Collective Biopolitics The Rights of Indigenous Peoples in Genetic Research

Ibrahim Garba

James E. Rogers College of Law, University of Arizona

Abstract: This essay considers issues implicated in biobanking with indigenous peoples, a population increasingly recognized as having a collective right to participation under international law (e.g., the United Nations Declaration on the Rights of Indigenous Peoples (2007)). In contrast, prevailing notions of participation within the field of human rights (including the right to health) presuppose an individualist notion of citizenship. This essay compares the indigenous collective right to participation with "molecularized biopower", the theory that biopolitics in modern democracies is becoming increasingly individualized in an unprecedented way. Using a US biobanking case study, this essay argues that two aspects of the indigenous collective right to participation (i.e., self-determination and the "empowerment" framework), not only counter the claim for a pervasively individualized biopolitics, but also demonstrate the importance of collective rights for indigenous participation in genetic research generally.

Keywords: indigenous, biobanking, biopolitics, genetic, collective, biopower

Corresponding author: Ibrahim Garba, Indigenous Peoples Law and Policy Program, James E. Rogers College of Law, University of Arizona, 1201 East Speedway Boulevard, Tucson, Arizona, USA 85721 – E-mail: garbai@email.arizona.edu

I. Introduction

In early 2015, the Precision Medicine Initiative (PMI) was announced by then-US President Barack Obama. The major undertaking was billed "to develop the nationwide infrastructure necessary to implement precision medicine in the United States" (Sankar 2017). The central endeavor of the PMI is the formation of a genetically diverse cohort of one million volunteers through the *All of Us* Research Program administered by the National Institutes of Health (NIH). Volunteers' biospecimens indexed to their health data will provide a centralized resource for researchers to investigate the varying impacts of genes, lifestyles, and environmental fac-



Italian Journal of Science & Technoloav Studies

tors on the etiology of different diseases.

Another crucial component of the PMI is a central biobank, defined as "an organized collection of human biological material and associated information stored for one or more research purposes" (Kaufmann 2008). The PMI repository will be hosted under contract by the Mayo Clinic in Rochester, Minnesota. Although several significant repositories indexed to volunteer health data exist in the US (e.g., the Department of Veterans Affairs *Million Veteran Program*, and the National Genome Research Institute-funded eMERGE Consortium), the PMI biobank will support the country's largest longitudinal study to date.

Because the *All of Us* Research Program aims to recruit a genetically diverse cohort, the program has actively engaged the nation's nearly 600 officially-recognized indigenous peoples to encourage enrollment. US indigenous peoples have raised concerns regarding participation that touch on a variety of issues including informed consent, secondary uses of biospecimens, and privacy (NCAI 2018). These concerns present an opportunity to consider the social and political factors that influence participation in genetic research and associated activities such as biobanking.

Indigenous peoples provide an interesting case study to explore these factors, because the collective aspects of indigenous social and political life contrast with the individualist models of citizenship prevalent in most modern democracies. These models also form the implied backdrop to scholarly discussions in the fields of international human rights and Science and Technology Studies (STS). By focusing on the rights of indigenous peoples in the context of genetic research, this essay further diversifies existing literature on human rights and global health, which has been dominated by the individualist framework expounded in the Universal Declaration of Human Rights (1948) (Mann 1997; Meier and Fox 2010). In addition, the essay's emphasis on indigenous peoples enriches STS literature by discussing the impact of advanced health technologies on societies whose structures do not fit the conceptual categories typically applied in sociological and critical analyses of modern political life.

In this essay, I use indigenous participation in the PMI as a case study to discuss the effects of individualist models of citizenship on analyses of participation in genetic research. In particular, I focus on the concept of "molecularized biopower" as articulated by Paul Rabinow and Nikolas Rose, a notion advancing the view that biopolitics has taken a drastic turn, from population-based top-down state interventions, to citizenship driven from below by novel forms of individual participation. Focusing on recent developments in international law and on STS work on biopower, I argue that a claim for a new individual "biopolitics from below" is not borne out by current state practice with respect to indigenous peoples. Additionally, I argue that collective forms of participation are crucial for fostering indigenous participation in genetic research. I begin with a brief overview of the status of indigenous peoples in international law.

2. Indigenous Peoples in International Law

In international law, the term "indigenous" has a technical meaning that is not merely a synonym for "native," "local," or "colonized." The most influential definition of indigenous peoples was developed by Jose Martinez Cobo (1986), a UN-appointed expert on minority rights:

Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal systems.

