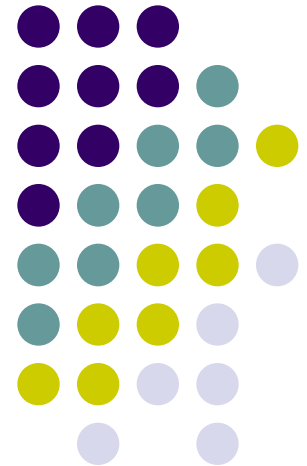


# Ethical Attitudes

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Rev Kevin McGovern,  
Caroline Chisholm Centre for Health Ethics:  
SJGHC Human Research Ethics Committee,  
18 March 2015





- What is the purpose of a HREC?
- How does ethics work?
- A case study

# The purpose of a HREC



- HRECs facilitate good research.
  - At our best, HRECs *add value* to research.



# 1999 *National Statement*

- “primary purpose”: “protection of the welfare and the rights of participants in research”
- “secondary purpose”: “to facilitate research that is or will be of benefit to the researcher’s community or to humankind.” (1999 *NS*, p. 1)

# 2007 *National Statement*

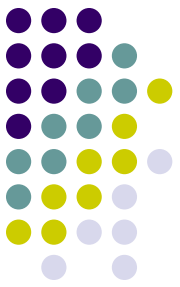


- “purpose”: “to promote ethically good human research”
  - “Fulfillment of this purpose requires that participants be accorded the respect and protection that is due to them.”
    - I see this as a secondary concern. It is necessary but not sufficient.
  - “It also requires the fostering of research that is of benefit to the community.” (2007 *NS*, p. 6)
    - I see this as the primary concern.

# What we do to facilitate good research



- affirm the purpose of the proposed research
- confirm the plans for the proposed research
- offer suggestions of possible improvements
- if there are problems, try to suggest solutions
- do all this in a timely manner
  - therefore, using appropriate processes
- monitor research



# What we should avoid

- Avoid ‘aggro’ (aggression and aggravation)
  - towards researchers
  - within the HREC
- Don’t sweat the small stuff
  - “Am I right in thinking that what we’re discussing is a relatively minor point?.... We’ve spent about 10 minutes on this. Could we resolve this matter now and move forward?”
- Don’t try to do too much to PICFs (Patient Information and Consent Forms)



# How does ethics work?

- Values
- ↓
- Principles
- ↓
- Guidelines
- ↓
- Decisions about cases





# How does ethics work?

- Values



- Principles **are like Policies**



- Guidelines **are like Procedures**



- Decisions about cases

# Values



- life
- bodily health
- knowledge of truth
- appreciation of beauty
- skill at work
- skill at play
- self-integration
- practical reasonableness
- justice
- friendship
- religion and meaning in life
- marriage and family

# Values



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# Principles

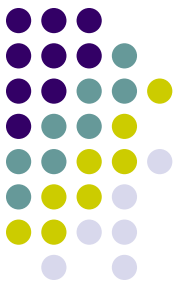


- Positive precept: Because of the great value of human life, we should be **generous** but **realistic** in our efforts to preserve human life and to ensure that each person receives what is necessary for a decent human life
  - **generous** because of the great value of human life
  - **realistic** because our resources are always limited
- Negative precept: Because of the great value of human life, it is almost always wrong to kill another human being. For the few exceptions to this general rule, two conditions must simultaneously be present:
  - i. Someone must pose a serious and imminent threat to human life or to values virtually as important as life (e.g. liberty).
  - ii. The only way to eliminate that threat is to kill this person.



# Areas of Application

- world poverty
- epidemic (plague)
- war
- resisting lethal attack
- capital punishment
- pain relief which may shorten life
- euthanasia and assisted suicide
- obstetric pathology (e.g. ectopic pregnancy)
- termination of pregnancy (abortion)



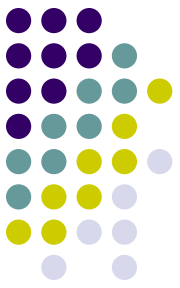
# Areas of Application

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# Guidelines

- If my attacker clearly threatens my life, I can use lethal force.
- If my attacker only wants my wallet or other property, I should not use lethal force. (I may use non-lethal force.)
- If the situation is unclear so that the attack may threaten my life, I can use lethal force.



# Decisions about Cases

- “These ethical guidelines are not simply a set of rules. Their application should not be mechanical. It always requires, from each individual, deliberation on the values and principles, exercise of judgment, and an appreciation of context.” (2007 *NS*, p. 11)
  - not ‘mechanical,’ ‘mathematical,’ or overly literal
  - requires practical wisdom and discernment





- Values
- ↓
- Principles
- ↓
- Guidelines
- ↓
- Decisions about cases



# An example

- *NS 1.5* “Research outcomes should be made accessible to research participants in a way that is timely and clear.”
  - What does this mean in the context of a researcher-initiated study with limited resources – where the researcher says that she doesn’t have the resources at the end of the study to send a report letter to each participant?

