne recently found that over 50% of participants, once told of the risk that if they accepted advice and information pointing to the need to be genetically tested then they would have to disclose this to insurers, decided the risk of insurance discrimination was worse than that of not finding out their genetic profile [4].

### **IV. The nature of the public interest objectives served by the proposed interference with privacy.**

What are the public interest obligations on the doctor seeking to provide unsolicited partial medical advice? The literature indicates that a clinician should need to justify this decision on the basis of substantial evidence-based consensus about the risk factors in the particular case [1, 3, 5]. What will occur if the doctor is wrong and the relative has disclosed the information to insurers that may share or sell the information? Will a recipient of genetic information or patient have any remedy, or will the doctor’s good intention shield him or her from responsibility? I’m also uncertain of whether a doctor-patient relationship exists with the third parties the clinician may seek to give unsolicited and incomplete advice.

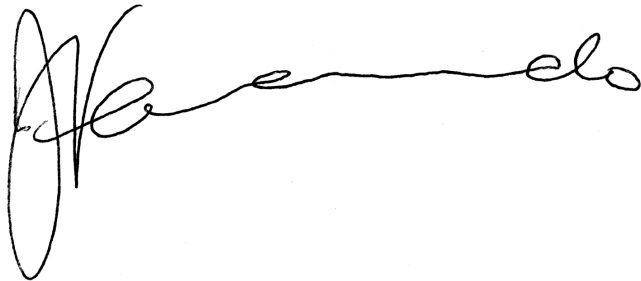
### **V. The need to balance the competing interests contained in section 29 of the Privacy Act.**

Privacy is a fundamental human right. Individuals have a reasonable expectation to control their own medical data. Instead, the PID inherently assumes that care information is the doctor's to control, and that 'public interest' can be claimed in a broad and vague way without a robust consideration of the risks (and wishes of other parties), demonstration of claimed benefits, or considering the options for only creating strict narrow limitations on the new exception so as to permit unwanted disclosure in only ‘serious’, severe, highly probable or urgent cases. The risk of damage to the emotional state, self-perception and social wellbeing of affected relatives does not seem to have been balanced with a competing public interest.

## **VI. The impact on the public interest if the proposed act or practice is not permitted.**

The PID does not link the proposed act or practice to the public interest. The weight of evidence suggests important limitations to using patient contact details to communicate with genetic relatives about serious illness. There is no direct evidence the PID may lead to improved clinical outcomes in family members related to a patient with serious illness. The literature, underpinned by anecdotal evidence, supports the conclusion that the PID will have only weak clinical utility, while substantially harming the interests of a patient's genetic relatives.

Yours sincerely



Juanita Fernando  
Chair, Health Sub Committee  
Australian Privacy Foundation

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<http://www.privacy.org.au/About/Contacts.html>

## REFERENCES

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**Australian  
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8 September 2009

Commissioner Karen Curtis  
Office of the Privacy Commissioner  
GPO Box 5218  
Sydney NSW 2001

Dear Karen,

**Re: Application for a Public Interest Determination under the *Privacy Act 1988*  
on the collection and/or use of contact details for a patient's genetic relatives**

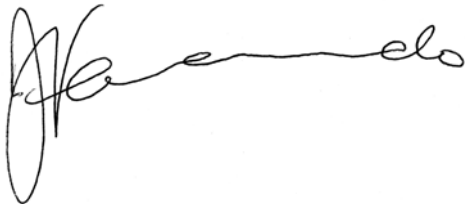
I recently commented on Dr Elizabeth McClusker's application concerning the collection (secondary) or use of the contact details of a patient's genetic relatives to inform the relative about the patient's genetic information for the relative's own health.

As you may be aware, research conducted by the School of Population Health at the University of Melbourne recently found that participants who opted to have genetic testing for health reasons, many of whom might save their own lives by doing so, declined testing when they were advised the genetic findings would need to be disclosed for life insurance purposes (Cresswell, A. Insurance fears deter bowel cancer tests. *the Australian*, <http://www.theaustralian.news.com.au/story/0,25197,26036192-23289,00.html>). In this context, the number of participants opting for genetic testing dropped from 80% down to 50% or less.

