SANDRA LEE: Okay! Good morning! Afternoon, or evening, depending on where each of you are Zooming into today. I am Sandra Lee from the division of ethics at Columbia University, and I'm delighted to welcome you to our November ELSI Friday Forum, Benefit-sharing and Pharmaceutical Development in Africa: What Does Equity Mean? The forum is held on the second Friday of every month for one hour starting at 12 noon Eastern. We will also have a Zoom room reserved for more informal discussion immediately after the panel for about 30 minutes, so we hope that you can enjoy -- join us there.

For those of you who might be new to the Center for ELSI Resources and Analysis, or CERA, we provide resources to support the research on the ethical, legal, and social implications of genetics and genomics and serve to connect scientists, scholars, policy-makers, journalists, members of the public, and others to engage ELSI issues. The CERA is funded by the National Human Genome Institute at NIH, and is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University.

I encourage you to visit CERA's online platform, ELSIhub.org, for the recording and transcript of this forum and related references.

We're very pleased to announce the publication of our newest ELSIhub Collection. Please use the link in the chat to access Advancing Ethical Engagement and Benefit-sharing within International Collaborative Genomic Research Partnerships in Africa, a set of readings that clarify the processes and reasons for establishing equitable partnerships with communities that host genomics research. And this is a collection that is curated by Joseph Ali and Erisa Sabakaki Mwaka.

Please also go to the website to join the scholar directory, sign up for the newsletter and other events like this. You can also get news on Twitter.

So, just for some quick housekeeping information. If you wish to use closed captioning, please turn on the CC button at the bottom of your screen. The panelists' presentations will be very brief in order to conserve a significant portion of our time in discussion. So please use the Q&A button, which you will find at the bottom of your screen, to write in questions for the panelists at any point during the session. You can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box. The chat box is available for further engagement. We will post links to resources referenced in today's discussion there as well. And if you have any questions at any time, please e-mail at info@eLSIhub.org.

So now it is my absolute pleasure to introduce our moderator for today's discussion, Dr. Jantina De Vries. She is an associate professor in the department of medicine at the University of Cape Town. She obtained a degree at the University of Oxford, and undergraduate and postgraduate degrees in sociology. She has been at the University of Cape Town since 2011. Professor De Vries codirects the IFGENERA -- pronounced genera, I believe. She was the founder of the working group on ethics and served 2013 to 2016. She is a member of the research ethics board of Medicins Sans Frontiers, the steering committee of the global forum for bio-ethics and research, the Africa steering committee, and she sits on a number of advisory boards for ongoing international genomics research as well as ethics training projects.

It is my absolute pleasure to now turn it over to Professor De Vries, who will introduce the topic of our session today as well as the speakers.

JANTINA DE VRIES: Thank you, Sandra. And hello, everyone. I'm absolutely delighted to be here to guide through a discussion of a new benefit-sharing model that has emerged quite recently from a private sector company conducting genomics research in Africa and other places.

I am joined today by Professor Michele Ramsay of the University of Witwatersrand. Michele has vast international experience, as a member of the inter-committee group of persons working on human genome editing. She's also a part, and has been part, of the leadership of East Africa for many years, and has met with a huge number of African scientists to promote capacity strengthening for genomic research in African settings.

We are also joined by Dr. Nchangwi Munung, who is the director of health sciences at the University of Cape Town. Nchangwi has done work previously on benefit-sharing and African genomics research, and has been involved with myriad or several genomics research initiatives across the African continent. She was very much involved with ethics discussions around justice, fairness, and equity in the context of the ebola 2014 West African outbreak, and is currently very actively involved in terms of patient and community advocacy in the context of sickle cell disease genomics research.

So with those two excellent panelists, let me introduce today's topic to you. So as you are probably aware, genomics research on the African continent has been steadily growing, and not in the least through initiatives like H for Africa, which you may have heard of. But you should also know that research on the African continent is often conducted in the context of deep ethical concerns around fairness and exploitation. And exploitation not just of African researchers, but also of African research participants. And specifically the worry is that the large-scale, en masse collection of biological materials and data may be used to generate value for others elsewhere with little to no benefit for patients and participants on the African continent. And our collective inability to provide even the most basic health care to the world's poorest populations, evidenced very, very strongly during the COVID pandemic, this provides a very stark reminder of the reality of this concern.

