

Health Ethics

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This month in health ethics

Welcome the August edition of Health Ethics News!

In the past few months, the Health Ethics Branch has been busy with preparations for the commencement of the Health Records and Information Privacy Act 2002 on 1 September 2004. I hope all NSW Health HRECs are aware of their role under the new legislation. More information is provided in this edition.

The beginning of June saw the transfer of the NSW Central Cancer Registry to the Cancer Institute NSW. Requests for access to data from the registry will be considered by NSW's newest

HREC, which was recently constituted by the Institute. We profile the Institute's HREC in this newsletter.

Please remember that the annual meeting of Chairs and Executive Officers of NSW Health HRECs will take place on Friday 29 October 2004. We will be presenting an overview of the evaluation of the Shared Scientific Assessment Scheme pilot, discussing indemnity and insurance issues, and updating you on our training and support program for 2005. As we will be discussing SSAS, chairs of scientific sub-committees are also invited.

Profile: Cancer Institute NSW Ethics Committee (CIEC)

The Cancer Institute NSW was established in August 2003, after the NSW Parliament passed the *Cancer Institute (NSW) Act 2003* in recognition of the importance of accelerating improvements in cancer control in NSW. The Cancer Plan 2004-06 is available at www.cancerinstitute.org.au

The Cancer Institute NSW is governed by a Board and is guided by a number of advisory committees and expert working parties. A major advisory committee is the Cancer Institute NSW Ethics Committee (CIEC). The CIEC operates in accordance with the NHMRC *National Statement on Ethical Conduct in Research Involving Humans*. Currently CIEC has 11 members, nominated after a call for Expressions of Interest in the local media.

The establishment of the Cancer Institute NSW has seen the management of the NSW Central Cancer Registry (CCR) and the NSW Pap Test Register (PTR) transfer from the Cancer Council NSW to the Cancer Institute NSW. Consequently, the CIEC is now responsible for the ethical review and monitoring of all projects accessing data held in these registries, including those proposals that were previously approved by the Cancer Council Ethics Committee and were ongoing at the time of transfer of the CCR and the PTR.

The CIEC will review all proposals that require:

- Access to identifying or potentially identifying data owned or held by the Cancer Institute NSW, for research or other purposes
- Linkage of data obtained from different sources within the Cancer Institute NSW or the linkage of data from a Cancer Institute NSW data collection with data from another source
- Research initiated, facilitated or conducted by staff of the Cancer Institute NSW

- Access to de-identified data for research.

Whilst the CIEC will determine the ethical acceptability of proposals accessing data in the CCR and the PTR, the authority to release data lies with the Director-General of Health or his/her delegate for identified data, and the Chief Health Officer of NSW or his/her delegate for de-identified data.

The committee had its first meeting in June, the purpose being to orient members to ethics review, the key issues involved in reviewing projects that involve access to data, the privacy legislation and an overview of the NSW Central Cancer Registry and the NSW Pap Test Register.

CIEC will meet regularly on the third Thursday of each month. New projects will be accepted for review at the September meeting.

Please refer to the website at

http://www.cancerinstitute.org.au/cancer_inst/research/ethics.html

For further information about the CIEC, contact:

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SSAS Final Evaluation

The report of the final evaluation of the pilot Shared Scientific Assessment Scheme (SSAS) is due for completion this month. The SSAS Reference Group will convene early in September to discuss its recommendations, including the continuation and possible expansion of the Scheme. It is anticipated that the report will be published in September, and presentation of its main findings will be made at the upcoming meeting of Chairs and Executive Officers. SSAS continues to operate, pending the outcome of the final evaluation.

Health Ethics Branch would like to thank all HRECs and their Executive Officers for their continued support of this important initiative. For further information, contact:

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Health Records and Information Privacy Act 2002

The Health Records and Information Privacy Act 2002 (HRIPA) commences on 1 September 2004. Health Ethics Branch has produced the following documents:

- Additional questions for HREC application forms, which elicit from researchers all the information they are required to provide to the HREC under HRIPA; and
- An information paper for researchers, explaining why the extra questions are necessary.

