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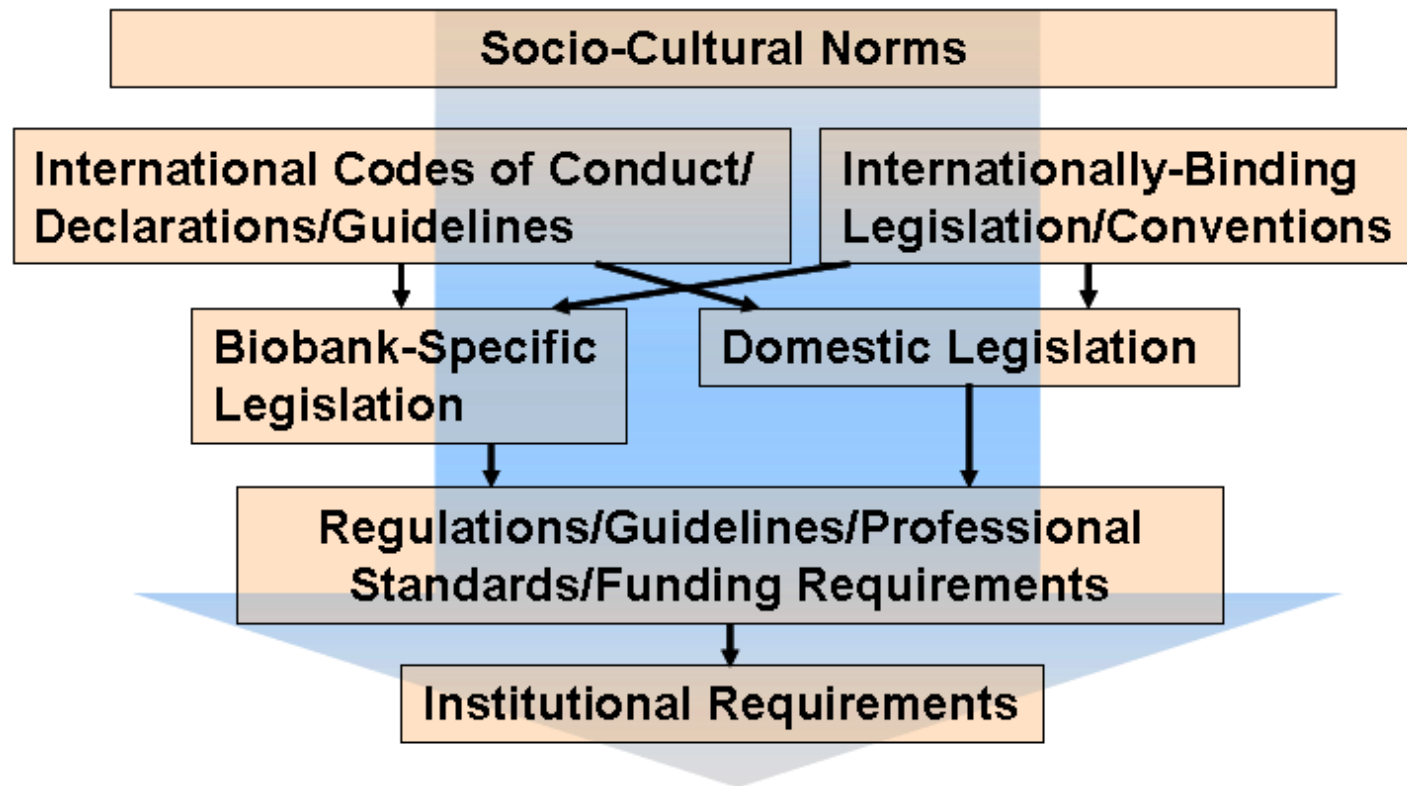
Building a model framework for the governance of biobanks

