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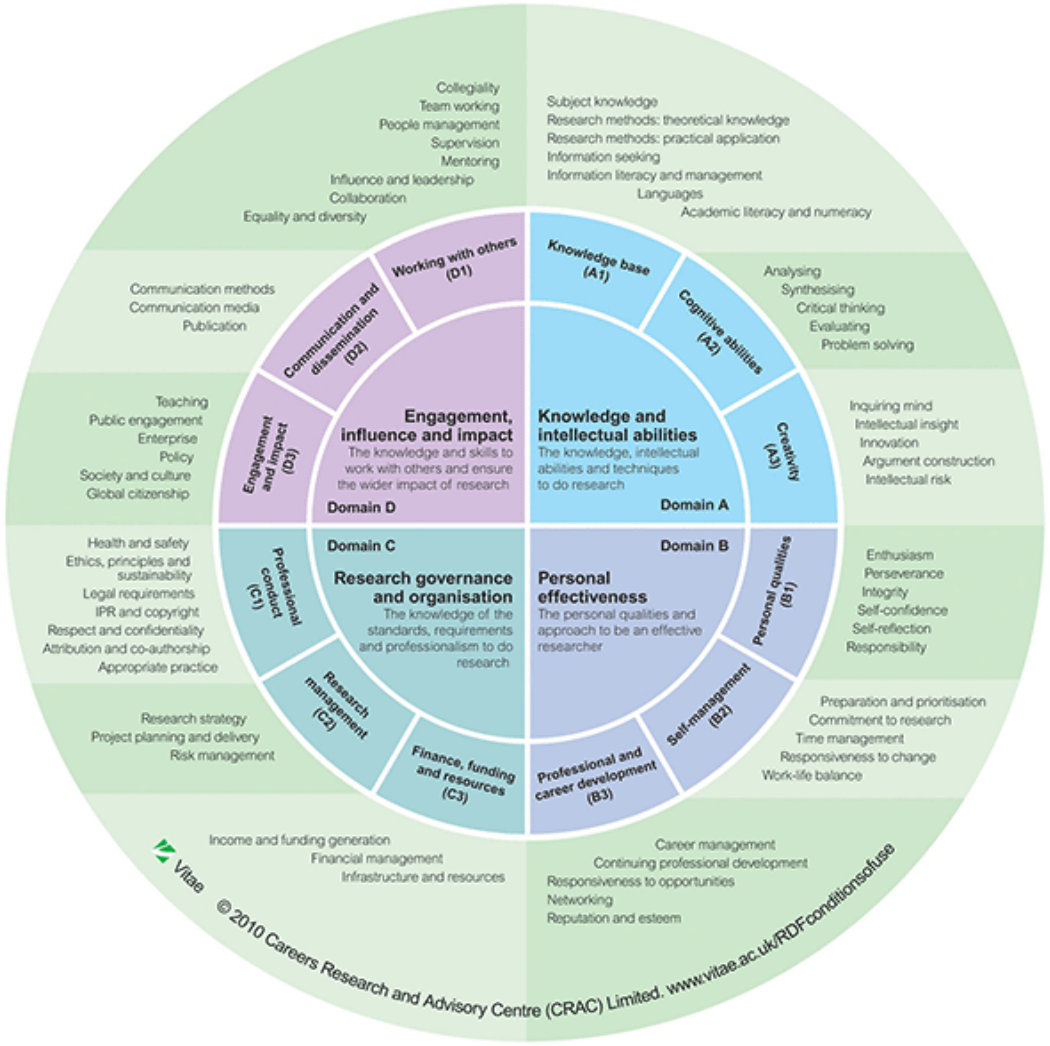
Practical Research Ethics

Lecturer: Gaye Stephens Gaye.stephens@tcd.ie

CS7CS6 – Researcher Skills and Characteristics



An example Research Development Framework

A. Knowledge and Intellectual abilities

B. Personal Effectiveness

C. Research Governance and Organisation

D. Engagement, Influence and Impact

https://www.adelaide.edu.au/carst/about/research-development-framework/
https://www.vitae.ac.uk/researchers-professional-development

Business Innovation and MSc Research

- **Business Innovation**
  - Business Innovation technical product
    Business Model Canvas and supporting material e.g. personas, economic models, market description.
    Ethical implications of the technology were considered using the ethics canvas.

