



## A. Distinct characteristics

- Unspecified Future Research
- Many sites/collaboration with other countries
- Used after Death
- Researchers Return Results to Database
- Communication Strategies



## B. Distinct ethical underpinnings

- Public/common good
- Solidarity
- Citizenry
- Socio-demographic
- Open/controlled Access



## C. Distinct ethical issues

- Validity of consent
- Immediate feedback
- Recontact
- Withdrawal

## C. Distinct ethical issues

- Ethics review
- Security
- Governance



- “Restrictions on access to information at any stage of the innovative process obstruct the flow of scientific information and thereby impede scientific progress. Such restrictions are also contrary to the needs of scientific inquiry and are inimical to openness and transparency.”

- The University of Manchester, Institute for Science, Ethics and Innovation, *Who Owns Science? The Manchester Manifesto*, 2009.

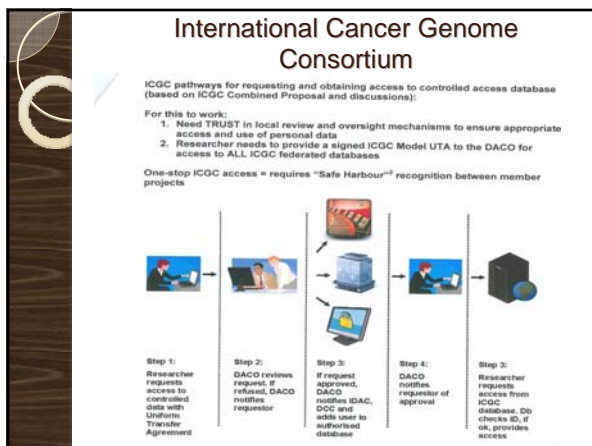
= D. Distinct review?

- Why?
- Single body (IPEG)?
- Data oversight body/Privacy Officer
- Transparency/Efficiency/Cost
- Accountability
- Sustainability

### Models?

- Draft Tri-Council Policy Statement (Data vs. Samples)
- International Cancer Genome Consortium

“The databank would be glad to give you information about yourself, but unfortunately the databank is not convinced that you are really you.”



« Such research can be granted ethical endorsement under the principle of reciprocity, which encompasses the idea that accepting benefit from past medical research, inherent in the utilisation of medical services, carries some expectation of a willingness to participate in research for the common good. »

- Bioethics Advisory Committee, *Personal Information in Biomedical Research*, Singapore, 2007