

THE OTTAWA GE³LS WORKSHOP REPORT

OTTAWA, ON

FEBRUARY 6-7, 2006

REPORT AND RECOMMENDATIONS TO THE SCIENCE AND INDUSTRY ADVISORY COMMITTEE AND THE BOARD OF DIRECTORS, GENOME CANADA

Report Prepared by: Sarah Hartley and Bryn Williams-Jones, on behalf of:
THE OTTAWA GE³LS WORKSHOP STEERING COMMITTEE

- Paul Thompson (Chair), Michigan State University
- Michael McDonald (Meeting Chair), University of British Columbia
- Denise Avard, Université de Montréal
- Joerg Bohlmann, University of British Columbia
- Fern Brunger, Memorial University of Newfoundland
- Timothy Caulfield, University of Alberta
- Sarah Hartley, Genome British Columbia
- Eric Higgs, University of Victoria
- Alison Kraft, University of Nottingham
- Mark Samuels, Dalhousie University
- Bryn Williams-Jones, Université de Montréal

INTRODUCTION

One of Genome Canada's mandates is to "Ensure leadership in ethical, environmental, economic, legal and social issues related to genomics and proteomics research (GE³LS)". Genome Canada approaches this mandate through: 1) large-scale GE³LS research, 2) GE³LS components integrated in large-scale science projects, and 3) a national GE³LS program that includes symposia and outreach activities. The appropriateness of Genome Canada's approach to its mandate was referred to during the Ottawa workshop; however, participants agreed that recommendations in that area were beyond the ambit of the workshop. Consequently, the recommendations in this report should be viewed within the context of Genome Canada's current mandate and activities.

Nine large-scale GE³LS projects have been funded over the course of three Genome Canada sponsored competitions: three in Competition I; two in Competition II; and four in Competition III. These nine projects are recognised nationally and internationally for their contribution to GE³LS research.

In addition to funding large-scale GE³LS projects, Competition III supported the integration of GE³LS activities into large-scale science projects. Given these developments, the GE³LS community has expanded in numbers and diversity of disciplinary background. This "loose knit" collection of researchers and professionals employs a diversity of methods and modes of analysis with sometimes conflicting goals and objectives.

This broadening of the GE³LS community should be viewed against the backdrop of calls from within the community to create a rich and robust GE³LS culture in Canada. Members of this community have also expressed interest in bridging the traditional divisions between genomics science research and GE³LS research to achieve a more integrative interdisciplinary community that encompasses shared learning.

Genome Canada and the Genome Centres can and are playing an important role in supporting and facilitating the development of a GE³LS culture. This workshop is part of that on-going process.

WORKSHOP OVERVIEW

On February 6 and 7, 2006 the Science and Industry Advisory Committee (SIAC) of the Board of Directors of Genome Canada brought together in Ottawa representatives from various stakeholder groups (see Appendix 1) to discuss and make recommendations to SIAC on current and future Genome Canada GE³LS initiatives. Prior to the workshop, a Steering Committee (see Appendix 2) developed a questionnaire (see Appendix 3) which it sent to members of the broader GE³LS community; the responses to the questions informed and stimulated discussion in the workshop. Two particular areas of concern identified by the questionnaire are the large-scale funding and co-funding models employed by Genome Canada.

Genome Canada's President, Martin Godbout, opened the workshop with a helpful presentation on Genome Canada's mission, the current commitment to large-scale and integrated GE³LS research, and the mechanisms for financing and supporting GE³LS and genomics projects. Participants engaged in vigorous and collegial debate, initially focusing on the questions presented in the questionnaire. Through these discussions, the participants identified two themes to be addressed by the workshop: *Improving Integration of GE³LS into Genomic Science* and *Creating a GE³LS Culture*. Participants agreed that this generalization was needed to facilitate a productive discussion and that in practice, these themes and the goals they speak to significantly overlap.

SUMMARY OF GOALS AND RECOMMENDATIONS

The following is a summary of the goals identified by the workshop participants and the subsequent recommendation to SIAC and the Board of Directors of Genome Canada.

G1 ENSURE INTERNATIONAL LEADERSHIP IN LARGE-SCALE GE³LS RESEARCH

R1) Maintain a rigorous peer-review process, and support high-quality and innovative research.