Now, H for Africa research has been ongoing for almost a decade. And in that context, we had spent some time thinking through how such research could benefit participants and communities. And Nchangwi has been a leader in that space in her work. For instance, ensuring that any technological innovations coming out of research would be applicable to them as well as others around the globe. So arguments around the importance of diversity have and are frequently being made in the context of genomics.

Other benefits she identified include, for instance, research capacity building, or temporary employment for community members. With many of the communities that participate in genomics research in Africa... are low resourced, and they have impaired access to health care, limited opportunities for education and employment, and they sometimes struggle to feed their children. Right? This is the reality! And against that background, offers of better health care or knowledge that is more representative of human diversity... seem inadequate to say the least. Right?

So in the context of need, if all you can offer is a promise for better care in the future, then that leaves -- that is unsatisfactory, often.

And it is -- yet it is also not clear, as people involved in ethics research or genomics research, what the alternatives are. Right, what else could we do other than make those promises of, of some kind of future benefit?

Now, against that background comes a new pharmaceutical company with radically different ideas about how we could share benefits. This company proposes to give communities that participate 10% of the project budget upfront, up to a maximum contribution of $100,000. So 10% of the research budget. That, this is the proposal that the company put on the table. Is that 10% of the research budget will be distributed to communities that participate upfront. In addition, the company will share 4% of its yearly revenue, defined as income before expenses, with the communities who data contributed to potential future pharmaceutical products. So the idea is that over time, this company would use genomic data to generate or produce pharmaceutical products, and that once it starts to have a revenue, that every year it will transfer 4% of that revenue to the communities, the collective communities whose data participated to the production of those pharmaceutical products.

If the company is ever sold or goes public, then the arrangement is that those communities will receive 4% of the company's equity value.

Now, these percentages and amounts are formalized in contracts with the community. And in other words, and perhaps a bit starkly put: What this company is doing is that it will reward participation with tangible material benefits, rather than these kind of soft promises that I spoke about.

So when I first came across this proposal, I was rather taken aback -- and you might be, as well. And I was immediately worried that this would constitute some form of exploitation and would be impossible to enact. But over time, and the more that I thought about it, the more intrigued I became. Because you well all know that research is expensive and that we spend hundreds of millions of dollars on research every year. Research participants, in several empirical ethic studies -- for instance, those conducted by colleagues at the McHenry Welcome Project Program in Kenya -- have queried for years why the huge resources generated from or available through research were not shared with them. What these participants and empirical research reported is that they saw fancy buildings, new cars, and well-paid staff visiting their compounds without any apparent wealth ever being shared with them. Their situation did not fundamentally change. Yet the careers and the futures of the institutions that they supported with their data and their samples changed enormously.

Now, in research ethics, we come up with very good reasons for why we shouldn't pay for participation. But they often feel so unfair in practice, especially when we work with communities who need so much of what we cannot offer. So it is in this space that this new company is now shaking things up in ways that force us to think about our own assumptions about what is possible and what is right. Obviously, there are also many questions that need to be interrogated, and not least in terms of the ethical challenges that partnerships with pharmaceutical companies raise, and what can be disrupted by the use of money in this space.

So I am delighted today that you've joined me in a conversation with my two colleagues to explore this new benefit-sharing model. What is the potentials, and what is the risks that it raises?

So, without further ado, I'll hand over to Michele to kick off. So Michele... please go ahead. You have -- you are a researcher that has participated in this model. So... so, please, go ahead.

MICHELE RAMSAY: Indeed. Thank you so much, Jantina. And I too am delighted to be at the Friday ELSI Forum. So Sandra, thank you for this kind invitation. And to share this platform also with Nchangwi is really a pleasure.

So, compared to the developed world, there's very little research and data from people living in Africa. And this is especially true when it comes to genomic research and associated health-relevant data. So if Africans are to benefit equally from genomics research, we need more research, and we need to share our data.

So in my research, I involve different groups in South Africa from rural and urban areas. And many of the people we work with are really economically and socially disadvantaged. And they really don't have good access to health care, and there is very high unemployment. So against this setting, you know, what does it really mean for a community to benefit from genomic research?

So, you know, as Jantina said, over the past decade or so -- you know, we evolve our thoughts around benefit, and about working with commercial entities. You know, we're frequently reminded that benefit potential is enhanced through public-private partnerships. But how would this actually work?

