

Analysis of Discussions

ERA-SAGE Workshop II

**Canadian GE³LS Research Funding:
Articulating Best Practices and Exploring Future Directions**

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**Genome Canada, the Canadian Institutes of Health Research and the
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by Garth Williams, Ph.D.
Principal, Public Knowledge Canada
www.publicknowledge.ca

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Table of Contents

ERA-SAGE	...4
Canadian Participation in ERA-SAGE	...4
ERA-SAGE Workshop II	...5
Discussion	...6
1. Enduring Societal Challenges	...6
2. Characteristics of GE ³ LS Research	...7
3. Funding Issues and Recommendations	...9
a. Coordination of GE ³ LS Research Funding	...9
b. GE ³ LS Research and Genomic Science	..10
c. Co-Funding	..11
d. Public Engagement	..12
e. Sustainability	..12
4. The Promise of GE ³ LS Research in Canada	..12
Next Steps	..13
Appendices	
A: Summary of Recommendations from ERA-SAGE Workshop II	..14
B. Summary of Responses to the “Request for Input”	..16
C. ERA-SAGE Workshop II Program	..20
D: ERA-SAGE Workshop II Participants’ List	..23
E. ERA-SAGE Workshop II Program Advisory Committee	..24
F. ERA-SAGE Workshop II Inter-Agency Coordinating Group	..24

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ERA-SAGE

The European Research Area – Societal Aspects of Genomics (ERA-SAGE) is an international consortium of eleven agencies in nine countries who have come together to develop a durable partnership in policy and practice and a transnational research agenda on the ethical, environmental, economic, legal and social aspects of genomics (GE³LS). Formed in May 2005, ERA-SAGE is funded by the European Commission through the European Research Area Network program (ERA-NET).

Partners in ERA-SAGE are committed to an ambitious program of study, collaboration and action broken down into five stages or “work packages”:

- Work package 1: Synergy building – Producing a broad overview of programs and policies in member countries.
- Work package 2: Needs assessment – Understanding research trends and best practices in research funding and development of a strategic plan.
- Work package 3: Capacity building – Developing common standards for evaluation and common grounds for program development and management.
- Work package 4: Human Resource Management and Mobility – Improving co-ordination and mobility and to develop a shared training agenda.
- Work package 5: Research building – Developing and implementing transnational programs and research activities.

Canadian Participation in ERA-SAGE

The Social Sciences and Humanities Research Council of Canada (SSHRC) serves as the Canadian representative in ERA-SAGE. The Council works in close collaboration with Genome Canada and the Canadian Institutes of Health Research (CIHR) to create new opportunities for Canadian scholars, share Canadian expertise, learn from others and participate in the development of an international research agenda for GE³LS scholarship.

In collaboration with other Canadian agencies, SSHRC prepared a broad inventory of GE³LS funding programs for ERA-SAGE work package 1 that was summarized in the document *Public GE³LS Research Funding in Canada*.¹ For work package 2, which aims to map research trends and identify best practices in research funding, SSHRC and its partners adopted a two-stage approach to the preparation of the Canadian submission.

At the first stage, SSHRC engaged Denise Avard² and Michele Veeman³ to prepare compendia of research projects that were publicly funded in Canada and the United States during the year 2005-2006. Drawing on the compendia, as well as interviews with leading scholars and stakeholders, Avard and Veeman produced analyses of current trends in their respective areas of expertise: GE³LS research on human genomics (Avard)⁴ and GE³LS research on agricultural, fish, forest and plant genomics (Veeman)⁵. Their work informed discussions at ERA-SAGE

¹ Available at <http://www.genomecanada.ca/erasage/documents/ge³lsCanadaPartII.pdf>.

² Research Director for the Genetics and Society Project of HumGen International at the Université de Montréal. See: <http://www.humgen.umontreal.ca/int/team.cfm?Id=6>

³ Professor of Agricultural and Resource Economics in the Department of Rural Economy at the University of Alberta. See: <http://www.re.ualberta.ca/People/Index.asp?Page=Directory&ID=872>

⁴ Available at <http://www.genomecanada.ca/erasage/documents/area.pdf>.

⁵ Available at <http://www.genomecanada.ca/erasage/documents/trendsAgriForFishEn.pdf>.

Workshop I, held in Ottawa, in May 2006. These discussions are summarized in the report *Trends in North American Research on the Ethical, Legal and Social Aspects of Genomics in Canada* (Ottawa, 2006).⁶ Taken together, the compendia, analyses and report form the first part of the Canadian submission for ERA-SAGE work package 2.

The second part of the Canadian submission, focusing on best practices and future directions in GE³LS research funding, was the subject of ERA-SAGE Workshop II and is reported in this document.

ERA-SAGE Workshop II

Organized jointly by Genome Canada, CIHR and SSHRC, ERA-SAGE Workshop II on *Canadian GE³LS Research Funding: Articulating Best Practices and Exploring Future Directions* took place in Ottawa on November 16-17, 2006.⁷ This event brought together leading scholars and research administrators from academe, funding agencies, government departments, non-governmental organizations and the private sector (see Appendix D: Participant List).

The workshop provided an opportunity for these experts in project and program management to review the inventory of GE³LS funding programs in Canada and consider input from members of the GE³LS research community and the Canadian public who generously contributed their thoughts through a formal “request for input” prior to the workshop (see Appendix B: Summary of Responses to the Request for Input).⁸

The program (see Appendix C: Workshop Program⁹) featured keynote presentations by Tim Caulfield¹⁰ and Michael Burgess¹¹ as well as group discussions on four major themes:

- Funding strategies;
- Quality management;
- Capacity, specialization and diversity; and
- GE³LS and Genomic Science

Based on the documentation provided, the keynote presentations, group discussions and plenary sessions, participants were asked to identify:

- Similarities, differences, gaps and complementarity in Canada’s funding strategies;
- Emerging issues within the funding field, and

⁶ Available at http://www.sshrc.ca/web/about/publications/era_sage_workshop_e.pdf.

