Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism

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As genomic science has evolved, so have policy and practice debates about how to describe and evaluate the ways in which genomic information is treated for individuals, institutions, and society. The term genetic exceptionalism, describing the concept that genetic information is special or unique, and specifically different from other kinds of medical information, has been utilized widely, but often counterproductively in these debates. We offer genomic contextualism as a new term to frame the characteristics of genomic science in the debates. Using stasis theory to draw out the important connection between definitional issues and resulting policies, we argue that the framework of genomic contextualism is better suited to evaluating genomics and its policy-relevant features to arrive at more productive discussion and resolve policy debates.

Keywords: genetic exceptionalism, genomic contextualism, stasis theory, bioethics

Debates about genetics often become mired in concerns about genetic exceptionalism, the idea that genetic information is special or unique. In these arguments, disputants are often unable to agree on how to resolve the important considerations regarding whether genetic tests and results from those tests ought to be handled differently than other types of medical information. Questions regarding whether genetics should merit special consideration impact a number of important approaches to genetics policy and practice, such as procedures for ordering genetic tests, educating patients about genetics within a health system, how to communicate results of genetic tests to patients and their families, and how to appropriately integrate genetic information into patient health records. While debates about genetic exceptionalism seem to have waned in the early 2000s, we are concerned about the return of genetic exceptionalism as a feature of similar policy debates in the genomic era. We contend that both appeals to genetic exceptionalism and accusations of genetic exceptionalism play a counterproductive role in many debates related to genetics and genomics. We offer genomic contextualism as an alternative idiom, or way of talking, about genetics and genomics that we hope will support more productive debates and even help resolve them. Relevant to these debates, the proposed idiom of genomic contextualism encourages individuals to recognize a fundamental duality: Genomic tests both share characteristics with other types of medical tests and represent a combination of features that make them distinct. The ways in which genomic tests are both distinct from and similar to other tests are relevant to many policy and practice debates. These relationships depend on the context where these policies will be considered and applied. This reconsideration of idioms for policy debates is particularly timely given continuing advances in genomics that have generated a wide array of debates in a number of scholarly, policy, and community contexts.

In this article, we start by examining in more detail the idiom of genetic exceptionalism and how the idiom of genetic exceptionalism has persisted.
into the genomic era, shaping and limiting how we understand and respond to the exigencies raised by developing genomic technologies, and thus forestalling important policy debates. In this section, we utilize debates about secondary and incidental findings as an example to illustrate our points. We then turn to scholarship on rhetoric to develop a framework for analyzing extant debates and argue that productive debates have been stalled by a lack of consensus about how genetic information, and its similarity to other domains of science and medicine, should be understood. Debates rooted in this dissensus are often marked by fallacious *tu quoque* arguments, where one asserts that the opponent is hypocritical or inconsistent in the claims they make. Finally, we pivot to a discussion of genomic contextualism as a rhetorical shift that may support more productive and resolvable debate. Using secondary and incidental findings as key examples to demonstrate these challenges, we assess the utility of the rhetorical shift to genomic contextualism in individuals and families, clinical and research institutions, and society at large. For each domain, we apply the rhetorical framework developed in the second part of the essay to demonstrate the value of approaching these debates with the new idiom of genomic contextualism.

**REVISITING GENETIC EXCEPTIONALISM**

Where did the idea emerge that genetic information is “different” and thus might need special treatment? It is clear that this perspective is rooted in long-standing cultural and social beliefs regarding the importance of DNA in shaping our health and identity. Genetic inheritance, for example, has long held an enormous amount of power as an explanatory model for human characteristics such as appearance, behavior, and personality. Similarly, there is a range of deep-seated cultural beliefs about the determinative power of genetics for human life, including human health (Condit 2010; Collins 2006; Nelkin and Lindee 1995). Given the remarkable power of these views on genetics, it should not be too surprising that many involved in policy debates related to genetic information have concluded that decisions to conduct a genetic test or disclose genetic information need to be treated differently from similar decisions in health and medicine.

Claims that genetic testing and genetic information require specific, tailored policies have appeared for decades in discussions of clinical care, health research, legal policies, and social uses of genetic technologies. We can find ample evidence, for example, of policy debates related to the first wave of predictive genetic tests developed in the 1980s and 1990s, including reproductive genetic testing and heritability of IQ, which featured claims that genetic testing and genetic information should be treated as special, or exceptional (Block 1995; Clayton 1993; Green and Botkin 2003; Manjrekar 1984). These examples suggest that genetic results may be exceptional because they predict phenotypes that are not yet manifest using other methods and because they may reveal information about an individual that can only be uniquely discovered pre-symptomatically through genetic sequencing (Berg et al. 2011; Biesecker and Green 2014; Green and Guyer 2011; Khoury 2003).