G2 ENSURE INTERNATIONAL LEADERSHIP IN INTEGRATING GE³LS AND GENOMICS RESEARCH

R1) Merge, where appropriate, the development and implementation of research questions and methods in the two types of research

R2) Collaborate on projects, encourage student participation across-programs and engage in shared learning

R3) Mix science and GE³LS conference presentations

R4) Evaluate the integrative model used in Competition III.

G3) STIMULATE A GE³LS CULTURE AND COMMUNITY

R1) Re-organize the annual Genome Canada science symposium as the main GE³LS/genomics research networking event

R2) Facilitate and fund approximately four GE³LS workshops per year to create opportunities for disciplinary and interdisciplinary research and collaboration

R3) Strike a permanent GE³LS Steering Committee to organize symposia and oversee the GE³LS workshops.

G4) EVALUATE AND PROMOTE GE³LS

R1) Support the continuous review and assessment of GE³LS research through the publication and promotion of findings and results

R2) Develop a “GE³LS Canada” website that facilitates networking and community building, and acts as a GE³LS-related information clearing house by (amongst other things) disseminating publications and providing information on funding and research opportunities

R3) Genome Canada should work closely with the federal and provincial granting councils and funding agencies to share GE³LS-related information and enhance funding opportunities for GE³LS research.

G5) CLARIFY WHAT IS MEANT BY “SOCIO-ECONOMIC BENEFITS”

R1) Genome Canada should examine and explain the distinction between “GE³LS” and “socio-economic benefits” for future competitions through discussion with the GE³LS community.

GOALS AND RECOMMENDATIONS

G1) ENSURE INTERNATIONAL LEADERSHIP IN LARGE-SCALE GE³LS RESEARCH

R1) Maintain a rigorous peer-review process, and support high quality and innovative research

- Support large-scale, internationally competitive GE³LS projects
- Investigate current and other models of co-funding for large-scale GE³LS (and science) projects and develop and make accessible a portfolio of best practises
- Support sustained, in-depth research that contributes to an interdisciplinary dialogue and critical debate across the full diversity of GE³LS issues, within and outside the practice of genomics research
- Identify and understand gaps in GE³LS knowledge to facilitate the conduct of better genomics science
- Contribute to policy development and evaluate the outcomes (e.g., changes in policy debate and/or in public policy decisions on the uptake of genomics technology).

G2) ENSURE INTERNATIONAL LEADERSHIP IN INTEGRATING GE³LS AND GENOMICS RESEARCH

R1) Merge, where appropriate, the development and implementation of research questions and methods in GE³LS and genomics research

- Funded GE³LS research components must be more than a mechanism for satisfying regulatory demands (e.g., the demands of research ethics boards and animal care committees). Genome Canada should work with and use the expertise of the Canadian Council for Animal Care, (CCAC), the National Council Ethics in Human Research (NCEHR) and the Interagency Panel on Research Ethics
- Genome Canada to decide whether to mandate a universal GE³LS component for all future science projects
- All genomics projects should be encouraged to include a GE³LS component. Project leaders should be expected to seriously evaluate the need for and benefits to be derived from including a GE³LS research component in their work

- Provide assistance to scientists to identify relevant GE³LS components and find appropriate GE³LS research partners
- Consider involving the public in Genome Canada funded projects. This could include input into the role, type and timing of public consultation, or participation in review panels
- Genome Canada should make public details of the GE³LS components of Competition III projects, including statistical information regarding co-funding offers for funded vs. non-funded proposals.

R2) *Collaborate on projects, encourage student participation across-programs and engage in shared learning*

- Educate the genomics science community to the benefits of becoming GE³LS-aware and GE³LS champions
- Encourage GE³LS researchers, where appropriate, to collaborate with lab scientists so that genomics research is continually informed by GE³LS considerations and GE³LS research is informed by a deeper understanding of genomics research.

R3) *Mix science and GE³LS conference presentations*

- Integrate the annual GE³LS symposium and the annual science meeting (see G3)
- Genome Canada to work with scientific associations to include GE³LS sessions in a variety of scientific meetings.

