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# International data-sharing: standardisation, harmonisation and ethics

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# Michael Jackson

- Who's watching me
- I don't know anymore  
Are the neighbors  
watching me  
Well, is the mail man  
watching me  
(Tell me who's watching)  
And I don't feel safe  
anymore  
Oh, what a mess  
I wonder who's watching  
me now  
(Who)  
The IRS
- I always feel like  
Somebody's watching me  
And I have no privacy  
I always feel like  
Somebody's watching me  
Tell me is it just a dream



# Chinese policeman



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# What I have to say

The issues: data, infrastructure, interpretation

Emphasis on **frameworks of interpretation**

‘Only connect’ – between **spheres** of interpretation

Standardisation can take us only so far

Privacy – trumps, trades or **transparency?**

In ethics harmonisation – multiplicity of voices - is important

# The **issues**: international data-sharing

3 categories

- The data
- The infrastructure
- The framework of interpretation

# The data

- Informatisation of the body (van der Ploeg)
- Identifying information
- Collection, storage, sharing and access
- Interoperability and exchange
- Values and interests in tension

# The infrastructure

- Technologies
- Privacy threatening technologies
- Privacy enhancing technologies (PETS)
  - Pseudonymisation
  - Data minimisation
- The ‘design turn’ in ethics
- Governance instruments (ethics and regulation, e.g European Directives)

# Secure IDs and Human Rights: The Case for Secure Foreign Resident ID Documents in Costa Rica

**Monday, June 29, 2009**

Costa Rica's express will to endow its immigration laws and policies with the responsibility for achieving the highest standards of human rights gave rise to a people-centric ID card program that inextricably links document security with individual rights. Setting a clear framework in which human rights are prioritized enabled technology choices that reflected the need to safeguard individual information, privacy and personal identity without sacrificing the state's ability to protect itself.



From the start, the government of Costa Rica was unambiguous in its commitment to link such measures to Human Rights.. the overriding goal of the new legal framework was to ensure protection of Costa Rican citizens' rights and to spell out the country's obligations to assist legal migrants.. Additionally, the country aimed to integrate migrants by encouraging their active participation in philanthropy and social work, and promoting their contribution to the nation's well-being and stability.

An essential aspect of the transformation was replacement of the country's paper-based foreign resident documents with a highly secure, counterfeit-resistant Foreign Resident ID card. Based on optical memory technology, the nation's new "DIMEX" cards introduced in 2008 provide multiple tiers of security and the ability to securely store and protect large quantities of personal and biometric data.

Further, the solution addressed privacy considerations since each individual carries his own data rather than having it accessible from many points online, which carries the associated risks of potential database hacking. Confidential personal data is stored in a zone that only a customized secure inspection reader can access. All data is unalterable and what is readable at will is limited to the most basic information. Placing the data within a card that is under the personal control of each individual also takes a major step forward in ensuring that the data will only be shared under the principle of informed consent.

# Governance and regulation: a standard?

- UK Biometrics Industry Signs Up To Brand New Guidelines 29 June 2009
- The first ever occupational standards for the UK's human identity and biometrics industry have been introduced following unprecedented growth in the sector - which now has an estimated value of over £250m.

# National Occupational Standard for Human Identity and Biometrics

You should be able to recognise what information is required to be confidential and what can be shared

You will be expected to know and understand why it is important to conserve confidentiality

But framework of interpretation?



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# The Butler and Wilson eye

- Big brother?
- Fashion icon?

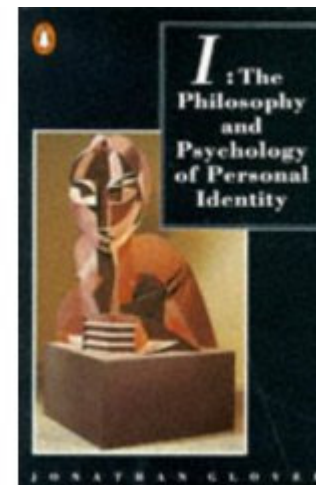
# Frameworks of interpretation

- Conceptual
- Ethical
- Social context
- Different spheres
- Different **meanings**

# Frameworks: conceptual

Identity – different meanings in different contexts cf. ‘self-creation’

Mind-body dualism



# Conceptual cont.

- Identification and verification
- Facial recognition and diagnosis (by ‘look’)
- Privacy (e.g., spatial, informational, decisional)
- Privacy (liberty vs oppression)

# Frameworks of interpretation: ethical

- Social context
- Different traditions: American values, European values, Asian values
- Different spheres (cf Walzer's *Spheres of Justice*)
  - Security context; medical context

# Different spheres

- Ethical issues concerning function creep and subversion suggestive of need to look at different spheres

# Health: rationale for data sharing in biobanks

- Biomedical quality-assessed samples and data as well as biomolecular resources and molecular analysis tools are essential for clinical, academic and commercially-driven research to treat and prevent common and rare human diseases, including cancer. Although currently established biobanks and biomolecular resources are a unique European strength, valuable national collections typically suffer from fragmentation of the European biobanking-related research community.

