# Ethical and Legal Principles: Privacy and Sharing

Howard P. Levy, MD, PhD
Johns Hopkins University

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# Disclosures

- About me:
  - Primary care internist
  - Clinical geneticist
  - Epic physician champion/super user
- Financial conflicts: none
- Collaborators on this work:
  - John J. Mulvihill, MD, U. Oklahoma HSC
  - Ingrid A. Holm, MD, MPH, Harvard Medical School

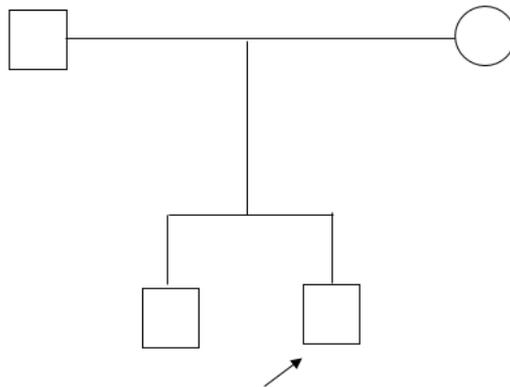# *Imagine…*
## *(It's easy if you try)*



Lennon J, 1971

- Each person uniquely identifiable
- Full interoperability of all EHRs (and other medical data sources)
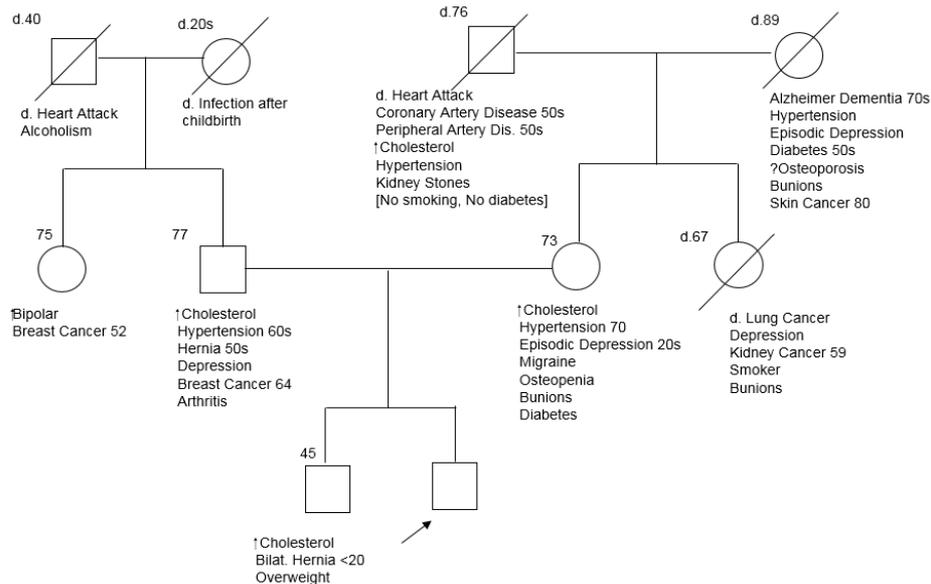
# Ideal FHx Tool, Redux

- Patient uniquely identifies close relatives

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- IT automatically identifies…
  - Additional relatives
  - <u>All</u> medical data about the relatives

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- Interoperability automatically identifies...
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✓ (Accurate) Data viewable when desired

✓ CDS: advice at point of care when appropriate

✓ **Minimum effort (clinicians & patients)**

✓ **Maximum quality & utility**

# Legal Concerns

HIPAA & Protected Health Information

- Restrictions? Allowances? Uncertainties?

Laws

- What does society want?

- Can be changed

# Ethical Concerns

- Privacy, Security & Autonomy

- Beneficence & Justice

- Duties

Ethics

- What is right?

- Is it situational?

- Easy questions; tough answers

# Shared Content

Entire record or only certain elements?

- Diagnoses
- Surgeries & procedures
- Medications & allergies
- Vital signs & measurements
- Structured phenotype (exam) data
- DNA test results
- Other lab results, imaging, etc

# Sensitive Data

Should any data always be excluded?

Should individuals be able to select data to exclude?

- Sensitive diagnoses (e.g. psychiatric or sexual)
- Adult-onset untreatable or poorly treatable conditions (e.g. Huntington or Alzheimer)
- Variants of uncertain/doubtful significance
- Reduced fertility/assisted reproduction
- Adoption, paternity, maternity, consanguinity, abortion

# Consent-1

Opt-in, Opt-out, or No option?

Who can grant or withhold consent?

Allow sharing with some but not all relatives?

What about special populations?

- Minors

- Limited cognitive ability

- Deceased

# Consent-2

- What about 2$^{nd}$ degree, 3$^{rd}$ degree & more distant relatives?

- Can consent be time limited or retracted?

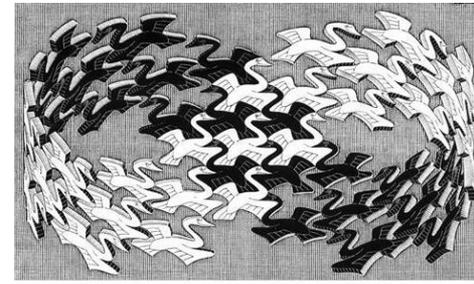- What about secondary, tertiary, etc release of data?

**Whose data is it?**

# Duty to Share (Warn)?

- Individuals' duties to their relatives?

- Duties to society (e.g. advancing knowledge)?

- Clinicians' duties to at-risk relatives?

- Laboratory's duties to update interpretations?

**Does the answer change if IT can automate data sharing (warning)?**

# How Does it all Fit Together?

- Obtaining & documenting consent

- Respecting limitations on types, uses & distribution of data
  - Maintaining those limitations through iterative secondary releases

- Reconciliation of errors & conflicting or discrepant information

- Tracking & documenting modifications, updates, and original sources over time

# This is Complicated!

- Don't share anything automatically?

- Share (almost) everything automatically?

**Privacy & Autonomy**

**vs.**

**Duties & Beneficence**

# Public Health as a Model?

- Mandated reporting of communicable disease
  - Including sexually transmitted infections
  - <u>Privacy</u> sacrificed for others' <u>beneficence</u>

- Genetic traits as communicable disease?
  - Sexually transmitted (to offspring, not partner)
  - Relevant to the entire world population

**Is colon cancer different from syphilis?**
- Curable
- Potentially fatal
- Sexually (genetically) transmitted

*You may say I'm a dreamer*
*But I'm not the only one*
*I hope someday you'll join us*
*And the world will be as one*

Lennon J, 1971

# Let's share the data!*

## *my personal opinion