These claims have evolved in the genomic era. While the use of genomic tests, including whole exome and genome sequencing, raises issues similar to those of first-generation genetic tests, it also raises a host of more complex challenges. For example, members of the Personalized Health Care Work Group of the American Health Information Community (AHIC) argued that genomic information may need special policy and practice protections within the context of electronic health records (McGuire et al. 2008). In order to support this claim, they highlighted characteristics that genomic data shared in common with genetic information: the uniqueness of DNA, the immutable nature of DNA through a patients’ lifetime, the potential impact of genomic information on families, and the historical misuse of genetic information. They also raised a number of concerns that are more specific to genomic data, such as the complexity and scale of this information, and the difficulties posed by representing this complexity in electronic health records.

From our contemporary perspective, we are able to recognize these views on genetic and genomic information as *genetic exceptionalism*. In fact, for most of us there is no meaningful difference between the view that genetic tests and information need “special” policies, and the idiom of genetic exceptionalism that we use to make arguments about that view. In this discussion, we focus primarily on the idiom—the way of talking or writing about the issue—because the idiom of genetic exceptionalism is often cast as binary. Referring to “genetic exceptionalism” invites disputants to accept that genetic tests and information are exceptional or unique, or to reject that view altogether. When it comes to policy debates related to genetics and genomics, disputants are left with only two options for framing genetic tests and information: it is exceptional, or it is not.

Despite the widespread use of this idiom, a number of authors have advanced more nuanced views of the distinctive features of genetics. In a 2003 piece, for example, Green and Botkin concluded that genetic testing is not per se exceptional, and instead suggested that individual genetic tests should be evaluated in terms of their effects on patients, including their relative risk for exacerbating stigmatization, their potential to inform clinical care, and the complexity associated with interpreting test results (Green and Botkin 2003).

Unfortunately, debates on specific practices or policies have typically excluded these more nuanced perspectives. Disputants in these debates, often trapped in a binary idiom, have tended to argue that genetic
testing/information is exceptional, and therefore an exceptional policy is required—or, in contrast, that genetic testing/information is not exceptional, and therefore no special policies are required. As an example, many arguments around genetic nondiscrimination legislation, and later specifically about the Genetic Information Nondiscrimination Act (GINA), followed this pattern and ultimately resulted in the creation of a law to protect against discrimination (Federal Register 2013; H.R. 493. 2007). Some authors have argued that genetic information is exceptional, and therefore warrant special protections against genetic discrimination (Hellman 2003). Others have challenged the claim that genetic information is unique and thus deserving of specific protections, and some, alongside this claim, argue that broader protections not limited to genetic information are required (Gostin and Hodge 1999; Rothstein 2007).

This polar dynamic is harmful to effective debate, for at least two reasons. First, this rhetorical framing reinforces the assumption that tailored policies are only justified if genetic tests and information are globally exceptional. There is no room for exploring whether specific characteristics or combinations of characteristics that we can observe about genetic tests or information would directly justify a particular policy that is genetics-specific. Second, this polarity in the debate makes it inevitable that genetic exceptionalism will become a straw man. Any perspective that argues for tailored policies for genetic tests and information becomes subsumed under the label of “genetic exceptionalism” and can be discounted by arguing that genetic tests and information are not different or should not be treated differently. This critique often misses the point, however, since tailored policies for genetic tests and information need not be predicated on a claim of global exceptionalism.

Over time, and increasingly in recent years, an even more troubling pattern has emerged. For reasons that are unclear, scientists, clinicians, ethicists, and policy analysts have increasingly assumed that it is unwarranted to regard genetic and genomic tests and information as unique. As we would anticipate based on the idiom of genetic exceptionalism, this has made it increasingly difficult to defend policies and practices that are tailored to genetic and genomic tests or information. In fact, the idiom of genetic exceptionalism is now rarely used by disputants to support their claim that genetic information requires policies or practices that are tailored to this context. Rather, it is an idiom that is used almost exclusively as an accusation for justifying the rejection of policy and practice proposals made by others: disputants label policy and practice proposals as being based on “genetic exceptionalism” solely to reject them.

This development has proven extremely problematic in recent debates on ethical, legal, and social issues related to genetic and genomic information. These include debates about the inclusion of genomic results in electronic medical records (EMRs), the context and manner in which it is appropriate to return results to patients, the use of genomic technologies across different community contexts, and many others (Catz et al. 2005; Magnusson 2002; Miller et al. 2008; Sanderson et al. 2013). These important debates have become mired in claims that any policy and practice proposals that would vary from practices in other medical domains are rooted in genetic exceptionalism. Because this claim can be used by both sides of a debate to reject potential solutions designed to address challenges raised by genomic information, productive discussion is stymied, and consensus is precluded.

A striking example where disputants were being accused of treating genetics as exceptional can be found in the controversy that emerged in response to a 2013 recommendation by the American College of Medical Genetics and Genomics (ACMG) (Green et al. 2013). In this recommendation document, the authors argued that laboratories performing clinical sequencing should analyze sequence data to look for incidental findings in a specified panel of important genes, which they called the “minimal list.” This group explicitly recommended that a search for incidental findings in these genes should be performed by laboratories regardless of the medical indication that prompted the testing, and that any positive results be returned to the patient, regardless of their preferences.