Indigenous peoples are communities that descend from societies predating foreign subjugation, and who view themselves as distinct from the general population of the states that have developed as a result of such historical domination. As suggested in Cobo's definition, indigenousness has a subjective component (i.e., self-identification) and an objective aspect (i.e., shared experiences of dispossession, and a common agenda focused on preserving identities, traditions, institutions, and territories). By this definition, groups who consider themselves distinct from the rest of society and who have also continuously inhabited the same territory for many generations, but who lack a history of sustained and systematic dispossession may not meet the formal requirements of indigenousness (e.g., Andalusians of Spain) (Anaya 2009).

In contrast, other groups who have been conquered and colonized may not qualify as indigenous peoples because they do not aim to separate themselves from the population of the resulting postcolonial state (e.g., the majority of ethnic groups in sub-Saharan Africa). The global population of indigenous peoples is around 370 million persons (World Bank 2018), and a few examples include the Maori of New Zealand, the Aboriginals of Australia, the Inuit of the Arctic (Canada, Greenland, Alaska), the Sioux of the United States, the San of Southern Africa, the Miskito of Central America, the Chacobo of Bolivia, the Sami of Scandinavia, and the Adivasi Janajati of Nepal.

3. Molecularized Biopower

In discussions of Michel Foucault's thoughts on biopower, the writings of Paul Rabinow, Nikolas Rose, and their colleagues have been especially notable within the scholarship of theorists who have extended Foucault's ideas to recent developments in the life sciences (Rabinow and Rose 2003, 2006; Rabinow 1996; Rose 2001, 2006; Rose and Novas 2004). In particular, their notion of "molecularized biopower" is characterized as a stark departure (Rose 2001; Rose and Novas 2004) from the model of societal regulation at the population level, which, Foucault argued, had become the dominant mode of control at the dawn of modernity (Yang 2018). Such governance at the population level – "a power to *foster* life or *disallow* it to the point of death" – was described by Foucault as gradually displacing "the ancient [sovereign] right to *take* life or *let* live" exercised on individual bodies (i.e., "anatomo-politics") (Foucault 1978).

Rabinow and Rose (2006) update the concept of biopower to consist of the following three elements, which may vary in expression over time:

(1) One or more truth discourses about the "vital" character of living human beings, and an array of authorities considered competent to speak that truth. (...)

(2) Strategies for intervention upon collective existence in the name of life and health, initially addressed to populations that may or may not be territorialized upon the nation, society or pre-given communities, but may also be specified in terms of emergent biosocial collectivities, sometimes specified in terms of categories of race, ethnicity, gender or religion, as in the emerging forms of genetic or biological citizenship.

(3) Modes of subjectification, through which individuals are brought to work on themselves, under certain forms of authority, in relation to truth discourses, by means of practices of the self, in the name of their own life or health, that of their family or some other collectivity, or indeed in the name of the life or health of the population as a whole (...).

The three elements together provide complementary perspectives on the bases of the claim that biopower, in its current molecularized form, signals a seismic change from the previous iterations described by Foucault (i.e., anatomo-politics of the human body and biopolitics of the population). The first element refers to "truth discourses" about human life and their legitimating institutions. For Rabinow and Rose, the relevant discourse for this new form of biopower comprises the life sciences, specifically the field of genetics (Raman and Tutton 2010). As Rose (2007) argues, genetics has altered the discourses surrounding medicine by fragmenting the human body into a composite of molecularized units, thereby facilitating the application of biopower at the molecular level. The second element refers to interventions aimed at collective life, with the qualification that the collective in question may not refer to a predefined group such as the territorially defined population of a state. This point acknowledges a diminution in the power states have historically wielded to implement collective interventions for hygienic and eugenic purposes (Rose and Novas 2005). This decline in state power corresponds to an increasing transfer of responsibility for personal and collective

Garba

health to individual citizens, the "subjectification" described in the third element. Part of "work[ing] on themselves" involves citizens leveraging scientific knowledge and forging partnerships with various stakeholders (e.g., patient support groups, disease advocacy organizations, pharmaceutical companies, scientists) in new forms of civic engagement, biosociality, and citizenship: a biopolitics rising from below, rather than imposed from above (Raman and Tutton 2010).

