



# GENOMICS IN SOCIETY

## **Expert Panel**

Integrated GE<sup>3</sup>LS Research Review Report



**GenomeCanada**

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GLOBAL CHALLENGES + GENOMIC SOLUTIONS



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## Expert Panel

### Executive summary

Genome Canada’s mandate focuses on genomics; however, it not only invests in scientific advances and technological developments, but also supports research that is generally conducted by social scientists, legal scholars and humanities scholars who investigate the implications of genomics in society. Known as GE<sup>3</sup>LS research (an acronym that historically referred to genomics and its ethical, environmental, economic, legal and social aspects), it represents an investment of \$121 million to date. Such investment was made through three funding models: integrated GE<sup>3</sup>LS research, which is being reviewed in this Report; large-scale standalone GE<sup>3</sup>LS research projects; and translational networks.

Genome Canada is recognized as a “world leader” in GE<sup>3</sup>LS research. However, in Genome Canada’s 2014 Five Year Evaluation, it was recommended that *the effectiveness of integrated GE<sup>3</sup>LS in facilitating the translation of genomics research* be assessed. This task has been assigned to the ad hoc Genomics in Society Expert Panel (the Expert Panel), established by Genome Canada’s Science and Industry Advisory Committee (SIAC).

### Mandate and Methodology

The Expert Panel’s mandate was to undertake a review of Genome Canada’s integrated GE<sup>3</sup>LS research to understand how it is being conducted and whether it is achieving the stated objective of facilitating the uptake of genomic-based applications, and to identify factors that contribute to or hinder this success. In doing so, the Expert Panel was asked to produce the following three key deliverables:

1. A definitional framework for integrated GE<sup>3</sup>LS research in Canada.
2. The identification of key indicators of success; factors that contribute to the successful integration of GE<sup>3</sup>LS research; factors that may inhibit success; and strategies for removing these barriers.
3. An assessment of the effectiveness of integrated GE<sup>3</sup>LS research in contributing to the overall uptake of genomic-based applications.

Complementary methods were relied on to gather data that would inform the Expert Panel’s deliberations and recommendations. Genome Canada staff reviewed documents (e.g. applications, final reports) related to nine projects and conducted interviews of nine Project Leaders and eight GE<sup>3</sup>LS Leads, as well as six users of the research and four members of

Research Oversight Committees for a total of 26 separate interviews. Eight of these projects were developed as case studies selected from Large-Scale Applied Research Project (LSARP) competitions held between 2008 and 2015, which span several sectors.

Genome Canada staff also undertook a survey of peer reviewers who reviewed LSARP applications in the four most recent competitions (2012, 2014, 2015, 2017).

In addition, Genome Canada staff carried out telephone interviews with stakeholders of the Genomics Enterprise, including 10 Genome Centre staff, one Genome Canada staff and one external consultant with expertise in Genome Canada's competitions.

Informed by the evidence and discussions amongst the Expert Panel over the course of several meetings, which resulted in a consensus amongst all members, the Expert Panel offers four recommendations in response to the key deliverables.

## Recommendations

### **Recommendation 1: Affirm the Value and Vision of Integrated GE<sup>3</sup>LS Research**

The Expert Panel's first recommendation is a strong endorsement of the value of GE<sup>3</sup>LS research and the integrated model. The Expert Panel determined that the research community and other stakeholders view Genome Canada as a leader regarding GE<sup>3</sup>LS research and believes it should maintain this role and continue to support such research.

Additionally, the Expert Panel believes that, despite some misunderstanding about the GE<sup>3</sup>LS acronym, the term should continue to be used to refer to this unique research approach. However, the Expert Panel believes the term GE<sup>3</sup>LS should be interpreted broadly to refer to "research into the implications of genomics in society."

The Expert Panel recognizes that integrated GE<sup>3</sup>LS research has evolved and that a definitional framework must place the emphasis on researchers with diverse disciplinary backgrounds collaborating to conduct applied research that potentially will result in genomic-based applications that can generate benefits.

#### **THEREFORE, THE EXPERT PANEL RECOMMENDS:**

Genome Canada should reaffirm its commitment to the value of research into the implications of genomics in society by strengthening its support for the integration of GE<sup>3</sup>LS research in large-scale projects to foster the responsible and effective development and uptake of genomic-based applications.

Recognizing that the GE<sup>3</sup>LS acronym has historic and ongoing relevance, the Expert Panel recommends that it be retained. Nevertheless, Genome Canada should promote a broader interpretation of GE<sup>3</sup>LS as “research into the implications of genomics in society” that extends beyond the narrow focus on topics and/or disciplines that make-up the acronym and should encourage innovation in GE<sup>3</sup>LS research strategies and methods to help accelerate the translation of genomics solutions into benefits to society.

To ensure that the broader interpretation of integrated GE<sup>3</sup>LS research is better understood, Genome Canada should adopt a definitional framework that emphasizes the following elements:

- Adopting a team-based approach where researchers with diverse expertise, using a variety of research strategies and methodologies, collectively contribute to a broader understanding of the scientific problem;
- An investigation of factors that may facilitate or hinder the acceptance and uptake of the genomic-based application(s); and
- Provision of evidence that may be useful to inform and help implement changes in policy or practice related to its use.

The Expert Panel further recommends that Genome Canada undertake a targeted communication initiative to advance these objectives within 12 months of adopting these recommendations.

Recommendation 1 fulfills Deliverable 1 by presenting a definitional framework that supports a broad interpretation of integrated GE<sup>3</sup>LS research.

