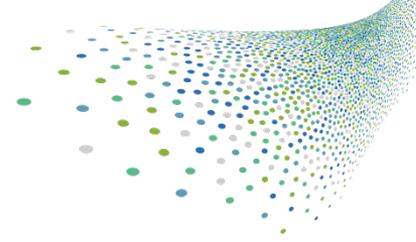


HEALTH DATA GOVERNANCE IN OECD COUNTRIES – PRIVACY, MONITORING AND RESEARCH

EU Bridge Health Meeting
21 September 2017
Jillian.Oderkirk@oecd.org



Culmination of 6 years' work



Dementia Research and Care
CAN BIG DATA HELP?



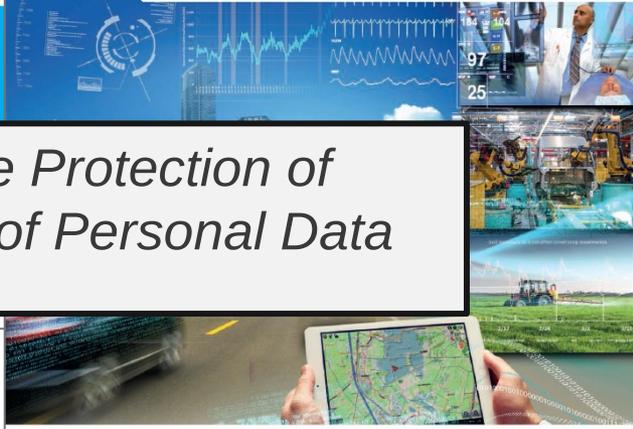
OECD Health Policy Studies
Health Data Governance
PRIVACY, MONITORING AND RESEARCH



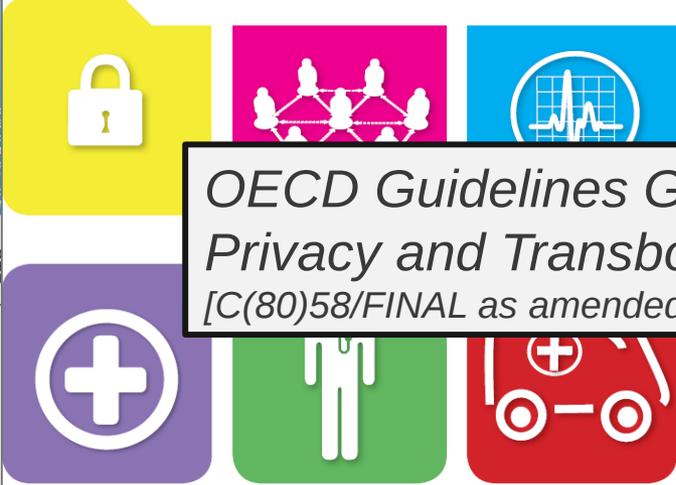
OECD Health Policy Studies
Strengthening Health Information Infrastructure for Health Care Quality Governance
GOOD PRACTICES, NEW OPPORTUNITIES AND DATA PRIVACY PROTECTION CHALLENGES



Data-Driven Innovation
BIG DATA FOR GROWTH AND WELL-BEING

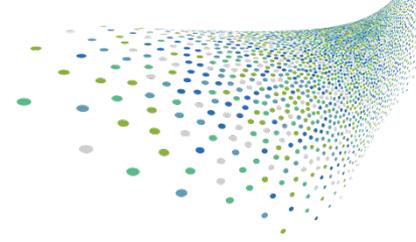


OECD Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data
[C(80)58/FINAL as amended by C(2013)79]

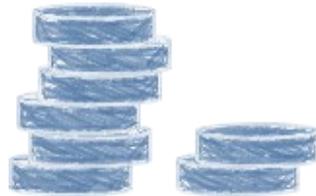




Drivers of Data Use



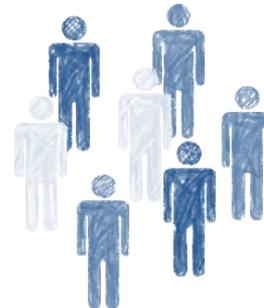
Tight fiscal conditions put pressure on health systems to deliver value for money



Increasingly complex care needs make delivering high quality care more challenging

