

# From urban NPOs to rural knowledge networks: applying benefit-sharing models to African genomics research

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Despite repeated calls from international governing bodies for benefit sharing in biomedical research as a means of promoting mutual trust and reciprocity, real-world examples of benefit sharing are lacking. Here, we discuss benefit-sharing initiatives instituted as part of human genomics research projects carried out in both semi-rural and urban settings in South Africa. We explore lessons learned from applying different approaches to benefit sharing, as well as recommendations for ways to enhance success for future initiatives. Ultimately, we advocate for the adoption of flexible benefit-sharing models that take into consideration community representation and engagement, benefit management mechanisms, and long-term sustainability.

Benefit sharing has emerged as a pivotal concept in biomedical research ethics and resource governance. Rooted in the principles of equity and justice, the notion of benefit sharing gained prominence through international agreements such as the Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization.<sup>1</sup> This protocol underscores the imperative of sharing benefits derived from natural resource extraction with local communities.<sup>1,2</sup> However, it does not address the distribution of benefits arising specifically from the use of human genetic resources (as opposed to other natural resources). In the realm of global health research, benefit sharing has become a cornerstone strategy for addressing moral concerns and enhancing the social value

of research conducted in resource-poor settings. In 2024, the WHO issued a set of globally applicable principles designed to promote more equitable human genomic research.<sup>3</sup> This notion of social responsibility in research is complex and can take many forms depending on the context.<sup>4</sup>

Community benefit sharing refers to the practice of distributing the benefits derived from the exploration, utilization, and commercialization of resources or knowledge among the communities or stakeholders affected or involved in the process.<sup>5-7</sup> This concept differs from either individual-level benefit sharing or participant remuneration (e.g., the common practice of offering nominal compensation to each study participant for their time), in that communities receive

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benefits following the implementation of a study, irrespective of which individuals do or do not participate in research. It is often applied in various fields such as biodiversity conservation, genetic research, pharmaceutical development, and natural resource extraction.<sup>1,2,5,6</sup> Community benefit sharing aims to ensure that local communities, Indigenous Peoples, or other stakeholders receive fair and equitable compensation, recognition, or other forms of benefit for their contributions, traditional knowledge, resources, or participation in research, development, or commercial activities.<sup>8,9</sup> It encompasses tangible benefits—such as improved healthcare, education, infrastructure, or economic opportunities—as well as intangible gains related to knowledge dissemination and capacity building.<sup>10</sup>

In biomedical research, international regulations and guidelines have increasingly recognized the importance of both community engagement and benefit sharing. Initiatives such as the Human Heredity and Health in Africa (H3Africa) consortium have incorporated principles of community engagement and benefit sharing into their research frameworks, aiming to foster trust, equity, and sustainability in genomic research on the African continent.<sup>11</sup> Additionally, international governing bodies such as UNESCO and the WHO<sup>12</sup> have made calls for benefit sharing in biomedical research as a means of promoting mutual trust and reciprocity in community-based research relationships.

Despite the proliferation of guidelines advocating for the integration of benefit sharing into research practices, its implementation and uptake in low-resource environments such as African countries remain limited. This is largely due to the fact that benefit sharing is still not incorporated into traditional funding models as a requirement or official policy. What is more, researchers lack practical guidance and successful examples around the distribution of benefits arising specifically from the use of human genomic resources.<sup>13</sup> This is particularly relevant in the context of genomic and biobanking research, which has witnessed significant growth in Africa in recent years. Against this backdrop, the importance of community benefit sharing is underscored by landmark agreements, such as the one signed in May 2003 between the South African San Council and the South African Centre for Scientific and Industrial Research, pertaining to the equitable sharing of benefits derived from genetic research on the Hoodia plant<sup>7</sup>, as well as the Rooibos Benefit Sharing Agreement signed in March 2019 between the San, the Khoi, and the South African rooibos industry.<sup>14</sup> These agreements represent pioneering efforts to ensure that local communities benefit from the commercialization of genetic resources and traditional knowledge.

