

Attachment re: Item 5.2

Summary Report to the Board of Directors, Genome Canada

The Vancouver GE²LS Workshop

Vancouver, B.C., January 21, 2002

Report Prepared by:

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Workshop Objectives

The Genome Canada GE²LS Workshop was convened in Vancouver on January 21st, 2002, with the purpose of developing short and long term strategies for the evolution of GE²LS research and networking in Canada. Of particular concern were the issues of community building, the need to expand the scope of research, and develop strategic initiatives.

Steering Committee Members

The Genome Canada GE²LS Workshop Steering Committee was comprised of the following individuals:

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<p>Ned Ellis (Observer) Vice-President, Programs SSHRC 350 Albert St., Box 1610 Ottawa, ON, K1P 6G4 E-mail: ned.ellis@sshrc.ca</p>	<p>Isabelle Blain (Observer) Corporate Secretary, Council Secretariat NSERC 350 Albert Street Ottawa, ON, K1A 1H5 E-mail: isabelle.blain@nserc.ca</p>
<p>Therese Leroux (Observer) Director, Ethics Office CIHR 410 Laurier Avenue W., 9th Floor Address Locator 4209A Ottawa, ON, K1A 0W9 E-mail: tleroux@cihr.ca</p>	

GE²LS Workshop Presentations

I. Canadian GE²LS Work: Current Genome Canada Initiatives

The GE²LS Workshop (Agenda – Appendix I) began with brief presentations by David Castle, Edna Einsiedel and Beatrice Godard, providing overviews of their three respective projects funded through the first Genome Canada competition, at the Ontario Genomics Institute, Genome Prairie, and Genome Québec. This was followed by informal presentations from researchers applying to Genome Canada’s competition II, and whose proposals have a GE²LS component: Claude Laberge (*CART-a-GENE*, in Québec), Michael Burgess (*Genomics, Democracy and Ethics*, in B.C.), and Donal Hickey (*Genetics and Biodiversity*, in Ontario). The purpose of these overviews was to provide the assembled workshop participants with a sense of the type and scope of current GE²LS initiatives.

II. Canadian GE²LS Work: Future Directions

With this background, the workshop focus shifted to future directions for GE²LS research in Canada, with presentations on social science research and genomics (Margaret Lock), GE²LS and economic research (Michele Veeman), pharmaceutical industry perspectives (Susan Grant), and global perspectives and knowledge gaps (Christina Zarowsky). There followed an animated discussion about the possibility (and pitfalls) for effective and equitable technology transfer of genomics knowledge and biotechnology, from developed nations such as Canada to the developing world. Another topic of discussion dealt with the need for genomics and science researchers to be modest about the real potential for application from genomics research, and their (and GE²LS researchers more generally) responsibility to educate the public, media, and each other.

III. Overview of GE²LS Research in Canada, US, UK and EU

The morning’s presentations were concluded with a brief overview by Bryn Williams-Jones of GE²LS research and funding in Canada, the U.S., the U.K. and Europe, which summarised the GE²LS Backgrounder document that had been distributed to all participants in advance and at the workshop (Appendix II). This presentation began a discussion on a number of issues that continued through the rest of the workshop, e.g., the nature of Genome Canada

funding for GE²LS with regards to matching funds, difficulties in the peer-review process and the apparent inability of the federal and provincial funding agencies to co-ordinate GE²LS funding, and the need for closer collaboration between the diverse disciplines engaged in GE²LS research.

IV. Strategic Options: Priming the Discussion

In order to assist the breakout groups to focus their discussion, the Workshop Steering Committee members formulated a number of areas in which strategic options were to be formulated. These options, presented to the workshop attendees by Bartha Maria Knoppers, included:

- Capacity building
- Networking
- Research projects
- Other

These broad areas were presented to facilitate the workshop discussion and not intended to limit the recommendations made by the breakout groups in any way. Inclusion of the “other” category was intended to permit the breakout groups to be innovative and to think outside clearly defined categories. Workshop participants were asked to consider possible advantages and issues and to bring forward a list of preferred strategies that Genome Canada could use to facilitate and encourage GE²LS research in Canada.

V. Breakout Groups

Workshop attendees were assigned into one of four distinct breakout groups (Appendix III). The groups were assembled and asked to meet for approximately one hour, with the objective of formulating recommendations to be presented to the Board of Directors of Genome Canada. At the end of the breakout period, the larger group reconvened in a plenary session wherein one representative from each breakout group presented their group’s strategic options to the Workshop. Tim Caulfield led the plenary discussion of all options presented by the breakout groups.