4. The Limits of Molecularized Biopower: A Case Study

The new account of biopower proposed by Rabinow and Rose has been assessed by various writers (Raman and Tutton 2010; Arnason 2013; Heinemann and Lemke 2014). In this essay, I am particularly interested in critiques that challenge the contention that the "molecularization" of life in Western democracies has wrought an unprecedented change in the manifestation of biopower in those societies. Building on these assessments, this section argues that two factors associated with the development of indigenous peoples' rights under international law demonstrate clear countercurrents to the prevalence of molecularized biopower in modern states. The two factors are (1) explicit recognition of collective rights to complement individual rights, and (2) adoption of the principle of self-determination as a prerequisite for indigenous peoples' participation in state "citizenship projects" (Rose and Novas 2005) such as the PMI.

4.1 Collective Rights and Indigenous Sovereignty

In their evaluation of molecularized biopower as described by Rabinow and Rose, Sujatha Raman and Richard Tutton (2010) assert:

It is misleading to assume that state biopolitics has simply given way to "ethopolitics" where individual judgment and reshaping of the self are paramount and where the state merely exerts pastoral power in the domain of life. By focusing on cases where biopolitical claims and counterclaims are framed in terms of individual choice, there is a danger of implying that individualism is the only discourse that is permitted in the political landscape today and that one must necessarily work within its confines even to challenge dominant practices. Even if we allow that the language of individual choice, rights, and freedom is clearly dominant, we need to examine how it is linked with or challenged by political discourses that appeal to some notion of the collective.

In their critique, Raman and Tutton point to the underlying premise of molecularized biopower expressed in the term "subjectification": a focus on the individual as the driving force of biopolitics, often at the expense of the state. Against the pervasive individualism presupposed in the work of Rabinow and Rose, they argue that research design in the life sciences continues to be framed in population categories. Raman and Tutton cite the example of the US Health Revitalization Act of 1993, which mandated the National Institutes of Health (NIH) to require inclusion of women and minority populations in funded research. The field of public health genomics also exemplifies the persistence of population level models and interventions, including in genetic research (Khoury et al. 2017; Meslin and Garba 2011).

4.1.1 International Law

The focus on the individual in molecularized biopolitics has an analogue in international law. Since the end of World War II, the global mechanisms of human rights protection through the United Nations have focused on individual claims "of freedom, equality, participation, and economic and physical security vis-à-vis the state" (Anaya 2009). However, developments in indigenous peoples' rights have trended toward an increasing recognition of collective rights due to the failures of the individual-based system to protect indigenous communities adequately. In this section, I briefly trace this evolution in international law and note its implications for molecularized biopower.

Due to their adoption both as a legal standard and as a requirement for membership in the United Nations, human rights have been influential in shaping international policy since the middle of the 20th century. Starting with the Universal Declaration of Human Rights (UDHR) (1948), an impressive edifice of treaties with associated monitoring institutions has evolved to protect member states' citizens. Alongside the wide-ranging International Covenant on Civil and Political Rights (ICCPR) (1966) and equally expansive International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966), other human rights agreements address the rights of women, children, the disabled, and migrant workers while others address issues such as racism, genocide, torture, and forced disappearances.

As the genetic revolution gained momentum, the United Nations Educational, Scientific and Cultural Organization (UNESCO) took advantage of the adaptability and transnational influence of human rights by adopting three declarations to address the novel ethical issues being raised by genetics. These were the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003), and the Universal Declaration on Bioethics and Human Rights (2005). Treaties, being legally enforceable agreements between states, represent the strongest form of obligation in international law. Breaches of such agreements can trigger a variety of measures to ensure compliance. However, because treaties on complex issues involving a large number of states take a long time to negotiate and sign, groups of states (e.g., United Nations, Organization of American States, European Union, African Union) sometimes opt for declarations. Though lacking the specificity and detailed sanctions of treaties, declarations take less time to enact, outlining an area of concern while establishing a platform for coordinated action. Declarations also typically serve as drafts of future treaties (as the UDHR did for ICCPR and ICESCR). At a minimum, the UNESCO declarations reflect a consensus among member states on the need to address the implications of genetic research for the international community.

However, even as human rights were being endorsed as an ethical, legal, and policy guide for genetic research, discussions persisted on their limited application for engaging certain populations, among them indigenous peoples and other sociopolitical collectives (e.g., ethnic groups in sub-Saharan Africa). A recurring critique of the human rights system, an edifice based on the UDHR as noted earlier, was the structure's emphasis on the individual person as the chief focus of ethical and legal analysis (Anaya 2009; Mutua 2008; Cobbah 1987).