As a group of scientific researchers, community engagement officers, and industry employees representing institutions in South Africa and the United States, we advocate for the adoption of a collective-interest, community-driven model of benefit sharing in human genomic research studies. While we design studies to include many important non-monetary benefits (e.g., knowledge generation for future health impact, education and information sharing, workforce training and local capacity development), here we focus on an approach that also includes immediate financial benefits for the communities participating in research. Ensuring that tangible benefits reflect local priorities and reach those who contribute to genomic research is paramount for community well-being and sustaining engagement. Such engagement, which considers the interests and priorities of diverse stakeholders, in turn leads to more equitable and socially responsible outcomes. Prior studies have demonstrated that community benefit-sharing initiatives hold promise in empowering communities to enhance control over the research conducted in their regions, thereby fostering autonomy and decision-making authority.<sup>15,16</sup>

In this perspective, we specifically explore the implementation process of financial benefit-sharing initiatives for two human genomic research studies in South Africa: (1) a study arising out of the AWI-Gen

Collaborative Centre as part of the Human Heredity and Health in Africa (H3Africa) Consortium and referred to as the Southern African Blood Regulatory (SABR) resource, and (2) a study with the South African arm of the African Research on Kidney Disease (ARK) Consortium. For each of these studies, Variant Bio, a genomics-driven drug discovery company based in the United States that has established a [collective-interest, community-driven model of benefit sharing](#) for genomic research studies, distributed 10% of the project budget to community-identified organizations supporting the groups participating in research.

The exploration and utilization of genetic resources hold immense potential for scientific advancement and therapeutic innovation.<sup>2</sup> However, these pursuits often intersect with ethical and social considerations, particularly regarding the fair distribution of benefits derived from research activities. In response to these challenges, a collective-interest, community-driven benefit-sharing program seeks to operationalize principles of equity, transparency, and community engagement, thereby promoting mutually beneficial outcomes for researchers and local populations. Against the backdrop of evolving norms and guidelines on benefit sharing, this perspective seeks to evaluate the efficacy and implications of one such benefit-sharing program. By examining the program's design, implementation, and outcomes across different study sites in South Africa, we highlight key insights and lessons learned for the broader field of community-engaged genomic research. We discuss the challenges encountered in the process, including those involving mechanisms for managing funds, approaches to identifying and narrowing down potential beneficiaries, the risk of undue influence and structural coercion among participating communities, gender and other power imbalances, and long-term sustainability concerns. An understanding of the acceptability of models among diverse communities is important in co-designing benefit-sharing models that accommodate local perspectives.<sup>16</sup> We hope that these examples can inform future initiatives in genomic research and benefit sharing, ultimately promoting mutually beneficial outcomes for researchers and local populations while fostering trust, equity, and sustainability in genomic research endeavors on the African continent and beyond.

### Case study 1: The Southern African Blood Regulatory study

The Southern African Blood Regulatory (SABR) resource study was a collaboration between the Sydney Brenner Institute for Molecular Bioscience at the University of the Witwatersrand in Johannesburg, South Africa, and Variant Bio in the United States. It was co-developed as an independent project, but leveraged prior information from the Africa Wits-INDEPTH Partnership for Genomic Studies (AWI-Gen), and entailed a partnership with the three South African AWI-Gen study centers, located in the provinces of Mpumalanga (Agincourt), Gauteng (Soweto), and Limpopo (DIMAMO) (Fig. 1). The aim of the project was to create a blood regulatory variant database of information from ~750 South African individuals in order to understand how genetic variants influence gene expression and how this may impact health.<sup>17</sup>

In 2021 and 2022, members of the SABR team met in person with community representatives in each of the three study locations in South Africa to discuss the proposed collaborative research project with Variant Bio and respond to any questions or concerns. In the semi-rural settings of Agincourt and DIMAMO, established community advisory boards (CABs) at the South African Medical Research Council/Wits-Agincourt and University of Limpopo DIMAMO Health and Demographic Surveillance Sites (HDSSs) served as the key conduit for communication between researchers and community members. CABs were initially established at these sites to ensure that community concerns and ideas are fully considered in all research activities conducted there. CAB members are volunteers nominated by elected Community Development Forums.<sup>18</sup> They consult with their respective traditional councils and Chiefs, and report any questions or input back



**Fig. 1 | Map and photos illustrating the SABR study locations in South Africa.** Clockwise, L to R: The three SABR study locations in South Africa; the semi-rural setting of DIMAMO (photo taken by Michèle Ramsay); the semi-rural setting of

Agincourt (photo taken by Sarah LeBaron von Baeyer); the urban setting of Soweto (photo taken by Sandra Maytham-Bailey).

to the HDSS Public Engagement Offices. These Public Engagement Offices are intrinsic to the HDSS structure, and in recognition of the critical role they play, the staff and functions of the office are funded by each of the research units, as opposed to outside entities such as industry partners.