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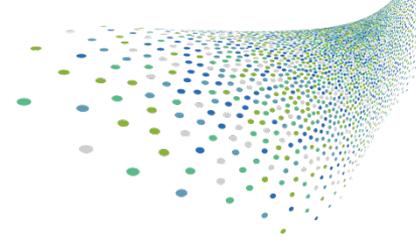
New therapies and better research rely on our ability to make better use of data



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

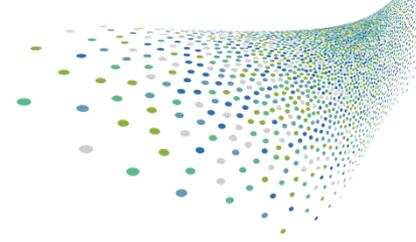


Electronic health records (EHRs)

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

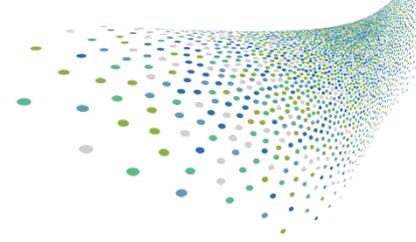
- **FDA (US):**
Post-market surveillance of medical technology to improve safety

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 Triggle
Health correspondent

19 February 2014 | Health | 354

POLICY

ONE STEP TOO FAR FOR LEGENDARY DANISH TRANSPARENCY

25 MARCH, 2015 | JENS DEGETT | 6 COMMENTS

Danish regional health authority have collected data from patients illegally in the past seven years, in a scenario reminiscent of George Orwell's 1984 ★1



FINANCIAL TIMES

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Digital health [+ Add to myFT](#)

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

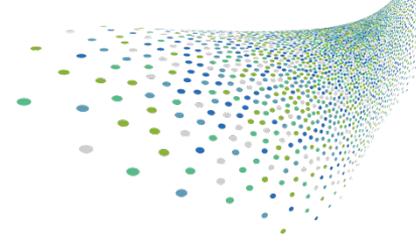
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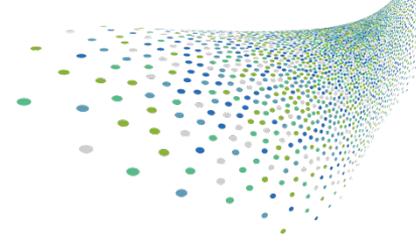
OECD Study of Health Data Governance



- 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-respectful data use
- Guided by experts in law, privacy regulation, IT, policy, statistics, and research
- 22 countries participated