Provisions of the major human rights treaties ratified since the UDHR's adoption (e.g., ICCPR, ICESCR) have generally been construed as protecting the rights of individuals, not collectives. For example, the right to health has been interpreted by ICESCR's monitoring body as an obligation that governments owe to their individual citizens (UN Committee on Economic, Social and Cultural Rights 2000). Even when a right has patently collective dimensions, as with minority rights to language and culture, the relevant monitoring body has consistently adopted an individualist hermeneutic (UN Human Rights Committee 1994).

In contrast, political institutions (e.g., systems of restorative justice) and economic practices (e.g., common ownership and stewardship of land) among indigenous peoples give substantial weight to collective considerations (Zehr 2002; Ortega 2004). This inattention to collective aspects of social life in the UDHR-based system spurred efforts to bridge the normative gap in indigenous communities, resulting in the incorporation of collective rights in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (Anaya 2004; UN General Assembly 2007). Although there have been treaties that have addressed issues of concern to indigenous peoples through the International Labor Organization, UNDRIP is the first international instrument drafted with significant indigenous input (Anaya 2009).

UNDRIP's Preamble describes collective rights as "indispensable for [indigenous peoples'] existence, well-being and integral development". Among other provisions, Article 1 secures for indigenous peoples, as both individuals and collectives, the enjoyment of all human rights codified in international law and in major UN documents, while Article 7.2 describes "a collective right to live in freedom, peace and security as distinct peoples". UNDRIP also incorporates collective features pertaining specifically to the right to health. Article 21 of UNDRIP describes a collective right "to the improvement of . . . economic and social conditions, including... health," while Article 24 recognizes the collective right indigenous peo-

ples have "to their traditional medicines and ... health practices".

In summary, the collective features of UNDRIP have incorporated into international law a maturing consensus on standards for protecting the rights of groups as groups, not merely as aggregates of individuals. Alongside the persistence of population categories in research design, this consensus on collective rights adds to arguments against the claim by Rabinow and Rose that growing "subjectification" marks a revolutionary restructuring of biopower in the direction of individual activism in modern democracies.

4.1.2 United States Case Study

Although they are not recognized as sovereign states under international law, the 573 indigenous peoples in the US have a unique government-to-government relationship with federal authorities. The qualified sovereignty implied in this arrangement is a result of past treaties between them, court decisions, and executive orders. Tribal sovereignty is the basis of collective existence for the nation's indigenous peoples, and also shapes the policy context for engaging them in projects such as the PMI.

As the Tribal Collaboration Working Group (TCWG) (2018) of the *All of Us* Research Program explains,

[t]his sovereign status, which is a political designation, gives tribes legal rights and privileges that are distinct from racial and ethnic groups. Research partnerships with [indigenous] populations require unique considerations, including greater input and oversight by tribal communities on data and biospecimen policies, beyond those for other groups.

The distinction highlighted here between the country's "racial and ethnic groups", on the one hand, and indigenous peoples, on the other, echoes the difference noted in the earlier discussion of international law. Like the individualist interpretations of the major UDHR-based human rights treaties, US constitutional law protects citizens as individuals, not collectives (Chemerinsky 2016). In its report, however, the TCWG affirms that the sovereign status of US indigenous peoples furnishes "rights and privileges" that justify their treatment as collectives.

In the context of the PMI, an important means of implementing the collective principle is the TCWG's recommendation to obtain community (or tribal) consent prior to recruiting indigenous individuals on indigenous territory (TCWG 2018). In making the recommendation, the TCWG acknowledges complexities that can arise in certain situations, such as deciding whether community consent may still be required when recruiting indigenous persons permanently living outside indigenous territory or judging what level of data to record upon enrollment to protect collective indigenous interests.

These complexities notwithstanding, the TCWG's recommendation aligns with ethics guidelines for research with indigenous peoples that propose applying both individual and collective analytical frameworks. The use of both frameworks in research regulation is a function of the collective social organization of most indigenous societies (as noted above), as well as the risks of identification and stigmatization associated with genetic studies in small populations (Kowal 2015; Garrison 2013).

