

Information, Privacy, and the Individual and Public Good

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Privacy as a Right Grounded in Autonomy

European Convention on Human Rights, Article 8:

“Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right . . .”

Privacy appears to be an absolute right grounded in the principle of autonomy.

Individuals control what information about themselves they wish to reveal and to whom and for what purposes and under what circumstances.



Respect for Autonomy

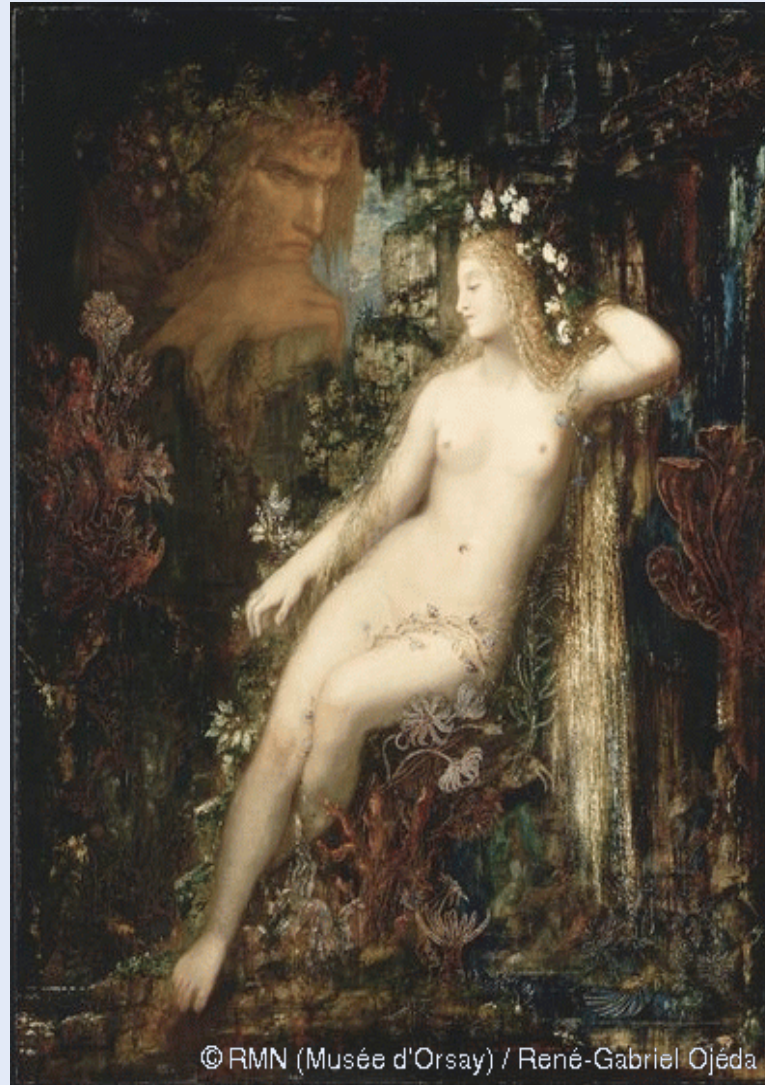
Each individual is a law unto himself or herself

Interference is not permitted in the right of others to decide from themselves about matters that involve themselves (uncoerced, if capable)

One of the four (five) principles of bioethics

Principles of Biomedical Ethics. Beauchamp TL, Childress JF.

Principles (self violated by others) view of privacy



Why Principles Won't Get the Job Done

- Underdetermination (prima facie rights)
- Indeterminacy (dilemmas)
- Balance implies higher principle
- Post hoc use
- Wrong model
 - Individual in relation to abstract principle
 - Individual in relation to others (private – public interface)

Privacy as a Relationship among Individuals

European Convention on Human Rights, Article 8:

“Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right **EXCEPT in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others.**”

We have to find a reasonable way to harmonize the interests of individuals and the community.

Information Has No Intrinsic Value

- Given away and still 100% retained
- Virtually no cost for duplication and transmission
- No value from duplicate accumulation
- Cannot be previewed
- Value of information is in its potential to change relationships



Invasion of Privacy: A First Peek

- Being forced or tricked into revealing information one would prefer were not known
- Issues of
 - Perspective
 - Nature or context of event
 - Use of information
- Primary and secondary invasion of privacy



Invasion of Privacy: Primary Sense



- Discovering others in compromised actions; asking embarrassing questions; hospital gowns that don't tie in back
- Immediate, irreversible, emotionally impactful violation of sense of identity
- Requires mutual recognition that violation has occurred
- Recognition that relationship has changed with respect to one's identity

