Studies in Ethics, Law, and Technology

Volume 6, *Issue* 1 2012 *Article* 2

Genomics and Public Involvement: Giving Justifications Their Due

Gabriele Badano, *Centre for Philosophy, Justice and Health, University College London*

Recommended Citation:
Badano, Gabriele (2012) "Genomics and Public Involvement: Giving Justifications Their Due," *Studies in Ethics, Law, and Technology*: Vol. 6: Iss. 1, Article 2.
DOI: 10.1515/1941-6008.1176

Genomics and Public Involvement: Giving Justifications Their Due

Gabriele Badano

Abstract

The involvement of the public in the governance of genomics has become a topic of growing interest among scholars, practitioners and policy-makers. The implementation of public involvement programmes may be expensive, and the design and evaluation of public participation is a matter of controversy. Thus, this paper examines the justifications for public participation in the governance of genomics to help understand whether public involvement is worthwhile and to provide a guide to the design of public participation.

I identify four primary justifications in support of public involvement. I argue that three of them have serious flaws: neither an increase in the stability of institutions, nor the positive effects on individual virtues, nor the epistemic merits of participatory activities provide a solid ground for the engagement of the public in the governance of genomics. However, the ideal of legitimacy in the exercise of coercive power appears to lend strong support to public involvement programmes. Given that the reasons why public involvement is sought shape the design of the participatory activities, restricting the range of valid justifications promises to simplify the task of designing and evaluating public involvement.

KEYWORDS: genomics, public engagement, deliberative democracy

Author Notes: Centre for Philosophy, Justice and Health, University College London, gabriele.badano.10@ucl.ac.uk

Introduction

Over the past two decades the involvement of the public has taken centre stage in both the academic literature and the wider debates about the governance of medical and scientific research. Given the major ethical controversies involved, the need to engage the public has been perceived as especially compelling in the case of genomics. As a result, there has been considerable effort to investigate the ways in which members of the public can effectively be involved in the governance of genomic research.

This paper takes a step back from the design of public involvement activities. In fact, my aim is to outline a critical assessment of the main reasons for engaging the public in the governance of genomics. The importance of this exercise is twofold. First, public participation is not the only option available to shape genomic research, and can be expensive. Therefore, societies need to investigate whether the involvement of the public is worthwhile.

Second, the design of public engagement activities should rest on an in-depth analysis of the reasons for involving the public. Varying arguments lie behind the idea that the public should be engaged in the governance of genomic research. As it is shown towards the end of the paper, depending on which arguments we emphasize the most, the design of public involvement programmes is pulled in opposite directions. So, a critical analysis of the arguments supporting public participation is needed to address the issues of design in a satisfactory manner.

Given the link between justification and design, my arguments stand in contrast with those authors who deal with issues of design but do not analyze the reasons why public participation is necessary.[1] In addition, this paper embeds a sense of dissatisfaction with those who, when it comes to the justification of public involvement, endorse multiple arguments without making any distinction between them.[2] As it is argued below, there are stronger and weaker arguments supporting public engagement, and some of these arguments do not fit well together. Notably, however, the proposed shift from design to justification does not have deconstructive aims.[3] Far from claiming that the deepest motives behind public involvement are questionable, I argue that a compelling argument for the participation of the public in the governance of genomics can be sorted out from the range of available justifications.

My argument is structured as follows. Each of the next four sections is devoted to the critical analysis of an argument in support of the engagement of the public

---

1 Among others, see Abelson et al. (2003), Ahmad et al. (2006), Godard et al. (2004) and Rowe et al. (2004).

2 See Avard et al. (2009) and O'Doherty and Hawkins (2010).

3 In contrast, Goven (2006) aims to stress the inconsistency between the purpose of public involvement and what public involvement can actually achieve.

in the governance of genomics. Three arguments have serious flaws and provide a shaky ground for public involvement in the governance of genomics: the stability of institutions, the individual virtues spread by public involvement and the epistemic powers of popular participation. However, the requirements of legitimacy in the exercise of coercive power constitute a strong rationale for engaging the public in the governance of genomic research. In the concluding section, I substantiate the claim that procedural design depends on a critical assessment of the justifications supporting public involvement. Thus, restricting the range of acceptable justifications promises to simplify the task of designing and evaluating public engagement programmes.

