

Addendum 1 - Genetic Research

Will this research involve the use of any material such as tissue, blood samples, etc. for genetic study?

Yes No

If yes, provide details:

The researcher must obtain informed consent from the participant and report results to that individual. Provision should also be made for the participant to access genetic counselling, where appropriate. Has this information been included on the genetic information sheet and/or consent form? Yes No

If yes, describe what is said in the consent form.

If no, please justify:

As genetic research involves the family and/or the community in terms of family history, linkage, and other studies, informed consent must also involve these social structures as far as is practical and possible. Researchers must reveal potential harms to families and groups participating in genetic research studies, as well as outline how such harms will be dealt with as part of the research study. Has this information been included on the genetic information sheet and/or consent form? Yes No

If yes, describe what is said in the consent form.

If no, please justify?

How will the researcher ensure that the results of genetic testing and genetic counselling records are protected from access by third parties unless the participant gives consent? Provide details. The following information should also be added to the genetic information sheet and consent form. "We will take all reasonable steps to keep your research information confidential. Should someone not involved in the research find out that you took part in this research study, or if you choose to share your results (if they are provided to you), there is a possibility that this could affect your insurance or employment."

If any of the genetic material is to be banked, the researcher must satisfy the REB and prospective research participants that they have addressed the issues involved in banking of genetic data including confidentiality, privacy, storage, use of the data, and results to come, withdrawal by the participant, and future contact of participants, families, and collectivities. Participants must also be informed. Has this information been included on the genetic information sheets and/or consent forms? Yes No

If yes, describe what is said in the consent form.

If no, please justify?