

Research Ethics: Orientation

Design for Informatics

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The plan for today

1. Idea of ethics
2. Public and private spaces and activities: what can we observe?
3. Informed consent
4. Data management and protection
5. ECA ethics forms

But first... why do we care?

Why talk about ethics?

- There are external requirements to approve human participation and handle data in certain ways-- must comply with Uni rules, data protection, etc.
- It is the right thing to do. Ethics is not the same thing as legality, but “legal” does not mean we are acting morally and with integrity as designers, researchers, members of the community.
- Pushes us to do clear advance planning, practice communicating about our research, reflect on what information we need/want to collect and disseminate

What this session tries to do

- This session is a **basic orientation** to the idea of ethical research conduct, ethics paperwork, and some of the main issues.
- Goal is to **make you aware of requirements and responsibilities** and set your “ethics alarm” so you will check yourself--“hmm, I think there might be a problem with that”
- It **WILL NOT** tell you everything you will need to know about ethics for your group’s project
- You **DO** need to read the listed resources!

1. Ethics introduction

Activity 1: What is ethics, why the rules and forms?

Discuss the following with a partner:

1. Based on your course readings, general knowledge, and previous degrees/coursework, what do you think “**ethics**” is? (Not what things specifically are/are not ethical, but what we refer to when we say ethics)
2. Why do universities, hospitals, local governments (etc.) have strict rules about research with people and animals, and require new work to have ethical approval?

Research ethics as rules, standards

- **Ethics are a set of standards for conduct, of an individual or a profession**
- Ethics are rules of conduct underpinned by a set of moral values (NB: a particular group or culture's values, at a particular time) (*Ransome 2013, p4*)
- Ethics establish a framework within which action (or research work) is considered acceptable. Outside of that framework, it is not. (*Ransome 2013, p4*)
- “The ethics of research concern the appropriateness of the researcher's behaviour in relation to the subjects of the research or those who are affected by it.” (*Gray, 2014, p68*)
- **When we talk about ethics and values, we must ask about WHOSE ethics and values? These are not universal, uncontestable, neutral, or self-evident**

Guiding ideas—mostly shared!

- Seeking to achieve the greatest good through research, seeking to avoid harm and distress to participants (and communities)
- Weighing the potential risks and benefits of a piece of research as part of deciding whether, and how, to do it
- Acting with honesty and integrity, as researchers and professionals
- Respect for people's rights and dignity, including their right* to privacy and anonymity

**Different professional codes and different countries treat this as a legally protected right (vs a reasonable expectation of privacy) to different extents. Generally, privacy laws are far stricter in Europe than the US.*

Grim lessons from history

- Self-regulation has failed, much harm has been done.
- Up to recent decades, researchers and doctors around the world have done terrible things in the name of “advancing science”. They sometimes seriously harmed participants--with full *knowledge* would harm them.
- Horrifying Nazi experimentation on concentration camp victims led to international outrage post-war, creation of Nuremberg Code (1947) as a direct result (*see Gray ch 4*)
- Superseded by Declaration of Helsinki (1964), seeking to better balance human protection with need for research
- Many nations, national science bodies now have own general human-subjects ethics codes, revised over time.

Ethics today

- Professional, national, Uni **ethics codes** seek to **provide guidance** for decision-making and priorities, may also establish punishments for poor conduct
- **Ethical approval forms and processes checks and balances:** someone else looks at planned research and also considers its risks, benefits, alternatives. Some ethics committees include non-scientist members of public—important for publicly funded science, programmes!
- Social science, humanities, arts ethics procedures have been heavily influenced by medical ethics approval processes— are these always appropriate?

Ethics is not just a “step”

- Ethical concerns present at all stages of research, from planning to post-publication
- Ideally, research team is repeatedly re-visiting ethical issues and decisions. Work DOES evolve, additional approval and participant consent may be needed
- Where work involves stakeholders, it is important to discuss ethics with them. Stakeholder, participant and community views on ethics may be **very different**, e.g. what they think “counts” as a risk, whether it is “worth it” to do that research, in light of the risk.

References for this section

- Ransome, Paul (2013). Ethics and values in social research. Basingstoke : Palgrave Macmillan.
- [CH 4 REQUIRED READING] Gray, David E. (2014). Doing research in the real world. Los Angeles, SAGE.
- Goodwin, C. James (2008). Research In Psychology: Methods and Design. 5th edition. John Wiley & Sons, Ltd.