The increasing recognition of both individual and collective frameworks in US indigenous research is consistent with the critique of molecular biopower advanced by Raman and Tutton: state biopolitics continues to play out at both individual and population (i.e., collective) levels in modern democracies. The claim by Rabinow and Rose of a revolutionary "subjectified" (i.e., individualized) biopolitics warrants qualification given the case study of the PMI.

4.2 Self-Determination and the "Empowerment" Framework

In reference to a discussion of biological citizenship by Rose and Carlos Novas (2003), Vilhjalmur Arnason (2012) comments:

The distinctive feature of deliberative democratic theory is its emphasis on the quality of arguments and reasons used to justify policy and that validity of these reasons needs to be tested in communication that is free from deception and coercion. (...) [T]he first social purpose "served by deliberation in democracy" is promoting the democratic legitimacy of political decisions.

Arnason's remarks are made in response to what he views as the broad and, therefore, vague models of biological citizenship described by Rose and Novas (2005). By extension, he questions the analytical purchase of molecularized biopower as characterized by Rabinow and Rose (2006), a view that features declining state interventions "from above" and creative alliances by individual citizens to advance life claims "from below". He argues that "[t]he notion of citizenship implies not just any activity of citizens. It refers to activities that are different from ... those characteristic of a colleague, a customer or a consumer" (Arnason 2012). Arnason here questions whether the alliances individual citizens forge with certain entities (e.g., pharmaceutical companies) to advance their individual life claims fall properly under the rubric of citizenship. In other words, Arnason is concerned not just about the fact of participation but its quality.

4.2.1 International Law

Arnason's focus on legitimacy as a condition for genuine democratic participation reflects trends in the rights of indigenous peoples. The principle of self-determination in UNDRIP underscores the continuing importance of collective institutions for fostering "democratic legitimacy" in deliberations, an emphasis that is inconsistent with the individualizing subjectification that characterizes molecularized biopower. In this section, I discuss the principle of self-determination and how, through the "empowerment" framework, the principle helps ensure meaningful participation in state projects among indigenous peoples.

Stated simply, self-determination recognizes the inherent capacity of indigenous peoples *as collectives* to develop culturally, socially, and economically along lines consistent with their respective histories and values. The principle appears in the UN Charter and is codified in identical language in the two principal human rights treaties mentioned earlier (i.e., ICCPR, ICESCR): "All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development." Self-determination is unique in both treaties because it is, by definition, a collective right, whereas, as noted earlier, other treaty provisions have consistently been construed as applying to individuals.

As the text reads, self-determination applies to "all peoples." The principle was crucial in establishing new states in formerly colonized territories after World War II. UNDRIP applies the right specifically to indigenous peoples, using identical phrasing in Article 3. Indeed, selfdetermination can be seen as the touchstone of UNDRIP, providing the policy framework for indigenous rights across a variety of areas, including land, culture, religion, health, education, and political structures.

The connection between the right to self-determination and collective rights is straightforward: collective rights provide a legal mechanism for preserving the ability of indigenous peoples to exercise their right to selfdetermination. Given the fact that they are, by definition, embedded in states from which they "consider themselves distinct" (Cobo 1984), indigenous peoples must strike a balance between exercising their right to self-determination and managing the inevitable impact of state dominion on their affairs. Self-determination in UNDRIP gives indigenous peoples a measure of control over the terms of their engagement with state power (i.e., participation) through what Anna Cowan (2013) calls the "empowerment" framework.

The main features of the empowerment framework can be understood by tracing the complementary relationship between "internal" and "external" aspects of participation.¹ Article 18 of UNDRIP provides for indigenous peoples to participate in states' decision-making processes when the measures in question affect indigenous interests (i.e., external participation). This article corresponds to Article 25 of the ICCPR, which describes a right for the individual citizens of states to participate "in the conduct of public affairs." In contrast, Article 4 of UNDRIP contains a right to indigenous self-government and autonomy with respect to "internal or local affairs" (i.e., internal participation). This collective right of indigenous peoples to autonomy over their internal affairs does not apply to other constituencies in the ICCPR (e.g., non-indigenous minority groups).

Article 5 of UNDRIP combines both internal and external aspects of

participation. The provision acknowledges indigenous peoples' right to "maintain and strengthen their distinct . . . institutions" (i.e., internal participation), while preserving an indigenous right "to participate fully, if they so choose, in the political, economic, social and cultural life of the [s]tate" (i.e., external participation). Empowerment refers to the ability of indigenous peoples to govern indigenous affairs through their own institutions as well as to influence decisions made outside indigenous communities that affect indigenous affairs.

