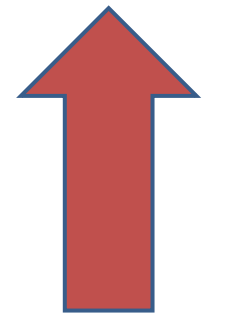


# **PUTTING DATA TO WORK FOR BETTER HEALTH AND HEALTH SYSTEMS**

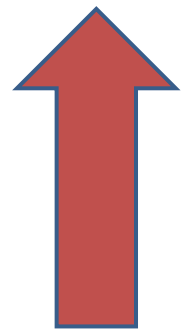
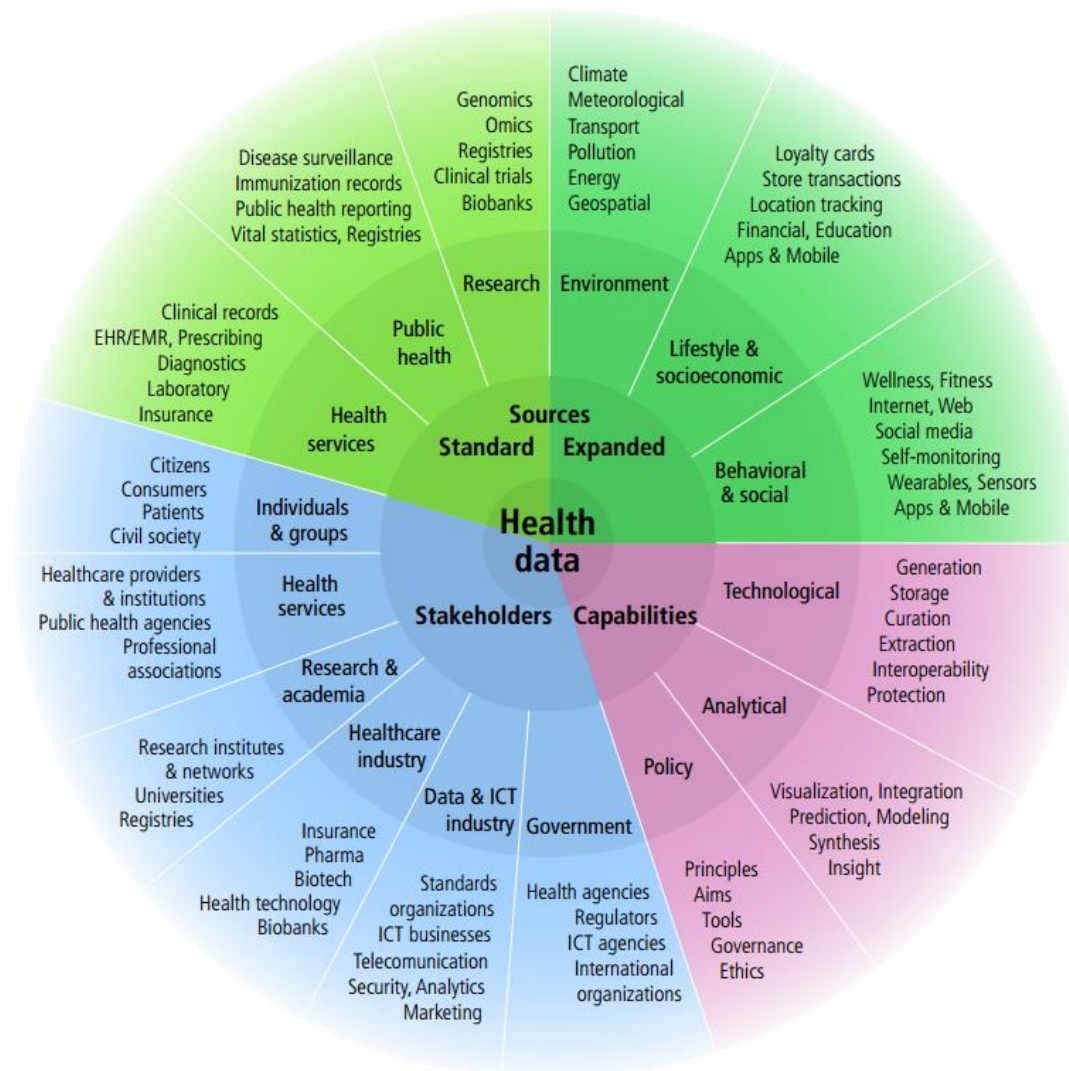
Luke Slawomirski  
Eindhoven, ND  
12 April 2018



# The health data ecosystem is evolving and growing



Volume & velocity



Capacity to store, process & analyse



This bestows immense opportunities ...