Other resources for this section

On why we should care about ethics:

[Chs 1-2] Israel, Mark (2006). Research ethics for social scientists : between ethical conduct and regulatory compliance. London : Sage

NB: Newer edition available as an e-book

On historical basis of ethical codes, informed consent:

Gaw, Allan (2011). On moral grounds : lessons from the history of research ethics. Glasgow : SA Press

2. Public and private spaces and activities

Warning: lack of consensus ahead

Public spaces

“A public setting is any social context to which members of the public routinely have access. Examples might include a railway station, a city centre, a large department store, a motorway, a public swimming pool, or parts of some educational institutions. Perhaps the most significant ethical problem when conducting research in such settings is the extent to which people are entitled to privacy.” *(Oliver, 2003, p86)*

Or, perhaps we should ask about the extent to which people *reasonably expect* privacy– not quite the same!

But it's not that simple...

“We must take account of conventions used by [people] to establish private territory in places that are in a formal sense public, of the signal uses to discourage direct observation” (*Homan, 1991, p44-45*)

For example, indicating that a space is symbolically filled (e.g. bag on empty bus seat) and that occupying that space would be intruding on that person.

So, we have 'normatively' private spaces inside of public spaces. This makes things complicated!

Trying to define privacy

“I shall define privacy as the condition of being protected from unwanted access by others-- either physical access, personal information, or attention.” (*Bok, 1984, p.10-11, as cited in Homan 1991, p. 42*)

“The control of information about natural living persons, by those persons.” (*Michael, 1984, p.135, as cited in Homan 1991, p. 42*).

- Current concepts of privacy as having strong element of self-control, self-determination, people as own “gate-keepers”
- Privacy not only about information, but about intrusion into spaces, interference from others (e.g. in decision-making).
Informational sense of privacy historically later!

Naturalistic observation in public spaces is generally OK when...

- We are respecting privacy as much as possible (space, interference, information) and with reference to the norms of the place and culture we are in
- Any violations of privacy are fairly small, and are outweighed by possible benefit
- There is no risk of individual persons being identified (i.e. people are anonymous) or harmed by your data collection. This means that notes are generally always safe, but photos and videos become problematic.
- Our observation does not disturb or change the subjects' behaviour
- We ONLY observe, and do not approach or interact with subjects

This is deliberately a more conservative list—different disciplines also have different norms!

Two helpful heuristics

“If the study occurs in a place where anyone could be observed by anyone else, then consent is not needed”
(Koocher & Keith-Spiegel, 1998, as cited in Goodwin, 2008).

“Unless those observed give their consent to being observed, **observational research is only acceptable in situations where those observed would expect to be observed by strangers.** Additionally, particular account should be taken of local cultural values and of the possibility of intruding upon the privacy of individuals who, even while in a nominally public space, **may believe they are unobserved.**” *(British Psychological Society Guidance, as quoted in Gray 2014, p 77)*

Activity 2: Is that a public space and activity?

Discuss the following in a small group (3-4 people):

Given this information on how we might distinguish public/private places and activities, look at the **list handout** and decide how to classify each example. Do you think it is a public place and activity?

(NB: List of examples on next slide, given as paper handout in class.)

1. Counting the number of pedestrians who walked through a particular street
2. Filming the pedestrians who walked through a particular street
3. Observing shopper behaviour inside of a large grocery store
4. Observing the interactions and conversations of people on Princes Street who are begging for money, collecting for charity, or handing out leaflets
5. Outside Waverley station, you overhear a businesswoman on her mobile phone, explaining to someone why she is getting a taxi instead of walking.
6. Remarks made by different people at a “town hall” type meeting on city-centre issues, to which local government, residents, and businesses have been invited
7. Remarks made at a meeting of the Edinburgh University cycling club
8. Making notes on what people say to each other while waiting at a busy city centre bus stop

References for this section

- Oliver, Paul (2003). *The Student's Guide to Research Ethics*. Open University Press, Maidenhead, Berkshire, UK.
- Goodwin, C. James (2008). *Research In Psychology: Methods and Design*. 5th edition. John Wiley & Sons, Ltd.
- [CH 4 REQUIRED READING] Gray, David E. (2014). *Doing research in the real world*. Los Angeles, SAGE.
- Homan, Roger (1991). *The ethics of social research*. London : Longman. *NB: This is an older resource, but highly recommended especially for its discussion of public spaces and norms*

Other resources for this section

Privacy and norms, especially as related to technology

Tavani, Herman T. (2011). Ethics and technology : controversies, questions, and strategies for ethical computing. Hoboken, N.J. : Wiley.