  - Process of gathering evidence to validate or disprove your hypothesis about customer segments, market size and type etc.
    This collection process may have involved surveying or interviewing people.
    The ethical implications of this collection process could be considered too.

MSc Research

In your MSc research project, you will most likely have a technical artefact and may have to collect information from people e.g. to collect requirements or to validate the artefact.

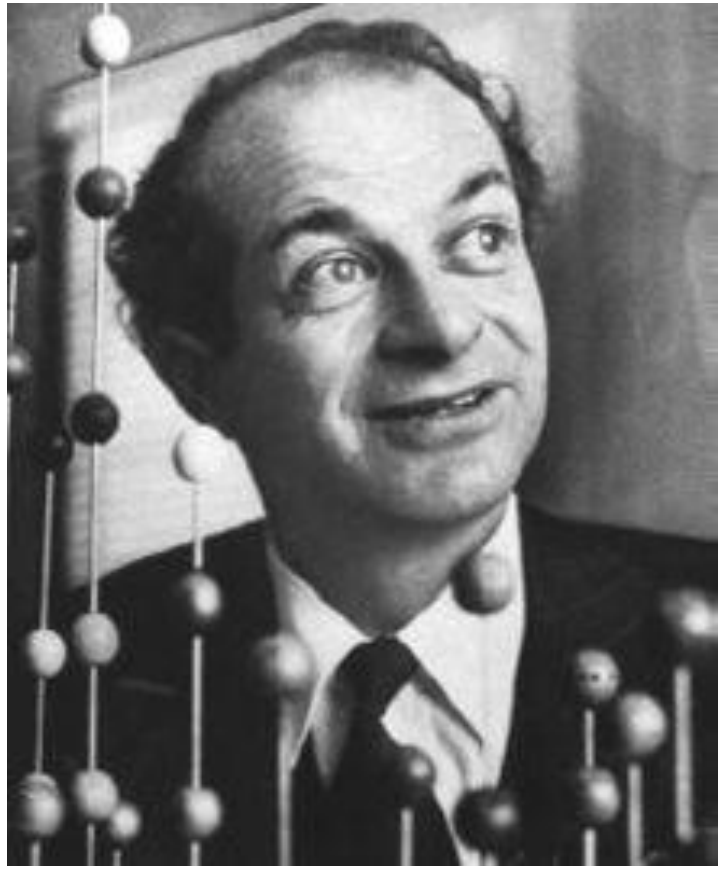
For research involving collection of data from people, ethical approval must be granted before data collection begins.

CS7CS6 – Common Phases of Research Process

Phase	Goal
Idea-Generating Phase	The goal of this phase is to have chosen a research area of interest based on personal experience, published work of others, ideas mentioned by others in future work sections of papers and dissertations.
Problem Definition Phase/ Background	The goal of this phase is to have one or more questions(that is answerable) based on others work and your own ideas. You may also be investigating background information on tools/technologies.
Procedures-Design Phase	The goal of this phase is to have a plan of what methods you will use to answer your research question in an ethical fashion, with your available resources and skills and based on how others answer questions of your type and within a research framework.
Observation Phase/ Action phase	The goal here is to conduct some primary research which involves doing something practical-prototyping, managing/processing data, testing, designing etc.
Data Analysis Phase	The goal here is to analyse the data you have collected in a way that allows you to answer your question.
Interpretation Phase	The goal of this phase is to place the findings from the literature and your primary research together in a way that answers the research question you asked.
Communication Phase/ Ongoing	The goal here is to present in a formal or informal way, 1)what you have done, 2)your motivation for doing it, 3)how you did it, 4)how it fits in with others work, 5)your findings, 6) limitations and 7)possible future work.

