



“Do the right thing”

- Spike Lee
- Immanuel Kant



Outline

- History of privacy
- Ethical theories
- Categorizing privacy arguments
- The balancing act
- Using ethics in communications



History

- Privacy through the ages



Hippocrates



- c. 430 BC, near the beginning of formal medicine in Greece
- One of the first paid teachers of medicine
- Hippocratic oath
- “Whatever I see or hear, professionally or privately, which ought not to be divulged, I will keep secret and tell no one.”



Declaration of Geneva



- Adopted 1948, World Medical Association
- At the time of being admitted as a member of the medical profession:...
- I will practice my profession with conscience and dignity;
- The health of my patient will be my first consideration;
- I will respect the secrets which are confided in me, even after the patient has died;...



Louis Brandeis

- “[T]he right to life has come to mean the right to enjoy life, — the right to be let alone...”
- “It is like the right not to be assaulted or beaten, the right not to be imprisoned, the right not to be maliciously prosecuted, the right not to be defamed.”
- Violating the right to privacy violates the person.



Louis Brandeis 1890

- “Recent inventions and business methods call attention to the next step which must be taken for the protection of the person...”
- “[Technology has] invaded the sacred precincts of private and domestic life; and numerous ... devices threaten to make good the prediction that ‘what is whispered in the closet shall be proclaimed from the house-tops.’”

Universal Declaration of Human Rights



- UN
- Article 12: No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation



California Constitution



- Article 1, Section 1
- All people are by nature free and independent and have inalienable rights. Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and privacy.



Council of Europe



- Convention for the Protection of Human Rights and Fundamental Freedoms
- Right to privacy added 1990



Article 8 – Right to respect for private and family life

- Everyone has the right to respect for his private and family life, his home and his correspondence.



Public Law 104-191 §264

- The recommendations under subsection (a) shall address at least the following:
- The rights that an individual who is a subject of individually identifiable health information should have.
- The procedures that should be established for the exercise of such rights.
- The uses and disclosures of such information that should be authorized or required.



HIPAA preamble



- It is important not to lose sight of the inherent meaning of privacy: it speaks to our individual and collective freedom. — DHHS
- Few experiences are as fundamental to liberty and autonomy as maintaining control over when, how, to whom, and where you disclose personal material. – Janna Smith

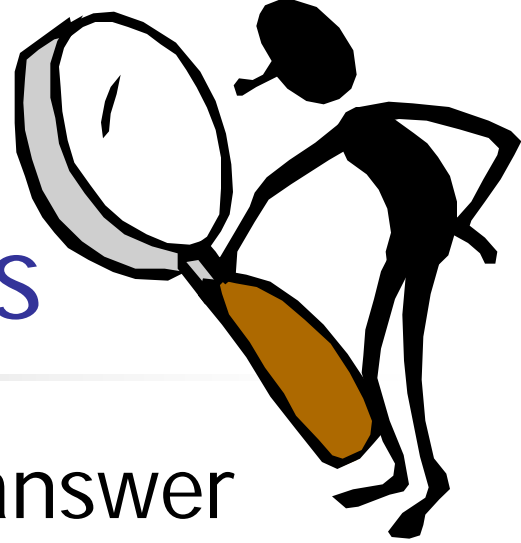


HIPAA preamble

- One in six Americans reported that they have taken some sort of evasive action to avoid the inappropriate use of their information by providing inaccurate information to a health care provider, changing physicians, or avoiding care altogether.
- Association of American Physicians and Surgeons reported 78 percent of its members reported withholding information from a patient's record due to privacy concerns



Different ethical lenses



- Ethical systems attempt to answer moral questions; distinguish right from wrong
- Different “right” answers
- Review of a few ethical frameworks
 - Ethics of consequences
 - Ethics of intentions
 - Ethics of rights
 - Ethics of character



Ethics of consequences

- Utilitarianism
- Jeremy Bentham, John Stuart Mill
- Do that which maximizes the good
- What is “good”?
 - Pleasure
 - Happiness
 - Justice and freedom
 - QALYS — quality-adjusted life-years
- Measure the outcomes, not the motives



Utilitarianism flavors

- Act
 - Gives case-by-case answers
 - Ignores “Justice”: e.g., hobo with TB
- Rule
 - Produce greatest amount good for society as a whole
 - Ignores exceptions: e.g., Anne Frank
- Practice
 - Justifies general practice but not each act



Ethics of Intentions

- Ethics of duty and respect
- Immanuel Kant
- “Do the right thing”
- Unlike utilitarianism, looks at motivations



Intentions

- An action has greater moral worth if it is done for the sake of duty
 - Duty, not self-interest
- An action is morally correct if its maxim can be willed as a universal law
 - Subjective rule that would be best for everyone to follow
- We should always treat humanity, whether in ourselves or other people, as an end in itself and never merely as a means to an end
 - Respect people; don't use them



Problems with intentions

- Devalues those who enjoy doing the right thing
- Emotional judgment doesn't count
- Actual consequence of act has minimal importance

More problems with intentions





Ethics of rights

- Ethics of entitlements
- Central role in politics today
- John Locke
- Negative right: entitlement to do something without interference from others
- Positive right: entitlement obligating someone else to assist you



Types of rights

- Natural rights (human rights): inherent to every human
- Legal rights: belong by virtue of being in a country
- Moral rights: justified by moral theory



Strength of rights

- Can have at most one absolute right, probably none
- Some trump others
 - moral equivalent of rock-paper-scissors



Strength example

- Right not to be tortured
- Right to live
- Right to private property
- Right to breathe unpolluted air
- Right to smoke



Declaration of Independence

- We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.