So as a researcher, I value meaningful community engagement and gaining an understanding of the community's perspectives of our research and the potential for benefit. So for most of my career, the discussion has been about more or less future or less tangible benefits. And you know, we often acknowledge to people that these are people who need food and a safe place to live. And, and yet, as researchers, we often have little else to offer.

So, when Variant Bio approached me, I was quite interested. So as with many stories, our journey began with Variant Bio at a conference presentation, and meeting afterwards in the corridor of the venue. And at first I was quite skeptical. But after two and a half years of vocational discussions, I decided to apply my mind to potential partnership. And it's about trying to find that sweet spot, and interest for what both parties want to do and value. And then once you find that, it's about building trust before discussing the practicalities of the partnership. So a lot of discussions before you actually start. So it's important to be realistic and practical about managing expectations, especially when we work in communities over many years. And this has been done through careful communication with the communities where we perform our work. And we also need to understand that there's no one-size-fits-all approach. For example, rural communities can be very different to urban communities in terms of what they value and what they would consider a benefit.

So the case study I'm bringing you today is a jointly-developed project between my research team at the university, and the U.S.-based venture capital company called

Variant Bio. So the byline for Variant Bio is "people-driven therapeutics." So it says, Variant Bio is developing therapies that will improve global health by studying the genes of people with exceptional health-related traits.

So what is this project all about? So globally, there's no resource on gene regulation variation based on data from Africans living in Africa. There is no data to understand how similar or different this is to the ample data from populations of European origin. So what we want to do is to build a database of regulatory variance in an African population that could be used to understand the function of genetic variance associated with diseases, and that could ultimately lead to insights that could, one day, possibly be clinically useful. And what we established early on was that for both parties, we understood that for maximum benefit, this resource also had to be available to the broader scientific community.

So as you've already heard, Variant Bio has a two-tiered benefit sharing model. And in my view, they really are pioneers in thinking around meaningful short-term and long-term benefit-sharing. So the benefit includes the following areas, though others may be considered. So it is about capacity development. Contributing to education or health care. Or some project that contributes to sustainable development.

So I think that Jantina has nicely outlined the short-term benefit, which is 10% of the cost of the project. And this actually comes to a substantial amount, because genomic research is so expensive. And then of course, thinking about that long-term benefit, which is the 4% of the annual revenue that would go back to actively-participating studies every year.

So, our project takes place in three communities in South Africa, one urban and two semirural. And I'll describe the process for the two rural communities in the northern regions of South Africa, one being Mpumalanga. So in May this year, despite COVID, we met in person with community representatives in these two regions. And for both study sites, which are actually groups of villages, they are embedded in health and demographic surveillance centers. And this really makes our work much easier, because they have contact with researchers over a long period. Decades, even. And to do this effectively, this community engagement, it's important to identify community representatives and to set up community advisory boards through discussion with community leaders. And very often, these people are also elected by their community, and they change from year to year; they're not necessarily the same ones all the time. So there will be some pictures of our visits on the blog for Variant Bio, so I think you will have access to that link, which will be posted in the chat or elsewhere.

So we presented the study to the community representatives and spoke about our partnership with Variant Bio. And we raised the issue of benefit-sharing. So they were very interested in this, this issue, but they also wanted to know more about the research. So they were not totally focused on the sort of tangible benefits; they also wanted to know about, you know, was this going to advance knowledge. And at one of the meetings, there was a concern raised about potential corruption, and whether the benefits would actually reach the people who contributed to the study. So we had quite a lot of discussion, and it was agreed that we would work through the HDSS community offices to jointly discuss and agree on a suitable project and the way in which the funds would be managed. And they thought this would be acceptable. And they also liked the two-step benefit model, and the way that this was structured. And they didn't really express any concerns other than the corruption issue.

So, we've now started our data and sample collection, and we hope to have this completed before the end of the year. And in addition, the discussions about benefit-sharing is... in progress, with these centers and with their community engagement teams.

So, although there have been other projects with benefits in the past, this is the largest amount yet from a research study. So it's a substantial amount at 10% of the budget of the project, and it can really make a difference.

So in the community in Mpumalanga, they've now identified that what they're interested in is having water supply at community gatherings. Like weddings, funerals, parties, other large events. Because they don't have easy access to water. So they came up with the suggestion of buying water tanks. And these are huge tanks with a capacity of 5,000 liters. And the idea is to buy a tank for every village in the community, and that these tanks will be stored on the properties of the indunas or the chiefs of the village. And they will be used for events. So they will be transported on a truck, and the municipality will come along and put water in the tank, and as the event proceeds people can tap the water for their needs.