Invasion of Privacy: Secondary Sense

- Using tissue samples from research for undisclosed purposes; selling lists of patients; loose talk about patients in the community
- Unfair use of information
- Principle of justice
- Four steps in the information value chain where privacy can be violated (unfairly used)



Information Privacy Value Chain

#1: Obtaining Information

- Health history, surveys, research data
- Straightforward exchange of valued information to get care, money, prestige, etc.
- Rule: It is unethical for others to exchange information when they would decline to do so if they felt the exchange were unfair

Information Privacy Value Chain

#2: Information Confidentiality

- Passing information on to third parties, use for non-disclosed purposes
- Source of information is entitled to share in the benefits of reuse of information
- Rule: It is unethical to deprive others of their share of the value deriving from information they provide

Information Privacy Value Chain

#3: Information Security

- Charts left in public places, failure to code research data to make participants anonymous, missing laptops
- An agreement reached between individuals for fair use of information can be presumed to be a private agreement that excludes others from benefiting from use of the information
- Rule: It is unethical to place less value on the information exchanged than the value assumed by the other party to the exchange

Use of Technology for Information Security



Information Privacy Value Chain

#4: Negotiating Information Exchange

- Explaining why information is needed, what will be done with it, confidentiality and security, reaching agreement
- Rational, mutually satisfactory understanding about use of information in particular relationship
- Rule: It is unethical to misrepresent, force, change one's mind, or collude regarding use of private information

Fundamental Principle of Information Privacy

- Informed consent frame:
 - Neither patient nor practitioner should have to engage in practices they would decline if they knew all the relevant information
- Equilibrium frame:
 - An ethical practice with regard to private information is one that neither the patient nor the practitioner would choose to alter

Common Conventions Regarding Agreements on Private Information

1. Either party can voluntarily terminate agreement if they feel they lack necessary information
2. Only competent and concerned individuals can participate in agreements
3. Confidentiality precludes access to information by all not agreed to need the information for purposes of agreement
4. Confidentiality will be waived if there is imminent danger to others
5. Reasonable steps will be taken to ensure security from unwarranted intrusion
6. Information will not be used for any purpose not previously agreed
7. Subsequent discovery of new information that has bearing on the agreement will be shared in a timely fashion
8. Either party may ask for reconsideration or may withdraw at any time

Invasion of Privacy Is Not Always What It Looks to Be



Full Symmetry of Information Privacy:

There is no privileged person or perspective

Practitioner/government Patient/public

Extraction

Dentist uses recognizable patient photos in CE talk after promising not to

Researcher bribes NIDCR employee to get information about future funding priorities

Imposition

Government propaganda on health issues, e.g., South African position on AIDS

Patient protests by blocking entrance to dentist's office, disrupting access of others

Ethics Based on Relationships Rather than Principles

- The concept of an equilibrium in relationships: There is always a mutual set of actions that guarantees neither party would be better served by doing something else
- Ethics is the practice of helping people find the equilibrium and protecting against people cheating to create false equilibria that unfairly favor them



Five Requirements for Creating Ethical Equilibria

1. The community owns the game: establishes the rules and some of the payoffs
2. Circumstances determine most of the possibilities and payoffs
3. All parties are assumed to follow more or less consistent self-interests
4. Empathy allows parties to see what others value and to realize that others see the same in them
5. Both parties are best off when choosing the equilibrium

Second-Person Perspective

- Mutually recognized empathy
(Criterion 4)
- Face-to-face relationship
- Recognizing one's self in other
- Possibility of interchangeability
- Not equality based on knowledge, position, circumstances
- Equality of personhood (the only basis for ethics)
- Patients and others are not *objects* of ethical behavior



Cheating

- Creating a *false* equilibrium for personal advantage by not playing the game fairly while expecting that others will
- Deception: Misleading others about what is at stake in the game
- Coercion: Denying others opportunities the community would expect them to enjoy
- Reneging: Failing to follow through on consequences after game has been played
- Collusion: Players agreeing to cheat the larger community

Examples of Cheating

Practitioner/government

Patient/public

Extraction

Dentist uses recognizable patient photos in CE talk after promising not to

RENEGING

Researcher bribes NIDCR employee to get information about future funding priorities