A metaphor useful for describing the complementary fit of internal and external participation employs images of a sword and a shield. External participation functions as a sword, equipping indigenous peoples with a means of influencing outside processes potentially bearing on indigenous affairs. Internal participation works as a shield, creating a protected communal space in which indigenous peoples can deliberate on their collective destinies insulated from the dominating influence of state power. Both aspects are essential for a meaningful exercise of the right to self-determination.

The empowerment framework, comprising both internal and external participation, reinforces Arnason's point on the importance of legitimacy in participation. To extend his analysis, the ability of indigenous peoples not only to participate in "the political, economic, social and culture life of the [s]tate" (UNDRIP 2007) but also to deliberate on state action in their own indigenous institutions increases the legitimacy of indigenous decision-making. Moreover, the recognition of "internal participation", which adds a collective component to "democratic legitimacy", runs counter to the relentless individualizing trend claimed of molecularized biopower by Rabinow and Rose.

4.2.2 United States Case Study

The 573 federally-recognized indigenous peoples in the US have a legal right to self-determination. The national policy on self-determination is codified in the Indian Self-Determination and Education Assistance Act (1975). Along with the governments of Canada, Australia, and New Zealand, the US government initially voted against UNDRIP when it was adopted in 2007, but endorsed the Declaration in 2010.

A major component of the federal policy on self-determination is the tribal consultation policy, a function of the government-to-government relationship described earlier. The policy requires federal government agencies considering a measure that could significantly affect indigenous peoples (e.g., drafting regulations, making budgets, crafting policy) to consult with tribal leadership throughout the planning process. Several federal departments have tribal consultation policies in place, including the Departments of Interior, Education, Treasury, and Health and Human Services. Subsidiary agencies within a department may also adopt a tribal consultation policy tailored to their narrower mission. For instance, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) within Health and Human Services both have tribal consultation policies that provide for agency leadership to meet regularly with their respective Tribal Advisory Committees. Because these policies are based on the government-to-government relationship, committee members are required to be officers of their tribal governments (National Institutes of Health).

Being a major undertaking with potential to affect the nation's indigenous peoples, the PMI has been a topic of consultation with the NIH Tribal Advisory Committee. This committee has 17 members, 12 members corresponding to the geographic regions served by the Indian Health Service and 5 at-large members. At various meetings since the presidential announcement of the PMI, NIH officials have briefed committee members on the history and features of the program, updated them on developments, responded to their questions, and consulted them on the impact of PMI on their communities (NIH Tribal Health Research Office).

Consultation through the NIH Tribal Advisory Committee is an example of external participation in the empowerment framework, a form of engagement that enables indigenous peoples "to participate fully ... in the political, economic, social and cultural life of the [s]tate" (UNDRIP 2007). Furthermore, because committee members are officers of their respective governments, they are also in a unique position to facilitate internal participation when they return to their communities. In this position, committee members are able to mediate their communities' concerns about the program such as the collection, storage, and use of tissue in the PMI central biobank. For example, the *All of Us* Tribal Collaboration Working Group (TWCG 2018) observes that,

[i]n some tribal cultures, everything that comes from the body, including blood and hair, is sacred, so donation of a biospecimen is a significant act, as it may feel like the researcher is taking a piece of the individual's spirit and soul. Due to these cultural beliefs, [indigenous] individuals will be especially interested in knowing how their biospecimens will be used, where they will be stored, and how they will be disposed of upon the donor's death.

Addressing such concerns that implicate cultural, spiritual, and ethical issues requires intentional and thoughtful deliberation. The empowerment framework (i.e., internal participation through tribal government; external participation through the NIH Tribal Advisory Committee) creates a legal channel for indigenous peoples – who make up only 1.7% of the US population (TCWG 2018) – to engage in as complex a state undertaking as the PMI as collectives, not just individual citizens.

This engagement "as collectives" fosters what Arnason describes as democratic legitimacy, because the quality of deliberation made possible through the empowerment framework would not be possible were US indigenous peoples to approach participation in the PMI as individuals. This collective form of deliberation supports Arnason's contention that the individualized forms of participation presupposed in molecularized biopower do not adequately define the range of biopolitics in modern democracies.

