

Why community consultation matters in genomic research benefit-sharing models

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The importance of benefit sharing in genomic research

Despite increasing calls for benefit sharing to promote greater equity in human genomic research, established precedents across the private and public spheres are lacking. Moreover, the few existing models for benefit sharing with populations that participate in genomic research are largely limited to intangible or nonfinancial benefits, or to top-down initiatives that generally do not draw on direct input from participating populations. Here, we present a model of financial benefit sharing that goes hand in hand with other important benefits such as scientific capacity building and data sharing and in which the priorities and needs of participating communities are identified and used to steer funding decisions. By discussing the implementation of this collective-interest model in the context of an industry-funded genomic research project in Madagascar, we offer a practical example for how to institute community-driven distribution of financial benefits. Despite the challenges involved in this process, we believe that consulting communities around financial benefits serves to both increase equity in genomic research and support locally determined needs.

Using a collective financial benefit-sharing model driven by community input affords researchers a means to strengthen reciprocity by giving stakeholders who participate in genomic research a say in how financial benefits are invested, as opposed to relegating them to the passive role of merely receiving money borne from top-down expenditure decisions. In addition, this trust-building approach facilitates the disbursement of tangible, near-term benefits that more closely align with communities' local knowledge and priorities. Moreover, this model has the potential to begin to redress some of the historical wrongs committed in genomic research, as well as its precursors in biomedical research, including breaches of privacy, misuse of data, lack of true informed consent, no sharing of results, and the absence of material and other benefits for research participants.

These ethical breaches have caused serious damage, both by causing lasting harm to individuals and populations who shared

their data and by eroding trust in the scientific relationship. Not surprisingly, past ethical violations have had particularly noxious repercussions for African-origin and Indigenous populations around the world. The most infamous cases of abuse in the United States—for example, Henrietta Lacks and the immortalized HeLa cell line or the Arizona State University diabetes study with the Havasupai tribe—are only the tip of the iceberg among scores of lesser-known cases of unethical biomedical research practices around the world (Sterling 2011). From the vantage point of scientific innovation, this legacy is catastrophic. Genetic diversity in genomic studies is critical to the generation of novel discoveries relevant for understanding and treating disease, yet this broken trust has restricted researchers' ability to recruit diverse pools of participants for genomic research. As of 2022, 91.2% of all complex-trait GWASs had been performed in people of European ancestry, meaning that most databases lack a high enough representation of diverse populations to accurately predict allele frequencies (Fitipaldi and Franks 2023).

Scholars and governing bodies have made repeated calls for benefit sharing in biomedical research as a means of promoting greater reciprocity in the research relationship (Bedeker et al. 2022; Tone-Pah-Hote and Redvers 2022). Specifically, the "Sharing of Benefits" article of UNESCO's 2005 Universal Declaration on Bioethics and Human Rights and, more recently, the 2022 WHO Science Council Report both make calls for the generalized sharing of benefits and knowledge from genomic research to the broader public. Historically, however, this broad application approach has been implemented at the expense of marginalized populations, who have not received an equitable distribution of benefits or results, and few precedents exist to replace these outdated and extractive models (Tsosie et al. 2021). The Indigenous data sovereignty movement, which works to protect the collective rights and interests of Indigenous Peoples in research, has quickly gained traction on an international scale. A key element of this movement includes a call for the provision of tangible benefits to Indigenous communities in exchange for genomic and other data (Claw et al. 2018; Hudson et al. 2020).

However, despite the importance of benefit sharing in forging an ethical way forward in genomics, researchers lack practical guidance around the implementation of a financial benefit-sharing

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Article published online before print. Article and publication date are at <https://www.genome.org/cgi/doi/10.1101/gr.278308.123>. Freely available online through the *Genome Research* Open Access option.

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model at either the individual or collective level. LunaDNA—a private platform offering, in exchange for genetic and health data, virtual shares in the company proportional to the amount of data shared—provides one example of an individual-interest model, whereas a number of biotechnology companies (such as Regeneron, GSK, and Novo Nordisk) invest funds to support global initiatives around health, science, and environment, among others.

Nonmedical industry actors in markets including rooibos tea and diamonds in southern Africa have afforded some useful collective frameworks for what Fox (2020) calls “community-partner-based benefit sharing,” in which communities as a whole receive benefits from the sale of natural resources derived from their land and/or culture (Schroeder et al. 2020). These examples represent concrete implementation of the Nagoya Protocol on Access and Benefit Sharing (known as the Nagoya Protocol for short); however, the question remains of how to address the distribution of benefits arising specifically from the use of human genetic resources. Although groundbreaking and important, the Nagoya Protocol, including the Conference of the Parties’ recent decision to establish a mechanism for benefit sharing from the use of digital sequence information on genetic resources, neglected to address the distribution of benefits arising specifically from the use of human genetic resources (as opposed to other natural resources).

