

## INFORMATION SHEET

### Reconstructing Australia's past via genetic analyses of historic Aboriginal hair samples

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HREC ethics approval ID: H-2014-252 ([hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au))

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Dear Participant,

You are invited to participate in a study of hair samples from different communities and groups of people who live and have lived in Australia in the past.

A member of the project team will talk to you about the project and how it might affect you. He/she will explain what you will have to do if you decide to participate in the study or if you consent on behalf of a close relative.

You can choose whether or not to participate.

You can also withdraw from the study at any given time.

Please read this form carefully. If you do not understand something, please ask the researcher to explain it. If you prefer, someone will read this to you. If you decide to participate, please sign the accompanying consent form.

#### **Background and Purpose:**

The South Australian Museum Archives has in its custody collections relating to Aboriginal people dating from the 19<sup>th</sup> and 20<sup>th</sup> century. A significant part of this collection has been collected on the Board for Anthropological Research (BAR) expeditions. Established in 1926, scientists from The University of Adelaide collaborated with SA Museum to record anthropological and anthropometric data from Aboriginal people continuously until the late 1960s. The purpose of these expeditions was explained to communities.

The records include data cards, hair samples, maps, film, sound, genealogies, photographs, drawings and journals kept by scientists whilst on the expeditions.

These BAR records proved to have been invaluable in reconnecting thousands of Aboriginal people with families and communities and to reinvigorate language and culture over the last 25 years. Aboriginal people have accessed the archives for family and community history, stolen generation, exhibitions, publications, dictionaries, teaching material, research and performing and visual arts.

The archives indicate that data was collected from you, your family, or from people of your community. All this information is freely available to you. If you wish to obtain a copy of the data, please express your interest by filling in a family history application form, which you will find attached.

Hair samples were also collected during the BAR expeditions, but have not been used for research since. These form an additional level of information that requires consent from you to be studied in our proposed project.

This project is a national effort to collect genetic data from hair samples from Aboriginal and Torres Strait Islander People, which have been collected during anthropological expeditions between 1926 and 1963. Our aim is to reconstruct human populations events in Australia's past by mapping diversity that has contributed to the genetic patterns we see today. These hair samples come from groups that are likely to have lived in the same place for a long time, with minimal or varying intermarriage from outside and neighbouring groups. Our goal is to understand the relationships between genetic, linguistic, cultural and historical data for all Aboriginal people and most importantly to make all such information available to the people from whom the hair samples have been collected. Such data can be used by any person or community to examine which group/community/family line they are most closely related to in the region and/or if these similarities relate to 'songlines' or other paths of contact among groups.

### **What will be studied?**

We wish to survey the DNA (this is genetic information stored in your cells known as **Deoxyribonucleic Acid**) from the hair sample for genetic variation. Small changes in particular portions of your DNA over time create "markers" that, over countless generations, can be used to study individuals, groups and populations. These markers are vital in studying human history because many of them cluster together in specific ancestral lines of descent (also called family lineages). As these markers are passed directly from parent to child, we can trace their passage through family lineages stretching from the present to the very distant past with a high degree of accuracy. In this study, we will determine a subset of the markers carried in the DNA of the hair samples (known as genotyping) and use these to reconstruct a genetic map of Aboriginal Australia.

If you decide to participate in this study, you can consent to one of the two following genotyping options:

- 1) **Male/female lineages only.** This is DNA that is inherited only through one sex over successive generations; i.e. mitochondria (also known as mtDNA, which is passed down through females) and the Y-chromosome (passed down through males).
- 2) **All markers, including male/female lineages.** This includes DNA that is inherited only through males or females *and* the rest of the DNA in the genome, which is passed down from both parents. Note that this option includes the DNA in option 1.

The main benefit of option 2 is that it allows us to obtain much more genetic information than is possible under option 1, which will result in a better understanding of the genetic relationships within and between Aboriginal groups and also make it possible to study adaptation to local environments. *An important difference between the nuclear DNA and the mtDNA/Y-chromosome is that nuclear DNA may contain markers of medical relevance; however, we will not*

*use this information for medical research purposes and all personal information will be removed such that it cannot be used to identify any medically relevant traits that you/your ancestor may have.*

There will be no other use of the hair sample other than outlined. No clinical data or information on medical history will be collected from you, and neither will the hair samples from your ancestors be used for any medically-related inquiry or genetic testing. The genetic tests will not be used to gain information about your/your ancestor's health or about any related health problems. This is an anthropological study only.

The information gained from many lineages can also help us to reconstruct patterns of human movement through Australia in the past. It can provide a shared story of the genetic history of Aboriginal and Torres Strait Islander People as part of the human family tree.

