



Information for communities scientific testing on Indigenous ancestral remains

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Purpose

The purpose of this paper is to provide an overview on the issue of scientific testing on ancestral remains in relation to Indigenous repatriation. The paper aims to provide broad information that may assist individuals or communities in conducting further research on the issue.

Background and history

The historical context in which ancestral remains were acquired and the conditions under which past research was undertaken are important considerations. In the past the rights of Indigenous people over their genetic resources were not always recognised, protected or respected. A significant amount of scientific research was undertaken either without any consent or with only limited, and perhaps misunderstood, consultation. These background factors are not unique to Australia, and are a worldwide issue for Indigenous peoples.

Scientific testing of human remains (including bones, teeth, tissue and hair) may provide knowledge about the geographic origin of ancestral remains (birthplace) when all other archival research and non-invasive examination has been exhausted. It is also thought that such testing may provide insight into the genetic relationships of living peoples to the deceased and information about historical population movements, past diets, diseases and lifestyle.

Different definitions are used for human remains in legislation and regulations in Australia and overseas. Most refer to bones, teeth and skin (in the case of mummification), some exclude hair and many do not mention some types of materials such as blood samples. In addition, there are different legal treatments of remains depending on when the individuals died (e.g. if taken from graves, sacred sites) or when the samples were collected; usually remains more than 100 years old are treated differently from more recent remains. When human tissue is intrinsically part of an object (for example, as part of a secret sacred artefact), the issue should then be considered on a case by case basis.



Scientific testing involves complex ethical and cultural sensitivities, and in many cases raises more questions than answers. For example, some of the techniques and processes used in scientific testing are considered 'invasive', resulting in damage or destruction of the physical remains. The need to balance the risks of such harm or loss against the potential benefits of the knowledge gained is one of many difficult decisions Aboriginal and Torres Strait Islander peoples face when considering whether to allow scientific testing on ancestral remains.

Types of scientific testing

Ancestral remains that are part of collections in museums or other institutions may be subject to a range of scientific tests. These include DNA testing, carbon dating and fluoride testing. New techniques are continually being developed, such as sequencing collagen from bones.

For genetic relationships and geographical studies the two most important processes are DNA sequencing and stable isotope analysis. Both are considered destructive tests in that they destroy small amounts of the original material. Analysis of ancient DNA (aDNA) is used to genetically determine gender, genetic relatedness, understand marriage patterns, and investigate prehistoric population movements.

Scientific testing of human remains does not always produce conclusive results about origins and genetic relationships. As with any research, there is potential for error, misinterpretation or bias. The potential knowledge that can be gained depends on how the remains have been treated since death and the testing techniques used. DNA testing in particular can result in unreliable or inconclusive data, which is often referred to as 'ambiguous results'. Since DNA begins to deteriorate after death, aDNA is more challenging to work with than DNA samples taken from living people. The risk of contamination and mutation in aDNA is also a significant concern for researchers.

To determine the genetic relationships between living people and populations of the past, it may be necessary to obtain samples from present day Indigenous peoples for comparison and reference. The ethics of maintaining and protecting these modern samples is a further challenge that needs to be recognised by all stakeholders.

Stakeholders

The main stakeholders in scientific testing on ancestral remains are the Indigenous communities from which the remains originate. Community members may act as individuals or be part of an organisation accepted within that community, or both.

Other stakeholders include the researchers, the researcher's host institution, the collecting institutions holding the materials (in-trust or not), and the funders of research. All of these organisations are governed by codes or regulations concerning the ethical conduct in human research, and operate under guidelines for obtaining informed consent.

Consultation and informed consent

The Australian Government Policy on Indigenous Repatriation states that the study of ancestral remains should always be undertaken in consultation and with the informed consent of Aboriginal and Torres Strait Islander Traditional Owners or their identified representatives. Consent should be provided by direct descendants, if they can be traced, or by appropriate community representatives. Occasionally, both relatives and community representatives give consent.

According to the Australian National Health and Medical Research Council: 'The guiding principle for researchers is that a person's decision to participate in research is to be voluntary, and based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it.'¹

Furthermore: 'The process of communicating information to participants and seeking their consent should not be merely a matter of satisfying a formal requirement. The aim is mutual understanding between researchers and participants. This aim requires an opportunity for participants to ask questions and to discuss the information and their decision with others if they wish.'²

During consultation Indigenous communities should ensure that:

- The aims of the proposal, the approach to be used and the implications of potential knowledge gained are in 'plain English', including an understanding of what the research will be used for.
- They apply their own ethical standards but also require that the research proposal has passed a Human Research Ethical Committee. The latter is good practice if not a formal regulatory requirement for older remains but is important for DNA studies linking remains to the living.
- They have fully explored the implications of the potential results with the researchers, including ambiguous results.
- Opportunities for the involvement of individuals from Indigenous communities in the research have been identified and significant involvement of Indigenous peoples are recognised in the authorship of the scientific paper where appropriate.

Collecting institutions and researchers need to ensure that:

- requests from community to release materials are from the appropriate individuals or representatives
- there is evidence that the consenting group does indeed understand what will be done in the research (e.g. destructive testing, exploring the 'genetic genealogy' of individuals) and its implications (e.g. the impact on a community of new knowledge or ambiguous results)
- given a presumption against destructive sampling, the potential knowledge gained outweighs the damage to the remains
- that the request is in line with institutional or national policies on use of results (e.g. protecting rights for commercial exploitation).