## **Recommendation 2: Enhance Implementation of the Integrated GE<sup>3</sup>LS Research Vision in Large-Scale Projects**

In developing its second recommendation the Expert Panel identified factors and elements of the LSARP competition process that may contribute to or hinder successful integration of GE<sup>3</sup>LS research and the uptake of genomic-based applications.

The Expert Panel concluded that all elements of the competition process – the development of the team, the preparation of applications, the review process and the execution of the research – must reinforce a clear and common understanding of the nature of integrated GE<sup>3</sup>LS research to increase the likelihood of achieving the desired outcomes.

### **THEREFORE, THE EXPERT PANEL RECOMMENDS:**

Genome Canada should review its competition processes used to support funding of large-scale projects to address perceived or identified barriers to selecting strong integrated GE<sup>3</sup>LS research. Program requirements, activities to assist team formation and research development, review criteria and processes, the selection of peer reviewers and members of Research Oversight Committees are amongst the key elements that must be aligned with the definitional framework suggested in Recommendation 1, particularly to reflect the diversity of research expertise involved in projects, and to account for the complexity of translating (genomics and GE<sup>3</sup>LS) research results into tangible benefits.

The Expert Panel strongly encourages Genome Canada to take all appropriate actions at the earliest opportunity, starting with the 2018 LSARP competition, and to be completed over the next two competitions.

This second recommendation responds to Deliverable 2, regarding key indicators of success and factors that contribute to, or inhibit successful integration, along with strategies to remove barriers.

### **Recommendation 3: Enhance Capacity to Conduct and Support Integrated GE<sup>3</sup>LS Research**

Through this Review, the Expert Panel identified two distinct yet interdependent aspects of capacity that deserve attention: the capacity within the research community **to conduct** integrated GE<sup>3</sup>LS research, and the Genomics Enterprise's capacity **to support** integrated GE<sup>3</sup>LS research. Recognizing that integrated GE<sup>3</sup>LS research is a unique model, targeted actions will be required to enhance capacity in each of these two areas.

### **THEREFORE, THE EXPERT PANEL RECOMMENDS:**

To strengthen integrated GE<sup>3</sup>LS research, Genome Canada should undertake the following actions to increase capacity:

1. Build capacity to conduct GE<sup>3</sup>LS research as part of large-scale projects:

Genome Canada should commit to increasing the breadth of researchers pursuing GE<sup>3</sup>LS research as part of large-scale projects, including early career researchers, including through the development of training opportunities.

Genome Canada should seek ways to enhance the collaborations with partners that support social sciences and humanities research and other interdisciplinary research, including universities, federal granting councils and other national or international stakeholders.

2. Build capacity to support GE<sup>3</sup>LS research leadership to enhance integration in large-scale projects:

Genome Canada should reinstate a national senior position whose role would include long-term visioning and oversight of the GE<sup>3</sup>LS research program and, in the short term, supporting the timely execution of the recommendations set out in this Report.

Genome Canada should provide targeted resources to support the Genome Centres' efforts to enhance integrated GE<sup>3</sup>LS research as part of large-scale projects. Where appropriate, Genome Canada should assist in the coordination of such work, or in the development of tools or other material that facilitates it.

By proposing actions related to those who conduct research and those who support it, Recommendation 3 also addresses Deliverable 2 about factors that contribute to or inhibit successful integration of GE<sup>3</sup>LS research in LSARPs.

#### **Recommendation 4: Accountability for the Implementation of the Recommendations**

The Expert Panel's fourth recommendation focuses on accountability, in two regards. First, the Expert Panel believes the recommendations presented in this Report should be discussed by the wider stakeholder community before Genome Canada takes further action. Genome Canada should be accountable to stakeholders and maintain transparency in the decisions it will make in relation to these recommendations, thereby following an accountability pathway in the implementation of the recommendations.

Secondly, the Expert Panel acknowledges the importance of demonstrating the value and impact of GE<sup>3</sup>LS research and encourages the development of key performance indicators as part of the evaluation strategy for LSARP competitions.

#### **THEREFORE, THE EXPERT PANEL RECOMMENDS:**

Implementation and evaluation go hand in hand. The following actions are called for:

1. Recognizing the interest in this Review, the Expert Panel encourages Genome Canada to undertake a comprehensive consultation with the research community, Genome Centres and other stakeholders on the findings and recommendations of the Expert Panel. Following the consultation, the results should be shared with the Genome Canada Board through SIAC to help inform decision-making. In this way, Genome Canada would follow an accountability pathway for the implementation of this Expert Panel's recommendations.

2. Genome Canada should strive to assess the overall value of integrated GE<sup>3</sup>LS research, its outcomes and its impact within Canada through the development and application of key performance indicators that capture the diversity of this research and its translational pathways. This should be part of an overall strategy for longitudinal performance evaluation.

The Expert Panel encourages Genome Canada to initiate these actions in partnership with Genome Centres, within 12 months of adopting these recommendations.

Recommendation 4, through its focus on accountability and evaluation, responds to Deliverable 3 regarding an assessment of the effectiveness of integrated GE<sup>3</sup>LS research in contributing to the uptake of genomic-based applications.

## Conclusion

The three key deliverables outlined in the Expert Panel's mandate are presented through four recommendations, to assist Genome Canada's Board of Directors in its decisions related to GE<sup>3</sup>LS research and its integration in large-scale, applied genomics projects.

Moreover, the Expert Panel notes that, even though this Review focused on integrated GE<sup>3</sup>LS research, there also was evidence that diverse funding structures are required to ensure a more comprehensive understanding of the full range of implications of genomics in society. Therefore, Genome Canada should maintain a suite of research funding models to investigate the implications of genomics in society.



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