Efforts to address the question of benefit sharing in human genetic research in particular date at least as far back as the North American Regional Committee of the Human Genome Diversity Project’s Proposed Model Ethical Protocol for Collecting DNA Samples (Weiss et al. 1997). This document, in addition to acknowledging the provision of benefits to participating communities as an important part of any ethical research design, highlights some of the common challenges arising from such an obligation. It suggests that the three basic principles of honesty, legality, and appropriateness should govern researchers in this regard, and advocates for the provision of medical services and useful information about human genetics as possible forms of benefit sharing. Still, scant practical guidance exists when it comes to putting these principles into practice and to establishing acceptable benefit-sharing models.

In this article, we describe a community-driven collective financial benefits model (Fig. 1) funded by the US-based genomics-driven drug discovery company Variant Bio and offer a case study from Madagascar. We highlight the ways in which local residents

were consulted and ultimately shaped the distribution of benefit-sharing funds. Despite the time investment and challenges involved in this process, we argue that it affords a vehicle to both increase equity for participating communities and ensure that financial investments tangibly support locally determined needs.

The development of a collective financial benefit-sharing model

As industry employees and advisors, academic researchers, and Indigenous thought leaders in genomics, we have advocated for benefit sharing as a means to promote a more just and equitable research exchange. A critical step in learning how to do this at Variant Bio was the formation of an independent ethics advisory board where Indigenous and other key opinion leaders provided suggestions to the company for sharing financial benefits that steered sharply away from prior charity-driven models. Taking as guidepost the Indigenous data sovereignty movement, the board argued to distribute benefits at the community (rather than individual) level and to do so in the short and long term, regardless of what researchers did or did not discover from studies.

The decision to distribute benefits at the collective scale was based on several factors. First, the distribution of sizable funds at the individual level would most certainly raise red flags among institutional review boards related to issues of possible “undue influence” on research participants. On a more fundamental level, however, the misuse of genomic research in the forms of genetic essentialism and biological determinism inflicted damage that reached far beyond individual research participants to impact their wider communities and even broad “social categories” of people (Sterling 2011). These collective-level abuses arose from the fact that individual genetic data inherently insinuates data about a person’s family and larger community and thus enables the telling of potentially dangerous and damaging stories that affect a wide swath of people (Sabatello and Juengst 2019). In essence, genomics—and the potential harms and benefits from it—must be understood as a collective community venture.

Variant Bio therefore committed to distribute financial benefits in both the long and short term to communities that partner with the company in genomic research studies. This program—formalized as a binding pledge in 2020—commits to sharing long-term benefits divided among partner communities in the

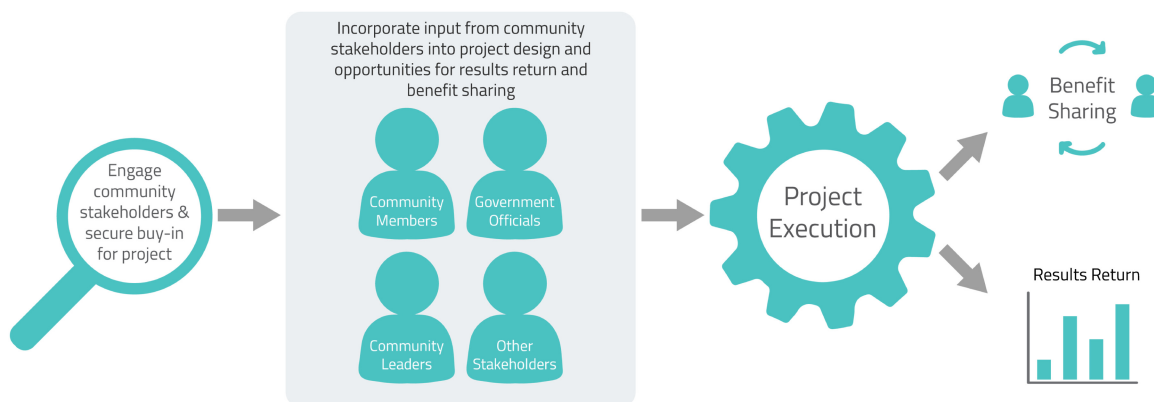


Figure 1. Approach to community engagement that results in benefit sharing.

