



THE STATUS AND CHALLENGES FOR HEALTH PRIVACY PROMOTING THE EVOLUTION OF HEALTH PRIVACY REGULATON

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|| The Regulation of Health Privacy

Principle based not rule based

Evolution from regulators not courts

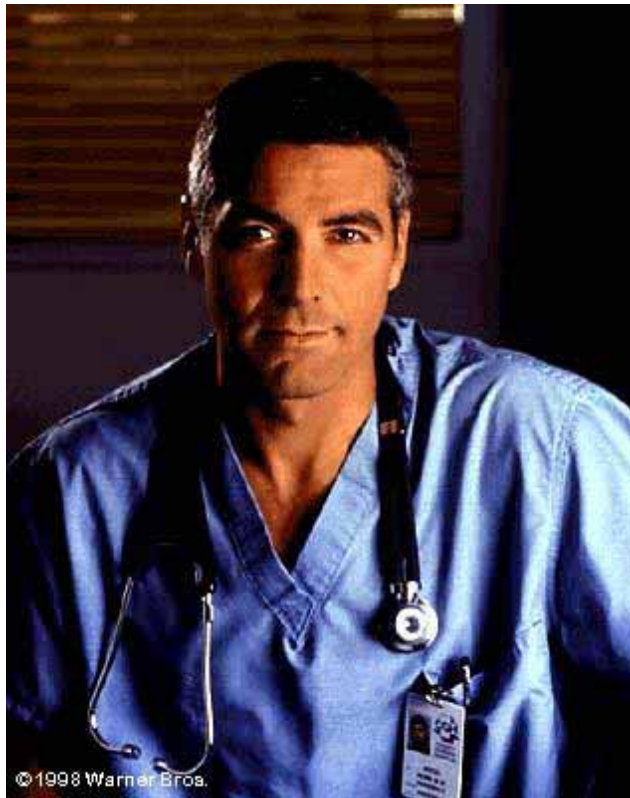
Evaluative Terms

- Reasonably ascertainable
- Reasonable expectations



Opposing views

Doctors



Regulators



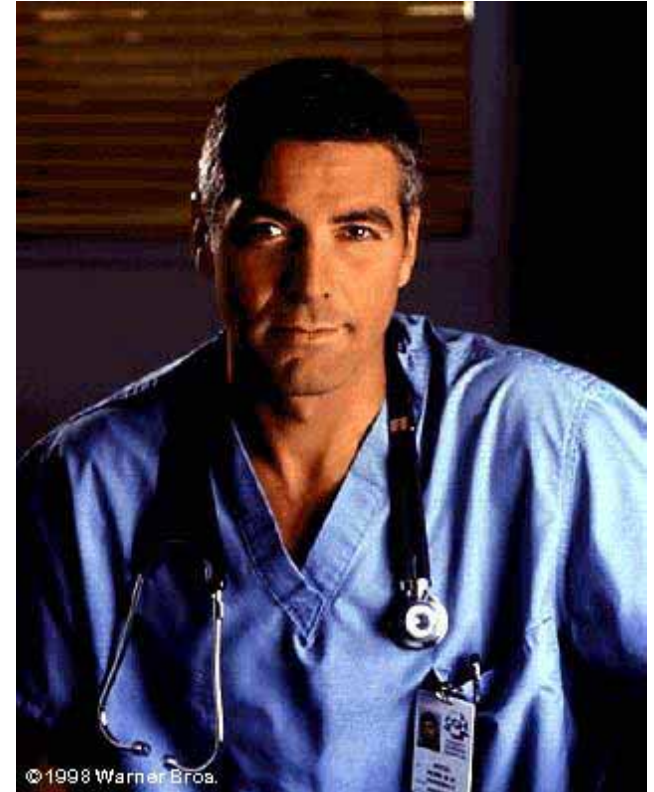


||| Opposing views

Doctors



Regulators



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Occupational Health and Safety

Principle based not rule based

Manual handling

Major hazards facilities

Evaluative Terms (reasonably practicable)

Evolution from regulators not courts

Occupational Health and Safety

Differences

- Single regime – clear justification
- Good data
- Criminal sanctions - publicity
- Motivated 'customers'



Justifying a specific regime for health privacy regulation

Information is more sensitive?

If so, strict definition but broad controls.

Need more ways of collecting / using / distributing?

If so, broad definition but strict controls.

|| Justifying health privacy regulation

Do you think that medicine and science have the potential to help us live longer, healthier, lives?



|| Justifying health privacy regulation

Do you think that hospitals should monitor the quality of their operations to maximise patient safety?



|| Justifying health privacy regulation

Do you think that doctors need all relevant information about a patient in order to make the best decisions?



|| Justifying health privacy regulation

Do you support the disclosure of health information?



|| Justifying health privacy regulation

Do you trust large corporations to have your best interests in mind when they make decisions?



|| Justifying health privacy regulation

Do you think that computer security is sufficient to keep us safe from hackers?



|| Justifying health privacy regulation

Are you comfortable with people you've never met using your information without your permission for purposes you've never heard of?



|| Justifying health privacy regulation

Do you support the disclosure of health information?





|| The problem of anecdotal data

- Patients withholding important information
- Hospitals requiring consent before providing discharge summaries
- Practitioners refusing access to information
 - to patients
 - to other practitioners





Justifying health privacy regulation

Ethical – almost aesthetic – concerns

Speculation about how the health industry handles health information



Anecdotal



|| The problem of anecdotal data

Are these problems widespread?

Has Health Privacy legislation caused these problems?

Can the worst aspects of these problems be solved outside Health Privacy legislation?





Publicity

Complaints handled by specialist agencies

Don't go to court; rarely get in papers

Gatekeeper professions limited



If it bleeds, it leads



Reactive regulation





Publicity

The more that people are aware of the issue:

- debate is buttressed against crisis
- likelier to consent to use / disclosure
- understand what patients 'reasonably' expect
- accept a higher price for security



|| Motivated 'customers'

Learning to take advantage of options

Consent forms

Implied consent

De-identifying information



Summary – challenges of Health Privacy

Defining the problem(s)

Engaging the community

Educating stakeholders

Achieving consensus





Summary – challenges of Health Privacy

Deciding whether the legislation does what we want it to do