Compiled and modified from - Research Methods, a Process of Inquiry, A. Graziano, M. Raulin, 2014.

CS7CS6 – Idea Generation/ Problem Definition



Linus Pauling (1901-1994)
Winner of more than one Nobel Prizes
https://en.wikipedia.org/wiki/Linus_Pauling

When asked where scientists find their **good** ideas.

Linus Pauling replied

"Well, you have **lots** of ideas, and you throw out the **bad** ones"

What/whose work is your idea based on?
Selection of Literature

Developing great research questions, Earlene E. Lipowski, Am J Health-Syst Pharm—Vol 65 Sep 1, 2008
https://libraries.indiana.edu/sites/default/files/Develop_a_Research_Question.pdf
https://cirt.gcu.edu/research/developmentresources/tutorials/question
Example Question Frameworks- http://www.phcris.org.au/guides/formulating_research_question.php
Previous dissertations can be found at- https://www.scss.tcd.ie/publications/theses/diss/

CS7CS6 – Procedure/Design Phase

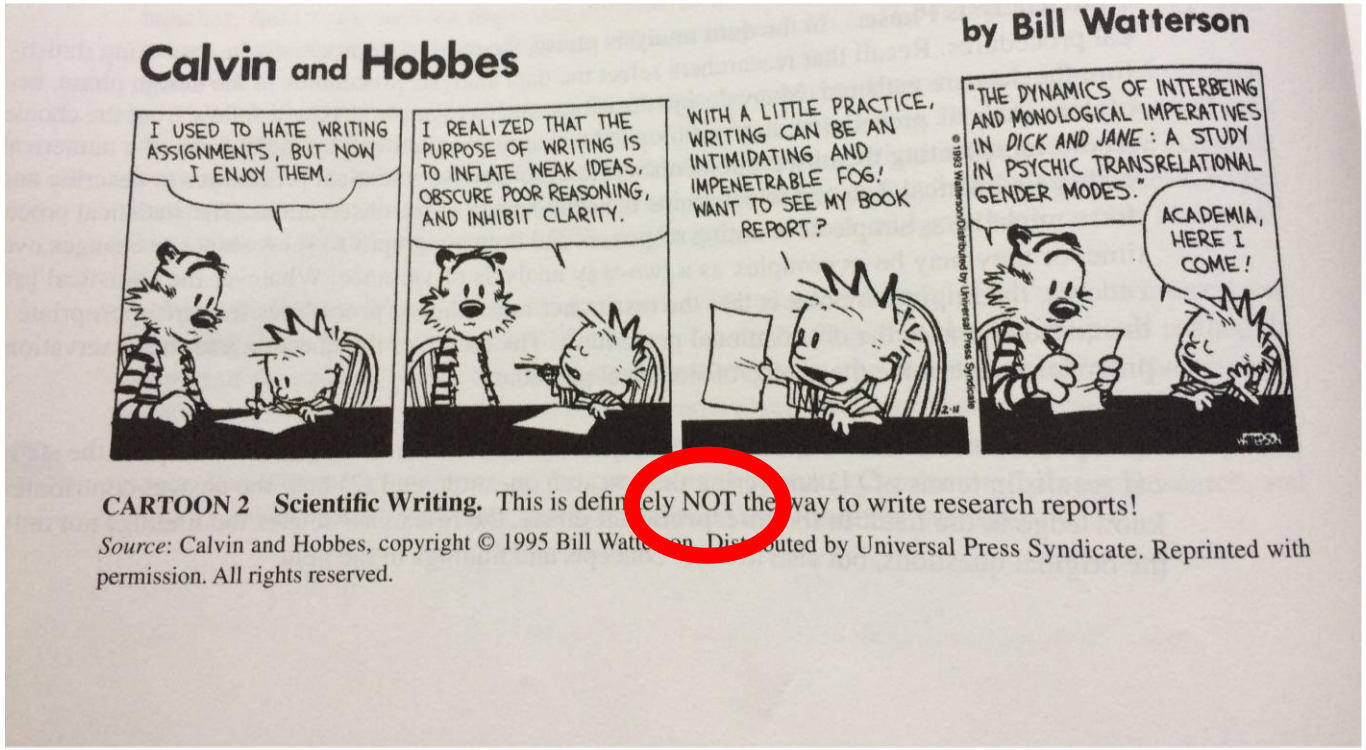
http://donalomahony.edublogs.org/action-research/

