

Volume 7, Issue 1, April 2010

THE HEALTH LAW INSTITUTE

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DOI: 10.2966/scrip. 070110.204



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1. Introduction

The Health Law Institute is a law and policy research and education centre in the Faculty of Law at the University of Alberta in Canada. It has operated continuously since its creation in 1977 by Madam Justice Ellen Picard, now of the Court of Appeal of Alberta, then a Professor in the Faculty of Law. This makes the Institute one of the oldest educational and research centres of its kind in the world. It began as a project to compile relevant case law in the area, as well as to educate in the health related faculties, such as the Faculty of Medicine and Dentistry. Its aims and role have expanded and the Institute currently has a staff of approximately twenty researchers, administrators and students as well as seven research fellows.

2. HLI Aims

The mission of the Health Law Institute is to initiate and promote interdisciplinary activities to raise awareness, enhance knowledge and understanding, and promote positive reform of Canadian and international health law and associated health policy and ethics. In furtherance of our mission, our aims are to inform and educate students and practitioners of law and the health care professions, the public, and law and policy makers; to contribute to, promote and publish innovative legal and interdisciplinary research; and to respond to the needs of the public, academic communities, professional communities, and health law and policy makers. To achieve these aims, we conduct research and devote significant resources toward legal education. The Health Law Institute is optimally positioned as an important resource centre and as an effective, recognizably non-partisan vehicle for educating and influencing in the area of law and policy creation.

3. Activities – Areas and Project Examples

The activities of the Institute include research and education which are often aimed at the reform of law and/or policy. As well as numerous publications authored by staff each year, we have two in-house publications: the *Health Law Journal* and the *Health Law Review*. The staff also participates in ethics, law and/or policy related committees and working groups and provides legal expertise regarding a wide range of issues in the health area.

3.1. Education

Staff and research fellows speak at numerous conferences and workshops locally, nationally and internationally each year. In 2009, talks were delivered at venues across Canada, the US and in countries such as Qatar, Australia, South Africa, Germany, Cuba, Belgium, Barbados, Spain and Switzerland. Many also teach at the University in faculties including law and medicine. We also devote significant resources to public education and provide these directly through various groups, venues, and our website. Our seminar series, which allows us to invite visiting speakers from other centres, is also a key educational tool. We have been fortunate in attracting world renowned scholars to lecture in this series.

The HLI also organises conferences and workshops. Two recent events are key examples of this educational initiative. The Fifth International DNA Sampling Conference saw scholars from around the world convene in Banff, Alberta in September 2009. Numerous timely issues on a wide array of genetics-related topics were examined through excellent presentations and a workshop. The HLI also organised a conference entitled “Giving Voice: Advocacy and Mental Health” held in November 2009. The forum sold out (with 200 participants) two weeks prior to the event and evaluations confirmed that this event had filled much-needed educational gaps on legislative reform and on the role of advocacy in general.

The HLI also works with the media to relay information to the broader public. One recent example is the work our Research Director, Professor Timothy Caulfield did to help create documentaries on stem cell tourism and genetic testing produced for organisations such as the BBC.

3.2. Research

The HLI has many areas of research interest, thanks to the wide-ranging work of staff and research fellows, funded through a variety of external grants and/or contracts with organisations. Staff and research fellows publish extensively in these areas, which include: genetics, stem cells, biobanks, intellectual property, public health, pandemic planning, health information and privacy, medical malpractice, end of life issues, mental health, consent issues in a variety of settings, substitute decision-making, organ donation, and a variety of legal issues around the delivery of health care services.

A huge focus in recent years has been in the area of genetics, stem cells, and related legal, policy and ethical issues. A number of external grants currently focus on this area. For example, Professor Caulfield is a Project Leader of “Genome Canada: Translating Science: Genomics and Health Systems”. This project investigates the broad question: How is genomics knowledge translated in health systems and what are the consequent policy implications? Processes of translation involve the production of scientific knowledge, the protection of such knowledge through forms of intellectual property, and the interpretation, application, and commercialisation of such knowledge. Health systems include health research networks that contribute to research and technological innovation; production systems (e.g. agricultural and pharmaceutical systems), social and health delivery systems that influence and oversee nutrition and health; regulatory and court systems for decision-making, monitoring and control; and groups of end-users (e.g. citizens) and other relevant stakeholders. The team did foundational work on the earlier translation challenges with its genomics, ethics, economic, environmental, legal, and social studies (GE3LS) project.

Another key, current grant in this area is “Stem Cell Network: The Stem Cell Research Environment: Drawing the Evidence and Experience together (PP2)”. This three year project commenced in October 2008 and draws together an international team of collaborators to examine the nature of the stem cell research environment and its impact on research strategies, movement of trained researchers, capacity to conduct research, intellectual property in and ownership of research outputs, funding opportunities, research productivity, reception of emerging technologies, public

perceptions of the research and future investment mechanisms. This work will seek to inform public policy and will contribute to the broader knowledge base surrounding the complex ethical, legal and social issues engaged by stem cell research and other novel technologies.

“Social Issues in Nutritional Genomics” focuses on regulation of genetic testing services, particularly direct-to-consumer marketing of novel genetic tests in the field of nutritional genomics. It also studies media representations of genetic tests, as well as attitudes and knowledge of lay consumers and members of health professional groups. The research has resulted in numerous publications, including a book co-edited by two members of the research team and featuring chapters by other team members.

