

Ethics - When, Why, How?

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Overview

- Why Ethics matters
- What to do when you do not collect new data from human participants
- What to do when you collect new data from human participants
- Additional points



**WHAT DO YOU GET
WHEN YOU CROSS A
COW WITH AN
OCTOPUS?**

**A VISIT FROM THE
ETHICS COMMITTEE
AND IMMEDIATE
WITHDRAWAL OF
YOUR FUNDING**

My Background

- Worked with medical data and patients
- Worked with doctors and psychologists
- Worked on mental health
- Led / substantially contributed to several NHS Ethics proposals; several proposals to the University of Edinburgh Psychology Research Ethics Committee
- Past member of the Ethics Panel, Convenor 2017/2018

Why Ethics Matters: Thou Shalt Not Harm

- Tuskegee Syphilis study:
 - aim: to investigate the natural disease course of syphilis
 - method: African American farm workers who had syphilis were not informed of their diagnosis, and not asked whether they wanted to take part in research. Instead, they were told that they had „bad blood“. When effective medication became available, this medication was withheld.

Thou Shalt Not Cause Distress

- Asking about traumatic events can cause profound distress
- Need to be clear with participants about what to expect

Other Examples

- Identifying people whose data were supposedly anonymous or confidential:
- „Don't Quote Me: Reverse Identification of Research Participants in Social Media Studies“

https://www.nature.com/articles/s41746-018-0036-2?fbclid=IwAR1G07O_6rQjhcWQ-AQ2ZVWSAoyFf5pCKhuc59BbTn6fhkJEJ64Lpvck5bQ

- Deanonymising South Korean Resident Registration Numbers in Prescription Data

<https://techscience.org/a/2015092901/?fbclid=IwAR2XylIwtNbZw23-8CEd6209cOPxhbiQBIYnNfBnGEOUH8GvOS3SI60tJFM>

Safeguarding Personal Data

People who provide the data have the authority to decide what is personal.

Just because it's public doesn't mean you can use it as you like.

Jolyon Maugham QC acted for one of the parties that were instrumental to Prime Minister Boris Johnson's defeat at the UK Supreme Court in 2019

 **Jo Maugham QC** ✓ @JolyonMaugham

From 6.30am til 10am on weekdays you can call @talkRADIO on 0344 499 1000 or 020 7782 6000, and ask @JuliaHB1 or her employer, politely, why she thinks it is appropriate to direct those issuing death threats to me to my family home.
twitter.com/JolyonMaugham/...

Jo Maugham QC ✓ @JolyonMaugham

In 2013, when I was not a public figure, I gave an interview to a local newspaper about my plans to restore a local heritage asset.
@JuliaHB1 has now issued an open invitation to those sending me death threats to come and find me and my three young children at that isolated spot.

 **Julia Hartley-Brewer** ✓ @JuliaH... · 1h

I for one think it is absolutely disgusting for Jolyon Maugham QC to have revealed in a newspaper where Jolyon Maugham QC lives. This is appalling behaviour. I stand with Jolyon.



Barrister plans to restore historic Sussex windmill
theargus.co.uk

4,670 6:06 AM - Sep 23, 2019

2,617 people are talking about this

If you don't collect it, they can't hack it!

- More stories here:
- https://pinboard.in/u:dsalo/t:horrorstories?fbclid=IwAR3BcvRBqjDqhf83zGy_R3eJ_cWWdwqulF-nN_TQQ1MioqEZBUtaMRGh0WM

But we are being nice!

Employers who pay the apps' developer, Ovia Health, can offer their workers a special version of the apps that relays their health data — in a “de-identified,” aggregated form — to an internal employer website accessible by human resources personnel.

“The real benefit of self-tracking is always to the company,” Levy said. “People are being asked to do this at a time when they’re incredibly vulnerable and may not have any sense where that data is being passed.”

<https://www.washingtonpost.com/technology/2019/04/10/tracking-your-pregnancy-an-app-may-be-more-public-than-you-think/>

This is your responsibility.

“It is just a student project.” -> That’s why you need to practice responsible data handling.

“Nobody will see the project anyway.” -> MSc dissertations are public unless made private.

“The information is on Twitter.” -> Sometimes, you need to protect people from themselves.

“Other researchers are doing it, too” -> Sometimes, the research community has bad habits.

**No excuse. It is your responsibility
to act as ethically as you can and think through the consequences.**

Do I need Ethics?

