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Privacy as Silence

The Case of Database Research Using Personal Health Information

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☐ Draft	☐ Overview
☒ Presentation	☐ Other

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Privacy as Silence: The Case of Database Research Using Personal Health Information

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Silence - Layers

- Confidentiality in the health care context
- Lack of patient knowledge that information being used for research

Hippocratic Oath

- “What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, ***I will keep to myself***, holding such things shameful to be spoken about.”

Exceptions Mandated by Law

- Statutory duties:
  - Child protection
  - Adult protection
  - Infectious disease
  - Automobiles
  - Judicial proceedings
  - Narcotics control

Exceptions That May Be Authorized by Law

- Circle of care
- Billing, audit, quality control
- Serious danger to third parties
- Research and surveillance

Background re Electronic Health Information

- Information accumulated since 1970s
- Vast quantities available (especially in Canada)
- Incredible resource for researchers
- Database linkage particularly rich

Examples:

- National diabetes surveillance system
- Pollution and asthma rates by region
- Single moms on social assistance and correlation with illness

So What's the 'Beef'?

- Happening primarily without consent or even knowledge of public
- Concerns re privacy
- Sense of loss of control re information
- Function creep heightened with electronic information

Informed Consent (Reibl v. Hughes)

- Developed in context of surgical interventions
- Marked fundamental shift in physician-patient relations
- Patient must be provided with, & comprehend, information necessary to make informed choice
- Uneasy fit with use of health information

Views on Informed Consent

- "By definition, HSPR (health services and policy research) is research for which **consent is not practical** (impracticable)..."

Pam Slaughter (ICES)
and Paulette Collins (MCHP)

Views on Informed Consent

- "If the secondary purpose is to track the efficacy of particular treatments, or monitor adverse side effects of medications detailed in the PBS data, or for any other purposes, then **the consumer's written informed consent must be obtained** prior to this occurring."

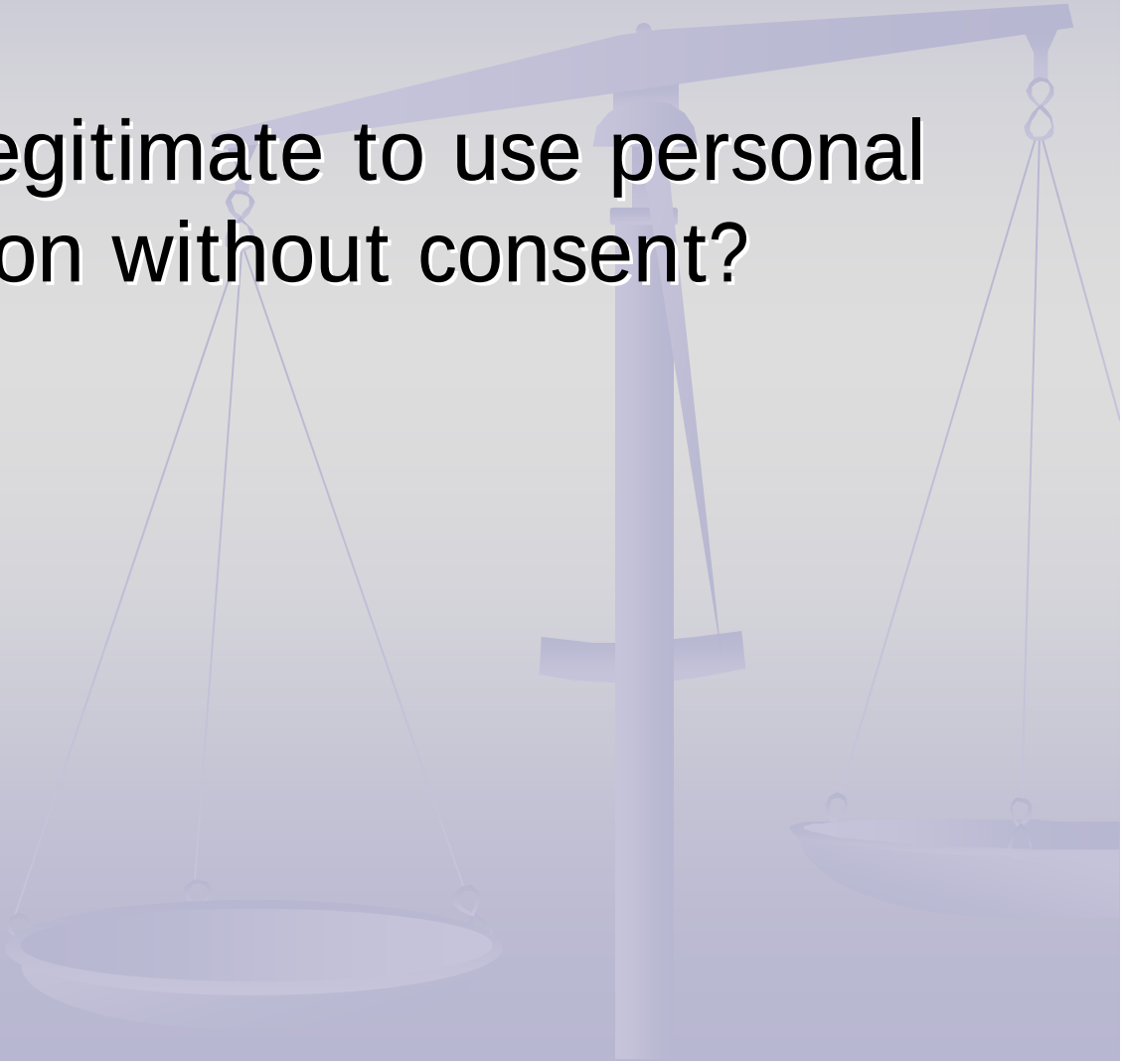
NNPPSCC, submission to Australian Privacy Commissioner