While the authors did not provide a detailed justification for this recommendation, they did provide the concise observation that when an incidental finding has a high prevalence and an effective intervention is available, both laboratories and health care providers would have a “fiduciary duty to prevent harm,” and that this beneficence-based duty “supersedes concerns about autonomy” (Green et al. 2013). In this document, the authors preemptively rejected a genetic exceptionalism critique by arguing that their recommendations were consistent with clinical practice in other areas. Specifically, they observed that the duty to report genomic incidental findings is the same as the duty to report potentially important incidental findings in other areas of medical practice.

However, critics of these recommendations were quick to utilize the idiom of genetic exceptionalism in their critique. In one response, Wolf and colleagues argued that “rejecting the need for the patient’s informed consent to look for mutations in a predetermined list of 57 genes is a profound departure from prevailing law and norms” (Wolf et al. 2012). Since this critique of the ACMG policy leverages the observation that seeking informed consent for receiving secondary findings is exceptional when compared to other domains of medicine, it is an implicit accusation based on genetic exceptionalism. These critics went on to argue that analogies with incidental findings in radiology were misplaced. Another set of authors argued that the process for
generating these ACMG recommendations did not account for patient perspectives on these issues. As a result, the critics argued, the recommendations “demonstrate an unfortunate kind of genetic exceptionalism” (Townsend et al. 2013). In response to these critiques, the authors of the ACMG recommendations responded in a number of contexts, often evoking the idiom of genetic exceptionalism in their defense. One piece, written by authors that included two of the leading committee members who developed the ACMG recommendations, was entitled “Reporting Genomic Sequencing Results to Ordering Clinicians: Incidental, but Not Exceptional” (Green et al. 2013). Here, the authors turned claims of genetic exceptionalism around, again claiming that it was their detractors who were guilty of committing this fallacy. They argued, “To date, the traditions of genetic testing and reporting have exceptionalized all genetic risk information as potentially dangerous,” suggesting that clinicians and patients, including their detractors, should reconsider this tradition in “the era of genomic sequencing.”

To be sure, this debate about reporting secondary findings from clinical genomic sequencing involved a wide range of issues, with genetic exceptionalism marking only one dimension of a complex set of perspectives. This case is illustrative, however, of the counterproductive role that claims (and, more commonly, accusations) of genetic exceptionalism have tended to play in these debates over practice and policy. As long as definitional issues, like the meaning of genetic exceptionalism, remain unresolved, disputants will find it very difficult to identify and address legitimate disagreements about values and policies. In the next section, we turn to the field of rhetoric to understand why this particular piece of language has become problematic, with the hopes of providing some insights that will lead to more substantive and effective debate.

RHETORICAL ANALYSIS OF GENETIC EXCEPTIONALISM

If we are to rehabilitate many of the debates related to policy and practices related to genomics, it is critical that we reconsider how the idiom—the vocabulary and related patterns of discourse—of genetic exceptionalism is utilized in these debates. A focus on language is important and appropriate because the idioms in which we speak shape how we think and argue about an issue (Billig 1996). In this case, the idiom of genetic exceptionalism limits the types of issues that can be productively considered.

In order to assess genetic exceptionalism as an idiom for debate, we turn to rhetoric, the classical art of argument and persuasion first codified by Aristotle about 2,500 years ago (Aristotle 1991). Contemporary application of this rhetorical tradition to scientific and medical communication emphasizes the ways in which language shapes how we talk about policy and practice (Druschke and McGreavy 2016). Rhetoric encourages a focus on the means of persuasion: how one argues for competing claims; what argumentative or emotional impact the names or descriptions used might contain; what evidence must be provided; what ancillary claims must be made in developing the case for one’s position; and so on. By examining the language used in arguing about the uses of genetic information, we can identify the operations and limitations of the idiom of genetic exceptionalism.

Classical rhetoric provides a wealth of concepts to use while analyzing arguments and discourses, but one useful tool for this case is “stasis theory” (Crowley and Hawhee 2012; Fahnstock and Secor 1988). Stasis theory was first developed as a series of “points,” or questions, that classical rhetoricians proposed for developing policy and legal arguments. The use of the questions proposed in stasis theory can help keep a debate focused on the issues at hand by providing a way for disputants to identify four key points of disagreement and contention between them (Brizee 2008; Fahnstock and Secor 1988; Marsh 2006; Weber 2016). It has also been applied productively to multiple scientific and biomedical areas including paleontology (Northcut 2008), space exploration (Weber 2016), and research on pain and pain management (Graham 2015). The theory is also equally useful for analyzing arguments after the fact since stasis theory provides a framework for “sorting out issues addressed in scientific discourse within quite complex rhetorical situations” (Prelli 1989, 174). We use stasis theory to analyze the arguments around genetic exceptionalism. First, we describe the points of stasis.