In other words, over 50% of participants, once told of the risk that if they accepted advice and information pointing to the need to be genetically tested then they would have to disclose this to insurers who may take it into account, decided that the risk of insurance discrimination was worse than that of not finding out their genetic profile.

I believe this new evidence is sufficiently convincing to be brought to your attention as a new factor to take into account in whether or not to approve the proposed TPID. Therefore, I ask you to consider limiting the proposed TPID in accordance with my correspondence of September 3, 2009, and these research findings

Yours sincerely

A handwritten signature in black ink, appearing to read 'Juanita Fernando', written in a cursive style.

Juanita

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Dr. Juanita Fernando  
Chair, Health Sub Committee  
Australian Privacy Foundation

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Contact Details for the APF and its Board Members are at:  
<http://www.privacy.org.au/About/Contacts.html#Officers>

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2 September 2009

Commissioner Karen Curtis  
Office of the Privacy Commissioner  
Level 8 Piccadilly Tower  
133 Castlereagh Street  
Sydney NSW 2000  
GPO Box 5218  
Sydney NSW 2001

Dear Karen,

**Re: Application for a Public Interest Determination under the *Privacy Act 1988*  
on the collection and/or use of contact details for a patient's genetic relatives**

Thank you for affording me the opportunity to comment on Dr Elizabeth McCusker's application concerning the collection or (secondary) use of the contact details of a patient's genetic relative to inform the relative about the patient's genetic information for the relative's own health. I have also been very grateful for the ongoing support provided by Ms. Catherine Rostron in response to requests for further information.

My comments on this application, including on the necessity for, and the possible scope and nature of a Temporary Public Interest Determination (TPID), are outlined below.

Summary

I am not persuaded of the urgency, either of the application being determined with minimal consultation, or of the scheme for the proposed disclosure. The application reads as the basis for a principle of general application, rather than a limited one off exemption. I understand the TPID would only last for 12 months and the Office of the Federal Privacy Commissioner (OFPC) expects either a legislative change may be made or a full PID process undertaken during that period. Nonetheless, I don't think the decision, as flagged, is suited to a TPID of this nature.

Dr McCusker does not appear to have contemplated all of the issues and implications although is apparently motivated by well-meaning good intentions mixed with concern. However the Doctor is seeking a 'business as usual' exception to this recently discovered

privacy issue. It is important to investigate the adverse potential impacts and implications of such a TPID.

There also seems to be an, arguably unwarranted, assumption by the OFPC that the narrow and specific changes to the Privacy Act in 2006 were intended to be accompanied by a range of exceptions. This is debatable. I would argue in general against assumptions that ancillary breaches of privacy were intended to be authorised by the amendments (other than those explicitly passed). I'm committed to the principle of staying within existing law.

### Scope

I am concerned about scope of the TPID. Despite the use of the word 'serious', there is potential for the TPID to cover a wide and growing range of genetic implications and symptoms, with a wide range of seriousnesses. The determination potentially authorises a wide range of reliability or confidence in a physicians' purported but uncertain 'reasonable' guess about the seriousnesses of levels of probability of any association.

According to Dr McCusker's letter to the OFPC, the basis for her request relates to situations where "Genetic information about a patient becomes available that, in the medical practitioner's view, suggests that the patient's genetic relatives may be at risk of developing a heritable condition." There are an ever-expanding number of conditions which are known to have some genetic component to them. This is particularly the case if the term "genetic information" includes enhanced susceptibility to conditions which on the face of it have other non-genetic causes as well. Indeed, this is likely to be among the main areas of expansion of medical knowledge this century.

I am grateful to Ms Rostron for explaining the driver for the OFPC is to have the TPID come into force at the same time as the s95AA guidelines (on the basis that the Commissioner approves the s95AA guidelines once they are formally received). Ms Rostron also pointed out that consideration of a PID or TPID takes time so the OFPC cannot wait until the guidelines are in effect to commence that process. Consequently, guidelines referred to in the draft TPID are not yet in effect and means the draft TPID is based on guidelines that presently do not exist and so have no legal force, yet may apply to the non-consensual disclosure of genetic information.