Possibility of Identification utilizing Non-Directly-Identifying Information (U.S. Study)

- Date of birth, gender – linked to voting registry: 29% identification
- Add general residential area: 69% identification

Conceptual Paradigms

- Question: Is it legitimate to use personal health information without consent?

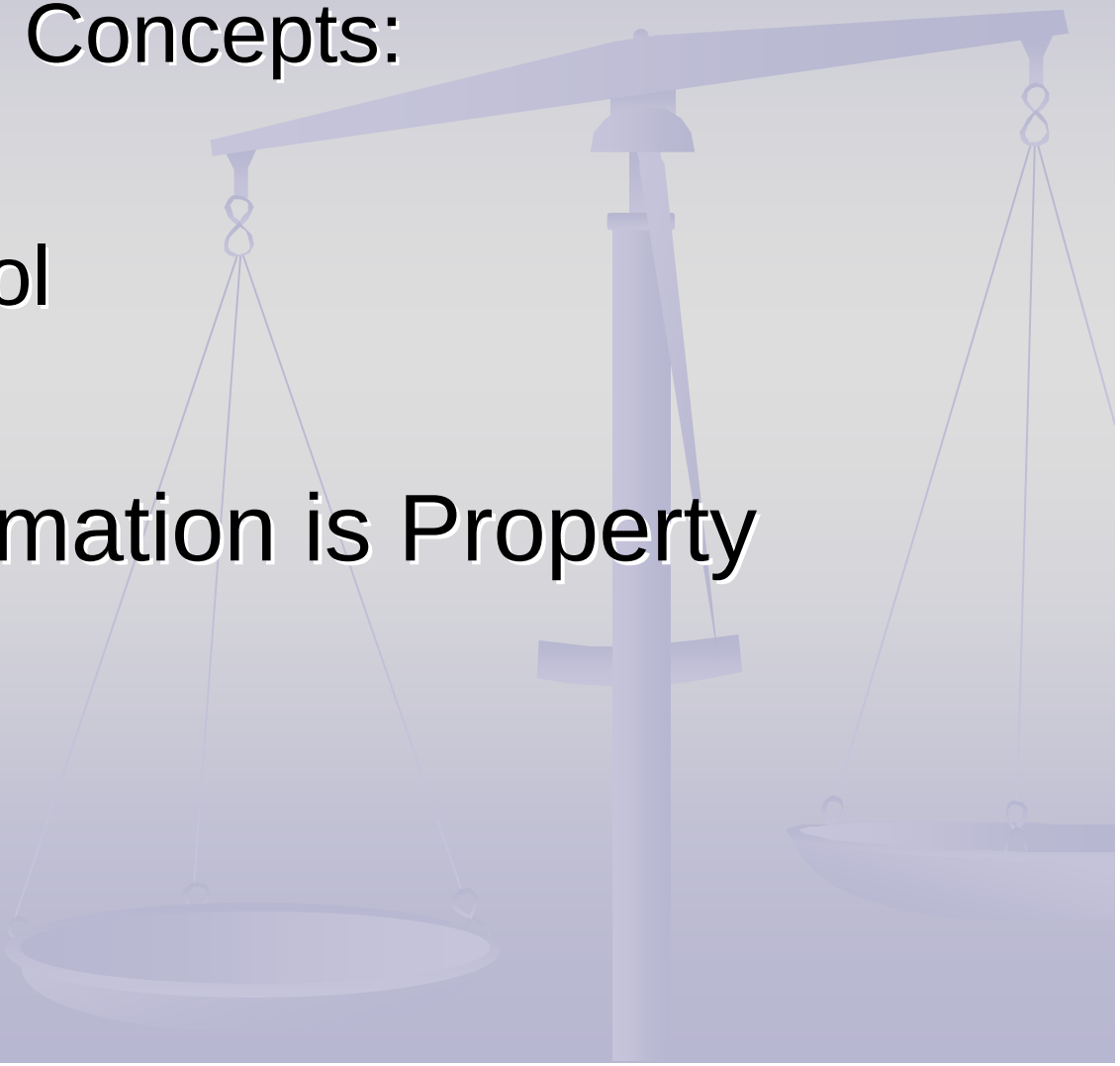


Paradigm - Liberalism

- Focus is on individual rights & autonomy
- Shields the individual from intrusion, in particular by government
- No-one should intrude on self-regarding activities
- Division private and public spheres
- Autonomy suggests right to make decisions re personal information, at least in private sphere

Paradigm – Free Market

- Property- based Concepts:
  - Ownership
  - Right to control
- Personal Information is Property



Paradigm - Relational Theory

- Challenges liberal conception of atomistic individuals
- Views people as inherently in relationships of interdependency
- Important to consider the contextual forces that shape decision-making
- Personal information decisions are shaped by relational aspects of one's existence