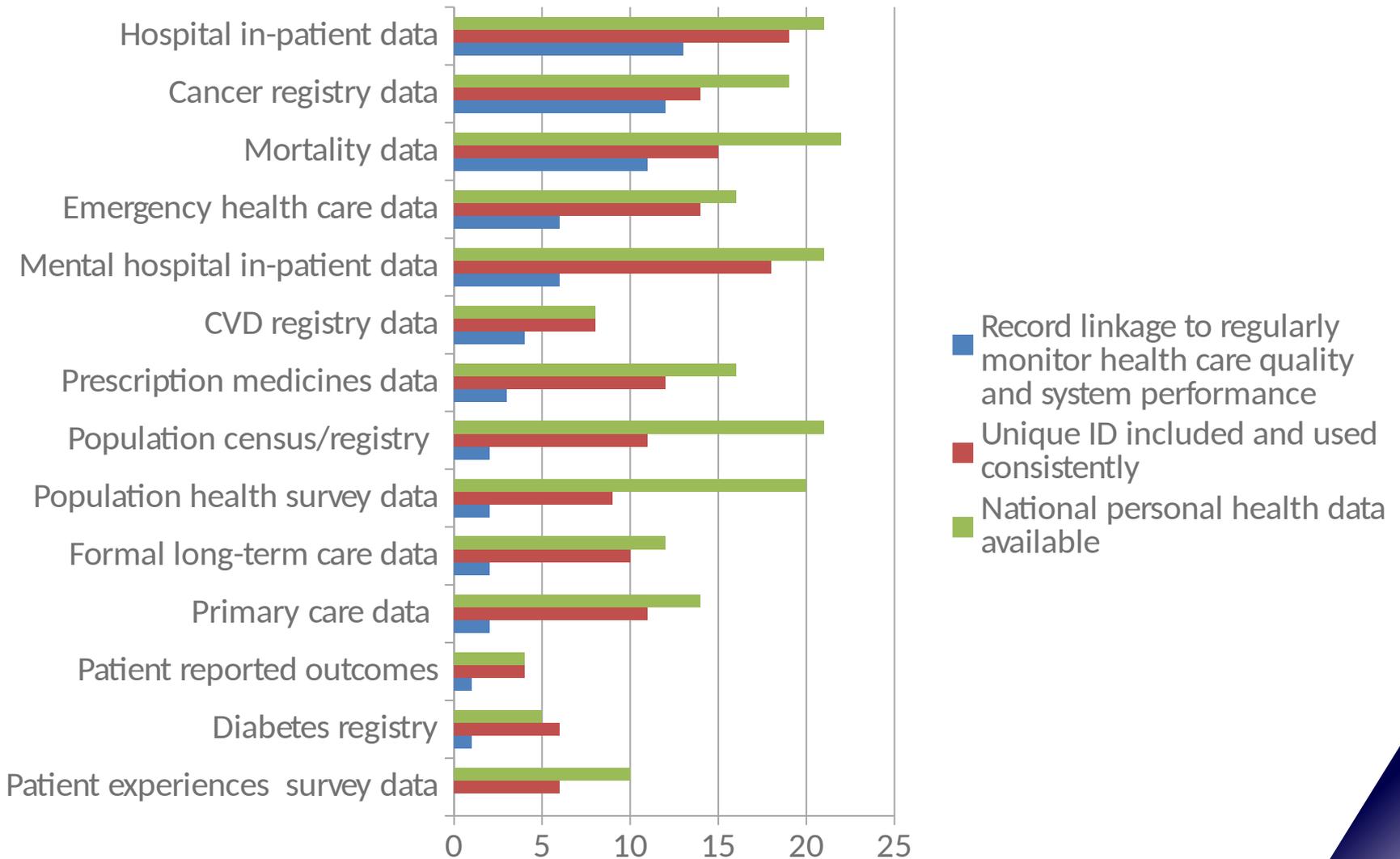
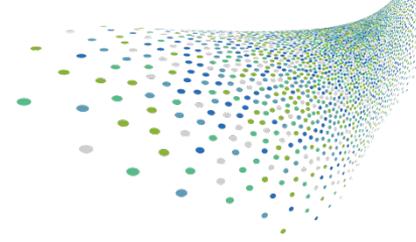
Indicators monitored



Dataset	Dataset governance	National health data governance
Coverage	Privacy officer	Privacy law
Coding	Training	Data processing centre
Collection method	Dataset sharing	Approval authority
Regular HCQ reporting	Data breach incidents	De-identification guidelines
Identifiers	De-identification	Challenges/difficulties:
Record linkage activity	Access to data	<ul style="list-style-type: none">• Data sharing
	Approval process	<ul style="list-style-type: none">• Data access
	Secure transfer/access	<ul style="list-style-type: none">• Extraction of EHR data

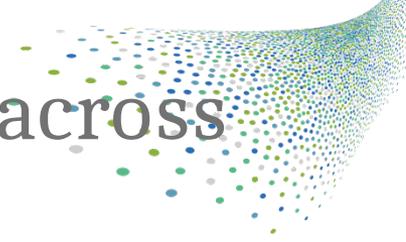


Little data linkage in key areas





13 countries regularly linking data across the pathway of care



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)				

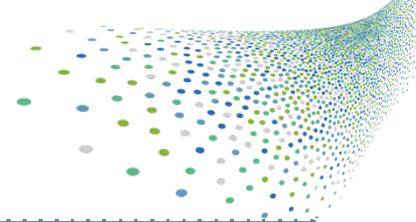


Study of the development and use of data from Electronic Health Record Systems

- Project of the HCQI expert group in 2012 and 2016 to:
 - Monitor progress in the development and use of EHR systems including data governance and use for research and statistics
 - 25 countries participated in 2012
 - 30 countries participated in 2016



