

**ERA-SAGE Research Area on Ethical, Legal & Societal Aspects of
Human Genomics**

**Review of Research in Canada and the United States and
Synthesis of Key Informants' Views**

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Executive Summary

1: Background

Research on “genomics: environmental, economic, legal and social issues (GE³LS)”—as it is described in Canada—and “ethical, legal, and social issues” (ELSI) research relating to human genetics and genomics—as it is called in the United States has become an important—and increasing large—area of study. In fact, over the past two decades, attempts to understand the impact of genetics and genomics research on society have received considerable attention by government institutions and non-governmental organizations. To understand the nature and trends in GE³LS and ELSI research endeavours in North America, our research team at the *Centre de recherche en droit public*, in collaboration with the Social Science and Humanities Research Council of Canada (SSHRC), collected a compendium of GE³LS and ELSI research projects funded by federal and provincial governmental and non-governmental organizations in Canada and federal governmental and non-governmental organizations in the United States in 2005-2006.

To complement and validate this compendium of funded projects, we interviewed key informants from different disciplines, organizations and governmental institutions to provide insight into the current and future trends of GE³LS research. Finally, a draft version of this report was submitted to the ERA-SAGE workshop on May 23, 2006, in Ottawa where participating researchers, policy-makers and analysts had a chance to critically review preliminary findings and suggest changes, additions, etc. This report provides a summary and analysis of our findings, based on the scan of publicly funded research in Canada and the United States, and on our interviews with key informants, including participants at the May 23 workshop.

2: Analysis of the GE³LS Research Compendium

The most frequent research themes are grouped under the following health and medical applications as well as ethical, social, and legal issues.

2.1: Health and Medical Applications

- The compendium demonstrates that GE³LS research projects funded in Canada and the United States cover a broad range of topics. The majority of research undertaken in 2005-2006 focuses on ethical issues associated with genetic testing/screening, cancer research and chronic diseases, and public engagement/consultation about genetics and genomics. Few studies focus on single-gene diseases. Most integrate into research such chronic diseases as breast cancer, prostate cancer, other familial cancers, cardiovascular disease, and psychiatric illnesses.

- Funded projects were predominantly large-scale—their budgets were greater than \$75 000 annually—and supported by governmental agencies rather than non-governmental agencies.

2.2: Ethical, Social and Legal Issues

- Other major GE³LS funded research includes public engagement and consultation, governance, and, especially in the United States, a focus on ethnic and cultural diversity. In both Canada and the United States, numerous projects address public engagement and consultation. Several projects study how best to communicate genetic information and explored such venues as theatre, citizen’s forums, and focus groups.
- Many projects address the ethical, governance and regulatory issues arising out of the use of biobanks (biological materials) and databases of all kinds (registries, longitudinal studies). Key concerns include privacy, security, cross-border issues, public participation, funding, legal status of samples, and ethics boards.

3: Analysis of Key Informant Survey

3.1: Issues Driving Public Interest in Genomics

- Respondents identified several key factors and tendencies driving public interest, among them funding agencies, media, public opinion, health applications, fear of misuse of genetic information, human dignity, and commercialization.

3.2: Emerging GE³LS Issues

- Respondents indicated the research is shifting from Mendelian diseases to more complex chronic or multifactorial diseases; from a focus on the individual to a focus on the health of populations; and from a curative approach to predictive medicine. The shift in the relative prominence of medical issues (from individual health problems to those at the population and community level, such as public health) was seen as creating major ethical dilemmas.
- Interviewees recognized governance as essential to building trust between the research community and the public.
- They also mentioned many other concerns – some emerging, others already known. Among the issues highlighted were the convergence of technologies (such as nanotechnologies and biotechnologies) with genetics and genomics, the social implications of genetic testing as a preventive measure for public health, the storing of genetic materials in biobanks, and the abuse of genetic information by health professionals, insurers, and employers. In addition, interviewees raised questions of

governance, legality, and inequality raised by the effects of genetic and genomic research.

3.3: Implementation Issues

- The integration component was often seen as a barrier to the research process. Many respondents noted problems with “downstream” research since GE³LS research seems always to lag behind scientific research.
- Private funding sources were seen as a source of tension and raised questions among respondents about, for example, conflict of interest and commercialization. Moreover, the private sector is not appropriately regulated.
- Interviewees perceived the undertaking interdisciplinary research as very difficult and underlined that funding agencies must recognize the need for institutional and financial support to facilitate communication between researchers from different disciplines.

Conclusions and Challenges

In this paper, we show that research investment in the social, ethical and legal issues of genomics have resulted in a wide range of different GE³LS research projects undertaken by a comparatively small and diverse group of researchers. Future research will depend on whether the pool of researchers of researchers working on GE³LS issues can be expanded to include individuals from a broader range of humanities and social science disciplines. There are many emerging and known concerns that still need to be explored fully. Examples include the convergence of technologies with genetics and genomics, such as nanotechnologies and biotechnologies; the social implications of genetic testing as a preventive measure for public health; the storing of genetic materials in biobanks; and the abuse of genetic information by health professionals, insurers and employers. All these issues will take time to come together and will require a nurturing research environment.

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Background

The rapid development in human genetic and genomic research in the last decades raise a host of important ethical, legal, and social issues. For example, questions around how current genetic knowledge will affect future generations, what risks are involved with this research, whether individuals own their DNA samples, and whether an individual's integrity and right to privacy is adequately protected under current legislation. For over twenty years, these social and ethical concerns have prompted health professionals and policy makers to seek understanding about the societal impact of human genetics research and to attempt to assess the impact of genetics and genomics in order to maximize benefits while minimizing risk.

Alongside the scientific development, studies of the societal consequences of genetics and genomics have proliferated: hence, the development of new terminology. As any literature review demonstrates, the acronyms GE³LS (Genomics: Ethical, Economic, Environmental, Legal, and Social Research; predominant Canadian terminology), ELSI (research on Ethical, Legal, and Social Issues (of genomics); most frequent terminology in the United States), and ELSA (Ethical, Legal and Social Aspects; prevalent terminology in Europe) have entered the vocabulary of socio-ethical and legal scholarship. The acronym GE³LS stands for the evaluation of ethical, environmental, economic, legal, and social implications of genomic research and development (the order follows the expression “genomics: ethical, environmental, economic, legal, and social” implications). “GE³LS” is unique to Canada. Both ELSI in North America and ELSA in Europe signify the ethical, legal, and social aspects or issues of genetics and genomics. These terms are extremely useful because the different concepts often overlap in studies of the social consequences of genetic developments.

Late in the 20th century, funding agencies devoted resources to stimulate research into the social, ethical, and legal implications of human genetics. In the United States, programs funding ELSI research were introduced in the early 1990's, starting with the Human Genome Program. Since the creation of the Canadian Genome Analysis and Technology (CGAT) program and its Medical, Ethical, Legal, Social Issues (MELSI) committee, the emphasis in Canada has been on promoting GE³LS research relating to medicine, genomics, and genetics. Supported projects had a theoretical focus, explored key issues, or concentrated on practical challenges. Overall, Canadian funding agencies recognised a need to link genetics to the field under study. In addition, Canadian researchers and research funders increasingly recognized the close, mutually-dependent relationship between scientific and societal considerations.

During the 1990's, Canada specifically committed resources to research and education related to genetics/genomics as well as to ethical, economic, environmental, legal, and social (GE³LS) issues. The federal government set out several initiatives which promoted or considerably impacted GE³LS research:

- the establishment of the Canada Research Chairs;

- the creation of Genome Canada;
- the establishment of Networks of Centres of Excellence (NCE); and
- the special initiatives of the Canadian Institutes of Health Research (CIHR) in capacity building.

Equally important to the research community were the continuing open competitions at the Social Sciences and Humanities Research Council (SSHRC) and CIHR, which helped to further advance social, ethical, and legal research in Canada. All of these initiatives advanced GE³LS and ELSI research and contributed to its current research status.

Today, GE³LS research remains important, and many governmental and non-governmental organizations continue to encourage high quality GE³LS research. Governmental (i.e. departments, agencies, etc.) and non-governmental (i.e. charities, foundations, centres of excellence) funding organizations have made GE³LS and ELSI research possible by offering grants to researchers, including graduate and post-doctoral students.

SSHRC, is currently collecting information on publicly funded GE³LS projects in Canada and the United States for the year 2005-2006. This project is a component of the workplan of the European Research Area – Societal Aspects of Genomics (ERA-SAGE) consortium. The consortium regroups national funding agencies from nine countries in an effort to achieve greater synergy and convergence in the support for research on the societal aspects of genomics. Each partner country in ERA-SAGE will conduct a similar analysis of research trends in their country. These reviews will assist the consortium in developing a strategic plan for common activities.

In this context, SSHRC commissioned a mapping and analysis of research on ethical, legal, and social issues involving human genomics and genetics, which have been funded in Canada and the United States. This review was conducted between January and May 2006 and was limited to publicly funded research activities. There are, of course, other research GE³LS projects, which are funded by the private sector (industry) and the public sector (including “in-house” research by governments. There is also “unfunded” GE³LS research in academic institutions. However, this review excluded these types of GE³LS research. To supplement the information collected in the compendium of publicly funded GE³LS research in 2005-2006, leading Canadian researchers, policy makers, and other key informants in the field were interviewed to identify emerging research issues and future directions of GE³LS research. A review of published literature on emerging social, ethical, and legal issues in human genetics and genomics was not in the mandate of this report.

This report has three **objectives**:

- To identify the range of current publicly funded research activities into the ethical, legal, social, and economic issues associated with human genetics/genomics at the federal and provincial levels in *Canada*;
- To identify the range of current publicly funded research activities into the ethical, legal, social, and economic issues associated with human genetics/genomics at the federal level in the *United States*; and

- To identify trends, over- and under-represented areas and emerging research themes, approaches, and methodologies.

Chapter 1 describes the initial results of the survey of publicly-funded research activities—government research institutions and non-governmental institutions engaged in GE³LS research in Canada and the United States.

Chapter 2 presents the results of the consultative process with key informant to establish emerging GE³LS issues.

GE³LS terminology is not consistent across all disciplines, which presents a clear challenge. This report is based on a very broad interpretation of the “GE³LS” field so as to include key aspects such as intellectual property, consent, privacy, ethics, governance, regulation, knowledge transfer, public consultation, and communities. Nevertheless, readers should keep in mind that interpretations as to what is included under “GE³LS” can and do vary.

Other potentially problematic terms used in this report are “genetics” and “genomics”, which often cause confusion. On the one hand, “genetics” is defined broadly as the study of the patterns of inheritance of specific traits. On the other hand, “genomics” refers to the study of the structure of genes, how they function with each other and with the environment. While these terms have different meanings from different scientific perspectives, this report uses “genomics” to refer to both “genetics” and “genomics”.

Chapter 1: Review of GE³LS Research in North America: Canada & US

1: Introduction

This review looks at Canadian and American human genetic and genomic research projects which include a GE³LS component that acknowledges the social, ethical, legal, and economic aspects of the work. Because GE³LS topics extend over many fields, this report includes a broad range of disciplines ranging from philosophy, ethics, and psychology to economics, law, and anthropology. In other words, we adopted a very general and all-embracing definition of GE³LS research. Given the interdisciplinary nature of the GE³LS area, we covered conceptual/theoretical and population-based research, as well as psychosocial and policy-oriented research in human genetics and genomics in the following areas:

- Consumer and social acceptance: perceptions, attitudes and/or acceptance;
- Commercialization issues: intellectual property, patents, adoption, economic impacts of market introductions;
- Education: communication studies, media influences, product representations, labelling issues, and consumer information;
- Policy development: public engagement, the development of regulations;
- Health, social and political impacts;
- Applications related to developing countries; and
- Other relevant areas: e.g. new applications like pharmacogenomics.

This report therefore analyzes a very wide breadth of research topics in human genomics.

2: Methodology

What follows is an abridged outline of our methodology.¹ The scope of this project is limited to projects funded during 2005-2006. Studies were included if they were publicly funded (at the national or federal, provincial, and territorial level in Canada; at the national or federal level in the United States) and came from the following agencies:

- Governmental ministries (Health, Justice, Environment, for example);
- Research funding agencies (CIHR; National Institutes of Health (NIH), for instance); and
- Non-governmental organizations funding research activities (for example, the National Cancer Society, Multiple Sclerosis Society of Canada).

¹ For a complete description, see Appendix A.

Data Collection

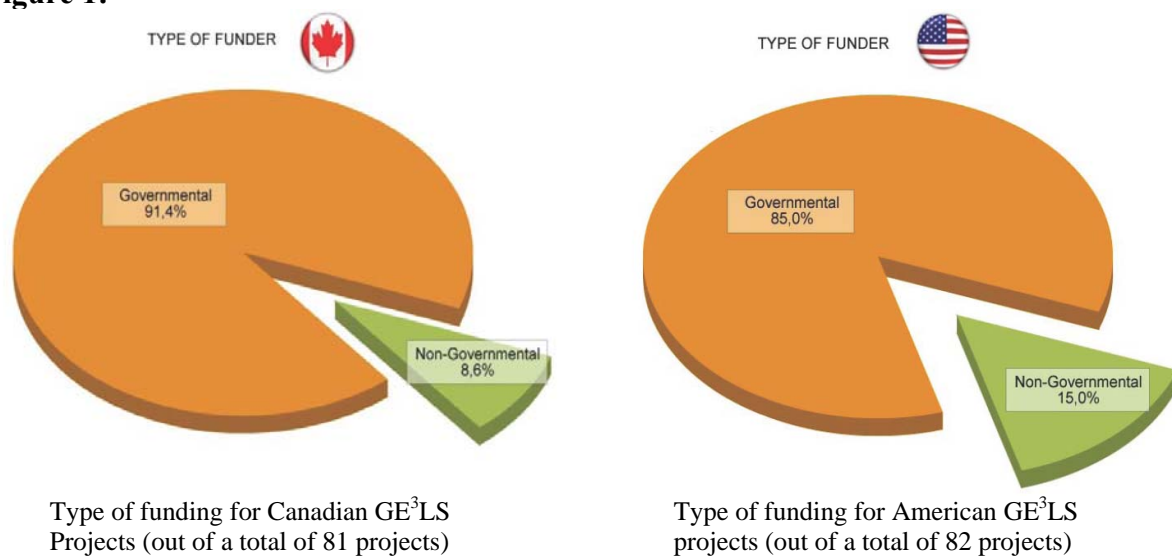
We identified federal and provincial organizations in Canada and federal organizations in the United States that funded GE³LS research in 2005-2006 using various reports and undertaking targeted web searches (detailed descriptions are included in Appendix A). This research covered 54 institutions in Canada and 14 institutions in the United States. When summaries of funded GE³LS projects were not available on the internet, the Manager of Policy and International Collaboration at SSHRC e-mailed a request (see Appendix F) for this information to the funding organization and/or the lead researcher. Appendix C lists GE³LS and ELSI funding organizations that were contacted. The compendium of funded GE³LS and ELSI projects is in Appendix G.

3: Findings

Our objective was to identify the range of current (2005-2006) research funding for studies about the ethical, legal, social, and economic issues associated with human genetics or genomics in Canada (both federally and provincially) and in the United States (at the federal level).

Publicly funded GE³LS and ELSI research in Canada and the United States is mainly supported by the two federal governments, while funding from non-governmental organizations (Figure 1) amounts to only 8.6% (Canada) and 15% (United States). The ratio of governmental to non-governmental funding in Canada and the United States is comparable, though the United States relies more on non-governmental funding than Canada.

Figure 1:

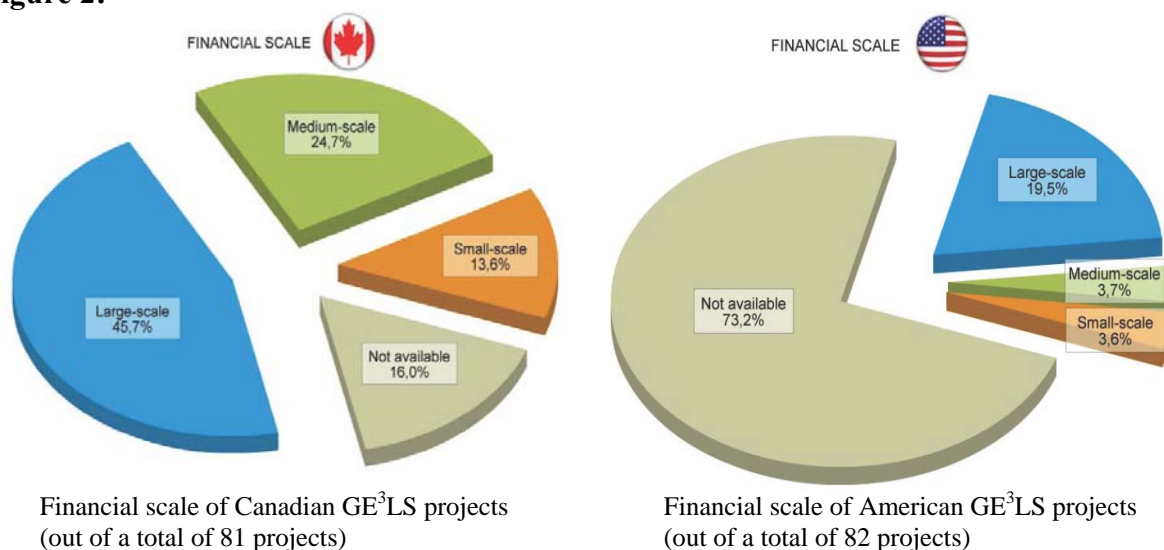


Issues related to the scale of funded research projects were raised frequently by key informants and workshop participants. For the purposes of our analysis, we classified funded projects in three categories: small-scale (less than \$25 000), medium-scale

(\$25 000), and large-scale (over \$75 000). In Canada, the projects are predominantly large-scale. We cannot draw conclusions for the U.S. because of the very limited information available. However, what data are available also point to an emphasis on large-scale projects in the States. (Figure 2).