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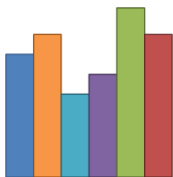
## Clinical practice improvement (quality)

- Faster access to critical information
  - Improved clinical decision making
  - Better patient experience and satisfaction
- 



## System management

- Monitor performance
  - Allocate resources better and reduce waste
  - Ensure better access to care
- 



## Surveillance

- Evaluate public health interventions
  - Faster detection and response to public health emergency
  - Inform policy
- 

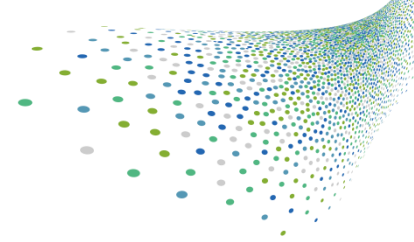


## Research & innovation

- Statistical power
- Vast and varied datasets
- 'Real world evidence' for innovation



.... but also risks



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### Health

## Care.data: How did it go so wrong?



Nick Triggle  
Health correspondent

19 February 2014 | Health | 354



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

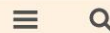
More from Nick

### 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

HOME WORLD US COMPANIES MARKETS OPINION WORK & CAREERS LIFE & ARTS

Digital health + Add to myFT

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

Academics concerned over company's access to private records for mobile app

Read next

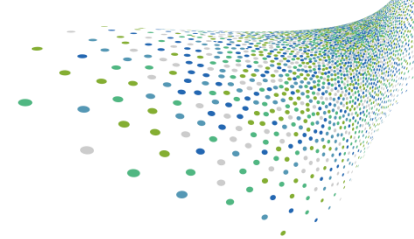
Could only to predict







# OECD work on health data governance commenced in 2010



## Dementia Research and Care

CAN BIG DATA HELP?



OECD Health Policy Studies

## Health Data Governance

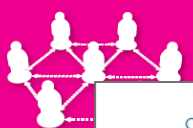
PRIVACY, MONITORING AND RESEARCH



OECD Health Policy Studies

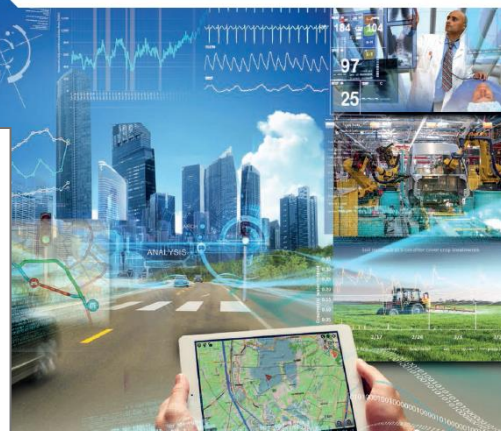
## Strengthening Health Information Infrastructure for Health Care Quality Governance

GOOD PRACTICES, NEW OPPORTUNITIES AND DATA PRIVACY PROTECTION CHALLENGES



## Data-Driven Innovation

BIG DATA FOR GROWTH AND WELL-BEING



OECD publishing

Please cite this paper as:

Oderkirk, J. (2017), "Readiness of electronic health record systems to contribute to national health information and research", *OECD Health Working Papers*, No. 99, OECD Publishing, Paris.  
<http://dx.doi.org/10.1787/9e296bf3-en>

