# DRAFT OECD COUNCIL RECOMMENDATION ON HEALTH DATA GOVERNANCE

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**OECD-HARVARD WORKSHOP**

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BETTER POLICIES FOR BETTER LIVES

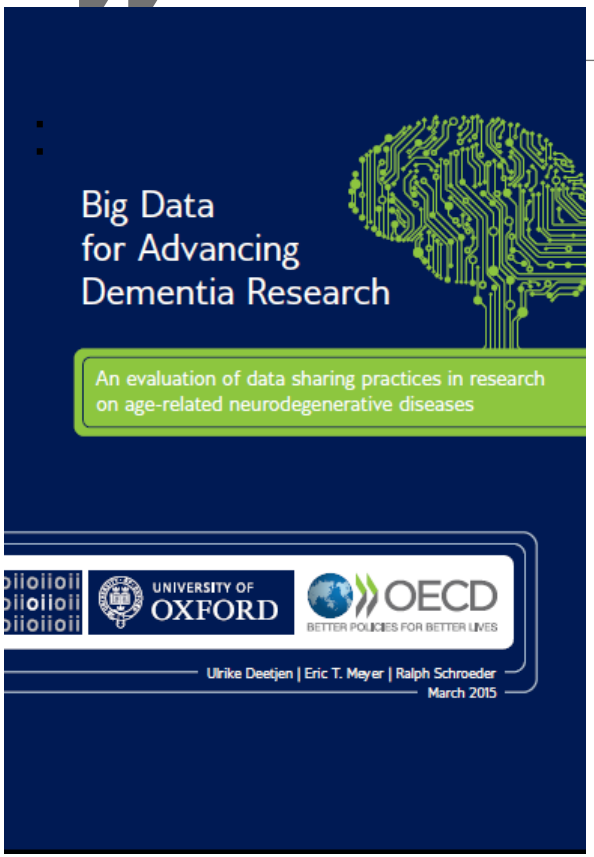
# *OECD Health Data Governance Recommendation*

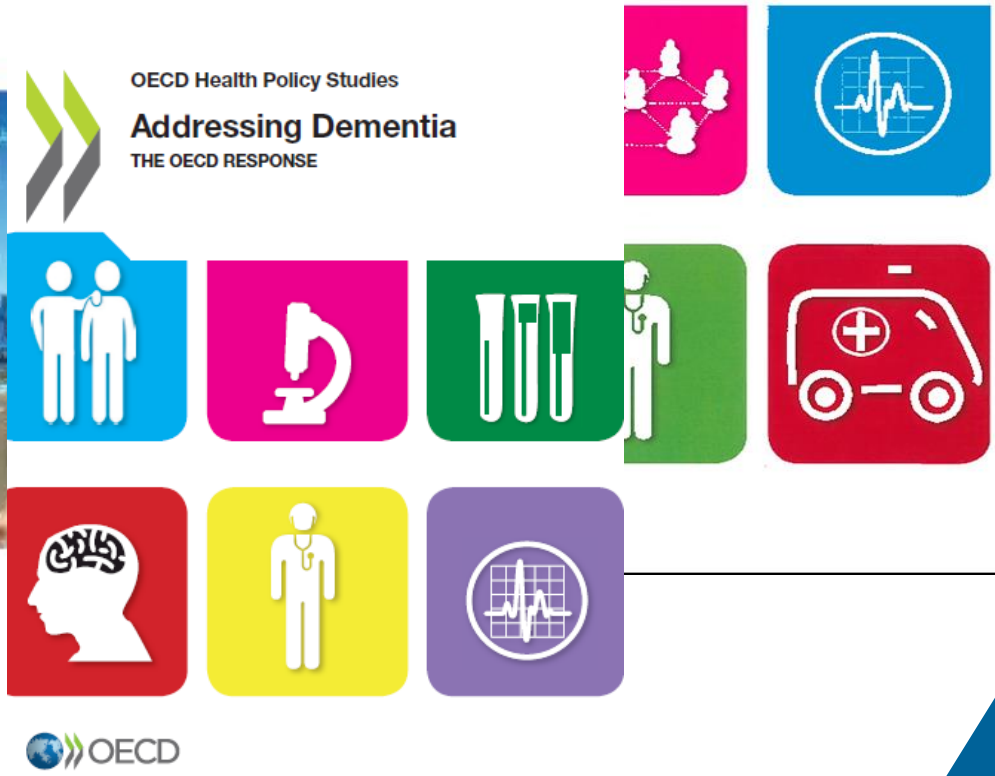
- OECD Council Recommendations represent the political will of Member countries –
- They are not legally binding
  - Expectation that Member countries will do their utmost to fully implement a Recommendation
  - Implementation of Recommendations is regularly monitored
- They require approval by the responsible Committee/Committees before proceeding to the OECD Council
- Examples: OECD Privacy Guidelines (OECD Guidelines on the Protection of Privacy and Transborder Flows)

