Privacy and evolving norms for using personal information

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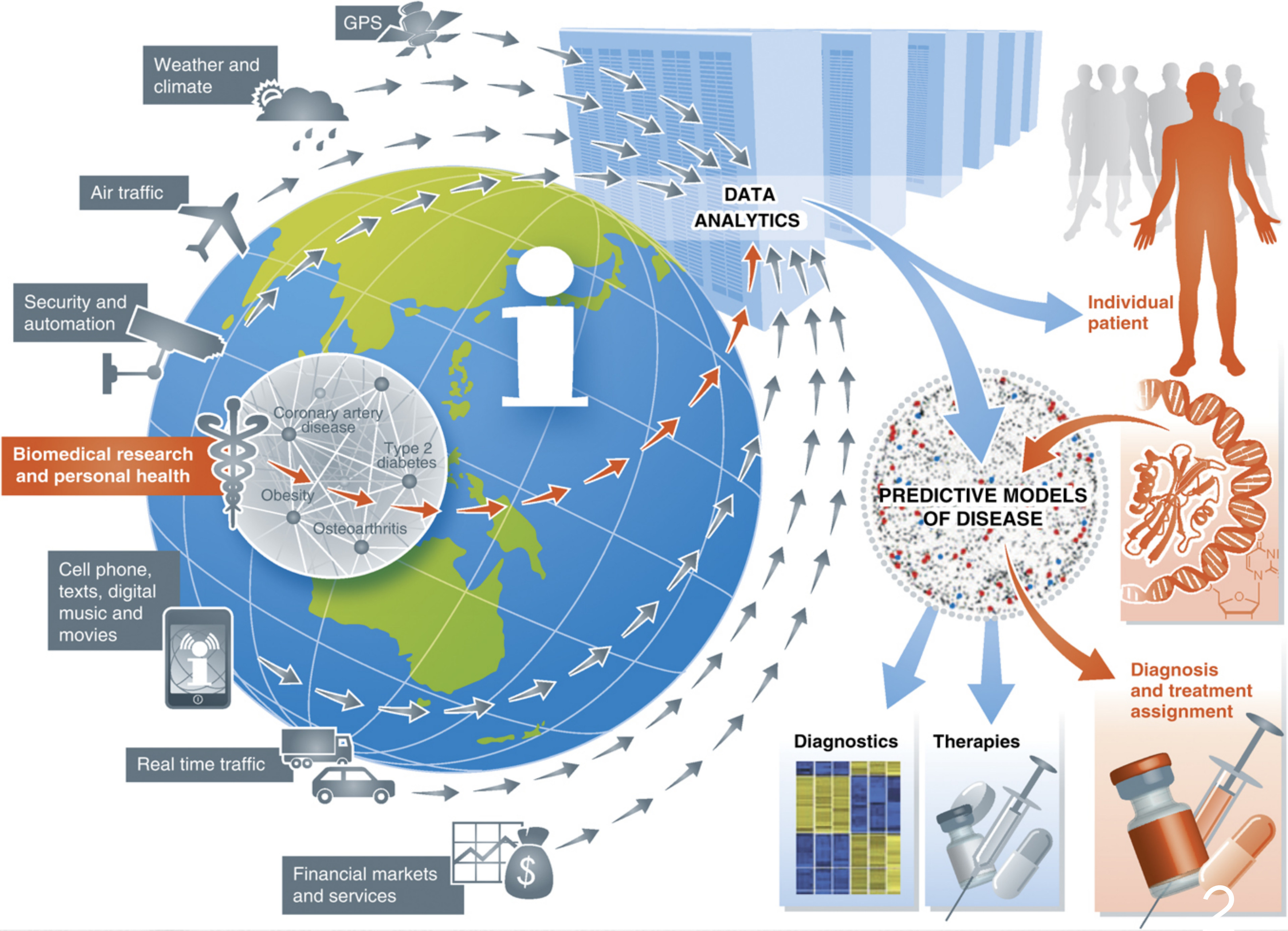

Eric E. Schadt, The Changing Privacy Landscape in the Era of Big Data, *Molecular Systems Biology* 8, 612 (2012).