The stability of institutions

Some democracy theorists argue that procedures involving members of the public in a transparent way improve the stability of institutions.[4] With regard to the governance of genomics, this argument can be rephrased as the claim that public engagement builds public trust in research and in public and private institutions that employ research outcomes. If publicly accessible, a detailed discussion of how genomic research should be governed can increase public understanding of the information and the arguments involved. In this way, a broader consensus is likely to emerge. In addition, even when no consensus is achievable, the public are more willing to trust institutions that involve their representatives in the process of governance. Furthermore, public engagement can identify the ethically sensitive research activities and applications that researchers should avoid.

We should not be impressed by this argument. My criticism is not that the argument from stability relies on controversial empirical claims or that transparent public involvement procedures would actually undermine trust.[5] Instead, I employ the argument that stability is not the kind of value that should govern our choice among forms of governance.[6] To be sure, institutions need to be sufficiently stable. Nonetheless, the stability of institutions alone cannot make them preferable over alternative arrangements. Indeed, institutional arrangements must display some "first virtue" that gives value to those institutions. In other words, however smoothly institutions may run, they are not justified unless it can be shown why such institutions should survive over time.

In summary, the ability to build trust is not an adequate justification for public participation if we do not show why it is desirable that a genomic community that involve the public in the process of governance be stable. So, our case for public

4 See Gutmann and Thompson (1996) and Habermas (1996).

5 For this kind of criticism, see Calabresi and Bobbitt (1978).

6 Here I draw on Rawls's remark that justice, as opposed to efficiency and stability, is the first virtue of institutions (see Rawls, 1999, p. 3).

involvement needs to rest on values that are different from stability - the relevance of stability is secondary and dependent on public involvement satisfying "first-class" virtues of institutions.

The virtues of discussion

An additional argument in support of public participation in the governance of genomics focuses on the virtues of citizens. It is argued that engaging the public in discussions concerning the common good would develop positive character traits in the citizens. First, the public would develop a more active attitude towards politics. Second, participation in public discussions would allow individuals to express their opinions and critically assess competing arguments. As a result, citizens would become better informed, develop an independent judgement and hone critical thinking abilities. Thus, the argument goes, we should create as many opportunities for public participation as possible and let the public discuss a broad range of topics.[7]

I posit that the argument that discussion develops virtues in individuals is flawed and should not be considered when determining the degree of public involvement in the governance of genomic research. As in the case of stability, my criticism is not that the empirical assumptions on which the argument under discussion rests are questionable. In fact, I do not draw on those arguments claiming that inclusive discussions concerning policy issues could foster conformism and manipulation rather than autonomy and critical thinking habits.[8] In my view, the main problem with this argument is the tension between the appeal to certain character traits and a broadly liberal commitment to equal respect.

Western societies are characterized by a wide pluralism of moral, religious and philosophical views; the opinions held by fellow citizens about such issues as the good life or the meaning of existence differ enormously from each other. This fact should be considered when institutions, laws and policies are shaped. Given that intelligent and good-willed persons provide different views of the same religious, moral or metaphysical issues, there are good reasons to believe that this kind of disagreement is a natural product of our reasoning faculties. Moreover, societies should always show respect to different opinions and the persons to whom these opinions are important. Therefore, liberal societies should do their best to justify their structure of institutions on the basis of no controversial claim. In this way, equal respect is shown to persons of all religious and philosophical backgrounds.[9]

---

7 For a classic example of this argument, see Mill (2003).

8 See Christiano (1997).

9 For the reasonable pluralism of comprehensive doctrines and the way in which liberal institutions should deal with it, see Rawls (1996).

