

PHR: The Disembodied Self

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PCHRI 2006, Countway Library, HMS

Information as Extended Self

- What is the “best outcome” for PCHR?
- Regard it as a technology, but conceptually.
- What do we want from technology?
 - Extend abilities, faculties
 - Greater reach, time, efficiency, strength, memory, comfort, safety
 - Expand choice
 - More, and more varied, means of satisfying needs and wants
 - Increase autonomy
 - More control, independence, privacy

Information as “Big Brother”

- A transmutation of properties
 - Disembodiment (not material)
 - Circulation (not physically contained)
 - Recombination (not permanently ordered)
 - Commodification (not transcendental)
- Opening up new possibilities for control
 - Other interests and values
 - Other viewpoints: outsiders looking in

Where do we turn for guidance?

- Constitutional framework
 - “Privacy” guarantees and their limitations
 - What does “reasonable expectation” mean against backdrop of change?
 - Will protection be afforded to average, least sensitive, or most sensitive individual (cf. environmental risks)?
- Market framework
 - Privileges innovation, risk-taking, extraction, change
 - Amplified through other institutions (cf. *Moore* case)

The Institutional Turn

- Why institutions are better than principles
 - Representative
 - Attuned to facts on the ground
 - Adjustment devices
- Some examples
 - IRB's
 - NIH RAC, ESCRO
 - Hospital ethics committees