Health Databases & Biobanks

Promoting & Protecting Public Health through Custodianship

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Francis P. Crawley
Clinical Practice Alliance – Europe
fpc@gcpalliance.org
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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.
‘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