⁷ See the workshop website at <http://www.genomecanada.ca/erasage/index.asp>.

⁸ The “request for input” is available at <http://www.genomecanada.ca/erasage/input.asp>. The Discussion Paper: “Summary of Responses to the Request for Input” is available at: <http://www.genomecanada.ca/erasage/>

⁹ Also available at <http://www.genomecanada.ca/erasage/program.asp>.

¹⁰ Canada Research Chair in Health Law and Policy at the University of Alberta. See: http://www.law.ualberta.ca/centres/hli/profiles/profile_caulfield.html

¹¹ Chair of Biomedical Ethics at the University of British Columbia. See: <http://www.ethics.ubc.ca/people/burgess/index.htm>

- Key elements of models for best practices and quality management in the funding of GE³LS research.

Participants' observations and recommendations regarding best practices and future directions in GE³LS research funding form the second part of the Canadian submission for ERA-SAGE work package 2. In addition, they will inform policy discussions on GE³LS research at all participating agencies and organizations in Canada.

Discussion

1. Enduring Societal Challenges

Breakthroughs in genomic science and biotechnology, with such promise for a better world, have captured the imagination of people around the globe at the same time their implications for society and humanity have come to fuel public debate. As both interest and concern with genomics have grown, so have the scale and scope of research addressing the ethical, environmental, economic, legal and social promises and implications of genomics. Today, this research has reached a new stage of complexity, and new paradigms are emerging, as humanists and social scientists push the frontiers of GE³LS research and seek better ways to mobilize their knowledge for the benefit of all.

In his keynote presentation, Tim Caulfield pointed to three examples in the area of human health to illustrate just some of the ways in which GE³LS research is helping governments, businesses, voluntary organizations, scientists and citizens anticipate, define and address the wide range of enduring social challenges presented by genomic science and biotechnology.

a. Biobanks, Consent and the Law

Biobanks hold genetic information that could dramatically improve public health. They are an essential building block for the Canadian Lifelong Health Initiative¹² and promise to play an ever-increasing role in Canadian health research, policy and practice. Yet they would not exist without the consent of individuals and consent, as a legal and ethical concept, is proving increasingly difficult to define – and obtain. Much current discussion centres on ways to modify standards of consent in order to reduce barriers and lower the costs of research. Engaging citizens in this discussion and defining standards of consent that both protect individuals and facilitate research for the public good represent important contributions of long-term interdisciplinary GE³LS research.

The basic interests that lie in the balance are those between human dignity and human rights as against public health, scientific progress and commercial interests in a free market. (World Health Organization, 2003).¹³

b. Public Health and Science Communication

¹² Information available at: <http://www.cihir-irsc.gc.ca/e/18542.html>.

¹³ Quote from World Health Organization. *Genetic Databases: Assessing the Benefits and the Impact on Human and Patient Rights*, Geneva World Health Organization, 200³, quoted in Timothy Caulfield, Roger Brownsword, "Science and Society: Human Dignity: a Guide to Policy Making in the Biotechnology Era?", *Nature Reviews Genetics*, Vol. 7 (January 2006), pp. 72-76 | doi:10.1038/nrg1744, <http://www.nature.com/nrg/journal/v7/n1/full/nrg1744.html#B21>.

Genomic scientists, using the information stored in biobanks, are increasingly capable of linking particular human traits with specific genetic characteristics. The way this knowledge is used, in government, medicine and business, and the way it is communicated to the public has generated new public health concerns, created a sense of fatalism among many and lent a semblance of scientific credibility to the concept of race – a poorly defined, little understood social construct – with dangerous implications for public health policy and the pharmaceutical business. GE³LS research offers insights into these developments and suggests ways to manage them.

This study indicates that some messages linking race, genes, and health produce increases in racist attitudes in some audiences...If these results are replicated and if medical research eventually indicates that there are clinically useful differences in frequencies of conditions that have components that are strongly linked to particular genetic variations, the benefits of utilizing these tools will need to be weighed against the social harm of discussing them (Condit, et al, 2004).¹⁴

c. The Law, Science Communication and Public Policy

Today, nearly twenty per cent of human genes are associated with at least one U.S. patent.¹⁵ This reality – “the ownership of life” – has created a moral dilemma that promises to stir controversy for years to come. Yet research shows that the controversies themselves, often arising around very particular cases, are having a profound impact on the development and definition of public policy. Politicians, business people, scientists and citizens turn to GE³LS research for ways to build public engagement and sustain deliberate democracy on these wicked new public policy problems that bridge religion, business, science and community and change rapidly over time.

The ownership of intellectual property rights – the ultimate source of wealth in a knowledge-based economy – is one of the most important and most contentious unresolved issues. (Lester Thurow, 2000¹⁶)

2. Characteristics of GE³LS Research

GE³LS researchers, in Canada and around the world, play a leading role in helping governments, research institutions, non-governmental organizations and private companies address these and many other enduring societal challenges presented by genomic science and biotechnology. Michael Burgess described the work of a GE³LS researcher and offered his reflections on the development of best practices in a keynote presentation that served as an introduction to group discussions on critical aspects of GE³LS research funding in Canada.