Nonsense on stilts — Bentham

- Who figures out what are rights?
- UN — Universal Declaration Human Rights:
 - No one shall be subjected to torture
 - Everyone has the right to own property
 - Everyone ... has the right to equal pay for equal work
 - Everyone has the right to rest and leisure, including ... periodic holidays with pay
 - Everyone has the right freely to ... enjoy the arts



Ethics of character

- Ethics of virtue
- Aristotle
- What kind of person should I be?
- Nourish both practical wisdom and uniqueness of each person
- Antireductionistic



Definition of a virtue

- Acquired, not inborn
- Involves both feeling and action
- Seeks the mean in all things
- “Prudent person” test for the mean



Examples of virtues

- Courage
 - Cowardice, Courage, Foolhardiness
- Compassion
 - Callousness, Compassion, "Bleeding heart"
- Self-love
 - Servility, Proper pride, Conceit



Problems with virtue ethics

- Fails to tell us how to act
- Must be complemented with ethics of action
 - Utilitarianism
 - Duty
 - Rights
 - Etc.



Arguments about privacy

- Consequences
- Rights
- Duty (e.g., Hippocratic oath)



Argument for privacy: consequences

- Bad things that happen when information gets distributed
 - Marketing
 - Identity theft
 - Loss of job
- Fear of telling doctor the truth



Argument for privacy: rights

- Autonomy: lose some when private information used without consent
- Ownership: the information belongs to the individual
- Privacy: the right to be let alone



Argument against privacy: consequences

- Infectious diseases
- Dangerous drivers
- Impaired practitioners
- Need to advance science



Argument against privacy: rights

- Autonomy: need to conduct our business
- Ownership: the information belongs to the person who developed it

Choosing between conflicting rights and/or consequences

- Conflict between individual and public good
- Research
- Public health
- Law, etc.
- How do you balance that which you cannot measure?





Article 8 – Right to respect for private and family life

- There shall be no interference by a public authority with the exercise of this right **except** such as is in accordance with the law and is necessary in a democratic society 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 or morals, or for the protection of the rights and freedoms of others.



Figuring out article 8

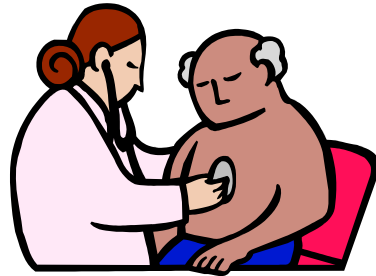
- Even if the infringement of privacy is in accordance with the law, and it is for one of the legitimate objectives, it must still be **proportionate** in order for it to satisfy *Article 8*. This is a very important requirement, meaning that the nature and extent of each interference must be evaluated with regard to the end to be achieved. This is often put colloquially as not using a sledgehammer to crack a nut. The more severe the infringement of privacy, the more important the legitimate objective in each case will need to be. It is likely that this will involve deciding whether the interference is required by a pressing social need, and analyzing the extent to which an alternative less intrusive interference would achieve the same result.



Use as a communication tool

Traditional medical viewpoint

- Doctor-patient
- Rest of world does not exist





Broadening the ethical arena

- Physicians used to moral decisions, but in a limited arena
- Consider effects (consequences) on others
- Consider interests (rights) of others
- Use their ingrained drive to “do the right thing”



References

- *Ethics: A pluralistic approach to moral theory*, by Lawrence M. Hinman
- *Defining moments: When managers must choose between right and right*, by Joseph L. Badaracco, Jr.
- *Pursuit of Privacy: Law, Ethics and the Rise of Technology*, by Judith Wagner Decew



Case study

- A judge has ordered Planned Parenthood officials to turn over within a month the names and addresses of women who took pregnancy tests at a Storm Lake clinic. The names and addresses are a last resort for county authorities, whose search has stalled for the mother of a newborn baby found dead at a recycling center in May.



The clinic refuses to obey

- “Astonishingly, PPGI apparently considers itself and its personnel to be above the law and not required to respond to a valid issued and served subpoena,” wrote Nelson, a Clay County judge.
- ... no doctor-patient privilege exists because Planned Parenthood employees don't have to be doctors or nurses to give pregnancy tests.



Who's right? Whose rights?

- Three other clinics in Buena Vista County have turned over pregnancy-test records, authorities said.