There are four points or questions identified by classical rhetoricians when discussing stasis theory (Table 1). These questions can be used to evaluate an argument and decide at what level a disagreement is taking place, and whether disputants are even arguing about the same thing. The four questions proceed in order from establishing the facts to proposing an action or policy. The first stasis point is conjectural (stochanos), which considers the facts and whether a thing or issue exists. When analyzing a debate, we might ask questions like “What is the thing we are debating about?” The next is definitional (horos) and asks, “What type of thing has been identified at the first stasis? How should it be named and understood?” The third is the qualitative stasis (symbebekos), which considers the question, “How should we value it?” In arguments about genomics, we can draw on the well-defined principles of biomedical ethics or the core principles of the Belmont Report to assess the respective medical or research-related values that emerge to address this stasis (Beauchamp and Childress 2013; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978). The fourth is the translative stasis (metalepsis) that addresses what types of action should be considered
As each point of stasis is addressed—the ideally by disputants coming to an agreement—the debate can move on to the next point of stasis. Yet if disputants do not agree on one of the points of stasis, the debate will become stalled there until it is resolved or until an outside authority overrides the disputants and forces one point of view on that stasis point (Brizee 2008).

By explicitly framing debates in terms of these four stasis questions, we can reveal the underlying source of disagreements that more informal assessments will miss. As an example, the debate over the 2013 ACMG recommendations focused on a number of key policy points related to returning secondary genomics findings. The backlash against the original 2013 ACMG recommendations resulted in a revised policy by the ACMG stating that returning secondary findings should be the default practice, but that patients (or their parents/guardians) could opt out of receiving secondary findings (ACMG Board of Directors 2015). It appears significant that this revised policy was released by the ACMG Board of Directors, and not the original authors of the ACMG recommendations. According to their contemporaneous publications, the original authors were not convinced that their original policy was in error (Green et al. 2013). Rather, the ACMG Board of Directors issued a revised policy as a political solution to address a debate that was not moving toward consensus. In order to resolve, or at least understand, the deadlock, it becomes necessary to understand what “deeper” levels of disagreement might be preventing each side from making arguments that would be convincing to the other. With respect to arguments about genetic exceptionalism, participants on both sides of the debate evoked this rhetoric to support their claim or attack their opponent’s claim.

The fact that disputants on both sides of the ACMG debate evoked genetic exceptionalism hints that this debate on policy involved, to some extent, the disputants “talking past one another.” That is to say, they were arguing about policy when they had not even agreed upon more fundamental issues about the way genetic information should be understood. The roadblock in the ACMG debate involved a disagreement over the second question of stasis, horos. As rhetorical theory would predict, a debate stymied in this way had resulted in both sides employing fallacious arguments. Specifically, this debate had veered into a fallacious mode of argument known as the tu quoque. Tu quoque, Latin for “you also,” is an informal logical fallacy in which disputants accuse each other of committing the same inconsistency.

(i.e., specific steps to protect information such as policies or strategies to make it available to patients, providers, and researchers, etc.). As each point of stasis is addressed—ideally by disputants coming to an agreement—the debate can move on to the next point of stasis. Yet if disputants do not agree on one of the points of stasis, the debate will become stalled there until it is resolved or until an outside authority overrides the disputants and forces one point of view on that stasis point (Brizee 2008).

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While identifying inconsistencies in the claims made for a position can be useful, it can also rapidly degenerate into tu quoque fallacies, and it is not always easy to identify in the midst of a debate when that move to fallacy has occurred. One clear sign of this move into fallacy, though, is the paradigmatic “you also” stage of an argument, when disputants/participants stop developing or modifying the claims being challenged and start trading accusations of committing the same inconsistency: when both sides of a debate announce their opponent is committing the inconsistency of which they have been accused, the debate is stalled in tu quoque fallacies.

We believe contemporary debates over a wide array have similarly devolved into tu quoque fallacies centered on the idiom of genetic exceptionalism. These include, for example, debates about whether special practices are needed for reporting genomic results in electronic health records (Hazin et al. 2013; McGuire et al. 2008). In retrospect, this should not be so surprising. After all, a commonsense consideration of genetics would indicate that genetics is “its own thing.” In the next section we take a closer look at genetic and genomic tests in order to understand how a binary rhetoric of genetic exceptionalism obscures important characteristics of genetic and genomic tests and information.

GENETICS AND GENOMICS IN CONTEXT

Information that comes from genetic and genomic tests may have features that are distinct from other medical diagnostics and information. There are at least three ways in which they are distinct. First, genetic and genomic tests represent a unique combination of characteristics. Second, genetic and genomic tests share individual characteristics with other domains of medicine, but these shared features can be subtly different in ways that are relevant to practices and policies. Third, there are important policy or clinical practice features that accompany genetics that are not easily discarded. Let us consider each of these senses in turn.

