

Good Research Ethics and Conduct: I Ethics, Morals and Research

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What Ethics Dictates and the Law of Demands

Key References

- ▶ Swedish Research Council, SRC (2017). Good Research Practice. Vetenskapsrådet, Stockholm.

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What Ethics Dictates and the Law of Demands



⁰Source: <http://theprofitrecipe.com>

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What Ethics Dictates and the Law of Demands

Ethics and Morals

- ▶ A clear distinction between “ethics and morals”
- ▶ **Morals:** everyone has a set of morals reflected in choices, actions and behaviour towards others
- ▶ **Ethics:** a set of principles acquired consciously and reflectively
 - ▶ Ethics therefore means a type of theory in the area of morals
- ▶ Ethics contains moral precepts that are conscious, reflected on and motivated

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What Ethics Dictates and the Law of Demands

Ethics and Morals Cont.

- ▶ **Research Ethics:** norms, (principles) formulated by the research community
 - ▶ These norms work together and offer guidance
- ▶ **A Code:** a collection of research ethics rules
 - ▶ More specified norms regarding a certain research area or certain stages of research projects
- ▶ Normative assumptions that dictate what is good or bad and that recommend or forbid different behaviours are parts of both ethics and morals

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What Ethics Dictates and the Law of Demands

Research Ethics and Professional Ethics

- ▶ **Research Ethics:** not well-defined
 - ▶ Links research and ethics as well as ethical standards
 - ▶ Key aspect: how people who participate in research as subjects or informants can be treated
 - ▶ People should be protected to the highest degree possible from harms or wrongs!
- ▶ **Professional ethics:** the researchers responsibility towards research and the research community
- ▶ Many of the issues we will discuss are of the professional ethics type

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What Ethics Dictates and the Law of Demands

Merton's CUDOS Norms

- ▶ Robert Merton (an American Sociologist in the 1940's): CUDOS norms
 - ▶ **Communism/Communalism**: the research community and society as a whole have the right to be informed of the results of research
 - ▶ **Universalism**: scientific work should be evaluated with reference to scientific criteria alone
 - ▶ **Disinterestedness**: the researchers should have no other incentive for his/her research than a desire to contribute new knowledge
 - ▶ **Organized Scepticism**: the researcher should constantly question and scrutinise, but also refrain from expressing an assessment until he or she has sufficient evidence on which to base it

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Merton's CUDOS Norms Cont.

- ▶ The position of the researcher changed a lot since formulation of Merton's CUDOS norms
 - ▶ Loyalty to organizations, superiors, financial and job security issues come into play
- ▶ Merton's norms are difficult to live up to in reality:
- ▶ The **disinterestedness** norm
 - ▶ Common for researchers to research to have other motives to do research - e.g., promotion
 - ▶ The key issue is to follow a good/ethical research conduct
- ▶ The **communism** norm difficult to live up to in some cases - e.g., industrial setting

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What Ethics Dictates and the Law of Demands

Ethics Codes

- ▶ **No harms or wrongs on research participants** (the protection of the individual criterion) - but trivial amount of harm should not prevent research
 - ▶ Research is important to improve health, the environment and quality of life
 - ▶ Research results are important in their own right (the research criterion)
- ▶ We need balance between the two criteria
- ▶ The discussion or research ethics took off after WWII
- ▶ The most significant code is the medical **Declaration of Helsinki** - 1964 & 2013
 - ▶ Rules from it have been effective in other research areas as well

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Research Ethics Scandals



⁰Source: <http://www.evident.net.au>

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Research Ethics Scandals

Research Ethics

- ▶ Some famous and some less-known research scandals
- ▶ See how they ultimately led to the practice of Ethics Committees
- ▶ The acts of Nazi Germany are assumed to be the main starting points for Ethics Committees
 - ▶ Both unethical research and ethical regulations preceded those events though

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Research Ethics Scandals

Edward Jenner's Smallpox Vaccine, England, 1776

- ▶ An 8-year-old child was injected with pus from a cowpox infection deliberately
- ▶ Reason: to study their acquired immunity
- ▶ The research was a great step forward
 - ▶ But it will be unlikely to be approved to be conducted today

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Research Ethics Scandals

The Neisser Case, Prussia, 1898

- ▶ Clinical trials on serum therapy in patients with syphilis
- ▶ Serum from patients with syphilis was injected into those who were admitted for other reasons
 - ▶ The patients were not informed + no consent = **no informed consent**
- ▶ Some of these patients contracted syphilis
- ▶ The tried vaccination for syphilis failed!
- ▶ This caught public attention

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Research Ethics Scandals

The Neisser Case, Prussia, 1898 Cont.