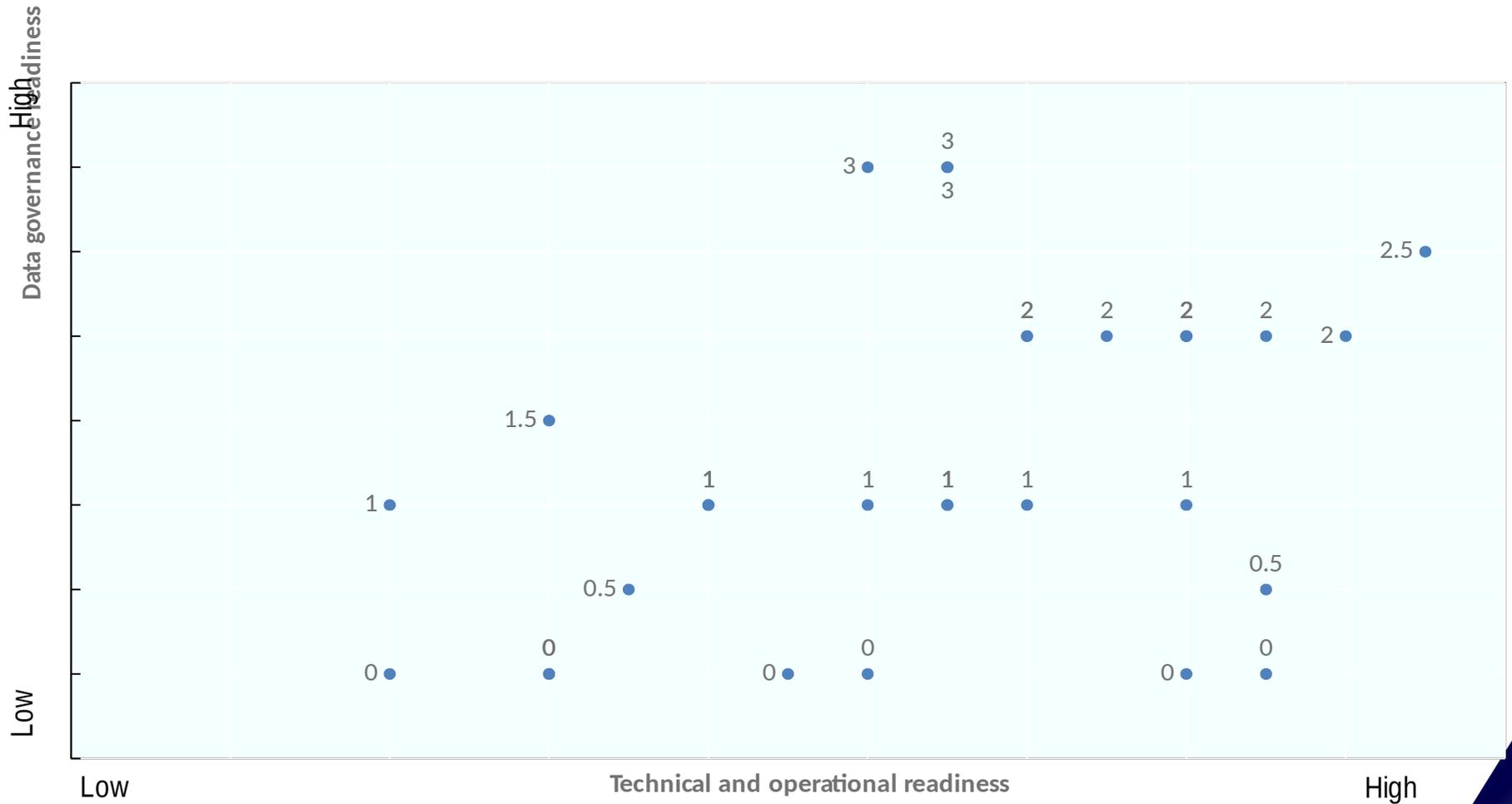
Indicators monitored



EHR system	EHR governance	Data use
Plans for development and data use	National organisation	Dataset development
Electronic record keeping	Standards development	Usability evaluation
Type of system	Legal requirements for adoption/standards use	Analytical uses of data
Data sharing	Vendor certification	Vendor tools and controls
Minimum dataset	Incentives	Challenges/difficulties:
Terminology standards	Data quality	<ul style="list-style-type: none">• Develop datasets
Identifiers	Laws/policies permitting statistical or research uses	<ul style="list-style-type: none">• Implement EHR system
Patient access		<ul style="list-style-type: none">• Use of data for statistics or research