Each individual feature of genetic and genomic tests may be analogous to other medical tests, but the precise combination of characteristics is unique. This is, in fact, one of the many ways that domains are distinguished from one another. For example, whole genome sequencing shares similarities to medical imaging in that it can generate incidental findings. Whole genome sequencing is also like an HIV test, or a breast cancer predisposition panel, in that these all have potential for predicting future medical problems (Green and Botkin 2003). However, medical imaging does not typically reveal something important about disease predisposition, and HIV tests are unlikely to generate incidental findings. Every domain of medicine demonstrates its own unique set of characteristics.

While genetic and genomic tests share individual characteristics with other domains of medicine, these features are not identical. Consider, for example, the capability of both whole genome sequencing and a medical resonance imaging (MRI) scan of the chest to reveal incidental findings. While this characteristic is shared between these two technologies, there are important nuances that are relevant to practices and policies for uncovering and handling incidental findings. For example, radiologists intentionally plan MRI scans to cover only specific sections of the human body. Within the sections of the body scanned, however, there is no practical way to obscure individual organs. For whole genome sequencing, these limitations are different. Genomic laboratories can build sequencing libraries to focus on specific subsets of the human genome, and can build analytical pipelines that only call variants in specific sections of the genome; thus, the ability exists to obscure parts of the genome. While the feasibility and ethical appropriateness of these practices can certainly be debated, the point is that genomic sequencing and MRI are not identical in their ability to generate (or suppress) incidental findings. These differences distinguish them from one another in ways that may be relevant to policy and practice debates, and these implications will vary in different contexts. For example, the authors of the ACMG recommendations suggested that their policies did not treat genetics exceptionally, since clinicians have a duty to report incidental findings discovered in other domains of medical practice, such as radiology. However, due to the fact that genomic analysis pipelines provide a number of opportunities to prevent clinicians (or, indeed, any human) from “seeing” unwanted incidental findings, it is quite possible that different policies are warranted in these two areas of medicine.

This brings us to the third, and perhaps most important, feature that makes genetic and genomic tests distinctive, even if they are not exceptional: context. Context refers to the circumstances around the situation, location, or event in which genomics is discussed. Even if disputants in a particular policy or practice debate agree on the two previous observations about genetics and genomics, they still must undertake important work to define the combination of characteristics that mark the genetic or genomic technology, test, or information that is being used in that context (the second point of stasis). They must then work to weigh how much value or importance should be given to those features within the context within which the policy or practice will be utilized (the third point of stasis). Finally, they must work through the decision-making process that is most appropriate for their context to settle on a specific policy and practice (the fourth point of stasis). None of this detailed process is possible if we allow the idiom of genetic exceptionalism to collapse all of these nuanced connections and implications into two possible categories. Because the idioms in which we speak shape how we
think and argue, we are often stuck in debate about policies and practices that are stymied because the disputants must utilize an idiom that describes neither side’s views fairly. And because most disputants have accepted that genetic exceptionalism is unfounded, it is a rhetorical weapon that can be fallaciously lobbed in both directions.

We identified three ways in which genetic and genomic information can both be similar to other types of medical or health information and maintain distinct qualities that differentiate it from other domains of medicine. This unique combination of characteristics—the overlaps with other domains of medicine, and the contextual features that play out in policy and practice—highlights the need to find better ways to assess these features and productively move debates forward. In the next section, we illustrate how the application of stasis theory in bioethics presents a framework for assessing features of genetics and genomics to address this fallacious forestalling of contemporary debates on genetic tests and genetic information.

**FINDING A BETTER WAY: GENOMIC CONTEXTUALISM**

We introduce the term *genomic contextualism* to describe the concept that genomic information can both be similar to and maintain distinct qualities from other areas of medicine. This new idiom highlights the fact that one cannot prioritize, a priori, whether a “similarity” or a “difference” is the more important characteristic of genomic information. Rather, these decisions must be resolved on a case-by-case basis through a process of debate and deliberation that considers each of the features of the particular technology being used, and that places these features within the specific context where the policy or practice will take effect. Genomic contextualism recognizes that the contexts where genomic information will be used will determine what qualities of genomic information are salient to the case at hand.

Important contextual elements to consider are the public perspectives about how genetic knowledge is utilized and understood in our social and physical environments. It is important to consider not only scientific expertise, but also public and community perspectives on genomic information, especially as they relate to one’s health, personal identity, and the information’s wider impact on families and communities. Historically, public views on genetics have emphasized the qualities of genomic tests that are different from other medical tests. This is most likely a result, at least in part, of the genetic exceptionalist framing of genetic and genomic tests by medical practitioners, scientists, and science journalists, but public beliefs about how biological inheritance works also play a major role (Condit 2010).