The argument that public engagement in the governance of genomics should be supported because it would contribute to increasing judgement autonomy, critical thinking and an active political attitude has to do with character traits that concern the deepest loyalties of persons and their regard for a comprehensive array of values and beliefs. In our diverse culture, there are reasonable persons who simply do not agree that these traits are virtues. As highlighted by John Rawls, persons holding certain religious doctrines might disregard the principle of criticizing principles and values. Instead of pursuing a strong ideal of autonomy, they might prefer to defer one's judgement to a priest or to their sacred books.[10] Consequently, a liberal society should avoid any appeal to strong moral autonomy and activism when shaping public institutions. Using these supposedly virtuous traits as the basis for the justification of laws and policies would not show equal respect to those citizens who consider deference to be a greater virtue than independent judgement or activism. In brief, the equal respect for persons holding incompatible conceptions of the good life prevents us from employing the argument from the virtues of citizens as a good case for involving the public in the governance of genomics.

Can public participation track the correct answer to our questions?

An argument that is often invoked to support participatory procedures stresses the epistemic powers of democracy. In brief, this argument states that involving a large number of decision makers is the best method available to approximate the correct answer to the questions at hand.

The epistemic arguments for inclusive decision-making procedures are often grounded in the Condorcet Jury Theorem.[11] In its more general form, this theorem states that if participants vote on the basis of what they believe to be the correct solution to the problem at hand, vote independently of one another and have an average probability of being correct that is greater than 0.5, the more the number of participants increases, the more the probability that a majority vote would yield the correct answer nears 1.

Alternatively, other advocates of the epistemic value of popular participation support the Deweyan idea that the social intelligence necessary for decision-making is rarely placed within an identifiable group. Fellow citizens come from various walks of life and have unique insights into specific problems. Thus, a participatory democracy is needed to pool our widely distributed social intelligence and yield the best decisions.[12]

---

10 See Rawls (1997, p. 778).

11 See Estlund (1997) and Gaus (1997).

12 Anderson (2006) and Bohman (2006) ground their epistemic account of the value of participation in Dewey's intuitions about social intelligence.

At first glance, these epistemic arguments strongly support the idea that the public should be engaged in the governance of genomic research. It seems that the governance of genomics should not be limited to experts, administrators and professional politicians because the involvement of the general public is needed to track the correct answers to the issues at hand. In contrast to this intuition, I put forward two lines of criticism of the idea that these epistemic arguments should be regarded as good justifications for public involvement in the governance of genomics.

First, the epistemic case for public participation flirts with the idea that the correct answers to the issues that are to be settled exist before any decision-making process takes place. In fact, the value of participatory procedures rests on the ability to track answers whose correctness is given by standards that are independent from the participatory decision-making procedures themselves. This is not the place, however, to take issue with the meta-ethical notion that there are cases in which the correctness of a decision of normative importance is not the product of the process through which the decision may be made. The scope of my criticism is much more limited: I argue that the idea that a correct answer exists independently of the decision-making activities is unconvincing as far as the governance of genomics is concerned.

The link between the correct answer and the process lurking in the background of the epistemic arguments is in contrast to an appealing idea that has emerged in the context of applied ethics. In brief, it is argued the application of the substantive principles of ethics cannot fully determine the appropriate solution to a large number of concrete dilemmas concerning, among other things, health and science. The more concrete and applied the issues are, the more fine-grained the substantive principles of ethics should be. Given the extreme concreteness and specificity characterizing many issues of applied ethics, it is apparent that, as far these issues are concerned, the idea of a process-independent standard that determines the correct solution loses its meaning. In fact, several authors claim that, before a suitably-defined decision-making process takes place, the more we can do is speak in the terms of a set of "just-enough" or, for the sake of my argument, "correct-enough" possible answers.[13]

For example, let us consider one issue that, central to the design of genomic research, is full of ethical implications: informed consent.[14] Is there any instance of the use of genomic information for which no informed consent should be sought (or sought again)? Should any form of statistical or scholarly research be exempted from the need to request consent? Under which conditions should donors be allowed to withdraw consent? Though of great ethical importance, these questions are far more concrete than the available substantive principles of

[13] This claim is put forward by Daniels and Sabin (2008) and Fleck (2009).

[14] See Secko et al. (2009).

ethics and require distinctions among highly specific circumstances. As far as such "interstitial" questions are concerned, the idea that a correct answer exists before a fitting decision-making process takes place is deeply unconvincing. Which substantive standard could distinguish a specific policy concerning consent and statistical research from a range of alternatives that are not only innumerable, but also differentiated by small details? Under these circumstances, it becomes apparent that substantive standards can at best tailor a range of correct-enough answers, and participatory procedures cannot be justified in virtue of their ability to track an answer whose correctness is given by an independent standard.