- Do you need to work with human participants or animals for your research?
YES
- Does your research involve confidential or personal data? YES
This includes analysis of social media data - people may reveal personal information. **We are more strict than other institutions.**
- Does your research involve developing countries (this list includes India and China)?
YES
- Does your research involve military applications?
YES
- Is your research about terrorist or extremist groups?
YES

The Informatics Ethics Form

- Legal and moral responsibilities
- Rights of human participants
- Potential harm, discomfort, or stress for people or animals
- Institutional permissions
- Dissemination
- Data Protection Impact Assessment

Legal and Moral Responsibilities

- Any conflicts of interest?
- Do you comply with GDPR? (don't know what it is? Take the training!)
- What relevant codes of conduct are there? (particularly important for medicine / psychology)
- Has the research been reviewed in other countries, if it takes place outside the UK?

Participant Rights

- Do you handle confidentiality adequately? Speak to your supervisor and complete a data management plan / data management training!
- Can the participants understand their rights and provide informed consent?
- Are participants aged 18 or older?
- Will you tell participants that you adhere to GDPR? (there is template text for you to use)

Institutional Permissions

- If you get data from other sources, do you have permissions to access it?
- Does your intended use comply with the terms of use?
- Will you handle the data according to your agreement with the institution?

Relevant for all who work with speech corpora / language data sets / medical data / images

Dissemination

- Who will benefit from the research?
- Will you make findings available to participants?
- How will you make sure that your findings are fed back to participants outside of the UK?

Additional Documents

What Should a Participant Information Sheet Cover?

- Who is conducting the study?
That's you!
- Who is responsible?
That is your supervisor!
- Who can people ask if they have questions?
That's the Ethics panel of the School that has approved the study, or an external expert
- Can people stop and withdraw from the study at any time?
The only correct answer is YES

Participant Information continued

- Why are you doing this study?

For your MSc project. If your supervisor will also use the data for their research, you must say so, and you must explain what that research is

- What will the study involve?

Describe what they will be asked to do, and how long the study will take

- What are the risks and benefits?

„furthering science“ is not a benefit

- What will happen to their data?

How will it be analysed? Where will it be presented? How will it be stored? Who will have access?

It is fine to ...

- ... be general about the topic of your research or your supervisor's research. Although if there is a funded study, do include a link to the project web site!
- ... be brief in your description of the study.

The Consent Form

- I confirm that I have read and understood the Participant Information Sheet
- I have been given the opportunity to ask questions
- I understand that I take part voluntarily, and that I can withdraw from the study at any time, without giving a reason
- I understand that my anonymised data will be stored for a minimum of 5 years
- I agree that my data can be used in further research which has Ethical Approval
- I agree that my fully anonymised data can be used in research publications and presentations
- I agree to take part in this study

When To Apply for Ethics

- If you do not work with human participants, but with data or tissues that relate to people or have been generated by people:
 - What possible harm could be done? Could people be damaged by the results of your research?
- If you work with human participants:
 - If somebody from another School with an Ethics Committee is involved:
 - ask your supervisor to get Ethics Approval from the other School
 - If nobody from another School is involved:
 - ask your supervisor to complete the Informatics self-certification form with you when you start your project in June

How to Apply for Ethics

- Ask for advice beforehand, if you're not sure!
- Prepare a Participant Information Sheet, Consent Form, and Data Management Plan
- Let your supervisor (!) read it, and have them complete the Ethics questionnaire with you
- Allow around a working week for someone from the Ethics Panel to pick up your application and come back to you to confirm that you've correctly self-certified

Additional Points

Working in Teams

- If you are working with industry partners or academics outside Informatics, do you have an agreement about their/your role?
- Will you ensure that everybody involved adheres to the University of Edinburgh's Research Integrity standards?
- Have you agreed rules for authorship, intellectual property, and publications?

How to Recruit Participants

- Always state who has granted Ethical Approval. If you had to self-certify, quote the number from the knowledge management RT thread
- Give people a copy of the participant information sheet when you recruit / when you send recruitment emails
- You will also need that number to book labs and equipment managed by Robin Hill.

Data Management

- You are all obliged to treat any data carefully and confidentially
 - Only collect and process the data you need
 - Is it possible for people to be identified? What would be the harm?
- Always read the terms and conditions under which the data are provided to you, and adhere to them
- Make sure you take the LEARN data management courses

Any Questions?

- <http://web.inf.ed.ac.uk/infweb/research/ethics-and-integrity>
- To contact the Ethics Panel: inf-ethics@inf.ed.ac.uk
- My email: maria.wolters@ed.ac.uk
- With many thanks to the members of the Research Companion Facebook group for additional links and sources, and to Victoria Lindström for her hard work on the new forms