1. Honesty in all aspects
2. No Plagiarism- include citations, acknowledgements
3. Include limitations
4. Consider the links between the research activities e.g. Will you be able to link findings from your literature review and participants selected for interview.

CS7CS6 – Data Analysis/Interpretation

- Beware of silently rejecting or ignoring evidence that doesn't match your work/beliefs
- Appropriate tools used correctly
- Beware of time constraints

CS7CS6 – Communicating Research



CARTOON 2 Scientific Writing. This is defi ely NOT the way to write research reports!

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Image taken from - Research Methods, a Process of Inquiry, A. Graziano, M. Raulin, 2014.

1. Explanation of what you did/doing/going to do should be clear
2. Basis for judgements should be included
3. Don't cherry pick results to communicate- avoid being selective/sensational
4. Appropriate publication credit
5. Use of language in yours and others work – watch changes in terminology over time
6. Acknowledging collaboration, funding, participation, conflicts of interest
7. Consider audience
8. Communication method- proposal, poster, presentations, dissertations, papers, interviews, informal

CS7CS6 – Observation/Action

http://www.karin-hess.com/single-post/2014/04/13/Educational-Research-in-Action

Health Informatics Society of Ireland Workshop – Nov 2016
In Electronic Health Records We Trust.

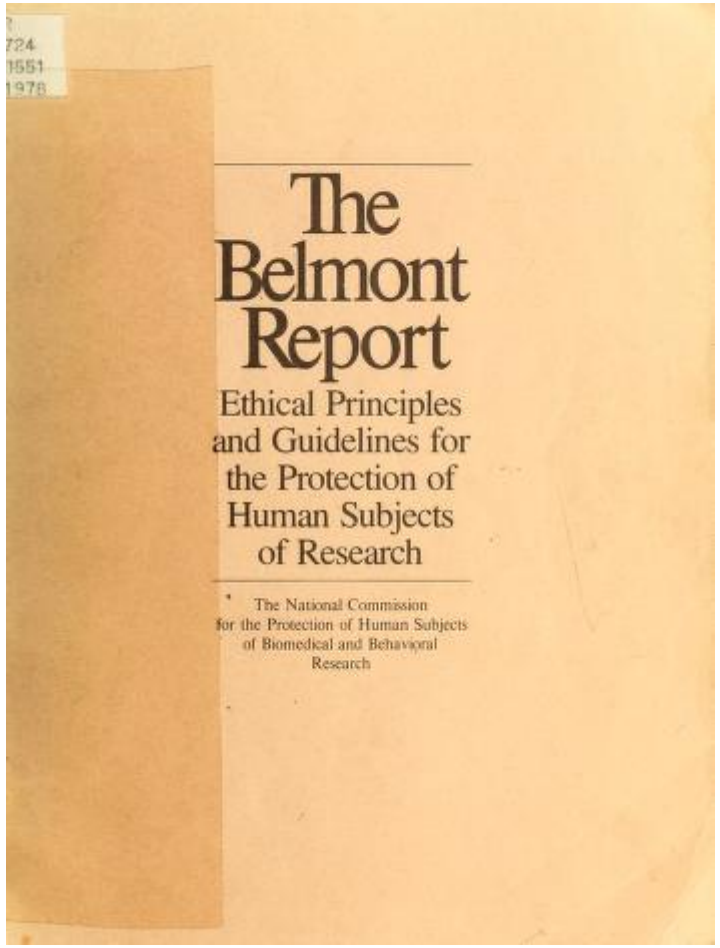
- Appropriate "management" of participants and their data during observation/action phases.
- Ethical design of artifacts.
- Informed Consent(informed about what you are doing, why, how and what they have to do)

