The History Of Research Ethics

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Abstract
Throughout the ages – and especially after the scientific revolution in the 17th century – the behaviour of researchers has been subject to some form of regulations that have reflected the normative system prevailing within the research community. In addition, researchers have also sought to show respect for general ethical rules and social norms. These are integral to research ethics.

Introduction
In the modern age – i.e. since the Enlightenment Era – these internal scientific norms have been accompanied by a positive view of science. Research, in the natural sciences in particular, has been regarded as an expression of liberation and progress. Research is encompassed and motivated by a positive assurance that its results will be applied for the benefit of humankind, as we can often read in political documents.

The Second World War – a watershed in research ethics
Many consider the Second World War as the most important landmark. This is mainly due to the reckoning with the scientific, medical experiments conducted on prisoners of war in the concentration camps. This research provided important results, but was based on causing injury or death to the people who participated in it. Other key events during the Second World War also helped raise awareness of the consequences of participation in research. One prime example is the Manhattan project, a large-scale research project to produce atomic bombs. The research succeeded, and the destructive consequences were made abundantly obvious in Hiroshima and Nagasaki
It was only in the wake of the Nuremberg trials that the World Medical Association started to prepare guidelines for biomedical research on humans: The Geneva Declaration (1947) and the Helsinki Declaration (1964). However, neither trials nor guidelines could prevent the abuse of people in medical research in the post-war years (see Ruyter 2003: 315–346 for examples). As a result, the World Medical Association in 1975 recommended the establishment of independent committees of research ethics to assess all medical research involving people. In my opinion, this measure has had the greatest effect on reducing the abuse of participants in medical research, and it has also helped promote good scientific practice. This establishment represents a new landmark in the form of an organised code of research ethics, which has enlisted a number of supporters.
Natural-science research on nuclear weapons was not brought to trial, but it ushered in a broad political and general debate on how the use of nuclear weapons best could be prevented. It is important to note that in this discussion, physicists and engineers in particular have assumed a significant role in influencing the public and the politicians, for example through the so-called Pugwash movement that was founded in 1957 and along with its founder Joseph Rotblat was awarded the Nobel Peace Prize in 1995. Dorothy Hodgkin, Nobel Prize Laureate in chemistry and president of Pugwash in 1976–1988, urged all Nobel Prize Laureates to sign the Pugwash declaration against nuclear weapons, and 111 of them did so. However, even the Pugwash movement appears to have realised that declarations and awards are insufficient instruments to prevent undesirable consequences of natural-science research. In 1997, Joseph Rotblat called on scientists to convene to establish an international ethics committee to monitor natural-science research "regardless of how unpleasant it will be for scientists to be monitored". No such committee has been established. There is no regulation of research in this area comparable to the one that is in effect in the field of medicine.
Pollution of the environment as a result of industrial development was the second major area of the natural sciences that gave rise to a focus on the consequences of research. Rachel Carson's Silent spring (Carson 1962) was probably the first book to articulate the widespread concerns about air pollution, by asking why the birds are disappearing. Over the years, the environmental problems have grown in scale, and they are characterised as being "anthropogenic and thus a result of human action" (Ariansen 1992:11) and often based on research. This was naturally followed by questions about how these problems could be rectified. The first major environmental conference was held in Stockholm in 1974, a precursor of the principles that have been enshrined in legislation from the 1970s onwards as well as in international conventions.

The social sciences have not seen the same dramatic abuse of research participants, nor have they been confronted with the same potential social consequences. This has not prevented powerful reactions to the publication of certain types of research projects. This has been a particular result of the use of sensitive personal information. On the basis of research projects, objections have been especially raised against the use of personally identifiable information without the persons involved (or their guardians) knowing that such information had been used for research purposes. It has also been claimed that this type of study violates privacy and that it is impossible to prevent such information from being abused in the future. One such project was the so-called Metropolitan study, which was conducted in Norway and Sweden in the 1960s (Johansen, Kaspersen and Skullerud 2001:35–37). The part of the study that attracted most attention involved schoolchildren. In 1964, the Oslo school board supplied information on boys born in 1954 to the project. The study was to follow the boys from age 11 until they had become well-established adults (at the age of approximately 30 years) with the purpose of providing better vocational guidance and social assistance to young people in the future. The information supplied by the school board included names, age, housing conditions, the guardian's profession, school grades and IQ. The project attracted harsh public criticism (including by law professor Knut S. Selmer), and demands for prior consent by parents and sufficient protection of the data were put forward. The researchers appeared reluctant to introduce amendments to a project that could plead such laudable aims, but they were willing to withdraw pupils from the study if protests were received. The consequence of this vehement public criticism was a potential weakening of trust in social research. As a result, the social researchers themselves took the initiative to establish a data protection secretariat under the Norwegian Research Council for Science and the Humanities. With the development of computers – and the question of protection of individuals – the Metropolitan study can be regarded as an essential reason behind the proposals for political measures to prevent abuse after 1967–68. This led to the Act relating to Personal Data Filing Systems in 1978 and the establishment of the Norwegian Data Protection Authority in 1980. Ten years later, the National Committee for Research Ethics in the Social Sciences and the Humanities was established, following a proposal in Report no. 28 (1988–89)

