

OECD RECOMMENDATION ON HEALTH DATA GOVERNANCE

17 January 2017



Rationale for an OECD Recommendation on Health Data Governance

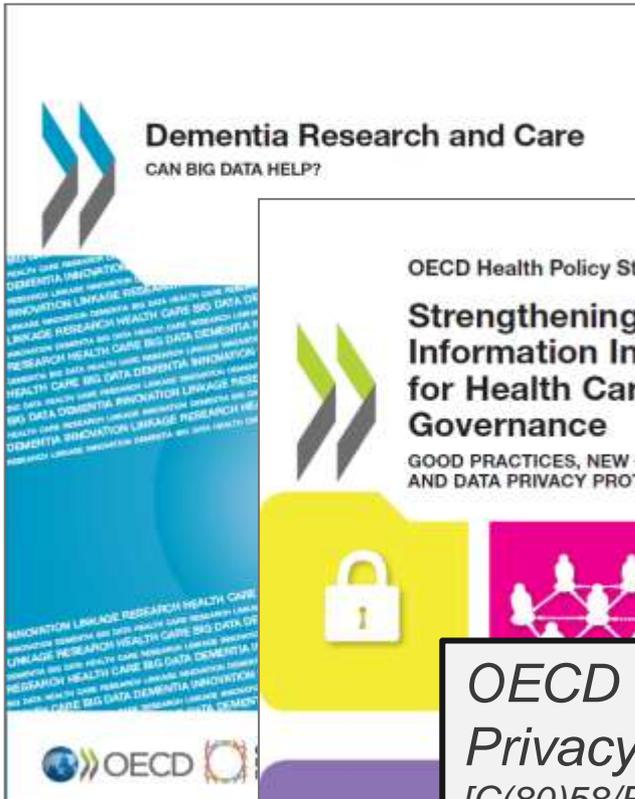
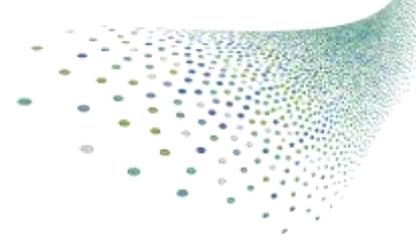
Using health data can advance health policy objectives

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

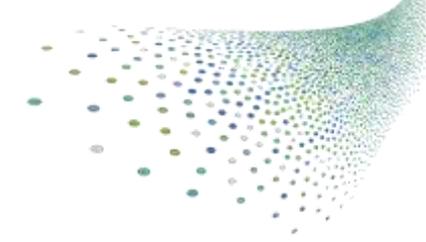


OECD Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data [C(80)58/FINAL as amended by C(2013)79]





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

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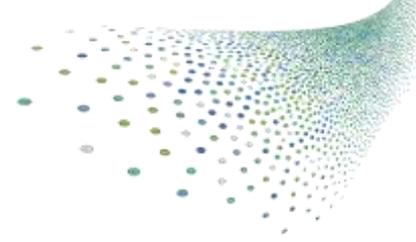
New therapies and better research
rely on our ability to make better use of data



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

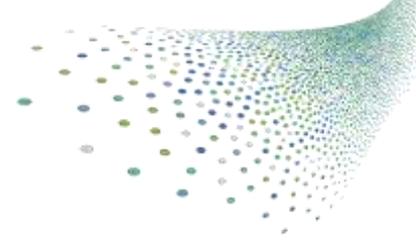


Electronic health records (EHRs)

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

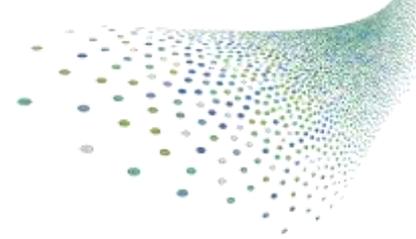
- **FDA (US):**
Post-market surveillance of medical technology to improve safety

Research and innovation

- **UK Biobank:**
Broad and deep data to prevent, diagnose and treat diseases



And setbacks



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Health

Care.data: How did it go so wrong?