While our analysis indicates that government funding is more common, it is important to note that in Canada, projects funded by Genome Canada also include private sector funding. However, it is impossible to establish whether this funding is associated with the GE³LS research. Various key informants raised this issue (see Chapter 2, section 3.3).

Figure 2:



Most GE³LS funded projects analyzed in this report can be grouped under two headings: (I) socio-medical applications; and (II) ethical, social, and legal issues.

3.1: Socio-Medical Applications

The compendium reveals some common themes in the fields of genomic health and medicine. In Canada, many of the projects address topics like cancer and other chronic diseases (23), genetic services (13), and genetic testing (12). The same three topics are commonly studied in the United States: 24 projects address cancer, 13 deal with genetic services, and 25 examine genetic testing and screening.

Introduction

The diversity of research topics highlights the heterogeneity of the research field. GE³LS research and its clinical applications include counseling, especially relating to hereditary breast and ovarian cancer. Research investigates issues of patient/doctor perspectives, especially with cancer. It also examines how research results are returned to participants and the roles and effects of technologies and information tools on data return. Other subjects into this category includes research on models for genetic testing and genetic screening, the use of genetic information by health professionals, the use of the “family

history” tool, the provision and care of “marginalized populations”, and the psychosocial implications of genetic testing.

Only a small number of studies focus on single-gene disease, and the majority of projects integrated into research such multifactorial diseases as breast cancer, prostate cancer, other familial cancers, cardiovascular disease, and psychiatric illnesses.

Table 1:

<i>Topic</i>	<i>Canada (n=81)</i>	<i>United States (n=82)</i>
<i>Cancer and other chronic diseases</i>	23 (28%)	24 (29%)
<i>Genetic Services</i>	13 (16%)	13 (16%)
<i>Genetic Testing and Screening</i>	12 (15%)	25 (30%)

3.2: Ethical, Legal, and Social Issues

Topics in this category include issues that address identity, consent and autonomy, privacy and confidentiality, governance, community consultation and other ethical and legal aspects related to intellectual property (Table 2). This research field is also very heterogeneous in its choice of ELSI areas. However, the survey reveals important subjects, with almost a third of Canadian and 41% of American projects carrying out general ELSI research.

Community Consultation and Public Engagement

In both Canada and the United States, numerous projects address public engagement and consultation. Several study how best to communicate genetic information and explore such venues as theatre, citizen’s forums, and focus groups. The topics in this category include theoretical investigations about the potential benefits and risks to populations participating in genetic research, and studies of the risks to specific minority groups, ethnic groups, and disabled people.

Governance and Regulatory Issues

Many projects (36% of Canadian and 13% of American) address the ethical, standard of care, and governance issues arising out of the use of biobanks (biological materials) and databases of all kinds (registries, longitudinal studies). Key concerns are privacy, security, cross-border issues, public participation, funding, legal status of samples, and ethics boards. The role of the public in governance of genomics is also addressed.

Social Divide – Diversity, Ethnicity, Culture, Race, and Equity Issues

Several projects, most of them in Canada, deal with genomic research, development, commercialization, public awareness, and capacity building in a global context, focusing particularly on the developing world.

Many studies explore how genetic information is influenced by socioeconomic factors, gender, and concepts of race, ethnicity, and culture. Research in this area is more common

in the United States (44%) than in Canada (17%). Perhaps this reflects NIH's goal to solicit research projects on ELSI issues, particularly for African American population.

Genetic Identity and Integrity

Several projects examine how knowing one's genetic identity may help define or reinforce an individual's identity and family relations. Others look issues of justice between generations and the obligation to future generations. Several studies investigate the ethical aspects of behaviour, human enhancement, and the relationship between brain, mind, and personality.

Consent and Autonomy

There is a lot of research on patient consent and autonomy. Key issues include individuals' informed consent to research participation and to genetic testing, and consent issues for vulnerable populations such as children, minority groups, and people with disabilities.

Privacy and Confidentiality and Access to Information

Several research projects probed key privacy issues, such the perception of preferred governance models for privacy, the sometimes contradictory relationship of privacy to population studies and longitudinal studies, and data-sharing with families and third parties (such as insurance companies and employers). In addition, some studies look at "the right to know" and the right to prevent information from being disclosed.

Finally, there are many potential situations in which agencies outside the medical setting may wish to access genetic information. Consequently, some studies take a closer look at the non-medical uses of genetic information by, for example, schools, the military, and immigration.

Intellectual Property and Patents

In this category, we grouped together projects dealing with human gene patents and their impact on, for example, the development of biotechnology policies. Other aspects of commercialization mentioned include academic and industry relationships and gene patenting.

Ethics of Stem Cells

Though scientifically distinct from genetics and genomics, stem cells and the science they produce raise many similar ELSI questions, like public trust, understanding and knowledge about new technologies, informed consent, and the donation of genetic material. Several projects on the ethics of stem cells and genomics are funded in Canada, possibly because of the support from the *Stem Cell Network*. In the United States, we found only one stem cell and genomics project, which is not surprising, given that the use of public funds for such research is prohibited in that country.

Table 2:

<i>Topic</i>	<i>Canada (n=81)</i>	<i>United States (n=82)</i>
<i>General ELSI</i>	26 (32%)	34 (41%)
<i>Community Consultation and Public Engagement</i>	20 (25%)	18 (22%)
<i>Governance and Standard of Care</i>	29 (36%)	11 (13%)
<i>Diversity, Ethnicity, Culture, Race, and Equity</i>	14 (17%)	36 (44%)

4: Summary

The compendium provides an overview of GE³LS research projects funded in Canada and the United States. While it covers a broad range of topics, the majority of research undertaken in 2005-2006 focuses primarily on ethical issues in genetic testing, cancer research, and public consultation/engagement and communication about genetics and genomics. Other major GE³LS topics include general ELSI topics, governance, and, especially in the United States, ethnic and cultural diversity research projects were more favoured. The projects reviewed are generally funded by government and are multi/interdisciplinary: our data show that 62% of GE³LS research in Canada is multidisciplinary, and 75% in the United States.

Chapter 2: Emerging GE³LS Issues in Human Genetics and Genomics Research: A Canadian Perspective

1: Introduction

The wide GE³LS field is not only informed by the humanities and social sciences (philosophy, theology, anthropology, law, sociology, economics, politics, education), but also by biomedicine (epidemiology, molecular biology, bio informatics), environmental and natural sciences and countless other disciplines. Experts in the ethical, social, and legal issues associated with genetics and genomics have a unique perspective on the current state of ELSI research in Canada and can offer valuable insights on the future direction of the funding and research of ethical, social, and legal issues.

For these reasons, and in order to explore the multifold perspectives related to GE³LS, the present SSHRC – ERA-SAGE review consulted Canadian scholars engaged in social, ethical, and legal aspects human genomics and genetics research. Interviews with these experts also helped to put some findings of the compendium in perspective and identify important challenges that may impact on research abilities. In addition, the experts helped to recognize emerging issues in human genetic and genomic studies and in research implementation. Both the compendium analysis and the expert consultation were designed to help ERA-SAGE and its partner organizations to improve the co-ordination and co-operation of national and regional research activities.

2: Methodology

For a complete description of the methodology and the interview process, from selection through analysis, see Appendix B. What follows is a short summary of our purpose and methodology.

In collaboration with SSHRC staff, we identified leaders in the field of GE³LS research and policy in Canada with a well-established interest in genetics and genomics. To achieve a comprehensive overview, we sought a broad range of opinions from the following stakeholders: decision-makers or program managers at funding agencies; research chairs or directors; investigators (including doctoral and post-doctoral students in anthropology, sociology, psychology, epidemiology, and more); and other key informants (e.g. ethics committee members, policy-makers, interest groups and other knowledgeable stakeholders able to identify key research and policy issues in their communities).

Capturing the breadth of research themes is extremely important to this study. To achieve a broad range of perspectives, we decided to interview individuals who would not attend the May 2006 workshop (a forum of experts who critiqued a draft version of this report) and

who would otherwise not have had a chance to be heard.² Similarly, to identify a broad range of issues, we included respondents from a variety of institutions and disciplines, primarily from the humanities, social sciences and medical sciences. We expected that this would help to highlight issues that might not have emerged from a group of individuals representing a homogenous background (only bioethics and law, for example).

As a result, we generated a long list of issues, such as genetic testing, genetic privacy, genetic modification, therapeutic cloning, reproductive cloning, embryonic stem cells, eugenics, genetics and ethnicity, behavioural genetics, pharmacogenetics, genetics and children, abuses of genetics, the economic-“genomic” divide, academic-industry relations and biobanks. Our challenge was to present clearly the most relevant topics and GE³LS issues. Though some specific ideas may have been overlooked³, the trends and themes identified nevertheless provide a satisfactory framework of the current orientation and future direction of GE³LS research.

Thirty key informants were invited, of which twenty responded. The consultations took place by phone. Between March 29 and April 15, 2006, Denise Avard conducted the interviews orally, while assistants Lucie M. Bucci and Beatrice Coly took detailed notes, or in writing. Participants responded verbally or in writing to the following six open-ended questions, developed in consultation with SSHRC staff:

1. What are the emerging GE³LS issues in human genomics/genetics?
2. What are your perceptions of the driving forces that make these GE³LS issues emerge?
3. Which emerging GE³LS issues are research priorities?
4. What areas of genomic/genetic research generate public interest or concern?
5. Regarding financing of research in human genomics/genetics, what are your thoughts about private- and public-sector funding?
6. What are your thoughts regarding the funding of GE³LS research per se and GE³LS research as part of larger genomics/genetics research projects?

We summarize information gathered in interviews of experts with a wide variety of backgrounds by gauging their (dis)agreement on commonly identified issues, trends and challenges.⁴

² See Appendix E for a full list of contributors.

³ Biopower, for example, a concept originating with Foucault that has received increasing attention in the last few years, is not specifically addressed in this report.

⁴ Interviews and written responses were analyzed in a similar way. Working under time and resource constraints meant that data extraction and synthesis could be done by only one person.

3: Findings

The analysis of the interviews suggested a grouping of issues in the following three main topical sections: (1) contextual issues driving public interest in genomics; (2) emerging GE³LS issues; and (3) implementation issues for genomic research in Canada. These topical issues are not presented in order of importance.

3.1: Contextual Issues Driving Public Interest in Genomics

Given the pervasiveness of genomic research in public discourse, there is great public interest in new developments. This concern is driven by several forces and factors raised by the interview respondents and outlined below.

Funding Agencies

There was strong consensus among respondents that Genome Canada and its regional partners, in addition to funding agencies such as CIHR and SSHRC, play a leading and supportive role in genomic and GE³LS research in Canada. The majority of respondents indicated that leadership and investment from these agencies has helped to create a cohort of GE³LS researchers that includes intellectual drivers in the field.

Media

Experts repeatedly mentioned media coverage of genomic discoveries, which they considered a crucial source of information that generates sustained public interest in genomics and genetics. For example, media coverage of human stem cells and cloning research exemplified the kinds of stories that can monopolize public attention. Recent pertinent examples are newspaper headlines and TV newscasts such as those devoted to the South Korean cloning scandal or to the Raelians and their supposed cloned offspring.

Furthermore, interviewees often felt that inconsistencies in media reporting often helped to create the impression that investment in genomic research is not producing results. For instance, media reports created considerable confusion about the effects of genetics and genomics research on human health, lifestyle, and the environment. It is not clear whether the public in general engages in long-term reflection on these issues, but some respondents suggested people may be more sophisticated than is often recognized.

Public Opinion

Not surprisingly, respondents raised the issue of how public opinion influences advances in genomic research. While public opinion polls measure perceptions, attitudes, and views about public concerns, one respondent cautioned that, because the methodology and purpose of polls is not always clear, they should not be used to gauge opinion about GE³LS issues. That said, a majority of respondents indicated that polls are likely to play an important role in directing future investment in GE³LS research.

According to some respondents, government and industry have not demonstrated an awareness of the importance of GE³LS issues. Some saw a relationship between age and attitudes about social, ethical, and legal issues, noting that older generations hold less

favourable views of genomics than youth while also expressing more concerns about its risks.

Health Applications

Many respondents noted that interest in genetics is most evident among those who experience “real” health problems. For example, a member of a family with a hereditary condition is more favourable to genetic history tools than an unaffected person. Some respondents suggested that the growing use of genetic tests and other gene technologies in clinics will increasingly bring genetics into everyday life. Other respondents stressed the public’s desire to know how research will improve their health, influence their medical care, and/or bridge the gap between diagnosis and treatment. Reproductive choice seems to arouse a great deal of interest, as are technologies that have the potential to cure diseases or to prolong/enhance life (nanotechnologies, pharmacogenomics).

Fear of Misuse of Genetic Information

According to our respondents, the public fears that genetic information can be used to deny employment or life insurance or to discriminate against ethnic groups. As one respondent noted, bioethicists raised such concerns before the availability of actual empirical data, but clinical reports suggest these concerns prevail among the general public as well. It was suggested that the fear might be fuelled by the creation of biobanks in the form of registries, longitudinal studies, and public health surveillance. Researchers consider biobanks helpful research resources, but the public worries about what may happen to their information and how will it affect their private lives.

Human Dignity and Life

Several respondents suggested the public worries scientists are “playing God,” citing genetic manipulation and the status of human life and when it begins as topics of particular concern. Others noted that, while these concerns are important, the public has not had much input in that debate.

Commercialization

Several respondents indicated that (possible) commercial gains raise social, ethical, and policy concerns amongst the public: research that generates commercial profit through gene patenting offends liberal democratic principles. Others are concerned that “the economic imperative”—marketing incentives and pressures—is too prevalent in the regulatory, scientific, political, and media arenas. There is also fear that market forces will rush the implementation of genetic services and tests before their efficacy and social ramifications have been properly evaluated.

Other Issues That Were Raised

- Xenotransplantation: a public attention-grabber which is often discussed during undergraduate courses and by several respondents.
- Bioterrorism, genetically modified foods (GMOs), the SARS outbreak, and the recent concern over the influenza pandemic.
- The impact of genomics on the environment.

- Bioinformatics, gene chips, tandem mass spectrometry, and other information technologies that make it possible to examine carefully the large-scale impact of factors like genetics on health outcomes.
- Cost factors, such as whether services that result from the research are or will be affordable for individuals.

Summary

Our interviews indicated that information and the media are key drivers of public interest in genomics. However, simply providing more information is unlikely to reduce related public interest and/or apprehension for two reasons. Firstly, the public tends to support the healthcare, and genomics offers benefits for an ever-growing list of medical conditions. Secondly, the fears delineated are often based either on misinformation that responsible scientists reject (for example, fantastic promises of disease-free immortality) or on legitimate concerns that can be addressed through well-constructed policies. While the relationship of information to public interest and apprehension may seem obvious, it is compounded by the fact that much of the public's knowledge of genetic technology derives from sensational media reports. On the other hand, many of the public concerns are not well known and understood in the research community. To improve this gap in understanding public concerns and interests, there must be more direct consultation and interaction with the public. This important work falls outside the scope of this review.

3.2: Emerging GE³LS Issues in Human Genomics/Genetics

Some of the issues raised by our key informants have been debated and discussed in academic literature over the past ten years, a period that has seen a proliferation of writings on the ethical, legal, and social sides of genomics.⁵ Our respondents reminded us that certain of these topics remain popular among researchers: DNA banking, cloning, reproductive medicine, concern for developing countries, and patenting. However, as genetic research progresses, additional GE³LS issues are emerging, which can be regrouped

⁵ Key articles include "The Practice of Human Genetics: Emerging Areas of Consensus?" by Timothy A. Caulfield in *Health Law Journal* 3 (1995), 307-320; "Human Genetic Research: Emerging Trends in Ethics" by Bartha Maria Knoppers and Ruth Chadwick, *Nature Reviews: Genetics* 2 (2005), 75-79; and *Genomics, Health and Society: Emerging Issues for Public Policy*, Bartha Maria Knoppers and Charles Scriver, eds. Policy Research Initiative, available online: http://www.policyresearch.gc.ca/doclib/genomicbook_e.pdf). For other wide-ranging discussions of GE³LS issues, see Ellen Wright Clayton's "Ethical, Legal, and Social Implications of Genomic Medicine" in *The New England Journal of Medicine* 349:6 (2003), 562-569; Brian Vastag's "Experts Wrestle with Social, Ethical Implications of Human Genome Research" in *Journal of the American Medical Association* 285:6 (2001), 721-722; and *Genome-based Research and Population Health: Report of an expert workshop held at the Rockefeller Foundation Study and Conference Centre* (Bellagio, Italy, 14-20 April 2005). Also, Steve Jones' "Genetics in Medicine: Real Promises, Unreal Expectations: One Scientist's Advice to Policymakers in the United Kingdom and the United States" (New York: Millbank Memorial Fund, 2000) provides a broad discussion. Many researchers are also looking to the future: e.g. "Ethical Issues in Genetics in the Next 100 Years," a lecture presented by Glenn McGee in Kobe, Japan, to the UNESCO Asian Bioethics Congress (Kobe and Fukui Japan, November 6, 1997); and, last but not least, Francis Collins *et al*'s seminal work: "A Vision for the Future of Genomics Research: A Blueprint for the Genomic Era" in *Nature* 422 (2003), 1-13.

under three general themes: (A) socio-medical issues, (B) ethical issues,⁶ and (C) legal issues.⁷

(A) Socio-Medical Issues

A number of the potential research topics that may be of importance include the following:

Shifting in Relative Prominence of Medical Issues

Genomics is challenging our traditional understanding of illness and disease. Several respondents indicated the research is shifting from Mendelian diseases to more complex or multifactorial diseases, from a focus on the individual to a focus on the health of populations, and from a curative approach to predictive medicine. Furthermore, there is an ever-increasing focus on multiple gene variants, both in candidate gene approaches and in “whole genome” association studies. Genetic and genomic research considerations will therefore likely shift from diseases in which genetic factors play a leading role—single gene diseases such as muscular dystrophy and haemophilia—toward complex and common diseases with known multifactorial causes like cancer, diabetes, heart disease, and asthma.

