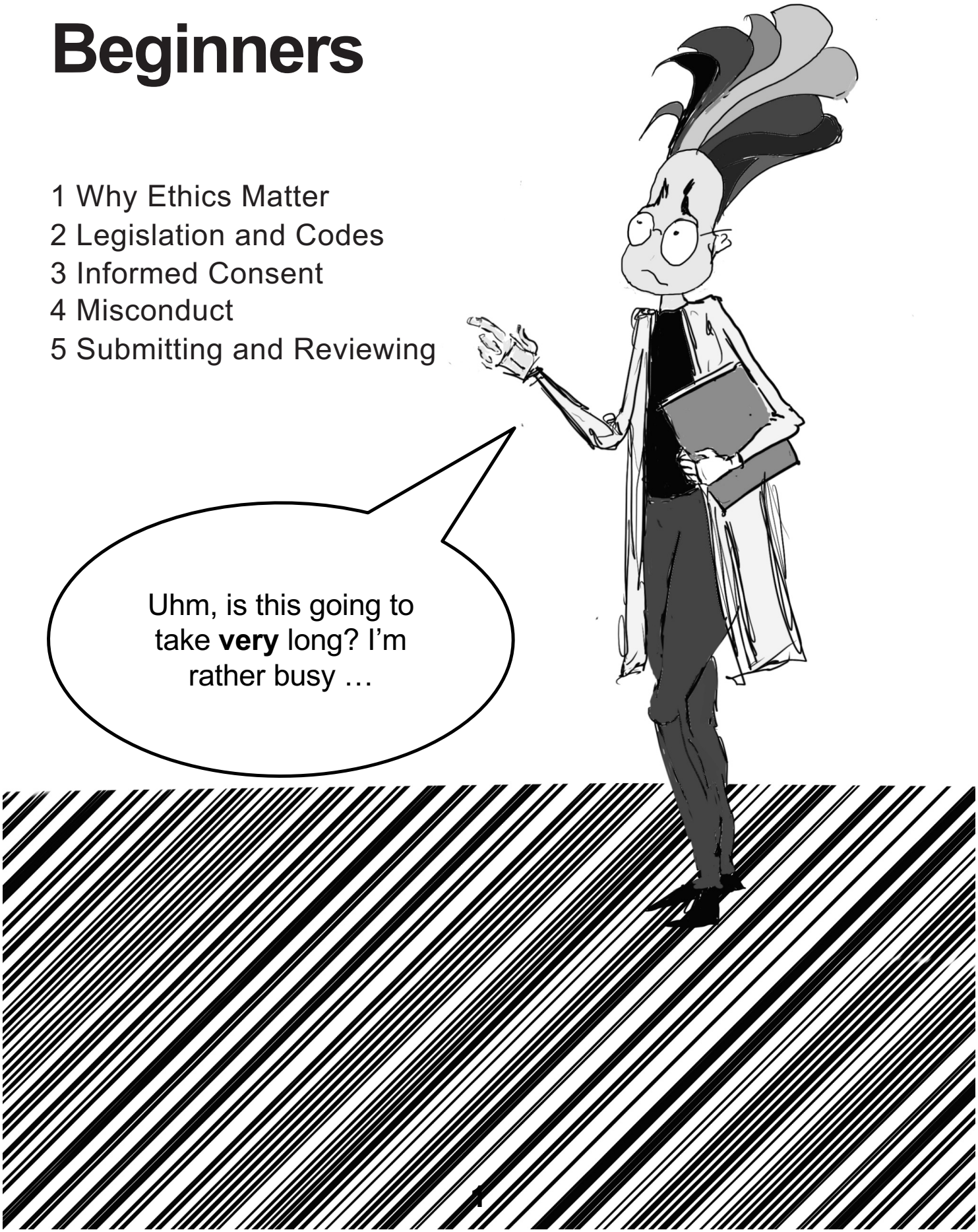
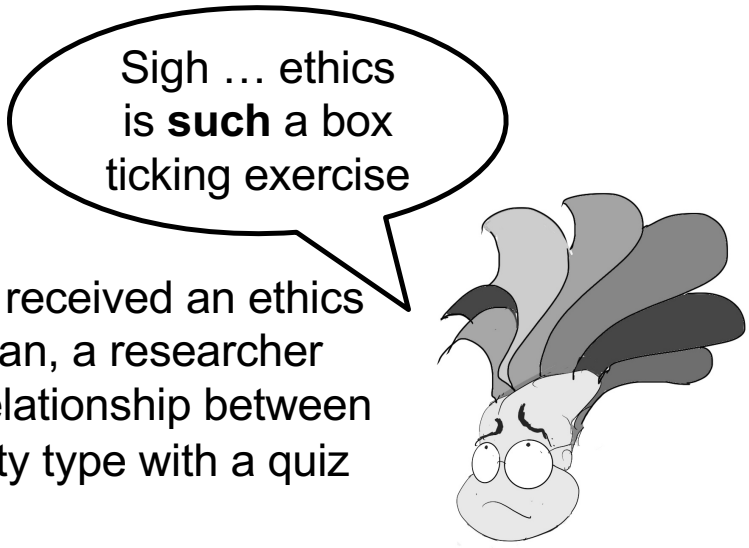
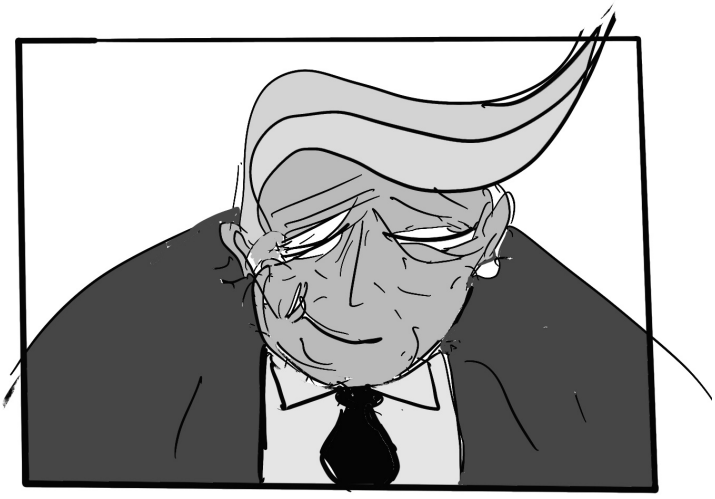
Research Ethics for Beginners