- ▶ Led to the Minister for religious, educational and medical affair's directive
 - ▶ All non-therapeutic research must have **unambiguous consent**
- ▶ Led also to the 1931 Guidelines for New Therapy and Human Experimentation
 - ▶ Calls for the necessity of considering the risks involved in research and seeking informed consent
 - ▶ In particular for non-therapeutic research

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Research Ethics Scandals

Medical Experimentation in Nazi Germany, 1939-45

- ▶ A number of horrific experiments conducted in Nazi concentration camps
 - ▶ Involuntary sterilisation
 - ▶ Subjection to radiation
 - ▶ Freezing to induce hypothermia
 - ▶ Intentionally infecting research subjects with malaria and tuberculosis
 - ▶ Conducted without the consent of subjects
 - ▶ Resulted in extreme pain, suffering, mutilation and death!

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Research Ethics Scandals

Medical Experimentation in Nazi Germany, 1939-45

- ▶ Big controversy arising from the results of these experiments
 - ▶ Whether using the results is ethical - not to do so does not help the victims
 - ▶ On the other hand, using the results implies endorsing the gathering of the data
 - ▶ Not an issue to ethics committees though - they work prospectively, not retrospectively
- ▶ The Nazi experiments led to the **Nuremberg Code** of 1947
 - ▶ A legal code that labeled Nazi research unethical and but also code for future research
 - ▶ Also played a role in the development of the **Helsinki Declaration** in 1964

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Research Ethics Scandals

Tuskegee Syphilis Study, United States, 1932-72

- ▶ A clinical study carried out 1932-72 in Tuskegee, Alabama by the US public health service
- ▶ Recruited 400 illiterate African-American men with syphilis, as well as 200 healthy controls
- ▶ Main aim: to study the natural progression of the disease when left untreated
 - ▶ Particularly to compare the results with earlier results from European origin subjects
- ▶ The participants were not told they were a part of a trial
- ▶ The tests were described to them as “special free treatments”

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Research Ethics Scandals

Tuskegee Syphilis Study, United States, 1932-72 Cont.

- ▶ During the trial, there was no effective treatment for syphilis
 - ▶ But since 1947, Penicillin had become effective in treating it
 - ▶ The subjects were neither informed nor provided penicillin!
 - ▶ They were even blocked from military conscription - which could have given them access for treatment
- ▶ At the end of the experiment, 74 subjects remained alive
- ▶ 40 of their wives had been infected
- ▶ 19 children were born with syphilis - which could have been prevented if the men received treatment!
- ▶ The Tuskegee scandal led to the formalisations of research ethics review in the US

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Research: What, Why, How and for Whom?



⁰Source: <https://www.uah.edu>

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Research: What, Why, How and for Whom?

Some Types of Research

- ▶ Diverse types of research
 - ▶ Hypothesis-generating vs hypothesis-testing
 - ▶ Qualitative vs quantitative
 - ▶ Research to explain why something has happened by showing that it can be explained under a natural law vs research that tries to increase and deepen our knowledge about events, processes or texts
 - ▶ From research ethics point of view:
 - ▶ Basic research: seeking new knowledge without a particular application in mind - may lead to unexpected/ground breaking discoveries
 - ▶ Applied & commissioned research: aimed at being of use to the party who initiated or ordered the research, the latter is more driven by the commissioning party

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Research: What, Why, How and for Whom?

Some Types of Research Cont.

- ▶ Research $\implies$ systematic search for knowledge
 - ▶ The knowledge must be new - not a simple compilation of what is known
- ▶ Replicating earlier studies however is research
 - ▶ Replication $\implies$ confirms soundness of the findings
- ▶ A systemic-critical review and compilation of previous studies is also research
 - ▶ If it raises our knowledge

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Research: What, Why, How and for Whom?

Why?

- ▶ Scientific research is an important element of society
- ▶ Basic research - to develop new knowledge
- ▶ Applied research - develop knowledge
 - ▶ That can lead to improved clinical diagnostics and treatment in medicine
 - ▶ To improve production or products
 - ▶ Improve planning and production decisions
- ▶ The benefits of research extend beyond producing more and new products and jobs
 - ▶ To promoting critical thinking and better quality of life

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Research: What, Why, How and for Whom?

Why?

- ▶ Unfortunately, research may have unintended consequences
 - ▶ Used for negative purposes by countries, terrorists or others
- ▶ A vibrant ethical discourse is necessary to weigh the benefits with costs
- ▶ The environment is crucial in determining what type of research is conducted
 - ▶ Commercialisation and patents are emphasised $\implies$ basic research will be limited
 - ▶ Too much focus on basic research $\implies$ isolated and elitist environment
- ▶ It is important to have balance!

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► **End of Presentation!**