VI. Workshop Conclusions

Overview of the Gaps Identified in Canadian GE²LS Research

Gaps in Canadian GE²LS research, as identified by the Workshop participants, fell into the following categories:

- How science is used in the regulatory process
- Appropriate principles to assess society’s use/misuse of science
- Public safety
- Issues of commercialization
- Unspoken background assumptions of various disciplines
- Reconciliation of competing interests/objectives

Primary Recommendations

A number of recommendations were made by the breakout groups and determined, by the larger group in the plenary session, to be possible strategy options for Genome Canada. It was agreed that the Summer Institute was the most viable option, best able to meet the range of needs (e.g., networking, funding small research projects, etc.), and thus to be strongly recommended.

- 1) Annual Summer Institute & GE²LS Symposium;
- 2) Research Networking;
- 3) Funding for Small Projects & Commissioned Works;
- 4) Central Resource Centres; and
- 5) Funding Problems: Cooperation Between Canadian Funding Agencies.

1) Annual “Summer Institute” and GE²LS Symposium

The dominant suggestion to emerge from the breakout groups and discussion in the plenary session was the creation of an annual “Summer Institute” to be hosted by Genome Canada, perhaps in combination with other agencies. It is important that, if adopted as a strategy by Genome Canada, the Summer Institute be seen as a first class, high profile endeavour that will build interest in GE²LS research across multiple academic disciplines. Despite being coined a “Summer Institute” this event will not necessarily be held in the Summer months and, in all likelihood, the first annual Summer Institute could not be held until Fall 2002 or Winter 2003 due to the complex organizational requirements of such an event. Moreover, it may be worth considering the use of another term, given that many Summer Institutes are little more than expensive, low level education or training courses, which is not the intent of the of the proposed gathering.

It has been suggested that each year a topic of particular interest to the GE²LS community (e.g., because it is an under discussed issue, or prominent in public debate) would be analysed in an intense and thoroughgoing fashion. In considering topics deserving of such intense focus, it must be recognized that the GE²LS research community needs to be expanded across various disciplines and genomes. Accordingly, it will be critical that basic scientists and GE²LS researchers be targeted to ensure that the Summer Institute is a worthwhile platform to facilitate networking amongst key players in various fields. It has been recommended that the Summer Institute agenda could (and should) be linked to other activities including conferences, workshops, stakeholder meetings, focus groups, etc., that would occur during the same time period.

There was a general comfort level with most Workshop participants that a Summer Institute is a potentially viable option for Genome Canada to consider. It was felt that the Summer Institute model could serve as an umbrella for achieving all of the desired objectives (capacity building, networking and research). Additionally, many of the suggestions made by individual Workshop participants or groups could be adopted or modified to fit into the Summer Institute model.

The Summer Institute model, as defined by the Workshop participants, is flexible and within this model, the following recommendations can be readily incorporated:

- i. partnerships with other funding agencies could be sought to further the interdisciplinary agenda;
- ii. junior scholar participation could be elicited through the development of background papers or involvement in other relevant projects. To this end, seed funding could be provided to junior scholars;
- iii. full day or half-day workshops on specific topics (e.g., for the development of consensus papers, etc.); and
- iv. a one-day conference could be held to allow the dissemination of research findings by junior and senior GE²LS scholars.

For the first annual Summer Institute, a Steering Committee will have to be formulated and designed to function in a top-down fashion. In order to mitigate both the perception and the effect of such a hierarchical committee, one of the fundamental mandates of the Steering Committee should be to engage as much of the GE²LS community as possible to ensure that a sufficiently broad array of topics and participants are considered and included in the Summer Institute. All attempts should be made to ensure that subsequent Steering Committees are more populist in nature and that the participating communities of the prior annual Summer Institute(s) have input into the agendas for subsequent years.

2) Research Networks

Another strategic option for Genome Canada to consider is that of “Research Networks”. Traditionally, 10-15 researchers from divergent disciplines would be brought together to work on a specific topic, concept or issue (e.g., intellectual property and genomics) as a “research network”. The bulk of funding to support research networks is expended on travel and related expenses. Research networks are generally seen to be a good way to meet the GE²LS community needs for networking, capacity building and research.

Research networks often focus on generating co-authored publications, books, or collections of essays that provide a timely, high profile, and relatively low cost mechanism for disseminating information. Funding agencies such as SSHRC, CIHR or ELSI subject ventures of this sort to peer review, thereby creating significant time delay and reducing the value of any output. By contrast, sidestepping the peer review process would permit research networks to be rapidly assembled and focused on a current of topical theme, with the results quickly and widely disseminated.

Peer review creates difficulties for more general funding (apart from Genome Canada) of research networks. Arguably, when peer review is required, an inappropriate time delay between application submission, the commencement of research, and the dissemination of research findings is created. Further difficulties with this process are evidenced by the way in which, for example, CIHR inappropriately has applied a science model to evaluate humanities and social science research. The interdisciplinary nature of GE²LS research introduces challenges to the traditional peer review process. For these reasons, many thought it would be advisable for Genome Canada to avoid the peer review process, where possible. Others, however, thought peer review is an essential element to maintain high quality investigative

research. It would be worthwhile for Genome Canada to consider alternative review mechanisms.