Why Ethics Matter



- In 2015 Cambridge University received an ethics application from Alexandr Kogan, a researcher proposing to investigate the relationship between Facebook likes and personality type with a quiz app he had made.
- The app allowed Kogan to take data not only from those who took the quiz but also all of their friends. It spread throughout the network and gave him access to 50 million profiles.
- The Ethics Committee rejected his application arguing that even though Facebook was already doing this kind of thing that did not mean it was OK for an ethical researcher to do the same
- This did not stop Kogan from selling his database to Cambridge Analytica. This firm used the dataset for “psychogeographic” profiling to target messages at particular Facebook users.
- In 2016, Cambridge Analytica ran both the digital campaign for “Vote Yes” during the UK’s EU referendum and Donald Trump’s Facebook campaign for the US presidential election



The **Stanford prison experiment** (1971) randomly assigned participants to the role of either prisoner or guard. The experiment had to be abandoned after six days because the students playing guards were inflicting such brutal psychological torture.

•**The Tuskegee Syphilis Experiment** was conducted **in**1932 by the US Public Health Service. They recruited 399 impoverished African-American males who had syphilis, in 1940 a cure was found (penicillin) but the researchers withheld treatment in order to continue studying the effects of the disease.

•During the second world war **Nazi doctors** conducted various ”experiments” on concentration camp prisoners to find out, for example, how long it takes a person to freeze to death in snow. Their defence at the Nuremberg trials argued that there was no international law dealing with medical experimentation and cited American Malaria experiments to claim that Nazi physicians followed common research practices.

Legislation and Codes

All research activity conducted by staff and students of UK universities must be subject to ethical review.
Research is defined as any “original investigation undertaken in order to gain knowledge and understanding” (UK Research Integrity Office 2009).This is because university research is regulated by international agreements and guidelines as well as specific legislation.

The Nuremberg Code 1947: states that research involving humans must include: informed consent, benefits to society, avoidance of harm and the right to withdraw.

The Declaration of Helsinki 1964 by the World Medical Association**:** affirms these principles: respect for the individual, the right to informed decisions,, special consideration for vulnerable people need, the welfare of participants must take precedent over research

The Singapore Statement on Research Integrity 2010: specifies these maxims: honesty and accountability in research, courtesy and fairness to others, good stewardship of research

•**The Human Tissue Act** (2004) regulates the storage and use of human tissue, which is defined as material that comes from a body or includes cells. It is unlawful to carry out human tissue research without a licence form the Human Tissue Authority

•**The Mental Capacity Act** (2005) applies to those who lack capacity to make a particular decision or take action for themselves. This may be permanent or temporary. It could be state-related (e.g. due to drug or alcohol use). If you are working with such participants, ethics approval must come from an "appropriate body" such as NHS ethics

•**General Data Protection Regulation** (2018): To comply with GDPR researchers must tell participants what they are doing and why, explaining what information will be gathered, whether and how it will be anonymised and how data will be stored and used after the project. Only make audio, video and photographic recordings of research participants with their explicit consent and store confidential data on secure, password protected platforms..

