‘To balance the rights of the living and the dead’: Reflections on issues raised in the Norwegian National Committee for Evaluation of Research on Human Remains

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Most of us will agree that when it comes to self-awareness and human rights, and the value of women and men, the times have generally changed for the better, except for some obvious setbacks. As the awareness of the value of humans has increased, dramatic and rapid changes in many sciences have also put ethical values under increased pressure. What was unthinkable yesterday is now easily taken for granted. The scientific innovations in the field of medicine and genetics often call for caution, because they endanger the integrity of individuals or groups.

In her book Human Remains. Episodes of human dissection (Melbourne University Publishing, 2005), Helen MacDonald tells
the scandalous story of how medical practitioners obtained the corpses upon which they worked before the study of anatomy was regulated in Australia and Britain, in the 18th century. Convicted murderers received the double sentence of both death and dissection. The poor who died in hospital were routinely turned over to surgeons as study objects, and men traded in human remains, including those of Aborigines. The book seems like a horror story, but similar things also happened here in Scandinavia and Norway not too long ago.

The Kautokeino rebellion of 1852 resulted in the beheading of the two Sami leaders. The heads were sent to the Institute of Anatomy at the University of Christiania, now Oslo, to be used for scientific purposes. Later on, Sami graves were exhumed for the purpose of science, which at that time meant race research, and the remains sent to the university collection. The most infamous case is the exhumation of 94 Samis at Neiden in 1915, in spite of local protests. These remains were reburied as late as 2011.

The fact that the Ministry of Education and Research set up The National Committee for Research Ethics on Human Remains in 2008, is in itself a result of the growing awareness of the complexity of these issues.

**BALANCING THE INTEGRITY OF THE DEAD AND THE THIRST FOR KNOWLEDGE**

It is not difficult to understand the Sami reactions, knowing the story behind this particular collection. However, the case has made it possible to reflect on not only the scientific value
of human remains in general, but also on the integrity of such remains, on the integrity of the deceased person long after he or she passed away.

Do the religious convictions of the deceased still have any significance? What about their views on the afterlife and their wishes concerning the treatment of their own remains? I believe our own Norwegian indigenous people have done the whole of society a great favour by inviting this debate. It has become possible to ask questions which for so long were not regarded as ‘progressive’ or politically correct.

Respect for the feelings and integrity of a group or individuals is only one aspect of this concern. Scientific ideas can lead us astray, such as the racial theories leading up to World War II, yes, but science is also the force that leads us to deeper knowledge, helps us to cure diseases, gives us better understanding of our past and makes possible an understanding of our future. Once the remains have been reburied, most of the clues they hide are lost forever.

There is a constant need for knowledge in all fields of science. There is a need for research material. Without the studies in anatomy undertaken by scientists in the past, medicine would definitely not be where it is today, and we would all be suffering from this ignorance. Without the studies of human remains, archaeology, the knowledge of history, anthropology and related fields of science would be much poorer, and we would not be as well equipped to meet the challenges of today.

On the other hand, the belief that pure knowledge in itself will solve all human suffering and fill all human needs is also a
cul-de-sac of modern man. We are perhaps wiser today. We see that human dignity is important and personal faith and religious convictions are also more acceptable again.

Who are we in the committee to give advice to research projects on human remains? Our committee does not consist of average Norwegians. We are biased in more than one way. Almost all the members are scholars. We cover a variety of scientific fields and a variety of knowledge and experience, and inevitably also different outlooks on life. In some ways we know better than many what research on human remains is about. Through our work in the committee we have also learnt a lot, by being ‘forced to’ meditate on difficult questions. Good ethics often means protecting the weak from the strong, asking the questions no one else dares to ask, and standing up for values when other forces have other priorities. Part of this is knowing where we lack knowledge, and I do believe we have become wiser, and perhaps also more humble when facing these questions and meeting with the scientists planning their research.

The cases we have considered so far have been diverse. The majority of the projects have, however, been in a category where human bones from a university collection are the basis for a research project. The bones in this category have in most cases been from the Middle Ages (which in Norway means before 1537), or much older. As long as the bones are treated with respect and discretion, and are not being harmed or disseminated, the important question of the project’s feasibility and aims will be key to an approval.
DESTRUCTION OF RESEARCH MATERIAL
The difficult cases in this sector have been when the research involves a degree of destruction. Destruction is inevitable in many kinds of modern research, such as DNA analysis. DNA analysis can give answers to vital questions, for example about origin. Destruction means that no one else can do the same research on exactly the same material. If one part of the bone has been utilised, one can always continue with a new project on another part. But many projects means greater consumption, and there is a natural limit to how many projects can be undertaken on the same material. The human remains are in these cases information resources, which are finite. And it will be unethical to consume today all the available resources and in that way prevent future scientists from carrying out their projects. For certain periods the Norwegian bone collections are much more limited than those of many other countries. We also know that in the future new methods and new technology will be developed. Hopefully, it will be possible to find answers without similar destruction of the research material. This is indeed a research ethical dilemma.