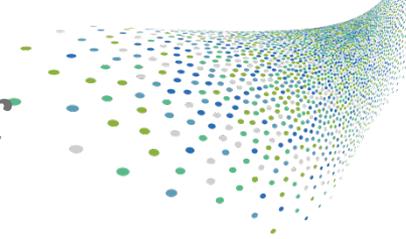


10 are ready to extract data from EHRs for health care quality monitoring

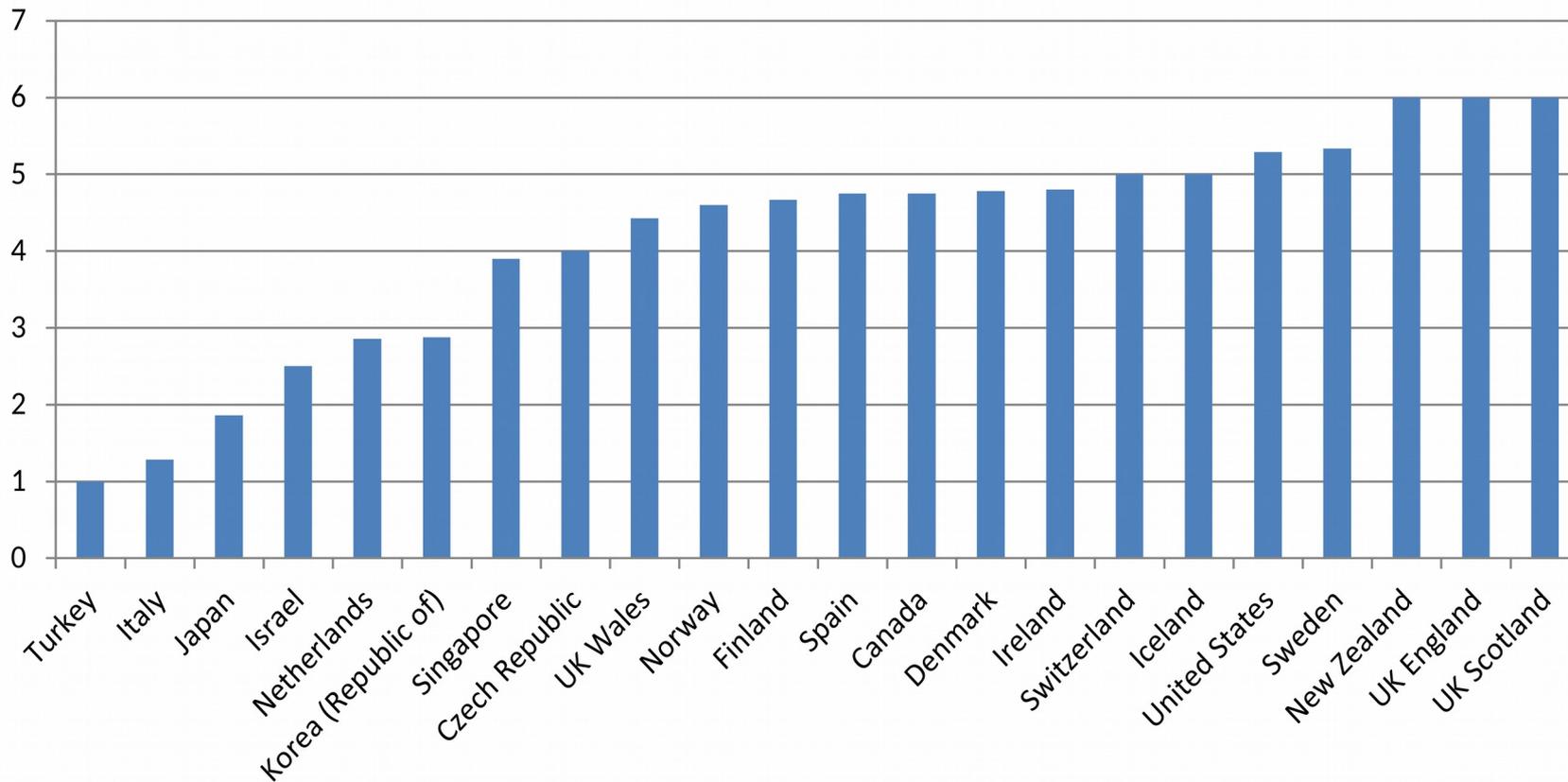




Sharing and accessibility of data for research and statistics

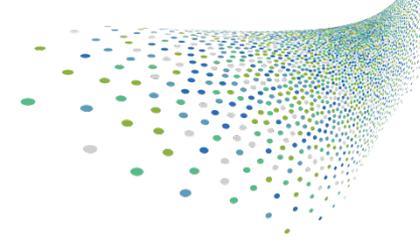


■ Score is the sum of the percentage of national datasets meeting 6 accessibility factors (Highest score =6)