My second criticism of the idea that these epistemic arguments should be regarded as good justifications for public involvement in the governance of genomics is that the epistemic arguments are based on an over-optimistic picture of the competence of the public. Indeed, the general public might be the best judge for a wide range of policy issues. However, as far as the governance of genomics is concerned, the general public appear to lack the necessary competence to support the Condorcet Jury Theorem or the Deweyan argument.

A good decision in the context of the governance of genomics needs to be a sensible decision on scientific and clinical matters. Let us consider the allocation of public resources among competing lines of genomic research. The scientific prospects of the competing research projects, and the methodology that is necessary for each project to be successful, need to be considered to make an adequate decision, let alone for the decision to be the correct one. Do the members of the general public really have more than a 0.5 probability of being correct with regard to those technical issues? Is the intelligence concerning the relevant scientific and clinical matters really spread throughout society? Such questions cast serious doubts on the applicability of epistemic arguments to genomics: the general public appear to be ignorant about most of the scientific and clinical matters that are crucial to any good decision in the context of genomics, with the relevant intelligence concentrated within communities of scientific and technical expertise.

Unfortunately, this is not the place to pursue a thorough analysis of the claim that, at least under certain circumstances, laypersons can be more knowledgeable about scientific matters than the relevant experts: for example, it is maintained that those who are directly affected by environmental change might have a deeper knowledge of its symptoms than scientific experts.[15] Here I can only point out that, on the whole, the scientific and clinical matters that make up genomics are different from environmental science. In the case of a community of farmers living near a malfunctioning nuclear plant, environmental scientists investigate the changes occurring to the "world" where the farmers live. Therefore, the

[15] See Funtowicz and Ravetz (1993).

farmers have a direct access to many issues discussed by the experts. In the case of the study of human genome, it is hard to imagine how laypersons could have direct access to the factual matters discussed within the relevant communities of expertise. As in the example of the competing research projects, laypersons appear to enjoy no privileged approach to the clinical and scientific matters that are crucial to any good decision in the context of genomics.

Coercion and legitimacy

Finally, the involvement of the public in the governance of genomics can be justified on the basis of legitimacy. The starting point of this argument is the recognition that political power is coercive and that persons have no real choice but to live under it. This recognition is coupled with a commitment to equal respect for persons or, as Rawls puts it, the idea that political power is ultimately the power of the public as a collective body.[16] Though apparently incompatible, coercive power and the idea that citizens are bearers of equal shares of political authority can be reconciled if binding decisions are reached through a legitimate process, i.e. embedding the Rousseauian notion that "obedience to a law one prescribes to oneself is liberty".[17]

In more practical terms, legitimate decision-making processes must be deliberative, in the sense that they should be aimed at reaching decisions that are acceptable to every citizen. However, deliberation cannot be the only component in a legitimate decision-making process.[18] This is because popular participation is necessary for procedures and resulting decisions to satisfy the ideal of legitimacy as self-rule.[19]

With regard to genomics, the research focus and regulation deeply affect the interests of the citizens. To give a few examples, public funds are often involved, many applications of genomics show beneficial promise, the manipulation of the human genome and the use of genomic information are delicate matters that touch deeply-held moral and religious beliefs. Once any decision concerning such momentous matters is made, it is backed by the power of the state, and the citizens are coerced into living with it as long as the decision is not overturned. Then, according to the argument from legitimacy, participatory and deliberative

16 See Rawls (1996, pp. 135-137).

17 Rousseau (1968, p. 65).

18 The idea that deliberation should be complemented with public involvement has received considerable support in the context of the allocation of medical care, which has many points of contact with the regulation of scientific research (see Emanuel, 2002, Friedman, 2008, Rid, 2009 and Sabik and Lie, 2008).

19 See Cohen and Sabel (1997).

procedures are necessary to make the governance of genomics compatible with the respect due to every citizen as a bearer of an equal share of political authority.