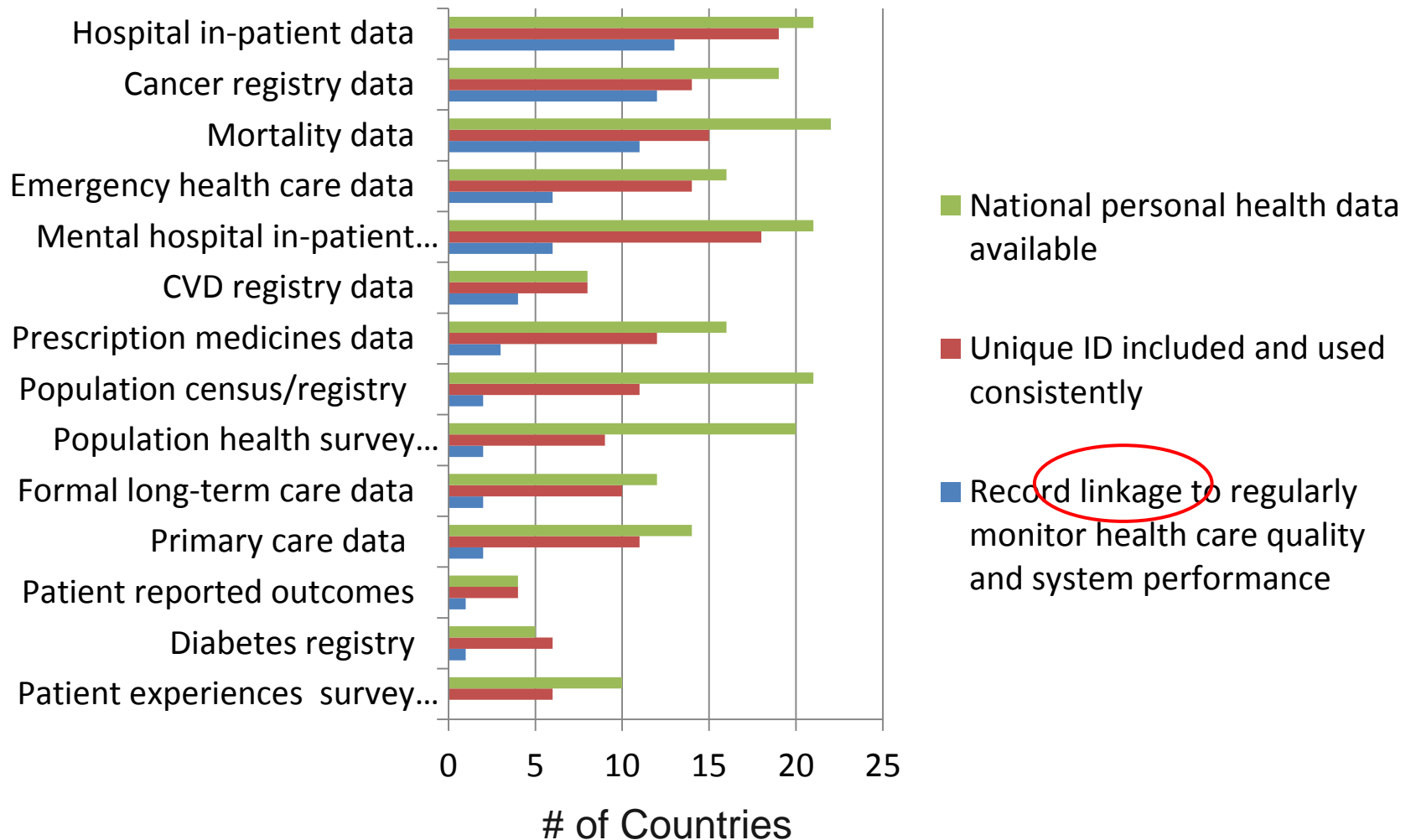
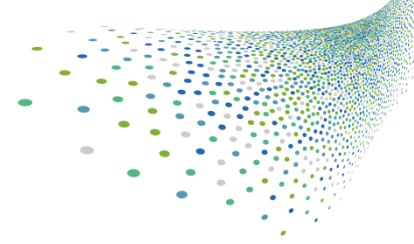
OECD Health Working Papers No. 99