Nick Trigg
Health correspondent

19 February 2014 | Health | 354

ONE STEP TOO FAR FOR LEGENDARY DANISH TRANSPARENCY

25 MARCH, 2015 | JENS DEGETT | 6 COMMENTS

sh regional health authority have
cted data from patients illegally in the
seven years, in a scenario reminiscent
orge Orwell's 1984 ★1



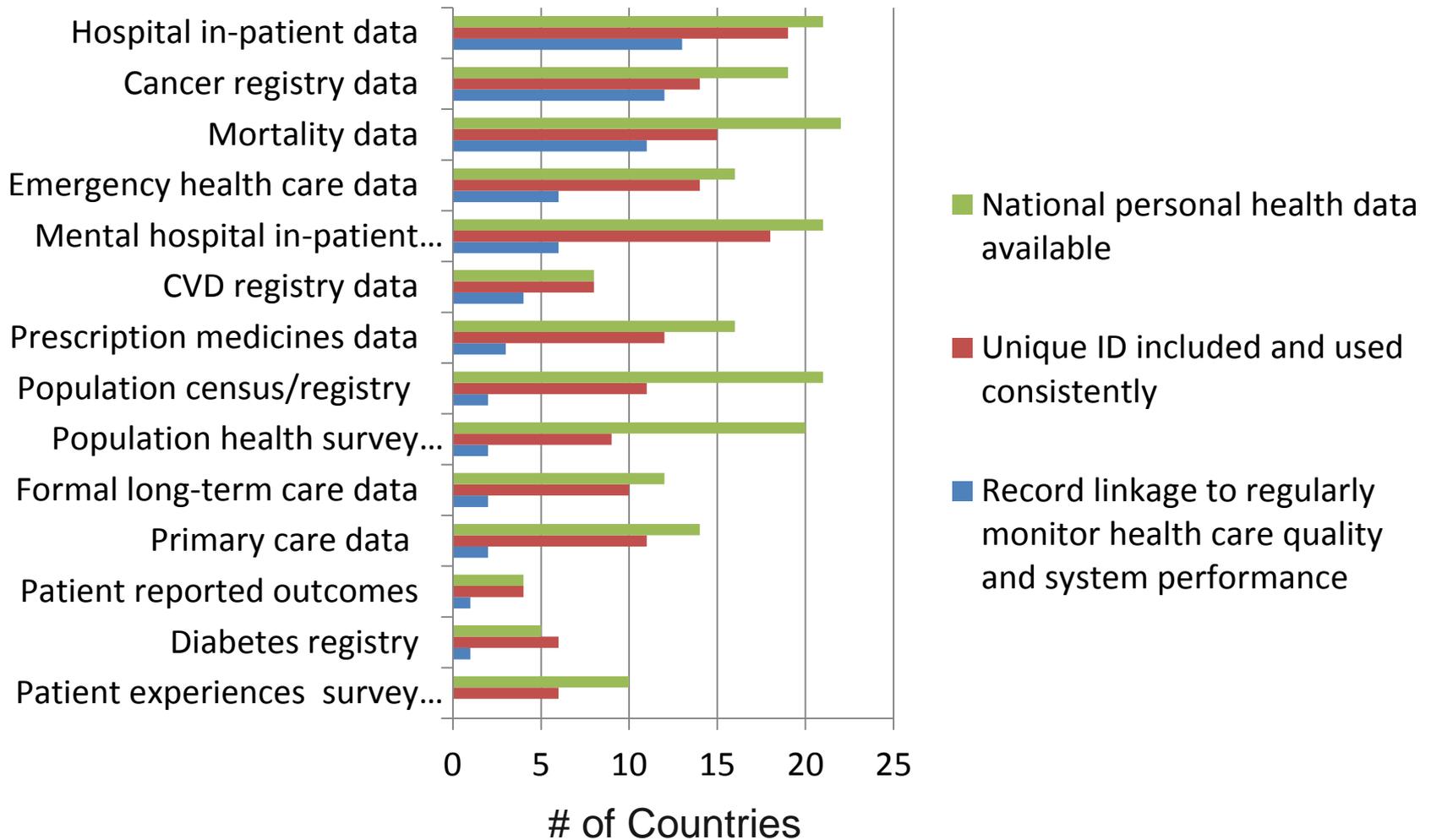
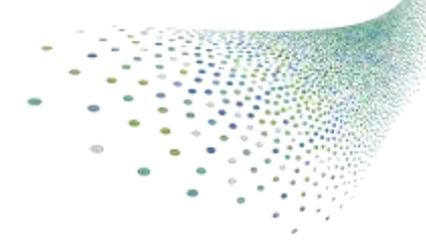
There comes a point when the weight of criticism becomes so much that the dam bursts