# Harmonisation

- Therefore harmonisation, both in science and in ethics, is necessary
- BBMRI initiative (Biological and Biomolecular Resource Infrastructure)

# Is it possible – in ethics?

- What does it mean?
- Harmonisation: making a system consistent
- Harmonisation or standardisation?
- Standard - one mechanism of harmonisation?
- Not enough – as ISO example shows

# Standards

- Standards as action-guiding
- Driving example (Busch)
- Who has the power to set the standards ?



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# Harmonisation

- In ethics, tends to be discussed in terms of ‘global ethics’ and end point view has tended to predominate
- Pragmatic guidelines or something more?
  - Human rights model (cf Costa Rica example)
  - Necessary conditions model
  - Cultural dialogue model (Fleishacker)

# Human rights model

- E.g. Universal Declaration on Bioethics and Human Rights 2005
- Criticisms include:
  - Rawlinson and Donchin
    - Concept of universality
    - Need for contextualisation

# Necessary conditions model

- Requires agreement on purposes to be achieved
- This may be a significant part of the problem
- Contested in the health context (opportunity costs)
- Contested in security context?
  - Surveillance societies
- Necessary conditions for human society

# Necessary conditions

- Ethics and conflicts of interest
- Different interests of different people e.g. power versus freedom
- Different interests of same people e.g. liberty versus security
- Same interests of different people e.g. organs

# Cultural dialogue model

- Fleishacker: production of a universal ethic  
- a very long process
- cf Karl-Otto Apel – incorporation of hitherto unheard voices (important in the security context, because of implications for marginalised or identity-*less* groups)

# Key points

- Multiplicity of voices
- Necessary conditions – relation to purposes
- But problem with seeing harmonisation as an end point
- Harmony as a process

# Unison versus harmony

- Harmony as a process – build on musical analogy
- Standards plus scope for variation
- Framework of interpretation – different performances of same work
- Not only between but within societies
- cf China – coexistence of eugenic/one child discourse and emerging privacy discourse

# Harmonisation and process

- It seems natural and right that music which is ... harmonious, should be highly regarded in civilised societies...there is a clear correspondence between the concept of society as a mutually supportive commonwealth, and those manifestations of concert and theatre music which attract the collective approbation 'civilised'.

## continued

- Collective performance, as in singing the same text to different but interdependent vocal lines, can be regarded as the musical correlate of civilized democracy (Whittall, 2002)
- But democracy itself not universally embraced – this is part of the issue of different frameworks of interpretation

# Identification of areas for standard setting in health and security: the ‘text’ around which the harmony plays

- Example of privacy

Here much to be learned from the ‘sphere’ of health

# Scope for variation/improvisation?

- Privacy – need for rethink (Lunshof et al, 2008) - in what areas is it an issue and can it be guaranteed?

# 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, *Nature Reviews Genetics* April 2008)

# 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

# Aspects of privacy

- Cf ‘informatisation of the body’
- 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

# Group privacy

- Whether it is based on genetic or other traits, 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.

# Threats to privacy

- Privacy can be violated by forces beyond individual or institutional control
- Reidentification of individuals is possible through genotype - phenotype inference, and ‘dictionary attacks’.
- L-diversity – a method for the protection of privacy against adversaries with background knowledge (design turn)

# From privacy to **veracity**

Individuals should realize that their data can be and likely will be accessed, shared and linked to other sets of information, and that the full purpose and the extent of further usage cannot be foreseen.

Alternative solutions are scarce. The most likely pragmatic solution would entail maximizing data protection while informing people about its limits.

# Trumps, trades, transparency?

- What form should a standard take and what scope for variation/harmonisation?
- Trump card? Setting the beat (OECD)
- Trade-off? Variations
- Replace with a different value? Can lead to discord

# Summary/Conclusions

Need for attention to frameworks of interpretation – includes but goes beyond ethical analysis

Standards can be set but important to look at ongoing process of harmonisation in relation to those, and scope for variation

Much to be learned from setting debate in context of what is going on in other ‘spheres’

# Summary/Conclusions

- May be a mistake to think in terms only of trade-off between competing values – consider options of trumps or replacement as well
- Negotiation over the nature of the problem and identification of areas of possible conflict prerequisite
- This requires listening to less heard voices

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