

Ethics of Human Research *week 12*

When conducting research studies including human participants in an active capacity or recording personal data, the principles of research ethics should be applied.

Informed and voluntary consent

The participant is given all information needed to decide whether or not to participate in a study. This information includes the researcher's identity, the study's purpose, the study's method, how the collected data will be used.

Informed also means understood. The information given to the participants should be short, simple, and clear. The participant should not just be given the opportunity to read this information, but the researcher must make sure that the participant does read it.

Participants should take part in a study willingly, knowing they are free to participate or not. They should have the right to withdraw without penalty, with all data immediately discarded at any time, even after the study has taken place.

Coercion is the act of exerting undue influence to incentivise participation. Types of coercion include physical (e.g. the threat of violence or harm), social (e.g. peer pressure), institutional (using authority, e.g. military, workplace, education), financial (e.g. offering enough money that would make a participant contradict their own self-interest), indirect (e.g. allowing someone else to influence participants on your behalf).

Gaining explicit consent is not always practical (e.g. tiny, low-risk studies, or studies with an immense number of participants, e.g. analysing tweets). Covert research conceals some or all details of the study, but consent must be gained after the study takes place. If gaining consent is impossible, the study isn't automatically ethical without gaining consent.

Favourable risk-benefit ratio

Do no harm vs. minimising risk and maximising benefit is an important decision to be made, e.g. letting a fire burn, or risking a firefighter's life to stop the fire. The researcher must have a good reason to expect the outcome of a study will be beneficial.

Potential risks to a human-computer interaction study include physical, emotional/psychological, social, financial, professional, and (most prevalent) privacy risks. These risks apply to both the participants and the researchers.

Confidentiality and data protection

Participants should be guaranteed confidentiality, particularly important for sensitive or stigmatised topics. Personal data (any information that could be used to directly or indirectly identify someone) should be kept private and safe. Data such as the participants name, a photograph, or their email address could be used to directly

identify someone, while information such as their age, gender, or postcode, could be used alongside other information to indirectly identify someone.

De-anonymisation is the act of identifying someone from anonymised data. Real-world examples include identifying people from their Netflix movie ratings or identifying someone's entire location history based on four known locations. Laws against re-identification of anonymised user data are difficult to enforce, stifle security research, and leave vulnerabilities undiscovered.

Sensitive personal data includes racial or ethnic origin, political opinions, religious beliefs, trade union activities, physical or mental health records, sexual life, and information about criminal offences. An especially high level of care should be given to this type of data.

Identifying information should be separated from other data, with a numeric index to link related information. Data should not be fully anonymised in order to allow consent to be withdrawn. Only required data should be collected (and therefore pre-made 'boilerplate' questionnaires should be avoided) and this data should only be kept as long as it is required. It should be kept secure in password-protected servers or locked containers.

In some exceptions, participants may wish to be fully identified (e.g. expert interviews) or they may partially waive their confidentiality (e.g. publishing photos of a study, in which case explicit consent is required). Evidence of crime, intent to commit crime, or risk to vulnerable persons should be reported to authorities and in these cases, confidentiality must be breached. Data is not protected from court orders.

Independent review process for research

The decision on whether or not research is ethical should not be left to the researcher. Committees/ethics boards make this decision.

Justice and inclusiveness

The benefits and burdens of the research must be similarly distributed and if a study will likely benefit a certain population, this should be reflected in the participant pool.

No group of people should be, without good reason, excluded from research activities in which the results affect them. For example, excluding young participants in a study about elderly support systems is ethical, though elderly participants cannot be excluded in a fitness training monitor study, just because they are not as likely as other populations to be affected by the results. Pregnant women, elderly people, and children are often excluded from studies without good reason.