



**Australian
Privacy
Foundation**

**APF submission on proposed
NHMRC approach to the
national harmonisation of
multi-centre ethical review
(HoMER) project**

February 14 2009

Re: Homer Public Consultation

The Australian Privacy Foundation (APF) welcomes moves by the NH&MRC to enable the harmonisation of multi-centre ethical review.

We also welcome acknowledgement in the consultation paper of the need to train members appropriately and provide ongoing legal support for cross institutional Human Research Ethics Committees (HRECs). Without this support, one jurisdiction might not be aware of subtle difference in privacy legislation between jurisdictions and yet be expected to make the single judgement about the balance of interests that will allow the information to be used in all jurisdictions. Nonetheless, there is no guarantee that any HREC will know enough about privacy law in its 'home' jurisdiction'. Only very important research, exceptions of direct benefit to public outcomes, needs a waiver from informed consent requirements. Hence, moves to support the enabling HRECs might also be applied to those committees reviewing research in single jurisdiction.

The APF has attached HoMER submission comments to this correspondence.

Kind regards

Chair
Health Sub Committee
Australian Privacy Foundation

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HARMONISATION OF MULTI-CENTRE ETHICAL REVIEW (HOMER) ENABLING SYSTEM

CONSULTATION DOCUMENT SUBMISSION FORM

Please complete this covering submission form and provide it with your submission. **Submissions that do not have this form attached will not be accepted.** This form is also available electronically at www.nhmrc.gov.au/health_ethics/homer/homer_consult.htm.

Any personal information provided by you will only be used for the purpose of developing the proposed national approach and will only be disclosed as identified information to members of NHMRC's HoMER Reference Group and HoMER Jurisdictional Group. Such information will not be used or disclosed for any other purpose without prior written consent.

1. Does this submission reflect the views of the organisation or an individual?

(An individual) (An organisation)

2. Contact Details of Respondent/Organisation (with contact name at organisation)

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Organisation: Australian Privacy Foundation

(if comments represent those of an organisation)

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3. How did you find out about the HoMER Consultation Document?

- (Email received direct from HoMER Project
- (Email forwarded from a colleague √
- (Link to NHMRC website received in Tracker
- (Press advertisement (please specify which newspaper): _____
- (Other (please specify): _____

4. Is this submission confidential/not confidential?

(**CONFIDENTIAL**

(**NOT CONFIDENTIAL** √

Please Note: Any submission, even if deemed confidential, made to the NHMRC may be subject to the requirements of the Commonwealth *Freedom of Information Act 1982*.

If the submission is confidential, please mark N/A to the following questions.

5. NHMRC has my permission to place my submission on the NHMRC website.

(**YES** √

(NO

(N/A

6. NHMRC has my permission to include my name, and where relevant, the name of the organisation I represent on the NHMRC website.

(**YES** √

(NO

(N/A

7. NHMRC has my permission to quote from my submission in any reports prepared about this document.

(**YES** √

(NO

(N/A

I am aware that if I agree to release all or part of my submission, it will be widely available. I am also aware that the information may be further referenced in later publications. If I have named an organisation at question 2, I agree that my comments are representing the views of the organisation.

Name (please print): Juanita Fernando

Signature:



HoMER Enabling System – Submission comments

Part A

3 Regulatory and administrative frameworks

Paragraph	General Comments
3.1	
3.2	
3.3	
3.4	
3.5	
3.6	
3.7	
3.8	
3.9	

Question	Response
3A	Yes (see below)
3B	A cross jurisdictional HREC must : <ol style="list-style-type: none">1. be advised by a suitably qualified legal practitioner and2. be provided with guidance as to the statutory and administrative frameworks operating in the jurisdictions where the proposed research will be conducted3. be subject to a credentialing process that is certified by the NH&MRC and4. be subject to guidelines issued by the NH&MRC so that an individual's privacy protections are not eroded by the change

HoMER Enabling System – Submission comments

Part B

5 Scope of the proposed HoMER enabling system

Paragraph	General Comments
5.1	
5.2	
5.3	
5.4	
5.5	
5.6	
5.7	
5.8	
5.9	
5.10	

Question	Response
5A	
5B	The APF supports the exclusion of the private sector from a cross institutional HREC
5C	The APF believes the scope of the proposed HoMER enabling system should be expanded to include research involving prisoners. Current legislative frameworks should be expanded to incorporate a single national approach to ethics, regardless of jurisdiction.
5D	Yes (see above).
5E	
5F	

HoMER Enabling System – Submission comments

Part C

8 Ethical and scientific review

Paragraph	General Comments
8.1	
8.2	
8.3	
8.4	
8.5	
8.6	
8.7	
8.8	
8.9	
8.10	
8.11	
8.12	
8.13	
8.14	
8.15	
8.16	
8.17	

Question	Response
8A	
8B	
8C	
8D	
8E	Yes
8F	Yes

HoMER Enabling System – Submission comments

Part C

9 Scheme to review and recognise Human Research Ethics Committees

Paragraph	General Comments
9.1	
9.2	
9.3	
9.4	
9.5	
9.6	
9.7	
9.8	
9.9	
9.10	
9.11	

Question	Response
9A	Yes
9B	
9C	Incentive- Public acknowledgment, the national government to underwrite actual costs

HoMER Enabling System – Submission comments

Part C

10 Research Governance

Paragraph	General Comments
10.1	
10.2	
10.3	
10.4	
10.5	
10.6	
10.7	
10.8	
10.9	

Question	Response
10A	
10B	Those involving humans, human tissue, therapeutic goods and genetic material.
10C	Probably, but it is difficult to envisage these at present. The concerns will need to be dealt with in an ad hoc manner in conjunction with the NH&MRC as they arise.
10D	

HoMER Enabling System – Submission comments

Part D

16 Training of key stakeholders

Paragraph	General Comments
16.1	
16.2	
16.3	
16.4	

Question	Response
16A	Training involves a session or sessions before the enabling system is introduced along with ongoing access to suitably qualified experts.
16B	HREC committee members, admin staff and legal advisors
16C	Scenario discussions together with legal advisors and perhaps, suitable representatives of the NH&MRC
16D	The NH&MRC