

What future for privacy?: reflections on the ethical brief on PETS

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Privacy no more...

Developments in both medical informatics and bioinformatics show that the guarantee of absolute privacy and confidentiality is not a promise that medical and scientific researchers can deliver any longer

(Lunshof, Chadwick et al, 'From genetic privacy to open consent' *Nature Reviews Genetics* April 2008)

Points to consider

- Changes in ethics, context important
- Misleading to ‘trade’ privacy for other things such as consent?
- Other principles or concepts may be more useful
- Why so concerned about privacy?

Three types of challenge to privacy

- (1) Intentional
- (2) Side effects of new technologies
- (3) Cultural change: the new exhibitionism

Three types of challenge to privacy

- (1) Intentional
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(1) Intentional

- Surveillance and security
- Governments and corporations
- Trade off
- Compare discussions about related concept of confidentiality in clinical genetics

(2) Side effects

- Collection and storage of information, data mining
- Forensic databases (third parties)
- Mobile phones
- Genomics

Phones: Sports Tracker

When Disklabs [a company that specialises in forensic use of mobile phone data] ran it through Google Maps and Street View, they were able to pull up images of the front of my office and my home – with the house number clearly displayed (Geddes, 2009)

Sports Tracker

- Sports Tracker also recorded what time I normally leave the house in the morning and when I return from work (Geddes, 2009)

Phones of the future

Nokia is experimenting with adding biosensors to phones capable of monitoring heart and breathing rates, as well as glucose and oxygen levels in the blood

Threats to privacy in genomics

- Privacy can be violated by forces beyond individual or institutional control
- Reidentification of individuals is possible through genotype - phenotype inference.

Developments in sequencing

- Now rapid advances in sequencing – comprehensive data sets to establish informatics links among ten thousand to a million human genome sequences and extensive phenotype analyses enable the identification of individuals whose sequences they contain

Aspects of privacy

- Informational privacy concerned with limits on access to personal information – confidentiality, anonymity and secrecy are related concepts
- ‘Genetic privacy’ emerged following the disclosure of the ‘invisible’ part of heredity at the molecular level as opposed to individual and family health history

Group privacy

- Whether it is based on genetic or other traits, it is argued that conventional individual privacy protection misses the point. It does not work in the case of non-distributive generalisations about groups in which the individual profile is indiscernible from the group profile.

Categorical privacy

- The concept of ‘categorical privacy’ has been proposed to overcome the inadequacies of traditional individual-centred concepts.

Responses?

- Privacy threatening technologies
- Privacy enhancing technologies (PETS)
- The ‘design turn’ in ethics
- Changes in expectations on part of the data subject?

c.f. open consent

- Research participants expect that:
 - Their data could be included in an open access public database
 - No guarantees regarding privacy etc
 - Participation involves a certain risk to self and others
 - Participation does not benefit participants in any way

Knoppers: Consent to personal genomics and privacy

“total protection of privacy is increasingly unrealistic in an era in which DTC genetic testing is offered on the internet”

“contexts of minimal risk.. Require structural governance reforms rather than the application of traditional ethics: consent and privacy” (EMBO reports, 2010)

(3) The new exhibitionism

- Physical – tattoos
- Informational – social networking, blogs
- Context and choice – there may be different expectations in different contexts (cf. Nissenbaum)?

Possible explanations for different perspectives

- The logic of the context – internal goods
 - E.g. medicine and friendship
- External goods (can be differences within a context too)
- Differences between publics e.g. generational
- Agency
- The qualities of the information
- Inconsistency

Agency and choice

- Is it a matter of choice?
- Revelations about third parties
- Cumulative effect of personal choices?
- But closely connected with why privacy is valued

Negotiating the internal-external boundary

- Emerging trends in ethics
- Norms applicable in a context can change – is this what is happening in medicine?
- Cf Bartha Knoppers

Privacy futures

- Dystopias
- Margaret Atwood *A Handmaid's Tale*
- Marge Piercy *Body of Glass*
- Possible utopia?

Reflections on the ethical brief: points to consider for insertion or

1. Definition of privacy (?)

- Spatial
- Informational
- Decisional

2. Death of privacy?

- Informational security the better concept?

3. Enhancing privacy

- Concept of enhancement?
 - Why enhancement?
 - How: anonymisation vs data minimisation
 - Quantitative or qualitative?

4. Solutions?

- Trade-off
- Win-win?
- Political commitments

5. Only connect...

- Different contexts e.g. genomics
- ‘Right to privacy’ versus norms of information flow
- Norms in a state of flux

6. Private-public spheres

- What is public?
- The notion of a public space
- Twitter etc

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