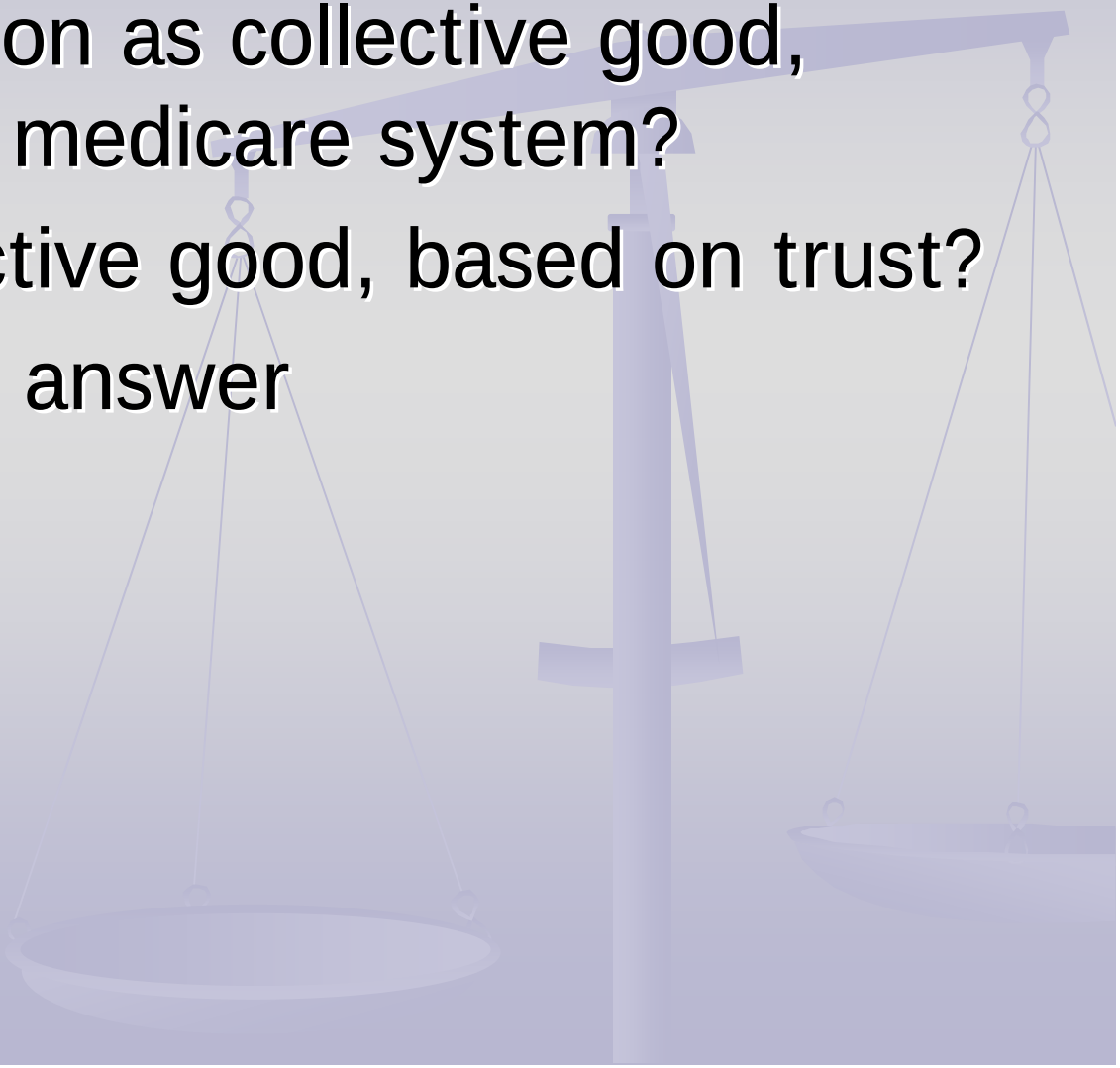
Paradigm - Communitarianism

- Humans are political and fulfil selves by participation in government
- Community has rights that at times override individual rights
- Differing views on privacy:

