



## Novel Benefit Sharing Programme in Agincourt

November 2024



A novel benefit sharing approach, co-developed with local communities was implemented in the MRC/Wits Agincourt HDSS.

Variant Bio is a start-up based in the United States seeking to develop a drug to treat kidney disease in the MRC/Agincourt HDSS communities. This is the first project in South Africa aiming to better understand genetic origins of kidney diseases in Africa.

Variant Bio has partnered with two genetic studies conducted at MRC/Wits Agincourt HDSS. The first is the African Research on Kidney disease (ARK) study in South Africa, Malawi and Uganda which is aimed at assessing genetic variants linked to kidney disease risk. The second is the AWIGEN Study in West, East and Southern Africa which aims to assess genetic and epigenetic risk associated with cardiometabolic disease.

Variant Bio is committed to sharing tangible benefits with research partners, both in the short and long term. Their short-term policy is to invest 10% of the total cost of each project back to the community. These benefits can include support for local healthcare, environment, education, and culture. The long-term policy is to invest 4% of the profit of any drugs they get to the market and the community will benefit from this 4% of the drugs are still selling.

In keeping with Variant Bio's benefit sharing principles, the asset/s that the communities choose was to be determined by the community. This set in motion a thorough stakeholder engagement process that would help finalise the item a community would ultimately receive.

The MRC/WITS Agincourt HDSS had two benefit sharing programmes. The first programme was smaller and was able to contribute JoJo water tanks to each village, depending on the size of the village some of the villages received two to three tanks. Variant Bio supported the purchase of 55 JoJos tanks to improve access to clean water across 31 villages



These tanks each hold up to 5,000 litres of water and were distributed in person to the different villages over the course of three weeks.

The second benefit sharing programme was larger than the first. Planning for the Benefit Sharing Programme began in June 2023. The MRC/WITS Agincourt HDSS study site team convened and strategized on implementation of the programme. During discussions suggestions were made about the items that could be purchased and they centred largely around assisting school children.

A rigorous consultation process with the various stakeholders unfolded. The Community Advisory Board (CAB), tribal authorities, school managers and principals from the five school circuits were consulted. After in-depth discussions between Variant Bio and the MRC/Wits Agincourt team, a decision was made to prioritise schools for this Programme. A total of 65 schools from the Agincourt HDSS and one nominated school from outside Agincourt HDSS would be the beneficiaries of the Programme.

The schools chose items based on their specific requirements. The items were generators, pull down screens and two projectors, tripod screens and two projectors, interactive white boards with one projector, printers and Wi-Fi.

All assets were procured in line with the applicable guidelines. The assets were registered and a serial number was attached to it. Delivery began in October 2023. The process did encounter logistical challenges such as, not having the correct personnel to install certain equipment and provision of training to teachers on the interactive white boards which were addressed.

The schools and the communities that benefited from this programme expressed their gratitude and had suggestions for continued collaboration from MRC/WITS Agincourt unit to address challenges they are facing within the education sector and the community at large.