Interoperability is an Ethical Issue – and Failure to Achieve it is a Betrayal of Our Patients

Health Level Seven International
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“Melodies cannot be written.”

Isidore of Seville (c. 560-636)
Standards as Ethics 1

e.g., HL7 EHR-System Functional Model, Release 2

• Function List: Overarching, Care Provision, Care Provision Support, Population Health Support, etc.

• Conformance Criteria: SHALL, SHALL NOT, SHOULD, MAY
Standards *as* Ethics 2

- Trust, safety, quality, efficacy
- Patients are not (mere) stakeholders
- Toward evidence-based patient-centered systems
- Utilitarian and rights-based foundations
Practical Small Examples

1. a. Fetal monitor output
   b. EHR input
   c. \( a \ (\not\exists \ \not\exists \ \not\rightarrow) \ b \)

2. Code status and advance directives
Ethics as Prohibitive

Often precautionary:
- Stop (e.g., reproductive cloning)
- Postpone (e.g., genetic engineering)
- Slow down (e.g., neuroethics)
Ethics as Prescriptive

Identification of duties:

• Reduce disparities

• Establish, foster and raise minimum standards

• Protect rights
“Progressive Caution”

Health information technology (HIT) introduces tools whose very availability entails an obligation to develop, adapt, use them more widely.
Ethics and Digital Science

- Software engineering
- Data sources, consent and privacy
- Evidence-based standards
- Patient-centered throughout
- Interoperability as necessary condition
Software Engineering

- Version control
- Provenance, attestation, version control
- Pareidolia and decision support
- Trust
Data, Sources, Consent, Privacy

- Privacy vs. other values
- Data sources, consent and privacy
- Applications
- Implied consent?
Collapse of a Distinction

Clinical data >
Research data >
Surveillance data >

*Undermining the myth of “secondary use,” especially for public health*
“Information Free-Riders”

• Emphasize privacy over public health
• Risk little if anything
• Benefit from others’ contributions of information
Analogues

- Vaccine refusers
- Organ donation refusers
- Infrastructure support refusers
Applications

• Decision support
• Exception management
• Anomaly detection > “incidental findings”
• Monitoring, surveillance, research
Learning Health Systems

• Require data interchange …
• Which is assumed by patients …
• And needed for clinical practice, public health and translational science
Practical Big Example

(Recall practical small examples)

• “File drawer problem”
• If goal of a LHS is to metabolize Big Data,
• Then bona fide interoperability is a corrective to reliance on the flawed publication record
Interoperability Ethics

• If interoperability improves outcomes, it becomes a duty to achieve it
• If it reduces cost and increases safety, quality, efficiency …
• If it fosters trust in our systems…. 
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