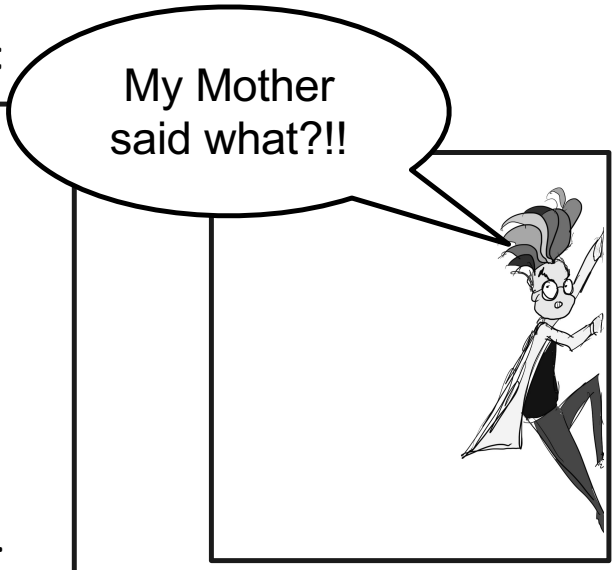
Informed Consent

Consent should be:

- **Voluntary**: without coercion or inducement
- **Informed**: given only after the study is explained
- **Indicated**: e.g. signing a form, ticking a box, clicking a link or making a recorded oral statement.

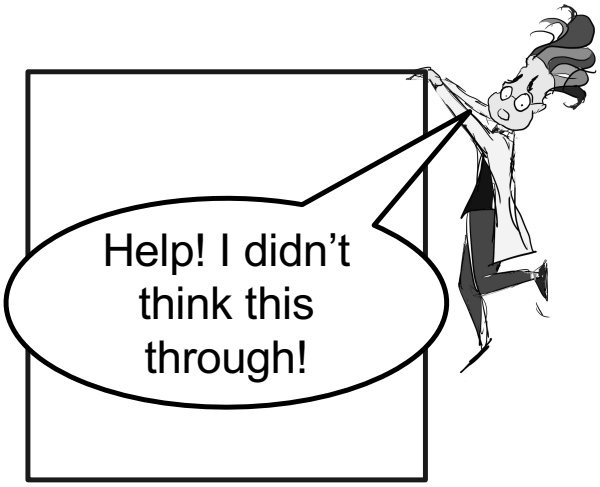
”opt In and “loco parentis” consent

- “Opt in” consent: adult participants are informed about the aims of the research and they agree to take part.
- “Loco Parentis” consent: f the individual is under 16 then consent may also be obtained from a parent, doctor or teacher.



The Right To Withdraw

- Your participants have the right to withdraw at any time.
- They may also withdraw their consent after the study within a reasonable timeframe.