Landmarks before the Second World War: the early days

In the context of the development of modern medical science and experimental methods, some interesting reflections were made regarding how one should proceed when the research process involves people or animals. Some reflections of this kind were provided by Claude Bernard (1813–1878), an influential French physiologist. Many consider him to be the founder of experimental medicine, since he established the principles for conducting experiments (Bernard 1965). In contrast to the long-standing tradition in research of using vulnerable people in experiments, Bernard proposed that the researcher should begin by using himself and continue by including family members and colleagues, before starting to use patients, for example, in experiments. This may seem like a reasonable principle in research ethics: if you do not want to expose yourself to something, you should not expose anybody else to it either. Or in other words: researchers, who are best qualified to understand any risks involved, should start by exposing themselves to the risks before proceeding with other research participants who are less well equipped to understand them. Self-experiments have been practised both before and after Bernard, and they are also specifically referred to in the Nuremberg Code, but they have never been used on a large scale. More commonly, there seems to have been little debate among researchers on moral problems associated with the use of vulnerable research participants. These were often exposed to a considerable risk, which was tolerated in consideration of the benefits to be gained from potential progress (cf. Elkeles 1996).

There were, however, reactions to the use of people in research that caused authorities other than the profession itself to attempt to set a standard. One example from Norway is the trial of Gerhard Armauer Hansen (1841–1912) in Bergen. He was deprived of his licence as a doctor at the Leprosy Foundation in Bergen. Hansen, who is one of Norway's most recognised researchers, is known for his discovery of the leprosy bacillus. In his investigation of the causes of leprosy he wanted to try to demonstrate that the disease is infectious by using a cataract needle to graft material from a sufferer into the eye of a patient who suffered from another type of leprosy

An interesting point in this connection is that the authorities in Prussia issued a directive in 1900 to regulate medical research (Ruyter, Føre and Solbakk 2000:250). The directive contains two material guidelines that can be found in all subsequent research ethics. The first is known from the Hansen case, here expressed as a requirement for "unambiguous consent". The second is the personal responsibility of the head of the clinic to ensure compliance with the directive. This directive appears to be the first document in which medical research is regulated by authorities other than the researchers themselves. The document places responsibility with the management, and its purpose is to protect patients in the clinics against being used in experiments that are harmful to them and undertaken without their permission.

The earliest example from Norway dates from 1969. (The journalist Kjell Pedersen drew my attention to this reference). In the minutes from a meeting of the Norwegian Council for Radiation Protection there is a call for "ethical/radiological committees" in the context of the need for advance approval of controversial research projects; the case in question involved "plans for a Nordic study of circulatory factors in the facial skin of Sámi people etc., with the aid of a method that includes exposing the research participants to radiation". In the investigation of radiation experiments in the USA, it was discovered that some rudimentary mechanisms for assessment of research projects, such as internal control, had existed since 1946 (President's Advisory Committee 1996:500). After various forms of internal control had been attempted in the USA, it was decided that all institutions must establish local committees of research ethics for peer review in order to provide sufficient protection to all research participants. In 1971, this was introduced as a condition for undertaking research that involved human subjects.

Conclusion

As a result of this development, Sweden established local committees of research ethics in all university hospitals in the late 1960s. The new element in the revised Helsinki Declaration was its requirement for independent ethical review. From this requirement we can find a direct link to the way in which the regional committees of medical and health research ethics were established in Denmark and Norway after 1985. The committees were not established locally, but regionally, with broad interdisciplinary representation, including laypeople. A precursor to the regional committees was the ethics commission that had been established by the Norwegian Research Council for Science and the Humanities in 1978 to assess ethical aspects of applications within this field, as well as the so-called Andenæs committee that deliberated guidelines and councils for professional ethics (1977).

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