So this is not the end of the story. So we continue to discuss benefit options with the other two communities. And we're really looking forward to their surprising suggestions and to dreaming with them in terms of something that could be of benefit. I won't give you any other examples right now, but perhaps in the discussion we can go there.

So we understand that this is relatively modest compared to the potential value of their data. But it is something that is being jointly planned by the community with us, and something practically meaningful to them.

So there's some questions that we raise. So we say, is this enough? And then we have to say, is it sustainable? And would it be possible for other projects to do the same? And then we have to say, you know... what are the other researchers' views on including -- or the funders' views, rather, on including budget for community benefit? Because this is not something that we would just have. And then will communities benefit once a product has been developed, based on the research from their data? And what mechanisms could be put in place to address this issue?

So my closing thoughts are just that it is really important to manage expectations of the communities, in terms of benefit-sharing from the research, and to be open and honest about what is and is not possible. And that really goes without saying. So, clear communication emboldening trust are essential for good outcomes, both in the short and the longer term.

So with those thoughts, I'd like to hand over to Nchangwi and let her share some of her thoughts with you. Thank you very much.

NCHANGWI MUNUNG: Thank you. Thank you, Michele. And hello to everyone. So, my task is to reflect on benefit-sharing and commercialization in the African -- in the context of African genomics research. And to do this, I will draw on some of the empirical work I've done at the consortium. (bad audio quality) Sharing genomics research in Africa. I will also draw from the African community concept of ubuntu to highlight how it informs discussions of benefit-sharing in my genetics research in Africa, and how I think... has sort of relied on that. I will then, based on that, highlight how in my opinion the Variant Bio model disrupts but also further opens up discussions on benefit-sharing in genetics research in Africa, and how -- around collaborations between academic and commercial entities could be best addressed. Next slide, please.

So this slide is just on the benefit sharing portion, which I wouldn't bore you. But I put it up to sort of highlight... so, what is highlighted in color is important for the gene, for the Variant Bio case. So benefit-sharing, the advantages and profits are a component of it. And the final definition of benefit-sharing puts an emphasis on the provision of benefits to those who may lack reasonable access to resulting health care products and services. So this is about more a sort of commutative justice. Next slide, please. Um, next slide, please.

So, why is benefit-sharing in genetics important, especially in this context? I think it has been seen as a way of addressing historical experiences of exploitation, especially through the context in the use of scientific settings. And another argument is political fairness. And that is where we have the common heritage come in. And the third argument for benefits sharing is around ensuring equity, or global equity. So preventing a genomics divide. To highlight the Variant Bio case, we can see how they have touched on these three arguments for benefit-sharing. Next slide, please.

So, this is some of the work we do on benefit-sharing in human genetics in Africa. And we basically ask African genetics researchers, what would be their justifications for benefit-sharing, and what would be the different types of benefit-sharing, and who should decide on benefit? And the arguments we talked for benefit-sharing was based on principles of fairness, solidarity, and reciprocity. Types of benefit-sharing, the return of results, the capacity building, and the sharing of profits. And I think the sharing of profits was one of the very interesting, the most contentious issue that came up from this study. But who decides what benefit a community gets, and what proportion or percent of profits, what proportion. And there was some concern that who is the community? How do you apply the community? Who do you involve in the discussions or the decision-making, around all of that? Next slide, please.

And because of the ideas of, the justifications for benefit-sharing based on solidarity and reciprocity, and because previous discussions in the consortium had sort of touched on, sort of brought up the issue of looking for an African ethic that could inform discussions on genetic -- on the ethics of genetics research in Africa, we sort of looked at how ubuntu -- which is a Southern African philosophy that is common across Africa -- could weigh in on benefit-sharing as a perspective. And so the question we're asking is how does ubuntu bring innovative insights, or how does it supplement or strengthen the GenEthics debate? Particularly in relation to macro-level justice issues in genetics, as is the case with benefit-sharing. Next slide, please.

And we did a conceptual analysis of ubuntu as a community-oriented ethic, and these are the principles. So that figure there gives you the different principles. But the principles that I think respond directly to the benefit-sharing debate: solidarity, reciprocity, shared decision-making, and social accountability. Next slide.

