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To [REDACTED]
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Subject Fw: SUBMISSION ON DRAFT GUIDELINES UNDER
SECTION 95AA PRIVACY ACT 1988 (CTH) - PROF
ERIC HAAN [No Protective Marking]

IN-CONFIDENCE



"Haan, Eric (CYWHS)"
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01/03/2008 07:51 AM

To [REDACTED]
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Subject SUBMISSION ON DRAFT GUIDELINES UNDER
SECTION 95AA PRIVACY ACT 1988 (CTH) - PROF
ERIC HAAN [No Protective Marking]

Ms Cheryl Cooke
Evidence Translation Section
NHMRC

SUBMISSION ON DRAFT GUIDELINES UNDER SECTION 95AA *PRIVACY ACT 1988*
(CTH)
DISCLOSURE OF GENETIC INFORMATION TO A PATIENT'S GENETIC RELATIVES
– GUIDELINES FOR HEALTH PRACTITIONERS IN THE PRIVATE SECTOR.

The committee has prepared an excellent set of guidelines that will greatly assist private sector clinicians who are considering disclosing genetic information without consent. I have comments on one section.

Page 32 Psychological harm

As I understand it, the Privacy Act does not allow disclosure of genetic information, without consent, to a relative in order to prevent 'a serious threat to the life, health or safety' of a future (unconceived/unborn) child.

The Guidelines seek to address the matter in an indirect way by defining 'psychological harm' as consistent with 'a serious threat to the life, health or safety' of a relative. This is done to permit disclosure of genetic information that would allow reproductive choice.

Comment 1: By creating a 'psychological harm' test in this setting, it seems to me that a loophole is created that could apply to other situations where until now, disclosure would be possible only if there is 'a serious threat to life, health or safety'.

Comment 2: One could argue that if a doctor discloses genetic information in this context, he/she will actually be creating a psychological threat that did not exist for a relative, who was unaware of their genetic risk up to that point in time. That is, the doctor will create a

serious psychological threat associated with making a reproductive choice' rather than 'lessen
a serious psychological threat associated with making a reproductive choice'

Comment 3: The first paragraph of the Psychological harm section refers to 'a serious
psychological threat associated with making a reproductive health choice'. This
'psychological harm' argument is artificial because it side steps the real issue, which is the
effect on psychological health of having an affected child, rather than the effect on
psychological health of making a reproductive choice.

Comment 4: Most couples planning a family in the context of genetic risk do not suffer
serious psychological threats or actual harms from the process of making reproductive
choices, although those choices can be difficult. The example given, Scenario 6, appears to
recognise this because it does not address psychological issues in relation to decision making
and instead addresses the psychological effects of having a child with cystic fibrosis. It also
stresses the benefits to the unborn child of early diagnosis and treatment - yet the Privacy Act
does not allow consideration of the life, health or safety of a person who does not yet exist.

Comment 5: Finally, Scenario 6 is less than ideal because, given the recessive inheritance of
cystic fibrosis, the chance that a collateral relative will have an affected child is low, as their
partner would also have to be a carrier of cystic fibrosis for the risk to be significant. In the
example given, the sibling of the infertile man has a 2 in 3 chance of being a carrier and
his/her partner, a 1 in 25 chance - as a couple their chance of having an affected child is 1 in
150. Disclosure of the genetic information would have created (rather than lessened) 'a
psychological threat in order to avoid a 1 in 150 risk of having an affected child. An X-linked
disorder would provide a much stronger case if the 'psychological harm' argument is to
remain.

I think it is up to the Privacy Commissioner to bite the bullet and address the real need - a
guideline that will allow disclosure without consent of information that some couples will use
to make reproductive choices that will avoid the birth of an affected child or which can be
used to ensure early diagnosis and treatment of an affected child.

Yours sincerely,

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