In contrast, in the urban setting of Soweto, a township of Johannesburg, an equivalent CAB and system of traditional leadership do not exist. Here, public engagement officers working within the SAMRC/Wits Developmental Pathways for Health Research Unit (DPHRU) carried out consultation primarily via meetings with elected Ward Councilors and other members of the public. Specifically, public engagement officers reached out to 50 individuals selected at random from the participant database at DPHRU to survey them about unmet needs in their community and gather suggestions for possible organizations to support. Ward Councilors were not asked to suggest potential beneficiaries, but were included in benefit-sharing discussions based on the suggestions put forth by individual community members.

Despite some differences across the three locations, community representatives in each location provided direct input into how the funds from Variant Bio's benefit-sharing program should be allocated. After community members identified, nominated, and interviewed relevant NPOs for the DIMAMO and Soweto sites, those NPOs submitted proposals for funding based on their specific objectives. SABR and Variant Bio team members then vetted these organizations according to certain established criteria (see Table 1) and narrowed the beneficiaries down to a final shortlist of nominees. Upon study completion in 2022, benefit-sharing funds totaling ~\$40,000 USD were distributed among the three study sites to support an aftercare center for children with cerebral palsy, a trauma counseling center, several homes for senior citizens, after-school centers for children aimed at enhancing their reading skills and exposure to sporting activities, and

the purchase of several water tanks (JoJos) (see Fig. 2). The process followed in Agincourt is described below for Case Study 2.

### Case study 2: The African Research on Kidney Disease study

Building on the ARK Consortium study in South Africa, researchers from the University of the Witwatersrand in Johannesburg and Variant Bio entered a collaboration in order to better understand kidney disease in Sub-Saharan African populations, specifically semi-rural communities around Agincourt in the Bushbuckridge sub-District of Mpumalanga Province in northeastern South Africa. This location was the same as the Agincourt site included in the SABR study (Fig. 1). In total, genetic and health data from 200 individuals were included in the initial pilot project, and 925 individuals in the subsequent study expansion.

Beginning in 2021, members of the ARK team carried out community engagement for the pilot project via the same HDSS Public Engagement Office in Agincourt as that used in the SABR study. Over many years, the HDSS has nurtured and sustained a strong relationship with communities included within their study site via a highly skilled team of trained staff, functioning as the Public Engagement Office, many of whom live within the HDSS. Communities are consulted about future studies and their research needs, and researchers provide feedback about study results. Central to the engagement are the HDSS's ties with elected village Community Development Forums, Indunas (the isiZulu word for village leaders, or headmen, which have historically been patriarchal, with increasing representation of women emerging), and, where relevant, education circuit managers. Interactions among these entities involve collaborative efforts to manage conflict, address local concerns, promote community development initiatives, and facilitate grassroots participation in decision-making processes, ultimately contributing to the holistic development of rural South African communities.

**Table 1 | Vetting criteria for proposed beneficiaries**

<b>Is the primary mission of the organization to support health, environment, education, and/or culture?</b>
Is it a registered non-profit organization? (In South Africa, registration can be found via the public database: <a href="https://www.npo.gov.za">https://www.npo.gov.za</a> )
Does the organization have a dedicated bank account that can accept wires of foreign funds?
Does the organization operate in the communities from which data was collected?
Does the organization have a track record of good governance and responsible reporting on funds?



**Fig. 2 | Examples of benefit-sharing initiatives supported through the SABR and ARK projects.** Clockwise, L to R: Portable generators for schools (photo taken by Sarah LeBaron von Baeyer); a home for senior citizens (photo taken by Michèle Ramsay); a community organization focused on youth and health (photo taken by Michèle Ramsay); distribution of communal water tanks (JoJos) (photo taken by Sandra Maytham-Bailey).

