What's new?

A. Dimension of biobanking

- Number of samples, persons, and structures
- Diversity and dynamics of structures
- Public and private sectors
- International dimension
- From research to health purposes

B. Relationship between society and biobanks

C. Technological developments (IT)

Privacy

- **Keeping control over personal data and samples: increased difficulties**
  - **Access to/use by whom**
  - **Access to results**

Anonymisation (unlinked)

- Anonymisation still feasable?
  - Role of Biobank in protection of privacy
- Compatibility with research objective?

"Information is vital"

A. Society

- Building trust in biobank research

B. Individual (autonomy & privacy)

- Informed decision-making
- Keeping control over samples and data (including withdrawal)

Consent as a process

A. Information and scope of consent?

- Questioning the approach to consent in Rec(2006)4

or

- Suggesting “new approach” to its implementation

B. “Dynamic”, on-going engagement

C. Children

- **Biobank essential biomedical research tool**

  Access to data and samples by researchers

- **Ethical concerns to be addressed**

  Measures to be taken by biobanks (means and structures to be developed)

- **Consistent Coherent international framework**
  - **Appropriate approach?**
  - **Soft law/ codes of conduct/Binding legal framework?**