NB: In many respects this book is sadly outdated, as it is a 2011 update of an older book. However, the privacy content (Ch 5) is a very useful addition to what is in the social science ethics books.

3. Informed Consent

Will you participate?

- In almost all other research that involves people, where we are not observing public activities in public places, **we will need to invite people to participate**
- This means informing them about our planned research, and gain their explicit agreement to participation.
- There are a few exceptions do NOT need explicit, fully informed consent. For us, the important one is: **Anonymous questionnaires/surveys** (no personal information collected at all)

INFORMED

Need to explain to people (usually in written information sheet) about...

- What our research is about, or tries to do, and why
- What participants actually asked to do, time commitment (e.g. 2-hour focus group)
- Information about benefits, *lack of benefit*, risks of harm (including psychological)
- All information is truthful, simple, direct, suitable for a non-specialist. ***Do not underestimate the difficulty of doing this!***

...and also inform them about

- Confidentiality and anonymity of their personal data, any exceptions to confidentiality
- How, where data will be stored securely, who can see it, how long it is kept
- What you plan to do with the information you collect
 - Analysis for student project, thesis
 - Academic publications
 - Use in teaching
 - Open data? Archive? Create app?
- Contact people for questions, complaints

... PLUS CONSENT

- Person indicating that they understand and are voluntarily agreeing to participate in the research
- May consent to multiple separate things: May agree to focus group, but not to be videoed— *think about “levels” of useful participation.*
- Person agrees s/he has opportunity for questions, these have been answered
- Person can withdraw at any time for any reason with *no consequences*, have personal data destroyed

Consent is also about data, results

- **Consent to a particular research activity is effectively consent to collect personal (and other) data and manage, use it in particular ways *that you have already specified in participant information***
- For substantially different uses, you WILL need to seek additional consent! [PhD example]
- In participatory research, action research, stakeholders may have additional input *after* study about what information disseminated, how they and communities are represented

Consent is a dialogue, negotiation

- It can take time to genuinely inform someone, answer questions, discuss their concerns, especially where there are complex, unfamiliar concepts like “open data”, where risks are unclear.
- Where **stakeholders** are more deeply involved in setting the research agenda, consent discussions may more substantially change what participants agree to do— *this is good!*
- **Taking time for consent discussions where you listen to participants is important to good research relationships, project success.**

Quick review

- Where we are not observing public behaviour OR doing anonymous questionnaire, we need to seek **informed consent** from participants
- This means using an **information sheet** as starting point to inform participants about the work, information collected, how we will use it
- People can ask questions and freely say yes or no to all (or part) of participation, recorded on a **consent form**

Informed Consent= Saying yes or no, without coercion, to something I can understand

Activity 3: Fast Hack revisited

Please join your Fast Hack group!

1. Quickly review how you collected data from/about people and activities
2. Are there instances where you think you *should have* sought informed consent? Consent for what, exactly?
3. Were there instances where no consent was needed? Why is that?

Be prepared to quickly present back to the class on at least one of your Fast Hack examples.

Don't forget to briefly remind us what you did re: participant information (e.g. "we asked people where they were going, as they waited at a bus stop.")

Consent is not a system to game.

- Consent forms and processes can seem scary, or obstructive—it would be easier if we didn't have to do this! Or if we didn't tell them that bit!
- If you want information that you think participants won't want to give, or they DO refuse to give, DO NOT try to pressure, persuade or trick them.
- YOU, as researcher, have likely misjudged what participants see as reasonable, or valuable. You think it's a small risk, they think it's big. You want too much time, they disagree with your goals...whatever!
- **You need them and what they know. They don't need you. Respect them and tell them the truth.**

Resources for this section

- Howitt, Dennis, & Cramer, Duncan (2011). Introduction to research methods in psychology. Harlow : Prentice Hall
- [CH 4 REQUIRED READING] Gray, David E. (2014). Doing research in the real world. Los Angeles, SAGE.
- Goodwin, C. James (2008). Research In Psychology: Methods and Design. 5th edition. John Wiley & Sons, Ltd.
- **On history of informed consent:** Gaw, Allan (2011). On moral grounds : lessons from the history of research ethics. Glasgow : SA Press

4. Data management and data protection

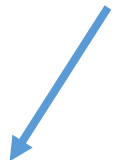
Does not include ANONYMISING DATA. Groups will be supported to do this later as needed, depending on the type of data they have and how they plan to use it.