Another externally funded research project, “Analysis of Privacy Policies and Practices of Direct-to-Consumer Genetic Testing Companies: Private Sector Biobanking and Privacy Protection Norms”, brings together the HLI’s experience in the genetics area with its expertise in the analysis of privacy issues and implications. The goal of this project is to identify and analyse privacy issues that arise in the context of private sector genetic testing services. A growing number of commercial firms are selling genetic tests directly to consumers. The companies obtain biological samples from individuals for DNA testing and collect personal information, including details about lifestyle, and individual and family medical history. The growth of direct-to-consumer (DTC) genetic testing companies means a proliferation of private sector biobanks. Moreover, some companies are establishing consortia with research institutions and health care organisations to pool resources that will facilitate even larger biobanks. This project aims to conduct research that examines the privacy policies and practices of a comprehensive sample of DTC genetic testing companies to assess their compliance with fair information principles. In addition to evaluating the extent to which these firms meet fair information practices, the analysis will consider whether clear privacy protection norms are emerging to govern how these companies handle genetic samples and personal information.

Additional work in the area of population genetic research studies is being conducted in “AllerGen NCE: Moving Forward with Birth Cohort Research in Canada: The Legal and Ethical Foundations for the CHILD Study”. This project focuses on legal, ethical and social issues related to participation of children in longitudinal, population genetic research studies. A comprehensive comparison of relevant legal and ethical rules in four countries (Canada, the United States, Australia and the United Kingdom) has been published, and a paper has recently been co-authored with Canadian colleagues that presents recommendations for ethical governance of such research.

Given our extensive work in the area of health information legislation and the legal and ethical obligations regarding the handling of personal health information, we have commenced work on a policy paper on consent and electronic health records. “Issues of Consent in Electronic Health Records: Canadian and International Perspectives” will examine the legislative frameworks in Canada and in selected jurisdictions internationally, and focus on both the clinical use of information in an EHR, as well as secondary uses, with research serving as a focus example. An international advisory committee of experts from a variety of fields is currently being struck to provide input to staff as this paper is crafted. Once completed, the paper will be forwarded to law and policy makers, as well as other relevant stakeholders. It is the aim to make this the first in a series of HLI policy papers on timely topics.

In a completely different area, a team is being developed under a grant running from 2009-2015 to develop the only comprehensive regenerative medicine training programme in Canada. This programme will identify and train scientists who will lead this important new field in health research, in partnership with industry.

The Neuroethics Initiative, launched in 2008 along with the Academy of Finland and the German Federal Ministry of Research and Education, aims to bring together relevant and competitive researchers and research teams from Canada, Finland and Germany to design and carry out jointly organised research projects in the field of neuroethics. Funding within this Initiative is available for multilateral collaborative research projects consisting of researchers from at least two of the partners. The HLI research team will partner with researchers from the University of Bonn in Germany, University of Helsinki in Finland, and the Institute for Science and Ethics in Bonn, Germany. The other research teams are independently funded by their respective national funding agencies.

The “Evidence, Ethics and Health Policy Research” project will engage policy makers, health care professionals, research ethics boards, patient advocacy groups and the general public and will produce a variety of outcomes relevant to allergy and asthma policy and research, including: consensus statements and recommendations (flowing from interdisciplinary workshops), academic articles, practical guidelines, and articles in the popular press. Public seminars will also be held. By gaining a greater understanding of both the relevant research ethics environment and the ways in which evidence is used to inform policy making, the aim is to make the process of creating evidence-based health policy more efficient and effective, thus heightening the value of research and contributing to the well-being and health of the population.

A great deal of research over the last five years has focussed on public health issues. Executive Director Tracey Bailey, Research Director Timothy Caulfield and Research Associate Nola Ries edited the first text in Canada in the area, *Public Health Law and Policy in Canada*, with a second edition now in print. A public health volume of *Halsbury's* is also in the publication process at present. A recent grant also funded one key area of such research: issues related to the obesity epidemic. The focus was on the use of legal tools to regulate food environments in an effort to promote healthier eating choices. In particular, food labelling, food advertising, restrictions on food ingredients, and analyses of recent governmental reports on policy options to address obesity were examined. Related research has examined media representations of genetic factors implicated in obesity.

A related coalition project, “Alberta Policy Coalition for Cancer Prevention”, aims to tackle behavioural risks for cancer through development, adoption, implementation, and evaluation of policy. The Coalition will build on the success of tobacco reduction and expand the policy scope to other behavioural risk factors for cancer, specifically obesity and related determinants such as unhealthy diet and physical inactivity. The Coalition will focus on three policy settings – schools, workplaces and communities.

In one final example, the grant “Rationing Publicly Financed Dental Care in Canada: Moving beyond individual and social responsibility” is studying the exact principles and rules used to ration publicly financed dental care in Canada and continuing research into the political economy of dentistry. Publicly financed dental care is gaining prominence as a health policy issue in Canada and, given the challenges that

continue to exist for low-income groups in need of dental care, this is a timely project in the Canadian context.

3.3. Committee and Policy Work

HLI staff and research fellows serve locally, nationally and internationally as members of many research ethics boards, clinical ethics committees, policy working groups, legal organisations, and other organisations aimed at the creation of law and/or policy. Contributions have again occurred on a wide range of issues including genomics, biobanking, stem cell research, ethics and pandemic influenza, the safe disposal of methadone/opioids, end of life decision-making, clinical ethics, research ethics, public health, global health, patient safety, injury prevention, confidentiality and handling of health information, substitute decision making, mental health and obligations of health care professionals.

4. Additional Information

The Health Law Institute has a wealth of on-going research, educational and law/policy reform projects underway on an on-going basis. Our work is both legal and multi-disciplinary, and we work with colleagues and teams from many different areas of expertise. Please see our website for further information about our publications, and other activities at www.law.ualberta.ca/centres/hli or by contacting Tracey Bailey (Executive Director) or Nina Hawkins (Administrator).