A potential pitfall of research networks is that they can become repetitive in terms of members, and result in the perpetuation of related and non-innovative opinions on a variety of GE²LS -related topics. It has been suggested that overarching research networks could be created utilizing funding previously allocated to the individual Genome Centres; this potential should be explored further.

3) Funding for Small Projects and Commissioned Works

One topic of discussion that surfaced throughout the Workshop was the need to have small grants available to fund GE²LS research that, although highly relevant and worthwhile, would otherwise not be funded because of the narrow scope of the topic or the isolation of a particular individual researcher in a discipline outside of the traditional GE²LS community. Further, making available small amounts of money to fund specific research to a number of individuals will inevitably further Genome Canada's objective of capacity building.

In the plenary discussion it was noted that if structured as a "Request for Proposals", small project funding as suggested would not conflict with funding provided by other agencies (e.g., SSHRC and CIHR which do fund small projects). Workshop participants recommended that funds be provided for, among other things, case study development, community consultation, small ethnographies, and the study of issues on health services integration. It was also noted that small projects or background papers could be funded in the Summer Institute model described above.

Genome Canada may want to consider the value of commissioning GE²LS related works from junior researchers in the GE²LS community. Such projects can be beneficial to junior researchers in a number of ways, including:

- i. funding support;
- ii. the opportunity to network within the GE²LS community; and
- iii. the development of a respectable publication base.

For example, if Genome Canada opts to pursue the idea of the Summer Institute, works commissioned by junior researchers may be useful in providing knowledge development on topical issues, or to support senior presenters at the Summer Institute with course materials or background preparation for lectures.

4) Central Resource Centre(s)

Another idea brought forth as a potential strategic option for Genome Canada is the creation of one or more central resource centres (e.g., virtual and web based, or within a research centre with an existing base of expertise) to provide basic information to individuals and each of the Genome Centres, without duplication of effort. For example, intellectual property is conceptually important to each Genome Centre and is highly relevant to many GE²LS researchers. Thus a resource centre could be established wherein core information concerning intellectual property is prepared and disseminated.

5) Funding Problems: Cooperation Between Canadian Funding Agencies

During the Workshop, numerous problems were identified concerning the funding of GE²LS research. It appears that GE²LS researchers are caught between the conflicting agendas. CIHR and SSHRC both believe that it is the mandate of Genome Canada to fund GE²LS related research, although they do fund some work in this area through the existing grant structures. When combined with the difficulties raised by conducting interdisciplinary peer review on GE²LS projects, many researchers may simply not be successful in gaining the required funds to pursue GE²LS research. In response to this problem, Genome Canada may be advised to seek clarification of the funding requirements for the various relevant federal and provincial agencies, and convey such information to GE²LS researchers. Moreover, Genome Canada may be in a position to help streamline and rationalize the process of GE²LS research funding and evaluation.

Conclusions

The Workshop, in large part due to the open and participatory manner in which participants were able to engage with each other, can be considered a successful first step in the development of a coherent, interdisciplinary GE²LS research community. A range of important (and sometimes contentious) issues was addressed during the Workshop, with particular attention on the need for improved organization of research funding, network building, and capacity development. Genome Canada can and should play an important role in developing and supporting GE²LS research in Canada.

Appendix I

AGENDA

Genome Canada GE²LS Workshop

(Ethical, Environmental Legal and Social Issues in Genomics Research)

Malaspina Room, Fairmont Waterfront Hotel,
Monday, January 21, 2002 – 8:00 am to 5:00 pm