Members of the Public Engagement Office also work with a CAB composed of representatives of all 31 villages contained within the Agincourt HDSS. These representatives are appointed by their elders and chiefs. The CAB’s responsibilities are to represent the interests of their communities and provide feedback about the health research projects being proposed. As far as is possible, engagement extends beyond the local sphere to encompass provincial government leadership, emphasizing the commitment to fostering dialog across governance levels. The CAB typically meets once a month, providing an ongoing basis of engagement.

For the collaboration with Variant Bio, community representatives within the Agincourt HDSS provided direct input via the Public Engagement Office and CAB into how benefit-sharing funds should be allocated. A multidisciplinary team was convened to lead discussions centered on identifying the most pressing needs in the community. Public engagement officers formed a WhatsApp group and used SMS messaging to inform community members of the meetings. After consideration of various proposals, a final list of initiatives was selected

based on the most important areas of unmet need identified by the community. In 2022, benefit-sharing funds totaling ~\$20,500 USD were distributed for the pilot phase of the ARK project and the portion of SABR that included the Agincourt site to purchase 55 JoJos (water tanks) for schools and community functions, primarily funerals, across the 31 villages. These tanks each hold up to 5000 liters of water and were brought to the different villages over the course of three weeks by public engagement officers involved in the project. In 2023, an additional ~\$73,000 USD in benefit-sharing funds were distributed following an expansion of the project, this time to purchase portable generators, whiteboards with digital projectors, and printers/wifi installation for all 65 schools within the Agincourt HDSS catchment area (see Fig. 2).

**Comparing benefit-sharing models in rural and urban settings**  
In rural South African communities, a hierarchical structure exists with traditional leaders, primarily Chiefs, holding the highest authority. Chiefs oversee multiple villages or areas within a region, delegating

responsibilities to appointed Indunas (village headmen) who manage specific villages under their jurisdiction. These traditional leaders play pivotal roles in decision-making, conflict resolution, and representing community interests to external authorities.<sup>19,20</sup> Traditional leaders are recognized by the Constitution of the Republic of South Africa (1996)<sup>21</sup> and, because they are not directly affiliated with particular political parties, their authority tends to persist independent of election outcomes.

In contrast, in urban settings in South Africa, where there is no comparable system of traditional leadership, elected Ward Councilors operate at the local government level, representing specific geographic areas known as wards. They play a key role in working with members of the public to address development priorities, allocate resources, and advocate for their constituents within the broader governmental framework.<sup>22</sup> Urban governance structures also involve multiple layers of authority (e.g., city councils, municipal bodies, district committees), which can make the decision-making process less streamlined than in rural settings. In the projects described here, there was a preference in the semi-rural sites to involve traditional leadership infrastructure over Ward Councilors. Having access to and an understanding of how to navigate these various levels of leadership across both semi-rural and urban settings was critical to building trust, fostering fairness and transparency, and soliciting direct input from community members themselves.

Reaching consensus over the allocation of funds required significant deliberation, especially in semi-rural settings where traditional leaders had some input, together with their communities, in the selection of beneficiaries. Traditional leaders at the DIMAMO and Agincourt sites had varying and sometimes conflicting opinions regarding how benefit-sharing funds should be used, and at times these also differed from the opinions of other stakeholders in the study regions. At the Agincourt site, for example, in the second phase of benefit sharing for the ARK project, traditional leaders advocated for the purchase of tents and chairs to be used for community gatherings. However, other stakeholders in the community, especially those represented by the CAB, preferred that funds go toward supporting school infrastructure. To address these different opinions, public engagement officers, including both women and men, carried out participatory consultations with all stakeholders – including Chiefs, Indunas, representatives from the Department of Education, and the CAB – to ensure that everyone's voice was heard before representatives from ARK and Variant Bio made a final decision regarding the allocation of funds. Public engagement officers also carried out a needs assessment with the various stakeholders involved so as to identify community priorities, aligning with the most urgent needs rather than individual preferences. Once educational infrastructure was selected as a local priority, the team then met with circuit managers for the District Education Office and school principals to identify and prioritize which items schools needed most. Although express approval was not sought from traditional leaders, they respect the consultative process and continue to support the research efforts and mitigate potential tension among stakeholders over the allocation of funds.