And I think much -- shared decision-making, we can highlight that. But I just want to say that reciprocity, as it is defined or seen in the ubuntu worldview, speaks to benefit-sharing. So, reciprocity, it is about mutual aid. So you need to be responsive to the needs of others. So it's about taking care of the community, and then the community takes care of you. So, you want to rule out any form of exploitation. Next slide, please.

And then in terms of accountability, it was more around social accountability. So ubuntu places emphasis on engaging relevant stakeholders, not just as key informants but as agents of change that are capable of addressing issues that affect their community. And in terms of decision-making, it is not about representation, although that is important; it is more about, ah, substantive representation and the willing suspension of disagreement. And we see how the Variant Bio case has these principles. Next slide, please.

So I think pharmaceutical development and benefit-sharing is not new, right. In the context of clinical trials, these discussions are well advanced. I think it is maybe a sort of... where the primary concern is genetics research. Because for clinical trials, it is more about access to a product that is being developed, or a product that is being tested, or an invention. But in terms of genetics or genomics research, it's not clear what the benefit is there that would be shared. So. But for more of the discussion on benefit-sharing or arguments for that, I think people have sort of pitched it as a way of actually being justice, of minimizing exploitation of certain communities, and as a way of preventing a genomics -- or, minimizing a genomics divide. Next slide, please.

And now, back to the case study of today, which is Variant Bio. So, Michele has already presented the benefit-sharing vision of Variant Bio. It is based on the, many of the things that were raised in the empirical study that we did. And that has sort of dominated the benefit-sharing discourse in genetics research in Africa. So Variant Bio is responding to bio-colonialism. It is responding to a legacy of extractive biomedical practices in the Global South. It is responding to structural racism. And it is responding to inequalities of health care systems around the world.

And so benefit -- ah... Variant Bio is saying that they will be ensuring that anyone who provides data is fairly compensated for, for that, regardless of whether or not that data is used. Or, the use of that data leads to an innovation. So it's not just a pat on the back. So they're saying it's not just a tokenistic approach. And yeah, emphasis on concrete and tangible benefits, as Michele has mentioned. Next slide, please.

So, Variant Bio, as I mentioned before, is committed to sharing concrete or tangible benefits. And these are the different approaches to -- or, these are the different types of benefits. And Michele already highlighted that. But I want to sort of just talk again around the sharing of revenues. So they will be sharing revenues, and they will be sharing -- they'll be giving out 4% of their equity value with the partner communities. And I think that is important, because I see that as a shift away from the profit -- they are not saying, we're going to give you 4% of the profit. They're saying we're going to give you 4% of the revenue that comes in. So that's where the disruption sits. Next slide, please.

So, the question is: Does Variant Bio disrupt the current benefit-sharing model, or the discussions around benefit-sharing in genetics research in Africa? My answer is yes. And it does that to a very large extent. Is it in a good way? I will say yes. Are there gaps? I will say yes as well.

How does it disrupt it? So I'm going to mention that they will be sharing revenue as opposed to profit. And so this begins to now push us to reflect on the definition of benefit-sharing as it has been traditionally used in the ethics discourse. Both as suggested -- or, as recommended by the organization? And in addition to that, they will be giving 10% of their budget to active -- of active projects, on short-term benefits. So that is something that wasn't covered in the initial... definitions, or discussions, around, ah... Sorry. Around benefit-sharing.

And to a large extent, Variant Bio has engaged openly, and they have used the people-centered approach, as they describe their benefit-sharing vision. And, so that begins to sort of answer the question: Who are these communities? Because I think that's a question that pops up all the time, for benefit-sharing, in the benefit-sharing discussion in Africa. We always get that question: Who are the communities? How do you identify these communities? And so Variant Bio has shown these discussions have actual communities.

I think the third way that Variant Bio has disrupted -- and in a nice way -- the benefit-sharing discourse is that it has, it shifts away from the contentious issue of intellectual property, patents, and ownership of genetic data. And so Variant Bio acknowledges that these things are important? For, for innovation. But it doesn't get into the way of their benefit-sharing vision. And so we remember that they're sharing revenue as opposed to profit. And why this disrupts is because... the ownership of genetic data invariably informs the models of intellectual property of patents that are adopted. And therefore, the profit system or model that comes into place. And so Variant Bio says, we are moving away from that, and we focus on revenue rather. And it's not whether they get some -- whether there is an innovation, whether or not that innovation is done, they are going to share with the communities.