Agenda

- 7:30-8:00 Breakfast in the foyer of the Malaspina Room
- 8:00-8:30 **Greetings, Introduction and Presentation of Goals:** Tim Caulfield
Brief introduction of Steering Committee
Goals: 1 - Community Building/Networking; 2 - Expanding the Scope of Canadian GE²LS Research; and 3 - Developing Strategic Initiatives
- 8:30-9:30 **Canadian GE²LS Work: Current Genome Canada Initiatives**
8:30-8:40 Current Initiatives: Ontario Genomics Institute - David Castle
8:40-8:50 Current Initiatives: Genome Prairie - Edna Einsiedel
8:50-9:00 Current Initiatives: Genome Quebec – Béatrice Godard
9:00-9:30 Questions for presenters
- 9:30-10:00 **Break**
- 10:00-10:40 **Canadian GE²LS Work: Future Directions?**
10:00-10:10 Social Science Research and Genomics - Margaret Lock
10:10-10:20 GE²LS: Economic Research - Michele Veeman
10:20-10:30 A pharmaceutical industry perspective on genome-based technology development – Susan Grant
10:30-10:40 Taking a Global Perspective: IDRC Experiences in Tackling Knowledge Gaps– Christina Zarowsky
10:40-11:10 Questions for presenters
- 11:10 -12:00 **Overview of GE²LS research in Canada, US, UK and EU**
11:10-11:30 Examples of research funded in other jurisdictions - Bryn Williams-Jones and Lori Sheremeta
11:30-12:00 Discussion of possible research gaps
- 12:00-1:00 **Lunch**
- 1:00-1:30 **Presentation of Example Strategic Options** – Bartha Maria Knoppers
- 1:30-2:30 **Break-out groups**
- 2:30-3:00 **Break**
- 3:00-5:00 **Plenary Discussion** – moderator: Tim Caulfield
3:00-3:05 Synopsis of discussion - break-out group 1
3:05-3:10 Synopsis of discussion - break-out group 2
3:10-3:15 Synopsis of discussion - break-out group 3
3:15-3:20 Synopsis of discussion - break-out group 4

3:20-5:00 Group discussion

Appendix II

GE²LS BACKGROUND

Backgrounder Genome Canada GE²LS Workshop

Vancouver, B.C.
Jan. 21, 2002

Prepared by:

- Bryn Williams-Jones, Graduate Research Associate, Centre for Applied Ethics, University of British Columbia
- Lori Sheremeta, Research Associate, Health Law Institute, Faculty of Law, University of Alberta

Purpose of this Paper:

The purpose of this paper is to provide a brief outline of GE²LS initiatives in Canada and in the international arena, with a particular focus on the types of research being funded, and how and to whom funding is made available.

1. Summary of the Genome Canada GE²LS Programs

Genome Canada, a not-for-profit corporation funded by \$300 million from the federal government, is responsible for the development of five regional genome centres (Genome Atlantic, Québec, Prairie, British Columbia, and the Ontario Genomics Institute) to facilitate research and development of genomics in Canada. One of the primary goals of Genome Canada is to “ensure leadership in ethical, environmental, legal and social issues related to genomics” and to that end, they have worked to develop a Genomics, Ethics, Environment, Law and Society (GE²LS) initiative. GE²LS research may be funded in three ways:

- i. through the Genome Centres, in the form of a large-scale project;
- ii. through the Genome Centres as a component of one or more large-scale projects; and
- iii. through a national research program which is currently being developed.

Competition I

As a result of the first general funding competition, 5 science & technology platforms and 17 research projects, 3 of which focus on GE²LS research, have been funded by Genome Canada:

1. **Commercialization and Society and its Policy and Strategic Implications, Genome Prairie**, Principal Investigators: Timothy Caulfield, Edna Einsiedel, Peter Phillips & Michelle Veeman.

Genome Prairie’s GE²LS proposal is headed by investigators from the Universities of Alberta, Calgary and Saskatchewan. The overall theme is commercialization and society and its policy and strategic implications. The investigators aim to map the development of controversial biotechnology applications from initial research to commercialization and will examine the

factors that contribute to public controversy. The researchers will also analyze the nature and source of socio-political concerns associated with the commercialization of genomic technologies and attempt to improve the understanding of how the transmission of information affects consumer behaviour relative to genomic technology. Finally, they will study the way intellectual property is created, managed and commercially exploited.

2. Canadian Program on Genomics and Global Health, Ontario Genomics Institute, Principal Investigator: Peter A. Singer, University of Toronto.

A research team of Canadian and international scientists aims to find ways to optimize the global health benefits from genomics and to minimize the risks associated with genomics through social evaluation of these advances as they occur. The team seeks to anticipate the social implications of particular technologies before stakeholders' positions become deeply entrenched. The investigators will examine the implications of genomics/biotechnology on disparities in global health. This will be accomplished by studying the biotechnology policies of governments in developing countries and examining their ability to exploit new technologies for the health of their population; looking at multinational corporations' decision making on health-related genomics/biotechnology; identifying best practices for the introduction of vaccines, nutrients and drugs in plants; and gathering international perspectives on the regulation of genomics research. The researchers will also examine the impact of genomics on health systems and insurance, and study issues surrounding transgenic animals. The team aims to develop best practice guidelines for governments, corporations, and technology creators.

