

# Democracy, Ethics and Genomics: Introduction to a special issue

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## 1 Introduction

Beginning with the discovery of the structure of DNA, genomic sciences have expanded rapidly, and in recent years we have begun to see the products of this vast research effort translated into technologies that are beginning to impact health-care, food production, ecosystem management and environmental remediation. While transgenic applications of genomic sciences have been controversial at times, other applications such as genetic testing have been considered more acceptable. Applications within the life sciences to improving our understanding of the processes of speciation and for exploring the role and function of genes in response to environmental change have also been valuable. It is also true to say that the gene has assumed mythical qualities in late modernity and it has an alluring mystique (Nelkin & Lindee, 2004) with broader social and political meaning loaded onto a scientific classification (Tansey & Burgess, forthcoming). Somewhat ironically, perhaps, while scientists increasingly seek to downplay the concept of genetic determinism and emphasise gene-environment interactions, proteomics and epigenetics, the concept of genetic determinism has established strong roots in popular culture and the media (Bates, 2005).

In another setting we might explain the pervasiveness of this myth by asking what kind of social and political work it does. In this special issue we focus in on a narrower set of questions related more directly to the governance of technology. Our central goal is to reflect on what might be called the ‘participatory turn’ in the governance of technology: a general and often unquestioned view that the public should assume some direct role in shaping the emergence of new commercial and public technologies. This special issue is the culmination of a three year study to evaluate a range of public engagement methods and to reflect on their usefulness for improving ethical understanding and governance

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of genomics. The original papers were written for an invitational workshop in Vancouver on March 16–19, 2005. Public engagement is practiced and promoted for a wide range of objectives, so it is worth briefly considering the purposes against which it is evaluated in this issue.

The project “Democracy, Ethics, and Genomics: consultation, deliberation and modelling” (DEG) had as its primary objectives to compare different approaches in applied ethics for addressing a common question, and to determine relative strengths and weaknesses of each approach. In contrast to the use of ethics expertise, theory, or principles as the basis for grounding ethical judgments, and its combination with scientific expertise to justify regulations, our approach committed ethics to public engagement. Recent experience and social analysis suggests that the norms or values used by experts and policy makers do not reflect the norms or values of those governed by the regulations. The authority of the regulators has traditionally been justified on the basis of elected representation. Technology policy has increasingly been influenced by international trade agreements, multinational corporations, and the flow of personnel between government and corporations (not to mention financial scandals). Liberal justice theorists have suggested that an important problem of justice that precedes determining the fair distribution of social resources is the question of who gets to participate in the social institutions that determine the values for fair distribution (Buchanan et al., 2000). Moral philosophers have insisted that policy related to biotechnology must “actively seek out moral perspectives that help to identify and explore as many moral dimensions of the problem as possible” (Sherwin, 2001).

The problem can be characterized as a “democratic deficit” related to the authority and justification of regulation in morally contentious areas. Most of the decisions about policy related to genetic sciences cannot be resolved by reference to widely held moral principles, whether or not there is a presumption of strong protection for non-interference in the affairs of industry. There is no common secular ethics or common global foundation that will serve as a basis for the policy decisions related to genetic sciences. Yet it is inevitable that decisions must be made that will enable or restrict genetic technology, its benefits, risks and distribution.

What is the use of ethics if it cannot provide authoritative answers to ethical questions? Applied ethics uses ethical theory to articulate the full complexity of practical ethical problems. Systematic collection of information related to the issues helps to avoid fallacies and unreliable interpretations, enables researchers to identify dimensions of the issue that engage theoretical resources, and widens the range of moral intuition and perspectives considered by the analysis beyond that of the analysts and their culture. Good applied ethics analysis will clarify the range of issues, articulate the considerations that are relevant, explain why other dimensions of the discussion are less helpful than initially apparent, and describe the options and values that support alternative choices. Applied ethics analysis presumes that it is impossible to remove analysts’ perspectives from the process and resulting analysis. This is one of the reasons that resolutions to the problems that applied ethics tackles tend to be procedural,

describing practical measures to address some of the major values that support the analysis and identifying what would constitute a fair way to make a decision that is unavoidably controversial and contestable.<sup>1</sup> If public engagement is to enrich and provide input to the resolution of ethical issues related to the genetic sciences, then the specific approaches selected will require careful evaluation.

Proposing democratic or procedural approaches to ethical issues and policy presumes that there are few issues related in this domain that are resolvable with reference to ethical principles, and that the most important role for applied ethics analysis is to inform and support public dialogue and the democratic determination of policy. Ethics is an important part of the process, but “ethics experts” should not be mistaken as having moral authority, objectivity or pre-science.

Emphasis on engaging practical ethical issues and information gathering requires that applied ethics analysis has a reasonably well defined issue or problem. Funded by Genome Canada and Genome B.C., DEG focused on one of the most important ethical problems for genomics and biotechnology: assessing the moral weight of public, and by implication expert, perspectives for policy and ethical analysis. We asked three central questions regarding the different approaches to data collection and ethical analysis between approaches grounded in (1) the interactive role of bioethics and consultation, (2) contemporary discussions of deliberative democracy and (3) evolutionary understanding of ethics articulated through online surveys and computer modelling.