Our abilities to map genetic results will be based on frequencies, and will be expressed in a likelihood value for a given lineage that it can be ascribed to one (or more) particular location(s). Here, 'geographic origin or location' is a matter of scale, where in most cases the level of genetic resolution will be too low to resolve local issues at which land rights claims operate. Importantly, the presence of one lineage does not exclude others. We would therefore advise against the use of genetic results in Native Title claims and land rights issues.

#### **Procedure 1:**

The BAR records held at the South Australian Museum indicate that you have participated in one of the anthropological expeditions in the past and that you have donated a hair samples. We would like to genetically analyse your hair sample.

If you decide to participate, we will ask you to fill in the consent form accompanying this information sheet.

We will ask you to confirm the family details that have been recorded in the expedition and you will be invited to update your family history if you wish. Participation and consent in the project will take no more than 15 minutes.

In approximately one year from now we will return to your community and deliver the result to you in person and provide you with a certificate. If you cannot meet with us when we visit we will send you the certificate by mail or email and offer to talk to you on the phone to explain the result.

#### **Procedure 2:**

You are identified as a direct descendent of a person that has participated in one of the past expeditions and who has donated a hair sample.

We will ask you to decide on behalf of your family member/ancestor whether to consent his/her hair sample to the study described above. If you decide to participate, we will ask you to fill in the consent form accompanying this information sheet.

We will ask you to confirm the family details that have been recorded in the past expedition and you will be invited to update your family history. Participation and consent in the project will take no more than 15-20 minutes.

In approximately one year from now we will return to your community and deliver the result to you in person and provide you with a certificate. If you cannot meet with us when we visit we will send you the certificate by mail or email and offer to talk to you on the phone to explain the result.

**Storage of sample and genetic data:**

The hair sample collection is securely stored at the South Australian Museum. A small fraction of it is used for genetic study and this sample will be processed and stored at the Australian Centre of Ancient DNA at the University of Adelaide. Here, the extracted DNA and the genetic data will be stored safely for 15 years after the completion of this project.

*In no circumstances will the sample leave Australia.*

The sample will not be used for any medically related study. However, the sample and/or the DNA may be used for further study to better understand human origins and the histories of your people as new information/techniques to study additional DNA markers become available. This will require a renewal of the consent form and you will be consulted should further projects arise from this study. Furthermore, you may at any point in the future choose to have the DNA sample removed from the project. You can do this by simply contacting the researcher and explaining your desire to have the sample removed or by completing the "Withdrawal of Consent" form given to you by the researcher. The DNA extract will then be immediately destroyed at the laboratory and all associated genetic data from the sample will be eliminated. Instructions on how to do this are explained below.

**Confidentiality:**

We will protect carefully the information that is available in the archives and that you tell us about yourself and your family, what we learn from your hair sample or the hair sample of your family member will be described only in a way that does not identify you. You will be given a unique code number for the sample. To protect your privacy, hair samples, DNA extracts and results will only be recorded with this unique code. Your name will only be recorded on the consent form. The unique code assigned to the sample will be kept in a locked file at the laboratory and will be carefully protected. Your original hair sample will remain under custody of the South Australian Museum. Your DNA extract will remain at the laboratory for 15 years.

The results of this study may be published in scientific journals and deposited in public databases, and thesis but without identifying you/your family member. No identifying information will be released or published.

Upon completion, the overall results of our project are also likely to be presented on television, the radio, and the internet and in newspapers, magazines, and other media. The University of Adelaide's Human Research Ethics Committee (HREC), an independent group of people who review research to protect the rights of those who take part, has reviewed this study.

**Risks:**

There are no risks in consenting to use a hair samples that has been donated during a previous expedition.

**Benefits:**

We will inform you personally about your results in a follow-up meeting to your community and hand over a certificate stating the genetic results. If you cannot meet with us when we visit we will send you the certificate by mail or email and offer to talk to you on the phone to explain the result.

The benefits to you from participating in this project will be to learn more about you and your family origins, your relationships to other Australian Aboriginal people and to those from around the world.

**Costs:**

You do not have to pay anything to be in the project. You will not be paid for being in this project.

**Participation:**

Your participation is entirely voluntary. You have the right to withdraw from active participation in this project at anytime and to ask that data arising from your participation are not used in the research project.

You may withdraw from the project at any time by completing the “Withdrawal of Consent” form, or by contacting the numbers below.

**Complaints or further specific questions:**

If you have any complaints or queries that the investigator has not been able to answer to your satisfaction, you may contact the Human Research Ethics Committee’s Secretariat on phone (08) 8313 6028. Please also refer to the Independent Complaints Form attached to this Information sheet.

If you have further specific questions at any stage of the project, please contact:

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