



Dear Sir/Madam,

We are writing regarding the MalariaGEN genomic epidemiology network project. In order to ensure global privacy of sensitive genetic information, we are seeking clarification on your data sharing policies.

We thus seek clarification on whether commercial partnerships are in place to use human genetic information and details on any data sharing policies, including on who may register for data access, if this includes private companies, insurance companies, law enforcement or immigration services.

We further seek clarification on exactly what data is shared, and what privacy protections are in place to prevent access to identifiable genetic information (including re-identifiable) in the hands of the project and third parties, by law enforcement and immigration services, including what policies are in place to prevent and monitor data breaches by your organisation or third party collaborators. Further, we seek clarification on whether such data is sold to third party companies. We note that IP protections may be sought on data, and thus seek clarification on any commercial developments that may arise from human genomic data usage.

We also request access to the consent forms that do not appear to be publicly available on the website. Moreover, we could not find any information on what occurs to data following withdrawal of participants and whether data is retained or deleted, and request clarification on this.

The information that is provided, or not provided to us, will be shared with the public in order to promote transparency and to inform on the privacy implications of growing genetic databases. We thus thank you for any information that you can share with us to facilitate this process.

Yours sincerely,

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Dr [REDACTED]

Policy Officer

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