PROVENANCE AND DESCENDANTS
One recurring issue is that of how the excavations were carried out—the provenance of the research material. Often the archaeological excavations were undertaken long ago, and the documentation and archaeological methodology were not, to say the least, as accurate as we would demand today. The scientists carrying out research on this material do not always take this into consideration, and the theories may therefore be based on
insecure foundations. Often members of our committee will know the collections far better than the researchers in question, and raise doubts if there are dubious items in a project.

The question of provenance is at the core of any project. If destruction of the material is involved, one should at least know for sure that the material is what the scientist believes it to be. The best DNA analysis will be of little use if undertaken on material of unknown origin.

The issue of provenance also includes the question of the circumstances under which the material was collected. The exhumation of the Sami graveyards at the beginning of the 20th century is a good example. If the material was collected against the will of the group to whom it belonged, it will be very difficult to support the project. On the other hand, material collected long ago, under what are today considered unethical circumstances, can still contain valuable information for the group to which it belongs. It is indeed important that such ‘owners’ consider thoroughly the pros and cons of allowing or preventing research on the material. They will have an obligation to their forefathers as well as to their children.

Ethnicity is an aspect we take seriously. The history of the indigenous Sami people and other minorities are a call to caution. A history of repression and disrespect makes research on the remains of these groups a sensitive issue.

The Sami authorities handle their cases in cooperation with our committee. The cases submitted to the Sami Parliament are sent to us for consultation before a decision is made. It can also happen that a research project does not consider the possibility of there
being Sami remains in the research material until our committee raises the question. In these cases we have a special responsibility.

The questions of ethnicity and provenance have also been raised when a research project involves remains from other countries and parts of the world. Other countries naturally have different traditions and histories, but our ethical standards cannot be relaxed due to this. A project undertaken by a Norwegian research institution will have to show the same caution and respect for foreign material as for Norwegian material.

**RESEARCH ON MORE RECENT REMAINS: WHO REPRESENTS THE DESCENDANTS?**
We do not deal only with pre-reformation material. There have also been cases involving more recent remains. One question concerned whether to open and take specimens from graves little more than one hundred years old at Spitsbergen. The motivation for the project was to find the causes of death of a group of people who had been forced to overwinter in the area, none of whom survived. In this case the respect for the deceased and their families is paramount.

The case raised an interesting question about the interest of the descendants. How much of a say should they have, and how does this say diminish over the generations? Furthermore, who are the relevant descendants after one hundred years?

**RESEARCH, EXHIBITIONS, AND SYMBOLIC SIGNIFICANCE**
How do we define ‘research’? From time to time definitions of words can present challenges. Our work is related to research.
An important part of research is the actual handling of the remains, especially in public spaces. The exposure of human remains in scientific exhibitions and elsewhere should pay respect to the same values and norms as the actual research. If people find some kinds of research on human remains unethical, they will also react against some types of exhibitions of the same material. And for the general public, going to an exhibition can also be a kind of research, in that it involves gaining knowledge.

Human remains carry symbolic significance. Our view of the exposure of human remains is formed by our culture. In Western culture, a skull is traditionally a more potent symbol of the personality or integrity of the deceased than a bone from a toe. In other cultures this might be different, or at least the toe may have a greater symbolic significance. When exhibiting or exposing human remains, one should also be aware of such diverse symbolic significances, because our contemporary culture is not as homogenous as it once was.

**DIALOGUE PARTNERS**

To expand our knowledge and to develop our understanding of the aims of the committee we have explored different fields.

Hedley Swain, Head of Museum Policy at MLA (Museums, Libraries & Archives, United Kingdom), shared his wide experience at a very early stage of our work. (Swain was previously the head of Early London History and Collections at the Museum of London, and is currently Director
of Museums and Renaissance at the Arts Council England.)

A visit to the Institute of Anatomy at the University of Oslo, guided by Professor Per Holck, to see the collections and learn about the way the human material is stored and treated, was very important and educational.

Dr. Kirsti Strøm Bull, Professor at the Faculty of Law, University of Oslo, looked into the difficult legal aspects of the Sami cases.

Berit Sellevold from NIKU, The Norwegian Institute for Cultural Heritage Research, Senior Researcher and osteologist, has also been of great help and has shared with us her knowledge and work on research ethics.

The scientific views have been of great importance to help us understand the value of the research and the collections. But there are also other ways into exploring the ethical dimensions. Ethnicity is another factor. Because of this aspect our relationship to the official Sami authorities is especially important. We therefore met with the Sami Parliament, Sametinget, a meeting which was important for understanding their views and their ways of working with these questions.

Ethics is very much about culture. Faith and religion, or the lack of those, are important ingredients. We have also explored this landscape. Norway, like all European countries, is absorbing a variety of ethnic and religious groups. Therefore, to be able to give good advice it is important to have a better knowledge and understanding of the traditions and faiths of the more recent minority groups. So far the rabbi
of the Jewish community in Oslo has lectured for us, as well as a Dominican prior, clergymen from the Lutheran Church of Norway, and the General Secretary of the Islamic Council Norway (Islamsk Råd Norge).