AI and the Ethics of Automating Consent, Meg Leta Jones, Ellen Kaufman, and Elizabeth Edenberg | Georgetown University, IEEE Security & Privacy (Volume: 16 , Issue: 3 , May/June 2018)
"…. The premise of consent is a legal fiction…" Beyond Consent-based Privacy Protection* Eloïse Gratton** 2016
The Limits of Notice and Choice, Cate, F.H., IEEE Security & Privacy IEEE Secur. Privacy Security & Privacy, IEEE. 8(2):59-62 Apr, 2010

CS7CS6 – Research Ethics Codes

https://en.wikipedia.org/wiki/Nuremberg

Nuremburg Code
10 principles



https://archive.org/details/belmontreporteth00unit

3 Principles

https://www.canarybooks.com/Declaration-of-Helsinki-2013

Combination of Nuremburg code and Declaration of Geneva

10 principles of the Nuremburg Code

1. Voluntary consent is essential
2. The results of any experiment must be for the greater good of society
3. Human experiments should be based on previous animal experimentation
4. Experiments should be conducted by avoiding physical/mental suffering and injury
5. No experiments should be conducted if it is believed to cause death/disability
6. The risks should never exceed the benefits
7. Adequate facilities should be used to protect subjects
8. Experiments should be conducted only by qualified scientists
9. Subjects should be able to end their participation at any time
10. The scientist in charge must be prepared to terminate the experiment when injury, disability, or death is likely to occur

https://www.imarcresearch.com/blog/bid/359393/nuremberg-code-1947

3 Principles from the Belmont Report

- **Respect for Persons**

The Belmont Report argues that respect for persons consists of two distinct principles: individuals should be treated as autonomous and individuals with diminished autonomy should be entitled to additional protections. The principle of respect for persons is interpreted to mean that researchers should, if possible, receive informed consent from participants, and the Belmont Report identifies two elements of informed consent: information, comprehension, and voluntariness. That is, respect for persons implies that participants should be presented with **relevant information in a comprehensible format** and then should voluntarily agree to participate.

- **Beneficence**

Beneficence can roughly be understood to mean having the interests of research participants in mind. The principle of beneficence is behind efforts by researchers to minimize risks to participants and maximize benefits to participants and society. For example, when considering a research design, the principle of beneficence should cause us to **ask if there is another way that we could obtain the same knowledge** but with lower risks to participants.

- **Justice**

The principle of justice addresses the distribution of the burdens and benefits of research. That is, **it should not be the case that one group in society bears the costs of research while another group reaps its benefits.** Issues of justice arise most strongly around questions about the selection of participants.
Applying these three principles to specific ethical situations can be difficult, and the principles sometimes come into conflict. However, even if they do not lead to clear decisions in all cases, keeping these three principles in mind helps clarify the issues.

https://msalganik.wordpress.com/2014/07/29/the-belmont-report-three-principles-for-ethical-research/

CS7CS6 – Many, Multilevel Research Ethics Codes

1. The Nuremburg Code- 1947

2. Fifty Years Later: The Significance of the Nuremberg Code, Evelyne Shuster, Ph.D., N Engl J Med 1997; 337:1436-1440November 13, 1997DOI: 10.1056/NEJM199711133372006

3. The Belmont report- 1978

4. Declaration of Helsinki- 1964(many revisions since. Currently 2013)

5. http://www.ucd.ie/t4cms/Code%20of%20Good%20Practice%20in%20Research%20090216.pdf