Burgess presented his own experience as an example of the rapidly evolving, increasingly interdisciplinary and much sought after work of a GE³LS researcher. His career, which began in bioethics, had moved steadily through ethno-graphics, health policy and science policy towards his current research on deliberative democracy. His pursuit of GE³LS scholarship, and GE³LS research funding, has challenged and extended the disciplinary boundaries of his research into

¹⁴ C.M. Condit, R. L. Parrott, B. R. Bates, J. Bevan, P. J. Achter, “Exploration of the Impact of Messages about Genes and Race on Lay Attitudes”, *Clinical Genetics*, Vol. 66, No. 5 (November 2004), pp. 402-408.

¹⁵ K. Jensen, F. Murray, “Intellectual Property Landscape of the Human Genome,” *Science*, Vol. 310. No. 5746 (14 October 2005), pp. 239 – 240.

¹⁶ L.C. Thurow, “Globalization: The Product of a Knowledge-Based Economy”, *Annals of the American Academy of Political and Social Science*, Vol. 570 (July 2000) - Dimensions of Globalization, pp. 19-31.

increasingly diverse areas. He noted that disciplinary boundaries were often more difficult to bridge than national ones.

Given this context, Burgess expressed concern that the definition of best practices in GE³LS research funding might be premature. He recognized that best practices offered economy for funders and scholars by reducing duplication but emphasized that these gains could only be realized when both the context and objectives for particular initiatives were consistent. He acknowledged, however, the value of best practices in controlling uncertainty, establishing clear objectives, identifying practical alternatives and facilitating the very difficult task of evaluation. He understood, also, that best practices sanctioned by senior scholars and administrators brought with them significant credibility – potentially of great benefit to all.

In his view, workshop participants must not take this responsibility lightly. He argued that the state of GE³LS research presents serious issues for the development of best practices in research funding:

- There are no established career paths that could be supported in order to encourage and sustain the long-term development of GE³LS research;
- GE³LS research objectives are – and should remain – variable and sometimes contradictory;
- The culture of discipline-based expertise makes it difficult for scholars in such a diverse and dynamic field to reach consensus on best practices for research funding;
- Many researchers could find the prospect of additional collaboration, through the ERA-SAGE initiative, daunting.

Despite these challenges, Burgess thought it was possible for workshop participants to establish objectives for GE³LS research that would help define its principal characteristics and, in so doing, identify policy and program goals best suited for future development of the field. He proposed a list of possible objectives corresponding to three different concepts of GE³LS research:

GE³LS as Knowledge Production

1. More engaged and critically capable public
2. Socially relevant GE³LS research
3. Enhanced GE³LS research capacity
4. "Improved" policy
5. Enhanced research in areas of GE³LS
6. Enhanced GE³LS "within" science

GE³LS as Justice

7. Improvement in fair distribution and justice

GE³LS as Method

8. Improved high technology outcomes
9. Enhanced economic activity

Burgess rejected the idea of GE³LS as method. He considered the possible objectives too narrowly focused to encourage the critical questions characteristic of a broad field of inquiry and questioned their compatibility with larger goals. Many scholars, he suggested, would accept the concept of GE³LS as justice, in the abstract, though he noted the potential for an inappropriate imposition of particular notions of justice on the conduct of GE³LS research. Consequently, Burgess argued that GE³LS research should focus uniquely on knowledge production.

Drawing on the work of Janet Atkinson-Grosjean, Burgess described GE³LS research metaphorically as both user-inspired basic research, situated between pure basic research and

pure applied research, and as a translational science, linking scholarship to worlds of profit, practice and people.¹⁷ It is a field of study that favours multiple approaches, incommensurable accounts and collaboration with scientists and policy makers. As a translational science, it recognizes that policy making requires trade-offs and understands that experts can undermine, as well as support, democracy and justice.

For such scholarship to thrive, Burgess argued that funding policies and practices must encourage multiple and contrary approaches; improved connections between disciplines, topics and geographical regions; integrated and independent approaches; policy relevance (recognizing translation as expertise); and political relevance (valuing non-policy but accessible outputs and effects). Above all, future funding policies and practices must encourage career development for young scholars to ensure the long-term sustainability of the field.

3. Funding Issues and Recommendations

In group discussions and plenary sessions, participants strongly endorsed Burgess' assessment of GE³LS research as an emerging field of scholarship characterized by tremendous growth, breadth, interdisciplinarity and translational activity. As a result, they focused on the urgent need to:

- a. Coordinate support across disciplines, sectors and borders;
- b. Improve the quality of engagement with genomic science, the private sector and the public; and
- c. Sustain the development of an emerging field of scholarship capable of addressing enduring societal challenges in Canada and abroad.

Discussions focused on these five issues:

a. Coordination of GE³LS Research Funding

The tremendous growth, breadth, interdisciplinarity and translational activity of GE³LS research force GE³LS scholars to confront institutional structures established to define and support older fields of study and other activities. Most significant in this regard are the challenges of coordination across disciplinary, sectoral and geographic boundaries institutionalized in university departments, funding agencies and government departments, distinctions between public and private sector activities, and provincial or national jurisdictions.

Participants identified three areas in which such boundaries affected the development of GE³LS research. In the first instance, disciplinary distinctions established in the arrangement, structures and administration of funding agencies make peer review of interdisciplinary GE³LS applications difficult. Even administrators of interdisciplinary programs frequently lack sufficient experience to frame terms of reference in a truly interdisciplinary manner or to select appropriate peer review committee members; while reviewers themselves too often continue to follow inappropriate discipline-specific norms.

Disciplinary, sectoral and geographic boundaries also shape GE³LS research by affecting the distribution of research funding. Participants argued that differences in the availability of funding across disciplines, granting agencies and government departments limit GE³LS research in areas outside human health such as agriculture, fishing and forestry. Weak linkages between federal-science departments and universities also hinder GE³LS research outside human health.

