

A dark, atmospheric landscape with mountains and a river, overlaid with a grid pattern and a red triangle.

# An Introduction to Research Ethics





# Ethical considerations: overview

- If we involve people in any form of user research:
  - Ethical obligation to inform them that we are collecting data from them and using it for a specific purpose
  - Must behave professionally and avoid exposing participants to treatments or situations that are unnecessarily distressing
    - National rules exist for what is allowed and when in the process
  - Must ensure participants consent to their data being collected



# Ethical considerations

- There are core principles for ethical research and development. These principles are:
  - Avoidance of harm,
  - Informed consent, and
  - Data protection.



# Avoidance of harm

The key principle underpinning the ethical standards which apply to academic activities is that of avoidance of harm. This principle spans a broad range of considerations, including:

- The welfare and interests of human participants (whether participating actively or through observation)
- The welfare and interests of those carrying out the activity
- Animals
- Cultural heritage
- The natural environment
- The reputation of the section, institute, the University and academia as a whole
- The welfare and interests of the wider community.



## Avoidance of harm

- Activities should neither include practices which directly impose a risk of serious harm nor be indirectly dependent upon such practices.
- We must always consider what ethical issues arise and show they are dealt with appropriately.



# Informed consent

- For research or further activity drawing on research involving humans (including participation, observation and/or data), the default position is that **informed written consent is required from those involved and/or their representatives.**
- Consent should be granted voluntarily



# Informed consent

- Where research involves vulnerable groups (e.g. children, prisoners, those suffering mental or physical illness), particular care should be taken to safeguard their welfare and interests.
- (See literature list for useful links on consent forms)





# Consent forms

- We use consent forms – whether we collect data FTF or online, to ensure we have informed consent from participants.
- Consent forms are confidential documents and must be securely stored – and you are legally obliged to do so.

## TEMPLATE INFORMED CONSENT FORM FOR SUBJECTS ABLE TO GIVE CONSENT

Full Title of Project:

Name of Principal Investigator:

Please initial box

1. I confirm that I have read and understand the subject information sheet dated ..... version ..... for the above study and have had the opportunity to ask questions which have been answered fully.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from [company/institution name] or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to access my records that are relevant to this research.
4. The compensation arrangements have been discussed with me.
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of Patient/Participant                      Signature                      Date

\_\_\_\_\_  
Name of Person taking consent  
(if different from Principal Investigator)                      Signature                      Date

\_\_\_\_\_  
Principal Investigator                      Signature                      Date

1 copy for patient/participant; 1 copy for Principal Investigator; 1 copy to be kept with hospital notes

**8.3 Appendix 3: Template Informed Consent Form for Adults without Capacity (For CTIMPS)**

*(Form to be on departmental headed paper)*



# Informed consent

- Participants must agree to the conditions of the study before it commences
- Must be allowed to withdraw at any time
- Must physically or electronically sign or electronically agree to indicate they have understood conditions
- It is your responsibility that they understand – not theirs - check participants understand what they are consenting to
- A copy of the consent form must be given to the participants – also for digital surveys



# Informed consent

- Key word: “informed”
- Deception?
- Debriefing
- What is acceptable? Ask yourself whether you think participants would be likely to withdraw consent once the full details have been explained to them. If yes, do not run the study in this form



# Data protection

- Particular care must be taken with collecting, handling and storing sensitive, classified and/or personal data, in line with GDPR rules
- Keep data securely protected from unauthorized access
- Any personal information must be kept confidential and anonymized
- Note that there is a **legal obligation** to protect data that can identify an individual as per the GDPT legislation.
- Do not show pictures or video of participants unless you have their consent (and even with consent, do not refer to them by name or other identifying information)



# Ethics of observations

## A note about observational data collection

- Unobtrusive measures do not influence behaviour (e.g., telemetry tracking)
- Informing participants that they are being observed may alter their behaviour
- Consider e.g., the “Hawthorne effect” and “social desirability bias”

No simple solutions - if possible, obtain consent from participants

Always be aware of sources of bias and noise in user research data, and do not make conclusions your data cannot support



# Summary

- Whatever method you use, you must **always** consider ethical issues when interacting or engaging with users, stakeholders or even just data from users.
- You must **always** ask participants in user research to provide their informed consent.
  - Lots of guidance in the Ethics Guidance and the reading materials for today
- **Observing ethical standards is a requirement for passing this course**



**Thank you**