In addition, genomics will facilitate a new understanding of multifactorial diseases by identifying the interaction of genes with the physical environment, lifestyle factors, and the environment or occupational settings. According to some respondents, these multiple factors will require a shift in thinking. Genes may not be primarily “deterministic,” but rather one of many determinants of health. One respondent stressed that this will help to stop labelling certain diseases as “genetic,” because genetic make-up is not the only determinant of health. Hence, using a multifactorial model to address how genes influence complex or multifactorial diseases may facilitate the shift from “genetic determinism” toward the recognition that health is influenced by many factors that may act alone or in combination with others, including gene-gene interactions.

While most genetic research has focused on identifying genes contributing to particular illnesses, researchers are now attempting to understand the gene variants that protect and promote health, growth, and development. Increasing our knowledge about how and why individuals are healthy may shift the emphasis from curative to preventive approaches.

Finally, the shift in the relative emphasis on medical issues and individual health problems to a concentration on issues at the level of communities in particular and of the population in general will impact which ethical issues will emerge. For example, there will likely be

⁶ These issues are also addressed in the literature: e.g. the discussion of databases in Anne Cambon-Thomsen *et al*'s editorial “Population Genetic Databases: Is a Specific Ethical and Legal Framework Necessary?” in *GenEdit* 3:1 (2005) 1-13; the exploration of governance in Elizabeth Dowdeswell *et al*'s “Realising the Promise of Genomics: Exploring Governance” in *International Journal of Biotechnology* 8:1/2 (2006), 132-140; and Celeste Condit's discussion of public opinion in “What is ‘public opinion’ about genetics?” in *Genetics* 2 (2001), 811-815.

⁷ Some of these issues are addressed in the following two articles: “Genetic Research Tool - The Research Exception and Open Science” by E. Richard Gold, Yann Joly, and Timothy Caulfield (*GenEdit* 3:2 (2005) 1-8) and *Biotechnology and the Health of Canadians: A Report from the Canadian Biotechnology Advisory Committee on Biotechnology and Health Innovation: Opportunities, Challenges and Public Policy* (December 2004; available at <http://www.cbac-cccb.ca>).

less of a focus on individual consent and privacy and more on community engagement and public health. These concerns are discussed in the ethical and legal issues section 3.2 of Chapter 2.

Converging Technologies

Another concern of our key informants was the convergence of genomics with biotechnologies, nanotechnologies and bioinformatics. These combinations create new challenges and may require a re-conceptualization of approaches to regulation and technology assessment. Some respondents suggested the issues emerging from GE³LS research could be applied to these emerging issues in medical research. However, others asserted that convergence presents a complex challenge that will require policies that coordinate and address emerging issues in both areas. It is unclear, for example, if issues of privacy and discrimination in genomics will apply to new biotechnologies. This uncertain situation provides an opportunity to discover whether a coherent and collaborative approach in GE³LS will influence other areas to consider systematic review/meta-analytic approaches.

Integration of Genetics and Genomics into the Health System

Ultimately, for health research to be relevant, it must be linked to health practice. There was a clear recognition amongst our expert respondents that the integration of genetics into health care and public health services is highly relevant. A number of respondents specifically discussed the integration of genetics into public health, pharmacogenomics, and reproductive health services.

Public Health

Several interviewees identified public health as an emerging health issue. The application of genetics or genomics to public health raises various ethical, legal, and social issues. Some suggested, for example, that the public health model of prevention generates concerns that genetic testing might lead to eugenics (i.e. preventing the birth of people with specific genotypes), thereby evoking fears of genetic engineering and of selective termination of pregnancies after prenatal diagnosis.

Respondents identified the following issues that public health decision-makers will have to address:

- the social implications of identifying common polymorphisms that predict chronic diseases;
- the risks and benefits of genetic testing for complex diseases;
- the economic and epidemiologic factors that determine the implementation of a screening program and decide whether the program should be voluntary or mandatory;
- the effects of genetic information on individual behaviour;
- the implications of genetic testing intended to prevent the birth of children with genetic diseases; and
- the question of whether testing and follow-up should aim to alleviate the manifestation of diseases.

Pharmacogenomics

Several respondents expected pharmacogenomics to improve disease management by providing personalized therapies with safer and more efficient drugs.

Reproductive Genetics

Reproductive technologies such as pre-implantation genetic diagnosis (PGD) and prenatal diagnosis (PD) raised various issues for interviewees, including concerns about eugenics, the commodification of life, the status of the embryo, reproductive autonomy, and human rights. They also raised further debate about the definitions of “disease”, “normalcy”, and “disability”.

Respondents thought that future GE³LS research could focus on trend analysis and the current uptake of PND in Canada. It could also include more data on women’s perspectives. It might also consider the following questions:

- In the 30 years that PND (CVS and amniocentesis) has been available, have the ethical concerns respecting this technology affected decision-making or society? How often is PND used for typically late-onset diseases or for HLA typing? Under what circumstances? Is it a cause for concern? Does the availability of support, education and quality, and co-ordinated medical care influence an individual’s decision to pursue prenatal testing? Do women feel pressured to undergo maternal serum screening?
- It would also be beneficial for research to examine how uptake, availability, and equity issues differ across Canada.

Other Health Topics

Respondents named several other health care research topics, some of which they suggested might come up in a clinical setting:

- When it comes to testing children, does the public share the same qualms as genetic counselors or ethicists? If not, why not? Does the public know enough to have an informed opinion? Do they have a different take on ethical and technical issues? Does it reflect a divergence of values? Who would be right in such a situation?
- Family history may again become an issue as it relates to complex diseases. Family physicians or other physicians—rather than geneticists or genetics clinics—may use the information in treatment.
- Direct to consumer marketing.
- Neurogenetics.

Educational Implications

Our respondents consistently identified two groups with a particular interest in the research into and use of GE³LS: health professionals and the public.

Educating all health professionals in genetics and its ethical implications was consistently mentioned. Not surprisingly, respondents stressed the need to promote the integration of GE³LS issues across all fields including the training of students, the scientific community, and the health workforce. In addition to providing more genetic information, there is a need to educate health care professionals about the proper benefits and limitations of this information.

One respondent noted that GE³LS information is largely absent in pharmacy and behavioral science curricula. As a result of recent developments in pharmacogenomics, it will become necessary for pharmacists to have the knowledge required to understand emerging policies and to help their customers. Similarly, psychologists will need to integrate genomics knowledge into their practice because uncovering genomic components is increasingly contributing to our understanding of behavioural and neurological conditions.

Connecting researchers and the public is of equal importance. This is based on the fact that people benefit from research based on an understanding of their needs. Respondents perceived the public to be poorly informed and confused about genetics, genomics, and genetic information. They suggested that some individuals have an understanding of heredity that may be a source of misinformation. Moreover, “community involvement” is not readily understood by either the public or the research community and has thus generated a number of important studies. Public consultations and engagements, focus groups, citizens’ juries, and public surveys/opinion polls may help to expand our empirical knowledge of this area.

Implications for Non-Medical Settings

The use of genomic information is not limited to healthcare; therefore, further research is needed in other settings. Several respondents mentioned the need to explore, for example, the appropriate uses of genetic testing information in non-clinical settings such as schools, workplaces, adoption agencies, child custody/child support arrangements, and immigration.

(B) Ethical Issues

Below are examples of some the key ethical issues that were identified.

Shifting Prominence of Ethical Issues

Interviewees anticipated that the growing research interest in chronic diseases, preventive medicine, and public health will prompt a shift in the ethical issues relevant to the new health issues in genomic research. The past decades of GE³LS research were framed to protect the public from potential negative ethical, social, and psychological implications and to focus on issues of consent, discrimination, privacy, and confidentiality. Several respondents suggested that, by reframing the goal of genetic research to understand the benefits of genomics and of population and public health, a new paradigm will likely emerge in ethics: the inclusion of principles of reciprocity, mutuality, solidarity, citizenry, and universality. Respondents also noted the following concerns:

- Privacy protection for medical and research data may be disproportionate to privacy concerns in other areas of public care.

- The GE³LS experts are perhaps promoting traditional ethical values that do not fit the norms of population research.
- Younger generations have different preoccupations about genetics information than do older generations.
- Issues of confidentiality, autonomy and discrimination.

Abuse of Genetics

Interviewees agreed that insurance discrimination remains a great public concern. Despite the lack of evidence, fear of discrimination seems to influence individual decisions on genetic tests for late onset diseases.

Biobanks

Several respondents also flagged biobanks as a public concern for a variety of reasons: sometimes, the use and purpose of the bank are not well known; storage practices vary widely; and oversight may not be transparent.

Genomics is a global phenomenon in which practices may vary across borders. Respondents thought that areas of research interest should include the harmonization of biological, medical, demographic, and social data so the information can be used for research and to develop health care solutions. Issues of integration and databases raise the following questions and requirements:

- Are research centres in Canada sharing tissue samples to create biobanks? What does the Canadian public expect about biobanks?
- Will a better understanding of cultural norms and contexts benefit the sharing of human genetic resources and help the development of best practice models?
- How can we establish overarching and consistent best practice models for security and access to existing collections of human biological material, as well as to provide guidance for the development of new repositories?
- What is the best way to ensure ethical consistency within and between jurisdictions (especially within and between developing countries)?
- How will we handle issues around secondary and future uses of informed consent, anonymization, the right to withdraw, commercialization, and the right of control over, for example, tissues once they have been collected?
- Is there guidance available on the duty to re-contact?

Governance

Interviewees recognized governance as essential to building trust between the research community and the public. They were concerned about the variable quality of ethical assessments and the ethics review process. Some respondents wondered what sort of ethics training would develop an understanding by ethics committees that while qualitative meta-analysis, case control studies, and qualitative studies do not have the same standards of experimental design, they are equally important. They also recognized a need to harmonize ethics reviews of multi-centre research initiatives because often the same project is not consistently evaluated according to the same standards.

Social Divide

Interviewees interpreted the inequality of access to genomic data and benefits as a key issue emerging in GE³LS research, especially in relation to industrialized and developing countries. One striking example is life expectancy, which in most industrialized countries is about 80 years and rising, while in many developing countries, especially in Sub-Saharan Africa, it is 40 years and falling. This discrepancy raises issues of morbidity, quality of life, and the broader effects on society.

Underlying the differences in health are inequities in knowledge. Most people are familiar with the “digital divide.” However, interviewees pointed out that the science and technology (S & T) gap extends to the biotechnology and nanotechnology sectors (prompting new terms: the “genomics divide” and “nano-divide”). Despite discussions about the role that research and technology development—and technology transfer—should play in developed countries helping developing countries to achieve greater economic and social stability, the science and technology divide continues to grow.⁸

Public Engagement

Community engagement aims to promote public involvement in the planning, understanding, and integration of genetic and genomics. In order to promote a more meaningful application of research findings, some respondents suggested that the GE³LS research community include members of the public, including representatives of minority groups and ethnic communities. At the moment, public consultation on issues identified by GE³LS experts is insufficiently developed to be useful to inform policy development, but there is growing emphasis on its importance. In the opinion of respondents, the development of public consultation will require research, collaboration, transparency, and public input.

(C) Legal Issues

We have grouped the legal issues raised in interviews into six sub-categories:

Impact on Vulnerable Individuals and Populations

The autonomy of children to make their own decisions on testing was a concern for the respondents. There is evidence of a growing willingness among clinicians to test children for late-onset disorders (example: BRCA testing for breast cancer).

Biobanking

Genetic research is an integral component of medical research. To carry out their work, genetic researchers require access to a large number of specimens, thus creating a demand

⁸ For example, the Global Forum for Health Research has documented that 90 per cent of all health research is targeted at problems that affect only 10 per cent of the world’s population. This so-called “10/90 gap” threatens to create even greater inequities between wealthier and developing countries, posing a critical challenge to the application of new knowledge and innovations for global human welfare. For more on the 10/90 gap, see “The 10/90 Report on Health Research 2003-2004” by the Secretariat of the Global Health Forum (under the direction of Louis J. Currat), (2004) available online at http://www.globalforumhealth.org/Site/002_What%20we%20do/005_Publications/001_10%2090%20reports.php.

for biobanks and other tissue banks. The mandate of biobanks is broad and can include research, drug or diagnostic development, as well as preventive and curative medicine. Banks may be disease specific or more general. They can extend from regional to national to international and may be sponsored by governments, public foundations, or commercial enterprises. In order to fully address the legal issues involved in storing biological samples from both living and deceased individuals, interviewees thought we must take into account the differences—for examples, in consent processes, governance, levels of anonymity—in these biobanks.

Intellectual Property

As financial payouts increase, the potential for conflicts of interest may also increase among scientists and students, as well as between universities, the private sector, and government agencies, which work on these scientific questions. Respondents suggested to explore the following areas associated with intellectual property:

- the effect of patented inventions in human genetics on health-care access;
- the potential for gene patents and platform technologies in biotechnology to create barriers to research and innovation;
- patent reform versus institutional responses to barriers blocking access to patented medical genetic innovations through strategic licensing practices;
- uptake of international guidelines and recommendations on licensing genetic inventions and the use of criteria in health funding bodies to shape licensing practices to promote greater access to innovations by researchers and health systems;
- mechanisms to support patent pools and other co-operative mechanisms that may clear patent obstructions in medical genetics and encourage collaborative research; and
- the interface between uptake of patented biotech health products in the health system.

Privacy

Respondents raised concerns about patient rights and safety as they relate to the applications of new technologies. These issues apply, for example, to informed consent associated with traceable human tissues—for example, embryos, blood cells, and umbilical cord blood—because of cultural and religious diversity. There are many other difficult questions to address: who owns the genetic information? Does it belong to the individual or to the family? How does the right to privacy relate to the right to know? Clinicians face similar questions as they relate to the duty of confidentiality and the duty to warn. The answers to these questions have significant implications for family dynamics and communication.

Regulatory Approaches and Safety Issues

Genetic medicines, tests, and therapies must be regulated with the same rigour as other health interventions. These new medical technologies must be proven safe and effective, and they must be reviewed according to health technology assessment standards. However, the development of such regulations is a very slow process that creates a serious hurdle to

clinical use of these innovations. Respondents suggested to explore the following research topics addressing health technology and quality assurance:

- Health Technology Assessment: Preventive Screening/Testing for Genetic Diseases.
- The current uptake of genetic tests including a trend analysis over the past 25 years, primarily for common multifactorial diseases.
- The healthcare costs of genetic tests and a determination if there are rising or decreasing health care costs related to genetic tests, including any treatment/screening/intervention options offered for mutation carriers as well as treatments that are stopped if testing determines a lower risk.
- The equity issues regarding tests/treatments.
- Research to help improve determination of test accuracy and precision (data analysis) and standardization of testing methodology by disease.
- Review educational requirements of genetic professionals, health care providers, and those offering genetic testing on a clinical or research basis.
- Investigate the number of genetic test kits expected to be put on the market in the coming years.
- Examine and determine the best practices in the transition of research into clinical.
- Evaluate the possible burden on patients needing to communicate disease risk to other family members (note: there is no legal right to access genetic test results in Canada).
- Examine the implications of increased availability and access to genetic testing as technology advances and as this becomes less costly and more available in the medical field.

Summary

In general, key informants raised many concerns, some of which only recently emerging, others already known, which must be explored fully. Examples include the convergence of technologies (such as nanotechnologies and biotechnologies) with genetics and genomics, the social implications of genetic testing as a preventive measure for public health, the storing of genetic materials in biobanks, and the potential abuse of genetic information by health professionals, insurers, and employers. In addition, there are questions of governance, legality, and inequality raised by the effects of genetic and genomic research that still must be addressed in order for the science to advance in partnership with—and with the support of—the social sciences, the humanities, and the general public.

3.3: Implementation Issues Surrounding GE³LS Research in Genomics and Genetics

The GE³LS issues discussed up to this point are important, but it is clear that in some situations, the real challenge is not determining research topics but rather understanding the research context and undertaking the research. We must consider the complex relationship of genomic research with politics, culture, social choice, commercial pressures, and the

environment: it is these interactions that make the implementation of research most problematic.

Our respondents agreed that GE³LS research must be funded but many of them also raised a number of concerns regarding the integration of GE³LS issues into genetics and genomics, the value of large- versus small-scale projects, the governance of research projects, interdisciplinary approaches, knowledge transfer, and the sharing of research resources.

