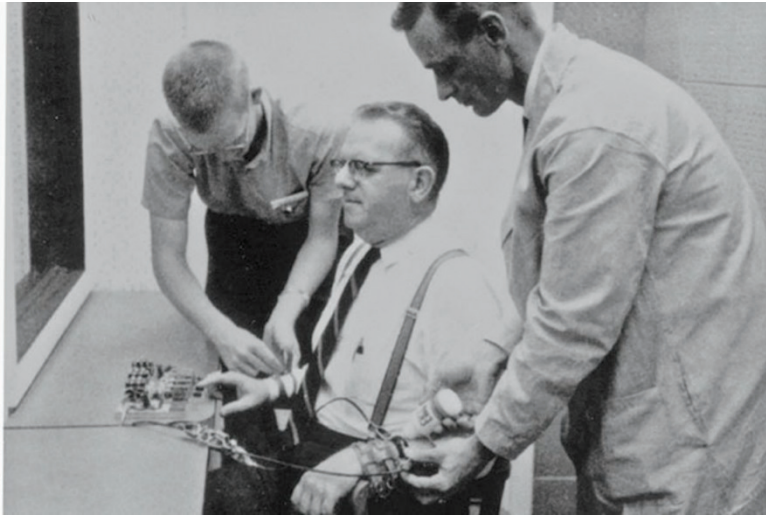


# Research Ethics

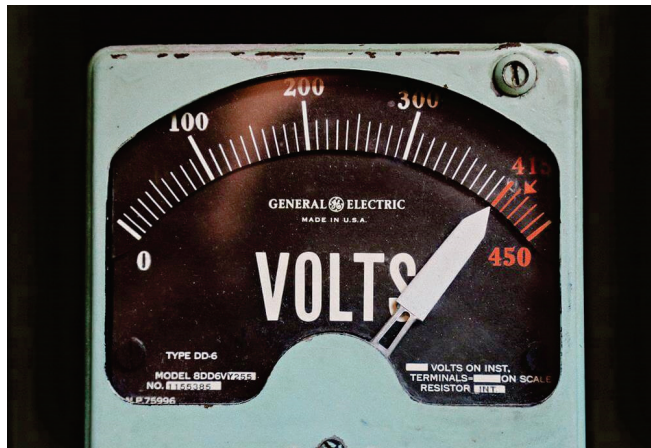
# Principles-based ethics

- Respect for Autonomy
  - individuals should be treated as capable of deciding for themselves
  - individuals whose autonomy is diminished need special protection
- Beneficence
  - Ensure the welfare of the persons concerned
  - maximise possible benefits
- Justice
  - Who benefits and who is burdened by the research?

# Autonomy - individuals should be treated as capable of deciding for themselves



- Milgram's Obedience Experiment
  - test the effects of punishment on learning
  - Teacher would administer shock to the learner for wrong answers
  - Shocks increased
  - 26 of the 40 participants were willing to administer the maximum shock
- In fact there was no electric shock, but no-one told the participants



What could/ should participants have been told?  
When?

# Informed consent

- Participants should know as far as possible what they are being asked to do
  - Goals of the study
  - Activities required
  - Risks
  - What happens if they don't take part?
  - How data will be stored, treated, reported (privacy, data protection...)
  - How will the data be used and results be communicated?

Informed: They know what they are being asked to do

Consent: They freely communicate a willingness to participate

# Is consent always required?

- A teacher wants to test a new approach to teaching material
  - Tests the students
  - Splits her class in two groups of comparable ability
  - Teaches one half in the traditional way, one half using the new method
  - Tests again and does a t-test to see if the control and experimental group have significantly different results
- Does the teacher have to ask for consent from students in this case?
- If so, how should the consent process be managed?

# Potentially Vulnerable Populations

- Those with limited autonomy or who may feel limited autonomy:
  - children;
  - adolescents (legal minors aged 14 years or more);
  - adults lacking capacity
  - pregnant women;
  - prisoners;
  - persons in emergency situations
  - students where the researcher is the teacher

# Exemptions from Informed Consent

- Informed consent may not be explicitly required at the point of data collection in some situations:
  - Non-vulnerable people completing anonymous questionnaires (consent is implied)
  - Anonymized analysis of pre-existing data sets
  - Observation of people in public places (People have expectation of privacy in relation to home, family and private life, mail and telecommunications).
  - Where research is part of the quality control of a service (analysis of student exams in university, “mystery shopper” in workplaces etc.
  - Where getting consent may damage the general good or may put the researcher at risk (Justice).

Informed consent is the general rule – exceptions need to be verified.

# Beneficence

- A teacher normally teaches a subject in a particular way, but their colleagues treat it differently. The teacher has good reason to (from research) to believe that their method is better. To explore this, the teacher splits the class in two comparable groups then teaches one group using their normal teaching strategy and the other group using their colleagues strategy. The teacher collects data and compares the results.

**Is this research ethical?**



# Review Process

- Typically you don't just make up your own mind – you have to ask others to validate your approach
- Especially important when
  - normal practices (e.g. informed consent) are not being applied
  - Populations are particularly vulnerable
  - Data is sensitive or personality type data
  - ...

# Data Protection and Privacy

- Swiss Federal Data Protection Act (DPA) and the Data Protection Ordinance apply to **personal data**, which means all information relating to an **identified or identifiable person**
- Covers collection, storage, use, revision, disclosure, archiving or destruction of data

## **Some key principles:**

- “Personal data can only be processed for the purpose indicated at the time of collection, that is evident from the circumstances, or that is provided for by law”
- “The collection of personal data and the purpose of processing must be evident to the data subject”

# Data Protection and Privacy

## **Sensitive and personality data:**

- Explicit consent is required for the processing of sensitive personal data or personality profiles
  - Sensitive data: relating to religion, political beliefs, trade union activities, health, race, social assistance or criminal records
  - Personality profile is a collection of data that permits a person's personality to be determined
- Declare and register data files with the Federal Data Protection and Information Commissioner

## **Cross-border storage and treatment of data:**

- Consent is required for cross-border data disclosure
- Adequate protection for subjects (maybe OK for EU but not outside)