The views of the public are not homogeneous, however. People from different communities, and even within a community, will have different perspectives on the significance of DNA in their lives. For some, genetic information can be viewed as different from yet complementary to other types of medical information, rather than exceptional. For example, some groups view many different types of biological material (such as DNA, blood, hair, tissues, and organs) as extensions of themselves, and thus treat it as special and hesitate to part with any of it for research purposes (Garrison et al. 2016; Lewis et al. 2013; Sahota 2014). Some Indigenous communities have expressed concerns about unapproved secondary uses of DNA samples and have demanded that their biospecimens be returned or destroyed after a study has ended. After the settlement of a lawsuit over misuse of DNA samples, the Havasupai Tribe retrieved the remaining samples and disposed of them with a ceremony (Harmon 2011). The Nuu-chah-nulth tribe also fought to have their DNA samples returned after learning that they had been used in secondary unapproved research studies including studies on human migrations that challenged their origin beliefs (Wiwchar 2004). Other Indigenous people have described blood and DNA as an extension of their selves and spiritual being and have special concerns about secondary uses of their samples (Sahota 2014). To address such concerns, some First Nations communities in British Columbia have proposed a “DNA on loan” approach in which the donors maintain ownership of the samples and specifically dictate how it may be used in research, with the expectation that unused samples would eventually be returned to the donors (Arbour and Cook 2006). These views indicate that these communities find something inherently special about biospecimens and want to exert stronger control over how they are used.

Other communities may make a greater distinction between genetic research and other types of research such as psychological research involving MRI scans. These individuals might be more willing to participate in some types of biomedical research, such as a study involving analyses of protein-based biomarkers, imaging results, or medical records, but would not be willing to participate in genetic research. For example, among NHANES participants who agreed to complete surveys, undergo a medical examination, and have their blood drawn, a subset were unwilling to also have their genetic material stored for future research (McQuillan et al. 2003). This difference in willingness to participate between genetic and nongenetic research was especially common in non-Hispanic black individuals. This phenomenon may be attributable to historical injustices committed against African-American research participants by medical researchers.

We believe the concept of genomic contextualism facilitates discussion and addresses important considerations, like the diverse views of Indigenous and other minority groups in North America, that are obscured by an exceptionalist perspective. Genetic tests can have
impacts that extend beyond the bounds of individuals, their families, and biomedical institutions. These impacts are manifold and include commercial, political, and legal implications. To explore the implications of genomic contextualism, we examine two examples where the framework can support productive debate about how genomic information is utilized across the domains of individuals and their families, medical and research institutions, and the broader society. For each of these examples, we turn to stasis theory to describe the steps in the argument and to demonstrate how genomic contextualism avoids the fallacious "tu quoque" arguments associated with genetic exceptionalism across the domains. These examples capture important similarities, but also highlight important differences between genetic and other nongenetic exceptionalism across the domains. These examples help us to provide an alternative analysis grounded in genomic contextualism to account for the multiple distinguishing features of genetics, the features it shared with other domains, and the importance of context in deciding when both similarities and differences matter.

**Genomic contextualism in secondary and incidental findings**

Genetic tests have long been utilized in clinical settings as a tool to diagnose the genetic basis of medical conditions or diseases. The results of genetic tests offer insights into human biology, but also uncover potentially surprising information about individuals and their close relatives. Many such surprises emerge as secondary genetic findings—results that are revealed even though they are unrelated to the reason for testing. Some have argued that revealing secondary findings to individual patients and their families may cause more harm than good, especially if the results are unexpected, are incidental, and offer no specific medical benefit (Lohn et al. 2014). Yet, patients undergoing radiological or conventional laboratory testing often are not offered the opportunity to decline receiving incidental findings because they are within view.

Debate over the ACMG recommendations stalled at this stage and, as we noted in the preceding, often turned to claims and accusations of genetic exceptionalism. Turning to the four questions in stasis theory allows us to provide an alternative analysis grounded in genomic contextualism. We begin with the presumption that the conjectural stasis—that genomic test results exist—has been resolved in favor of this position. Since genomic test results exist, we move to the definitional stasis, and we consider ways in which genomic test results are both distinctive and similar to other types of test results. Like other tests, the results can be predictive of health outcomes, can provide unanticipated results, and are often nondeterministic. Unlike some other tests, such as radiological findings, genomic test results indicate heritability. The number of results generated also distinguishes genomic testing from radiography, especially as the interpretation of some results is unclear and continually evolving as research continues. Finally, secondary genomic findings often require additional analyses to identify variants in off-target genes; they are not necessarily “incidental” in the way that unexpected masses may be incidentally identified when a body region is imaged.

We can manage the tension between these similarities and differences when we consider them in light of the values that ought to guide policy; this is the issue addressed at the third qualitative point of stasis, which considers the values that ought to guide the interpretation of the object we have identified and defined in the first and second points of stasis. Here, we draw on the widely accepted principles of medical ethics to help us organize the relevant values in this point of stasis (Beauchamp and Childress 2013; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978). Values that could be considered include patients’ preferences around receiving or declining results (respect for autonomy), and the potential for minimizing the social and psychological stress that might be imposed on patients and participants (nonmaleficence), while returning any actionable results that can lead to positive medical outcomes (beneficence). Lastly, we might consider the access and equity issues or the potential burdens placed on scarce healthcare resources if there is a mandate to return results (justice).