3. Genomics in Society: Responsibility and Rights, Genome Québec, Principal Investigator: Bartha Maria Knoppers, University of Montreal

This program involves researchers at Québec universities who will examine the ethical, legal and social issues involved in two broad areas: (1) population research; and (2) accountability. The first research component involves the study of: DNA sampling, banking, and other uses as well as, transfer and confidentiality mechanisms in order to develop and propose standardization and harmonization of approaches. The second research component on accountability will examine the issues of professional responsibility and liability for the communication of genetic

information for reproductive counselling, for recruitment, confidentiality, follow-up, and communication with the public as well as for oversight mechanisms for all genomics research. They will also look at issues surrounding the creation and use of transgenic animals and plants in research and medical treatment, the preservation of biodiversity, and the protection of the environment. The project will involve comparing international policies and reviews on the issues, using focus groups and interviews, and ethical analysis. The research team will also update the HumGen website that provides information on these topics, and will create a think tank and rapid action response team to respond to researchers' ethical concerns about genetic research. The project will create a second internet site, called TransGen, to address the scientific, ethical and legal issues surrounding the genetic manipulation of plants and animals. Finally, in addition to the think-tank and internet sites, research and activities on public consultation and communication constitutes a component of these infrastructures.

Competition 2

Genome Canada is considering new applications from the Genome Centres for projects and platforms requesting co-funding (50:50) by Genome Canada.

Broad Eligibility Criteria:

- i. projects must be large-scale (i.e., too large for funding by other granting agencies);
- ii. projects must focus on genomics in one of the areas identified as strategic to Canada (i.e. health, environment, forestry, fisheries, agriculture and GE²LS); and
- iii. projects must demonstrate a realistic management plan and a feasible plan to secure co-funding.

With respect to GE²LS research, Genome Canada has accepted submissions in the form of large-scale projects or as a component of other projects. Collaboration between centres is stated to be a priority.

2. Other Canadian Agencies Funding GE²LS Research

The primary funders of GE²LS research in Canada, apart from Genome Canada, are SSHRC and CIHR, although there are some research funds available through the CHSRF. Position papers and small research grants have also been commissioned by groups such as the Canadian Biotechnology Advisory Committee (CBAC) and Industry Canada. Further, a variety of charitable organizations and disease support groups, e.g., Associated Medical Services, Canadian Breast Cancer Foundation, etc., support GE²LS research.

Social Sciences and Humanities Research Council (SSHRC)

SSHRC funds basic and applied research in the humanities and social sciences through general project competitions, specific strategic initiatives, as well as capacity development for graduate students and post-doctoral fellows. It does not however have a particular GE²LS stream or focus for funding this type of research. An online search of SSHRC's database of funded research from 1992-2001 for "genetics" and "genomics" found only 20 projects. Of these, topics included commercialization, genetics and linguistics, intellectual property, indigenous knowledge, genetically modified foods, genetic testing, and behavioural genetics (See Appendix I).

Canadian Institutes of Health Research (CIHR)

CIHR does not have a particular GE²LS stream or focus for funding research. However, as with SSHRC they have funded a number of GE²LS related projects through their various institutes, e.g., new genetic technologies and justice, health ethics in genomics, community genetics, and gene therapy. Similarly, their capacity development is based on general competitions for doctoral and post-doctoral awards, but also includes new investigator awards, senior research fellows and senior investigator awards not available through SSHRC. An online search of the CIHR database for "ethics" yielded 27 hits with 11 of those potentially incorporating a GE²LS component (See Appendix I).

Canadian Health Sciences Research Foundation (CHSRF)

CHSRF supports applied health services and policy research programs or projects, commissioned research, and capacity development (doctoral, postdoctoral, clinical and policy placements). The focus is on policy development in the areas of human health, nursing leadership, primary health care and professional development; they do not explicitly mention GE²LS research in their mandate, although it is nonetheless possible to receive some support for GE²LS work with a policy development focus.

Provincial Funding Agencies

In addition to federal funding agencies, there are numerous provincial funding agencies that fund basic and applied research in a variety of disciplines. For example, the Alberta Heritage Foundation for Medical Research (AHFMR) funds biomedical and health related research in Alberta. It provides monies for, among other things, personnel support to senior researchers, studentships, fellowships and clinical fellowships.

3. GE²LS Research in the International Arena

There are a number of major groups involved in the funding of GE²LS related research in the international arena. The U.S. ELSI program through the NHGRI and DOE, and the U.K.'s Wellcome Trust, ESRC, and Nuffield Councils appear to be the most notable promoters of GE²LS research. It should also be noted that numerous international agencies including the WHO, the European Commission, HUGO, UNESCO and the Council of Europe are involved in GE²LS related research. Additionally, public action groups such as Greenpeace, RAFI, the Council of Canadians, etc. have directed their attention to certain social and environmental issues associated with the application of genetic technologies in a variety of industrial sectors.