And so I think that Variant Bio is leaning more towards power-sharing. So they are using the power-sharing -- so, it's a benefit-sharing model that is based, or that is structured around power-sharing. Next slide, please.

Is there a gap, in the Variant Bio model? Ah... yes. So I, I think it is yes. And I've just put there, on the slide, where that comes in. And that's the definition of benefit-sharing. So, so the emphasis on the definition is not just about shared benefits; it's about the provision of benefits to those who may lack reasonable access to the resulting health care products. So I, I think that that is the aspect that Variant Bio sort of has not discussed, or has not put forth in its discussions. And that is... I think that's something that needs to be looked at. Because otherwise, then the genetics divide or the genomics divide persist. Because if they develop new products or interventions, but these products are not accessible to these communities -- for example, the communities in Mpumalanga... how does it address the genetics divide? Even if they are being provided with water tanks. Right?

So... I think that is where there is a gap in the Variant Bio model. And I think also the gap is that it's unclear what the normative underpinning is of their benefit-sharing. If it's charity, if it's equity, or if it's justice. Next slide, please.

Oh, great. Thank you all.

JANTINA DE VRIES: Wonderful. Michele, for introducing us to the work you've done and the way that people have thought about, or the way that the communities you've engaged with have spoken about what benefits they would like. And I know there are many interesting examples that you've shared, that you didn't have time to share yesterday. Such as, I think, a cookbook. Like having resources to put together a cookbook. For instance. I mean, it's like really novelty stuff, and the excitement of dreaming together. Especially when, for so many years, you've been unable to dream together because you couldn't offer anything. I think I, that, that seems to be very important.

And thank you, Nchangwi, for focusing and anchoring... our minds, or anchoring this discussion into... two things. I think one is a broader benefit-sharing discussion and the arguments that are brought to bear when we think about the need to share benefits. But also, a reminder that when this research happens on the African continent, that we need to take seriously the normative guidance that we can derive from African philosophy in how we think about the work that we do and the obligations that we have towards our participants.

So we've gone a bit over time. We've only got about 20 minutes for discussion -- bit less than that, even. But, so what I'm going to do is draw on a combination of the questions that I had prepared and the questions that the participants have raised. I think overall, my sense is that people listening in to our discussion share a fascination with this model. Right, and I think it's fair to say that we're all fascinated by the model. Even if we're all a bit cautious, right? It's like, oh, what is this thing, and how is it going to disrupt? Right, and what is the outcome of that disruption.

And so, my first question relates to really, you know, what are the risks here? So the people kind of posing questions spoke about different kinds of risk. So, one is... a potential power asymmetry between research participants and the company, and... you know, people being persuaded to do things that they wouldn't normally be willing to do. So, a risk there of, you know, enticing people to participate. Particularly, and that's another -- so this was a question by Subhashini. There was another question -- let me see if I can find it; I think it was Dita -- Deian, who asked, well, how do we make sure communities with great needs are not coerced? And she said into accepting a smaller share of benefits. But I think also there's a broader question about coercion per se.

And so, Nchangwi and Michele, if I can ask you for just some brief reflection on the question of what are the risks here. Nchangwi, do you want to go first?

You're, you're on mute.

NCHANGWI MUNUNG: So, um. I think there is... the risk there is around... benefit-sharing or academic or commercial collaborations as -- and it is important, right. Those are the needs of communities. But a risk is that we begin to create an expectation that some basic services can be provided by research institutions. And that is risky in terms of -- in poor countries have limited budgets for this. So that begins to -- I would be more on the positive side. Because sometimes as researchers, are we listening to what communities need? So sometimes we think they need genetic testing, but maybe they need just water.

JANTINA DE VRIES: Great. Michele?

MICHELE RAMSAY: Thanks, Jantina and Nchangwi, for going through those questions. I think there are risks too good this, and it's really about... sustainability as well. Because once you do it, you know, the community then expects that it must happen again and again? And we know that this is not a normal model. This is a very new approach. So, you know, we've been very careful about talking to the community about it. And also thinking together about, you know, what may be useful. But I think what is really helpful in our case is that being embedded in these demographic surveillance centers, we know there will be continued contact. So they can continue the conversation. And you know, we have to explain that, you know, many research funders can't actually do the sort -- or, don't have a model for doing it. But I'm hoping that, you know, this model will be looked at very carefully. And that funders will start thinking. Especially research in low, middle income settings.