In order to identify a manageable and comparable set of problems we first identified a narrower range of topics related to genome research, including biobanking, salmon genomics, and “governance” of genomics. The consultative and modelling approaches gathered data for different topics, but focused on salmon genomics to support more detailed comparison at the workshop. These analyses were written up for the workshop and circulated to the participants. Deliberative democracy is often more concerned with theory related to the politically authority of institutional and political powers, and is sometimes less data-oriented. James Fishkin was recruited as an excellent representative of an applied approach to deliberative democracy. His paper was also circulated to participants and a modified and update version is included below. Participants were selected for their reputations, involvement in similar projects, as well as international and disciplinary diversity. They reviewed and submitted comments on the three papers prior to the workshop. The comments were made available through a private website, and served as the basis for initial organization of the three day workshop. Following the workshop, abstracts were solicited and invitations for papers extended. This issue of IA is the result of the peer review of the submitted papers. The first three papers present the different approaches using salmon genomics as a focus. The other authors assess the three approaches and develop implications for the wider area of public engagement,

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<sup>1</sup>Deliberative democracy literature reminds us that procedural does not mean void of substantive moral commitments. Recommending a public dialogue, for example, may be accompanied by commitment to strong substantive principles about respect of participants as moral equals and to inclusiveness of participation.

policy development, public dialogue, and the politics of biotechnology.

The workshop and the papers collected here are intended to put a hard edge on the evaluation of these approaches, but are also motivated to support matching approaches for other issues, as well as to consider how to rigorously design multi-method approaches. In fact, an outcome of the DEG project is a multi-method approach to defining interests, norms and issues related to genomics through “Building a GE<sup>3</sup>LS Architecture,” now funded by Genome Canada and Genome B.C.

## 2 The contributions

The first three papers in this special issue set the context for the workshop and for the papers that emerged out of it. These papers report on the findings of two contrasting approaches to public engagement in the governance of genomic research. In simple terms the paper by Tansey and Burgess takes norms described by the participants regarding the likely impacts of genomic technologies at face value, while the second paper by Ahmad et al. examines whether norms change in response to more information and to changes in the context in which information is presented. One view is that the difference between these two approaches reflects an important dichotomy in the ongoing debate about the role citizens ought to play in the governance of technology: one suggests citizen’s views should be treated as sovereign whereas the other suggests that citizen’s views may be responsive to context and information. We feel this distinction is too simplistic; rather the two approaches may be useful at different stages in the governance of technology. It is important both to bring to the fore under-represented views but it is also important to recognise that these views may not be stable.

These two papers also employ contrasting methods; the first solicited input using the medium of focus groups while the second used a structured web-based survey. While neither paper seeks to capture a representative sample of public opinion, the web-based approach has the merit of being more affordably scalable, assuming participants can be recruited to participate. In common with other survey methods, the web-based survey achieves this by largely determining what issues are important in advance (although with diverse expert input to the design process). The effect is to establish a controlled and shared context for responses, which means the data from different individuals are comparable. By contrast, the focus groups targeted specific sub-populations and to a large degree allowed the assembled participants to determine what counted as relevant issues for discussion. While the first method requires some standardisation and closure, focus groups remain more open to new insights.

These contrasting approaches emerged out of a competition between methods within a single project. It is not clear that there is a clear winner, although the reader may judge according to his or her own criteria which paper makes a more compelling case. Instead, it might be that the methods developed in the two papers really have different applications and are non-substitutable.

Briefly, Tansey and Burgess describe the findings of a series of one-off focus groups to explore the hopes and concerns participants anticipate will emerge from research on salmon genomics and salmon aquaculture. While salmon genomics is an emerging technology with a range of potential applications in the commercial, conservation and research sectors, salmon aquaculture is a well-established commercial technology. The paper describes the range of hopes and concerns associated with both technologies and compares these with the issues revealed by a literature review. One of the key findings of the paper is that the hopes and concerns are framed by the wider changes within the coastal communities likely to be affected by the two technologies. For instance, could these technologies help to stem the declining economic viability of coastal communities? The implication is that these technologies emerge onto a landscape that already has a distinct form and topology. This implies that it is as important to understand the context into which the technology will emerge as it is to accurately describe its technical characteristics.