  - Threat to community may lead to personal information as public resource

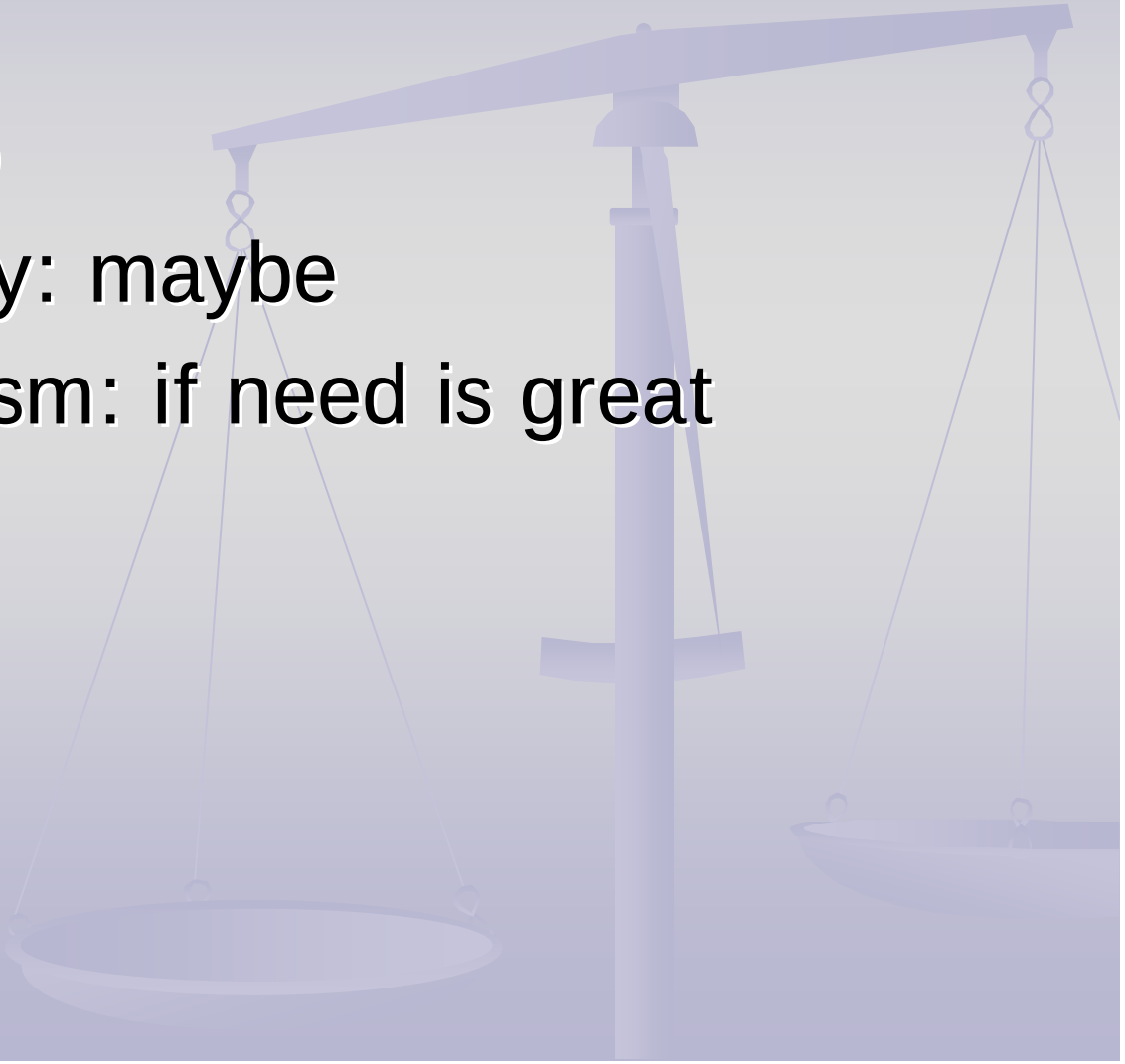
  - Potential ‘spin’: Privacy as collective good; personal information worth protecting

- Health information as collective good, based on public medicare system?
- Privacy as collective good, based on trust?
- Paradigm drives answer



