

Research Ethics by Design & in Practice

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Introductions

- Social science trained
- Qualitative researcher
- Chair, FHM Research Ethics Committee
- LU Research Ethics Committee
- NHS Research Ethics Committee
- Adviser, UK Research Integrity Office

Today

- **Aims:**
 - Understand the origins of research ethics today
 - Explore the key ethical considerations when designing research
 - Consider what ethical research looks like in practice
- **Format**
 - Mixture of theory and application
 - Interactive session i.e. raise hand/chat function
 - Facilitate the discussion i.e. no easy answers, experienced but not expert
 - Break

Today

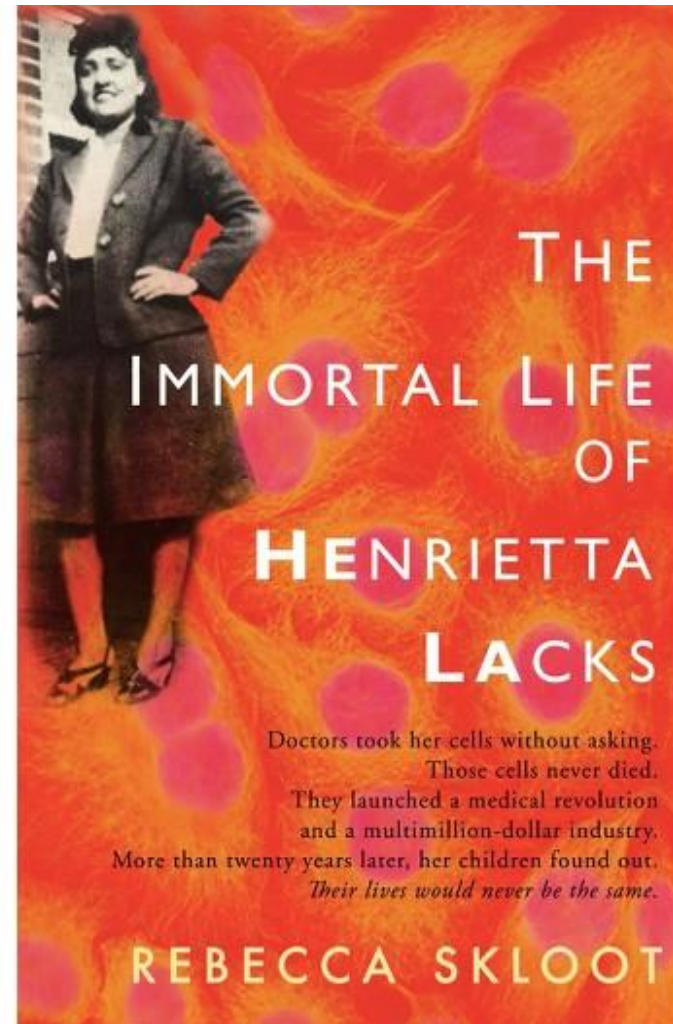
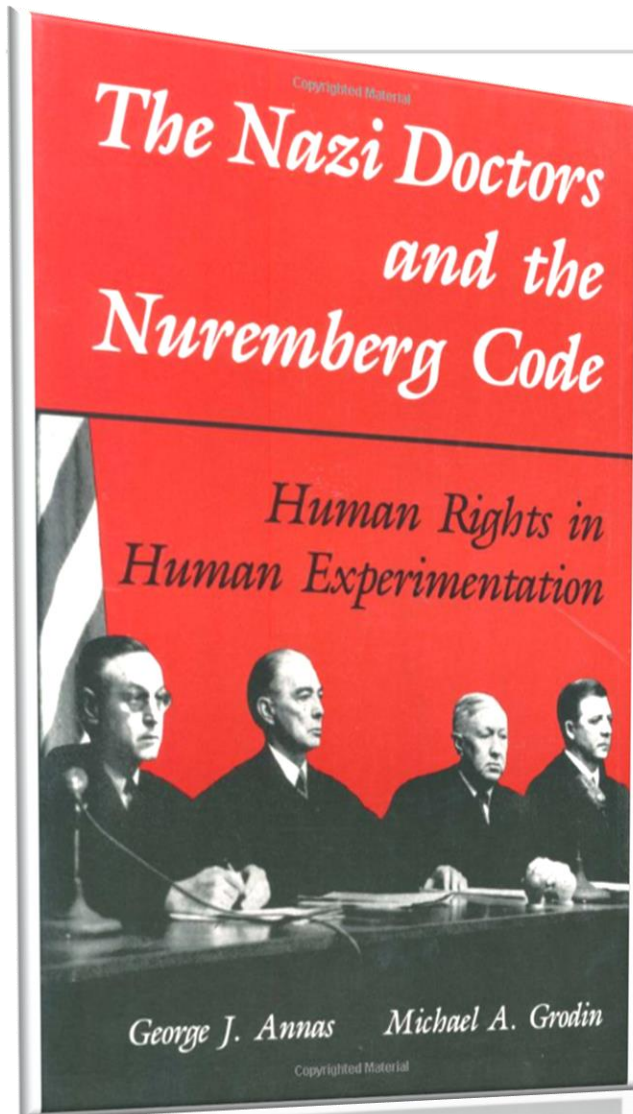
- Session format
 - Mixture of theory and application i.e. relevant to your research
 - Interactive session i.e. raise hand/chat function
 - Facilitate the discussion i.e. no easy answers, experienced but not expert
 - Breaks

Some Origins of Research Ethics

Understanding why we are where we are...