United States - ELSI Program

The Ethical, Legal and Social Issues (ELSI) program was established in 1990 at the National Human Genome Research Institute (NHGRI), the National Institutes of Health (NIH), and the Office of Biological and Environmental Research (OBER) at the Department of Energy (DOE). The ELSI program is the major funder of GE²LS related work in the United States. Research is funded through NHGRI and DOE; the former is more complex to navigate in terms of seeking research funding but also the larger of the two, while the latter is easier to navigate but under staffed (1 person). Since 1990, the NHGRI and DOE ELSI programs have supported over 300 research and education projects. Within ELSI, projects fall into four general program areas:

- i. privacy and fair use of genetic information;
- ii. clinical integration of genetic technologies;
- iii. ethical issues surrounding genetic research; and
- iv. education and resources.

Weaknesses identified in ELSI research in the United States include content gaps in each of the four program areas listed above and recognition that there are a number of emerging issues that need to be addressed. Identified emerging areas of interest include, inter alia:

- i. behavioural genetics;
- ii. genetic enhancement techniques;
- iii. foetal cell sorting;
- iv. pre-implantation genetic diagnosis; and
- v. genetic testing for late-onset disorders in children (or foetuses whilst in-utero).

The U.S. ELSI initiative has also been criticized for being too narrowly focused on applied or practical issues and problem solving, without more explicitly exploring various theoretical approaches to address the larger context. In other words, their work has focused too specifically on particular cases and laws or rules to regulate them, and not enough on the broader, systemic issues in genetics, genomics and ethics. They are not funding very much research dealing with the broader issues of GE²LS, such as stem cells, cloning, agricultural biotechnology, environmental impact, etc. Nor are they looking at issues in the global context of genetics and genomics, despite the fact that many of these issues will have to do particularly with situations in the developing world, e.g., the impact of agricultural biotech and human subjects research, bioprospecting and DNA banking. Finally, the ELSI program has been criticized for being insufficiently interdisciplinary, and still restricted to particular disciplines such as economics, medicine, law, or health policy.

A large amount of funding is directed towards research and capacity development (e.g., doctoral, post-doctoral, and clinical training fellowships).

United Kingdom

The two main funders of GE²LS research in the U.K. are the Wellcome Trust and Economic and Social Research Council (ESRC).

1) The Wellcome Trust is one of the largest non-profit funders of biomedical research in the United Kingdom. It funds GE²LS related work through its Medicine in Society Programme which is divided into two arms: (1) Consultation and Education, and (2) Biomedical Ethics. The former is concerned with encouraging public discussion (e.g., in schools, universities, general public) of the social and ethical implications of biomedical developments, by sponsoring social research into the relationship between scientists and the public. The Biomedical Ethics arm is concerned with academic research into the social, ethical and other consequences of developments in medicine and biology. There is also an emphasis on capacity building through genetics and ethics, and bioethics training courses; scholarships and fellowships to attract academics to this area; and effective communication of research for the purposes of academic development and public policy. The main areas of research are on issues relating to the human genome project, genetic technologies, privacy, DNA banking, pharmacogenomics, and genetic testing.

2) The Economic and Social Research Council (ESRC) is similar in nature to humanities and social science funding agencies such as SSHRC. They are developing a “Research Centre for the Social and Economic Context of Genomics” and are seeking applications from the UK social science community. ESRC is particularly interested in globalization and public engagement in science, innovation, R&D and the commercialization of genomics; science, engineering and technology; governance and regulation; genomics and the environment; genomics and health; personhood, culture and the media. To date, the majority of their GE²LS related research has been funded as specific research projects or doctoral and post-doctoral fellowships.

3) The Nuffield Council is an independent think tank-type organisation, conducting research on a range of ethics issues, not exclusively focused on genomics. To a large extent their GE²LS related work has focused on genetics and reproductive technologies, although they have also done work on cloning, stem cells, and DNA patenting.

4. Gaps in Canadian GE²LS Research

The two most pressing issues in Canada related to GE²LS research appear to be: (1) the need to ensure sustained research funding; and (2) capacity development. Apart from Genome Canada, there are no dedicated funding venues for GE²LS research, although work is being supported by SSHRC, CIHR and CHSRF. Importantly, Genome Canada has, to date focussed on the funding of large-scale initiatives. At some point, this focus must be shifted so as to not stifle the development of relevant GE²LS research in the form of small projects or theoretical projects concerning important, related subject matters. However, this problem may be mitigated by increased networking between researchers in the various science, social science, ethics, and

policy disciplines, and by ongoing interactions between Genome Canada and Canadian GE²LS researchers, to say nothing of international collaborations.

With respect to capacity development, Genome Canada should consider whether there are sufficient up-and-coming researchers equipped with a sufficient range of ethics, social science, law, policy and science backgrounds necessary to understand and analyse the social and ethical issues arising from advances in genomic knowledge and technology. There are only a few groups in Canada doing active GE²LS related research, e.g., University of Montreal, McGill University, University of British Columbia, Dalhousie University, University of Toronto, and University of Alberta. These groups are capable of supporting relatively small numbers of graduate students and post-doctoral fellows, due in large part to fiscal constraints. As with more general research funding, there are no dedicated GE²LS fellowships from the major granting agencies. Graduate students and post-doctoral fellows are, therefore, supported through general scholarship/fellowship competitions, or through project/research centre-based grants.

