

Health Databases & Biobanks

*Promoting & Protecting Public Health
through Custodianship*

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The Purpose

to promote
public health & individual health

Three Key Concepts

- Health is our greatest good. Promoting health is a first responsibility of governments and our best investment.
- ‘My health is (y)our health; (y)our health is my health.’
- Health is a shared interest and a shared responsibility.

The Core Value

‘It is the duty of the physician **to promote and safeguard the health**, well-being and rights of patients, including those who are involved in medical research. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.’

Paragraph 4, Declaration of Helsinki, 2013

Considerations Regarding the WMA Draft
Declaration on Ethical Considerations
Regarding Health Databases and Biobanks (2015-03-18)

- **Distinguish** between human persons & communities and materials & data derived from human persons
- Achieve a renewed concept of consent
→ **participatory consent**
- **Custodianship** should be the principle framework for health databases & biobanks

Custodianship

- Health data may not be considered as other kinds of data; health data is **a public good** (*res publica*)
- Health data, healthcare practice, health sciences, health knowledge may **not be owned**
- Replace ‘ownership’ with ‘custodianship’
- Health (data) custodianship = ‘the **responsible** reception, organization, protection, and sharing of health data, information, and knowledge’

‘the good health custodian’ = ‘the good health librarian’

The Need for Public Authorities

- The collection, storage, and use of health databases & biobanks should be overseen, regulated, and evaluated by **public (health) authorities**
- Current (research) **ethics committees** should maintain a focus on research on human persons