The additional questions will also guide you on how to complete your HREC's annual reporting requirements to the NSW Privacy Commissioner. These documents can be found on the Health Ethics Branch intranet page. If you would like copies in Word format, please contact:

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NSW Health Privacy Manual (Version 1) 2004

The first edition of the NSW Health Privacy Manual is now in publication. The Manual supersedes the *Information Privacy Code of Practice (IPCOP)* which has been the main privacy policy document for the NSW public health system since May 1996. It applies to personal health information held by the NSW public health system.

The aim of the Manual is to provide assistance and practical tips for compliance with the *Health Records and Information Privacy Act 2002* which is due for commencement on 1 September 2004. The Manual will be a consultation document until 31 January 2005, and will be finalised by July 2005. Submissions regarding the content of Version 1 of the Manual will be accepted until 31 January 2005.

The NSW Health Privacy Manual is available online via the NSW Health intranet at the Legal and Legislative Services Branch Privacy Information page
<http://internal.health.nsw.gov.au/legal/Privacy/>

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General Retention and Disposal Authority – Public Health Services: Patient/Client Records (GDA 17)

This general retention and disposal authority commenced in May 2004 and covers records documenting the provision of health

care to patients and clients of the NSW public health system. It contains the authorised retention periods and disposal actions applying to the classes of patient and client health care records maintained by public health services.

Of particular relevance to HRECs, is Section 8.1.0 which relates to research projects. This section covers the retention periods for records relating to the conduct of clinical research, the conduct of non clinical research, requests to access records for approved clinical research where the research proceeds, requests to access records for approved non clinical research where the research proceeds, and requests relating to projects where the research does not proceed. This does not apply to records created and maintained by HRECs to oversee the conduct of research activities. Retention periods are based on the NHMRC *National Statement on Ethical Conduct in Research Involving Humans* (1999).

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Review of the National Statement

As HRECs are aware, AHEC is revising the *National Statement on Ethical Conduct in Research Involving Humans* (1999) during its 2003-2005 triennium. Health Ethics Branch has submitted comments to AHEC on the current National Statement, and will be involved in making a formal submission once a consultation draft of the revised National Statement is available. Health Ethics Branch's comments on the current National Statement relate to issues surrounding multi-centre research, transparency and accountability, clinical trial research and tissue banking. If you would like a copy of the submission, please contact:

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Clinical ethics: advance care directives

Health Ethics Branch has released guidelines on advance care planning. There is a growing expectation that one's wishes for medical care at the end of life will be respected even if progressive disease takes away decision-making capacity. There is also a need for improved mechanisms whereby an incompetent person's prior wishes about end of life care can be known and considered at the time that treatment decisions need to be made. This guide aims to assist health professionals in discussing advance care planning with patients, and to clarify how to use an advance care directive as part of that process.

See **Using Advance Care Directives (NSW)** at
http://www.health.nsw.gov.au/pubs/2004/adcare_directives.html

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A reminder about important dates

Below are dates of events, seminars and conferences in 2004.

Friday 29 October 2004 12.30 to 5.30 p.m.	Annual Meeting of NSW Health HREC Chairs and Executive Officers	Harbourview Hotel, Blue Street, North Sydney
Friday 12 October to Sunday 14 October	Australasian Bioethics Association (ABA) and Australian Institute of Health Law and Ethics (AIHLE) Conference: Contesting freedoms in health care policy practice and ethics	Sydney For more information, see the website at http://www.australasian-bioethics.org.au/conference/index.html
Tuesday 9 November to Friday 12 November 2004	7 th World Congress of Bioethics	Sydney For more information, see the website at http://www.bioethicsworldcongress.com/
Saturday, 5 to 9 December 2004	Intensive Research Ethics Course Centre for the Study of Ethics in Medicine and Society (Monash Medical School, Alfred Hospital)	Portsea, Victoria For more information, send an email to ethicscentre@med.monash.edu.au

Letters to the editor

The HEB would like to encourage you to submit any ideas, questions or other issues you would like considered for publication.

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