Ahmad et al describe a custom-built web interface known as Norms Evolving In Response to Dilemmas (NERD). Focusing on human health genomics they use the case of  $\beta$ -Thalassæmia to provide a context for exploring the mutability of social norms regarding genetic testing. Grounding the study in this case allowed the authors to develop a series of plausible dilemmas. The survey participant is presented with an increasingly complex context and is asked to indicate how they would respond. Respondents were able to draw on advice from fictional but realistic advisors, who represented contrasting views about the issue of  $\beta$ -Thalassæmia testing. The paper describes a series of nested findings. Firstly it describes the common clusters of responses revealed through the questionnaire. Secondly the paper subdivided respondents into two groups; one group was given feedback about how earlier users had responded to the questions, while the other gave blind responses. Thirdly, the authors were able to explore how the relationship between the direction of the participants' responses and the advice they sought. Do respondents seek confirming or contrasting advice?

Fishkin offers a third alternative to contrast with the first two papers in this special issue. Deliberative polling is intended to satisfy both the criteria of representativeness and reflective deliberation. It is explicitly critical of approaches that capture 'top of head' responses to issues and seeks instead to engage citizens in an active and intensive process of learning and deliberation. By drawing participants selectively and proportionately from across society, deliberative polling seeks to create a temporary microcosm of society for the purpose of evaluating a specific policy choice. While Fishkin has yet to apply this process to the issue of genomics, he draws on a number of large scale examples completed to date to illustrate how the methodology works. Importantly, in some of the applications he describes, the results of the deliberative polling exercise have had a direct influence on policy.

The remaining papers in the special issue respond to questions raised by these three initial papers and also discuss the wider context within which public consultation and engagement occurs. Focusing on the governance and regulation of transgenic salmon in Canada and the US, Marden, Longstaff and Levy

suggest that the design and implementation of public consultation needs to take account of the specific policy arena where decisions are ultimately made. They ask how public consultations vary according to which authority convenes them and they ask whether consultation should, in fact take place independent of the policy context. Their paper provides a detailed and useful review of the regulatory system surrounding transgenic salmon in the US and Canada and acknowledges the complex array of overlapping responsibilities within each jurisdiction. Drawing on this forensic analysis the authors offer some preliminary conclusions about the relationship between the policy context and the form of consultation.

Goven asks us to take a step back from a debate about the relative merits of various methods of public consultation. Rather than ask 'how' to consult with the public, she prefers to explore the justifications for why we should consult with the public. In reframing this question in this way, Goven draws attention to broader political changes in advanced industrial democracies. In particular, she interprets the participatory turn in policy-making as symptomatic of a broader neo-liberal agenda and an inevitable consequence of a shift from practices of government to practices of governance. Her goal is to problematise widely accepted public consultation practices by suggesting they support a wider agenda—an agenda of which she is critical.

Campbell follows a similar tack to Goven and in his paper seeks to provide a richer historical context for the development of industrial agriculture. He points out that genomics is simply the latest incremental intensification of agricultural production created by an industrial system that has steadily built up momentum over many decades. He fundamentally questions the integrity of commercial actors and their role in influencing the trajectory of the agricultural system. He concludes by drawing attention to the role of audit cultures in improving the accountability of the key players involved in the governance of industrial agriculture and argues that they may represent an important mechanism for enabling meaningful public engagement and scrutiny.

In the last paper in this special issue, Castle and Culver draw attention to one of the core dilemmas faced by social scientists who engage with the social, ethical and economic issues associated with major research regimes such as the Human Genome Project or Genome Canada. The default role for social scientists is reactive and they seek to make a case for a far more active role. The perception from some quarters is that the quality and integrity of social science is compromised when researchers engage with and are funded by science based programmes that seek to develop commercial technologies. The authors recognise that some research amounts to little more than marketing in support of research programmes, but suggest that the quality of social science research in this domain can be improved through more active involvement by social science researchers. In making this point they distinguish broadly between disengagement, engagement and consultation respectively and identify the conditions for more meaningful participation by social scientists in helping to evaluate the social acceptability of new and emerging technologies.

### 3 Conclusion

The empirical papers developed by the project team (Tansey and Burgess and Ahmad et al.) benefited greatly from the extended and detailed critiques provided by the participants in the workshop. Hopefully the revisions to these papers do justice to the quality of these contributions. James Fishkin presented an ambitious and challenging framework that could be used to support decision making around new and emerging genomic technologies. While these initiatives are expensive, they represent a fraction of the costs associated with the failures that appear when the wrong decision is made: consider the cost and disruption of controversies like Monsanto's attempt to introduce genetically modified products to the European market. Moreover, if we are to take the democratisation of technological development seriously, then this commitment needs to be underpinned with resources.

The other contributions to this special issue examine the broader social and policy context within which public consultation and engagement typically occurs and raise provocative questions, some of which question the framing of our approach to the research effort in general. They remind us that the very basis on which technological governance ought to be undertaken remains deeply contested. Surfacing these positions involves both the kind of empirical work described in the first three papers in this special issue combined with the of reflexive use of theory that characterises applied ethics, moral philosophy and social science generally. For those ultimately responsible for decision making in modern industrial societies, the difficult pill to swallow is that even the best designed research efforts may reveal contradictory certitudes about the appropriateness of technological choices; in Hampshire's (2000) terms, it may simply be the case that justice is conflict.

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