amount of 4% of revenue every year and 4% of equity value should the company go public or be acquired, as well as short-term benefits in the amount of 10% of the total study budget (up to a maximum of \$100,000 in US dollars). The maximum cap for short-term benefits was determined together with Variant Bio's investors who are on the board of directors and the ethics advisory board. The goal was for this amount to be significant enough for participating communities in terms of investment potential, while not distributing too much of the company's initial capital before it reached the point of generating revenue. Only the short-term benefits are tied to a project budget. Long-term benefits will be dispersed evenly among participating locations (excluding pilot projects). Variant Bio is bound to these commitments via contracts signed with research partners, hence the "binding pledge."

This benefit-sharing program functions in concert with other important commitments formalized via Variant Bio's research collaboration agreements, including (1) an affordable medicine pledge that aims to ensure the financial accessibility of any drugs the company eventually develops to the communities whose data led to identifying the discovery, (2) data cogenerated together with research partners, (3) the sharing of relevant research results with participating populations, and (4) capacity building through the promotion of genomic literacy and training for local study staff.

Incorporating community feedback into benefit-sharing decisions

A key aspect of creating a communal-level benefit sharing model for Variant Bio was determining how to afford communities meaningful input into how the money would be spent. This commitment is in keeping with the Indigenous data sovereignty movement's push for agency and self-determination of Indigenous research participants (Oguamanam 2020). Community engagement with local populations around any aspect of research has been shown to engender respectful and ethical relationships at study sites and thereby improve the local relevance of research more broadly (Blacksher et al. 2021; Ogunrin et al. 2022).

Anthropologists helped frame, design, and implement a community engagement model that the company uses to elicit pre-study feedback as well as input on benefit sharing and return of results (see Fig. 1). Anthropology as a discipline is painfully aware of its colonial roots, including the unfortunate legacy of harm and exploitation of Indigenous populations. It is indebted to postcolonial, postmodern, feminist, and intersectional scholarship for the more critical, self-reflexive approach it takes today. It is precisely this reflexivity—and the emphasis that cultural anthropology in particular places on understanding diverse perspectives and experiences through participant-observation, as well as the relationship between history, power, and culture—that informs Variant Bio's approach to community-engaged research. This model incorporates third-party consultants, fellows who work locally in the region, or research partners with local knowledge and long-standing community relationships to perform community engagement at study sites.

Those leading community engagement identify and consult with local stakeholders before the study begins to document what they consider to be the region's most salient needs and priorities for future investment and to gather suggestions for specific, trusted organizations that work in those areas. In the event that no local organizations exist to address these needs, funds may be

directed instead toward larger organizations that can support specific initiatives.

Since formalizing this model, Variant Bio has performed community consultation around short-term benefit sharing in all research studies involving new recruitment. In certain instances, consultation around benefit sharing happens poststudy as opposed to pre-study owing to concerns expressed by research partners or institutional review boards that speaking about benefits before the study could lead to undue influence or to setting unrealistic expectations among the local population. To date, the company has distributed or is in the process of distributing short-term benefits according to the community consultation model for projects in South Africa, French Polynesia, Uganda, Kenya, India, Indonesia, New Caledonia, and Madagascar (see case study below).

Case study: Madagascar

Learning about what the people want

In 2020, a research team, led by biological anthropologists from the University of Antananarivo's Department of Anthropobiology and Sustainable Development in collaboration with Variant Bio, conducted a pilot project on Madagascar's genetic diversity in relationship to disease. Previous studies had shown that highland populations in Madagascar are more genetically similar to southeast Asian populations, whereas residents of the west coast are more genetically similar to African populations (Rakotoarivony et al. 2019). This research consisted of a comparative analysis of health information and genetic samples from highland and coastal regions of Madagascar.

The first phase of study design consisted of 3 wk of formal community engagement in three locations across Madagascar. The research team used semistructured interviews with community leaders, key stakeholders, and other citizens to explain the purpose of the project, assess local interest and study feasibility, and discuss their questions and concerns, as well as to gather input from community members about how best to allot benefit-sharing funds.

Upon their return to the University of Antananarivo, the team collated and analyzed the data from the stakeholder interviews and created a list of the five most commonly cited priority areas across the three locations. These included lack of access to public toilets, lack of clean drinking water, poor school infrastructure, deforestation and other environmental issues, and the need for language training (Fig. 2).