The fourth stasis is translative, where we ask, “If we agree on the facts, definitions, and values, then what ought we to do?” One possible policy outcome, depending on the context, is that individuals and families should have the choice of receiving or declining secondary findings. Alternatively, a policy could state that patients should not be able to decline highly actionable genetic findings. Another option might be to engage communities in discussions about what types of results would be meaningful and to develop policy guidance based on these perspectives. The range of possible policy options emerges from the fact that genomic test results, like radiological tests, can be predictive of health and provide unanticipated findings. Yet we cannot treat genomic test results identically with other types of clinical diagnostics, because the issues of heritability and the need to specifically search for these results complicate the simple calculus of beneficence that drives the automatic return of radiological findings. We must also consider the autonomy of patients and research participants whose context informs their perspective, especially given that some individuals say they want to receive this type of information while others would prefer not to receive it (Brothers et al. 2017). In this way, the stasis analysis leads to possible policy outcomes that recognize the contexts in which genomic test results may be generated. These policy options are line with the intuition that a
### Table 2. Using stasis theory to address impacts of genetics.

| Example                          | Conjectural                                                                 | Definitional                                                                 | Values                                                                 | Policy                                                                 |
|----------------------------------|------------------------------------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------|-----------------------------------------------------------------------|
| Secondary findings               | There is a test that has generated genomic results.                         | Like other tests:                                                            | Patients have preferences about receiving or declining results (autonomy) | Potential policy: When actionable results are available, patients should have the choice of receiving results. |
| from clinical sequencing          | OR                                                                           | • Predictive of health                                                       | Actionable results allow patients to do something about them (beneficence) | OR Agreement to undergo testing should be accompanied by consent to receive highly actionable findings. |
|                                  | Genetic test results can be disclosed to the patient or not disclosed to the patient. | • Unanticipated findings                                                     | Protect privacy and minimize harms (nonmaleficence)                    | OR Use community insights to set preferences about results.          |
|                                  |                                                                               | • Non-deterministic                                                         | • Returning results is expensive and can exacerbate access and equity issues (justice) |                                                                       |
| Data sharing in genomic research  | There are various genetic test results.                                      | Like other tests:                                                            | Respect privacy preferences (autonomy)                                 | Potential policy: Genomic test results—like other medical tests and personally identifiable material—deserve robust privacy protections. |
|                                  | OR                                                                           | • Some information should be kept private.                                   | Knowledge can maximize benefits for individuals (beneficence)           | OR All studies should allow for broad data sharing to maximize scientific progress. |
|                                  | Sharing genetic data can allow other investigators to do research.           | • Privacy violations can cause harm.                                         | • May require a high resource burden to protect data and there are concerns about equitable access to genomic tests for patients (justice) |                                                                       |
|                                  |                                                                               | • People value privacy protections.                                         |                                                                       |                                                                       |
|                                  |                                                                               | • Sharing data could advance scientific productivity.                        |                                                                       |                                                                       |
|                                  |                                                                               | Unlike other tests:                                                         |                                                                       |                                                                       |
|                                  |                                                                               | • People could be reidentified.                                              |                                                                       |                                                                       |
|                                  |                                                                               | • People find their genetic information to be particularly sensitive.        |                                                                       |                                                                       |
range of return policies may legitimately respect autonomy and beneficence while also considering the resource burden of returning results (Jarvik et al. 2014).

Genomic contextualism and data sharing

Increasingly, both clinical and research institutions are generating immense amounts of genetic and genomic data through large-scale biobanking efforts that enroll thousands of patients. The genomic research results generated through these large-scale efforts are intended to be used repeatedly in research studies to advance our understanding of human health. This goal might involve research by investigators at just one institution, but could be attained more effectively through the sharing of genomic data with investigators at other institutions and around the world. Data sharing, the practice of making scientific information obtained from research studies available to other investigators, can utilize a range of strategies, including depositing data into a central database that is then accessible to other researchers. Databases may operate under different models of oversight, ranging from closed or restricted access (Mailman et al. 2007), to open access where information is more freely accessible (The 1000 Genomes Project Consortium et al. 2010). The sharing of genomic data between institutions is an important example of a debate affecting clinical and research institutions where genetic exceptionalism is often invoked.

Some have advocated for increased oversight and protection of biospecimens containing genetic material, and of the genomic information derived from these samples and stored in research databases. From 2011 to 2017, bioethicists and health policy experts debated a set of possible revisions to the Common Rule, the federal regulations in the United States that govern the protection of human research subjects. One proposed change was to encourage broad consent to allow for a wide range of uses of biospecimens, thus prompting several studies to assess people’s willingness to give broad consent (Garrison et al. 2016; Sanderson et al. 2017). Another important locus of controversy was a proposal to require consent for all research utilizing biospecimens, even if direct identifiers like name and medical record numbers were removed. Previously, deidentified biospecimens could be used for research purposes—and shared with other investigators—without consent. This debate focused on the potential to identify the donor of a biological sample based on analysis using genomic technologies (Federal Register 2011, 2017; Gymrek et al. 2013; Homer et al. 2008). This policy debate was just the most recent in a broader discourse about the protection of biospecimens containing genetic material—and the genomic data derived from those samples—in research repositories.