**Readiness of electronic health record systems to contribute to national health information and research**

 OECD

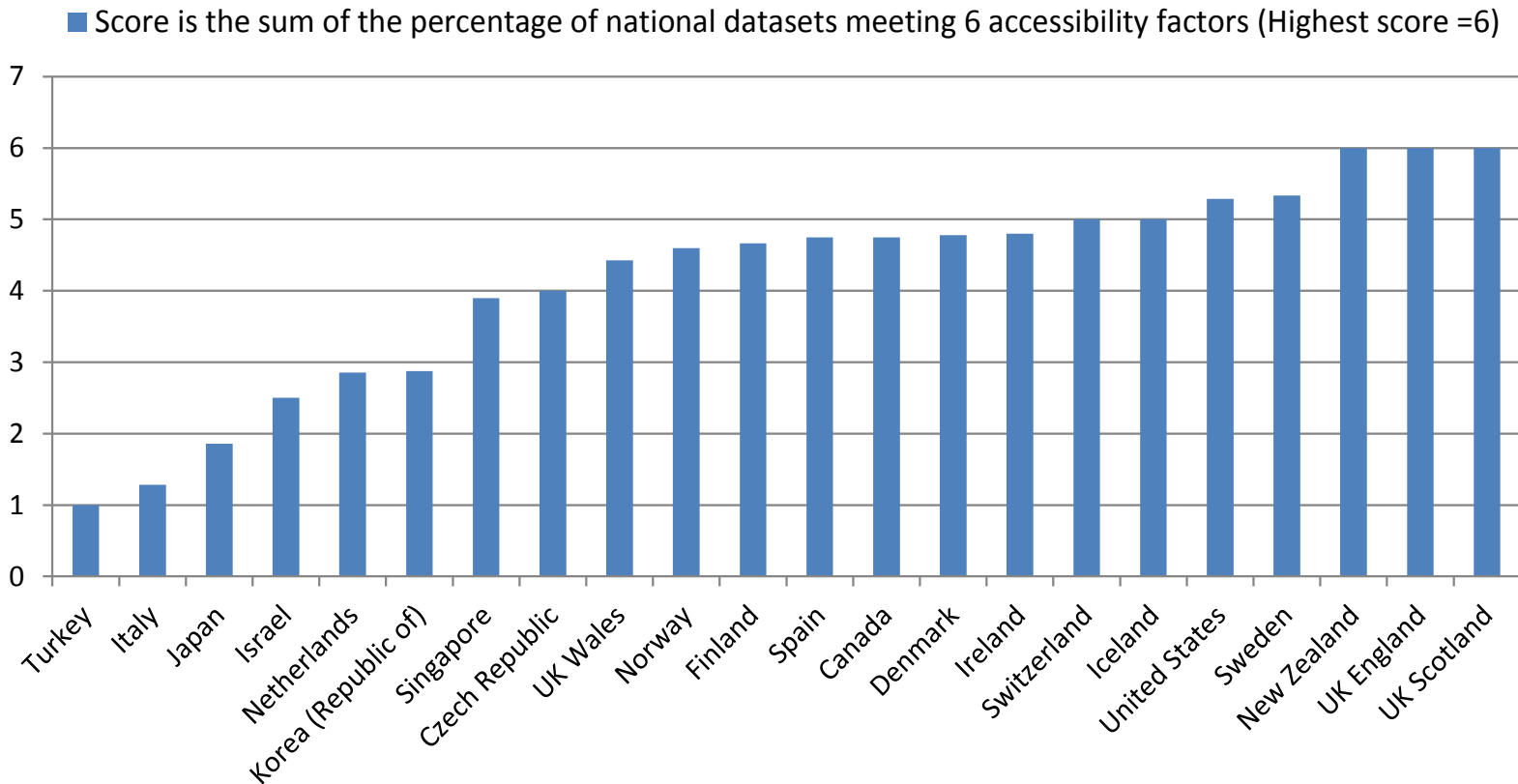
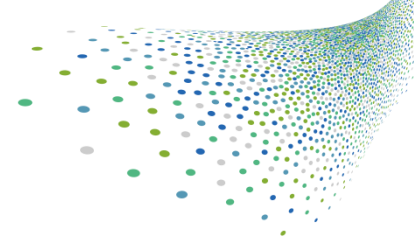