Themes

1. Reconciling science and law
2. OECD Recommendation 2017
3. Other positive trends: the GDPR?
4. Modifications to data sharing
5. Conclusion

1. Reconciling science and law

- Data protection premised on silo-building
- Regulators did not follow evolution of scientific research but focused international trade
- OECD 2012 report documents negative impact of regulation on effective and cost-efficient health care delivery
- Data protection legislation a significant barrier to improving health outcomes

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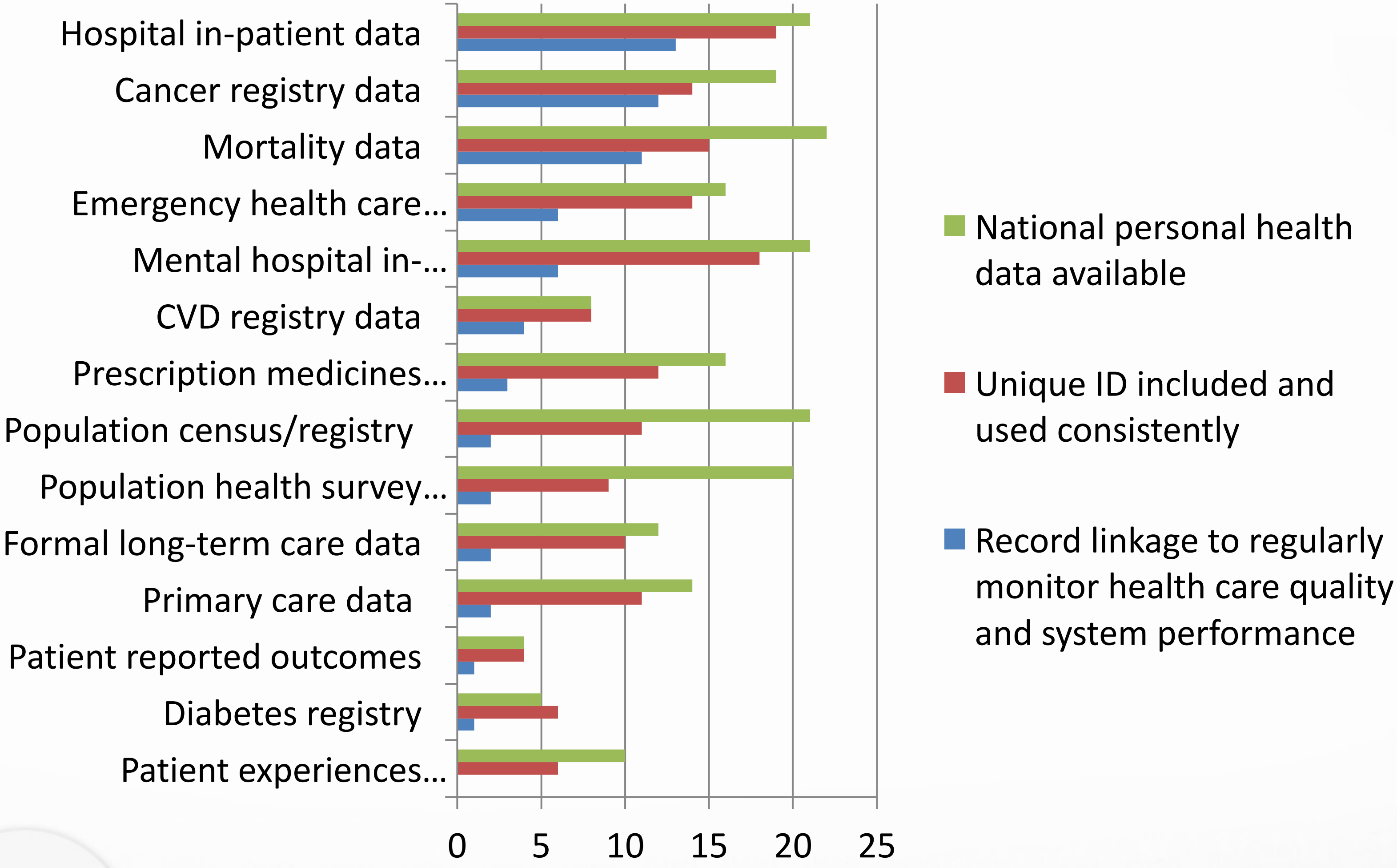
OECD Study of Health Data Governance

- Project of the Health Care Quality Indicators Expert Group in 2013/14 to:
  - Uncover and document governance practices and
  - Identify governance mechanisms to enable privacy-protective data use
- Guided by experts in law, privacy regulation, IT, policy, statistics, and research
- 22 countries participated in 2013-14

Little data linkage in key areas



OECD takes up the Challenge

- OECD work documents negative impact regulation on effective and cost-efficient health care delivery
- Join health and privacy/security committees 2014
- Member countries appoint experts for additional input
- Results in Recommendation on Health Data Governance for OECD meeting of health ministers Jan 2017.

2.OECD Recommendation on Health Data Governance 2017

- Access and processing personal health data brings social and individual benefits
- Volume of electronic data, often in various public sector silos, can be linked and analysed for significant public interest purposes
- Still need to maintain public trust and confidence, foster compliance privacy laws and policies

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OECD Recommendation

IV. OECD recommends “that governments <u>support transborder cooperation in the processing of personal health data</u> for health system management, research, statistics and other health-related purposes that serve the public interest subject to safeguards consistent with this Recommendation” and

i. “Identify and remove barriers to effective cross-border cooperation …”

ii. “Facilitate the compatibility and interoperability of health data governance frameworks.”