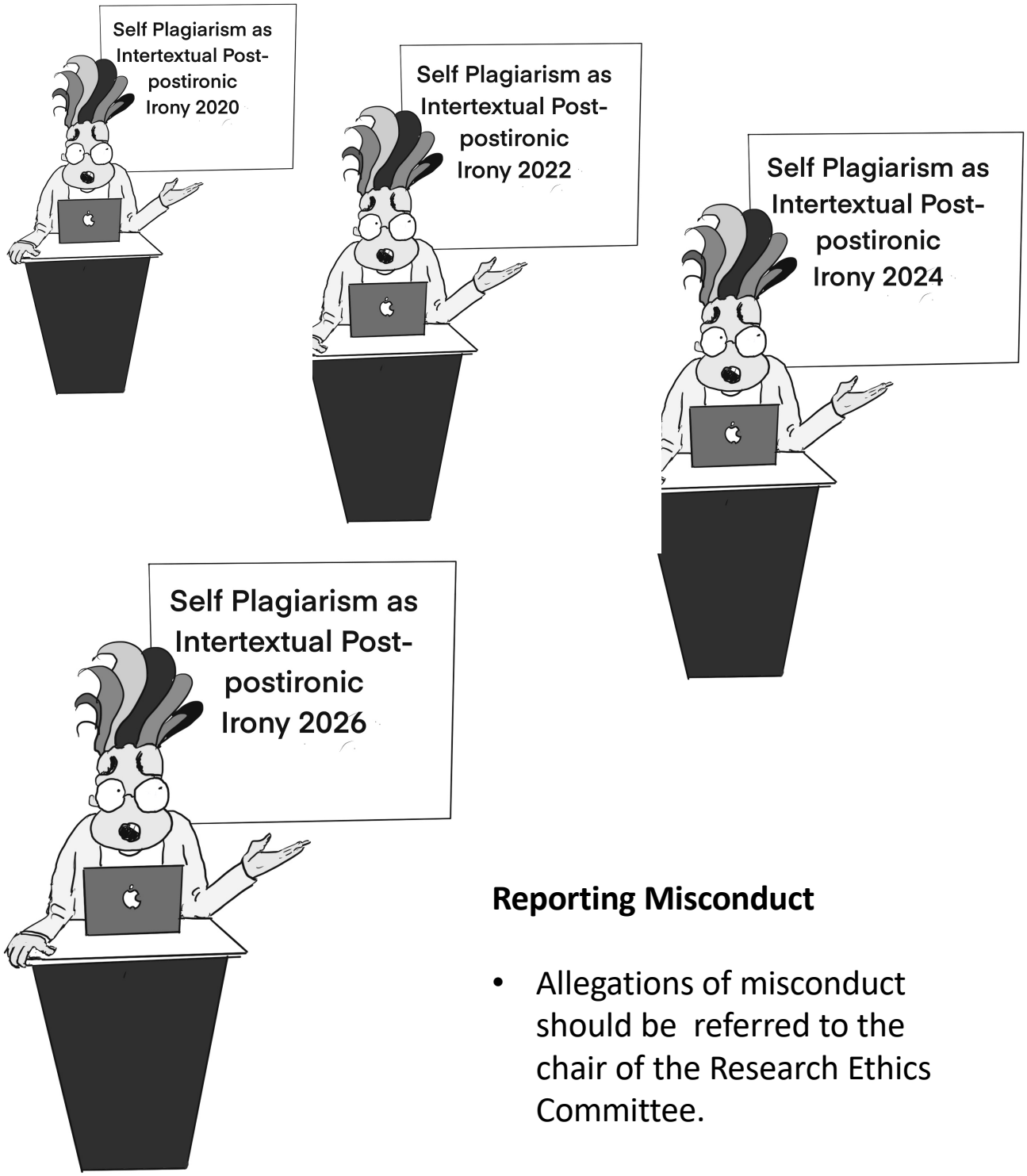


Information sheets and consent forms must be written in "plain English": use everyday words, write short and simple sentences and avoid jargon. State:

- the aims of the research and the criteria for taking part
- any payments or incentives
- any invasive techniques (e.g. blood samples)
- any possible emotional harm and the measures taken to prevent it
- how confidentiality will be maintained
- how data will be stored
- That participants can refuse to answer any questions
- that they can withdraw at any time

Misconduct

- **Plagiarism** - copying or taking credit for someone else's work
- **Falsifying Data** – distorting or inventing data
- **Breach of Duty of Care** – failing to protect participants or researchers



Reporting Misconduct

- Allegations of misconduct should be referred to the chair of the Research Ethics Committee.

Definition of Authorship

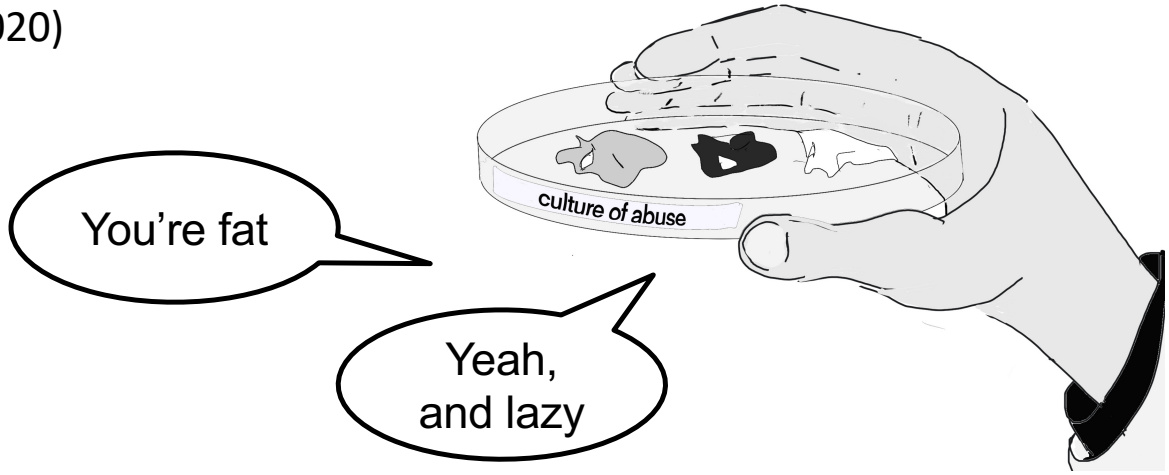
The “publish or perish ” culture has encouraged bad practice around authorship. Northumbria University subscribes to the Singapore (2010) Statement on Research integrity which states:

“Lists of authors should include all those *and only those* who meet applicable authorship criteria.” (Singapore Statement 2010)

- The ICMJE recommends four criteria for authorship:
    - 1) substantial contributions to the conception of the work or acquisition, analysis and interpretation of data **AND**
    - 2) drafting the work or revising it critically **AND**
    - 3) final approval of the published version **AND**
    - 4) agreement to be accountable for all aspects of the work. (International Committee of Medical Journal Editors 2020)

Authorship Abuse

- **Ghost Authorship:** failing to acknowledge someone who has made a “substantive contribution” as defined above.
- **Gift Authorship**: crediting someone who has not made a “substantive contribution”. Discussing a paper or making editorial suggestions does not make you an author. Acknowledgements should be used to recognize this kind of contributions Gift authorship is increasingly recognized as ”dishonest and fraudulent” (Committee on Publication Ethcis 2020)
- **Brokered Authorship**: quid pro quo authorship – I’ll make you an author on my group’s papers if you make me an author on yours. (Engle 2020)



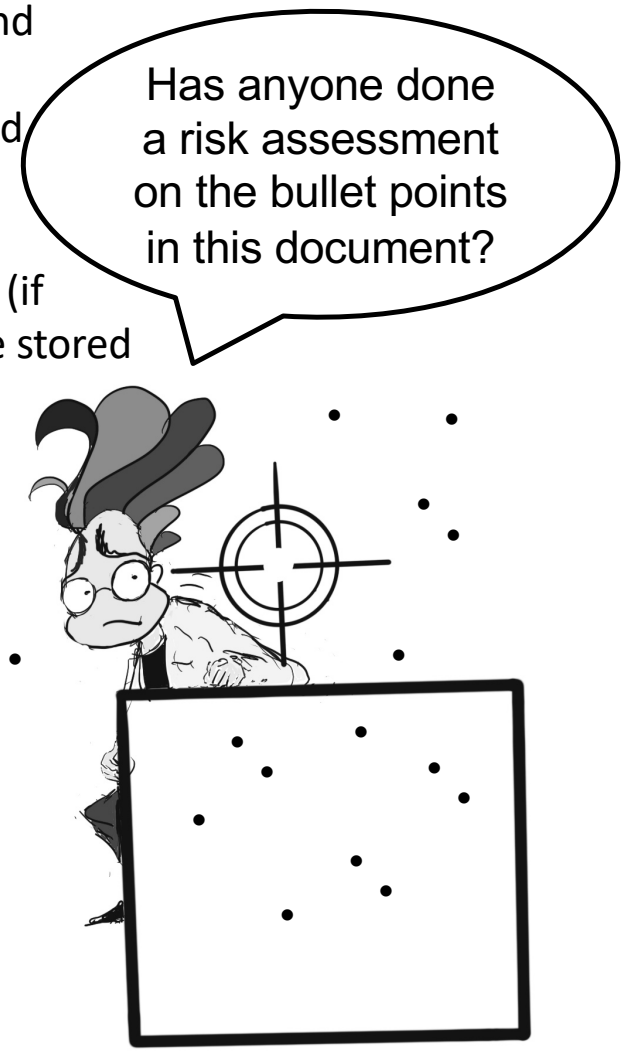
Submitting and Reviewing

Getting Ethical Approval

- To gain ethics approval you have to submit an application through the university website under “Ethics and Governance”.
- Your submission must describe the project and include: an **information sheet**, **consent form,** and **data management plan**
- It will be assigned one or two reviewers depending on risk level and they will either accept, reject or ask for changes.