Engaging a wide range of stakeholders was logistically challenging, both in dispersed semi-rural settings such as those of the DIMAMO and Agincourt study regions, and in the densely populated urban setting of Soweto. The Agincourt study site comprises ~120,000 people spread across 31 villages and 420 km<sup>2</sup>, while the DIMAMO study site comprises ~116,000 people across ~57 villages (18 of which were included in the collaboration with Variant Bio). In order to reach people effectively, public engagement officers across these two sites had to be flexible about the timing of meetings, and to rotate the villages in which meetings took place. Community meeting participants, including CAB members, received transport reimbursements to offset their travel expenses, and catering was also provided during

these meetings. Since CABs consist of volunteer members not on a payroll for their services, this helped ensure consistent attendance. Similarly, catering was provided during meetings with school principals and circuit leaders for the Department of Education.

In Soweto, an urban township comprising nearly two million people residing across ~200 km<sup>2</sup>, there was no equivalent mechanism for community engagement and the study team could not rely on local social networks in the same way. Instead, the team selected 50 participants at random from previous research studies to provide information about NPOs in their communities. From these suggestions, they identified ~30 NPOs. They then narrowed down the list to 15 through a shortlisting process, which required the NPOs to submit relevant registration documents and describe the impact that funds would have on communities. This shortlisting was conducted by community engagement officers, and the 15 shortlisted NPOs were then forwarded to the main researchers from SABR and Variant Bio for final selection. Three NPOs were then selected as recipients of benefit-sharing funds based on specific criteria (Table 1). The NPOs submitted a list of needed items to the Community Engagement Office, which then audited the purchases, amounting to a total of \$13,500 USD, to ensure everything on the list was acquired once funds were received. Ward Councilors were involved only to verify the existence and track record of the selected NPOs, and to sign off on a form for each.

At the DIMAMO study site, NPOs were also selected as the delivery mechanism for distributing benefit-sharing funds, but the process of community engagement there more closely resembled that of Agincourt. After receiving nearly 20 proposals from NPOs, the DIMAMO team and a panel made up of members of the CAB, tribal authorities, and the Department of Public Health selected three finalists based on established criteria (Table 1). Much like in Soweto, these three finalists submitted lists of needed items, and purchases to the value of \$13,500 USD were audited by the local community engagement team. Thus, the selection of beneficiaries at DIMAMO, like at Agincourt, was based on more direct deliberation with community representatives than was the case in Soweto. Ultimately, the final selection decision at each site was made by community engagement officers and principal investigators from the research team, based on input from local community members. Researchers from Variant Bio were involved in the decision only insofar as verifying that the selected organizations met their requisite legal/compliance criteria.

### Lessons learned and recommendations for future projects

Throughout the process of identifying and selecting beneficiaries and distributing benefit-sharing funds for these two projects, a number of challenges emerged. First, while funds for the SABR project were distributed via NPOs serving communities in two of the study locations in South Africa (DIMAMO and Soweto), for the Agincourt site included in both the SABR and ARK projects, the funds were managed and distributed via the Wits Health Consortium (Pty) Ltd, a wholly owned company at the University of the Witwatersrand, with local project champions anchored in the surrounding region of Bushbuckridge. Because of its close and longstanding ties to the Agincourt HDSS, and because of the lack of eligible NPOs serving the community that participated in the study, the Wits Health Consortium was nominated instead of an NPO as the most appropriate entity through which to channel and manage the funds. Prior to initiating procurement of identified assets, the Wits Health Consortium waived a 10% administrative fee, recognizing the program's significance to the communities. This gesture ensured that the total budget allocated for community benefit would reach the community.

The Agincourt team implemented benefit sharing without relying on local NPOs as the result of a unique combination of trust, long-term relationships, direct community ties, and alignment with local priorities. This approach allowed the Agincourt HDSS the opportunity to leverage its established community trust, local networks, and deep

understanding of community needs. The HDSS directly oversaw all benefit-sharing activities and was able to respond swiftly to any challenges. For example, on one occasion, when the wrong brand of generators was delivered to schools, the HDSS acted quickly in order to obtain the correct generators. This model strengthened the HDSS's standing as a trusted community partner and ensured that the program's benefits were felt immediately and directly by local residents. Leaders from the schools were also involved in consultative and update meetings, and their regular feedback was instrumental in understanding how to optimize the newly purchased items for the schools.