Data governance to maximise benefits and minimise risks

8 key mechanisms

1 Health information system

2 Legal framework

3 Public communication plan

4 Certification or accreditation of processors

5 Project approval process

6 Data de-identification steps

7 Data security and management

Evaluate benefits and risks of proposed data uses

Benefits

- Rights to health
- Societal values toward health
- health care quality & efficiency
- scientific discovery & innovation

Risks

- Rights to privacy
- Societal trust in government & institutions
- Societal values toward privacy & sharing data

Take informed decisions to process personal health data

KEY ELEMENTS OF A MONITORING PLAN

Key Elements

Co-ordination between agencies

Specific, actionable provisions

Open to non-members

NGOs encouraged to adopt measures and principles

Monitor progress through HC & CDEP

Report to Council in 5 years

12 Key elements to establish and implement National health data governance frameworks

1.Engagement and participation	**UK** public consultation on data security and opt-out model; **Wales** SAIL consumer panels and outreach
2.Coordination and cooperation	Iceland ministry agreement; **UK** Farr Institute harmonisation work
3.Capacity of public sector health data systems	**HCQI** reports
4.Clear provision of information	**UK ICO** website check list; Canadian privacy breach toolkit
5.Effective consent and choice mechanisms	Provisions of the legislation in **Iceland** and **UK**
6.Approval procedures for the use of personal health data	Role of **Israel's** REB; Norway's Regional REC; **New Zealand's** REB

12 Key elements to establish and implement National health data governance frameworks

7.Public disclosure and transparency	Netherlands' RIVM website about data; Finland THL's website about applying for access and approvals
8.Maximising use of technology	Korea's HIRA data use and reporting; Kaiser Permanente big data applications
9.Monitoring and evaluation mechanisms	No examples (new activity)
10.Training & skills development in privacy and security	USA NCHS and Finland THL's training of employees and external researchers
11.Controls and safeguards	CIHI website of policies; Canada best practice guidelines; UK code of practice; New Zealand guidelines
12.Demonstrating expectations have been met	UK accredited safe havens; Australian Accredited Integrating Authorities

3. Other positive trends: the GDPR May 2018

- Research occupies privileged position within GDPR (Maldoff)
- Organizations processing for research purposes can avoid restrictions on secondary processing and sensitive data (art 6(4), recital 50)
- With appropriate safeguards can override objection to processing or request for erasure (art 89)

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General data protection regulation

- Consent may not always be needed for research purposes (art 6 (1) (f), recital 47,157)
- In isolated cases may transfer personal data to third countries for research purposes without other data transfer mechanism (art 49 (h) recital 113)
- Research includes activities of public and private entities (recital 159)

What is research

- Scientific research defined in broad manner (recital 159)
  - technological development
  - fundamental research
  - applied research
  - public health research
  - privately funded research

- Question re corporate research which does not circulate

Code of Conduct

- Article 40(1) of the GDPR
  - "The Member States, the supervisory authorities, the Board and the Commission shall encourage the drawing up of codes of conduct intended to contribute to the proper application of this Regulation, taking account of the specific features of the various processing sectors"

- Clear guidance on duties
  - standard for identifiability
  - data "controllers" vs. data "processors"
  - data subjects' rights: including the right to object, data portability, to access, to erasure, etc.

4. Modifications to data sharing

In France, the CNIL has been pulled back from the authorization of research projects

only does periodic audits

In Canada, major study 2015 emphasizes need for streamlined data access process.

Ontario creates new body, ICES ,to prepare data for researchers

Quebec clings to opaque, slow, formalized process

Ongoing challenges

- Data breach apprehension generally
- Increasing penalties and publicity make many administrators wary of sharing
- Media attention on scams, impropriety
- Public alarmed by misuse of personal information
- Growing class action activity

Challenges to data sharing

- Governments espousing open data approaches without a sophisticated understanding effects on privacy

- Unfortunate early example of data mining without respecting existing safeguards (Google Deep Mind and UK Royal Free Hospital)

5. Conclusion

- Data protection philosophy is evolving and taking into account scientific and technological needs
- BUT there may often be a less relaxed environment for research as increasingly strict sanctions for data misuse
- Fundamental approach to data protection is still to build a wall against everything

Future actions

- Need for ongoing conversations across sectors and among data regulators, health researchers, platform designers, etc.
- Research community needs to make working prerequisites appreciated
- Next challenge :inevitable complications around the use of health data collected on personal apps.