I concur with point made by Ms Rostron that for situations where a doctor can already disclose genetic info (with the consent of their patient) the TPID will overcome a potential barrier to actually doing that. I am more concerned by situations where the TPID enables a doctor to disclose genetic information about a patient without their consent. The OFPC, quoted in the 2008 NHMRC consultation draft says "serious" means it "must reflect significant danger to the individual and could include a potentially life-threatening situation or one that might reasonably result in serious illness or injury". In the context of these guidelines, this may also include the threat of a disease or psychological harm that may result in death or disability without timely decision or action."

Some examples in NHMRC consultation draft paragraph 3.2.3 demonstrate a concern to stay within the 'serious' category. However, they also refer to other examples such as financial distress due to psychotic behaviour that seem to contemplate only a loose connection to the genetic evidence. In other examples they are quite vague about whether 'serious' means 'likely', or 'severe' - one interpretation would be the former, and quite mild disorders could be considered 'serious' if quite likely. While this approach to risk analysis may be arguable, it is of concern that the meaning of 'serious' and the required degree of certainty are both ultimately quite vague.

Accordingly, decisions made under this TPID based on draft s95AA guidelines (see draft at [http://www.nhmrc.gov.au/guidelines/consult/consultations/disclosure\\_genetic\\_info.htm](http://www.nhmrc.gov.au/guidelines/consult/consultations/disclosure_genetic_info.htm)) raises concerns about the clarity of the requirement for this to be an exception. The concern is that this loophole becomes a licence to see disclosure without consent as something relatively routine, rather than a matter which is exceptional and which risks the basis of trust between doctor and patient.

The threshold for exceptions should require 'necessity', as with the existing loophole. Presently, the NPP 2.1 (a) and (e) exceptions permit disclosure when it is "necessary" to lessen or prevent a serious threat. But the OFPC summary of the applicant's case simply "suggests there is potential" for serious threat, and that disclosure "may" lessen or prevent such threat. This much looser language would, in effect, authorise genetic information based on almost any hunch being passed on, without either patient or recipient permission. Given the very broad scope of the potential genetic information affected, a main concern is that much disclosure is probably of very limited practical use, despite providing the basis for major and ongoing lifelong concern, or significant disruption in families, or breakdown of trust with doctors. Such risks should be based on a requirement for a very high degree of "necessity". Furthermore, the TPID would in effect, authorise the doctor to weigh up all this without any standards of prior research or material to confirm confidence levels about assertions made to others about their genetic profile and risks. In effect Dr McCusker's application indicates that patients should, 'trust me, I'm a doctor.'

If there is to be a TPID, I propose a requirement to research, record and pass on to the patient and related recipient the basis for this hunch: the reason the doctors think that the disclosure is "necessary" to lessen the threat. Why is it serious? Why does it affect the chosen individual? To minimise the risk that the involuntarily forwarded information is in practice just alarming or depressing without being of any "necessary" value in mitigating a serious threat, the disclosing doctor should be obliged to record the basis for their belief about necessity and seriousness for later audit by the OFPC should the need arise. This measure is designed to assist doctors to understand the decision and the extent that the evidence is actually persuasive with regards to the doctor's conclusion.

### Urgency

I would suggest there is no need for an urgent determination regarding use under the draft TPID's paragraph (3), since if the threat is imminent; there is already a loophole to permit it. In effect the draft TPID paragraph (3) regarding disclosure or use applies to matters which are not imminent. These need not be considered in haste since genetic propensities are by definition long term probabilities, not imminent threats. The Privacy Act NPP 2.1 (e) already applies to permit use or disclosure where "the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent:

(i) a serious and imminent threat to an individual's life, health or safety; or  
(ii) a serious threat to public health or public safety". If the threat is imminent, NPP 2.1 (e) can be used to permit use. But we are dealing here with an adjunct to the 2.1 (e) and (a) exception for genetic material, in the case where the threat is not imminent and the individual is a 'blood relative'.