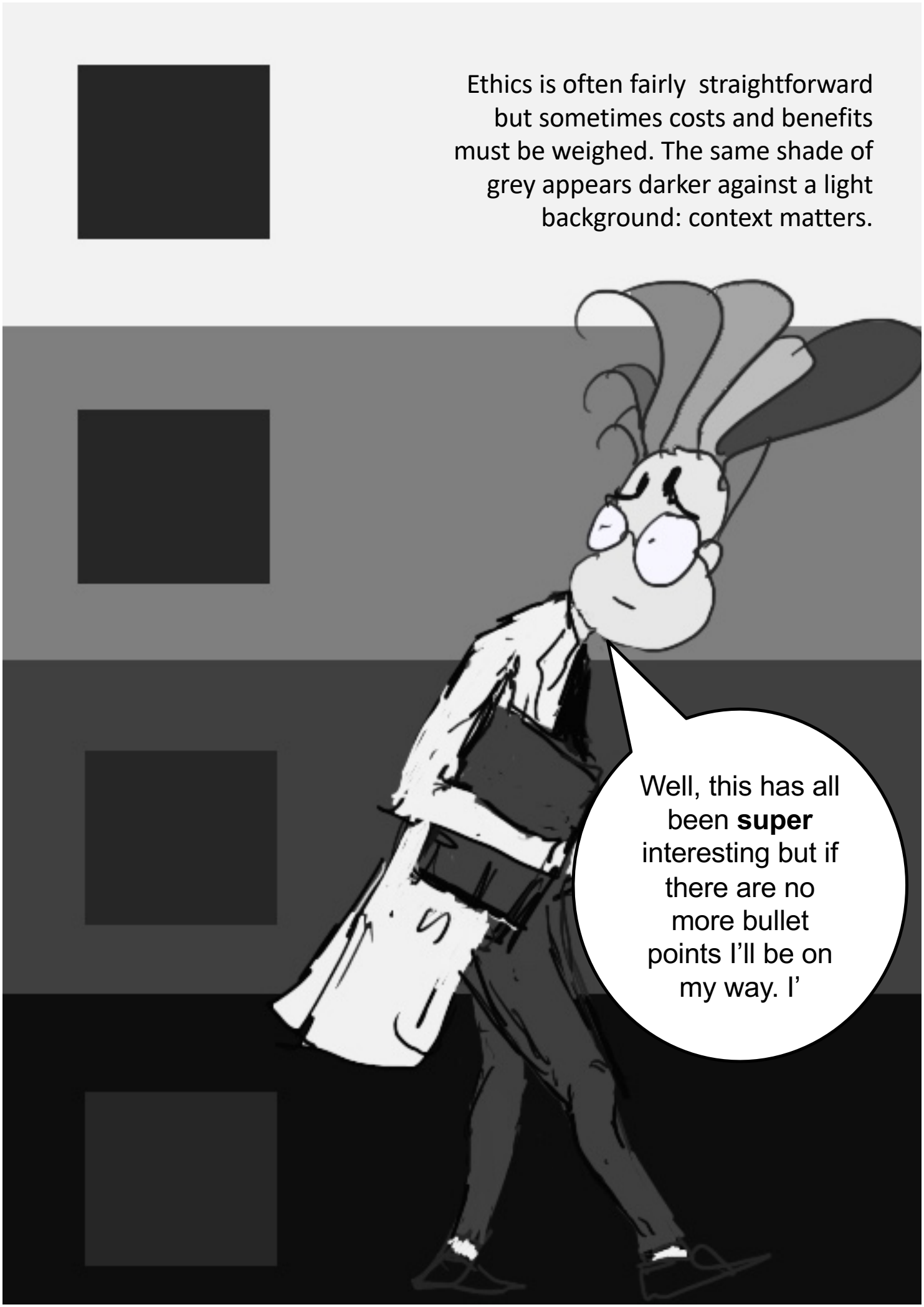
Data Management Plans

- RCUK and other funders now mandate a data management plan. The rationale is that publicly funded research should be available and understandable to others.
- Plans should cover: types of data stored intellectual property, ethics, storage,\ encryption and sharing.
- Data should be anonymous and coded (if identifiers are collected they should be stored separately)



Risk Assessments

- Anything you are planning that involves risk for participants or researchers must be risk assessed.
- Risk Assessment is also online but separate to the ethics application


Ethics is often fairly straightforward but sometimes costs and benefits must be weighed. The same shade of grey appears darker against a light background: context matters.
Well, this has all been **super** interesting but if there are no more bullet points I'll be on my way. I'