The argument from legitimacy provides the strongest case for the involvement of the public in the governance of genomics. This argument addresses one of the first problems of political theory, namely coercive power. Legitimacy reconciles coercion with an appealing account of equal respect through what my paper is striving to justify, i.e. public participation in the decisions concerning the common good.

Moreover, the idea of legitimacy offers significant advantages over alternative justifications for the engagement of the public in the governance of genomics. Legitimacy differs from stability in that it provides a reason why a structure of institutions should survive over time. Unlike the appeal to the virtues spread by discussion, the principle of legitimacy through participatory-deliberative procedures does not clash with important conceptions of the good life that flourish in our pluralistic societies.

Unlike the epistemic account of the merits of public participation, the principle of legitimacy does not rest on questionable assumptions concerning the clinical and scientific knowledge of laypersons. Further, the argument from legitimacy is consistent with the idea that, as far as numerous questions about genomics are concerned, the notion of a substantive standard that fully determines a correct answer loses much of its meaning. This last remark highlights a profound difference between these two arguments. While the epistemic arguments place importance on participatory procedures because of their relationship to a substantive outcome (the correct decision), the argument from legitimacy works the other way round: a decision is valuable only as the product of a legitimate decision-making process. This inconsistency should make us especially suspicious of any attempt to juxtapose epistemic arguments with arguments from legitimacy in support of public involvement.

Conclusion: for a "normatively conscious" design of public involvement

A critical analysis of the main reasons why the public should be engaged in the governance of genomics was attempted in this paper. I concluded that the argument from legitimacy strongly supports the involvement of the public in the governance of genomic research. On the contrary, the stability of institutions, the positive effects on individual virtues and the epistemic powers of public participation are flawed in important respects.

Given the great amount of issues involved in the critical assessment of any argument, this analysis is not meant to be conclusive. In essence, my aim is to provide an outline of the critical exercise that should be performed (and taken to a further level of complexity) by those who are interested in the design of

procedures for public involvement in the governance of genomics. In fact, underlying my arguments is the often-overlooked fact that the design of procedures for public involvement is dependent on the reasons for engaging the public. Thus, a critical analysis of the reasons supporting public involvement is required to answer the issues of design in a satisfactory way.

To show how deeply procedural design is affected by the arguments supporting public involvement, let us briefly consider two broad questions of design. One of them concerns the timing of public involvement, and asks how early the public should be involved in the governance of research or, in other words, how many normative issues should be settled before the public are engaged. The other question concerns the impact on policy that public involvement should have. To a considerable extent, the answers that a supporter of public involvement should give seem obvious: the earlier the involvement of the public, and the greater its impact, the better. Nevertheless, a closer look reveals the dangers involved in overlooking such obvious questions and shows that the design of public involvement activities is lead in different directions by different arguments supporting the engagement of the public.

In regard to the timing of public participation, a proponent of public involvement placing the greatest importance on the argument from stability might propose that public participation should be limited to the latest stages, when the most concrete applications of research are at stake. In fact, the distrust felt by a public that is not consulted could be prevented by well-publicized public engagement activities occurring at a late stage. Furthermore, late-stage involvement could still identify the research applications that should be avoided to prevent the most hostile reactions. Regarding the impact of public involvement programmes, those who focus on the character traits spread by popular engagement are lead to the conclusion that no strong influence on policy is needed. After all, it is discussion, not its impact on policy, that has valuable effects on the virtues of individuals.

As the examples of timing and impact show, even the answers to apparently obvious questions of design might be influenced by our choice of rationale for public engagement. Thus, procedural design needs to be grounded in a critical analysis of the justifications for public involvement. In particular, such analysis should go deep enough to see that there are strong and weak justifications, as well as justifications that do not fit well together. As shown by the critical analysis outlined in this paper, a narrow range of arguments should be employed to justify public involvement. Getting rid of several arguments that, at times, lead public involvement in opposite directions will simplify the task of designing and evaluating public engagement activities.

References

Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. Deliberations about deliberative methods: issues in the design and evaluation of public participatory processes. *Social Science and Medicine* 2003; 57: 239-251.

Ahmad R, Bailey J, Bornik Z, Danielson P, Dowlatabadi H, Levi E, Longstaff H. A Web-based Instrument to Model Social Norms: NERD Design and Results. *The Integrated Assessment Journal* 2006; 6: 9-36.