Even where generous local administrative support is available, however, those involved in managing benefit sharing must make sure ahead of time that budgets cover costs related not only to the procurement of infrastructure (e.g., water tanks or whiteboards) but also their installation. In order for this type of infrastructure investment to have the most likelihood of impact, beneficiaries should also be involved early on in discussions and commitments around long-term support, e.g., regarding repair, maintenance, training, supply issues, and security.

Because of the challenges typically involved in securing such long-term support, international development and aid scholars increasingly caution against funding one-time, brick-and-mortar projects without well-established long-term sustainability plans. Instead, they advocate for lighter-touch interventions, such as cash transfers, which are backed by rigorous evidence demonstrating their efficacy in achieving a broad range of shorter-term and longer-term impacts.<sup>23</sup>

Besides identifying an appropriate entity to manage the funds for and then install the generators, whiteboards, and printers/wifi for schools around Agincourt, several related challenges arose with regards to supplying these items and the chain of procurements involved. For example, while the purchase of generators was very well received by community members, benefit-sharing funds were also required for the fuel needed to supply them. Load shedding or planned power outages—a common occurrence in South Africa used to avoid excessive strain on generating plants—frequently interrupted the supply of electricity needed to operate the new devices, and required backup power arrangements. Rural infrastructure limitations such as insufficient Wi-Fi coverage required signal boosters to enhance connectivity. Additionally, teachers at the schools were not necessarily comfortable with the new technologies provided. Fortunately, staff from the Agincourt HDSS were able to provide them with training on how to use items such as whiteboards and digital projectors. Security was another issue, given the economic value of these resources, and school managers had to figure out how to safely lock and store the items outside of school hours. Such follow-up support would not have been possible without the extensive local relationships and networks of knowledge already established via the Agincourt HDSS. However, if such challenges are not sufficiently anticipated and planned for in advance, they can lead to the failure of otherwise well-intentioned benefit-sharing initiatives.

When it comes to the most cost-effective approaches to educational outcomes in particular, the Global Education Evidence Advisory Panel recommends what it calls “Smart Buys” for improving learning in low-and middle-income countries. According to the Panel's 2023 report, investing in hardware like laptops, tablets, and computers alone, when other issues are not addressed, is considered less cost-effective than other investments such as scholarships and pedagogical training and support.<sup>24</sup> There is an inherent tension, then, between following recommendations such as these and respecting the priorities and needs put forth by community members themselves. To mitigate against the legacy of top-down, paternalistic approaches to international aid and development, local stakeholders should be involved in the decision-making process for the distribution of funds, including discussions of how best to address long-term sustainability.

Another key difficulty was figuring out how to narrow down and select eligible beneficiaries for each site. At the DIMAMO site, for example, authorities expressed an interest in the funds supporting needed local infrastructure such as a library or community hall. However, these types of projects went beyond the scope of available funding, and community members were concerned that channeling funds directly through the government might lead to conflicts of interest. Requiring that the beneficiary be a registered NPO (Table 1) was critical to mitigating against such concerns, and to managing authorities' expectations around the allocation of funds.

In Soweto, where participants nominated a total of 30 potential beneficiary organizations, the study team then screened them in order to narrow down to a shortlist of 15 based on NPO status and the level of impact they would have on participating communities. A key challenge here was that many of these organizations were not officially registered as NPOs or did not have an established bank account that could accept foreign currency, and so had to be removed from the shortlist. On the other hand, establishing clear criteria ahead of time such as the ones found in Table 1 can help researchers streamline the selection process, and ensure that funds reach communities in as timely a manner as possible.

The process of meaningful engagement is time consuming and requires discussions over extended periods, and the commitment of skilled negotiators who are employed for this purpose by research entities. In the cases described here, it is also heavily reliant on the members of Community Advisory Boards or Ward Councilors and their commitment to the needs of the communities they represent, and can be influenced by the individual representatives. Furthermore, meeting stakeholders in person during the COVID-19 pandemic presented numerous challenges, and study teams had to take various precautions (e.g., masking, social distancing) in order to overcome these limitations and stay meaningfully engaged with communities.

In any discussion of benefit sharing with community leaders and representatives prior to study recruitment, researchers must take measures to mitigate against the potential risk of undue influence or structural coercion among participants, for example by: (1) submitting the proposed benefit-sharing process to ethics review boards; (2) discussing the selection of potential beneficiaries with representatives of the broader communities at the study sites, and not the individual participants themselves; and (3) ensuring that individual informed consent always takes place in an environment where potential participants are not coerced, and remains a separate process from earlier community engagement involving community leaders and representatives.

