OECD RECOMMENDATION ON HEALTH DATA GOVERNANCE

EU-Bridge Health Meeting
22 September 2017
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OECD Council Recommendation on Health Data Governance
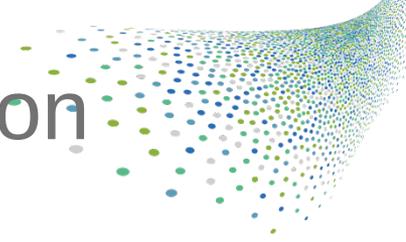
- Collaboration of health ministries through the Health Committee and data privacy authorities through the Committee on Digital Economy Policy

- Expert input across domains of health, policy, law, ethics, privacy, research, statistics, IT from government, industry and civil society

- Adopted by the OECD Council on 13 December 2016

- Welcomed by Health Ministers at their OECD meeting on 17 January 2017

- Not legally binding but represents a moral force and outcomes of Adherents will be monitored
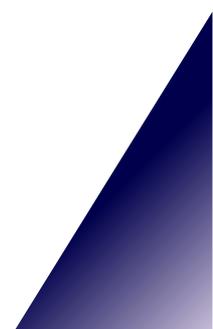
Scope of the Recommendation
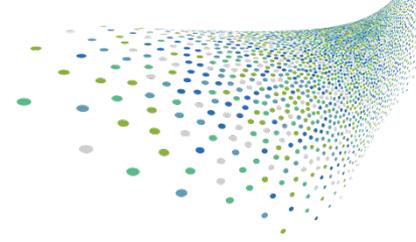
1. Establish national health data governance frameworks

- 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

12 Elements of National Health Data Governance Frameworks

1. **Engagement of stakeholders** in the development of a national health data governance framework

    • Public consultation about the processing of personal health data under the framework

    • Public dissemination of the major findings of the public consultation

2. **Co-ordination** within government and co-operation among personal health data processors to encourage common data-related policies and standards

    • Coordinate toward common data definitions, formats, interoperability standards and quality assurance approaches

    • Develop common policies and procedures that minimise barriers to sharing data while protecting privacy

3. Reviews of the **capacity of public sector health data systems** to serve public interests

    • Review data availability, quality, fitness for use, accessibility, and privacy and data security protections

    • Examine current approaches to dataset transfers and linkage of dataset records

12 Elements of National Health Data Governance Frameworks

4. **Clear communication** to individuals about the processing of their personal health data

    - Individual notification about a breach of their personal data is a legal requirement

    - Public information describes how and when individuals are informed about processing of their data

5. Processing of personal health data by **informed consent and appropriate alternatives**

    - A policy or guideline is available to the public that explains the legal authority under which health data may be processed

    - Approach to consent and legal exemption to consent requirements protect data privacy and do not create undue impediments to scientific research and the monitoring of health care quality and health system performance

6. Implementing **review and approval procedures** to process personal health data

    - There are criteria that must be met to approve requests to process personal health data, including requests for dataset linkages and extraction of data from clinical records

    - The criteria are fair and applied consistently, and approval decisions are timely.

    - Approach to project approval supports scientific research and the monitoring of health care quality and health system performance

12 Elements of National Health Data Governance Frameworks

7. **Transparency** through public information about the processing of personal health data

- The criteria that must be met to approve data processing are publicly available

- Summaries of decisions to approve processing are publicly available

- The national health data governance framework and its implementation plan are publicly available

8. Maximising the development and **use of technology** for data processing and data protection

- New opportunities for data development and data protection are identified and assessed.

9. Mechanisms to **monitor and evaluate** the impact of the national health data governance framework

- Periodic review of developments in personal health data availability and changes in the data needs of health research and public policy communities

- Periodic assessment and updating of policies and practices to manage privacy protection and security.

- Periodic assessment of whether the uses of personal health data have met the intended health-related public interest purposes and brought the benefits expected from such uses.

12 Elements of National Health Data Governance Frameworks

10. **Training** and skills development of personal health data processors

• There any national requirements for health data processors to institute training programs in data privacy and security for any persons that will be accessing personal health data.

11. **Controls** and safeguards within personal health data processors

• National policies or guidelines ensure appropriate controls and safeguards to protect data privacy and security

• Health data processors are audited for compliance with policies or guidelines to ensure appropriate controls and safeguards are in place

12. Requiring that personal health data processors **meet the expectations** set out in the national health data governance framework

• Organisations processing personal health data demonstrate that they meet national standards for health data governance through accreditation or certification programmes or through other mechanisms

# Elements related to harmonising frameworks between countries
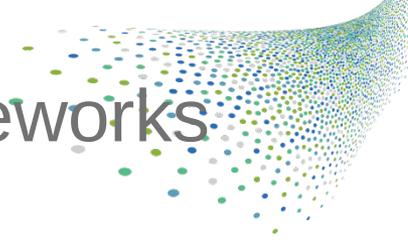
1. Identify and remove barriers to cross-border cooperation

2. Facilitate the compatibility and interoperability of health data governance frameworks

3. Share outcomes and best practices in data availability and use

4. Develop mechanisms that enable the efficient exchange and interoperability of health data

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
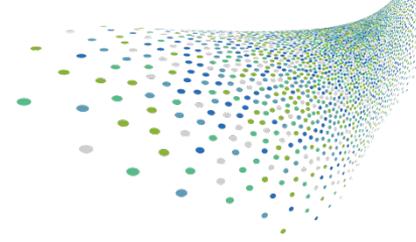
Implementation guide
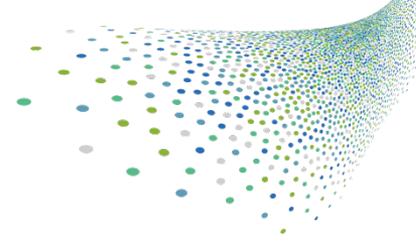
- Being developed to provide:
  - Background information on the Recommendation and the expectations of Adherents.
  - For each of the elements of the Recommendation
    - The intention of the element
    - Examples of good practices related to the element
    - Expectations of Adherents (attention points)

Monitoring plan
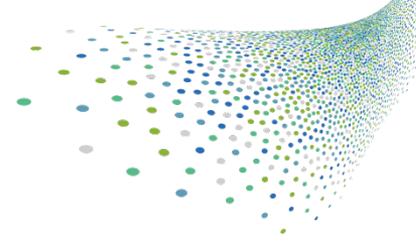
Being developed and could include:
- Indicators from OECD surveys of
  - Health Data Development, Use and Governance (2019)
  - Electronic Health Record Systems and Data Use (2020)
- Context from studies of developments in digital privacy and security policies and the interoperability of legal frameworks
- Results from Interviews with senior officials to assess progress toward the key elements of the Council Recommendation (2021)

- Monitoring Report January 2022