R4) *Evaluate the integrative model used in Competition III*

- Genome Canada to strike an interdisciplinary working group to develop indicators for success in integrating Competition III GE³LS components into genomics science projects
- Evaluate the integration of Competition III GE³LS components into genomics science projects. The evaluation should include accepted and rejected proposals, an assessment of outcomes and measures of success, and a basic description of each GE³LS component's research agenda and budget. Use the evaluation to develop a knowledge base with historical validation

- Consider coordinating and/or comparing Genome Canada's integrative model with the Social Sciences and Humanities Research Council of Canada (SSHRC) and the Canadian Institutes of Health Research (CIHR) experiences, and with the US model for integrating GE³LS into science in its National Nanotech Initiative.

G3) STIMULATE A GE³LS CULTURE AND COMMUNITY

R1) Re-organize the annual Genome Canada science symposium as the main GE³LS/genomics research networking event

- Integrate the annual GE³LS and genomics science symposia, starting in 2006, to help build a GE³LS culture and facilitate interaction between GE³LS and genomics researchers
 - one day should be dedicated to GE³LS, one day should combine GE³LS and science presentations and one day or more should be dedicated to genomics science
 - the GE³LS component should be run as a traditional conference – calls for papers, student presentations, plenary and breakouts, etc
- Ensure a greater lead time for organizing and advertising GE³LS symposia.

R2) Facilitate and fund approximately four GE³LS workshops per year to create opportunities for disciplinary and interdisciplinary research and collaboration

- Support and allocate resources sufficient for a series of (approximately four) annual workshops organized around specific GE³LS themes. The workshops should:
 - be open to participants from the GE³LS and genomics science research communities; and
 - include two categories:
 - syntheses or state of knowledge workshops, intended to gather people around emerging research or policy matters; and
 - frontiers or emerging issues workshops.

R3) *Strike a permanent GE³LS Steering Committee to organize symposia and oversee the GE³LS workshops*

- Genome Canada should establish an inclusive steering committee to organise the annual GE³LS symposia and workshops. The committee should:
 - include representation from the following: Genome Centres, large-scale GE³LS projects, Competition III GE³LS projects, and the broader GE³LS community
- Ensure workshops focus on GE³LS and related topics while remaining open to various workshop models. For example, the committee could equally support one-off workshops or a number of small sequential meetings built around a desired end product
- Create an international profile for the outputs of the workshops, including (but not limited to) profiling the outputs at the annual symposia and on the website (see G4)
- Include a selection of workshop topics that involve the genomics science community
- Support workshops proposed by the researcher community, as well as the standing committee
- Solicit proposals for workshops that profile GE³LS and the integration of GE³LS and bench science, stress the importance of interdisciplinarity, and are of an international quality
 - consider a mix of think pieces and topics with clear outputs, including possible recommendations
- Ensure that the workshop proposals are peer reviewed before a decision from the standing committee.

G4 *EVALUATE AND PROMOTE GE³LS*

R1) *Support the continuous review and assessment of GE³LS research through the publication and promotion of findings and results*

- Investigate how to reach key decision-makers on genomics science topics of social significance.

R2) *Develop a “GE³LS Canada” website that: facilitates networking and community building, and acts as a GE³LS-related information clearing house by (amongst other things) disseminating publications and providing information on funding and research opportunities*

- A national “GE³LS Canada” website should be funded by Genome Canada. The site would link to project and regional Genome Centre websites, as well as education websites, and should include:
 - Researcher profiles
 - One-page lay-summaries of *all* Genome Canada funded GE³LS projects (these should appear on Genome Centre websites until the national website is established)
 - GE³LS publications
 - GE³LS events
 - Recommendations
 - Workshop and symposia outputs
 - Discussion/networking forums.

R3) *Genome Canada should work closely with the federal and provincial granting councils and funding agencies to share GE³LS-related information and enhance funding opportunities for GE³LS research.*

- Monitor the “portfolio” of funding available to GE³LS researchers and adjust funding opportunities to avoid the potential “oasis/desert” phenomenon that is commonly associated with the large-scale research model
- Make available information on the portfolio of funding opportunities available to Canadian GE³LS researchers (e.g., CIHR Institute of Genetics “Facing the Future” start-up grants for junior scholars)
- Work with CIHR and SSHRC to explore the issue of capacity-building in the GE³LS community.