5. Conclusions

This essay responds to the work of Paul Rabinow, Nikolas Rose, and their colleagues on "molecularized biopolitics." In particular, it addresses their claim that "subjectification" – the increasingly central role of the individual citizen in animating a biopolitics from below – is part of a radical transformation of biopower. This essay argues, in contrast, that developments in the rights of indigenous peoples reflect the continuing salience of collective biopolitics, from perspectives of both the state (i.e., policies of self-determination) and indigenous governance structures (i.e., the "empowerment" framework).

The essay also raises crosscutting issues with other STS scholarship. For example, the empowerment framework, featuring internal and external aspects to enhance the democratic legitimacy of collective decision-making, has implications for "technical democracy" (Callon et al. 2009; Lamard and Lequin 2017). Both notions are concerned with ensuring that citizens potentially affected by major technical endeavors (in this case, biobanking to support genetic research) have effective channels to participate in deliberation.

Finally, the essay demonstrates the utility of multidisciplinary work for analyzing the sociopolitical impacts of complex technical undertakings. In the PMI case study, bringing to bear the concept of indigenous selfdetermination on biobanking allows the application of analytical tools from international law to illuminate issues surrounding democratic legitimacy for major state-sponsored technical projects. In a similar vein, the observations of Rabinow, Rose, and their colleagues on receding state power as well as the rising prominence of individual activism in contemporary biopolitics help identify and frame issues needing thoughtful engagement from the field of international law. It is hoped that this essay will be but one among a growing number of multidisciplinary explorations of strategies to harness and manage the promises and risks of advanced technology for all segments of contemporary society.

Acknowledgments

I am grateful for support from the Indigenous Peoples Law and Policy Program at the University of Arizona James E. Rogers College of Law. My sincere appreciation also goes to the editors of the special issue on biobanking for their collegiality and ready assistance.

References

- Anaya, S.J. (2009) International human rights and indigenous peoples, Austin, Wolters Kluwer Law & Business.
- Anaya, S.J. (2004) Indigenous peoples in international law, Oxford, Oxford University Press.
- Árnason, V. (2013) Scientific citizenship in a democratic society, in "Public Understanding of Science", 22 (8), pp. 927-940.
- Callon, M., Lascoumes, P. and Barthe, Y. (2009) *Acting in an uncertain world: an essay on technical democracy*, Cambridge, MA, MIT Press.
- Chemerinsky, E. (2017) Constitutional law, New York, Wolters Kluwer Law & Business.
- Cobbah, J. A. (1987). African values and the human rights debate: an African perspective, in "Human Rights Quarterly", 9 (3), pp. 309-331.
- Cobo, J.R.M. (1986) *Study of the problem of discrimination against indigenous populations*, Geneva, United Nations Economic and Social Council.
- Cowan, A. (2013) UNDRIP and the intervention: indigenous self-determination, participation, and racial discrimination in the northern territory of Australia, in "Pacific Rim Law and Policy Journal", 22 (2), pp. 247-310.
- Foucault, M. (1978) *The history of sexuality: an introduction. vol. 1.*, New York, Vintage 208.
- Garrison, N. (2013) Genomic justice for Native Americans: impact of the Havasupai case on genetic research, in "Science, Technology, & Human Values", 38 (2), pp. 201-223.
- Heinemann, T. and Lemke T. (2014) Biological citizenship reconsidered: the use of DNA analysis by immigration authorities in Germany, in "Science, Technology, & Human Values", 39 (4), pp. 488-510.
- Khoury, M.J., Bowen, M.S., Clyne, M., Dotson, W.D., Gwinn, M.L., Green, R.F., Kolor, K., Rodriguez, J.L., Wulf, A. and Yu, W. (2017) From public health genomics to precision public health: a 20-year journey, in "Genetics in Medicine", 20, pp. 574-582.
- Kowal, E.E. (2015) Genetics and indigenous communities: ethical issues, in Wright, J. (ed.), "International Encyclopedia of the Social & Behavioral Sciences, 2nd ed.", Oxford, Elsevier, pp. 962-968.
- Lamard, P. and Lequin, Y.C. (2017) *Elements of Technical Democracy*, in "Journal of Innovation Economics & Management", 1 (22), pp. 171-181.
- Mann, J. M. (1997) *Medicine and public health, ethics and human rights*, in "Hastings Center Report", 27 (3), pp. 6-13.
- Meier, B.M. and Fox, A. (2010) International obligations through collective rights: moving from foreign health assistance to global health governance, in "Health and Human Rights," 12 (1), pp. 51-72.