With respect to topical gaps in GE²LS research in Canada, it appears that most funded projects focus on human genomics in the medical context and too few focus on the unresolved issues of genetic engineering of plants and animals. It has been suggested that the GE²LS research in Canada is not sufficiently forward-looking.

Conclusion

This brief outline of GE²LS initiatives in Canada and the international arena, and the gaps therein, makes it readily apparent that Genome Canada is ideally positioned to establish funding policies to synthesize and rationalize GE²LS research strategies in Canada. Greater detail concerning research initiatives that have been completed, recently commenced, or that remain at the application stage under the auspices of all potentially relevant Canadian (and U.S.) funding agencies may be helpful for better elucidating gaps in GE²LS research in Canada. Such information may also prove valuable in helping Genome Canada formulate a coherent policy concerning GE²LS research, and go a long way to ensuring that Canadian researchers become international leaders in this field.

Appendix I

FUNDED GE²LS PROJECTS: SSHRC & CIHR

SSHRC Projects

Principal Investigator	Affiliation	Title of Proposal	Year Applied For
Arifovic, Jasmina	McGill University	Modelling learning of economic agents using genetic algorithm and other parallel learning algorithms	1992
Davis, Steven	Simon Fraser University	The genetic basis of language Vancouver, BC February 12 - 13, 1993	1992
Knoppers, Bartha Maria	Université de Montréal	Professional ethics in the practice of human genetics	1992
Marusich, Alexander A.N.	University of Toronto	A biogenetic structural analysis of ideology, socialization and commit	1992
Gopnik, Myrna L.	McGill University	The linguistic properties of genetic language impairment	1993
Gopnik, Myrna L.	McGill University	Linguistic, genetic and neurological properties of familial language impairment	1994
Taylor, Kathryn M.	York University	Ethical social behavioural and legal implications of genetic testing and counselling for heritable cancer risks (PDG)	1994
Bouffard, Marcel	University of Alberta	Self-directed learning of movements, a microgenetic approach	1995
Knoppers, Bartha Maria	Université de Montréal	Genetic filial identification testing and its effects on Canadian family law and policy	1997
Small, Robert D.	The University of British Columbia	Understandings of cancer genetics: the case of colon cancer	1997
Korneluk, Yolanda G.	University of Ottawa	Predictive genetic testing for breast cancer: assessing attitudes and psychological functioning of high risk adolescents	1998
Caulfield, Timothy A.	University of Alberta	Exploring and addressing the legal, ethical and policy concerns associated with the commercialization of human genetic research	1998
Coombe, Rosemary J.	University of Toronto	Genetic Markets: Indigenous peoples in transitional economic relationships	1999
Winston, Andrew S.	University of Guelph	Intelligence, race, and genetics, 1930-1970: an analysis of continuity and change in academic	1999

		psychology	
Lock, Margaret	McGill University	The New Genetics and the reinvention of normal	1999
Robertson, Ann	University of Toronto	Towards a phenomenology of risk: the case of genetic testing for breast cancer	2000
Coombe, Rosemary J.	University of Toronto	Genetic markets, indigenous knowledge and the globalization of intellectual property norms	2000
Heslop, Louise A.	Carleton University	Genetically modified foods: consumer choice, attitudes and preferences	2001
Hoffman-Goetz, Laurie	University of Waterloo	Mass media, ethnicity and meaning of genetic risk for cancer	2001

CIHR Projects

Principal Investigator	Affiliation	Title of Proposal
Baylis, Françoise	Dalhousie University	Justice for all: novel genetic technologies and obligations to future generations.
Daar, Abdallah	University of Toronto	Health ethics in the genomics era.
Gaudet, Daniel	Centre Hosp. De L'Université de Montreal (CHUM)	Ecogene-21: From DNA to the community. An alliance for research in community genetics.
Glass, Kathleen	Undetermined	Research ethics: the tension between theory and practice.
McDonald, Michael	University of British Columbia	Ethics of health research training program.
Roberts, Jason	Dalhousie University	Conceptual and bioethical issues at the intersection of genomics, developmental biology, ecology, and health.
Shanner, Laura	University of Alberta	Ethics, law and policy of reproduction: promoting the health of women and children.
Singer, Peter	University of Toronto	Resource allocation for new and emerging technologies.