6. http://www.cit.ie/contentfiles/postgrad/Policy%20Docs/Code%20Good%20Practice%20in%20Research%20adopted%20May05.pdf

7. https://www.scss.tcd.ie/postgraduate/ethics/
8. https://www.tcd.ie/research/dean/assets/pdf/FINAL_Good%20Research%20Practice%20policy_COUNCIL%20APPROVEDandminutedgg.pdf

9. http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf
10. https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics

11. http://intro2res2014.blogspot.ie/2014/09/biomedical-research-ethics.html

CS7CS6 – Research Ethics- SCSS

- Ethics Committee has 6 Members at present (2 full time SCSS academic staff, 2 part-time SCSS academic staff, 1 part-time administrator, external member with legal expertise)

- Linked to TCD college ethics committee

- **Level 1** and **Level 2** applications

- Level 2 applications require review by two members of the committee and possibly the legal member of the committee. Therefore the ethical review may take more time.

- 4-6 weeks response time for first response

- Submitting an ethics application- https://www.scss.tcd.ie/postgraduate/ethics/
    - Online System, User guide available
    - FAQ are included on the site
    - Samples of forms are provided on the site
    - Application form template included on the site
    - An ethics application submission should consist of **One** PDF document.

CS7CS6 – Considerations relating to potential participants

Consideration	Example	Example Issues arising
Participant's Profile	Vulnerability, Health Status, Age, Education Support structures	Use of language on the information sheet and consent form, Protection
Participants as a group	Diversity, Access to their contact details,	Skewing results
Participant Recruitment	Access to their contact details, recruitment location	Breach of data protection
Researcher's Profile	Student/professional affiliated to, role, qualifications, funding	Raising false expectations Conflicts of interest
Usual Roles of researcher and participants	Teacher/student, Employer/Employee, Funder/Fundee	Choosing freely to take part Implications fro learning outcomes if participants are students. Employers/Board Of Management permission may be needed.
Research setting	Safety, Confidentiality/security, Participant Effort, Comfort, informed consent, Withdraw at any time, Work, Leisure, Receiving treatment	Fully informed, Temporal issues, Choosing freely to take part, availability of care professionals/advice, debriefing, physical preparations
Research results dissemination	Participants Identification, Data management, Publication, Audiences	Participants being identified without their consent
Artifact Design/Data	Type of data, Use of data, how can technology be used/combined, Data Management	Participants need to be fully informed about the data to be collected by any technical artifacts used in the research.

CS7CS6 – SCSS Research Ethics- Documents

1. Application form with signatures(applicant and supervisor)
2. Information Sheet(s) to be used in the research
3. Consent Form(s) to be used in the research
4. If relevant, Link to an Online Survey
5. If relevant, A copy of the survey(online or paper) in your application.
6. If relevant, Interview questions/themes (these should be informed by your literature review)
7. Research Proposal including

   Title of project
   Purpose of project including academic rationale
   Brief description of methods and measurements to be used
   Participants - recruitment methods, number, age, gender, exclusion/inclusion criteria, including statistical justification for numbers of participants
   Debriefing arrangements
   A clear concise statement of the ethical considerations raised by the project and how you intend to deal with them.
   Cite any relevant legislation relevant to the project with the method of compliance e.g. Data Protection Act, GDPR.

CS7CS6 – Research Ethics

Some easy things to fix before submission of your application(based on observations of previous applications)

- Make sure no parts of the document are missing.
- Explain clearly and concisely what you are doing, why you are doing it and how you want to do it – including participant recruitment process.
- Make the English simple and clear.
- Write the information sheets with the correct audience in mind – The intended audience of the information sheet are the potential participants of the research.
- Explain about the management of the data.
- Acknowledge relevant ethical issues and describe actions you have taken to address them e.g. students' learning being compromised, knowing the participants, usual roles of the researcher and participant.
- Where relevant, Include a copy of any online survey with the application.

That’s All Folks Thank You for Listening