### Scope of persons covered

There is potential for blood relative to include a wide range of individuals; arguably the more remote the relationship the greater concern for the application of this exception. The 2008 NHMRC consultation draft on the s95AA approved NHMRC guidelines suggests "disclosure without consent is generally limited to blood relatives no further removed than grandparents or first cousin (third degree relatives)." But note that the 2006 amendments add a broad definition to s6 Privacy Act: "**genetic relative** of an individual (the **first individual**) means



another individual who is related to the first individual by blood, including but not limited to a sibling, a parent or a descendant of the first individual."

In the worst case scenario, blood relatives may go back and forward over several generations to rapidly involve a very large number of people. It seems ultimately to be up to the doctor's judgment how far backward or forward or sideways this disclosure would be justified, even if outside the 'general' case flagged by NHMRC.

In our experience, this kind of information disclosure to genetic relatives is of interest to a wide range of commercial concerns, including insurance companies. There are potential conflicts of interest in the collection and use of this sensitive information, which is relevant and linkable to a lot of people, even beyond those directly identified in the medical record. A new model of a family tree is a likely result of the issuing the proposed TPID, yet its implications have not been explored and do not seem to be contemplated by the Doctor. The blood relationship scope of this draft TPID should be specified, and arguably limited to the greatest extent possible.

Doctors willing to consider using this non-consent based draft TPID model for collection and use of relative contact details to take advantage of the NPP 2.1 (e) and (a) loophole in their practice should be obliged to notify patients that they may use the patient's genetic and ID info in this way, preferably before the patient has consented to treatment and genetic examination. Doctors who choose to commit to only working on consent based genetic disclosure models need not make this disclosure; if necessity drives them to it, they should be obliged to notify the patient after the fact. A doctor who does not plan to use this TPID but who has already done so should fall into the first category, of needing to inform the patient. I propose a notification to patient of the intent, or past practice, to use this TPID.

This requirement restores some capacity for the patient to choose the basis on which they interact with a doctor. It would prevent some disclosures, but ensure that others are made with more notice that they could occur and more trust. Objections to this requirement may reveal that the doctor is unwilling to deal with the patient on the basis that the patient is aware of their possible non-consensual disclosure practices. While this may comfort the doctor and reinforce their capacity to choose to act independently of the instructions and wishes of the patient without having to be explicit about this practice, arguably it removes the obvious privacy-respectful model of accountability and choice.

Model of accountability and choice should be considered a necessary safeguard for the temporary authorisation of unlawful unauthorised collection and use of sensitive contact information about non-patients. A more carefully considered and balanced general guideline may include other safeguards which reduce the importance of this one or reduce the risk of unintended consequences and unforeseen adverse effects.

#### Other

I am uncomfortable about the critical thinking applied to the requested application or remedy. Simple safeguards seem not have been contemplated. It seems to be making an assumption that this proposition need not get any serious critical scrutiny on ethical, epidemiological or efficacy grounds, risk analysis or entitlements to privacy, or explorations of other mechanisms to achieve the allegedly beneficial results which it claims warrant the exemption. Should the draft TPID be issued, obligations to arrange mandatory follow-up, genetic counselling or other assistance to deal with what might be unwanted, traumatic, alarming or incomprehensible, practically useless information or a domestic health information bombshell should be instituted.

Furthermore, the draft TPID overlooks treatment of the personal information security risks to the various individuals, especially once this goes into a networked system without any established and agreed health privacy framework in place, as seems likely. The draft does not seem concerned about an individual's intrinsic claim to have first right to control their own medical data, nor of the degree and seriousness of public interest analysis that should be required as a basis for setting this right aside. Instead, there seems to be an assumption that care information is the doctor's to control, and that 'public interest' can be claimed in a broad and vague way without a robust consideration of the risks (and wishes of other parties), demonstration of claimed benefits, or considering the options for only creating strict narrow limitations on the new exception so as to permit unwanted disclosure in only 'serious', severe, highly probable or urgent cases.