# Background

- 2010: health ministers called for more effective use of collected health data
- 2011 – 2014: OECD work on improving the Health Information Infrastructure:
- Understand the potential, the barriers and the best practices in the use of personal health data to improve health care and research.
- Explore the privacy and data security environment
- 2015 – OECD work on Data-Driven Innovation: Big Data for Growth and Well-Being-
- 2015- OECD work on Big Data for Advancing Dementia Research

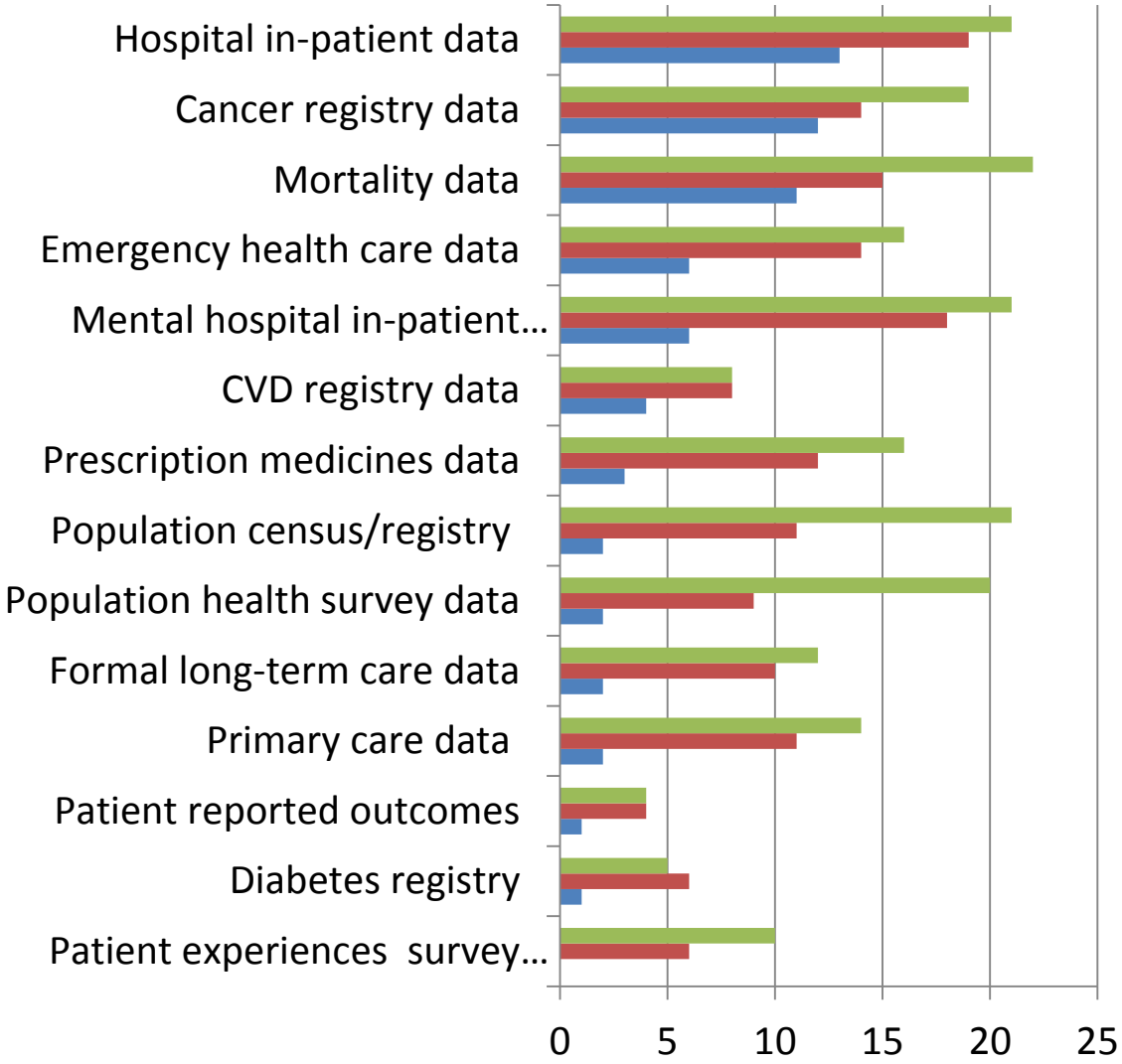
# Origins of the Project






Growing concern in the public health and research community on limitations to data access and sharing

# The studies uncovered significant barriers to data linkage and sharing




**22 Countries**

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

Source: OECD HCQI Country Survey, 2013/14

# Key Policy Challenges

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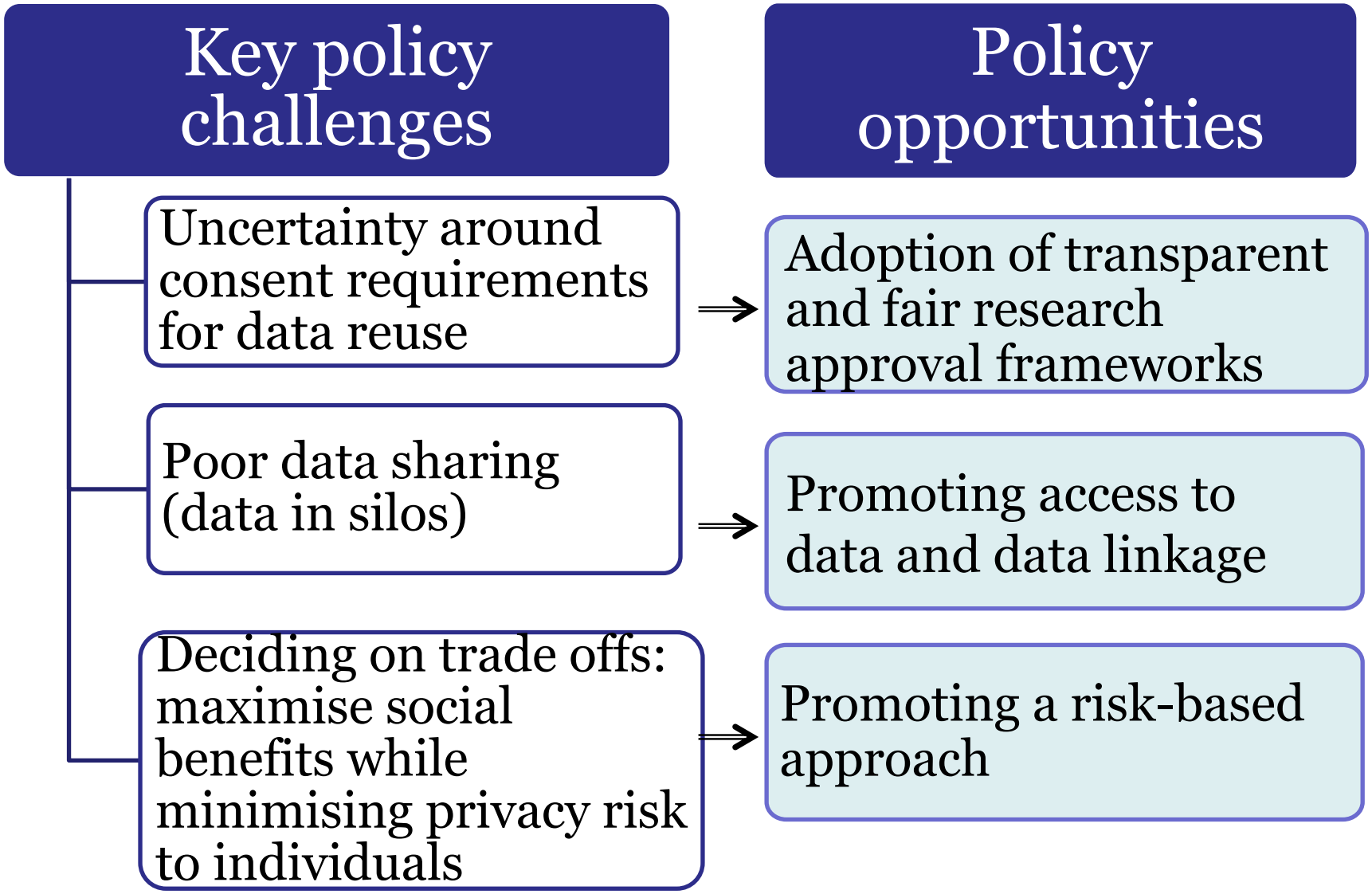
# *Key policy challenges and opportunities*



