Ethics - When, Why, How?

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Overview

- Why Ethics matters
- Why Research Data Management 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
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
• Currently 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 share croppers 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.

• Asking about traumatic events can cause profound distress
Other Examples

- Identifying people whose data were supposedly anonymous or confidential:
  - „Don’t Quote Me: Referse Identification of Research Participants in Social Media Studies“
    https://www.nature.com/articles/s41746-018-0036-2?
    fbclid=IwAR1G07O_6rQjhcWQ-AQ2ZVVSAoyFf5pCKhuc59BbTn6fhkJEJEj64Lpvck5bQ

- Deanonymising South Korean Resident Registration Numbers in Prescription Data
  https://techscience.org/a/2015092901/?
  fbclid=IwAR2XyliwtNbZw23-8CEd6209cOPxhbiQBIYnNfBnGEOUH8GvOS3Sl60tJFM

- CRISPR babies
If you don’t collect it, they can’t hack it!

- More stories here:
  - https://pinboard.in/u:dsalo/t:horrorstories?fbclid=IwAR3BcvRBqjDqhf83zGy_R3eJ_cWWdwquIF-nN_TQQ1MioqEZBUtaMRGh0WM
Research Data Management

• You are all obliged to treat any data carefully and confidentially

• 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
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

- 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
Level 1 versus Level 2?

• This is not really relevant at the moment, because the Ethics process at the School of Informatics, University of Edinburgh, needs urgent revision
Old Forms or New Forms?

• You should all self-certify using the new forms, which will be available by Summer 2019

• I have not added a link to the current Informatics Ethics forms, as these will be superseded.
The New Informatics Ethics Form (Summer 2019)

- Legal and moral responsibilities
- Rights of human participants
- Potential harm, discomfort, or stress for people or animals
- Institutional permissions
- Working in teams
- 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 at a 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!
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?
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?
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 New Consent Form
(Current Draft)

- 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
How to Apply for Ethics
(from Summer 2019)

• Ask for advice beforehand, if you’re not sure!

• Prepare a Participant Information Sheet and Consent Form, if you will be gathering new data, or tell us how you’ll tell participants about your study and obtain consent online.

• 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. Around 25% of you will make one or more mistakes.
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.
Any Questions?

• 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