G5) *CLARIFY WHAT IS MEANT BY “SOCIO-ECONOMIC BENEFITS”*

R1) *Genome Canada should examine and explain the distinction between “GE³LS” and “socio-economic benefits” for future competitions through discussion with the GE³LS community.*

- Clearly define the meaning and purpose of the SEB component in relation to the GE³LS component and provide operational guidelines for addressing these areas in research proposals for future competitions. For example, the SEB component could require research of the same calibre as the current GE³LS component

- Provide greater lead time following major updates to forms for proposals to be developed
- Include input from GE³LS experts on the distinction between GE³LS, and SEB.

APPENDIX 1: WORKSHOP PARTICIPANTS

NAME	ORGANIZATION
Avard, Denise	University of Montreal
Bell, Cindy	Genome Canada
Bellemare, Guy	Genome Quebec
Carpentier, Richard	National Council Ethics in Human Research
Castle, David	University of Guelph
Caulfield, Timothy	University of Alberta
Chapman, Sheila	Canadian Institutes of Health Research
Crichlow, JoAnn	Genome Canada
Downey, Robin	University of Calgary
Elmslie, Kimberley D.	Canadian Biotechnology Secretariat
Gauthier, Clement	Canadian Council on Animal Care
Green, Shane	Ontario Genomics Institute
Hartley, Sarah	Genome British Columbia
Higgs, Eric	University of Victoria
Kraft, Alison	University of Nottingham
Lewis, Patrick	University of British Columbia
Lock, Margaret	McGill University
MacDonald, Chris	Saint Mary's University
McDonald, Michael (Chair)	University of British Columbia
Montpetit, Eric	University of Montreal
Paquette, Sylvie	Social Sciences and Humanities Research Council of Canada
Paré, Isabelle	University of Montreal
Popov, Milka	Canadian Institutes of Health Research
Potter, Beth	University of Ottawa
Samuels, Mark	Dalhousie University
Singer, Peter	Joint Centre for Bioethics University of Toronto
Tsang, Adrian	Concordia University
Veeman, Michele	University of Alberta
Williams, Garth	Social Sciences and Humanities Research Council of Canada
Williams-Jones, Bryn	University of Montreal

APPENDIX 2: STEERING COMMITTEE MEMBERS

NAME	ORGANIZATION
Paul Thompson (Chair)	Michigan State University
Michael McDonald (Meeting Chair)	University of British Columbia
Denise Avard	Université de Montréal
Joerg Bohlmann	University of British Columbia
Fern Brunger	Memorial University of Newfoundland
Timothy Caulfield	University of Alberta
Sarah Hartley	Genome British Columbia
Eric Higgs	University of Victoria
Alison Kraft	University of Nottingham
Mark Samuels	Dalhousie University
Bryn Williams-Jones	Université de Montréal

APPENDIX 3: STEERING COMMITTEE'S MANDATE AND COMMUNITY SURVEY

FEBRUARY 2006 GE³LS WORKSHOP: STEERING COMMITTEE'S MANDATE AND COMMUNITY SURVEY

The Steering Committee was asked to develop the Agenda for a National *GE³LS Workshop* that would facilitate discussion and recommendations to SIAC and to the Board of Genome Canada regarding:

1. Vision for a National GE³LS Program

In January 2002 Genome Canada held a GE³LS Workshop with the purpose of developing short and long-term strategies for the evolution of GE³LS research and networking in Canada. Participants will be asked to reconsider the recommendations of the Vancouver 2002 GE³LS Workshop, and to comment on the relevance of these recommendations in the context of the current environment, recommending changes and charting a new course as appropriate.

2. Integration of GE³LS research into “mainstream” genomics projects

How do we ensure that genomics and proteomics researchers consider the ethical, economic, environmental, legal and social implications of their research?

3. How to support project-based GE³LS research

Are there new ways of working within Genome Canada's funding framework to facilitate a more inclusive (casting a wider net) funding framework for GE³LS research? How can funding guidelines, for example, be framed so as not to exclude certain groups of Canadian GE³LS researchers, and to continue to stimulate the interests of new GE³LS researchers?

4. Definition of GE³LS

GE³LS, as defined by Genome Canada, currently encompasses ethical, environmental, economic, legal and social aspects of genomics and proteomics research.

- Is this framework appropriate for future Genome Canada research programming. For example, are there elements or approaches that should be removed, or added, to this GE³LS framework?