# *How to reconcile varying interests?*

| **Foster the sharing and use of health data for the broader public interest** | **Address legitimate privacy concerns raised by individuals** |
| --- | --- |
| • For public health<br>• To empower consumers through data portability<br>• To monitor the quality of care<br>• For greater evidence-based medicine….. | • Risk of accidental release of identifiable data<br>• Data re-identification<br>• Illicit or inadvertent access…… |

# *Bringing privacy protection into the 21st century*

*We remain hampered by 20th century tools to deal with 21st century privacy problems….*

*Daniel Therrien* (appointed Privacy Commissioner of Canada in 2014)

# The OECD Recommendation

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# *Main Challenges*

- Develop a Recommendation that will be applicable in the era of “big data” in health care.
- Data should serve multiple purposes and be governed in a way that will protect patients’ fundamental rights. For example:
  - Scope must be relevant today and as new data sources emerge in the future
  - Wording to encompass the possibility of exemptions to patient consent requirements subject to suitable safeguards
  - Describing data de-identification and digital security risk management processes in a way that will be relevant in the future as new technologies emerge

# *Scope of the Recommendation*

- Focus on areas where there is widely recognized, obvious and substantial public interest in health research, health care and health system improvements
- Acknowledge the continuum of health data use
- Adopt a broad definition of health data
- Build on the OECD Privacy Guidelines and other relevant frameworks
- The Health Committee study is a key input to the drafting of the recommendation

# *Scope of the Recommendation*

The draft Recommendation:

- ✓ recognises that personal health data is processed by a broad spectrum of actors, including but not limited to national and sub national levels of governments, profit (or not) government organisations, health and social care providers and universities
- ✓ encourages the availability and use of personal health information to improve health care quality and performance
- ✓ promotes the use of personal health data for public policy objectives, while maintaining public trust and confidence that any risks to privacy and security are minimized and appropriately managed

# *Structure of the Draft Recommendation*

Cover Note – rationale, scope and process

Preamble

“Having regard” paragraphs, and “Agrees” paragraphs containing explanatory text on main terms used and of scope ( *the public interest* )

Operative clauses

Recommendation outlining 12 measures to establish and implement a national health data governance framework including a recommendation on how governments can support interoperable trans border sharing of personal health data

# Key principles

- 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

# *Governance: Advisory Expert Group (AEG) and Drafting Group*

- AEG includes 65 members with expertise in privacy, law, statistics, research, IT and health policy from government, industry, academia and civil society
- Drafting Group : Mark Taylor, (Senior Lecturer, *University of Sheffield , UK)* ; David Smith, (former *Assistant Privacy Commissioner of the , UK)* ; Bartha Knoppers, (*Director of the Centre of Genomics and Policy, McGill University ,Canada) ;* Jillian Oderkirk (Consultant OECD); Elettra Ronchi (OECD Senior Policy Analyst) ; Celine Folsche (OECD Legal Advisor) Claire Hilton (OECD).
- Co chaired by Jennifer Stoddart (former Privacy Commissioner of Canada) and Paivi Hamalainen (Chief Specialist- National Institute for Health and Welfare , Finland)

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# *Eight Key Data Governance Mechanisms*

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|---|---|
| #1 | Coordinated development of high-value, privacy protective health information systems |
| #2 | Legislative framework permits privacy-protective data use |
| #3 | Open and transparent information system that builds trust |
| #4 | Accreditation/certification of data processors to promote data security and access |
| #5 | Transparent and fair project approval processes |
| #6 | Data de-identification practices that consider “the big picture” – data protection, security and utility |
| #7 | Data security practices that meet legal requirements and public expectations |
| #8 | Data governance practices that are continuously assessed and renewed |