¹⁷ Atkinson-Grosjean, *Public Science, Private Interests: Culture and Commerce in Canada's Networks of Centres of Excellence* (Toronto: University of Toronto Press, 2006). The concept of "user inspired basic research" was originally proposed in Donald E. Stokes, *Pasteur's Quadrant: Basic Science and Technological Innovation* (Washington, D.C.: Brookings Institution Press, 1997).

Distinctions between areas of public and private sector responsibility reinforce these differences. For example, public sector responsibility and funding for human health has helped make bioethics an area of research strength for Canada while the lack of private sector leadership has curtailed GE³LS research in agriculture, fishing and forestry. Participants also found that differences in the availability of funding between “have” and “have not” provinces had created gaps in the development of GE³LS research geographically while disciplinary distinctions had created gaps in the availability of funding for certain types or sizes of projects (this was particularly true for mid-sized projects that fell between SSHRC and Genome Canada funding criteria).

Finally, participants found similar challenges when seeking to organize purposeful scholarly activity. Their work often goes unrecognized in university departments or does not come to the attention of colleagues in other departments, other organizations or other provinces. Scholars and policy makers are both looking for ways better than email, teleconferences and endless air travel for connecting with colleagues and potential collaborators. All agreed that disciplinary, sectoral and geographic divisions represented important obstacles to the development of GE³LS research in Canada and abroad.

Despite these challenges, participants acknowledged that GE³LS scholarship – as a broad, interdisciplinary and translational undertaking – required access to an equally diverse range of research funding programs and supports. As a result, they called for greater coordination between funding agencies, sectors and provinces rather than a consolidated approach to research funding.

They recommended the development of an Inter-Agency GE³LS Research Strategy to place GE³LS research in the context of Canada’s broader science and technology goals and facilitate coordination in three areas:

i. To improve the distribution of funding across disciplinary, sectoral and provincial boundaries, and fill gaps in available funding, participants urged greater coordination in the development and design of funding programs. For example, each agency might offer GE³LS funding for a particular purpose or for projects of a particular size.

ii. To improve peer review and the administration of programs for interdisciplinary GE³LS research, participants urged funding agencies to adopt a more closely coordinated approach to program management. In particular, they recommended that funding agencies:

- Establish inter-agency, international, interdisciplinary peer review committees;
- Encourage the exchange of information between program officers responsible for GE³LS-eligible funding programs; and,
- Cross-promote GE³LS-eligible funding programs on agency web sites.

iii. To improve collaboration between GE³LS scholars across disciplinary, sectoral and geographic boundaries, participants urged agencies to coordinate collaborative programs and networking initiatives. For example, agencies might:

- Collaborate on joint initiatives involving multiple sectors and governments (provincial and national);
- Offer exchange programs to encourage movement between disciplines, sectors and provinces or nations;
- Support a regular and systematic review of the latest developments in genomic science to facilitate GE³LS research and inter-disciplinary collaboration on the leading edge.
- Provide support for scholars to develop proposals, travel and build collaborative relationships with colleagues in other disciplines, other provinces and other countries;
- Develop and support networks of GE³LS scholars that facilitate sustained collaboration across disciplinary, sectoral and geographic boundaries.

b. GE³LS Research and Genomic Science

One of the defining characteristics of GE³LS research is its close collaboration and examination of a different field of scholarship: genomic science. It is, perhaps, the most difficult and essential disciplinary boundary for GE³LS researchers to bridge and a relationship that is, in practice, profoundly shaped by institutional funding structures.

In Canada, there are – broadly defined – two funding models for GE³LS research. Most programs support GE³LS research that is independent of genomic science. In addition, however, Genome Canada offers integrated funding through a major granting program that requires GE³LS researchers and genomic scientists to collaborate on a single large project.¹⁸ Genomic scientists, as the principal investigators on such projects, are also obliged to secure an equivalent amount of matching funds from outside federal granting agencies before the project can begin.

Workshop participants emphatically supported the need for both independent and integrated funding models. They recognized that without an obligation to collaborate at some point the exchange of knowledge and learning between the two fields would not be as rich. At the same time, both GE³LS scholars and genomic scientists at the workshop identified particular problems with the current integrated funding program. Most notably, it affords little time to develop partnerships. By compelling genomic scientists to secure funding for GE³LS research within their own projects, and giving them control over that funding, it gives them undue control over the GE³LS component of the study. It fails to recognize cultural differences between the two fields, particularly in a peer review process that is inadequate for GE³LS research. And it creates a misguided expectation among genomic scientists that GE³LS researchers are to provide ethics or communications services rather than lead scholarly activity.

To overcome these problems while retaining the benefits of an integrated funding model, workshop participants proposed that funding agencies:

- Create opportunities and provide support for the development of collaborative initiatives between GE³LS researchers and genomic scientists prior to a major integrated funding competition (front-end approach); and/or,
- Hold a separate competition for GE³LS research funding, peer reviewed by GE³LS scholars, following a major competition for genomic science funding – and require collaboration between GE³LS scholars and genomic scientists in order for both to secure their respective funds (back-end approach).

c. Co-Funding

The requirement of Genome Canada for scholars to secure fifty per cent of their funding from outside federal granting agencies also contributes to the shaping of GE³LS research. This approach encourages a certain form of user engagement, attracts additional resources and increases the potential for conflicts of interest between scholars and funders. It is also perceived to place an additional burden on principal investigators as co-funding for GE³LS research is often more difficult to obtain than for genomic science.