Integration of GE³LS Issues into Genetics and Genomics Projects

GE³LS research is recognized as an important part of genomics/genetics research that helps integrate the ethical, legal, and social aspects of research into the science. The majority of respondents acknowledged the pressing need to integrate GE³LS research into the science to better inform policies and to accelerate the transformation of science into health benefits. Several respondents made the case that GE³LS deserves equal status to science that it must not be treated as a token or add-on in larger science projects, which is meant to reassure the public or smooth the way for private development. The development of multidisciplinary teams with basic science, social sciences and humanities researchers collaborating together has influenced positively the development of studying the GE³LS aspects of human genetics. Respondents acknowledged the need to expand GE³LS research as the application of genomics to healthcare increases.

Several respondents expressed uncertainties about or perceived limitations in the integration of GE³LS into genomic research projects. For instance, while the idea of introducing GE³LS research into large genomic projects is a good one, there are no guarantees of success. One respondent expressed the concern that, because current GE³LS research is following genomic applications, it is imperative that such research gets embedded in new potential applications.

Interviewees also judged it important to recognize the need for non-integrated GE³LS research projects that allow the development of sensitive studies and that can address issues that are too threatening within science projects.

Public/Private Funding

Funding of genomic research is a much contested area. The majority of respondents agreed that both public and private funding is good and “here to stay.” For several respondents rigorous, transparent, and consultative GE³LS research would have to be a critical and obligatory component of any related government-funded project. However, several respondents recognized that GE³LS research would likely not have been a success without financing from private foundations and private-sector partnerships. The coupling of governmental and non-governmental funds seems to occur because governments opt out of funding, thus forcing researchers to seek private funds. Many respondents felt that the coupling of private and public GE³LS research funding could be beneficial. However, several respondents indicated that, if public-private partnerships continue, it will be necessary to build more trust in the general public by making such arrangements transparent and accountable, something that has not yet been achieved.

A minority of respondents—reinforced by some workshop participants—was firmly opposed to private funding. These respondents characterized public funding as accountable, regulated, and focused on the progress of knowledge. Following, in no particular order, is a list of some of the concerns raised in relation to the joint public/private funding of GE³LS research:

- Private funding has a more practical application.
- Private funding is commercial.
- Public-private funding raises issues about conflict of interest and commercialization of research.
- The private sector is not appropriately regulated.
- Private sector researchers are increasingly interested in research and consultation on the GE³LS impacts of their science and product development in order to mitigate potential risks in terms of safety, negative social impact, and public perception about these issues.
- There will always be suspicions that private sector funding has an alternative agenda; the more private funding, the lower the public trust.
- There is a fear the economic imperative is too influential in the regulatory, scientific, political, and media arenas.

One respondent suggested that creating a pool of funds from private-sector donations might be a way to work around these issues.

Large or Small GE³LS Projects?

Some respondents questioned whether smaller GE³LS projects could not come up with the same results as larger, more expensive studies. Given financial constraints, there was a sense among interviewees that the substantial resources devoted to large projects might often be better used on many smaller projects.

Governance Issues

Respondents noted that they found themselves increasingly entangled in a web of bureaucracy that makes research difficult. In some cases, researchers experienced very long delays before receiving approval from ethics committees, particularly for multi-location studies. In other instances, they received contradictory advice about privacy and confidentiality issues at different research institutions. Furthermore, at times, research is carried out in one jurisdiction but funded in another, so considerable time and effort is required for the obligatory multiple ethical reviews which, in practice, do not seem to contribute to the protection of research subjects.

Many respondents complained that quarterly reporting required for research projects is another source of bureaucracy that impedes research. Researchers feel they spend so much time on administrative duties that they have little time left for thoughtful compilations of relevant research findings.

Interdisciplinary/Multidisciplinary Research

Although the idea of interdisciplinary research attracts much interest and support, many interviewees stated that actually undertaking it is very difficult. If the GE³LS community and genomics research are to grow, funding agencies would have to recognize the institutional support structures required to facilitate communication between researchers from different disciplines.

Respondents also felt the need to build capacity regarding the ethical aspects of genomics, especially in the humanities. Comparing the situation in this country to that in the United Kingdom and in France, they observed that Canada has a very strong cohort of bioethics and legal scholars but a small number of social scientists focusing on GE³LS research in human genomics.

Interviewees also suggested that GE³LS research expand from such traditional disciplines as philosophy, ethics, and law to include a wider array of disciplines such as political science, sociology, economics, psychology, the environment, public policy, theology, and anthropology. Historically, some of these disciplines have paid little attention to genomics. However, they could have a potentially significant influence on ethics and would complement the perspectives of disciplines such as philosophy, law, and bioethics. This observation is particularly interesting in light of our overview, in Chapter 1, of current GE³LS research in Canada. We found that, based on funding data, social sciences and humanities researchers are initiating few or no GE³LS projects, which means that GE³LS research is concentrated in a few disciplines, conducted by a comparatively small number of researchers. Respondents repeated their call for humanities researchers to enter the discussion about the ethics of genomics in order to ensure that society's interests be best served.

Knowledge Transfer

Although the importance of knowledge transfer is widely accepted, not everyone agrees what the concept means. Still, the general view of interviewees was that information generated from GE³LS research should be better integrated into health services, policies, and public awareness, in order to encourage the use of GE³LS information.

Given the wide range of views we observed, any overview of knowledge transfer is a minefield. Nonetheless, what follows are some of the challenges presented by our key informants.

Several respondents complained about the fact that science and technology studies underutilize GE³LS information. One respondent suggested GE³LS research occupies a ghetto in which researchers feel unappreciated because experts in other fields consider the work irrelevant and obstructionist to scientific advances.

In order to achieve integration, interviewees suggested that many partners from the science and technology sectors would have to be involved, as well as the public. Successful integration requires gathering expert and stakeholder input from the individuals who rely on the fruits of genetic and genomic research. At a fundamental level, there needs to be increased collaboration, communication, and interaction between the GE³LS research

community and the science community in order to strengthen the integration of GE³LS, to encourage the use of GE³LS information, and to promote collaborative approach.

Also, researchers must synthesize and disseminate their work in a manner that considers the needs of their colleagues and the community they are trying to reach.

Shared Resources

The increasing focus on multiple genes and on gene-gene and gene-environment interaction highlights formidable methodological problems, as well as the need to build institutional bridges to facilitate greater interactions. Respondents remarked on the emergence of a consensus that there is a need for synthesis to assess the consistency of findings, to test hypotheses and explain inconsistencies, to investigate specific subtypes of disease or health defined by more detailed phenotyping than in the past (using molecular biomarkers and CAT scans, for example), and to have adequate power to develop and validate genomic profiles and to investigate gene-environment interaction. The approach requires sharing data and possibly new methods of publication.

Summary

This final section summarizes the important considerations related to GE³LS research as identified by informants:

- Many respondents noted problems with “downstream” research, namely that GE³LS research seems always to lag behind scientific research instead of being integrated right at the beginning.
- The sources of funding of GE³LS research remain controversial. In particular, private funding is highly controversial, is suspicious in itself, and generates fears about attempts to influence research on the part of the funder. Public funding, on the other hand, is seen as a more transparent, providing for greater academic freedom.
- Over the last five years or so, large sums of public funds have gone towards GE³LS research in Canada. Some respondents and workshop participants questioned whether more small-scale projects could not produce similar or more research results as fewer large-scale projects. Some interviewees felt that large-scale projects absorbed almost all available financial resources for GE³LS research and almost no resources were left for small-scale projects.
- Respondents saw a clear challenge associated with implementing larger multi- and interdisciplinary research projects. Consequently, they also saw a need for funders to recognize the importance of process, rules and regulations that facilitate multi- and/or interdisciplinary collaboration. There is also a deficit in the number of scholars conducting GE³LS research.

Conclusion and Important Challenges

The first aim of this study was to take stock—in the form of a compendium—of GE³LS research projects publicly funded in Canada and the United States in 2005-2006. The second aim was to identify emerging issues relating to human genetics and genomics. This was done in the form of a consultation of leading Canadian researchers, policy makers, and stakeholders in the GE³LS field. The following observations are thus based on the data in the compendium, on our interviews of key informants, and on comments on a previous draft version by participants in the May 23 workshop in Ottawa.

Our study reveals important future trends and challenges for GE³LS research. We noted that many research activities were confined to genetic testing. In particular, there is a large focus on family cancers. There is also interest in cultural and religious values, which influence people's reactions to and experience regarding genetic research. Additionally, our interviews revealed that GE³LS researchers face the challenge of more effectively communicating with and disseminating information to the public and policy-makers. Most respondents agreed that the future of GE³LS research involves three areas 1) developing and evaluating educational approaches for all stakeholders; 2) recognizing the shifting emphasis from individual health research towards population health issues and concerns; and 3) building bridges between the producers and users of GE³LS research. Finally, while there is a considerable amount of GE³LS research underway in Canada and the US, several respondents expressed uncertainties about the integration of GE³LS into genomics projects, policy development, and the clinical setting.

This summary raises many further questions. Firstly, what are the “real” emerging issues? What is the role of key informants, the public, and academic leaders in establishing the direction of research? Is the GE³LS community doing enough to raise awareness about their research among policy makers, health professionals, researchers and the public? Is there enough integration of GE³LS research into health services and policy development? Has funding of GE³LS research yielded acceptable returns on investment, i.e. significantly enhanced our understanding of GE³LS issues? Has public/private co-funding helped advance GE³LS research in Canada and North America? How can sectors such as universities, charities, professional associations, industry, and provincial governments contribute to future GE³LS research in Canada? Can these sectors work more closely to create the optimum environment for GE³LS research? Finally, will genomics play a critical role in non-medical fields such as immigration, adoption, insurance, schools and the workplace? Research in these areas is lacking.

We hope that these questions can serve as a call to action to both new and established GE³LS researchers. The science of genomics is making huge strides as it becomes increasingly cheaper and faster, more accurate and more useful. Furthermore, public interest in genomics remains high, which therefore leads policy- and decision-makers to also examine the area. GE³LS research is a necessary component of every aspect of genomics, from research on human subjects to its implementation in the clinical setting and with the environment. The multitude of uncertainties surrounding GE³LS issues will

hopefully challenge researchers in all relevant disciplines to pursue these questions as we enter the exciting new paradigm of genomics research.

Appendix A: Methods for Reviewing GE³LS Research in North America: Canada & United States

The present review began in mid-January 2006 and is intended to be as comprehensive as possible. However, it is possible that some relevant research projects have been overlooked.

Scope

In order to identify the most current initiatives in the GE³LS field, the scope of the present review is limited to projects funded during 2005-2006. Projects were included if the funding came from the following public agencies and institutions:

- governmental departments and ministries (e.g. Health, Justice, Environment);
- research funding agencies (e.g. Canadian Institutes of Health Research, National Institutes of Health); and
- non-governmental organizations funding research activities (e.g. National Cancer Society, Multiple Sclerosis Society of Canada).

Political Jurisdictions

- Canada: federal/national, provincial, and territorial.
- United States: federal/national.

Data Collection

First, we identified institutions and agencies in Canada and the United States that funded GE³LS research in 2005-2006. Then, our search proceeded as follows:

Canada: Federal and Provincial

The following reports and websites of federal bodies were examined and searched to identify human genomics GE³LS research:

- ERA-NET SAGE Questionnaire (Work Package 1);
- the Social Sciences and Humanities in Health Research: A Canadian Snapshot of Fields of Study and Innovative Approaches to Understanding and Addressing Health Issues (2005);
- Summary Report to the Board of Directors, Genome Canada, Vancouver, 2002;
- the website of the Canadian Research Information System (http://webapps.cihr-irsc.gc.ca/cris/Search?p_language=E&p_version=CRIS);
- the website of the Canada Research Chairs program (<http://www.chairs.gc.ca/>);
- the website of the Government of Canada (<http://www.gc.ca>) to find links to federal institutions that fund research;
- the websites of provincial governments and their ministries using the keywords: provincial (name of province); research; ethical, legal, social; funding; genetics; genomics;

- the internet using the following keywords: Canadian research foundations; Canadian charities; funding opportunities.

United States: Federal

- the websites (<http://www.gov.gov>) of the United States federal government to find links to federal institutions that fund research;
- the website of non-governmental organizations (NGOs), using the following search keywords: ELSI, research grant opportunities, foundation grants, charities grants, and genetics and genomic research;
- the website of CRISP (Computer Retrieval of Information on Scientific Projects), which holds information on grants from NIH, NHGRI, CDC, and NCI (<http://crisp.cit.nih.gov/>);
- the awards search engine of the National Science Foundation (NSF; <http://www.nsf.gov/awardsearch/>); and
- the website of the Department of Energy (DOE; <http://www.energy.gov/>).

Appendix G contains the complete compendium of GE³LS and ELSI funding organizations that were contacted. When summaries were not on the Internet, specific information was obtained from the funding organization and/or the lead researcher. SSHRC's Manager of Policy, Planning and International Affairs e-mailed requests for information as required (see Appendix D).

The identified GE³LS projects yielded the following information:

Lead Researcher	Only the leading Principal Investigator noted
Title	Title of the project
Summary	A summary extracted from the internet
Timeframe	The duration of the project
Disciplinary Focus	Whether or not the project involves several academic disciplines
GE3LS	Socio-medical health topics and GE3LS issues
Funder	Whether the funding is governmental or non-governmental
Financial Scale	Whether the resources for the project are small, medium, or large

Appendix B: Methods for Consulting and Identifying Emerging GE³LS Issues in Human Genetics and Genomics Research: A Canadian Perspective

Rationale for Sampling

In collaboration with SSHRC advisors, we identified leaders in the field of GE³LS research and policy with an interest in human genomics. To promote a comprehensive overview, we sought a broad range of opinions from the following stakeholders:

- a. decision-makers or program managers at funding agencies;
- b. research chairs or directors;
- c. investigators including doctoral and post-doctoral students from such disciplines as anthropology, sociology, psychology, and epidemiology; and
- d. “other” stakeholders: Ethics committees, policy makers, interest groups, and other knowledgeable stakeholders able to identify key concerns in their communities.

With the goal of building the broadest range of views, we decided to interview individuals who did not attend the May 2006 workshop and who would otherwise not have had a chance to be heard. See Appendix E for a full list of contributors.

Process of Consultation

We sent out 30 e-mail invitations with a short description of the project, a questionnaire, and an assurance that each individual’s views would be treated anonymously. The intent of this assurance was to encourage complete openness, especially about sensitive topics. Twenty people responded (see Appendices E and F). The consultations and interviews took place by phone (or in writing as per a questionnaire) between March 29 and April 15, 2006. During a 30-minute telephone call, participants were asked six open-ended questions:

- 1) What are the emerging GE³LS issues in human genomics/genetics?
- 2) What are your perceptions of the driving forces that make these GE³LS issues emerge?
- 3) Which emerging GE³LS issues are research priorities?
- 4) What areas of genomic/genetic research generate public interest or concern?
- 5) Regarding financing of research in human genomics/genetics, what are your thoughts about private- and public-sector funding?
- 6) What are your thoughts regarding the funding of GE³LS research per se and GE³LS research as part of larger genomics/genetics research projects?

In an effort to identify a broad range of issues, we included respondents from a variety of settings and disciplines, primarily from the humanities, social sciences, and medical sciences. We anticipated this would help to highlight issues that might not have emerged had we only selected individuals from a homogenous background (bioethics and law, for example). We are confident that this consultation can help identify most issues, gaps, and future avenues for research.