Despite the challenges involved in effectively managing a benefit-sharing program such as the one outlined here, the study teams involved gained many important learnings from this process. For one, the value of involving people in the study who really know the communities in question cannot be overstated. In all of the study sites described, the teams included public engagement officers with long-standing, direct ties to local communities. Many of them were born or had grown up in the areas where the study took place, and were well versed in local cultural and linguistic contexts. They received salaries for their work, and were employed full-time throughout the duration of these research projects.

Wherever possible, researchers should consider establishing or engaging with communities via pre-established CABs. CABs have become crucial for involving communities in clinical trials, particularly in developing countries.<sup>25</sup> CABs serve as a guiding framework for researchers, helping them to understand the cultural contexts and needs of the communities being studied while also conveying community concerns back to the research team. What is more, they tend to have more balanced gender representation than do elected or traditional leadership bodies, allowing team members to mitigate against the gendered power relations shaping research. Numerous research

regulations and guidelines now require researchers to establish CABs as part of their community engagement efforts. This priority has been reinforced by international research funding organizations, including the Joint United Nations Programme on HIV/AIDS (UNAIDS) through its “Good Participatory Practice Guidelines for Biomedical HIV Prevention Trials,” and the U.S. National Institute of Allergy and Infectious Diseases (NIAID) via its “Recommendations for Community Involvement in NIAID HIV/AIDS Clinical Trials Research” report.

In the absence of an appropriate non-profit organization through which to channel funds, researchers should identify a local organization that serves as both an effective benefit-sharing mechanism and a champion for the community in question. Additionally, while community liaisons working on behalf of the organization should be remunerated, it is important that benefit-sharing funds be allocated primarily to communities as opposed to absorbed as institutional overheads.

Finally, given the challenges identified around the long-term sustainability of any benefit-sharing initiative, researchers should find ways to involve potential beneficiaries and other relevant stakeholders early on in these discussions. One solution is to include a selection criterion from the outset that addresses this, e.g., Does the organization have a system in place for long-term support of the proposed program? Consulting with stakeholders from local departments of health and education can also be helpful in ensuring that the proposed allocation of funds is not redundant with existing services or projects planned by the government, and that questions of security and maintenance are adequately addressed from the outset.

### Benefit in the context of genomics research in Africa

Genomic projects require specific care and in-depth discussions with communities about sharing of sensitive personal and population-defining genomic data are essential. African populations harbor the greatest genetic diversity as a result of the out of Africa migration of our species which resulted in just a sub-set of genetic variation leaving the continent and populating the rest of the world. For this reason, the impact of including African data has relevance and benefit not only for the local communities and the African diaspora, but also for the global community.<sup>26</sup> It is therefore imperative to ensure that consent is well informed and that the issue of data sharing is carefully addressed, considering context and diverse cultures across the continent. The value of African genomics data should not be underestimated and communities need agency in benefit negotiations.

Published in 2022, the need for accelerating access to genomic medicine for all people world-wide was the focus of the first report of the WHO Scientific Committee.<sup>27</sup> It underlines the need for including underrepresented and underserved groups in research and product development for improved prevention, diagnosis, and treatment to improve global health outcomes. Having appointed a Technical Advisory Group of Genomics (TAG-G), the WHO is developing universal principles for sharing genomic data which place emphasis on respect for communities and the need for effective communication of findings to broad stakeholders.<sup>12</sup> This is also emphasized in BePrecise guidelines for publishing research to facilitate and accelerate equitable implementation of precision medicine, where a cross-cutting theme is equity, inclusion, diversity, and patient- or participant-reported outcomes and experience.<sup>28</sup>

In this perspective our focus is on examples of effective community engagement with participating communities for research projects where data will be shared with the wider research community. Similar strategies could be deployed when engaging specifically in projects with a commercialization focus that also involve genomic data, and in such cases could be extended to include the equivalent of [an affordable medicines pledge](#) by the industry partner.