Anderson ES. The Epistemology of Democracy. *Episteme* 2006; 3: 8-22.

Avard D, Bucci LM, Burgess MM, Kayne J, Heeney C, Farmer Y, Cambon-Thomsen A. Public Health Genomics (PHG) and Public Participation: Points to Consider. *Journal of Public Deliberation* 2009; 5: article 7.

Bohman J. Deliberative Democracy and the Epistemic Benefits of Diversity. *Episteme* 2006; 3: 175-191.

Calabresi G, Bobbitt P. *Tragic Choices. The conflicts society confronts in the allocation of tragically scarce resources*. New York: Norton and Company, 1978.

Christiano T. The Significance of Public Deliberation. In Bohman J, Rehg W, eds. *Deliberative Democracy: Essays on Reason and Politics*. Cambridge: MIT Press, 1997: 243-277.

Cohen J, Sabel C. Directly-Deliberative Poliarchy. *European Law Journal* 1997; 3: 313-342.

Daniels N, Sabin JE. *Setting Limits Fairly: Learning to Share Resources for Health*. Second Edition. New York-Oxford: Oxford University Press, 2008.

Emanuel EJ. Book review of *Setting Limits Fairly: Can We Learn To Share Medical Resources? New England Journal of Medicine* 2002; 347: 952-954.

Estlund DM. Beyond Fairness and Deliberation. The Epistemic Dimension of Democratic Authority. In Bohman J, Rehg W, eds. *Deliberative Democracy: Essays on Reason and Politics*. Cambridge: MIT Press, 1997: 173-204.

Fleck L. *Just Caring: Health Care Rationing and Democratic Deliberation*. New York-Oxford: Oxford University Press, 2009.

Friedman A. Beyond Accountability for Reasonableness. *Bioethics* 2008; 22: 101-112.

Funtowicz SO, Ravetz JR. Science for the Post-Normal Age. *Futures* 1993; 25: 739-755.

Gaus GF. Does democracy reveal the voice of the people? Four takes on Rousseau. *Australasian Journal of Philosophy* 1997; 75: 141-162.

Godard B, Marshall J, Laberge C, Knoppers BM. Strategies for Consulting with the Community: The Cases of Four Large-scale Genetic Databases. *Science and Engineering Ethics* 2004; 10: 457-477.

Goven J. Dialogue, governance, and biotechnology: acknowledging the context of the conversation. *The Integrated Assessment Journal* 2006; 6: 99-116.

Gutmann A, Thompson D. *Democracy and Disagreement*. Cambridge: Harvard University Press, 1996.

Habermas J. *Between Facts and Norms: Contributions to a Discourse Theory of Law and Democracy*. Cambridge: MIT Press, 1996.

Mill JS. *On Liberty*. New Haven-London: Yale University Press, 2003.

O'Doherty K, Hawkins A. Structuring Public Engagement for Effective Input in Policy Development on Human Tissue Biobanking. *Public Health Genomics* 2010; 13: 197-206.

Rawls J. *Political Liberalism*. Paperback Edition. New York: Columbia University Press, 1996.

Rawls J. The Idea of Public Reason Revisited. *University of Chicago Law Review* 1997; 64: 765-807.

Rawls J. *A Theory of Justice*. Revised Edition. Cambridge: Harvard University Press, 1999.

Rid A. Justice and procedure: how does "accountability for reasonableness" result in fair limit-setting decisions? *Journal of Medical Ethics* 2009; 35: 12-16.

Rousseau JJ. *The Social Contract*. London: Penguin, 1968.

Rowe G, Marsh R, Frewer LG. Evaluation of a Deliberative Conference. *Science, Technology, and Human Values* 2004; 29: 88-121.

Sabik L, Lie R. Principles versus procedures in making health care coverage decisions: addressing inevitable conflicts. *Theoretical Medicine and Bioethics* 2008; 29: 73-85.

Secko DM, Preto N, Niemeyer S, Burgess MM. Informed consent in biobank research: A deliberative approach to the debate. *Social Science and Medicine* 2009; 68: 781-789.