Workshop participants wanted to retain the engagement and resources that come with co-funding and proposed two ways to mitigate problems associated with it. They suggested that agencies:

¹⁸ For details, see the background document *Public GE³LS Research Funding in Canada*, available at <http://www.genomecanada.ca/erasage/documents/ge³lsCanadaPartII.pdf>.

- Provide guidance on the arm's length relationship between researchers and funders in both public and private sectors. At a minimum, guidelines should cover governance, data ownership and knowledge translation priorities.
- Establish an independent trust to attract private sector resources with which to match public funding for GE³LS research. An independent trust would reduce the burden on principal investigators and establish a clear arm's length relationship between GE³LS scholars and private sector funders.

d. Public Engagement

Workshop participants and respondents to the request for input considered public engagement as a responsibility, a subject of GE³LS research and an element of adjudication and evaluation criteria in agency programs. In all cases, they urged colleagues and councils to do more.

Public engagement is challenging in multicultural societies, noted one respondent, more needs to be done...to engage the Canadian population in thinking about and expressing their wishes and concerns about GE³LS related issues. With the potentials of genomics for public health increasing it is of paramount importance that the public is engaged in this field and the developments are aligned with public perception of risk and cultural acceptability.

As an element of adjudication and evaluation, participants called for greater clarity from granting agencies on the range of public engagement and knowledge mobilization activities appropriate for particular purposes – and the outcomes expected. They debated, in particular, the value and quality of public engagement in the peer review process, and strongly recommended that funding agencies make a concerted effort to assess current research on public engagement and knowledge mobilization in order to provide such direction.

e. Sustainability

At the outset, Burgess voiced a concern, shared by many participants, that the academic community had not yet established a formal career path in GE³LS research. Opportunities to obtain the interdisciplinary training necessary are rare, difficult to arrange, time consuming and often unsupported. Moreover, there are few established positions in GE³LS research within Canadian universities. Participants urged funding agencies to work with universities to address these issues and recommended that they:

- Create doctoral and post-doctoral fellowships with interdisciplinary components for GE³LS researchers and genomic scientists.
- Support small workshops, bringing together graduate students and senior scholars from Canada and abroad, to promote knowledge synthesis, research training, professional development and networking.

4. The Promise of GE³LS Research in Canada

The senior scholars, administrators and members of the GE³LS research community who participated in ERA-SAGE Workshop II, or responded to the request for input, brought a sense of ambition and determination to their discussions: to build a research community of extraordinary importance for Canada and the world. Recognizing that GE³LS research remains a new, diverse and rapidly evolving field, they were reluctant to discuss best practices but did not hesitate to express a vision, suggest measures for improvement and propose innovations to create a field of true expertise within the Canadian and international academic communities.

Canadian GE³LS researchers and administrators recognize the importance, promise and complexity of their work: to address the enduring social challenges presented by genomics and biotechnology – and to create a broad, interdisciplinary and translational science, with its own expertise and an unrivalled capacity work with genomic scientists, governments, businesses and citizens alike. They see, too, on the horizon, the potential of prospective work, relevant to multiple technologies, and understand that they have a unique opportunity to pursue it in a country unusually willing to approach challenging issues with an open mind. They see a future of truly adaptive GE³LS research, taking Canadian and international scholarship into “the great wide open.”

Next Steps

Bringing the workshop to a close, Christian Sylvain emphasized the tremendous opportunity presented by ERA-SAGE for Canadians to share in the development of an international GE³LS research agenda. There was much to contribute, he thought, from Canadian experience with models of governance, co-funding, the coordination of projects and programs and public engagement. The Canadian vision should become part of the international agenda.

As a member of the ERA-SAGE Steering Committee, he highlighted five challenges facing the consortium as it develops a strategic plan for transnational GE³LS research funding:

- *Governance*: Balance national perspectives and an emerging international agenda in the management of both research programs and the interface between society and decision-makers;
- *Autonomy*: Reconcile national research traditions to achieve the right mix of independent and integrated programs of support for GE³LS research;
- *Context*: Find appropriate societal contexts for GE³LS research in a multi-national, multi-disciplinary, and multi-stakeholder environment;
- *Implementation*: Ensure that ERA-SAGE provides “added value” to national funding schemes when developing transnational programs;
- *Communications*: Define appropriate initiatives and audiences for increasing the visibility and impact of GE³LS research.

Sylvain indicated that recommendations from the workshop would feed into development of a strategic plan for ERA-SAGE to be released in Autumn 2007. He also assured participants, on behalf of SSHRC, CIHR and Genome Canada, that those agencies would consider ideas put forward at the workshop in future development of their respective programs.

Appendix A: Summary of Recommendations from ERA-SAGE Workshop II

Participants described GE³LS research as an emerging field of scholarship characterized by tremendous growth, breadth, interdisciplinarity and translational activity. As a result, they focused on specific recommendations for funding agencies in each of the following areas:

a. Coordination of GE³LS Research Funding

Develop an Inter-Agency GE³LS Research Strategy to place GE³LS research in the context of Canada's broader science and technology goals and facilitate coordination in three areas:

- i. To improve the distribution of funding across disciplinary, sectoral and provincial boundaries, and fill gaps in available funding:
 - Coordinate the development and design of funding programs. For example, each agency might offer GE³LS funding for a particular purpose or for projects of a particular size.
- ii. To improve peer review and program administration:
 - Establish inter-agency, international, interdisciplinary peer review committees;
 - Encourage the exchange of information between program officers responsible for GE³LS-eligible funding programs; and,
 - Cross-promote GE³LS-eligible funding programs on agency web sites.
- iii. To improve collaboration between GE³LS scholars across disciplinary, sectoral and geographic boundaries:
 - Collaborate on joint initiatives involving multiple sectors and governments (provincial and national);
 - Offer exchange programs to encourage movement between disciplines, sectors and provinces or nations;
 - Support a regular and systematic review of the latest developments in genomic science to facilitate GE³LS research and inter-disciplinary collaboration on the leading edge.
 - Provide support for scholars to develop proposals, travel and build collaborative relationships with colleagues in other disciplines, other provinces and other countries;
 - Develop and support networks of GE³LS scholars that facilitate sustained collaboration across disciplinary, sectoral and geographic boundaries.