More from Nick





Little data linkage in key areas



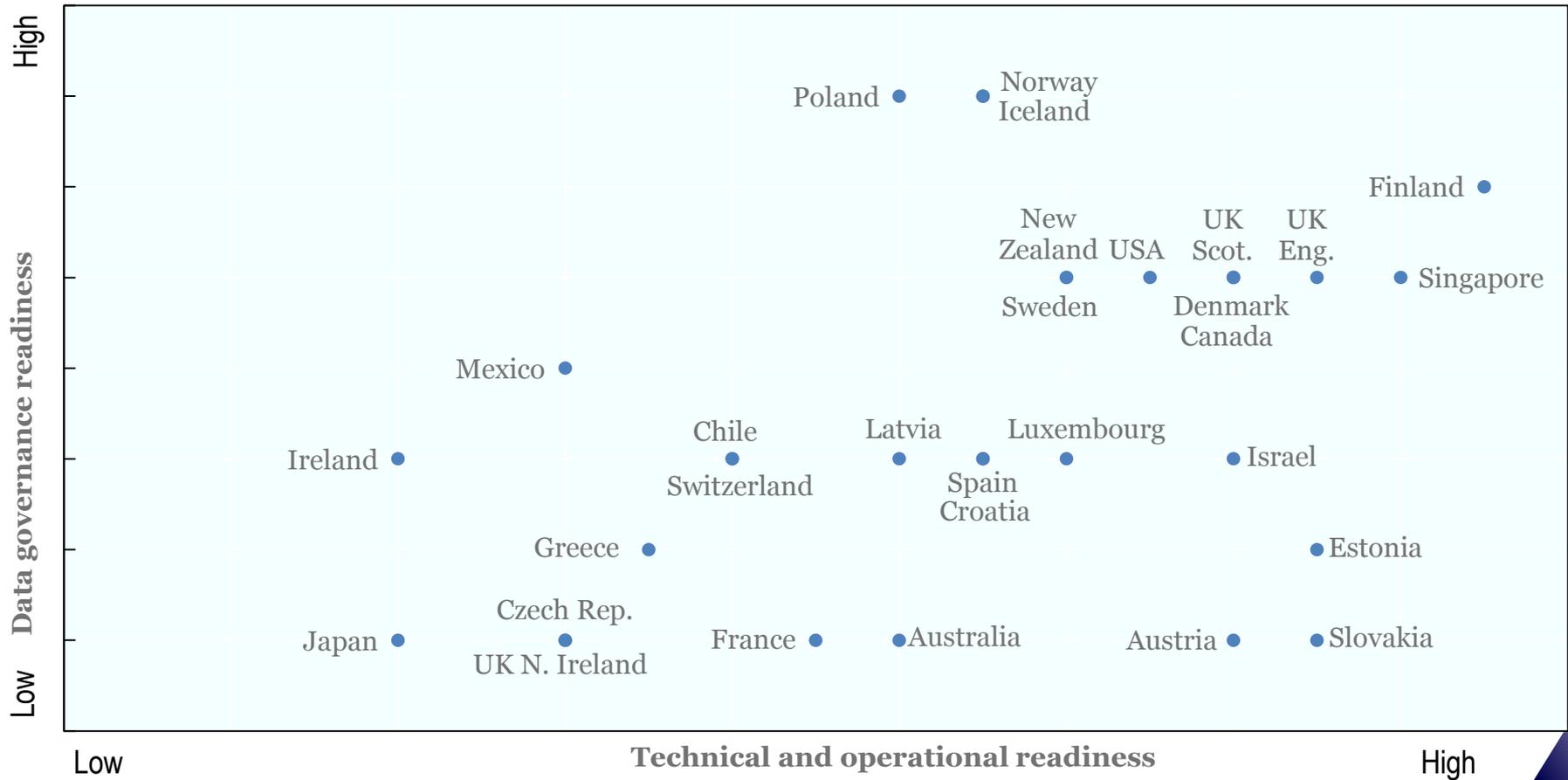


13 countries regularly linking data to monitor quality and conduct research

| A | B | C | D | E |
|--|---|---|---|---|
| Regularly linking hospital in-patient, cancer registry data and mortality data | Linking datasets in A + emergency care data | Linking datasets in A + prescription medicines data | Linking datasets in A + long-term care data | Linking datasets in A + primary care data |
| Canada | Canada | Canada | Canada | Korea |
| Czech Republic | Israel | Denmark | Finland | Singapore |
| Denmark | Korea | Finland | Israel | UK (Wales) |
| Finland | New Zealand | Korea | Korea | |
| Israel | Norway | New Zealand | Singapore | |
| Korea | Singapore | Sweden | UK (Wales) | |
| New Zealand | Sweden | UK (Scot. & Wales) | | |
| Norway | UK | | | |
| Singapore | | | | |
| Sweden | | | | |
| UK (Eng., Scot. & Wales) | | | | |



10 countries are ready to analyse clinical data for health care quality monitoring