Appendix C: Research Funding Bodies 2005

Appendix C1: Canada (Federal)

	Federal	Surveyed (√ Organization funded GE ³ LS)
Governmental	Canadian Institutes of Health Research (CIHR)	√
	Natural Sciences and Engineering Research Council of Canada (NSERC)	
	Social Science and Humanities Research Council of Canada (SSHRC)	√
	Stem Cell Network (Centre of Excellence)	√
	Canada Research Chairs	√
	Canada Foundation for Innovation (CFI)	
Non-Governmental	Alzheimer's Society of Canada	√
	Banting Research Foundation	
	Bayer Institute for Health Care Communication	
	Canadian Breast Cancer Research Alliance	√
	Canadian Cystic Fibrosis Foundation	
	Canadian Diabetes Association	
	Canadian Genetic Diseases Network (Centre of Excellence)	√
	Children's Health Research Institute	
	Canadian Health Services Research Foundation	
	Canadian Women's Health Network Change Foundation	
	Community of Science	
	Crohn's and Colitis Foundation of Canada	
	Huntington Society of Canada	
	International Development Research Centre	
	Juvenile Diabetes Foundation	
	MS Society of Canada	√
	Muscular Dystrophy Association of Canada	
	National Cancer Institute of Canada	√
	National Heart, Lung & Blood Institute	
	Parkinson's Foundation of Canada	
Rick Hansen Institute		
St-Joseph's Health Care Foundation		
Sick Kids Foundation		

Appendix C2: Canada (Provincial)

	Provincial	Surveyed (√ Organization funded GE ³ LS))
Governmental	Alberta Heritage	
	BC Innovation Council	
	BC Medical Services Foundation	
	Fonds de la recherche en santé du Québec	√
	Génome Canada/Génome Alberta	√
	Génome Canada/ Génome Atlantic	√
	Génome Canada/ Génome BC	√
	Génome Canada/ Génome Prairie	√
	Génome Canada/ Génome Quebec	√
	Manitoba Health Research Council	
	Génome Canada/ Ontario Genomics Institute	√
	Ontario Innovation Trust	
	Saskatchewan Research Council	
	Valorisation-Recherche Québec	√
Non-Governmental	Beauséjour Medical Research Institute	
	The BC Research Institute for Children & Women's Hospital	
	Canadian Breast Cancer Foundation- Ontario Chapter	√
	Canadian Breast Cancer Foundation- BC/Yukon Chapters	
	Canadian Breast Cancer Foundation- Atlantic Chapter	
	Michael Smith Foundation for Health Research	
	New Brunswick Medical Research Fund	
	Ontario Cancer Research Network	
	The Cancer Research Society	
	Saskatchewan Health Research Foundation	

Appendix C3: United States (Federal)

	Federal	Surveyed (√ Organization funded GE ³ LS))
Governmental	Centre for Disease Control and Prevention (CDC)	
	Department of Energy (DOE)	
	National Cancer Institute	√
	National Human Genome Research Institute (NHGRI)	√
	National Institutes of Health (NIH)	√
	National Science Foundation (NSF)	√
Non-Governmental	Alzheimer's Association	√
	American Cancer Society	√
	Howard Hughes Foundation	
	Komen Foundation	√
	The Michael J. Fox Foundation for Parkinson's Research	√
	National Multiple Sclerosis Society	√
	Rockefeller Foundation	
	Greenwall Foundation	

Appendix D: ERA-SAGE State-of-the-Art Review of Research in Canada and the US

Appendix D1: Letter to Organizations

Dear Madam, Dear Sir,

The Social Science and Humanities Research Council of Canada (SSHRC), in collaboration with the European Research Area - Societal Aspects in Genomics (ERA-SAGE; <http://www.erasage.org/>), is currently collecting information on funded research on the economic, legal and social aspects (ELSA) of genomics in Canada and the United States for the year 2005-2006. This project is part of a major international effort to achieve greater synergy and convergence in their support for research on the societal aspects of genomics. SSHRC has asked the Centre de recherche en droit public (CRDP) at the Université de Montréal to conduct this search on their behalf. Dr. Denise Avard is the project lead, supported by Ms. Lucie Marisa Bucci.

In order to better understand the nature of the projects funded by your institution, we would like to ask that you send us information (lay summaries, timelines of projects, name of principal investigator) for the following projects: **(insert names of projects)**. The information you provide will help us identify the range of current research-related activities in projects dealing with ELSA genomics research, especially human genetics. In addition, this information will be included in a high-level compendium on ELSA-related funded research projects for the year 2005-2006. Finally, an analysis of research trends will be produced. Once finalized, we would be happy to share these documents with you.

Your participation in this information-gathering exercise is really important for our international effort, and we very much appreciate your co-operation. We kindly ask that all information about the projects be sent directly to either Dr. Avard at denise.avard@umontreal.ca or Ms. Bucci at lucie.marisa.bucci@umontreal.ca. For further information about this endeavour, please do not hesitate to contact us.

Yours sincerely,



Sylvie Paquette
Manager, Policy and International Collaboration
Policy, Planning and International Affairs
Social Sciences and Humanities Research Council of Canada (SSHRC)
Tel.: (613) 992-3146
Fax: (613) 943-1153
Email: sylvie.paquette@sshrc.ca
<http://www.sshrc.ca>

Appendix D2: Letter to Researchers

Dear Madam, Dear Sir,

The Social Science and Humanities Research Council of Canada (SSHRC), in collaboration with the European Research Area - Societal Aspects in Genomics (ERA-SAGE; <http://www.erasage.org/>), is currently collecting information on funded research on the economic, legal and social aspects (ELSA) of genomics in Canada and the United States for the year 2005-2006. SSHRC is a member of the nine-member ERA-NET SAGE consortium consisting of government agencies and departments in Austria, Finland, Germany, Israel, the Netherlands, Norway, Switzerland and the United Kingdom. ERA-NET SAGE aims to achieve greater synergy and convergence in their support for research on the societal aspects of genomics.

SSHRC has asked the Centre de recherche en droit public (CRDP) at the Université de Montréal to collect information on its behalf. Dr. Denise Avard is the project lead, supported by Ms. Lucie Marisa Bucci. In order to better understand the nature of your research, we would like to ask that you send us a one-page summary of the following project: **(insert name of project)**. The information you provide will help us identify the range of current research-related activities in projects dealing with ELSA genomics research, especially human genetics. In addition, your information will be included in a high-level compendium on ELSA-related, funded research projects for the year 2005-2006. Finally, an analysis of research trends will be produced. Once finalized, we would be happy to share these documents with you.

Your participation in this information-gathering exercise is really important for our international effort, and we appreciate your co-operation. We kindly ask that your one-page research summary be sent directly to either Dr. Avard at denise.avard@umontreal.ca or Ms. Bucci at lucie.marisa.bucci@umontreal.ca. For further information about this project, please do not hesitate to contact us.

Yours sincerely,



Sylvie Paquette
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Policy, Planning and International Affairs
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Appendix E: List of Key Informants

Name	Affiliation	Response
Bouffard, Chantal	Anthropology, Université de Sherbrooke	Received
Burgess, Mike	Chair in Biomedical Ethics, University of British Columbia	Received
Caulfield, Tim	Canada Research Chair in Health Law and Policy, University of Alberta	Received
Costea, Irina	Community Medicine, Université de Montreal	Received
Taylor, Andrew	Joint Centre for Bioethics, University of Toronto.	Received
Dorval, Michel	Psychology, Université Laval	Received
Engler, Todd Lori	Health Canada	Received
Isasi, Rosario	Centre de Recherche en Droit Public, Université de Montréal	Received
Joly, Yann	Centre de Recherche en Droit Public, Université de Montréal	Received
Karmali, Mohamed	Public Health Agency of Canada	Received
Knoppers, Bartha Maria	Canada Research Chair in Law and Medicine, University of Montreal	Received
L'Archevesque, Paul	Genome Quebec	Received
LeBris, Sonia	Industry Canada	Received
Leroux, Therese	University of Montreal	Received
Letendre, Martin	Ethical (private sector)	Received
Little, Julian	Canada Research Chair in Human Genome Epidemiology, University of Ottawa	Received
Lock, Margaret	McGill University, Montréal	Received
Mehta, Michael	Sociology, University of Saskatchewan	Received
Singer, Peter	Joint Centre for Bioethics, University of Toronto	Received
Wilson, Brenda	Community Medicine, University of Ottawa	Received

Appendix F: ERA-SAGE State-of-the-Art Review of Research in Canada and the United States: Letter for Key Informant Interviews

Dear Sir/Madam,

The Social Sciences and Humanities Research Council of Canada (SSHRC), as part of the *European Research Area - Societal Aspects in Genomics* (ERA-SAGE; <http://www.erasage.org/>), is collecting information on funded research on the ethical, economic, environmental, legal and social aspects of genomics and genetics (GE³LS) in Canada and the United States. Through this study the ERA-SAGE network, which consists of nine government agencies and departments including: Austria, Finland, Germany, Israel, the Netherlands, Norway, Switzerland and the United Kingdom, aims to achieve greater synergy and convergence in their support for research on the societal aspects of genomics.

In the context of this project, SSHRC has asked me to interview experts to comment on what you see as the major future trends in GE³LS research in Canada.

This questionnaire will take approximately 30 minutes. You may reply either by phone or by e-mail, whichever approach you find the most convenient, and your responses will remain anonymous. I hope you are able to find some time to answer the following questions between **March 29th and April 7th**.

Questionnaire

1. What are the emerging GE³LS issues in human genomics/genetics?
2. What are your perceptions of the driving forces which make these GE³LS issues emerge?
3. Which emerging GE³LS issues are priorities for research?
4. What areas of genomic/genetic research generate public interest or concern? Why?
5. Regarding financing of research in human genomics/genetics, what are your thoughts about private and public sector funding?
6. What are your thoughts regarding the funding of GE³LS research per se and GE³LS s research as part of larger genomics/genetics research projects?
7. Have you written or collaborated with the writing of reports or articles that address emerging GE³LS issues? Are you aware of recent publications which discuss future GE³LS issues that have been examined or brought up?

I kindly ask that you inform me of your participation as soon as possible by responding to this e-mail. Should you decide to answer the questionnaire by phone, I ask that you indicate this in your email so that I can call you to confirm a date and time.

I hope to hear from you soon, and I thank you for taking the time to participate.

Sincerely,

Denise Avar, PhD
Centre de recherche en droit public
Université de Montréal
Tel. 514-343-7702
Fax. 514-343-2122

Appendix G: Compendium of GE³LS Projects

This Appendix is divided in multiple parts:

- G.1: The complete Compendium: an alphabetical (by researcher's last name) list of Canadian projects followed by a similar list of American projects
- G.2: Canadian projects organized by genetic/disease classification
- G.3: American projects organized by genetic/disease classification
- G.4: Canadian projects organized by GE³LS issues addressed
- G.5: American projects organized by GE³LS issues addressed

Appendix G.1: The Complete Compendium

Appendix G.2: Total of 81 Canadian Projects - Genetic/Disease Classification



Classification	# of Projects	PI, Title
Behavioural Genetics	2	S Scherer, <i>Autism Genome Project</i> J Mogil, <i>Designer Pain Relief</i>
Biobanking/ Databases	11	G Bouchard , <i>Fichier de Population Balsac</i> M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i> T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i> P Durie, <i>The Contribution of Genetic Modulators of Disease Severity in Cystic Fibrosis to other Diseases with Similarities of Clinical Phenotype</i> S Scherer, <i>Autism Genome Project</i> T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i> B Godard, <i>Consulting Cultural Communities for Large-Scale Genomic Databases : An Analysis of Interests and Values</i> T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i> D. Pullman, <i>Sorry, You Can't Have That Information: Stakeholder Awareness, Perceptions and Concerns Regarding The Disclosure and Use of Personal Health Information</i> B Knoppers , <i>The Future of Cord Blood Banking in Canada</i> B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i>
Cancer	14	C. Fernandez , <i>Returning Research Results to Research Participants: A Needs and Attitudes Assessment of Research Participants and their Guardians.</i> T Power, <i>Psychosocial Issues Regarding Genetic Testing for Oncogenes</i> S Kenyon, <i>Trajectories of Health and Adaptation after Pediatric Stem Cell Transplant</i> R Hegele, <i>Structural and Functional Annotation of the Human Genome</i> C Guidos, <i>Identification of Genetic Pathways that Regulate the Survival and Development of Cancer and Cancer Stem Cells</i> P Wells, <i>Testing for Inherited Thrombosis – The Ethical Dilemma</i> M Marra, <i>High Resolution Analysis of Follicular Lymphoma Genomes</i> J Little, <i>From Genes to Genetic Pathways: Fulfilling the Promise</i> S Lambert, <i>The Impact of Interactive Health Communication on Psychosocial Adjustment to Breast Cancer</i> A. Chiarelli, <i>Screening Behaviours and Outcomes Among Relatives of Women With Breast Cancer</i> M Esplen, <i>A Randomized Controlled Trial of a Group Intervention for Women With a Family History of Breast Cancer</i>

		<p>S Latosinsky, <i>A Surgeon Forum for Translating Knowledge and Making Improvement in Breast Cancer Care</i></p> <p>S. Narod, <i>The Contribution of BRCA2 to Ovarian Cancer</i></p> <p>J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p>
Conceptual Models	13	<p>H Vézina, <i>Caractérisation des Effets Fondateurs Québécois et de leurs Ramifications Spatiales à partir d'Analyses Généalogiques de Sujets Atteints de Maladies Héritaires</i></p> <p>M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i></p> <p>C. Weijer, <i>Re-Examining the Moral Foundations of Research</i></p> <p>F. Miller, <i>Re-Defining Disease: Mapping the Contours of Genomic Medicine</i></p> <p>M Mullen, <i>Towards Developing Valid and Feasible Outcome Measures for Clinical Genetics Services</i></p> <p>J Lopez, <i>ELSI research and the construction of "legitimate" expertise</i></p> <p>F Baylis, <i>Conceptual and Ethical Issues at the Intersection of Genomics, Developmental Biology, Ecology, and Health</i></p> <p>M Burgess, <i>Democracy, Ethics and Genomics: Consultation, Deliberation and Modeling</i></p> <p>M-H Parizeau, <i>Ethical Questions at the Heart of Public Debates</i></p> <p>E Potter, <i>Approaches to Considering Social, Ethical, and Legal Issues in Health Technology Assessment: Application to Neonatal Screening Programs for Cystic Fibrosis</i></p> <p>M. Schwartz, <i>Responsibility and Preventive Medicine: Ethics, Genetic and the Asymptomatic Ill</i></p> <p>F. Baylis, <i>Justice for All</i></p> <p>F. M Brunger, <i>Protecting Communities in Population-Based Genetic Research: A Cultural Analysis of a Canadian Policy Dilemma.</i></p>
Gene Therapy	3	<p>E Simpson, <i>Pleiades Promoter Project</i></p> <p>F Baylis, <i>Therapeutic Hopes and Ethical Concerns: Clinical Research in the Neurosciences</i></p> <p>C. Condin, <i>Managing Hope and Balancing Expectations: Exploring How Families Understand and Choose to Participate in Gene Transfer Research</i></p>
Gene-environment	7	<p>J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i></p> <p>T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i></p> <p>L Mirea, <i>Family-Based Genetic Association Analyses of Longitudinal Trait Measurements</i></p> <p>J Little, <i>From Genes to Genetic Pathways: Fulfilling the Promise</i></p> <p>J. O'Loughlin, <i>Seeds of Disease: Investigating Childhood Determinants of Adult Chronic Disease</i></p> <p>M-H Parizeau, <i>Ethical Questions at the Heart of Public Debates</i></p> <p>J Mogil, <i>Designer Pain Relief</i></p>
Genetic Screening	3	<p>D Avard, <i>Techniques of Investigation and Parameters Development for the Study of Ethical and Social Issues of Genetic Screening for a Multicultural Community: Sickle-Cell Disease Pilot Project</i></p> <p>A. Chiarelli, <i>Screening Behaviours and Outcomes Among Relatives of Women With Breast Cancer</i></p> <p>E Potter, <i>Approaches to Considering Social, Ethical, and Legal Issues</i></p>

<p>Genetic Services</p>	<p>13</p> <p>M Samuels, <i>Atlantic Medical Genetic and Genomics Initiative</i> R. Battista, <i>Research Program to Support Health Politics in Genetics, Concerned with Quality, Efficiency and Social Welfare</i> F. Miller, <i>Re-Defining Disease: Mapping the Contours of Genomic Medicine</i> F Baylis, <i>Therapeutic Hopes and Ethical Concerns: Clinical Research in the Neurosciences</i> M Mullen, <i>Towards Developing Valid and Feasible Outcome Measures for Clinical Genetics Services</i> B. Wilson, <i>Translating Genetics Discoveries Into Appropriate Health Policy and Services: Enhancing Research Capacity and Developing Interdisciplinary Approach</i> T Caulfield, <i>Defining the Boundaries of Genetic Research</i> S. Cox, <i>Appropriate Uses of Genetic Information in the Diagnosis Treatment and Prevention of Autosomal Dominant Polycystic Kidney Disease and Rheumatoid Arthritis</i> P Singer , <i>Bridging the Emerging Genomics Divide</i> T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i> D.C Schachter , <i>Neuroethics New Emerging Team Grant: Informed Consent for Psychoactive Medications and Genetic Testing in Adolescent Patients with Mental Health Difficulties</i> T Caulfield, <i>Translating Science: Genomics and Health Systems</i> J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p>
<p>Genetic Testing</p>	<p>9</p> <p>T Power, <i>Psychosocial Issues Regarding Genetic Testing for Oncogenes</i> P Wells, <i>Testing for Inherited Thrombosis – The Ethical Dilemma</i> J Fosket, <i>Genetic Testing for Alzheimer's Disease in Canada and the U.S.: A Comparative Study of Meanings of Risk, Aging and Normalcy</i> M Hayden, <i>Genetic Discrimination in Mutation Carriers Identified Through Predictive Genetic Testing for Huntington Disease</i> S. Cox, <i>Appropriate Uses of Genetic Information in the Diagnosis Treatment and Prevention of Autosomal Dominant Polycystic Kidney Disease and Rheumatoid Arthritis</i> M Esplen, <i>A Randomized Controlled Trial of a Group Intervention for Women With a Family History of Breast Cancer</i> B Banwell, <i>Prospective Study of the Clinical Epidemiology, Pathobiology and Neuroimaging Features of Canadian children with Clinically Isolated Demyelinating Syndromes</i> D.C Schachter , <i>Neuroethics New Emerging Team Grant: Informed Consent for Psychoactive Medications and Genetic Testing in Adolescent Patients with Mental Health Difficulties</i> S. Narod , <i>The Contribution of BRCA2 to Ovarian Cancer</i></p>
<p>Genetics/Genomics</p>	<p>13</p> <p>E Simpson, <i>Pleiades Promoter Project</i> R Hegele, <i>Structural and Functional Annotation of the Human Genome</i> Kevin Kain, <i>Quantum dot diagnostics: simultaneous genomic and proteomic profiling of multiple pathogens at point-of-care</i> T Hudson, <i>The GRID Project: Gene Regulators in Disease</i></p>