b. GE³LS Research and Genomic Science

Retain both independent and integrated funding models. To improve the delivery and outcome of integrated funding:

- Create opportunities and provide support for the development of collaborative initiatives between GE³LS researchers and genomic scientists prior to a major integrated funding competition (front-end approach); and/or,
- Hold a separate competition for GE³LS research funding, peer reviewed by GE³LS scholars, following a major competition for genomic science funding. Require collaboration between GE³LS scholars and genomic scientists for both to secure their respective funds (back-end approach).

c. Co-Funding

Retain co-funding where it exists. To improve the delivery and outcomes from co-funding:

- Provide guidance on the arm's length relationship between researchers and funders in both public and private sectors. At a minimum, guidelines should cover governance, data ownership and knowledge translation priorities.
- Establish an independent trust to attract private sector resources with which to match public funding for GE³LS research. An independent trust would alleviate the burden on

genomic scientists and establish a clear arm's length relationship between GE³LS scholars and private sector funders.

d. Public Engagement

Public engagement is a responsibility, a subject of GE³LS research and an element of adjudication and evaluation criteria in agency programs.

- As an element of adjudication and evaluation, greater clarity is required with respect to the range of public engagement and knowledge mobilization activities appropriate for particular purposes – and the outcomes expected.
- Make a concerted effort to assess current research on public engagement and knowledge mobilization in order to provide better guidance for scholars and their partners.

e. Sustainability

To help sustain GE³LS research as a field of scholarship:

- Create doctoral and post-doctoral fellowships with interdisciplinary components for GE³LS researchers and genomic scientists.
- Support small workshops, bringing together graduate students and senior scholars from Canada and abroad, to promote knowledge synthesis, research training, professional development and networking.

Appendix B: Summary of Responses to the “Request for Input”

Discussion Paper: Summary of Responses to the “Request for Input”
Prepared for ERA-SAGE Workshop II on Canadian GE³LS Research Funding: Articulating Best Practices and Exploring Future Directions by Garth Williams, 16 November 2006.

Introduction

This summary of responses to the “request for input” on GE³LS research funding issues has been prepared to assist participants and stimulate discussion at the ERA-SAGE Workshop on “Canadian GE³LS Research Funding: Articulating Best Practices and Exploring Future Directions”, Ottawa, November 16-17, 2006.

The paper does not represent a systematic analysis of GE³LS research funding issues in Canada. Rather, it is a summary analysis of individual responses to the short “request for input” document distributed to workshop invitees and members of the GE³LS research community, and posted on the Genome Canada website, between October 2³ and November 7, 2006. The “request for input” sought only the personal opinion of respondents regarding emerging issues in GE³LS research funding; current strengths, weaknesses, gaps and overlaps in current funding policy and practice; and, where possible, information regarding non-governmental funding programs.

Seventeen respondents provided input based on their experience in academe (10 respondents), government (5) and non-governmental organizations (2). Twelve of the seventeen respondents will be workshop participants. The organizers thank them all for their contributions.

Overview

The respondents emphasized that Canada’s greatest strength with respect to GE³LS research funding is the mixture of programs and approaches adopted by Genome Canada, the Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council of Canada (SSHRC) and other funding and research organizations. They noted that such a *“multi-pronged approach...is often the most effective in ensuring that objectives are met.”*

Individual respondents added that support for large-scale GE³LS projects had made Canada a leader in the field and commended Genome Canada for:

- Its ambitious integration of GE³LS research into genomic and proteomic projects;
- Encouraging the development of linkages between the policy and research communities;
- Recognizing that GE³LS research applies to more than human genetic applications;
- Developing national strength in bioethics.

Respondents identified emerging issues, weaknesses, gaps and overlaps in GE³LS research funding in four broad subject areas. These concern:

1. The purpose, engagement, and impact of GE³LS research;
2. The organization or coordination of funding strategies, programs and program-types;
3. Resources and research capacity, overall and in particular areas; and,
4. Interdisciplinarity.

These broad subject areas largely correspond to the themes identified for group discussions at the workshop (as they appear in the program). It should be noted, however, that respondents were not aware of the discussion group categories when preparing their submissions. They

developed and linked issues in ways that were meaningful to their own understanding of GE³LS research funding in Canada. As a result, the subject areas described here do not correspond perfectly with the themes proposed for group discussions at the workshop.

1. Quality Management: A Question of Purpose

A number of respondents held that *“the most important issue for GE³LS research is to show value.”* More than simply acknowledging the limitations of standard measures of research productivity, they urged greater attention to the relationship – grounded in policy and practice – between GE³LS research and national goals or the public good.