In 2021, the research team returned to the field for study implementation, which included collecting biological samples and health information. As part of this phase, they conducted an exit survey with study participants to gauge opinions about priority areas to address through benefit-sharing distribution. Each participant was presented with a list of the previously identified five key priority areas and was asked to select the most important one. Regional differences were observed among the 257 responses, with participants from the west coast more commonly selecting the lack of clean drinking water as the prime issue, whereas participants in the two highlands sites prioritized making improvements to poor school infrastructure.

Funding what the people want

The research team then worked to craft benefit-sharing initiatives to address these issues within the confines of the modest funds available (approximately \$12,000 US) for this initial pilot project



Figure 2. Overview of benefit sharing for a genomic research project in Madagascar. (A) Map of Madagascar study site locations and corresponding areas of unmet need selected for benefit sharing. (B) Project timeline. (C) School roof supplies distributed in the southern highlands. Photograph by Germain Jules Spiral. (D) Water pump installed on the west coast. Photograph by Rindra Rakotoarivony. Both photographs are used with permission.

that recruited a total of 264 participants across the three villages. The team in Madagascar started by researching local organizations with the capacity to institute the initiatives within the timeline and budget determined for the project. Because options on the ground were extremely limited, the team opted for alternative distribution channels including a pump installation company and two local groups capable of carrying out grassroots projects. Following sample collection and data entry, funds were disbursed to support (1) a local company to build a water pump in Tsianaloka village on the west coast, (2) the purchase of materials for a new high school to be built by community members in Tsiandatsiana village in the southern highlands, and (3) the provision of materials for community members to install a new roof for a school located in Ampandrialaza village in the central highlands.

In all three study locations, community members expressed deep gratitude, but also surprise, to see researchers stay true to their word and return within just a few months of sample collection to disburse short-term benefits. On the west coast, community members of all ages gathered to watch the installation of the new water pump, and leaders from one of the highland villages hosted a church ceremony to give thanks for the school improvements. As one of the members of the research team from the University of Antananarivo put it, “People in these villages are very used to politicians making promises they never keep. It is such a different experience for them to feel they not only have a say in which benefits their community receives, but also that we came back so soon and actually delivered them.”

Challenges in funding what the people want

Although the direct community consultation in Madagascar resulted in highly relevant and desirable investments, there were also significant challenges. These ranged from logistical difficulties—such as community-based organizations lacking established

bank accounts, bureaucratic hurdles to international wire transfers—to more fundamental ethical matters such as those considered next.

First, no clear definition exists of what constitutes a given “community” and thus, by extension, who should be included in community consultation processes. Community can be conceived of in terms of a disease community, a cultural, linguistic, or political community, and so on and so forth, but as with all identities, these groupings are porous, shifting, and heterogeneous. The research team in Madagascar drew the line by the village’s administrative boundaries, but even then, it was impossible to consult with every single member of the three “communities.” To redress this limitation, the research team consulted with key representatives of diverse subgroups they identified according to age and gender breakdowns. They also consulted with local administrative authorities for each of the three villages, including village mayors and district heads. Although it is critical to engage local government officials in this process, it is equally important to consult with ordinary citizens so as not to give a determinative voice to any single stakeholder. This is especially critical because, in many contexts around the world, the perspectives of government officials from a country or region’s majority population are not necessarily aligned with or representative of those of minority or Indigenous groups.

A second challenge involved using an exit survey question as a means to identify a single priority area to support via Variant Bio’s short-term benefit-sharing program. Researchers from the University of Antananarivo worried that asking participants to select only their top choice (e.g., poor school infrastructure) might not capture the full range of community priorities or else might appear as a promise to necessarily fund one area over another. To mitigate against this, the team offered participants the option of ranking any or all of the five priority areas, as well as the option of filling in an open-text answer. For transparency, they also

explained to participants that no single area was guaranteed to be prioritized over another through Variant Bio's benefit-sharing program and that participants' input would be taken together with other stakeholder feedback in order to determine funding priorities for the community in question. Although it took more time for the team to later collate and tally these answers than a simple multiple-choice survey question, this approach afforded participants more flexibility and nuance in their response and helped ensure that their input was included in the decision-making process.