Ownership of scientific data

Collecting institutions have a responsibility for the long term care and responsible use of remains.

Clear agreement is needed in advance on what happens to the:

- results of the research—the presumption should be publication in the peer-reviewed scientific literature. Communities should explore the use of anonymised data, as is the custom in the medical literature to keep patient details confidential, to recognise the cultural sensitivity to public exposure of images, names, etc. of the dead
- data—the ownership of the data and its use beyond the formal publication (e.g., will it be put up on publicly accessible databases?)

¹ National Health & Medical Research Council (Australia), *National statement on ethical conduct in human research*, Chapter 2.2: 'General Requirements for Consent', p.16, available at: <http://www.nhmrc.gov.au/guidelines/publications/e72>.

² *ibid.*

- materials used in the research—some scientific procedures generate intermediate materials from the original, such as in DNA extraction and subsequent sequencing. The fate of these or unused materials needs to be tightly specified.

These and other details, such as restrictions on passing data and materials to third parties, should be covered by a ‘materials transfer agreement’. Many collecting holding institutions use these, and for good practice, communities should too.

Costs

Scientific testing can be costly and is dependent upon many factors including the techniques used; the quantity and quality of samples to be tested; and access to resources and funding within institutions and their research partners.

The Indigenous Repatriation Program does not provide funding to undertake invasive research of ancestral remains.

Other sources of information

- Australian Government Policy on Indigenous Repatriation, available at: <https://www.arts.gov.au/sites/g/files/net1761/f/australian-government-policy-on-indigenous-repatriation-august2011.pdf>
- Aboriginal and Torres Strait Islander Heritage Protection Act 1984, available at: <http://www.comlaw.gov.au/Search/aboriginal%20heritage%20protection%20act>
- National Museum of Australia (Canberra), Aboriginal and Torres Strait Islander human remains policy, available at: http://www.nma.gov.au/_data/assets/pdf_file/0008/1412/POL-C-011_Aboriginal_and_Torres_Strait_Islander_human_remains-2.2_public.pdf
- Australian Museum (Sydney), Repatriation of Indigenous Secret/Sacred and Ancestral Remains policy 2012, available at: <http://australianmuseum.net.au/document/Repatriation-policy/>
- Museum Victoria (Melbourne) policy statement, Repatriation Of Aboriginal And Torres Strait Islander Cultural Property, available at: http://museumvictoria.com.au/pages/53296/mvpolicy_repatriation_of_aboriginal_and_torres_strait_islander_cultural_property.pdf
- National Health and Medical Research Council (Australia), National statement on ethical conduct in human research (specifically chapter 4.7 on research with Aboriginal and Torres Strait Islander groups, and section 2.2 on informed consent), available at: <http://www.nhmrc.gov.au/guidelines/publications/e72>
- Australian Institute of Aboriginal and Torres Strait Studies, Guidelines for ethical research in Australian Indigenous Studies; and Guide to the informed consent form, available at: <http://www.aiatsis.gov.au/files/research/GERAIS.pdf>
- Nuffield Council on Bioethics [UK]: The ethics of research related to healthcare in developing countries, 2002, 2005 (specifically chapter 6 ‘Consent’ and chapter 9 ‘What happens when the research is over’, includes role of funding agencies and institutions as well as researchers. Included here because it address inequalities in power, etc), available at: <http://nuffieldbioethics.org/project/research-developing-countries/>

Definitions

ancient DNA (aDNA): the DNA present in remains of people, animals and plants. After death, DNA begins to deteriorate and therefore it is difficult to work with compared to DNA from living people. Often aDNA work fails to produce results.

DNA sequencing: DNA, the material in cells that store genetic information, is found in the nucleus of cells (in chromosomes) and in mitochondria, the energy producing parts of a cell. Nuclear DNA is inherited from both parents and mitochondrial DNA (mDNA) from the mother only. Because there are more copies of the mDNA it is often better preserved in human remains. After death, DNA breaks down into fragments and these small amounts need to be increased or 'amplified' so they can be studied. The usual method of 'amplification' is the Polymerase Chain Reaction (PCR). The sequence of the four building blocks of DNA varies between individuals and groups of people and can therefore be used to study the genetic relationships between people or populations.

Human Research Ethics Committee (HREC): most research organisations (universities, institutions, some museums) will have an HREC. It evaluates the ethical basis of the research, especially the nature of informed consent. Usually HREC's consider research on the living or the recently dead (eg retention of materials from post mortem's) but in the special case of Indigenous or developing country communities they take a wider remit. Institutions that don't have HREC's usually arrange to use a partner institution's committee. It's not an obstacle to research but to help improve its appropriateness in a wider context.

Material Transfer Agreement (MTAs): terms under which material (remains) are being released. An MTA describes what is to be done with the material (methods); whether unused material and, in the case of DNA studies DNA amplification products (from PCR), are returned or destroyed; where copies of results are lodged; terms for commercial exploitation; etcetera.

Stable isotope analysis: most chemical elements occur in different forms called isotopes. Isotopes in rocks, water, plants and animals are incorporated into the tissues of people from the food they eat and the water they drink. Measuring the ratio of different isotopes potentially allows us to identify where a person came from (Strontium, Oxygen) or what they ate (Carbon and Nitrogen). Minute samples from bones, collagen or teeth are vaporised in a machine called a mass spectrometer to determine their composition.