		<p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>M Marra, <i>Dissecting Gene Expression Networks in Mammalian Organogenesis</i></p> <p>R Hancock, <i>The Pathogenomics of Innate Immunity (PI2)</i></p> <p>P Durie, <i>The Contribution of Genetic Modulators of Disease Severity in Cystic Fibrosis to other Diseases with Similarities of Clinical Phenotype</i></p> <p>S Scherer, <i>Autism Genome Project</i></p> <p>J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i></p> <p>A Kroker, <i>Decoding the Digital Future</i></p> <p>M Burgess, <i>Democracy, Ethics and Genomics: Consultation, Deliberation and Modeling</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p>
	22	<p>M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i></p> <p>T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i></p> <p>E Simpson, <i>Pleiades Promoter Project</i></p> <p>R Hegele, <i>Structural and Functional Annotation of the Human Genome</i></p> <p>C Guidos, <i>Identification of Genetic Pathways that Regulate the Survival and Development of Cancer and Cancer Stem Cells</i></p> <p>R Hancock, <i>The Pathogenomics of Innate Immunity (PI2)</i></p> <p>M Samuels, <i>Atlantic Medical Genetic and Genomics Initiative</i></p> <p>R. Battista, <i>Research Program to Support Health Politics in Genetics, Concerned with Quality, Efficiency and Social Welfare</i></p> <p>S Scherer, <i>Autism Genome Project</i></p> <p>S Lambert, <i>The Impact of Interactive Health Communication on Psychosocial Adjustment to Breast Cancer</i></p> <p>B. Wilson, <i>Translating Genetics Discoveries Into Appropriate Health Policy and Services: Enhancing Research Capacity and Developing Interdisciplinary Approach</i></p> <p>J Nisker, <i>Theatre as an Innovative Tool for Public Engagement in Health Policy Development</i></p> <p>J. O'Loughlin, <i>Seeds of Disease: Investigating Childhood Determinants of Adult Chronic Disease</i></p> <p>S. Cox, <i>Appropriate Uses of Genetic Information in the Diagnosis Treatment and Prevention of Autosomal Dominant Polycystic Kidney Disease and Rheumatoid Arthritis</i></p> <p>M. Phillips, <i>Pharmacogenomics of Drug Efficacy and Toxicity in the Treatment of Cardiovascular Disease</i></p> <p>P Singer, <i>Bridging the Emerging Genomics Divide</i></p> <p>B Knoppers, <i>Genomics in Society: Responsibilities and Rights</i></p> <p>S. Hamilton, <i>Out of Order: Law, Media, and Citizenship</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>T Caulfield, <i>Commercialization and Society and its Policy and Strategic Implications</i></p> <p>J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p> <p>A. Daar, <i>Strengthening the Role of Genomics and Global Health</i></p>
Knowledge Transfer		
Nanotechnology/ Biotechnology	7	<p>Kevin Kain, <i>Quantum dot diagnostics: simultaneous genomic and proteomic profiling of multiple pathogens at point-of-care</i></p> <p>M Marra, <i>High Resolution Analysis of Follicular Lymphoma Genomes</i></p> <p>A Kroker, <i>Decoding the Digital Future</i></p>

		<p>C MacDonald, <i>Biotech Ethics: Corporate Decisions as Key to Better Health and Better Health Policy</i></p> <p>E. Einsiedel, <i>Public Participation, Institutionalization and Technology Assessment.</i></p> <p>P Singer , <i>Bridging the Emerging Genomics Divide</i></p> <p>P Singer , <i>Canadian Program on Genomics and Global Health</i></p>
Neurosciences	6	<p>C. Borck, <i>Modern Metamorphoses: How Changing Our Bodies Changes Us</i></p> <p>J Fosket, <i>Genetic Testing for Alzheimer's Disease in Canada and the U.S.: A Comparative Study of Meanings of Risk, Aging and Normalcy</i></p> <p>S Scherer, <i>Autism Genome Project</i></p> <p>M Hayden, <i>Genetic Discrimination in Mutation Carriers Identified Through Predictive Genetic Testing for Huntington Disease</i></p> <p>A Basset , <i>Unravelling the Mysteries of Schizophrenia</i></p> <p>D.C Schachter , <i>Neuroethics New Emerging Team Grant: Informed Consent for Psychoactive Medications and Genetic Testing in Adolescent Patients with Mental Health Difficulties</i></p>
Pharmacogenomics	4	<p>D Avard, <i>Pharmacogenomics with Children: Towards a Healthier Future</i></p> <p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>M. Phillips, <i>Pharmacogenomics of Drug Efficacy and Toxicity in the Treatment of Cardiovascular Disease</i></p> <p>A. Daar , <i>Strengthening the Role of Genomics and Global Health</i></p>
Population Genetics	11	<p>H Vézina , <i>Caractérisation des Effets Fondateurs Québécois et de leurs Ramifications Spatiales à partir d'Analyses Généalogiques de Sujets Atteints de Maladies Hérititaires</i></p> <p>G Bouchard , <i>Fichier de Population Balsac</i></p> <p>M Samuels, <i>Atlantic Medical Genetic and Genomics Initiative</i></p> <p>T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i></p> <p>B Knoppers , <i>Genomics and Public Health (GPH): Building Public "Goods"?</i></p> <p>B Knoppers , <i>Toward an Ethics of Genetics</i></p> <p>J Little, <i>From Genes to Genetic Pathways: Fulfilling the Promise</i></p> <p>P.A Singer , <i>Genomics and Global Health</i></p> <p>B Banwell, <i>Prospective Study of the Clinical Epidemiology, Pathobiology and Neuroimaging Features of Canadian children with Clinically Isolated Demyelinating Syndromes</i></p> <p>B Godard, <i>Consulting Cultural Communities for Large-Scale Genomic Databases : An Analysis of Interests and Values</i></p> <p>F. M Brunger , <i>Protecting Communities in Population-Based Genetic Research: A Cultural Analysis of a Canadian Policy Dilemma.</i></p>
Public Health/ Chronic Diseases	9	<p>R Hegele, <i>Structural and Functional Annotation of the Human Genome</i></p> <p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i></p> <p>D Gaudet, <i>From the Laboratory to the Community</i></p> <p>B Knoppers , <i>Genomics and Public Health (GPH): Building Public "Goods"?</i></p>

		<p>J. O'Loughlin, <i>Seeds of Disease: Investigating Childhood Determinants of Adult Chronic Disease</i></p> <p>M. Schwartz, <i>Responsibility and Preventive Medicine: Ethics, Genetic and the Asymptomatic Ill</i></p> <p>P Singer , <i>Bridging the Emerging Genomics Divide</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p>
	8	<p>C. Weijer , <i>Re-Examining the Moral Foundations of Research</i></p> <p>D Avar, <i>Pharmacogenomics with Children: Towards a Healthier Future</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>P Singer , <i>Canadian Program on Genomics and Global Health</i></p> <p>S Latosinsky, <i>A Surgeon Forum for Tanslating Knowledge and Making Improvement in Breast Cancer Care</i></p> <p>B Banwell, <i>Prospective Study of the Clinical Epidemiology, Pathobiology and Neuroimaging Features of Canadian children with Clinically Isolated Demyelinating Syndromes</i></p> <p>S Fox, <i>Centering the Human Subject in Health Research: Understanding the Meaning and Experience of Research Participation</i></p> <p>F. M Brunger , <i>Protecting Communities in Population-Based Genetic Research: A Cultural Analysis of a Canadian Policy Dilemma.</i></p>
	5	<p>T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i></p> <p>S Kenyon, <i>Trajectories of Health and Adaptation after Pediatric Stem Cell Transplant</i></p> <p>F Baylis, <i>Therapeutic Hopes and Ethical Concerns: Clinical Research in the Neurosciences</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>B Knoppers , <i>The Future of Cord Blood Banking in Canada</i></p>

Appendix G.3: Total of 82 American Projects – Genetic/Disease Classification



Classification	# of Projects	PI, Title
Behavioural Genetics	9	<p>J Lansing, <i>Austronesian Societies: Reading Social Structure From the Genome</i></p> <p>B. Koenig, <i>Genetics of Nicotine Addiction: Examining Ethics and Policy</i></p> <p>E Brodie , <i>Dissertation Research: Indirect Genetic Effects on Social Behavior</i></p> <p>M Cho, <i>Center for Integrating Ethics & Genetic Research</i></p> <p>B Koenig, <i>A Case-Based Ethics Curriculum for the Biotech Industry</i></p> <p>C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i></p> <p>E Singer , <i>Beliefs About Genes & Environment as Causes of Behavior</i></p> <p>K Stromswold, <i>Genetics of Linguistic and Non-Linguistic Development</i></p> <p>R. Wachbroit , <i>Identifying Neurogenetic Mechanisms: Social Implications</i></p>
Biobanking/ Databases	6	<p>R Deegan, <i>Duke Center for the Study of Public Genomics</i></p> <p>D Gordon, <i>"Engaging" Tuscans in Italy in the Haplotype Map Project</i></p> <p>B. Moulton, <i>NA Fingerprinting and Civil Liberties</i></p> <p>C. Mulligan, <i>Human Dispersals Out of Africa: Mitochondrial and Y chromosomal Genetic Analysis of Eritrean and Omani Populations</i></p> <p>R. Sharp, <i>Indian Perspectives on Human Genetic Variation Research (HAPMAP)</i></p> <p>L. Walters , <i>National Information Resource on Ethics and Human Genetics</i></p>
Cancer	21	<p>K. Tercyak, <i>Parent Communication of BRCA1/2 Test Results to Children</i></p> <p>A Abernethy,, <i>Understanding Cultural Factors in Cancer Screening</i></p> <p>L Acheson, <i>The Great System to Identify Familial Cancer Risk</i></p> <p>Grace Chang, <i>Mental Status Changes after Hematopoietic Stem Cell Transplantation</i></p> <p>G. Corbie-Smith, <i>Learning About Research in North Carolina (LeARN)</i></p> <p>R Crum, <i>A Prospective Study of Alcohol Intake, Genetic Susceptibility and Breast Cancer Overall Health Risk</i></p> <p>J Ford , <i>A Clinic-Based Study of BRCA Mutation Carriage, Differences in BRCAPRO Scores, and Breast Cancer Risk Factors Among Asians and Caucasians</i></p> <p>M Foster, <i>African American Community Review of Genetic Research</i></p> <p>A. Goel, <i>Improving Shared Decision Making Around Cancer Control Decisions</i></p> <p>V Grann, <i>Decision Analysis of Population Screening for BRCA1/2</i></p>

		<p><i>Mutations</i></p> <p>C Haiman, <i>A Comprehensive Genomic Approach to Characterize the Role of Genetic Variation in IGF Receptor Genes in Relation to Breast Cancer Risk: The Multiethnic Cohort</i></p> <p>R Leach , <i>The Role of Genetic Variation in Prostate Cancer Among Hispanics and Blacks</i></p> <p>A. Patenaude , <i>Prophylactic Mastectomy: The Patient Experience</i></p> <p>B Peshkin , <i>BRCA1/2 Education for Mothers and Their Teen Daughters</i></p> <p>A Ramirez, <i>Genetic Evaluation for Breast Cancer Susceptibility In Hispanic and Non-Hispanic White Women In South Texas</i></p> <p>S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i></p> <p>D Roter, <i>Genetic Counseling Processes and Analogue Client Outcome</i></p> <p>R Hamilton, <i>Decision Making in Young Women at Risk for HBOC</i></p> <p>P Spicer , <i>Trust and Genetics Research in Diverse US Communities</i></p> <p>G Tomlinson , <i>Ethnicity and Outcomes of Breast Cancer Genetic Counseling, Testing and Follow-up Risk Reduction Measures</i></p> <p>S. Vadaparampil, <i>Impact of Genetic Testing on Cancer Patients</i></p>
Conceptual Models	12	<p>A Abernethy,, <i>Understanding Cultural Factors in Cancer Screening</i></p> <p>R. Amundson, <i>Human Genome Project: Disability, Bioethics and Conflict</i></p> <p>E Brodie , <i>Dissertation Research: Indirect Genetic Effects on Social Behavior</i></p> <p>M Brown, <i>Toward a Political Theory of Bioethics: Participation, Representation, and Deliberation on Federal Bioethics Advisory Committees</i></p> <p>R Deegan, <i>Duke Center for the Study of Public Genomics</i></p> <p>S. Fullerton, <i>Negotiating Complexity: Common Disease & Diverse Genomes</i></p> <p>V Grann, <i>Decision Analysis of Population Screening for BRCA1/2 Mutations</i></p> <p>G. Henderson, <i>Social Construction of Benefit in Gene Transfer Research</i></p> <p>S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i></p> <p>M Stowe , <i>A Framework for Disability Perspectives on HGP</i></p> <p>M Sagoff, <i>Germ-Line Engineering and Three Concepts of Human Nature</i></p> <p>M. Bess, <i>Shifting Conceptions of Human Identity</i></p>
Gene Therapy	2	<p>G. Henderson, <i>Social Construction of Benefit in Gene Transfer Research</i></p> <p>M Sagoff, <i>Germ-Line Engineering and Three Concepts of Human Nature</i></p>
Gene-Environment	8	<p>W Burke, <i>Genomic Health Care and the Medically Underserved</i></p> <p>G. Corbie-Smith, <i>Learning About Research in North Carolina (LeARN)</i></p> <p>R Crum, <i>A Prospective Study of Alcohol Intake, Genetic Susceptibility and Breast Cancer Overall Health Risk</i></p> <p>R Leach , <i>The Role of Genetic Variation in Prostate Cancer Among Hispanics and Blacks</i></p> <p>G Marchant, <i>Genetic Susceptibility and Environmental Regulation</i></p> <p>S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i></p>

		E Singer , <i>Beliefs About Genes & Environment as Causes of Behavior</i> K Stromswold, <i>Genetics of Linguistic and Non-Linguistic Development</i>
Genetic Screening	5	P. Farrell, <i>Pulmonary Benefits of Cystic Fibrosis Neonatal Screening</i> T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i> D Paul, <i>A Policy-Oriented History of Newborn Screening for PKU</i> S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i> S Waisbren, <i>Expanded Newborn Screening for Metabolic Disorders</i>
Genetic Services	13	W Burke, <i>Genomic Health Care and the Medically Underserved</i> L Acheson, <i>The Great System to Identify Familial Cancer Risk</i> C Browner, <i>Use of Genetics in Neurologists' Clinical Practices</i> A. Gallo, <i>Parents' Interpretation and Use of Genetic Information</i> G. Geller , <i>Moral Distress and Suffering of Genetics Professionals</i> C Gill, <i>Clinical Versus Experiential Views of Genetic Disability</i> A. Goel, <i>Improving Shared Decision Making Around Cancer Control Decisions</i> R Leach , <i>The Role of Genetic Variation in Prostate Cancer Among Hispanics and Blacks</i> A. Patenaude , <i>Prophylactic Mastectomy: The Patient Experience</i> S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i> C Freund, <i>Clinical Use of Research Genetic Tests in Arrhythmia</i> D Roter, <i>Genetic Counseling Processes and Analogue Client Outcome</i> P Spicer , <i>Trust and Genetics Research in Diverse US Communities</i>
Genetic Testing	20	K. Tercyak, <i>Parent Communication of BRCA1/2 Test Results to Children</i> K Armstrong , <i>Distrust, Race/Ethnicity, and Predictive Genetic Testing</i> P. Brandt-Rauf , <i>The ELSI of Genetic Testing in the Workplace</i> L. Ellington, <i>A Biopsychosocial Approach to the Analysis of Cancer Genetics Communication</i> J Ford , <i>A Clinic-Based Study of BRCA Mutation Carriage, Differences in BRCA PRO Scores, and Breast Cancer Risk Factors Among Asians and Caucasians</i> V Grann, <i>Decision Analysis of Population Screening for BRCA1/2 Mutations</i> R. Green, <i>Risk Evaluation and Education for Alzheimer's Disease</i> I. Krantz, <i>Outcomes of Genetic Testing for Hearing Impairment</i> G Marchant, <i>Genetic Susceptibility and Environmental Regulation</i> J. Paulsen, <i>Response of a Sample Population with the Deleterious HD allele RESPOND-HD</i> B Peshkin , <i>BRCA1/2 Education for Mothers and Their Teen Daughters</i> A Ramirez, <i>Genetic Evaluation for Breast Cancer Susceptibility In Hispanic and Non-Hispanic White Women In South Texas</i> C Freund, <i>Clinical Use of Research Genetic Tests in Arrhythmia</i> D Roter, <i>Genetic Counseling Processes and Analogue Client Outcome</i> I. Shoulson, <i>Prospective Huntington At Risk Observational Study</i> E Singer , <i>Beliefs About Genes & Environment as Causes of Behavior</i> R Hamilton, <i>Decision Making in Young Women at Risk for HBOC</i> G Tomlinson , <i>Ethnicity and Outcomes of Breast Cancer Genetic Counseling, Testing and Follow-up Risk Reduction Measures</i> J Weitzel, <i>Genetic Discrimination Knowledge in Primary Care</i>