# Principlism



- Beauchamp & Childress's *Principles of Biomedical Ethics*, 7<sup>th</sup> ed.:
  - “Common morality”  
↓
  - Principles drawn from common morality and “specified”  
↓
  - “Reflective equilibrium”
- Priority Principle

# Common Morality



- a “set of universal norms” .... “that are not relative to cultures, groups, or individuals” but instead are “shared by all persons committed to morality” (*B&C 7<sup>th</sup> ed.*, p. 3)
- “the set of norms shared by all persons committed to morality” (*B&C 7<sup>th</sup> ed.*, p. 417)

# Principles



- “*drawn from*” common morality (*B&C 7<sup>th</sup> ed.*, p. 410)
- These principles are “a reasonable formulation of some vital norms of the common morality...” (*B&C 7<sup>th</sup> ed.*, p. 410)
- These principles must be “specified”: “Specification adds content.... Specification is a process of reducing the indeterminacy of abstract norms and generating rules with action-guiding content.” (*B&C 7<sup>th</sup> ed.*, p. 17)
- “As ethical reasoning progresses, a body of more specific moral guidelines is formed...” (*B&C 7<sup>th</sup> ed.*, p. 411)

# Reflective Equilibrium



- “All common-morality theories are pluralistic: they contain two or more nonabsolute (prima facie) moral principles.” (*B&C 7<sup>th</sup> ed.*, p. 411)
- Reflective equilibrium is “a way of bringing principles, judgments, and background theories into a state of equilibrium or harmony.” It requires us “to match, prune, and adjust considered judgments, their specifications, and other beliefs to render them coherent.” (*B&C 7<sup>th</sup> ed.*, p. 411)

# Reflective Equilibrium (cont'd)



- “Conflicts among principles cannot be resolved a priori.” (*B&C* 4<sup>th</sup> ed., p. 107)
- “It is therefore essential to leave room for interpretation, specification, and balancing of principles and rules in the face of recurrent and recalcitrant conflicts.” (*B&C* 4<sup>th</sup> ed., p. 107)
- “Here experience and sound judgment are indispensable allies.” (*B&C* 4<sup>th</sup> ed., p. 107)



# Priority Principle

- In common-morality principlism, none of the principles can ever be completely ignored. Each principle must be honoured at least to some degree.
- Even so, there is a priority principle
  - which should be considered first, and
  - which should be honoured as fully as possible.
- Honouring the priority principle as fully as possible may require some compromises with the other principles.



# Principles for Health Ethics



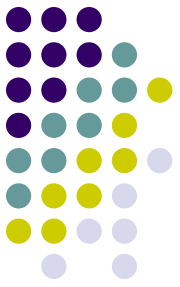
- Autonomy
- Nonmaleficence
- Beneficence
- Justice

# Principles for Health Ethics



- Autonomy
- Nonmaleficence
- **Beneficence**
- Justice
  - e.g. In an emergency, consent is not required.
  - e.g. The patient cannot demand any treatment at all. S/he can only choose among the treatments which the health professionals judge to be beneficial.

# Principles for Research Ethics



- Research merit and integrity
- Justice
- Beneficence
- Respect for human beings

# Principles for Research Ethics



- **Research merit** and integrity
- Justice
- Beneficence
- Respect for human beings

# Case Study



- Facebook study on emotional contagion
- for 1 week (11 to 18 January 2012)
- test group: c. 155,000 had 10 to 90% of **positive** posts removed
- control group: c. 155,000 had 10 to 90% of **random** posts removed
- Compared to the control group, the test group had a small **decrease** in **positive** posts, and a small **increase** in **negative** posts.
- test group: c. 155,000 had 10 to 90% of **negative** posts removed
- control group: c. 155,000 had 10 to 90% of **random** posts removed
- Compared to the control group, the test group had a small **decrease** in **negative** posts, and a small **increase** in **positive** posts.
- = the first experimental evidence for emotional contagion via social networks - in the absence of in-person interaction and non-verbal cues

# Case Study (cont'd)



- did not receive ethical review from HREC (Institutional Review Board or IRB)
- did not obtain informed consent from participants or permit them to opt out
- There were 'reasons' for both these decisions.
- Others found these 'reasons' unconvincing.

# The purpose of a HREC



- HRECs facilitate good research.
  - At our best, HRECs *add value* to research.

# Principles for Research Ethics



- **Research merit** and integrity
- Justice
- Beneficence
- Respect for human beings
  - Is there merit in doing research about the effect of social networks on emotion?
  - If so, how might we approve this research?



# Consent



2007 NS Chapter 2.3:

- limited disclosure
- opt-out approach
- waiver
  - all three specify “no more than low risk”:
  - “Research is low risk where the only foreseeable risk is one of discomfort.” (NS 2.1.6)

# Consent (cont'd)



- ‘mechanical’ application of the guideline:
  - “This is more than mere physical discomfort. This is emotional contagion! We cannot permit this research!!”
- ‘discerning’ application of the guideline:
  - “When the framers of the *NS* set out to specify ‘low risk research,’ they probably didn’t have this sort of study in mind.”
  - “‘Discomfort’ is a low-level physical outcome. At most, this study may cause a low-level emotional outcome.”
  - “Maybe it’s ok to grant a waiver of consent for this research...”

# What else?



- All Facebook users must agree to FB's Data Use Policy:
  - Does this have an explicit statement about research? If so, what does it say? If not, should something be said?
  - Could this include an opt-out mechanism for those who do not want to participate in research?
- Reporting on studies where consent has been waived (cf *NS 2.3.12*):
  - How could Facebook make its users aware of studies like this where consent has been waived? [Hint: Facebook is a way of communicating with people!]
  - Could this communication include information about opting out of future research?