As the Common Rule debate demonstrated, many consider genomic data to be special, since they are potentially identifying. This view has led to policies like new requirements from the National Institutes of Health for explicit permission for sharing of genomic data and special oversight from committees who decide on access and use of genomic data (National Institutes of Health 2014). On the other hand, while continuing to recognize the importance of protecting the identities of individuals who have donated biospecimens and data for research purposes, there were many researchers who felt the need to add increased consent requirements or additional oversight concerning the identifiability of genomic data was unnecessary or potentially burdensome to the research enterprise (Cadigan et al. 2015; Federal Register 2017). Future policy debates will have to address whether changes in our understanding of the identifiability of DNA or the potential misuse of shared genomic data merit further changes to human subjects protections.

In addition to identifying individual patients or research participants, genomic data can also contain information about a person that they would consider private and would not want to have shared, like predictions about their health or estimates of their genetic ancestry. Concerns about privacy are not unique to genomic data. Personal financial information, like credit card numbers and credit reports, can reveal important information about a person that they would consider private, including income and spending habits. When asked what types of medical information deserve extra privacy protections, 92% of participants in one study felt that Social Security numbers deserved extra protection, compared to 44% for genetic test results (Kaufman et al. 2009). Finally, context matters when it comes to deciding on levels of oversight. Some communities may be especially uncomfortable with donating their genetic data for research purposes and having it shared widely with other investigators. In a study of leaders in a black African immigrant community, several individuals voiced privacy concerns over sharing genetic information as it may have wider implications for their families and community (Buseh et al. 2013).

We again begin by presuming a resolution of the conjectural stasis: specifically, that the analysis of genetic material for research purposes can produce a variety of results. Next, at the level of definitional stasis, we consider the ways in which this stored genetic data is similar to or different from other research data. Many consider genetic information to be sensitive and private, and expect that disclosure of this information could bring about harms. There is also a possibility that people could be reidentified with genomic data and some basic demographic information. In this way, genetic data demonstrate both similarities and differences with other types of research data, and in some respects are quite similar to data stored by institutions for financial purposes.

We can then evaluate similarities and differences by drawing on the principles of biomedical ethics.
Researchers can demonstrate respect for individuals’ autonomy by eliciting and honoring their privacy preferences. However, policies must consider the trade-offs between restrictive data-sharing policies and the benefits that might be attained through the open sharing of genomic research data. The principle of beneficence supports the sharing of deidentified data so that patient populations might benefit from new discoveries. The principle of justice requires that data-sharing and oversight policies are developed in such a way that diverse communities will be willing to participate in research, and thus increase the chances that these communities will also experience a fair share of the benefits from research (Fullerton 2011).

One possible policy outcome is that genomic test results, like other medical tests and personally identifiable material, deserve robust policy protections. We base this policy outcome on the fact that genomic test results may contain information about a person that ought to be protected. Yet we cannot place so many restrictions that it becomes logistically impossible to share genomic data for secondary studies, given the potential benefits to society that shared resources would bring. Data can be shared with other investigators, but appropriate oversight measures should be in place to manage, in light of contextual factors, who will be allowed to access the information and to ensure that the data are used in ways that will reduce the risk of harm to donors. To address concerns about privacy, networked biorepositories should establish firewalls, protections, safeguards, and data access committees, and utilize closed or controlled access to limit the amount of data that is shared.

CONCLUSION

Health systems and users of genomic technology are increasingly contemplating the development of policies and practices that will facilitate the use of genomic information for clinical care and other social purposes. While the idiom of genomic exceptionalism will not solve all of the policy and practice debates that have arisen in the fields of genetics and genomics, we do believe that this analysis will help identify settings where meaningful debate has stalled as a result of genetic exceptionalism, a rhetorical oversimplification that has outlived its usefulness. This new idiom is better suited to the considerable tasks at hand, and provides a strategy for incorporating both similarities and differences into debates where context matters. The use of stasis theory can be utilized in many more areas of genomics, and can help to resolve debates around return of results, protecting against reidentifying participants, incorporation of genomics into electronic health records, and use of DNA in forensic settings or with genetic ancestry testing. We hope the genetics, bioethics, and health policy communities will remove the idiom of genetic exceptionalism from their rhetorical repertoire and join us instead in a more productive idiom for debate.

ACKNOWLEDGEMENTS

The authors thank Eric Juengst, Wylie Burke, and Ben Wilfond for their incredibly helpful suggestions and critical insights into our paper. We express tremendous gratitude to Eric Juengst for suggesting the phrase genomic contextualism, as he rightly pointed out that context matters. This work was supported by the National Human Genome Research Institute (K01 HG008818 and R01 HG008988).

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January, Volume 19, Number 1, 2019