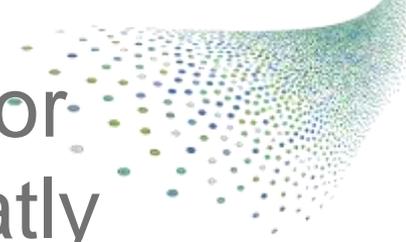


International legal instruments and guidelines protect information privacy

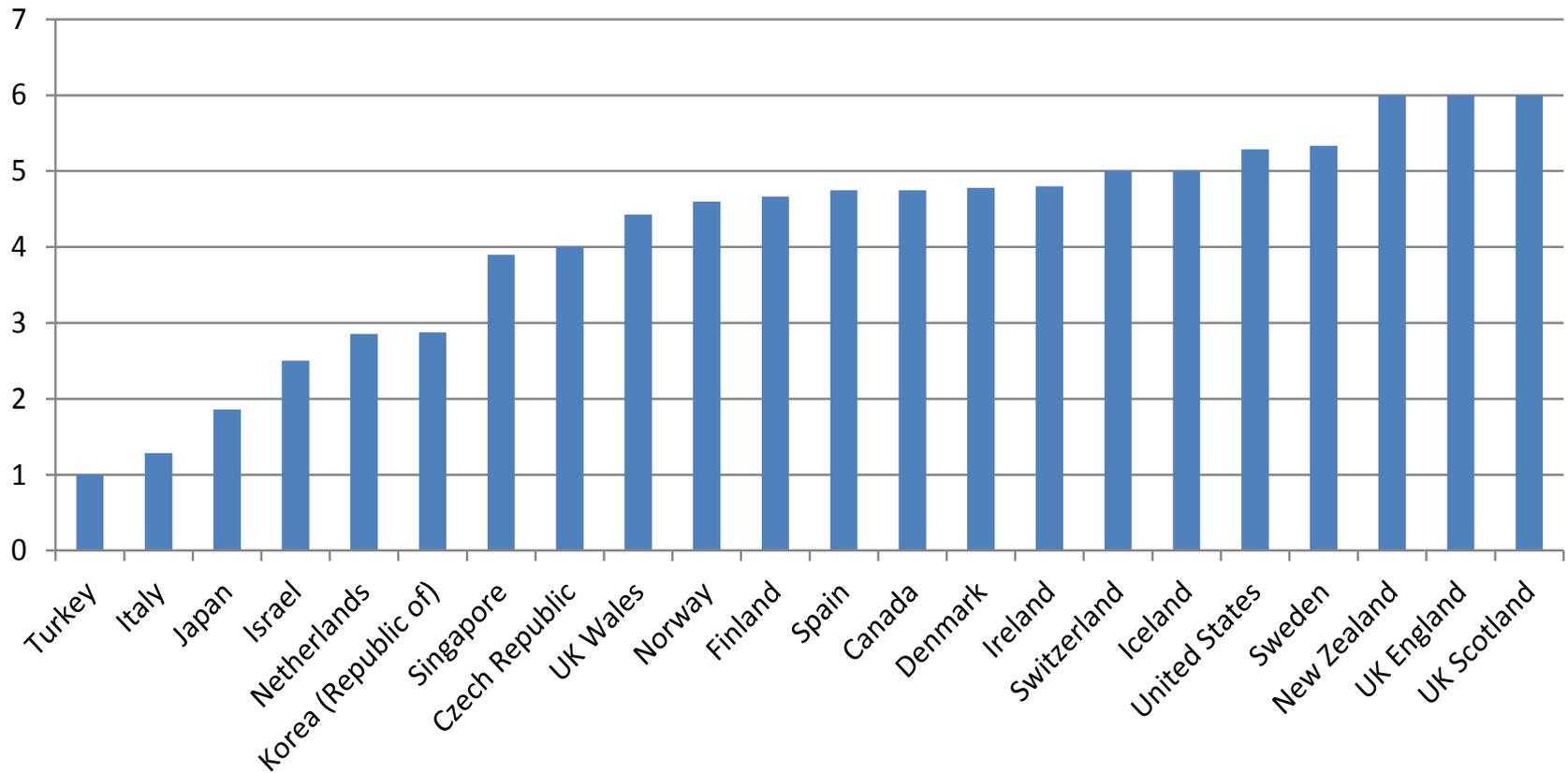
- Instruments include:
 - OECD Privacy Guidelines
 - EU General Data Protection Regulation (GDPR)
 - APEC Cross-Border Privacy Rules
- None are specific to the protection of health information privacy
- National interpretation for the governance of the use of health data has varied widely across countries



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)



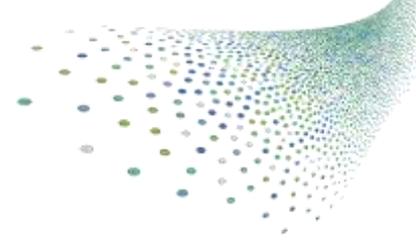


Process to develop the Recommendation

- 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

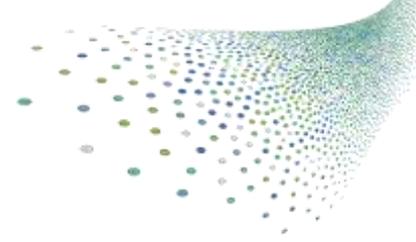
- Encourage availability & use of health data to advance public policy objectives
- Promote privacy protection & data security

2. Harmonise frameworks between countries

- Enable multi-country statistical and research projects



Draft Recommendation measures



Engagement and participation

Coordination and cooperation

Capacity of public sector health data systems

Clear provision of information

Effective consent and choice mechanisms

Controls and safeguards

Approval procedures for the use of personal health data

Public disclosure and transparency

Recognition of the role of technology

Monitoring and evaluation mechanisms

Training and skills development in privacy and security

Certification or accreditation



Implementation & monitoring