S Wallace, K Bedard, BM Knoppers

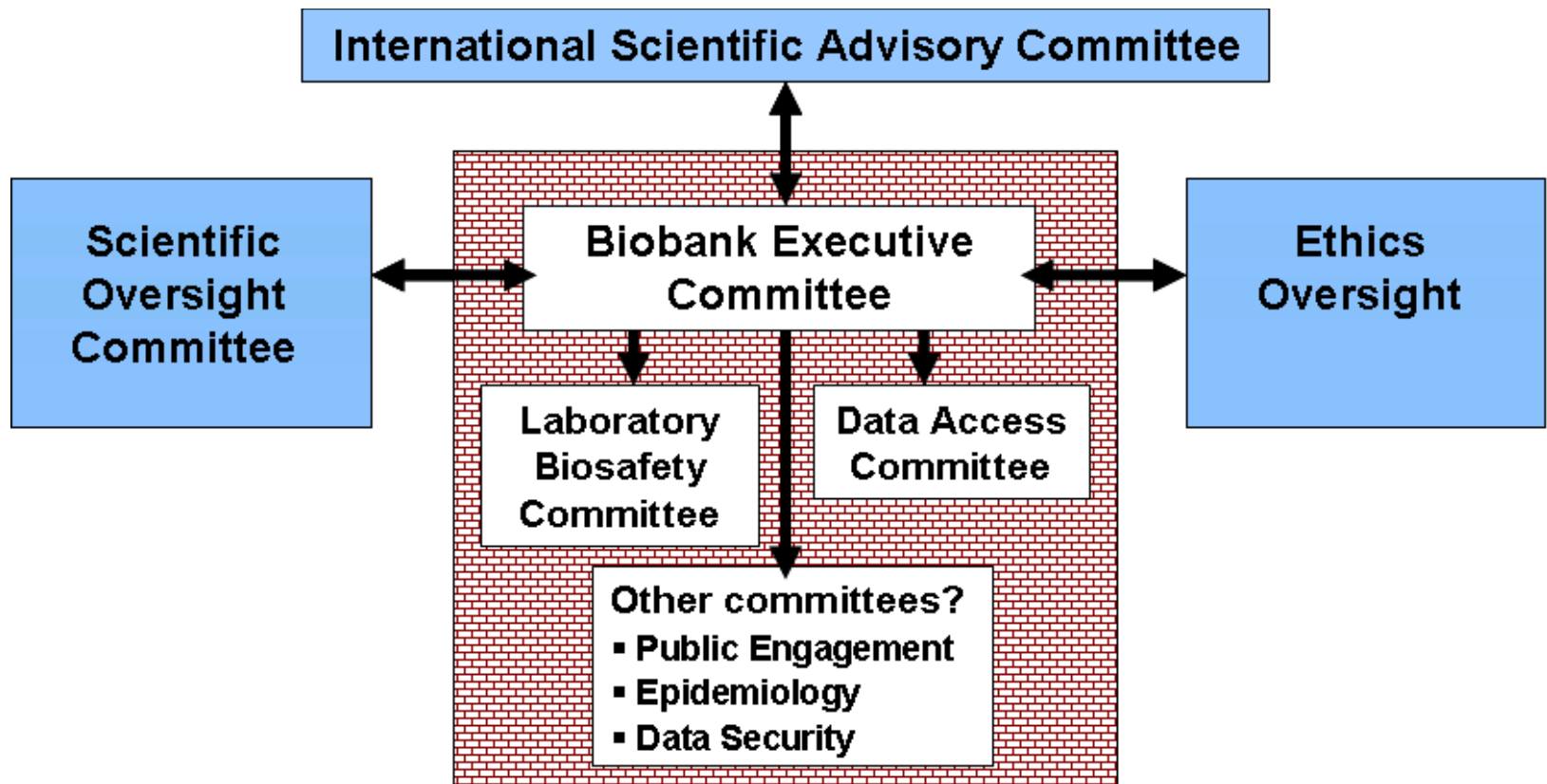
Universite de Montreal

<http://www.p3gobservatory.org/repository/ethics.htm>

External governance mechanisms



Internal governance mechanisms



Governance and biobank lifecycle

'Before'

Planning/Creation:

- **Public Engagement**
- **Legislation**
- **Funder Requirements**
- **Scientific Peer Review**
- **Ethics Review**

'During'

Set-up/Operations:

- **Executive Committee**
- **Scientific Oversight**
- **Ethics Oversight**
- **Sample Handling**
- **Data Management**
- **Participant Engagement**

'After'

Access to/Use of Resources:

- **Data/Sample Access/IP Procedures**
- **Public Outreach**

Minimum governance

- *Scientific aspects*
 - Research conducted will advance science and benefit the population and individuals in the future
 - Resource's procedures and activities will receive regular independent scientific review

Minimum governance

- *Ethical aspects*

- Confidentiality of personal information will be protected
- Resource's procedures and activities will receive regular independent ethics review
- Requests for access to data and samples will be reviewed at some level
- Resource will comply with all relevant legislation, guidelines and standards

Minimum governance

- *Expertise*

- There will be expert representations on all governance and oversight committees as appropriate (i.e.m epidemiologists, bioinformaticians, sociologists, geneticists, etc.)

Minimum governance

- *Communication aspects*
 - Population will be kept generally informed of the research conducted using their data and samples
 - Participants will be able to register their comments, queries and complaints to the resource, with the assurance that any complaints will be addressed



Tools and Training

Genetic Alliance BioBank provides the following tools and training opportunities to assist advocacy organizations in developing and managing registries and biorepositories.

BioBank Ambassadors

[GABB Ambassadors](#) provides a forum to connect organizations that have established registries or biobanks with new organizations that may be interested in creating these resources. Please email lhorn@geneticalliance.org for more information.

BioBank Boot Camps

Boot camps are in-depth, hands on training sessions to assist advocacy organizations in creating and maintaining a registry and/or biorepository.

- ▶ [Registry and Repository Boot Camp](#), January 10, 2010. [View boot camp agenda and materials here.](#)

BioBank Discussion Listserv

This listserv has been created to discuss issues surrounding registries and biorepositories. Please email lhorn@geneticalliance.org to join biobank_discussion@listserv.galists.org.

BioBank Videos

[Watch Sharon Terry](#), CEO of Genetic Alliance, discuss the important role for advocates in biobanking, how she became involved in the field, the challenges she faced, and how advocates working together can make a difference.

BioBank Webinars

This teleconference series offers information and discussion framework on topics relating to Genetic Alliance BioBank.

- ▶ [Registry and BioBank Question and Answer Session](#), September 1, 2011
- ▶ [Making Your Organization's Registry and/or Biobank a Reality](#), August 11, 2010
- ▶ [Genetic Alliance BioBank: A Virtual Tour of Registry Solutions to Accelerate Research](#), February 3, 2010
- ▶ [Genetic Alliance BioBank](#), May 20, 2009