But I think, you know, research can't fix everything. A country has a responsibility, in terms of their health infrastructure. And you know, I think as researchers, it's also our responsibility to talk to our governments... you know, local councilors and so on, about improving conditions for their communities.

So I think there are risks, but I think there are more benefits. I agree with Nchangwi that the balance is -- you know, that this can make a difference.

JANTINA DE VRIES: Wonderful. And just to remind some of -- so, there are quite a couple of questions asking about details about the 10 and 4%, and -- or, how they were arrived at. What the contractual conditions are, and so on. And I see a question by Eric Juengst. It's just disappeared -- oh, there it is. Asking what does the company mean by people who are outliers and exceptional traits and things like that. So, just to remind you that none of us represent the company. We are all public sector researchers who I think have been struggling with... the, the unsatisfactory nature of our responses when people ask us, you know, you want my blood but I need to feed my child. (chuckles) Then, you know, what do we do! Is it -- CAN we -- so, and this is why we're intrigued, right. Because I think the three of us feel that what we are able to provide, and what we are able to argue, is unsatisfactory at some level.

And so, just to remind you that we are not in any way representing the company in this discussion.

Great. There are quite a few other questions, and I hope I'll get to them. But I'm going to ask one that intrigues me particularly. So, some of you, or hopefully many of you, are aware of the gaining strength of arguments around de-coloniality. Right? So, decolonial theory forces us to think through questions like poverty, wealth, health inequities, and the state of the world, in substantively different ways. Right, thinking about systems more than just individuals and, and relations between individuals. And reconceptualizing something like, for instance, polity in Africa as a direct consequence of the looting of African countries during the colonial era.

So, in the context of those discussions, right, knowing that something has to shift... I'm really intrigued to think through whether and to what extent this particular proposal responds to some of that. Right? So is this really a proposal that shifts the way we think, for instance, about agency of people who live in resource-limited settings? Is this really shifting power, right, between the Global North and the Global South?

And so, Michele, I guess the question for you directly is: As a researcher in South Africa, have you got power in these discussions? And how has your role changed, if you think about, you know, other collaborations of this kind? And then for Syntia, I know you're more -- Nchangwi -- I know you're more steeped into these theoretical debates, and so I'd love to hear your thoughts on this broader question of the extent to which, you know, is this de-coloniality in action, or is it really just more of the same? Michele or Nchangwi?

MICHELE RAMSAY: Thanks. Maybe I'll go first on the question of, you know, as a researcher, do you think you have power to change things. And... you know, I think we all have choices in the way that we do things. And, um, I think we need to be open to... new models. Because I think -- you know, far too long, we've just gone in the straight, you know, you're funded for your research; you do your research. Then you move away; maybe you give information back. So we're very aware of the fact that community engagement, for example, needs to happen before a project starts! During the project! And very much afterwards! You know, sort of keeping the community informed.

So, you know, I don't feel I have power, but I do feel that I have choices? And I think, you know, the more we're supported by our institutions to do more meaningful research, the better it is for a country. So I think, you know, that culture of research is important, and being able to leverage funding. But I think Nchangwi also said one thing, and that is that very often, the funding that's available in Africa is very low. So we do rely on international funding. And... you know. I think that's really important? But it shouldn't be the only thing. And I think we really need to encourage our governments to spend a larger proportion of GDP on research. So I think, you know, it's about also changing that mind shift.

Nchangwi, I'll hand over to you for comments.

NCHANGWI MUNUNG: Thanks, Michele. I would say to an extent, yes. Because giving voice to those communities. So like Michele said -- so to me, you need to give voice to communities, in a way that was not done before. That has not happened before.

And... they're also beginning to understand -- some sort of gaining knowledge. They're beginning to start thinking about what does benefit mean to them, as participants, research participants. Whether they have -- I think, ah... like Michele said, I think they have a choice. Which is good also. But how their decisions are made is what we should worry about. Whether they understand -- (bad audio)

So there is that concern of how did they arrive at 4%, or how did they arrive at 10%. And I think I read that the 4% is sort of guided by what those institutions would typically get, when they get into collaboration information entities. And Michele, I think you can comment on that. Whether that kind of discussion has happened in the Pumalanga community, for example. Thinking about those basic services. And those basic services are important, right. So I have a choice around water, as opposed to some company. Um, yeah.