COLLUSION

Imposition

Government propaganda on health issues, e.g., South African position on AIDS

DECEPTION

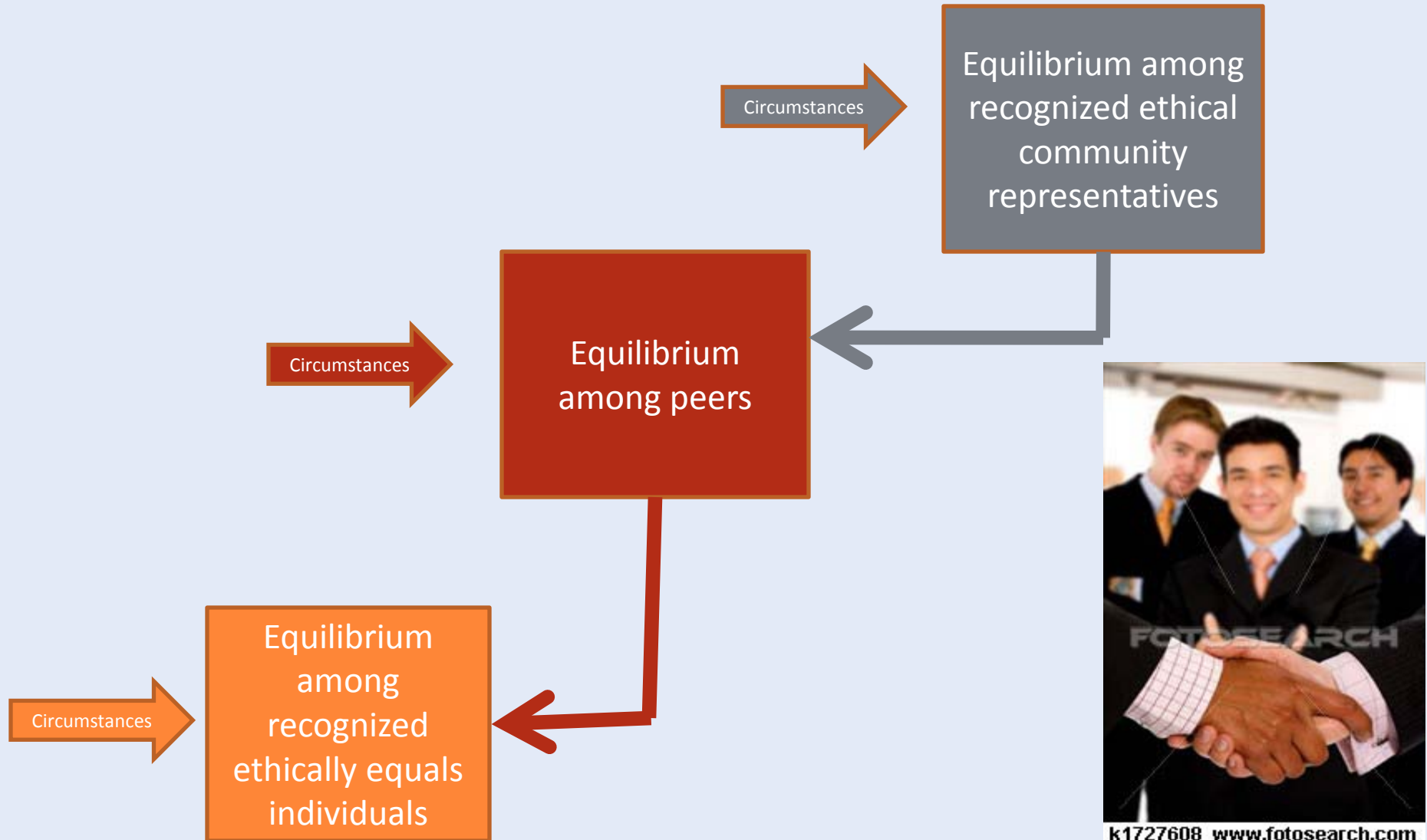
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COERCION

Role of Community in Information Privacy

- Community jiggles the balance of ethics by fine tuning the incentives that govern fair interactions among individuals (equilibrium)
- The community owns the game: establishes the rules and some of the payoffs
- Community can “cheat” by reneging on fair enforcement of the rules it has created

Nested Ethical Communities



Privacy as a Relationship among Individuals in the Context of a Community

European Convention on Human Rights, Article 8:

“Everyone has the right to respect for his private and family life, his home and his correspondence. No interference is permitted, except **such as in accordance with the law and is necessary in a democratic society** in the interests of national security, public safety, economic well-being of the country, prevention of crime or disorder, protection of health and morals, and protection of the rights and freedoms of others.” In accordance with the law

We may have found an ethical ground for privacy.

Role of Ethicists in Information Privacy

- Participate in the discuss at the community level: help shape the rules of the game and some of the payoffs
- Contribute to a just community by clarifying and establishing equilibrium – the mutual behaviors where no party would choose to behave differently

Where Is Your Place?



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