Appendix II

GE²LS-RELATED WEB SITES

Governmental Organisations

Canadian Biotechnology Advisory Committee (CBAC)

<http://www.cbac.gc.ca/english/reports/>

- GMOs, genetic privacy, patenting of higher life forms, biotech intellectual property

U.S. National Bioethics Advisory Commission (NBAC) – ended Oct. 3, 2001

<http://bioethics.georgetown.edu/nbac/pubs.html>

- reports on human subjects research, clinical trials in developing countries, stems cells, human biologicals, and cloning

U.S. National Human Genome Research Institute (NHGRI) ELSI

<http://www.nhgri.nih.gov/ELSI/>

- Funding GE²LS research
Office of Genome Research http://www.nhgri.nih.gov/About_NHGRI/Dir/Ethics/
- informed discussions, working groups, ethics consults, research ethics

U.S. Dept. of Energy (DOE) ELSI

<http://www.ornl.gov/hgmis/elsi/elsi.html>

- privacy, reproductive, clinical, environment, commercialisation,

U.S. Secretary's Advisory Committee on Genetic Testing (SACGT)

<http://www4.od.nih.gov/oba/sacgt.htm>

- genetic testing, privacy

Australia, former National Bioethics Consultative Committee, now at the National Health and Medical Research Council (a few GE²LS documents, not very recent)

<http://www.health.gov.au/nhmrc/publications/bioeth.htm>

- reproductive, surrogacy, cloning

Danish Council of Ethics (a few GE²LS documents, not very recent)

<http://www.etiskraad.dk/english/publications.htm>

- reproduction, genetic testing, cloning

U.K. Dept. of Health

Gene Therapy Advisory Committee <http://www.doh.gov.uk/genetics/gtac/index.htm>

Genetics and Insurance Committee <http://www.doh.gov.uk/genetics/gaic.htm>

Human Genetics Commission <http://www.hgc.gov.uk/>

U.K. Nuffield Council on Bioethics

<http://www.nuffieldbioethics.org/home/index.asp/index.html>

- genetic screening, human Tissue, xenotransplantation, GMOs, stem cells, clinical research in developing countries, patenting

U.K. Wellcome Trust Medicine in Society Programme

<http://www.wellcome.ac.uk/en/1/mismis.html>

- HGP, genetics, privacy, DNA banking, pharmacogenomics, genetic testing
- policy, education, public consultation
- Funding GE²LS research

HUGO - Ethics and Intellectual Property

<http://www.hugo-international.org/hugo/ethics.html>

- gene therapy, benefit sharing, patenting, cloning

Nordic Committee on Bioethics

http://www.ncbi.org/Html/eng_index.htm

- stem cells, DNA banking

UNESCO International Bioethics Committee

<http://www.unesco.org/ibc/en/themes/genome.html>

- diversity, population genetics, developing world, HGP, gene therapy, biotech

WHO Human Genetics Programme

<http://www.who.int/ncd/hgn/publications.htm>

- human genetics research, medical genetics

Public Action Groups

<http://www.ethics.ubc.ca/brynw/pag.html>

- list of public groups dealing with genetics and genomics issues, primarily focused on environmental activism, anti-GM, anti-commercialisation

Researchers and Centres

<http://www.ethics.ubc.ca/brynw/people.html>

- list of researchers, groups, and centres doing GE²LS related work

Miscellaneous

Genetics & Ethics (Bryn Williams-Jones)

<http://www.ethics.ubc.ca/brynw/>

[HumGen](http://www.humgen.umontreal.ca/en/) (CRDP, Universite de Montreal)

<http://www.humgen.umontreal.ca/en/>

Biomedical & Health Care Ethics Resources on WWW (Centre for Applied Ethics, UBC)

<http://www.ethics.ubc.ca/resources/biomed/>

Appendix III

ASSIGNED BREAKOUT GROUPS

Genome Canada GE²LS Workshop
January 21, 2002

Assigned Breakout Groups

Breakout Group 1

Laura Arbour
Katherine Barrett
Conrad Brunk
Tracy Burton
Edna Einsiedel
Richard Gold
Brian Harling
Patricia Kaufert
Claude Laberge
Marion Motari
Maynard Olson

Breakout Group 2

Ken Bassett
Françoise Baylis
François Belzil
Howard Bussey
David Castle
Tim Caulfield
Robin Downey
Susan Grant
Bruno Leclec
Georges Nguéfand
Jeff Nisker

Breakout Group 3

Judith Allanson
Fern Brunger
Howard Brunt
Brian Ellis
Anne Huennemeyer
Bartha Maria Knoppers
Charles Kurland
Michael Mehta
Alison Thompson
Michelle Veeman
David Walter-Toews

Breakout Group 4

Michael Burgess
Béatrice Godard
Michael Gray
Donal Hickey
Christina Holmes
Lyne Letourneau
Margaret Lock
Daryl Pullman
Melanie Rock
Steven Rothstein
Christina Zarowsky