# Research ethics
## practical matters and ethical principles

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# Practical matters

Two research ethics committees in Iceland

➢Bioethics committee – Vísindasiðanefnd (vsn.is)
  ➢Only medical related research
  ➢Only research that requires permission

➢University Ethics Committee on Scientific Research
  (https://www.hi.is/samstarf/sidanefnd_haskolanna_um_visindarannsoknir)
  ➢Other research
  ➢No permissions, only review

# Practical matters

University Ethics Committee on Scientific Research

➢ Who needs to apply?
  ➢ Research involving vulnerable groups
    ➢ e.g. children, immigrants, disabled people, victims of violence, …

  ➢ Research collecting sensitive data
    ➢ personal interviews, data on risk behaviour (both quantitative and qualitative), …

  ➢ Research where ethical review is a condition for publication or grant

# Practical matters

How to apply?

➢Application form at: https://www.hi.is/samstarf/sidanefnd_haskolanna_um_visindarannsoknir

➢Who applies: Principal Investigator (Ábyrgðarmaður)

  ➢If a student fills out the form, the principal investigator must read it over before it is submitted

➢Application form filled out in Icelandic unless special reasons for using English (such as researcher being English speaking)

# Practical matters

What accompanies an application?

➢CV for all applicants

➢Information letter for participants

➢Informed consent form

➢Contract if others (persons or institutions) are partners in the research

➢Interview guide

➢Questionnaire

➢… whatever else might be needed to evaluate the ethical aspect of gathering, processing and storage of data

# Practical matters

## Information letter for participants

➤ Written on formal letterhead with logo of the university/institution where the research is carried out

➤ Has a name of the research, date and location.

➤ Addressed to **potential** participants (not: "thank you for participating …")

➤ Explains the (i) **purpose** of the research, (ii) **who** is undertaking the research, (iii) **why** the person in question is being contacted, (iv) **what** the person will be expected to do or contribute, (v) how data will be stored and treated, (vi) how **anonymity** will be guaranteed, (vii) other relevant information such as:

    ➤ where interview will be taken, how long it will be, that a participant can stop at any point without any consequences, …

    ➤ what happens if participant feels discomfort after participating (whether in a interview or a survey)

➤ All letters must be written in language accessible for the reader (NO JARGON!)

# Practical matters

## Informed consent form

➢ Distinct from the information letter

➢ Written on formal letterhead with logo of the university/institution where the research is carried out

➢ Has a name of the research, date and location.

➢ Written in first person ("By signing this letter I..., I understand that...")

➢ Affirms that the participant has been given information about the research

➢ Affirms that the participant know that they can stop without explanation and consequences

➢ Is signed by the participant (affirming the above)

➢ Is also signed by the research affirming that the research will follow strict ethical rules

➢ The consent form verifies that the process is free from coercion and shows **mutual** commitments of participant and researcher

# Practical matters

Contract if others (persons or institutions) are partners in the research

➢ When research relies on the work of people or institutions outside the research group, for instance:

➢ Schools collecting data about students

➢ Schools or other organizations giving researchers access to their facilities

➢ Institutions in the welfare sector facilitating access to possible participants

➢ …

➢ … it is necessary that there be a contract between the researcher/research team and the institution detailing what is involved in the cooperation

➢ The contract must be written on formal letterhead and signed by both parties

# Practical matters

➢Interview guide

➢When research is based on interviews it is necessary to include an interview guide or frame

➢The interview guide should preferably show how the interview will be structured, thus divided into different parts such as

  ➢(a) introduction, going over information about the research and signing informed consent,
  ➢(b) main part where the research specific questions or issues appear, and
  ➢(c) closing where the participant is given an opportunity to add

➢It is necessary that the interview guide shows close fit between the questions or issues raised during the interview and the aim of the research

# Practical matters

Questionnaire

➤ Although quantitative research is often less sensitive than qualitative research, it should be born in mind that answering a questionnaire about sensitive issues can cause discomfort

➤ It is also important to design questionnaire in such a way that identities of participants will not be disclosed,

> ➤ Use age range rather than specific age
> ➤ Use region of the world rather than specific countries of origin
> ➤ …

# Practical matters

## Inclusive language

➢ Remember that genders are not only two. Pronouns to be used: he/she/they

    ➢ How to ask about gender in a survey:

> Woman
> Man
> Transgender
> Non-binary/non-conforming
> Prefer not to respond

    ➢ It is not enough to change only the "gender" question at the beginning of a survey, all questions must be checked for gender inclusiveness

➢ Language can be discriminating or demeaning in various ways:

    ➢ https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines

# Why all this trouble?

The European Code of Conduct for Research Integrity (2017)

➢**Reliability** in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.

➢**Honesty** in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way.

➢**Respect** for colleagues, research participants, society, ecosystems, cultural heritage and the environment.

➢**Accountability** for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts.

http://www.allea.org/wp-content/uploads/2017/03/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017-1.pdf

# Why all this trouble?

## Siðareglur háskólanna um vísindarannsóknir (2020)

➢ **Virðing fyrir manneskjunni:** Gerð er krafa til rannsakenda um að þeir virði sjálfræði þátttakenda og friðhelgi þeirra. Jafnframt þarf að tryggja vernd þeirra þátttakenda sem ekki geta tekið sjálfstæða ákvörðun í eigin málum.

➢ **Velferð:** Gerð er krafa til rannsakenda um að þeir dragi eins og hægt er úr áhættu þátttakenda og auki eins og unnt er ávinning af rannsókninni. Þeir skulu jafnframt gæta þess að vægi gagns og áhættu af rannsókninni sé viðunandi.

➢ **Skaðleysi:** Rannsakendum ber umfram allt að forðast að valda skaða. Áhætta skal ávallt vera innan ásættanlegra marka og ávinningur nægur til að réttlæta rannsóknina.

➢ **Réttlæti:** Gerð er sú krafa til rannsakenda að þeir tryggi að ábata og byrði af rannsókn sé dreift af sanngirni og að þeir misnoti ekki aðstöðu sína gagnvart viðkvæmum einstaklingum. Rannsakendur skulu taka tillit til kynja- og jafnréttissjónarmiða á öllum stigum, m.a. við val á rannsóknarefnum, aðferðum, túlkun, framsetningu og nýtingu niðurstaðna.

➢ **Heiðarleiki og vönduð vísindaleg vinnubrögð:** Rannsóknir skulu unnar af heiðarleika og samkvæmt viðurkenndri vísindalegri aðferðafræði.

https://www.hi.is/sites/default/files/ame18/reglur_sidanefnd_hv_5_nov_2020.pdf

# ➤ Why all this trouble?

The practical issues reflect the ethical principles

➤ Good research is ethical research
- ➤ If research violates some of the ethical principles, it is not good research
- ➤ Observing the ethical principles is part of good research design

➤ Science is powerful, it can do much good, it can also be harmful
- ➤ Science can be empowering, but it can also be objectifying
- ➤ Researchers often rely on people contributing time and effort to their research. Do they, or people in a similar situation, get something in return?