For one respondent, this implied careful consideration of the most appropriate “place” for GE³LS researchers in relation to other actors within a democratic society. For others, who emphasized public interest in GE³LS research and genomics, it implied a need for greater public awareness and public engagement. *“Public engagement is challenging in multicultural societies,”* noted one such respondent, *“more needs to be done...to engage the Canadian population in thinking about and expressing their wishes and concerns about GE³LS related issues. With the potentials of genomics for public health increasing it is of paramount importance that the public is engaged in this field and the developments are aligned with public perception of risk and cultural acceptability.”*

In policy terms, a number of respondents emphasized the need to consider GE³LS research in the context of Canada’s broader science and technology goals, the mandates of research and research funding organizations and its impact on the governance and management of genomic research. In practical terms, they called for greater clarity regarding the range of activities and expected outcomes for effective knowledge mobilization and public engagement. One question concerned the extent to which research depending on community partners should provide resources for capacity building in that community. Others focused on the range of knowledge mobilization programs possible; the different types of public engagement that require study; and the time required to evaluate complex research and training initiatives. It was suggested that a concerted effort be made to coordinate and create a critical assessment of current research on public engagement in order to answer such questions.

2. Funding Strategies: A Question of Coordination

Some respondents claimed that *“the main problem is that there is no coordination or overall appreciation as to what GE³LS research is and what it should aim to accomplish.”* While they recognized that Canada benefited from a wide range of research granting programs, they argued in favour of greater coordination between federal, provincial and not-for-profit funding agencies. They urged a more collaborative approach to strategic planning and program management to improve the administration of research and facilitate scholarship across disciplines, across provincial and international boundaries and between different types of funding programs.

These respondents suggested that greater coordination between funding agencies might distribute resources more evenly across disciplines, encourage programs that are complementary to one another and address gaps in the range of programs currently available. In this regard, a number of respondents emphasized that *“large scale Genome Canada projects...should not be considered the only appropriate venue for GE³LS research.”* They recommended the creation of a program to provide modest support for scholars to develop proposals, travel and build collaborative relationships with colleagues in other disciplines, other provinces and other countries. One respondent suggested that the ERA-SAGE initiative could be an important way to advance such collaborative possibilities and noted: *“many researchers are waiting to see what develops from this initial effort.”*

Respondents also suggested that greater collaboration between funding agencies could encourage more innovative GE³LS research by standardizing and simplifying application and

reporting processes that are, at present, both burdensome and constraining for scholars. Greater coordination at this level might also help address ethical concerns regarding private sector funding by improving the way *“partnership agreements are negotiated between government-funded contract and peer-reviewed sources and co-funding from private or NGO based sources.”* Respondents emphasized that *“the risks and benefits of alternative models of partnership in sponsoring GE³LS research need to be more explicitly spelled out in terms of research governance, data ownership and knowledge translation priorities.”*

3. Research Capacity: A Question of Resources

Almost all respondents identified insufficient funding for GE³LS research as *“one of the most important issues.”* One noted, in particular, that Genome Canada had *“not yet invested the 10 per cent (of its total funding) it suggested it would into GE³LS research.”* More specifically, however, respondents focused attention on programmatic means to increase research capacity across the field and in particular subject areas.

To increase overall research capacity, respondents recommended a program to provide modest support for students and researchers moving into GE³LS from other disciplinary backgrounds. A number of respondents recognised that funding from Genome Canada and CIHR for GE³LS research on issues related to human health had helped make bioethics an area of national research strength for Canada. They felt that a similar effort was needed to build Canadian expertise on economic, environmental, forestry, fisheries and aquaculture issues. As noted above, respondents made a similar suggestion with respect to public engagement and knowledge mobilization.

4. GE³LS and Genomic Science: A Question of Interdisciplinarity

Respondents focused considerable attention on issues related to the interdisciplinary nature of GE³LS research. As noted earlier, they called for capacity development in terms of training and research on the subject and methodologies of interdisciplinary scholarship. They also urged greater attention to two programmatic issues related to interdisciplinary scholarship.

In the first instance, respondents called for more research and increased clarity on the relative merits of – and appropriate balance between – independent or stand-alone GE³LS research projects and those supported and developed as components of larger genomic projects. Many recognized the benefits of integrated GE³LS projects while noting the particular challenges involved. They expressed concern that integrated GE³LS projects were *“sometimes superficial.”* They cautioned that such research should be peer review-able; clearly distinguished from the elaboration of research ethics requirements or economic analysis that serves only to enhance the social and economic benefits of genomics; and should also be clearly linked to personnel with expertise and institutional ties to GE³LS researchers. As a result, most also argued that independent GE³LS research – and opportunities to meet Canadian and international colleagues at subject specific gatherings – are now essential for the development and maturation of scholarship in the field.

In the second instance, respondents focused on the challenges of managing interdisciplinary peer review programs and adjudication. They claimed that administrators of both standard and targeted interdisciplinary programs frequently lacked experience in framing of the terms of reference and selecting peer review committee members and that reviewers too often continued to follow existing discipline-specific collaborative networks. Given these challenges, and the limited number of experienced reviewers in Canada, respondents warned against *“an appearance that self-selecting committees conduct themselves behind closed doors...Requests for Applications are designed to target particular interested groups and the rhetoric used excludes those who are not ‘in the know.’”*

Non-Governmental Funding Programs

Few respondents were aware of non-government funding programs for GE³LS research although some noted the availability of funding through the Pew Charitable Trusts, the Bill and Melinda Gates Foundation and the Canadian Breast Cancer Research Alliance. One respondent suggested that government departments conduct more GE³LS research within their policy divisions than through formal research programs.

Appendix C: ERA-SAGE Workshop II Program

ERA-SAGE Workshop II on Canadian GE³LS Research Funding: Articulating Best Practices and Exploring Future Directions, November 16 -17, 2006, Brookstreet Hotel, Ottawa, Canada

OBJECTIVES

- Identify the similarities, differences, gaps and complementarity of Canada's funding strategies for GE³LS research;
- Identify emerging new issues within the funding field of GE³LS research; and
- Identify key elements of models for best practices and quality management in the funding of GE³LS research.