		S. Vadaparampil, <i>Impact of Genetic Testing on Cancer Patients</i>
Genetics/Genomics	8	<p>B. Koenig, <i>Genetics of Nicotine Addiction: Examining Ethics and Policy</i></p> <p>R Klitzman, <i>Views of Privacy of Genetic Information</i></p> <p>P Ossorio , <i>Community Consultation as an Ethics Method</i></p> <p>S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i></p> <p>C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i></p> <p>B Strassmann , <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p> <p>L. Walters , <i>National Information Resource on Ethics and Human Genetics</i></p> <p>M Sagoff, <i>Germ-Line Engineering and Three Concepts of Human Nature</i></p>
Knowledge Transfer	19	<p>W Burke, <i>Genomic Health Care and the Medically Underserved</i></p> <p>L Acheson, <i>The Great System to Identify Familial Cancer Risk</i></p> <p>D Bailey, <i>ELSI Scale-Up: Large Sample Gene Discovery & Disclosure</i></p> <p>M Cho, <i>Center for Integrating Ethics & Genetic Research</i></p> <p>J Clayton, <i>Genetics in Literature, Film, and Popular Culture</i></p> <p>M Mumford, <i>EESE: Development & Evaluation of a Work Practices Approach for Ethics Education in Science & Engineering</i></p> <p>L. Ellington, <i>A Biopsychosocial Approach to the Analysis of Cancer Genetics Communication</i></p> <p>A. Goel, <i>Improving Shared Decision Making Around Cancer Control Decisions</i></p> <p>E Juengst, <i>Center for Genetic Research, Ethics, and Law (CGREL)</i></p> <p>E. McCabe, <i>Oral History of Human Genetics: The Intelligent Archive</i></p> <p>B. Moulton, <i>NA Fingerprinting and Civil Liberties</i></p> <p>T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i></p> <p>B Peshkin , <i>BRCA1/2 Education for Mothers and Their Teen Daughters</i></p> <p>S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i></p> <p>C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i></p> <p>P Sankar , <i>Advancing the Race Dialog: Genes, Forensics & Medicine</i></p> <p>A. Shields , <i>Genetics, Vulnerable Populations and Health Disparities</i></p> <p>B Strassmann , <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p> <p>N. Tuana, <i>Integrating Ethics into Graduate Training in the Environmental Sciences</i></p>
Nanotechnology/ Biotechnology	1	B Koenig, <i>A Case-Based Ethics Curriculum for the Biotech Industry</i>
Neurosciences	5	<p>C Browner, <i>Use of Genetics in Neurologists' Clinical Practices</i></p> <p>R. Green, <i>Risk Evaluation and Education for Alzheimer's Disease</i></p> <p>J. Paulsen, <i>Response of a Sample Population with the Deleterious HD allele RESPOND-HD</i></p>

		<p>I. Shoulson, <i>Prospective Huntington At Risk Observational Study</i> R. Wachbroit , <i>Identifying Neurogenetic Mechanisms: Social Implications</i></p>
Non-health Issues	10	<p>P. Brandt-Rauf , <i>The ELSI of Genetic Testing in the Workplace</i> J Clayton, <i>Genetics in Literature, Film, and Popular Culture</i> S Cole, <i>Criminal Justice Applications of Genetic Information</i> E. McCabe, <i>Oral History of Human Genetics: The Intelligent Archive</i> B. Moulton, <i>NA Fingerprinting and Civil Liberties</i> C. Mulligan, <i>Human Dispersals Out of Africa: Mitochondrial and Y chromosomal Genetic Analysis of Eritrean and Omani Populations</i> P O'Looney, <i>A Whole Genome Admixture Scan for the Multiple Sclerosis Genes</i> P Sankar , <i>Advancing the Race Dialog: Genes, Forensics & Medicine</i> B Strassmann , <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i> K Stromswold, <i>Genetics of Linguistic and Non-Linguistic Development</i></p>
Pharmacogenomics	1	<p>J Licinio, <i>Developing Educational Approaches to Genomics for Mexican-Americans in East Los Angeles</i></p>
Population Genetics	17	<p>J Lansing, <i>Austronesian Societies: Reading Social Structure From the Genome</i> M Cho, <i>Center for Integrating Ethics & Genetic Research</i> G. Corbie-Smith, <i>Learning About Research in North Carolina (LeARN)</i> J Ford , <i>A Clinic-Based Study of BRCA Mutation Carriage, Differences in BRCAPRO Scores, and Breast Cancer Risk Factors Among Asians and Caucasians</i> M Foster, <i>Using Third-Party Data in Pedigree and Subgroup Analyses</i> M Foster, <i>African American Community Review of Genetic Research</i> D Gordon, <i>"Engaging" Tuscans in Italy in the Haplotype Map Project</i> C Haiman, <i>A Comprehensive Genomic Approach to Characterize the Role of Genetic Variation in IGF Receptor Genes in Relation to Breast Cancer Risk: The Multiethnic Cohort</i> J Kahn , <i>Colliding Categories: Haplotypes, Race & Ethnicity</i> J Licinio, <i>Developing Educational Approaches to Genomics for Mexican-Americans in East Los Angeles</i> E. McCabe, <i>Oral History of Human Genetics: The Intelligent Archive</i> C. Mulligan, <i>Human Dispersals Out of Africa: Mitochondrial and Y chromosomal Genetic Analysis of Eritrean and Omani Populations</i> P O'Looney, <i>A Whole Genome Admixture Scan for the Multiple Sclerosis Genes</i> C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i> P Sankar , <i>Advancing the Race Dialog: Genes, Forensics & Medicine</i> R. Sharp, <i>Indian Perspectives on Human Genetic Variation Research (HAPMAP)</i> B Strassmann , <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p>

Public Health/ Chronic Diseases	3	B. Koenig, <i>Genetics of Nicotine Addiction: Examining Ethics and Policy</i> A. Shields , <i>Genetics, Vulnerable Populations and Health Disparities</i> M Stowe , <i>A Framework for Disability Perspectives on HGP</i>
Research	9	P Marshall, <i>Consent in Genetic Research: An International Trial</i> E Campbell, <i>Academic Industry Relationships in Genetics</i> M Mumford, <i>EESE: Development & Evaluation of a Work Practices Approach for Ethics Education in Science & Engineering</i> M Foster, <i>African American Community Review of Genetic Research</i> M Foster, <i>African American Haplotype Map Engagement and Follow-up</i> E Juengst, <i>Center for Genetic Research, Ethics, and Law (CGREL)</i> P Ossorio , <i>Community Consultation as an Ethics Method</i> C Freund, <i>Clinical Use of Research Genetic Tests in Arrhythmia</i> M Stowe , <i>A Framework for Disability Perspectives on HGP</i>
Stem Cells	1	Grace Chang, <i>Mental Status Changes after Hematopoietic Stem Cell Transplantation</i>

Appendix G.4: Total of 81 Canadian Projects - GE³LS



Classification	# of Projects	PI, Title
Access Info/Material	4	<p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i></p> <p>D. Pullman, <i>Sorry, You Can't Have That Information: Stakeholder Awareness, Perceptions and Concerns Regarding The Disclosure and Use of Personal Health Information</i></p> <p>J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p>
Autonomy	1	T Hudson, <i>The GRID Project: Gene Regulators in Disease</i>
Commercialization/ Intellectual Property/ Patents	9	<p>T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i></p> <p>Kevin Kain, <i>Quantum dot diagnostics: simultaneous genomic and proteomic profiling of multiple pathogens at point-of-care</i></p> <p>T Hudson, <i>The GRID Project: Gene Regulators in Disease</i></p> <p>M Marra, <i>Dissecting Gene Expression Networks in Mammalian Organogenesis</i></p> <p>S. Hamilton, <i>Out of Order: Law, Media, and Citizenship</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>R. Gold, <i>Legal Models of Biotechnological Intellectual Property Protection: A Transdisciplinary Approach</i></p> <p>T Caulfield, <i>Commercialization and Society and its Policy and Strategic Implications</i></p> <p>A. Daar, <i>Strengthening the Role of Genomics and Global Health</i></p>
Communication of Results	7	<p>C. Fernandez, <i>Returning Research Results to Research Participants: A Needs and Attitudes Assessment of Research Participants and their Guardians.</i></p> <p>E Simpson, <i>Pleiades Promoter Project</i></p> <p>P Wells, <i>Testing for Inherited Thrombosis – The Ethical Dilemma</i></p> <p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>A Basset, <i>Unravelling the Mysteries of Schizophrenia</i></p> <p>M. Schwartz, <i>Responsibility and Preventive Medicine: Ethics, Genetic and the Asymptomatic Ill</i></p> <p>B Knoppers, <i>Genomics in Society: Responsibilities and Rights</i></p>
Conflict of Interest	1	T Hudson, <i>The GRID Project: Gene Regulators in Disease</i>
Consent	3	F Baylis, <i>Therapeutic Hopes and Ethical Concerns: Clinical</i>

		<p><i>Research in the Neurosciences</i></p> <p>T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i></p> <p>D.C Schachter , <i>Neuroethics New Emerging Team Grant: Informed Consent for Psychoactive Medications and Genetic Testing in Adolescent Patients with Mental Health Difficulties</i></p>
	20	<p>G Bouchard , <i>Fichier de Population Balsac</i></p> <p>M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i></p> <p>T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i></p> <p>E Simpson, <i>Pleiades Promoter Project</i></p> <p>Kevin Kain, <i>Quantum dot diagnostics: simultaneous genomic and proteomic profiling of multiple pathogens at point-of-care</i></p> <p>D Avar, <i>Techniques of Investigation and Parameters Development for the Study of Ethical and Social Issues of Genetic Screening for a Multicultural Community: Sickle-Cell Disease Pilot Project</i></p> <p>R. Battista, <i>Research Program to Support Health Politics in Genetics, Concerned with Quality, Efficiency and Social Welfare</i></p> <p>T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i></p> <p>B Knoppers , <i>Genomics and Public Health (GPH): Building Public “Goods”?</i></p> <p>A Kroker, <i>Decoding the Digital Future</i></p> <p>J Nisker, <i>Theatre as an Innovative Tool for Public Engagement in Health Policy Development</i></p> <p>M Burgess, <i>Democracy, Ethics and Genomics: Consultation, Deliberation and Modeling</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>E. Einsiedel, <i>Public Participation, Institutionalization and Technology Assessment.</i></p> <p>S Latosinsky, <i>A Surgeon Forum for Translating Knowledge and Making Improvement in Breast Cancer Care</i></p> <p>B Godard, <i>Consulting Cultural Communities for Large-Scale Genomic Databases : An Analysis of Interests and Values</i></p> <p>B Knoppers , <i>The Future of Cord Blood Banking in Canada</i></p> <p>B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>T Caulfield, <i>Commercialization and Society and its Policy and Strategic Implications</i></p>
Consulting/ Public Engagement/ Collaboration		
Copyright	1	T Hudson, <i>The GRID Project: Gene Regulators in Disease</i>
Counselling (general)	5	<p>S Lambert, <i>The Impact of Interactive Health Communication on Psychosocial Adjustment to Breast Cancer</i></p> <p>M Esplen, <i>A Randomized Controlled Trial of a Group Intervention for Women With a Family History of Breast Cancer</i></p> <p>S Latosinsky, <i>A Surgeon Forum for Translating Knowledge and Making Improvement in Breast Cancer Care</i></p> <p>B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i></p> <p>J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p>

Discrimination	3	<p>M Hayden, <i>Genetic Discrimination in Mutation Carriers Identified Through Predictive Genetic Testing for Huntington Disease</i></p> <p>T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i></p> <p>S. Reuter , <i>Historicizing Tay-Sachs: Towards a Genealogy of Medical Racism</i></p>
Diversity, Ethnicity, Culture, Race	10	<p>H Vézina , <i>Caractérisation des Effets Fondateurs Québécois et de leurs Ramifications Spatiales à partir d'Analyses Généalogiques de Sujets Atteints de Maladies Héritaires</i></p> <p>R Hegele, <i>Structural and Functional Annotation of the Human Genome</i></p> <p>C Guidos, <i>Identification of Genetic Pathways that Regulate the Survival and Development of Cancer and Cancer Stem Cells</i></p> <p>D Avar, <i>Techniques of Investigation and Parameters Development for the Study of Ethical and Social Issues of Genetic Screening for a Multicultural Community: Sickle-Cell Disease Pilot Project</i></p> <p>J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i></p> <p>T Hudson, <i>A Haplotype Map of the Human Genome - Biomedical Tool for Genetic Research in Canada</i></p> <p>S. Reuter , <i>Historicizing Tay-Sachs: Towards a Genealogy of Medical Racism</i></p> <p>B Godard, <i>Consulting Cultural Communities for Large-Scale Genomic Databases : An Analysis of Interests and Values</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>F. M Brunger , <i>Protecting Communities in Population-Based Genetic Research: A Cultural Analysis of a Canadian Policy Dilemma.</i></p>
Education	3	<p>R Hancock, <i>The Pathogenomics of Innate Immunity (PI2)</i></p> <p>B. Wilson, <i>Translating Genetics Discoveries Into Appropriate Health Policy and Services: Enhancing Research Capacity and Developing Interdisciplinary Approach</i></p> <p>P Singer , <i>Bridging the Emerging Genomics Divide</i></p>
Equity	4	<p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>P.A Singer , <i>Genomics and Global Health</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>A. Daar , <i>Strengthening the Role of Genomics and Global Health</i></p>
Ethical, Legal, Social Review	26	<p>M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i></p> <p>T Caulfield, <i>Towards the Clinic?: Ethical, Legal and Social Issues (ELSI) Relevant to Emerging Stem Cell Therapies</i></p> <p>C. Weijer , <i>Re-Examining the Moral Foundations of Research</i></p> <p>R Hegele, <i>Structural and Functional Annotation of the Human Genome</i></p> <p>D Avar, <i>Pharmacogenomics with Children: Towards a Healthier Future</i></p> <p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>M Marra, <i>High Resolution Analysis of Follicular Lymphoma Genomes</i></p> <p>M Samuels, <i>Atlantic Medical Genetic and Genomics Initiative</i></p> <p>J Fosket, <i>Genetic Testing for Alzheimer's Disease in Canada and the</i></p>

		<p><i>U.S.: A Comparative Study of Meanings of Risk, Aging and Normalcy</i></p> <p>M Mullen, <i>Towards Developing Valid and Feasible Outcome Measures for Clinical Genetics Services</i></p> <p>S Scherer, <i>Autism Genome Project</i></p> <p>J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i></p> <p>J Lopez, <i>ELSI research and the construction of “legitimate” expertise</i></p> <p>S. Reuter , <i>Historicizing Tay-Sachs: Towards a Genealogy of Medical Racism</i></p> <p>C MacDonald, <i>Biotech Ethics: Corporate Decisions as Key to Better Health and Better Health Policy</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>A Basset , <i>Unravelling the Mysteries of Schizophrenia</i></p> <p>M-H Parizeau, <i>Ethical Questions at the Heart of Public Debates</i></p> <p>E Potter , <i>Approaches to Considering Social, Ethical, and Legal Issues in Health Technology Assessment: Application to Neonatal Screening Programs for Cystic Fibrosis</i></p> <p>B Knoppers , <i>The Future of Cord Blood Banking in Canada</i></p> <p>F. Baylis, <i>Justice for All</i></p> <p>S. Hamilton, <i>Out of Order: Law, Media, and Citizenship</i></p> <p>T Caulfield, <i>Translating Science: Genomics and Health Systems</i></p> <p>T Caulfield, <i>Commercialization and Society and its Policy and Strategic Implications</i></p> <p>S Fox, <i>Centering the Human Subject in Health Research: Understanding the Meaning and Experience of Research Participation</i></p> <p>J. Simard, <i>Interdisciplinary Health Research International Team on Breast Cancer Susceptibility</i></p>
Eugenics	2	<p>L Fenton, <i>Eugenics in Canada: A Trans-Atlantic Perspective</i></p> <p>S. Reuter , <i>Historicizing Tay-Sachs: Towards a Genealogy of Medical Racism</i></p>
Follow-up, Monitoring, Longitudinal	4	<p>L Mirea, <i>Family-Based Genetic Association Analyses of Longitudinal Trait Measurements</i></p> <p>J. O'Loughlin, <i>Seeds of Disease: Investigating Childhood Determinants of Adult Chronic Disease</i></p> <p>A. Chiarelli, <i>Screening Behaviours and Outcomes Among Relatives of Women With Breast Cancer</i></p> <p>B Banwell, <i>Prospective Study of the Clinical Epidemiology, Pathobiology and Neuroimaging Features of Canadian children with Clinically Isolated Demyelinating Syndromes</i></p>
Governance	17	<p>Kevin Kain, <i>Quantum dot diagnostics: simultaneous genomic and proteomic profiling of multiple pathogens at point-of-care</i></p> <p>D Avard, <i>Pharmacogenomics with Children: Towards a Healthier Future</i></p> <p>B Finlay, <i>Functional Genomics for Emerging Infectious Diseases (PREPARE)</i></p> <p>M Marra, <i>High Resolution Analysis of Follicular Lymphoma Genomes</i></p> <p>P Durie, <i>The Contribution of Genetic Modulators of Disease Severity in Cystic Fibrosis to other Diseases with Similarities of Clinical</i></p>

