OECD RECOMMENDATION ON HEALTH DATA GOVERNANCE

17 January 2017
Using health data can advance health policy objectives

There are obstacles to using health data effectively in most countries

Better policy frameworks are needed to get more out of health data
Culmination of 6 years’ work ….

OECD Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data
[C(80)58/FINAL as amended by C(2013)79]
Drivers of Data Use

Tight fiscal conditions put pressure on health systems to deliver value for money.

Increasingly complex care needs make delivering high quality care more challenging.

New therapies and better research rely on our ability to make better use of data.

Patient demands for modern experiences, responsiveness, communications and transparency.
Data needed to make progress

Pathways
- Processes
- Outcomes
- Costs

Data must describe

Key prerequisites
- Individual patients / person level
- Follow patients through cycle of care
- Link to outcomes

Data linkage leverages the value of data to answer specific questions

Electronic health records (EHRs)
Longitudinal record of treatments and outcomes
Success stories

Clinical practice improvement
• **Clalit (Israel):**
  Analytics to reduce readmissions in older patients

System management
• **THL (Finland):**
  Public indicators to improve the quality of hospital care

Surveillance
• **FDA (US):**
  Post-market surveillance of medical technology to improve safety

Research and innovation
• **UK Biobank:**
  Broad and deep data to prevent, diagnose and treat diseases
And setbacks

Care.data: How did it go so wrong?

Nick Triggle
Health correspondent

19 February 2014 | Health | 354

Ongoing regional health authority have collected data from patients illegally in the past seven years, in a scenario reminiscent of George Orwell’s 1984.

There comes a point when the weight of criticism becomes so much that the dam bursts.

Fears raised over Google’s DeepMind deal to use NHS medical data

Academics concerned over company’s access to private records for mobile app
Little data linkage in key areas

- Hospital in-patient data
- Cancer registry data
- Mortality data
- Emergency health care data
- Mental hospital in-patient data
- CVD registry data
- Prescription medicines data
- Population census/registry
- Population health survey...
- Formal long-term care data
- Primary care data
- Patient reported outcomes
- Diabetes registry
- Patient experiences survey...

- # of Countries

- National personal health data available
- Unique ID included and used consistently
- Record linkage to regularly monitor health care quality and system performance
13 countries regularly linking data to monitor quality and conduct research

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<td>Linking datasets in A + emergency care data</td>
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10 countries are ready to analyse clinical data for health care quality monitoring.

- Australia
- Austria
- Canada
- Chile
- Croatia
- Czech Rep.
- Denmark
- Estonia
- Finland
- France
- Greece
- Iceland
- Ireland
- Israel
- Japan
- Latvia
- Luxembourg
- Mexico
- New Zealand
- Norway
- Singapore
- Spain
- Sweden
- Switzerland
- UK Scot.
- UK Eng.
- USA
- UK N. Ireland
- UK
- USA
- UK

Data governance readiness vs. Technical and operational readiness.
International legal instruments and guidelines protect information privacy

- Instruments include:
  - OECD Privacy Guidelines
  - EU General Data Protection Regulation (GDPR)
  - APEC Cross-Border Privacy Rules

- None are specific to the protection of health information privacy

- National interpretation for the governance of the use of health data has varied widely across countries
Sharing and accessibility of data for research and statistics varies greatly.

Score is the sum of the percentage of national datasets meeting 6 accessibility factors (Highest score =6).
Process to develop the Recommendation

- Collaboration of health ministries through the Health Committee and data privacy authorities through the Committee on Digital Economy Policy
- Expert input across domains of health, policy, law, ethics, privacy, research, statistics, IT from government, industry and civil society
- Developed over two years with extensive consultations with governments, civil society, businesses and industry and OECD Secretariat
- Approved by the OECD Council in December 2016 and announced by OECD Health Ministers on 17 January 2017
- Represents a moral force and outcomes of Adherents will be monitored
Draft Recommendation: Scope

1. Establish national health data governance frameworks
   - Encourage availability & use of health data to advance public policy objectives
   - Promote privacy protection & data security

2. Harmonise frameworks between countries
   - Enable multi-country statistical and research projects
## Draft Recommendation measures

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<th>Engagement and participation</th>
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<td>Coordination and cooperation</td>
<td>Public disclosure and transparency</td>
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<td>Capacity of public sector health data systems</td>
<td>Recognition of the role of technology</td>
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<td>Clear provision of information</td>
<td>Monitoring and evaluation mechanisms</td>
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<td>Effective consent and choice mechanisms</td>
<td>Training and skills development in privacy and security</td>
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<td>Controls and safeguards</td>
<td>Certification or accreditation</td>
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Implementation & monitoring

- 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
Further reading

**Recommendation of the OECD Council on Health Data Governance** (OECD 2017)

**New Health Technologies - Managing Access, Value and Sustainability** (OECD 2017)

**Health Data Governance: Privacy, Monitoring and Research, Health Policy Studies** (OECD 2015)

**Dementia Research and Care: Can Big Data Help?** (OECD 2015)
http://www.oecd.org/health/dementia.htm

**Data Driven Innovation for Growth and Well-Being** (OECD 2015)
http://www.oecd.org/sti/ieconomy/data-driven-innovation.htm

**Strengthening Health Information Infrastructure for Health Care Quality Governance** (OECD 2013)
http://www.oecd.org/els/health-systems/strengthening-health-information-infrastructure.htm