Finally, funding locally relevant initiatives and organizations can raise issues related to sustainability. When the Madagascar research team returned to share results in 2022, they learned that the new water pump installed in Tsianaloka village was already broken owing to heavy usage and that community members lacked the funds to fix it. Given the important need that the water pump had addressed in the village, residents were frustrated and disappointed to learn that there would not be repair funds forthcoming. This finding highlights the need for researchers to carefully consider the durability of benefit-sharing projects and the need for long-term plans regarding maintenance and repairs. Considering that Variant Bio is still a relatively small company and has completed or is working on ongoing projects in over 20 different geographies, it does not have the in-house capacity to perform long-term evaluation of benefit-sharing outcomes. However, by building extensive relationships with local researchers and partner communities around the world, the company continues to informally track the outcomes of the projects it funds. A more formal way of measuring and monitoring benefit-sharing outcomes could be considered in the future, either by doing so directly or through local NGO partners. We hope that by implementing Variant Bio's long-term benefit-sharing model, partner communities will receive the support they need on a yearly basis, although long-term benefit sharing is dependent on Variant Bio generating revenue, and the company is not yet at that point.

Conclusions

Here we have offered a concrete example of how community-level benefit sharing was implemented in an industry-funded project that incorporated community consultation. Our intention is to share lessons that may assist other researchers in gaining meaningful local insights in order to both enhance the potential impact of benefit-sharing monies and avoid repeating tired legacies of colonial paternalism.

One obvious limitation of this approach is that it requires the availability of funds that are more typical of industry-funded projects, making its application to academic and other public sphere research more difficult. This is especially true with regards to long-term benefit sharing, which may not be feasible for academic projects that are time-limited and are not tied to specific company revenue or profit. Still, academic institutions have other ways of making a long-term impact, for example, through the provision of training and building long-term capacity. Furthermore, the case study from the pilot project in Madagascar shows that even smaller benefit-sharing investments that may be more scalable in the public sphere can lead to relevant local impacts. To start moving in this direction, it will be important for research teams to write benefit-sharing processes, shared equity, or community royalties into large-scale federal grants (e.g., National Institutes of Health, National Science Foundation, etc.).

However, we would also like to highlight that benefit sharing can take many important forms, some of which are decidedly less capital intensive. These can include (1) sharing authorship of major scientific publications with local scientists and engaged community members; (2) promoting and empowering informational and data sciences (IDSs) via the application of emerging data science tools to encourage rapid sharing, privacy, and protection of data, including blockchain (digital ledger systems), federated learning (collaborative machine learning), data trusts (data governance mechanisms), homomorphic encryption (secure computation methods), and differential privacy (privacy-preserving data analysis); and (3) building true local capacity by instituting internship programs, mentorships, and hiring and training local staff. Looking forward, it will be critical to start the groundwork for academic research to build and vertically integrate hardware (e.g., biobank, genome sequencing centers, cloud resources, cold data storage) in ways that benefit the broader community.

Wherever people share genomic data with researchers, collective benefits—be they financial or others mentioned above—should be shared with them in a manner that reflects the paramount need for reciprocity in research. This step is not only an ethical imperative but also a necessary requirement to expand the list of groups who choose to participate in genomic studies. Only through greater representation are researchers able to fully leverage the power of human genetic diversity to identify the basis of disease and to develop better therapeutics as a result.

Competing interest statement

The authors of this paper are either current or former employees and options or shareholders of Variant Bio (Sarah LeBaron von Baeyer, Rebecca Crocker, Stephane Castel, Andrew Farnum, Holly Vance, Noah Collins, and Kaja Wasik), an advisor to Variant Bio (Keolu Fox), or Variant Bio's research collaborators on a genomic research project in Madagascar (Rindra Rakotoarivony, Jean Freddy Ranaivoarisoa, and Germain Jules Spiral).

Acknowledgments

First and foremost, we thank the communities around the world who have shared their genomic and health data with researchers. May future generations receive the benefits they deserve. We also thank members of the Center for the Ethics of Indigenous Genomic Research at the University of Oklahoma and the Native Bio-Data Consortium, as well as Adia Benton, Huti Watson, Laura Hercher, Maui Hudson, Misha Angrist, Melissa Hendershott, Leslie Hepner, Erin Burke, Soanorolalao Ravelonjanahary, Brigitte Marie Raharivololona, José Mahenina Randria, Mosa Zafimaro, Tojo Julio Andriamahefa, Bodonomena Fitahiana Laza Rafidison, Rota Mamimbahiny Andriantsoa, Tsiorimanitra Aimée Randriambola, Severine Nantenaina Stephe Raveloson, Kate Orviss, and all participants of Public Policy Projects' Global Genomics Programme.

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Received September 14, 2023; accepted in revised form January 8, 2024.



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Genome Res. 2024 34: 1-6 originally published online January 31, 2024

Access the most recent version at doi:[10.1101/gr.278308.123](https://doi.org/10.1101/gr.278308.123)

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