
COMMENTARY

Entwined Processes: Rescripting Consent and Strengthening Governance in Genomics Research with Indigenous Communities

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In their paper in this issue, Prictor et al. propose using a dynamic consent approach for recruiting Indigenous Peoples into genomic studies as it has the potential to “provide for autonomous and informed choice by donors and their descendents.”¹ This approach can provide the foundation to honor Indigenous Peoples choices over time, allows for more bi-directional engagement with the researchers, and increases transparency and communication about new proposals to use existing samples.² Dynamic consent preferences can be captured through an electronic interface that allows donors to make, update, and review consent decisions over time. The tracking of participants’ preferences and allowing them to change their decisions over time is crucial to maintaining trust and accountability. Reaching all participants for updates might be prohibitively time-consuming and expensive, especially in low-resourced areas where internet is not accessible to all. Regardless, members of the research team should revisit these communities to update them on what has been done, to introduce proposed research, and to allow participants to update their consent if they feel compelled to do so.

Biological materials from Indigenous Peoples (including hair and blood) have been collected by social and biological anthropologists, geneticists, and other scientists to pursue scientific inquiry into the

origins of human populations, relatedness of current-day populations, disease history, and medical traits. Many of these existing collections are housed in a variety of places worldwide — museums, academic labs, and private collections. Current scientific practice expectations view broad access to existing biological materials or data derived from them for secondary use essential to innovation and discovery. For tribes who have experienced harms to their communities from researchers who used samples in secondary research in ways that challenges their beliefs or that exacerbate derogatory and detrimental stereotypes, there is a concern and hesitancy to allow research without extensive discussions about how the samples will be used and by whom.

There are many instances of researchers using biological samples from Indigenous Peoples in ways that donors did not foresee, such as for secondary research or research not explicitly agreed to, particularly when the consent language was broad or vague.³ Some of these cases resulted in lawsuits, the halting or banning of research, deep community distrust, the assertion of tribal control of research via review processes, and in some cases, the return of DNA samples to the community after demands were made or as a settlement.

As more precision medicine research and large, nation-wide genomics projects get underway, there is an even greater need to address concerns around secondary use upfront and even after a sample has been donated. Indigenous Peoples are already underrepresented in genome-wide association studies, and the percentage has declined over time, estimated at 0.06% in 2009, 0.05% in 2016, and 0.02% in 2019.⁴ This trend is bound to continue in the absence of better consent and governance structures that align with Indigenous Peoples’ values.

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While dynamic consent provides a more responsive and robust approach to consent, it should be seen in the context of generally improving the level of control that Indigenous communities have around the research enterprise. There is a preference among many Indigenous communities favoring re-consent for every use, which the concept of dynamic consent provides.⁵ However, as appealing as the idea is, we see a number of practical challenges before its potential could be realized especially in remote Indigenous communities. Accessibility to internet and limited awareness of research activities will always create questions about the informed nature of the consent. Similarly, the costs of maintaining the technical infrastructure and ensuring continued engagement or interest in the app that tracks preferences will affect uptake and use.

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The level of information shared to obtain meaningful consent is one component of building trust, enhancing accountability, and improving equity. However, participation in the governance, ethical review, and data access decisions is also necessary. For Indigenous communities it is important to recognize the underpinning rationale for balancing individual and collective rights through the use of both consent and governance mechanisms. Consent affirms that the risks and benefits have been assessed by the individual in relation to their participation in the research project whereas governance allows the representatives of the community to assess the risks and benefits of the project for the community as a whole.⁶ This distinction is important because individual participants are not necessarily in a position to consider the wider implications of partici-

pation, nor are they responsible or accountable to the rest of the community for their decisions.

Indigenous data sovereignty is the right of Indigenous Peoples and nations to govern the collection, ownership, and application of data about their peoples, lands, and resources.⁷ Indigenous Peoples are asserting their collective rights to control and interests in biological materials, developing laws and policies, and building capacity to house and oversee materials. Some tribes have exerted sovereign authority to govern their peoples and land and their laws must be respected.

Indigenous scholars and policy makers have developed new guidelines, protocols and research principles, and are advocating for ways to implement and enforce existing regulations.⁸ Some tribes have developed codes and research review boards to oversee all research within their tribe or community. Some already oversee the use of specimens derived from their community (Alaska Area Biospecimen Bank, Maori). Finally, Indigenous scholars have developed frameworks for better ethical engagement or to initiate much-needed discussions to develop guidance on ancient DNA research.⁹

Indigenous data sovereignty networks have emerged to refocus the locus of control with Indigenous Peoples. The CARE Principles for Indigenous Data Governance (Collective benefit, Authority to control, Responsibility, Ethics), developed by the International Indigenous Data Sovereignty Interest Group at the Research Data Alliance, serve as a guide to involve Indigenous Peoples in data policies and practices that strengthen Indigenous control of Indigenous data.²⁴

Reflecting on the crucial role of data in advancing Indigenous innovation and self-determination, the CARE Principles are meant to affect change within external data stakeholders and the secondary use of data. The CARE Principles expand on mainstream principles, e.g., FAIR (Findable, Accessible, Interoperable, Reusable) concerned with data attributes to bring people and purpose into focus for data policies and practices.¹⁰ Implementation of the CARE Principles through inclusion of Indigenous Peoples by data producers, stewards, and publishers leads to participatory governance towards innovation and beneficial data reuse.

Indigenous expectations of consent in relation to the varied contexts around which Indigenous genomes can be sampled will range from re-consent for historic samples to tiered consents for prospective samples.

Dynamic consent provides another way for individual participants to enhance their level of control around what their samples and data are being used for. If practical considerations around cost and accessibility can be addressed and it is applied alongside more participatory governance mechanisms, it could contribute towards realizing the aspirations of Indigenous communities, Indigenous scientists, and Indigenous data sovereignty movements.

Note

The authors have no conflicts to disclose.

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