		<i>Phenotype</i> S Scherer, <i>Autism Genome Project</i> B Knoppers , <i>Genomics and Public Health (GPH): Building Public “Goods”?</i> B Knoppers , <i>Toward an Ethics of Genetics</i> C MacDonald, <i>Biotech Ethics: Corporate Decisions as Key to Better Health and Better Health Policy</i> M Burgess, <i>Democracy, Ethics and Genomics: Consultation, Deliberation and Modeling</i> T Caulfield, <i>Defining the Boundaries of Genetic Research</i> P Singer , <i>Canadian Program on Genomics and Global Health</i> B Knoppers , <i>The Future of Cord Blood Banking in Canada</i> B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i> T Caulfield, <i>Translating Science: Genomics and Health Systems</i> S Fox, <i>Centering the Human Subject in Health Research: Understanding the Meaning and Experience of Research Participation</i> F. M Brunger , <i>Protecting Communities in Population-Based Genetic Research: A Cultural Analysis of a Canadian Policy Dilemma.</i>
Intellectual Property	1	T Hudson, <i>The GRID Project: Gene Regulators in Disease</i>
Justice	3	P.A Singer , <i>Genomics and Global Health</i> F. Baylis, <i>Justice for All</i> A. Daar , <i>Strengthening the Role of Genomics and Global Health</i>
Ownership	1	T Hudson, <i>The GRID Project: Gene Regulators in Disease</i>
Privacy/ Confidentiality	6	M Burgess, <i>Building a GE3LS Architecture (GE3LS Arc)</i> T Hudson, <i>The GRID Project: Gene Regulators in Disease</i> B Knoppers , <i>Genomics and Public Health (GPH): Building Public “Goods”?</i> T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i> D. Pullman, <i>Sorry, You Can't Have That Information: Stakeholder Awareness, Perceptions and Concerns Regarding The Disclosure and Use of Personal Health Information</i> B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i>
Psychosocial Aspects	12	C. Fernandez , <i>Returning Research Results to Research Participants: A Needs and Attitudes Assessment of Research Participants and their Guardians.</i> T Power, <i>Psychosocial Issues Regarding Genetic Testing for Oncogenes</i> S Kenyon, <i>Trajectories of Health and Adaptation after Pediatric Stem Cell Transplant</i> M Samuels, <i>Atlantic Medical Genetic and Genomics Initiative</i> J Fosket, <i>Genetic Testing for Alzheimer's Disease in Canada and the U.S.: A Comparative Study of Meanings of Risk, Aging and Normalcy</i> J Danska, <i>Genome-Environment Interactions in Type 1 Diabetes</i> C. Condin, <i>Managing Hope and Balancing Expectations: Exploring</i>

		<p><i>How Families Understand and Choose to Participate in Gene Transfer Research</i></p> <p>S Lambert, <i>The Impact of Interactive Health Communication on Psychosocial Adjustment to Breast Cancer</i></p> <p>A Basset , <i>Unravelling the Mysteries of Schizophrenia</i></p> <p>A. Chiarelli, <i>Screening Behaviours and Outcomes Among Relatives of Women With Breast Cancer</i></p> <p>M Esplen, <i>A Randomized Controlled Trial of a Group Intervention for Women With a Family History of Breast Cancer</i></p> <p>B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i></p>
Recruitment	1	C Guidos, <i>Identification of Genetic Pathways that Regulate the Survival and Development of Cancer and Cancer Stem Cells</i>
Respect for Human Life/Integrity/Identity	5	<p>C. Borck, <i>Modern Metamorphoses: How Changing Our Bodies Changes Us</i></p> <p>F Baylis, <i>Therapeutic Hopes and Ethical Concerns: Clinical Research in the Neurosciences</i></p> <p>F Baylis, <i>Conceptual and Ethical Issues at the Intersection of Genomics, Developmental Biology, Ecology, and Health</i></p> <p>F. Baylis, <i>Justice for All</i></p> <p>S. Hamilton, <i>Out of Order: Law, Media, and Citizenship</i></p>
Standard of Care	12	<p>M Marra, <i>High Resolution Analysis of Follicular Lymphoma Genomes</i></p> <p>B Knoppers , <i>Genomics and Public Health (GPH): Building Public “Goods”?</i></p> <p>T Caulfield, <i>Defining the Boundaries of Genetic Research</i></p> <p>S. Cox, <i>Appropriate Uses of Genetic Information in the Diagnosis Treatment and Prevention of Autosomal Dominant Polycystic Kidney Disease and Rheumatoid Arthritis</i></p> <p>E. Einsiedel, <i>Public Participation, Institutionalization and Technology Assessment.</i></p> <p>M. Phillips, <i>Pharmacogenomics of Drug Efficacy and Toxicity in the Treatment of Cardiovascular Disease</i></p> <p>E Potter , <i>Approaches to Considering Social, Ethical, and Legal Issues in Health Technology Assessment: Application to Neonatal Screening Programs for Cystic Fibrosis</i></p> <p>P Singer , <i>Bridging the Emerging Genomics Divide</i></p> <p>P Singer , <i>Canadian Program on Genomics and Global Health</i></p> <p>S Latosinsky, <i>A Surgeon Forum for Translating Knowledge and Making Improvement in Breast Cancer Care</i></p> <p>T. Caulfield, <i>The Collection, Use and Disclosure of Personal Health Information: The Health Care Information Directive Applied to Genetics</i></p> <p>B Knoppers , <i>Genomics in Society:Responsibilities and Rights</i></p>

Appendix G.5: Total of 82 American Projects - GE³LS



Classification	# of Projects	PI, Title
Commercialization/ Intellectual Property/ Patents	2	E Campbell, <i>Academic Industry Relationships in Genetics</i> R Deegan, <i>Duke Center for the Study of Public Genomics</i>
Communication of Results	6	K. Tercyak, <i>Parent Communication of BRCA1/2 Test Results to Children</i> C Browner, <i>Use of Genetics in Neurologists' Clinical Practices</i> L. Ellington, <i>A Biopsychosocial Approach to the Analysis of Cancer Genetics Communication</i> A. Goel, <i>Improving Shared Decision Making Around Cancer Control Decisions</i> G Tomlinson, <i>Ethnicity and Outcomes of Breast Cancer Genetic Counseling, Testing and Follow-up Risk Reduction Measures</i> S. Vadaparampil, <i>Impact of Genetic Testing on Cancer Patients</i>
Consent	6	P Marshall, <i>Consent in Genetic Research: An International Trial</i> M Foster, <i>African American Community Review of Genetic Research</i> M Foster, <i>African American Haplotype Map Engagement and Follow-up</i> D Gordon, <i>"Engaging" Tuscans in Italy in the Haplotype Map Project</i> G. Henderson, <i>Social Construction of Benefit in Gene Transfer Research</i> S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i>
Consulting/ Public Engagement/ Collaboration	18	W Burke, <i>Genomic Health Care and the Medically Underserved</i> M Brown, <i>Toward a Political Theory of Bioethics: Participation, Representation, and Deliberation on Federal Bioethics Advisory Committees</i> C Browner, <i>Use of Genetics in Neurologists' Clinical Practices</i> M Foster, <i>African American Community Review of Genetic Research</i> M Foster, <i>African American Haplotype Map Engagement and Follow-up</i> D Gordon, <i>"Engaging" Tuscans in Italy in the Haplotype Map Project</i> E Juengst, <i>Center for Genetic Research, Ethics, and Law (CGREL)</i> J Kahn, <i>Colliding Categories: Haplotypes, Race & Ethnicity</i> J Licinio, <i>Developing Educational Approaches to Genomics for Mexican-Americans in East Los Angeles</i> C. Mulligan, <i>Human Dispersals Out of Africa: Mitochondrial and Y chromosomal Genetic Analysis of Eritrean and Omani Populations</i> T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i> P Ossorio, <i>Community Consultation as an Ethics Method</i> S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i>

		<p>C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i></p> <p>P Sankar , <i>Advancing the Race Dialog: Genes, Forensics & Medicine</i></p> <p>R. Sharp, <i>Indian Perspectives on Human Genetic Variation Research (HAPMAP)</i></p> <p>M Stowe , <i>A Framework for Disability Perspectives on HGP</i></p> <p>B Strassmann , <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p>
	9	<p>R. Amundson, <i>Human Genome Project: Disability, Bioethics and Conflict</i></p> <p>L Acheson, <i>The Great System to Identify Familial Cancer Risk</i></p> <p>L. Ellington, <i>A Biopsychosocial Approach to the Analysis of Cancer Genetics Communication</i></p> <p>C Gill, <i>Clinical Versus Experiential Views of Genetic Disability</i></p> <p>A Ramirez, <i>Genetic Evaluation for Breast Cancer Susceptibility In Hispanic and Non-Hispanic White Women In South Texas</i></p> <p>S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i></p> <p>D Roter, <i>Genetic Counseling Processes and Analogue Client Outcome</i></p> <p>G Tomlinson , <i>Ethnicity and Outcomes of Breast Cancer Genetic Counseling, Testing and Follow-up Risk Reduction Measures</i></p> <p>S. Vadaparampil, <i>Impact of Genetic Testing on Cancer Patients</i></p>
Counselling (general)		
	3	<p>R Klitzman, <i>Views of Privacy of Genetic Information</i></p> <p>J. Paulsen, <i>Response of a Sample Population with the Deleterious HD allele RESPOND-HD</i></p> <p>J Weitzel, <i>Genetic Discrimination Knowledge in Primary Care</i></p>
Discrimination		
	34	<p>W Burke, <i>Genomic Health Care and the Medically Underserved</i></p> <p>J Lansing, <i>Austronesian Societies: Reading Social Structure From the Genome</i></p> <p>P Marshall, <i>Consent in Genetic Research: An International Trial</i></p> <p>B. Koenig, <i>Genetics of Nicotine Addiction: Examining Ethics and Policy</i></p> <p>A Abernethy,, <i>Understanding Cultural Factors in Cancer Screening</i></p> <p>K Armstrong , <i>Distrust, Race/Ethnicity, and Predictive Genetic Testing</i></p> <p>G. Corbie-Smith, <i>Learning About Research in North Carolina (LeARN)</i></p> <p>J Ford , <i>A Clinic-Based Study of BRCA Mutation Carriage, Differences in BRCAPRO Scores, and Breast Cancer Risk Factors Among Asians and Caucasians</i></p> <p>M Foster, <i>Using Third-Party Data in Pedigree and Subgroup Analyses</i></p> <p>M Foster, <i>African American Community Review of Genetic Research</i></p> <p>M Foster, <i>African American Haplotype Map Engagement and Follow-up</i></p> <p>V Grann, <i>Decision Analysis of Population Screening for BRCA1/2 Mutations</i></p> <p>R. Green, <i>Risk Evaluation and Education for Alzheimer's Disease</i></p> <p>C Haiman, <i>A Comprehensive Genomic Approach to Characterize the Role of Genetic Variation in IGF Receptor Genes in Relation to Breast Cancer Risk: The Multiethnic Cohort</i></p> <p>J Kahn , <i>Colliding Categories: Haplotypes, Race & Ethnicity</i></p> <p>R Leach , <i>The Role of Genetic Variation in Prostate Cancer Among Hispanics and Blacks</i></p>
Diversity, Ethnicity, Culture, Race		

		<p>J Licinio, <i>Developing Educational Approaches to Genomics for Mexican-Americans in East Los Angeles</i></p> <p>B. Moulton, <i>NA Fingerprinting and Civil Liberties</i></p> <p>C. Mulligan, <i>Human Dispersals Out of Africa: Mitochondrial and Y chromosomal Genetic Analysis of Eritrean and Omani Populations</i></p> <p>T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i></p> <p>P O'Looney, <i>A Whole Genome Admixture Scan for the Multiple Sclerosis Genes</i></p> <p>P Ossorio, <i>Community Consultation as an Ethics Method</i></p> <p>A Ramirez, <i>Genetic Evaluation for Breast Cancer Susceptibility In Hispanic and Non-Hispanic White Women In South Texas</i></p> <p>D Roter, <i>Genetic Counseling Processes and Analogue Client Outcome</i></p> <p>S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i></p> <p>C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i></p> <p>P Sankar, <i>Advancing the Race Dialog: Genes, Forensics & Medicine</i></p> <p>R. Sharp, <i>Indian Perspectives on Human Genetic Variation Research (HAPMAP)</i></p> <p>A. Shields, <i>Genetics, Vulnerable Populations and Health Disparities</i></p> <p>E Singer, <i>Beliefs About Genes & Environment as Causes of Behavior</i></p> <p>P Spicer, <i>Trust and Genetics Research in Diverse US Communities</i></p> <p>B Strassmann, <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p> <p>G Tomlinson, <i>Ethnicity and Outcomes of Breast Cancer Genetic Counseling, Testing and Follow-up Risk Reduction Measures</i></p> <p>M Sagoff, <i>Germ-Line Engineering and Three Concepts of Human Nature</i></p>
	10	<p>W Burke, <i>Genomic Health Care and the Medically Underserved</i></p> <p>L Acheson, <i>The Great System to Identify Familial Cancer Risk</i></p> <p>D Bailey, <i>ELSI Scale-Up: Large Sample Gene Discovery & Disclosure</i></p> <p>M Cho, <i>Center for Integrating Ethics & Genetic Research</i></p> <p>M Mumford, <i>EESE: Development & Evaluation of a Work Practices Approach for Ethics Education in Science & Engineering</i></p> <p>E Juengst, <i>Center for Genetic Research, Ethics, and Law (CGREL)</i></p> <p>B Peshkin, <i>BRCA1/2 Education for Mothers and Their Teen Daughters</i></p> <p>A. Shields, <i>Genetics, Vulnerable Populations and Health Disparities</i></p> <p>B Strassmann, <i>Collaborative Research on the Genetic Effects of Culture: Y Chromosome DNA, mtDNA, and Patrilineal Kinship in the Dogon of Mali</i></p> <p>N. Tuana, <i>Integrating Ethics into Graduate Training in the Environmental Sciences</i></p>
	2	<p>J Licinio, <i>Developing Educational Approaches to Genomics for Mexican-Americans in East Los Angeles</i></p> <p>A. Shields, <i>Genetics, Vulnerable Populations and Health Disparities</i></p>
	34	<p>P Marshall, <i>Consent in Genetic Research: An International Trial</i></p> <p>B. Koenig, <i>Genetics of Nicotine Addiction: Examining Ethics and Policy</i></p> <p>A Abernethy, <i>Understanding Cultural Factors in Cancer Screening</i></p> <p>R. Amundson, <i>Human Genome Project: Disability, Bioethics and</i></p>
Education		
Equity		
Ethical, Legal, Social Review		

		<p><i>Conflict</i></p> <p>K Armstrong , <i>Distrust, Race/Ethnicity, and Predictive Genetic Testing</i> D Bailey, <i>ELSI Scale-Up: Large Sample Gene Discovery & Disclosure</i> P. Brandt-Rauf , <i>The ELSI of Genetic Testing in the Workplace</i> M Cho, <i>Center for Integrating Ethics & Genetic Research</i> J Clayton, <i>Genetics in Literature, Film, and Popular Culture</i> S Cole, <i>Criminal Justice Applications of Genetic Information</i> M Mumford, <i>EESE: Development & Evaluation of a Work Practices Approach for Ethics Education in Science & Engineering</i> S. Fullerton, <i>Negotiating Complexity: Common Disease & Diverse Genomes</i> D Gordon, <i>"Engaging" Tuscans in Italy in the Haplotype Map Project</i> G. Henderson, <i>Social Construction of Benefit in Gene Transfer Research</i> E Juengst, <i>Center for Genetic Research, Ethics, and Law (CGREL)</i> J Kahn , <i>Colliding Categories: Haplotypes, Race & Ethnicity</i> B Koenig, <i>A Case-Based Ethics Curriculum for the Biotech Industry</i> I. Krantz, <i>Outcomes of Genetic Testing for Hearing Impairment</i> G Marchant, <i>Genetic Susceptibility and Environmental Regulation</i> E. McCabe, <i>Oral History of Human Genetics: The Intelligent Archive</i> B. Moulton, <i>NA Fingerprinting and Civil Liberties</i> T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i> P Ossorio , <i>Community Consultation as an Ethics Method</i> D Paul, <i>A Policy-Oriented History of Newborn Screening for PKU</i> J. Paulsen, <i>Response of a Sample Population with the Deleterious HD allele RESPOND-HD</i> S Ramsey, <i>A Genetic Screening Policy Model for Colorectal Cancer</i> S Rothman, <i>A Paradox of Genetic Research: Race, Ethnicity & Disease</i> C Royal, <i>Center on Genomics and Social Identity in the African Diaspora</i> A. Shields , <i>Genetics, Vulnerable Populations and Health Disparities</i> P Spicer , <i>Trust and Genetics Research in Diverse US Communities</i> M Stowe , <i>A Framework for Disability Perspectives on HGP</i> N. Tuana, <i>Integrating Ethics into Graduate Training in the Environmental Sciences</i> R. Wachbroit , <i>Identifying Neurogenetic Mechanisms: Social Implications</i> L. Walters , <i>National Information Resource on Ethics and Human Genetics</i></p>
Eugenics	1	R. Amundson, <i>Human Genome Project: Disability, Bioethics and Conflict</i>
Follow-up, Monitoring, Longitudinal	3	G. Corbie-Smith, <i>Learning About Research in North Carolina (LeARN)</i> L. Ellington, <i>A Biopsychosocial Approach to the Analysis of Cancer Genetics Communication</i> P. Farrell, <i>Pulmonary Benefits of Cystic Fibrosis Neonatal Screening</i>
Governance	5	P Marshall, <i>Consent in Genetic Research: An International Trial</i> R Deegan, <i>Duke Center for the Study of Public Genomics</i> E. McCabe, <i>Oral History of Human Genetics: The Intelligent Archive</i> T Murray, <i>Ethical Decision Making for Newborn Genetic Screening</i> M Stowe , <i>A Framework for Disability Perspectives on HGP</i>

Privacy/ Confidentiality	1	R Klitzman, <i>Views of Privacy of Genetic Information</i>
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