JANTINA DE VRIES: Michele, did you want to...?

MICHELE RAMSAY: To respond. Um, so... so I think, you know, it's not possible for a research grant to actually fix what's wrong in the community. So, you know, you can't give them better health care. What you can do is create awareness of the need. And then, you know, get the government to kind of give attention to it. But I think, you know, the amount is a token in many ways. It's not a huge amount. So I don't think it's an incentive. And I know some of you have been asking that in the chat. And the amounts were stipulated by Variant Bio, and there are no conditions. The only condition is that it can't be used for a person's personal gain! And you know, it has to somehow contribute to the community. So the benefit isn't to an individual, and not necessarily only to the individuals who donate their DNA. It's to the group as a whole.

So I quite like that distributed model as well. That they think, you know, not just of themselves, personal benefit, but benefit for those around them as well. So I think, you know, those are important conversations to have.

JANTINA DE VRIES: Wonderful. So we've got about 4 or so minutes left. So very short kind of concluding thoughts for both of you. And there's two different questions playing in my mind, and I think I'll give you the freedom to choose. The one is what next. Right? So what's the next frontier? So we've got a different model; what comes after this? And... one -- you might want to -- there are several questions in the chat about, or in the Q&A, about accountability. Right? Who's accountable? Are the accountability mechanisms built into... built INTO the model? Right? And how do we ensure this actually happens? And also, what other control would we want communities to have? So it's a query, a question. But the first is again Subhashini; the other comes from Eric. About what other control should communities have? What other power should be shared?

So Michele and Nchangwi, your final thoughts. You've got about a minute and a half each.

MICHELE RAMSAY: So, shall I start? Um, thank you, Jantina. So I think, you know, one of the next steps and the things to think about is really this co-creation of research projects and involving communities in having a say on what they want to know, in terms of knowledge gain. And I think, you know, often we don't listen enough. We go with a preconceived question. So I think that, you know, that's important for us to think about as researchers. If -- you know, we need to make the space and the time to do that.

You know, I don't know what next. Because for example, you know, we've now done this project. We're in the midst of the project; we will finish it soon. And we will continue going back to the community, because they're embedded in an infrastructure that allows us to do research again and again. So I'm hoping that, you know, we will also learn from this experience and hear from them about how they perceived it. And I'm hoping that this will also be a trigger for other funders and industry when they work with researchers to think about this... sort of tangible benefit, in addition to all those other things like knowledge gain -- which of course is also very important. Thank you.

JANTINA DE VRIES: Wonderful. Nchangwi?

NCHANGWI MUNUNG: Thanks. I think the next frontier for me would be to... to sort of look at the Variant Bio model. To say, is this something that moves us from the political discussions on benefit-sharing to a much more practical approach? And I think that it's now about time to start thinking whether power-sharing is a model of benefit-sharing. And what would be the relevant justifications for that. Because the Variant Bio case seems to me like there is a shift, in what we originally thought with discussions for benefit-sharing in Africa. And it's about beginning to reflect on where the choice -- it's... what people want, at this time. And to begin to cocreate our frameworks for benefit-sharing with communities.

JANTINA DE VRIES: Fantastic. So I am delighted by these discussions. I'm also delighted to see that some people have declared themselves in the chat as being members of this company. Again, our intention certainly was not to highlight this particular company, but rather to really question what this does in terms of our own understanding. So, please use the invitation in the chat to -- (snaps) Ask the difficult questions that need to be asked.

Sandra, over to you.

SANDRA LEE: Yes. Thank you so much to our panelists, all of whom have joined us from the African continent. It's quite late there, so thank you very much for bringing this very provocative case study and for catalyzing such a rich discussion.

For those of you who can, please join us for our post-event discussion. There is a separate link in the chat, and it will begin immediately following this session. And we hope to see you at our next ELSI Friday Forum. This, ah, that session will be on new ACMG guidance on carrier screening: more or less equitable, is the title of that session. Also, we will be sending out a survey, and I really wanna encourage you all to complete this, as our organizing committee takes your comments and suggestions very seriously. It has informed how we improve the forum and bring you topics and speakers to you. So please do fill that out.

Again, thank you all for your rich engagement and your wonderful questions, and we hope to see you in just a few minutes. And for those of you who can't join us, have a great weekend and take good care.