5. Integration of GE³LS Research.

How can Genome Canada encourage a more effective and interdisciplinary level of integration of GE³LS research into mainstream genomics and proteomics research projects and other disciplines?

In order to ensure that there was opportunity for the widest possible input into the Workshop deliberations the Committee initiated a national survey (copy attached). The responses to the survey will be shared with workshop participants and will inform the discussion of the key issues.

COMMUNITY SURVEY

TITLE: GE³LS: CURRENT ISSUES AND FUTURE DIRECTIONS

NAME:

INSTITUTION:

AREA OF INTEREST:

Please provide your views and insights on the following by January 26, 2006.

All comments should be sent in MS Word format to: ge3ls@genomecanada.ca

1. Definition of GE³LS

GE³LS, as defined by Genome Canada, currently encompasses ethical, environmental, economic, legal and social aspects of genomics and proteomics research.

- Comment on the appropriateness of this framework for future Genome Canada research programming. For example, are there elements or approaches that should be removed, or added, to this GE³LS framework?

2. Funding of GE³LS Research

Genome Canada's mandate is to support "large-scale research projects" in genomics and proteomics. The funding model is such that Genome Canada funded projects, including GE³LS projects, must leverage federal government funds dollar for dollar.

- Comment on the opportunities and consequences for GE³LS research in Canada created by the obligatory large-scale research approach of Genome Canada. In particular, are there new ways of working within this framework to facilitate a more inclusive (casting a wider net) funding of GE³LS research by Genome Canada?
- "Co-funding presents particular issues for GE³LS research." Provide your views on this statement and comment on creative and novel approaches to satisfying the requirement for co-funding.

3. Integration of GE³LS Research.

How can Genome Canada encourage a more effective and interdisciplinary level of integration of GE³LS research into mainstream genomics and proteomics research projects and other disciplines?

4. International GE³LS Symposia

Genome Canada has sponsored four international GE³LS symposia to facilitate research, capacity building and networking amongst key players, including mainstream genomics researchers and GE³LS researchers. In your view how successful have these been and what other approaches could be used to accomplish these objectives?

5. Other Issues

Briefly state specific issues that you would like to bring to the attention of the Workshop's participants.

COMMUNITY SURVEY – E-MAIL

Please provide your views and insights on the following by January 26, 2006.

Genome Canada is currently consulting the broader scientific community on a number of issues related to GE³LS (the ethical, environmental, economic, legal and social aspects of genomics and proteomics research). Your assistance in circulating this to members of your community who are likely to have an interest in these issues would be greatly appreciated.

Genome Canada's Science and Industry Advisory Committee, (SIAC) is hosting a GE³LS Workshop in Ottawa, ON - February 06-07, 2006. The purpose of the Workshop is to bring together representatives from different stakeholder groups to provide input on current and future Genome Canada initiatives related to GE³LS (the ethical, environmental, economic, legal and social aspects of genomics and proteomics research).

Since its creation in 2000, Genome Canada has resolved to ensure a steady growth in Canadian GE³LS research capacity. To date, Genome Canada has approved nine stand alone GE³LS research projects totalling \$30 million and has also placed great importance on ensuring that GE³LS research is integrated into genomics and proteomics research projects. In addition, Genome Canada has sponsored four major events dedicated to GE³LS issues and research.

It is now time to bring the community together again to share ideas on how to go forward in this exciting area of research.

As it is impossible to include everyone in the Workshop from whom we would like to receive input, the Workshop Steering Committee (see membership below) is seeking views from the broader community on a number of key issues that will be discussed at the Workshop. All comments received will be made available to the workshop participants in advance of the event and will be used to inform the discussions at the Workshop. Your input is welcomed, and the Steering Committee thanks you in advance for your contribution and will ensure you receive a copy of the Report of the Workshop.

Please do not hesitate to forward this request to colleagues whom you feel would be willing to provide their comments through this consultation mechanism.

Finally, the Steering Committee apologizes for duplicate postings of this document that you may receive.

GE³LS Workshop Steering Committee

Paul Thompson (Chair)

Michigan State University

Denise Avard

Université de Montréal

Joerg Bohlmann

University of British Columbia

Fern Brunger

Memorial University of Newfoundland

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