What risks to the patient and their genetic relatives have been considered when drafting the TPID? There is no consideration of cases where people are advised of information they do not want to know, patients whose interests are damaged, advice which is wrong, or in effect useless. What of the individual's rights not to be burdened with the knowledge of their likely death from certain causes if nothing can be done?

Will the draft TPID be implemented retrospectively or will it apply from a given date? If retrospective, from what date would the TPID apply? Are current clients aware of previous information disclosures made without their consent or is this irrelevant?

What are the obligations on the doctor seeking to provide unsolicited partial medical advice? Will the clinician have to justify this decision on the basis of substantial evidence-based consensus about the risk factors in the particular case? What will occur if the doctor is wrong? Does a recipient of genetic information or patient have any remedy, or is the doctor's good intention a shield from responsibility? I'm also uncertain of whether a doctor-patient relationship exists with the third parties the clinician may seek to give unsolicited and incomplete advice. The draft TPID, if issued, would be more useful if it contained obligations to conduct follow-up, examination, assessment, counselling or the like rather than randomly advising third parties of genetic information. If implemented, I'd be grateful if the TPID considered this aspect of information disclosure to genetic relatives.

### Conclusion

1. For situations where a doctor can already disclose genetic information (with the consent of their patient) the TPID will overcome a potential barrier to actually doing that. I am more concerned by situations where the TPID enables the doctor to disclose genetic information about a patient without their consent and the impact of such disclosures on the information recipient.
2. It is unclear whether the draft TPID will be implemented retrospectively.
3. I am not convinced of the need for urgency in this matter given:
  - 3.1 NPP2.1 which permits information disclosure when there is evidence of "a serious and imminent threat to an individual's life, health or safety;"
  - 3.2 There is no evidence of a serious and imminent threat to health in Dr McClusker's request.

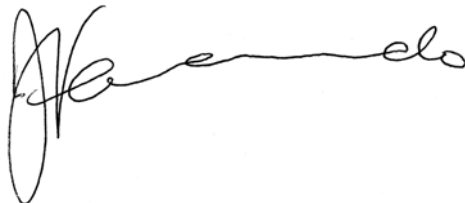
Serious but non-imminent matters, covered by NPP 2.1 (e) and (a), should be the subject of proper consideration, not the truncated 'urgent' model that is proposed.

4. The draft TPID framework is too liberal in light of the challenges identified herein. Key challenges are listed below.

- 4.1 Mandated safeguards should be implemented to reduce the risk of unintended consequences and unforeseen adverse effects as a result of information disclosure.
- 4.2 The blood relationship scope of the draft TPID should be specified, and arguably, limited to the greatest extent possible. That is how far backward (parent, grandparent) or forward (child, grandchild) or sideways (siblings and cousins) would disclosure would be justified?
- 4.3 Patients must be notified of the intent, or past practice, to use this TPID.
- 4.4 Prior research, or material to confirm a doctor's confidence levels about assertions made to others about their genetic profile and risks should occur prior to information disclosure. If there is to be a TPID, we propose a requirement to research, record and pass on to the patient and related recipient the basis for this hunch; that is the reason the doctors think that the disclosure is "necessary" to lessen the threat. Why it is serious? Why does it affect the chosen individual?
- 4.5 The disclosing doctor should be obliged to record the basis for their belief about necessity and seriousness for later audit by the OFPC should the need arise.

The overall cost and risk to the Australian community of the information disclosure seems to outweigh any benefit derived from the draft TPID. This is principally due to the threat to patient trust and confidence in medical confidentiality that will be caused over time by the excessively permissive model proposed and the consequent compromise to the frankness and completeness of information provision, or decisions to seek diagnosis or treatment. Therefore, should you issue the TPID, the costs of such should be limited in accordance with the suggestions above.

Yours sincerely



Juanita

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Dr. Juanita Fernando  
Chair, Health Sub Committee  
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