Modern Day Origins of Research Ethics



Modern Day Origins of Research Ethics

Common 'Ethical' Considerations

- Consent
- Anonymity
- Confidentiality
- Harm
- Burden
- Vulnerability
- Dignity and respect
- Justice
- Benefit
- Consequences

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He stripped the organs from every dead child he touched

Special report: Alder Hey hospital

Sarah Boseley and Helen Carter

The Guardian, Wednesday 31 January 2001 10.12 GMT

The pathologist at the heart of the Alder Hey scandal may face criminal prosecution after a devastating report revealed yesterday that he had stripped the organs out of every dead child who came into his hands over a period of seven years, whether the parents had consented or not.

Dick van Velzen, the Dutch pathologist who is already facing charges over organ storage in Canada, took the brunt of the criticism from the Redfern inquiry, which reported yesterday. He was responsible for the collection of children's body parts at the Liverpool hospital, but the hospital trust and Liverpool University, which appointed and failed to oversee him, also came in for savage criticism.

Research Governance

- Definition
 - Research governance is the broad range of regulations, principles and standards of good practice that ensure high quality research (NICE)
- Constitutes
 - Regulation and Ethics – they are different!
- Purpose
 - It sets the standards for research conduct; defines responsibilities of those involved in research; and safeguards the public

Dominant Research Ethics Principles

- **Four Principles** (Beauchamp & Childress)
 - **Respect for Autonomy**
 - we should respect a participant's right to make informed and voluntary choices about what happens to them
 - **Beneficence**
 - research that brings about goods / actions that promote well being in others / ought to prevent harm and promote good
 - **Non-Maleficence**
 - avoid the causation of harm
 - **Justice**
 - should treat participants fairly and equitably / all participants should be treated equally / fair distribution of benefits

Conducting 'Ethical' Research

What you need to consider when designing your research...



- Respects participants' autonomy
- Protecting the research relationship
- Complying with the law

Informed	Competent	Voluntary
<ul style="list-style-type: none">• Clarity of language• Explain nature of research• Outline risks and benefits• Clear about research process	<ul style="list-style-type: none">• Must possess mental capacity (Mental Capacity Act 2005)• If not, can consent be given on their behalf?• Non-competent can still dissent	<ul style="list-style-type: none">• Free from coercion• About patient perception (rational persuasion acceptable)

Consent

- Reasonable, transparent, explicit
- Time to decide, talk to others, ask questions
- Written / verbal
- PIS / consent form
- Literacy levels, online, in person, over the phone/skype
- Incentives
- Renegotiate / one-off
- Option to withdraw, a right to reply

‘Vulnerability’

- Who might we consider as ‘vulnerable’ in research?
 - People lacking or limited capacity e.g. children, dying, mental health
- Circumstances...not the person
 - Topic e.g. criminal activity, sexual health, child abuse
 - Location e.g. interviewing prisoners
 - Timing e.g. observing women in labour
 - Awareness e.g. chat rooms
 - Community e.g. commercial organizations
 - Position e.g. coroner in North West
- A right to benefit and gain through and from research?

Managing 'Vulnerability'

- Supporters
 - Collect consent by proxy
 - Timing
 - Set limits of confidentiality
 - Access to data
 - Anonymity
- Can you be vulnerable?
 - Physically though lone working
 - Mentally through sharing of personal details
 - Facebook / mobile phone / photograph
 - Leaving the field and boundary setting

- How might the issue of 'harm' arise when designing or conducting research? For whom? Why?

- Harm for the participants
- Harm for yourself
- Harm to others?
- Harm for the participants
 - Burden and inconvenience of research
 - Modest incentive?
 - Distress (topic, recalling experiences, stress, anger)
 - Stop the research, opt to withdraw, debrief
- Harm to participants and/or others
 - Breaching confidentiality
 - Serious / permanent
 - Line of reporting

Concluding Thoughts

- A set of **rules** exist...
...understand the difference between regulation and ethical codes surrounding research
As researchers, we need to recognize the components of research governance, and keep up to date with evolving regulatory requirements
- Set of **unknown** rules we all agree to...
...research ethics shift and evolve over time
As researchers, we need to keep our knowledge of conducting ethical research up to date
- A set of rules about how to **interact with people** in research...
... Treat people in research as you would in everyday interactions
As researchers, we should “never treat people as a means to an ends”, treat all those involved in research equally

Concluding Thoughts

- Recommended Resources:
 - Journals e.g. Research Ethics, Journal of Empirical Research on Human Research Ethics
 - Faculty Research Ethics Websites e.g. templates, guidance, advice
 - Discipline Associations/Colleges e.g. British Sociological Association, British Psychological Association

Case Study: Association for Research Ethics

- The aim is to study what people attending general practitioners/ family doctors think about routine screening for sexually transmitted infections (STIs).
- The student plans to provide information sheets, consent forms and questionnaires in the waiting rooms while patients are waiting to be seen.
- The questionnaires contain intimate questions. Participants are expected to provide consent and complete the questionnaire in the waiting room and return documents to the student.

What concerns could the ethics committee have?