- Meslin, E.M. and Garba, I. (2011) *Biobanking and public health: is a human rights approach the tie that binds?* in "*Human Genetics*", 130 (3), pp. 451-463.
- Mutua, M. (2008) *Human rights in Africa: the limited promise of liberalism*, in "African Studies Review", 51 (1), pp. 17-39.
- National Congress of American Indians. (2018) *NIH All of Us Research Program:* an update for tribal leaders (policy brief), in http://www.ncai.org/policyresearch-center/research-data/prc-publications/NIH_All_of_Us_Brief_2_9-_2018_FINAL.pdf (retrieved November 18, 2018).
- National Institutes of Health. *Tribal Advisory Committee Charter*, in https://dpcpsi.nih.gov/thro/tac/charter (retrieved November 18, 2018).
- Ortega, R. R. (2004) Models for recognizing indigenous land rights in Latin America, Paper No. 99, Environment Department Working Papers, Washington, DC, World Bank.
- Rabinow, P. and Rose, N. (eds.) (2003) Foucault today, in The essential Foucault: Selections from the essential works of Foucault (1954-1984), New York, New Press, pp. 1-30.
- Rabinow, P. and Rose, N. (2006) *Biopower today*, in "BioSocieties", 1 (2), pp. 195-217.
- Raman, S. and Tutton, R. (2010) *Life, science, and biopower*, in "Science, Technology, & Human Values", 35 (5), pp. 711-734.
- Rose, N. (2001) The politics of life itself, in "Theory, Culture & Society", 18 (6), pp. 1-30.
- Rose, N. (2007) *The politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*, Princeton, NJ, Princeton University Press.
- Rose, N. and Novas, C. (2005) *Biological citizenship*, in Ong, A. and Collier, S.J. (eds.), *Global assemblages: technology, politics, and ethics as anthropological problems*, Oxford, Blackwell Publishing, pp. 439-463.
- Sankar, P.L. and Parker, L.S. (2017) The Precision Medicine Initiative's All of Us Research Program: an agenda for research on its ethical, legal, and social issues, in "Genetics in Medicine", 19, pp. 743-750.
- Tribal Collaboration Working Group (All of Us Research Program). (2018) *Report: Considerations for meaningful collaboration with tribal populations*, in https://allofus.nih.gov/sites/default/files/tribal_collab_work_group_rept.pdf (retrieved November 18, 2018).
- Tribal Health Research Office. *Tribal Consultation Sessions*, in https://dpcpsi.nih.gov/thro/tac (retrieved November 18, 2018).
- United Nations Committee on Economic, Social and Cultural Rights. (2000) General Comment No. 14: the right to the highest attainable standard of health (Article 12), in http://www.refworld.org/pdfid/4538838d0.pdf (retrieved November 18, 2018).

- United Nations General Assembly. (1948) Universal Declaration of Human Rights, in http://www.un.org/en/universal-declaration-human-rights/ (retrieved November 18, 2018).
- United Nations General Assembly. (2007) United Nations Declaration on the Rights of Indigenous Peoples, in http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf (retrieved November 18, 2018).
- United Nations Human Rights Committee. (1994) General Comment No. 23: rights of minorities (Article 27), in http://www.refworld.org/docid/-453883fc0.html (retrieved November 18, 2018).
- United Nations General Assembly. (1966) International Covenant on Civil and Political Rights, in https://www.ohchr.org/en/professionalinterest/pages-/ccpr.aspx (retrieved November 18, 2018).
- United Nations General Assembly. (1966) International Covenant on Economic, Social and Cultural Rights, in https://www.ohchr.org/EN/Professional-Interest/Pages/CESCR.aspx (retrieved November 18, 2018).
- World Bank. Indigenous Peoples, in https://www.worldbank.org/en/topic/indigenouspeoples (retrieved November 18, 2018).
- Yang, J. (2018) Biopower, in Callan H. (ed.), The International Encyclopedia of Anthropology, Hoboken, NJ, John Wiley & Sons, Ltd, pp. 1-9.
- Zehr, H. (2002) *The little book of restorative justice*, New York, Skyhorse Publishing, Inc.

¹ The distinction made in this essay between "internal" and "external" participation is based on the distinction made between "internal" and "external" selfdetermination (Cowan 2013).