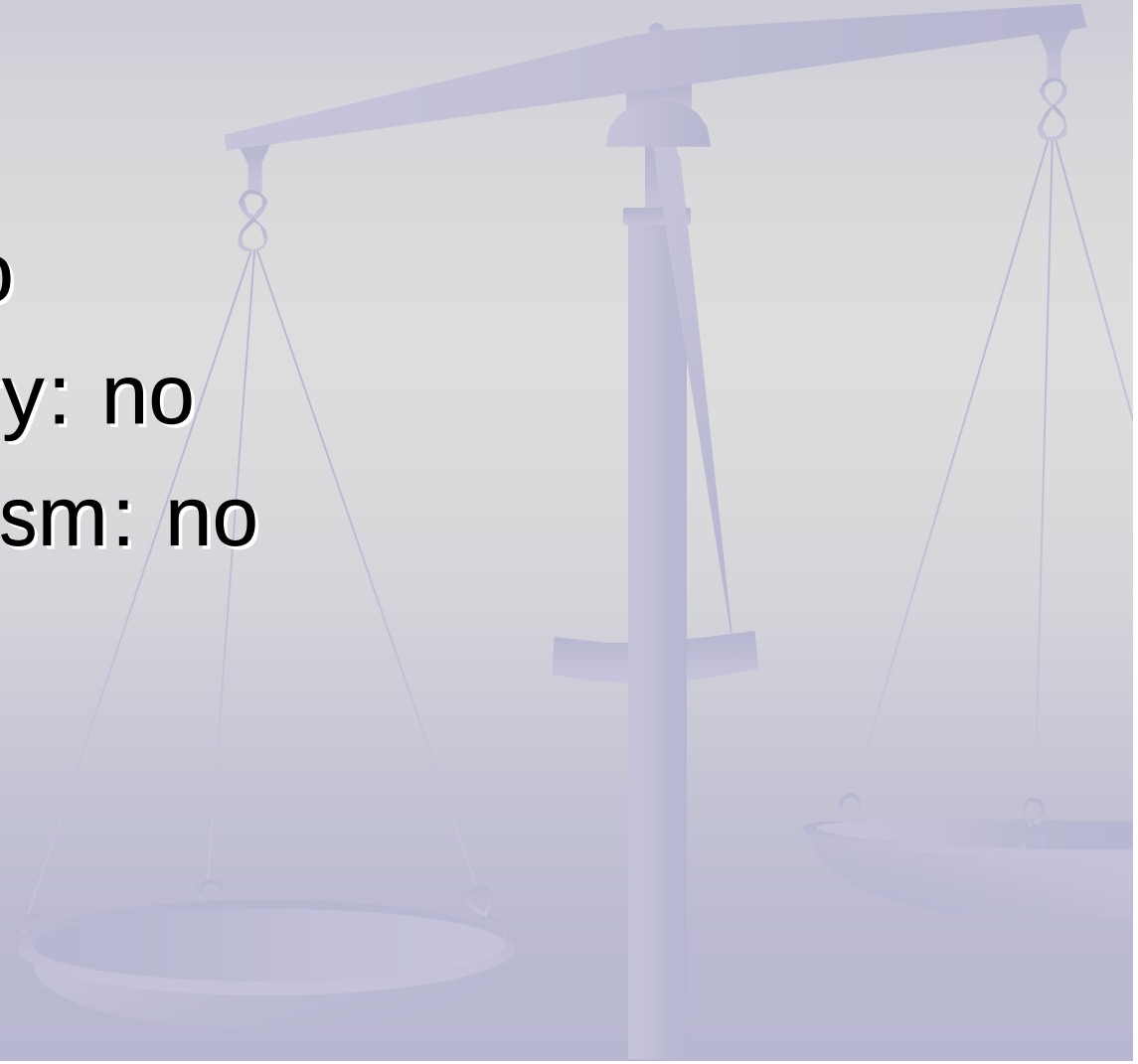
Is it legitimate to use personal health information without consent?

- Liberalism: no
- Free market: no
- Relational theory: maybe
- Communitarianism: if need is great



Is it legitimate to use personal health information without knowledge of individuals?

- Liberalism: no
- Free market: no
- Relational theory: no
- Communitarianism: no



Additional Factors to Consider:

- Sensitivity of information
- Degree of de-identification
- Commercial uses
- Aboriginal health information
- Social value to research

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