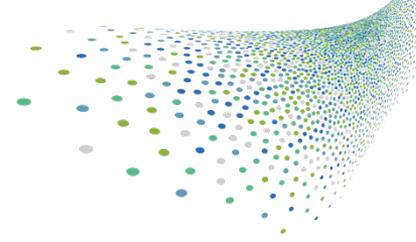
Data sharing and accessibility



Factors:	# of countries where <u>not</u> permitted for any national dataset	Example country where permitted for all key national datasets
Identifiable data is shared with another national data custodian or government entity	9	New Zealand 100%
Access to de-identified data:		
University/non-profit researchers may be approved	2	Japan 100%
For profit businesses may be approved	7	Switzerland 100%
Foreign government, university or non-profit researchers may be approved	5	UK England and Scotland 100%



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
- 8 Data governance review cycle

Evaluate benefits and risks of proposed data uses

Benefits

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

Risks

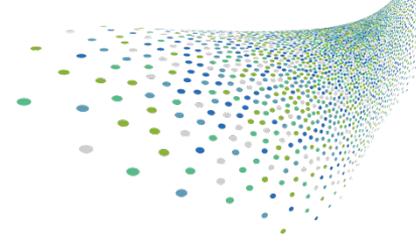
- Rights to privacy
- Societal trust in government & institutions
- Societal values toward privacy & sharing data



Take informed decisions to process personal health data



8 Key Data Governance Mechanisms



- 1 Coordinated development of high-value, privacy protective health information systems

e.g. Top health information systems in Denmark, Finland, Iceland, Israel, New Zealand, Norway, Korea, Singapore, Sweden, and the United Kingdom (Wales and Scotland)
- 2 Legislative framework permits privacy-protective data use

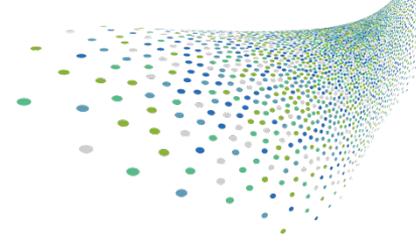
e.g. Sharing and accessibility of data is strongest in the UK, New Zealand, Sweden and USA
- 3 Open and transparent information system that builds trust

e.g. Finland and Iceland publish approval decisions for individual data linkage projects on a website
- 4 Accreditation/certification of data processors to promote data security and access

e.g. Australia and Scotland have accreditation for health data processors that ensure high data protection standards are met



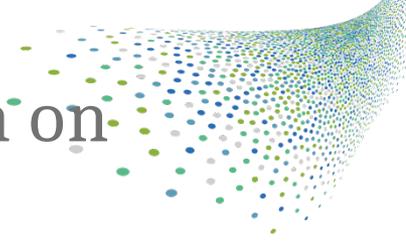
8 Key Data Governance Mechanisms



-
- | | |
|-----------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|
| 5 Transparent and fair project approval processes | E.g. Nine countries provide a website where the approval process to access to de-identified linked data is explained |
| 6 Data de-identification practices that consider “the big picture”: data protection, security and utility | E.g. The USA and UK consider the data security environment and the data use when deciding the degree of data de-identification required. |
| 7 Data security practices that meet legal requirements and public expectations | E.g. Secure, real-time, remote data access systems are available in Canada (Ontario), UK (Scotland and Wales), Netherlands & USA |
| 8 Data governance practices that are continuously assessed and renewed | E.g. OECD is monitoring countries’ progress in strengthening their health information infrastructure. |
- 



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



Further reading



Strengthening Health Information Infrastructure for Health Care Quality Governance - 2013

<http://www.oecd.org/els/health-systems/strengthening-health-information-infrastructure.htm>

Health Data Governance: Privacy, Monitoring and Research, Health Policy Studies – OECD 2015

<http://www.oecd.org/health/health-systems/health-data-governance-9789264244566-en.htm>

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>