## Data rich – information poor





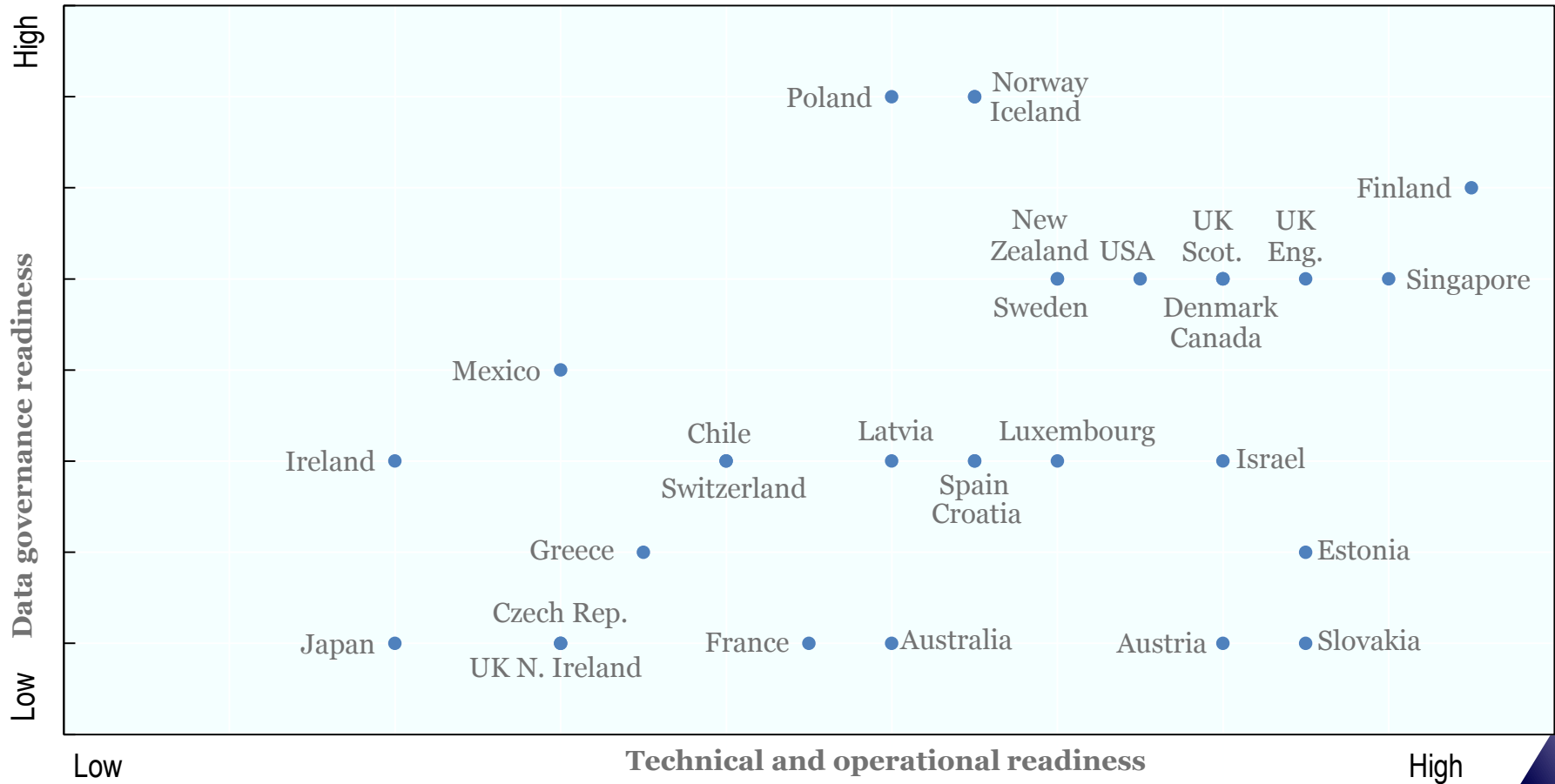
# Variation in sharing and accessibility of data for R&D purposes



2013/14 survey of 22 countries



# Harnessing Electronic Health Record (EHR) data



2016 survey of 25 countries





# A health data governance framework (2015)

## 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 data uses


### Benefits

- Rights to health
- Health care quality & efficiency
- Scientific discovery & innovation
- Not using available data is a risk – benefit foregone

### Risks

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

- Not a zero sum game
- Whole of government endeavour
- Across sectors

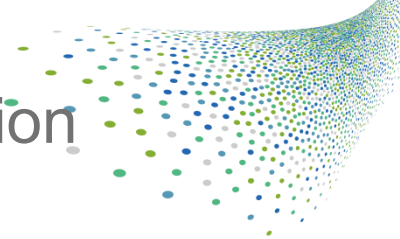


Take informed decisions to use personal health data

**Right data governance to maximise benefits and minimise risks**



... became an OECD Council Recommendation  
– January 2017



## 1. Establish national health data governance frameworks

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

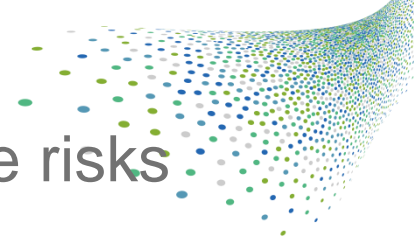
## 2. Harmonise frameworks between countries

- Enable multi-country research

[www.oecd.org/els/health-systems/health-data-governance.htm](http://www.oecd.org/els/health-systems/health-data-governance.htm)



# 12 measures to maximise benefits & manage risks



Engagement and participation

Approval procedures for the use of personal health data

Coordination and cooperation

Public disclosure and transparency

Capacity of public sector health data systems

Recognition of the role of technology

Clear provision of information

Monitoring and evaluation mechanisms

Effective consent and choice mechanisms

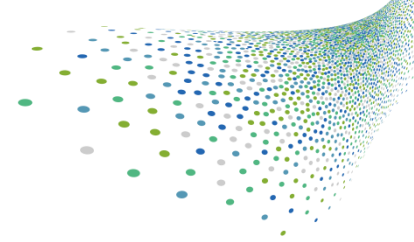
Training and skills development in privacy and security

Controls and safeguards

Certification or accreditation



# Thank you



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