ERA-SAGE Workshop II

THURSDAY, NOVEMBER 16, 2006

16: ³⁰	Registration	
17: ³⁰	Reception	
18:00	Welcome	Dr. Robin Hill, Director Knowledge Creation, Canadian Institutes of Health Research
18:10	DINNER	
19:00	Remarks	Dr. Chad Gaffield, President Social Sciences and Humanities Research Council
19:10	Keynote Address	Prof. Tim Caulfield, Canada Research Chair in Health Law and Policy, University of Alberta

FRIDAY, NOVEMBER 17, 2006

07:00	BREAKFAST	
08: ³⁰	Introduction	– Dr. Vardit Ravitsky, Facilitator

PLENARY PRESENTATIONS

Canadian GE³LS Research Funding Context and Overview

- 08:³⁵ Dr. Martin Godbout, President and CEO, Genome Canada
- 08:50 Dr. Michael Burgess, Chair in Applied Ethics,
Maurice Young Centre for Applied Ethics, University of British Columbia
- 09:³⁰ ***Plan for the Day*** - Facilitator
- 09:40 **REFRESHMENT BREAK**
- 10:00 **WORKING GROUP DISCUSSION THEMES**

Group 1 – Funding strategies: Open, strategic, public and private funding; large and small projects; scope – what is funded (Infrastructure, international collaborations, graduate/post-graduate students, conferences, travel, knowledge transfer, capacity building, training, public outreach, etc.); policies regarding "double dipping".

Group 2 – Quality Management: The review process; research integrity; accountability; evaluation of research impact; deliverables - what are they and how are they monitored? (For example, reports to funding agencies, communication of results to scientific community, to the public and, product development.)

Group ³ – Capacity Specialization and Diversity: Canada's overall research capacity and potential for international contribution; building areas of strength and expertise; promoting diversity in research and growing the pool of researchers and topics.

Group 4 – GE³LS and Genomics Science: Stand-alone/independent GE³LS projects and integrated GE³LS components (successful partnerships or 'forced marriage?'); co-funding/partnerships.

WORKING GROUP PLENARY PRESENTATIONS (Pres. 15 min – Q&A 15 min)

- 11:00 Group 1 – Funding Strategies
- 11:³⁰ Group 2 – Quality Management
- 12:00 **LUNCH**
- 1³:00 Group ³ – Capacity: Specialization and Diversity
- 1³:³⁰ Group 4 – GE³LS and Genomics Science

PLENARY DISCUSSIONS

14:00 Identifying Gaps and Synergies - Facilitator

15:15 **REFRESHMENT BREAK**

15:45 Identifying Best Practices and General Recommendations - Facilitator

16:45 ***Closing Remarks*** Christian Sylvain, Director, Policy, Planning and International Affairs, Social Sciences and Humanities Research Council

Appendix D: ERA-SAGE Workshop II Participants' List

SURNAME	NAME	INSTITUTION
Avard	Denise	Université de Montréal
Bell	Cindy	Genome Canada
Brown	Laura	National Research Council of Canada
Burgess	Michael	University of British Columbia
Carew	Richard	Agriculture and Agri-Food Canada
Caulfield	Tim	University of Alberta
Crichlow	JoAnn	Genome Canada
Culver	Keith	University of New Brunswick
Dewar	Karen	Genome Canada
Drouillard	Lisa	Health Canada
Edmonds	Stuart	National Cancer Institute of Canada
Einsiedel	Edna	University of Calgary
Elmslie	Kimberley D.	Canadian Biotechnology Secretariat
Flamenbaum	Jamle	Canadian Institutes of Health Research
Gaffield	Chad	Social Sciences and Humanities Research Council of Canada
Godbout	Martin	Genome Canada
Griener	Glenn	National Council on Ethics in Human Research
Griffin	Gilly	Canadian Council on Animal Care
Hannan	Mohammed	Canadian Institutes of Health Research
Hill	Robin	Canadian Institutes of Health Research
Kaufert	Joseph	University of Manitoba
Létourneau	Lyne	Université Laval
MacDonald	Chris	Saint Mary's University
McNaughton	Craig	Social Sciences and Humanities Research Council of Canada
Panford	Janet	ERA-Can Initiative
Popovich	Brad	Sirrus Genomics Inc
Pullman	Daryl	Memorial University of Newfoundland
Ravitsky	Vardit	Genome Canada
Sauvageau	Lyne	Fonds québécois de la recherche sur la culture et la société
Sheremeta	Lori	University of Calgary
Stipernitz	Boris	Social Sciences and Humanities Research Council of Canada
Sylvain	Christian	Social Sciences and Humanities Research Council of Canada
Tsang	Adrian	Concordia University
van Rooijen	Gijs	Genome Alberta
Williams	Garth	Public Knowledge Canada

Appendix E: ERA-SAGE Workshop II Program Advisory Committee

Adrian Alsop, Economic and Social Research Council

Michael M. Burgess, University of British Columbia

Eric M. Meslin, Indiana University

Penny Moody-Corbett, Memorial University of Newfoundland

Stephen W. Scherer, Toronto Hospital for Sick Children

Appendix F: ERA-SAGE Workshop II Inter-Agency Coordinating Group

Vardit Ravitsky, National GE³LS Program Consultant, Genome Canada

JoAnn Crichlow, Program Manager, Genome Canada

Jaime Flamenbaum, Senior Ethics Policy Advisor, Ethics Office, Canadian Institutes of Health Research

Boris Stipernitz, Policy Analyst, Policy, Planning and International Affairs, Social Sciences and Humanities Research Council of Canada