Big Data in Medicine: Data Protection Policies and Regulations

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- All the work, opportunities rest on the regulatory/ governance framework in which it is set.

- What's the problem? *Consent-driven individualist autonomy allows those who want to, to opt in, and that's privacy respecting and sufficient.*

  - Adequate for modern and future medicine as outlined by Peter Drury?

  - De identification only works for some research - e.g. double counting, or longitudinal work.

- Data Protection is Not the Problem

- The Privacy paradigm is a problem

- Where is the solution?

- Data Protection is not the Problem? - Qualified

  - Shared international basis but not harmonisation:

    - OECD 1980; CoE 1981; National Law

    - EU 1995

    - Revisions: OECD 2013, 2016; CoE 2018; EU GDPR 2016 national law, e.g. Canada, Australia, New Zealand, Japan

  - Variations on a common theme of "personal data protection"

    - Not just privacy, but privacy is a strong narrative running through the justifications for data protection.

GDPR 2016/679

Arts. 15 – 22
Data Subject Rights

Arts.
6 and 9

Routes to
Lawful
Processing

Arts.
13–14

Information
Provisions

Art. 5 - Data Protection Principles
(+ **Impact assessments - Art. 35**;
DP by design Art. 25;
Codes of Conduct - Art. 40)
increased sanctions

GDPR 2016/679
Linking already
gathered data

Withdrawal
"Right to be forgotten"

Arts. 15 – 22
Data Subject Rights

Informed
consent
Narrow/broad
Perishable?

Notification
and re-consent

Arts.
6 and 9

Routes to
Lawful
Processing

Arts.
13–14

Information
Provisions

Public
interest

Compatible
processing

Art. 5 - Data Protection Principles
(+ **Impact assessments - Art. 35**;
DP by design Art. 25;
Codes of Conduct - Art. 40)
increased sanctions

Data minimisation
Time
Amount

Data Controller
Data Processor

Transparency

- The Privacy Paradigm is a/the problem

  - The "Privacy" in privacy preserving is not understood

  - Clearly there are needs for protection about the results of processing personal data - fears about insurance, employment, mortgage - *consequential losses*

    - Not unfounded - unilateral variation in (State) contracts

    - But this is negotiable - see Murray 2009 Nuffield Lecture

    - altruism in, altruism out - reduce fears by evidence and fairness

  - But how far should we entertain the *fundamental loss*?

    - Where there is a breach and that is the only loss - almost a theoretical loss - someone might know something

    - Non-negotiable - part of the individual's identity (Murray)

- The Privacy Paradigm

  - not absolute - UDHR Art 12; ECHR Art. 8

  - "My data" - GDPR - "data that relate to an identified or identifiable individual"

  - Individualist - respecting "autonomy" - "get off my land" presumption

    - But contradiction - we want to be cured - requires (?) solidarity

    - What is the nature of liberal individualism? Shift in liberalism from 1970s

      - cf. Adam Smith *The Theory of Moral Sentiments*

      - Free up to harming others (Mill), whilst there is enough for others (Locke)

      - Not treating others as merely means to our ends (Kant), or accepting the reasonable intrusion on my self-interest (Rawls)

- A Question of Government

  - Is this a matter for individual choice, or for public policy?

  - Representative democracy not same as majority rule - a question of managing self-interest

    - See Jonathan Sumption, BBC Reith Lectures 2019 https://www.bbc.co.uk/programmes/m00057m8

- Who are we legislating for? Need to make the connection between "not-yet-patient" - patient - researcher

  - Who is a legitimate researcher? What is legitimate research? (For solidarity-based access to data?)

    - Research - including "applied research"

    - Outcome rather than category of data (e.g. consumer/health link)

- So...

    - Big Data and AI in medicine needs a different understanding of data use from the doctor-patient discrete interaction model - but accords with ends that are socially desirable (not just what majority want)

    - DP protection law already has the potential to work for big data

    - Privacy is not absolute, and the relationship is (arguably) not only an individual choice but of public policy in response to publicly expressed aspirations and contradictions

- How?

    - Data science safeguards - from trust to proof?

        - Changing the areas for fears in relation to consequential loss

    - A strong story from medicine and science in a language that the public can understand and become excited about

    - A strong political response: lobbying of decision-makers to take a courageous lead in regulation *in the public interest*

        - *EUDPB; National Supervisory Authorities; DPOs*

- Thank you

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