Data management

- About **having a plan** for what data you will collect, who will have access, how and where it will be stored, and making provision to document data, preservation over time, making publicly available (if this is part of your project...)
- “Data management refers to all aspects of creating, housing, delivering, maintaining, and archiving and preserving data. It is one of the essential areas of responsible conduct of research.” (*MANTRA data management unit*)


This means tasks like...

So important for teams!
Save your sanity!



- Choice of standardised naming conventions and file formats to be used across project
- Identifying software and tools you will need to collect, store, analyse, visualise data
- Copyright and intellectual property issues
- Who is responsible for data management and maintenance during and after project
- Plan for backing up data!!!
- Documentation re: how data collected, when, what it is

If you looked at this in a year for thesis, would you know what was in this spreadsheet?



Data protection—legal responsibility

Overlaps with data management, but is not the same thing!

From MANTRA unit on data protection:

“Data protection refers to the rights of the individuals whose data are being collected, held, and processed. Individuals have the right to have inaccuracies corrected and to know what data are being held and how they are being used.

The 1998 Data Protection Act (DPA) regulates how personal data may be held and processed...This is a UK Act passed to comply with the European Data Protection Directive.”

Personal information (Personal data)

- “**Personal data** simply refers to records or other information that on its own or linked with other data, can **reveal the identity of an actual living person**. So, for example, you may use numbers rather than names as identifiers in a survey, but if you hold another record linking those numbers to the actual names, then each record is considered to contain personal information.” *(UoE MANTRA course unit on data management)*
- Some items are considered **sensitive personal information** *when combined with “regular” personal information, i.e.*
 - racial origin
 - political beliefs, trade union membership
 - health conditions (and similar)
 - *You are very unlikely to need this information for your projects!*

Activity 4: Personal information

In a small group of your choice

1. Try to define ***personal information*** in your own words—in a simple way that you can remember it.
2. Try to generate two examples each of something that IS, and something that IS NOT personal information.

Be prepared to share your examples with the class (#2)

Data Protection Act (1998)

Under the act, “personal data must be

- *Obtained fairly and lawfully (i.e. with permission from the ‘data subject’)*
- *adequate, relevant, and not excessive in respect of the purpose for which it has been gathered*
- *stored securely*
- *accurate and kept up to date*
- *kept only for as long as is necessary for the stated purpose**
- *not transferred from one country to another without permission from the ‘data subject’”*

References for this section

- Ransome, Paul (2013). Ethics and values in social research. Basingstoke : Palgrave Macmillan.
- Rice, Robin & Ekmekcioglu, Cuna (2011? unclear). «Data protection, rights and access”. In University of Edinburgh MANTRA research data management online course.
<http://datalib.edina.ac.uk/mantra/protectionrightsandaccess/>
- Ekmekcioglu, Cuna (2011? unclear). “Data management plans”. In University of Edinburgh MANTRA research data management online course.
<http://datalib.edina.ac.uk/mantra/datamanagementplans/>
- University of Edinburgh Records Management (2015). “What is data protection?”. <http://www.ed.ac.uk/records-management/data-protection/what-is-it>

5. ECA ethics forms

Ethics for projects

- **All groups will need to complete the ECA (CHSS) ethics checklist** and have it approved before collecting data and working with participants.
- It looks like there are many questions-- there are, but some likely will not apply to your project.
- **Your group will be required to do quite a bit of up-front planning** of what information you will collect from which people, what you will do with it later, and how you will store it.

Activity 5: What does this form ask?

With at least one other person,

Read through the blank ECA ethics forms. Can you interpret all of the questions?

Do you understand what you are being asked to do or record? Flag up any questions or terms you cannot interpret!

NB: We did not have time to do this activity in class.

**References are at the
end of each section**