### Conclusion: toward a flexible model of benefit sharing

In the end, the collective-interest, community-driven benefit-sharing process for the SABR and ARK projects followed three different approaches tailored according to the unique nature of each study site: (1) at the DIMAMO site, an established community engagement process led to the selection of NPOs through which to distribute funds; (2) at the Agincourt site, which followed a similarly robust community engagement process, an alternative mechanism for managing funds was selected in lieu of NPOs; and (3) at the Soweto site, community engagement was less structured and formalized, but feedback from study participants ultimately informed the selection of NPOs through which to distribute funds. In all three scenarios the communities played a pivotal role in decision making related to benefit sharing. One potential limitation of this approach is that the research team members, rather than community representatives, were ultimately responsible for the final vetting and selection of beneficiaries. We recommend exploring options for how to improve on this process by involving community representatives during the final phase of decision making as well.

For benefit sharing to be successful, it must follow a flexible model, as opposed to a one-size-fits-all approach. In the different contexts described above, study teams adopted different models of engaging with communities, as well as different modes of delivering benefit-sharing funds, in order to reach organizations directly serving the communities involved. Other approaches to benefit sharing, for example that described by Variant Bio and collaborators working on a genomic research project in Madagascar, include the use of an exit survey in order to identify priority areas to address through benefit-sharing distribution.<sup>8</sup> Such an approach aims to include the voices of community members who might not otherwise be represented via existing platforms such as CABs and traditional leadership.

Regardless of the approach taken, conversations around benefit sharing should start early on in a study – ideally before recruitment begins – to allow research teams and communities enough time to determine the most appropriate model of benefit sharing, and to solicit as much feedback as possible from diverse community stakeholders regarding local priorities and areas of unmet need, as well as the most viable mechanisms through which to deliver funds. Additionally, a process of sustained and regular engagement over time is needed in order to properly manage community expectations, address questions and concerns that may arise, and build consensus among stakeholders over the allocation of funds. This process should be separate from participant recruitment in order to mitigate against the risk of undue influence and structural coercion; it should also seek to mitigate against patriarchal dynamics and other potential power imbalances by structuring community engagement at multiple levels of society and by involving both female and male community liaisons. At the same time, the process for determining beneficiaries should involve community representatives as much as possible in order to avoid a top-down approach to benefit sharing whereby participating communities have little to no say in how funds are used.

The initiatives described in this article represent a modest step toward implementing a collective-interest, community-driven model of benefit sharing for human genomic studies in South Africa, with implications for human genomic research projects around the world. Despite international accords and consensus, these benefit-sharing programs are new to most researchers and communities, especially in low-and-middle-income countries (LMICs), and there remain many challenges to address. For example, the question of how to measure and define the impact of benefit-sharing initiatives for communities participating in genomic research, including incorporating additional qualitative or quantitative data to substantiate the impact of benefit-sharing initiatives, is an important area in need of further exploration. While a formal comparative analysis of the effectiveness of benefit-

sharing models in semi-rural versus urban settings is beyond the scope of this paper, it is a topic worthy of future research and analysis.

Additional issues that need to be addressed include: (1) differences in access to benefits based on communities' positioning vis-a-vis research-driven infrastructure; (2) challenges around sustainability and how best to ensure that communities take ownership of an initiative following the initial distribution of benefit-sharing funds; (3) the risk that benefit sharing may be perceived as an incentive to participate in research; and (4) the power differentials involved between high-income countries (HICs) and LMICs when it comes to funding and how to successfully negotiate/advocate for benefit-sharing monies as a part of these grants.

Here, we have presented examples from both semi-rural and urban settings in South Africa in order to illustrate how communities participating in research can be effectively engaged in the distribution of benefits across different contexts. Regardless of where a study takes place, for benefit-sharing models to foster trust and equity in genomic research, they must take into consideration community representation and engagement, benefit management mechanisms, and long-term sustainability.

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## Author contributions

All authors contributed to the work discussed, and to the drafting and revising of this perspective. Together with N.N., J.F. and S.L.v.B. contributed equally to the writing.

## Competing interests

E.B., P.K., and S.L.v.B. are either current or former employees and options or shareholders of the US-based genomics-driven drug discovery company Variant Bio. M.R. is a consultant to Genetec (Roche) on Race, Ethnicity, and Ancestry: Application and Use in Clinical Trials and Product Development. The remaining authors declare no competing interests.

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