



# Biobanks around the World: Current trends and context

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GenomeCanada

## OUTLINE

3 dimensions of the biobanking landscape:

- 1. Diversity
- 2. Globality
- 3. Complexity (of research collaboration using biobanks)

# 1. DIVERSITY

## Biobanks : what are we talking about?

- Definition
- ‘A collection of biological material and the associated data and information stored in an organised system, *for a population or a large subset of a population.*’
- Source: OECD - Creation and Governance of Human Genetic Research Databases, OECD. Paris – 2006

# 1. DIVERSITY

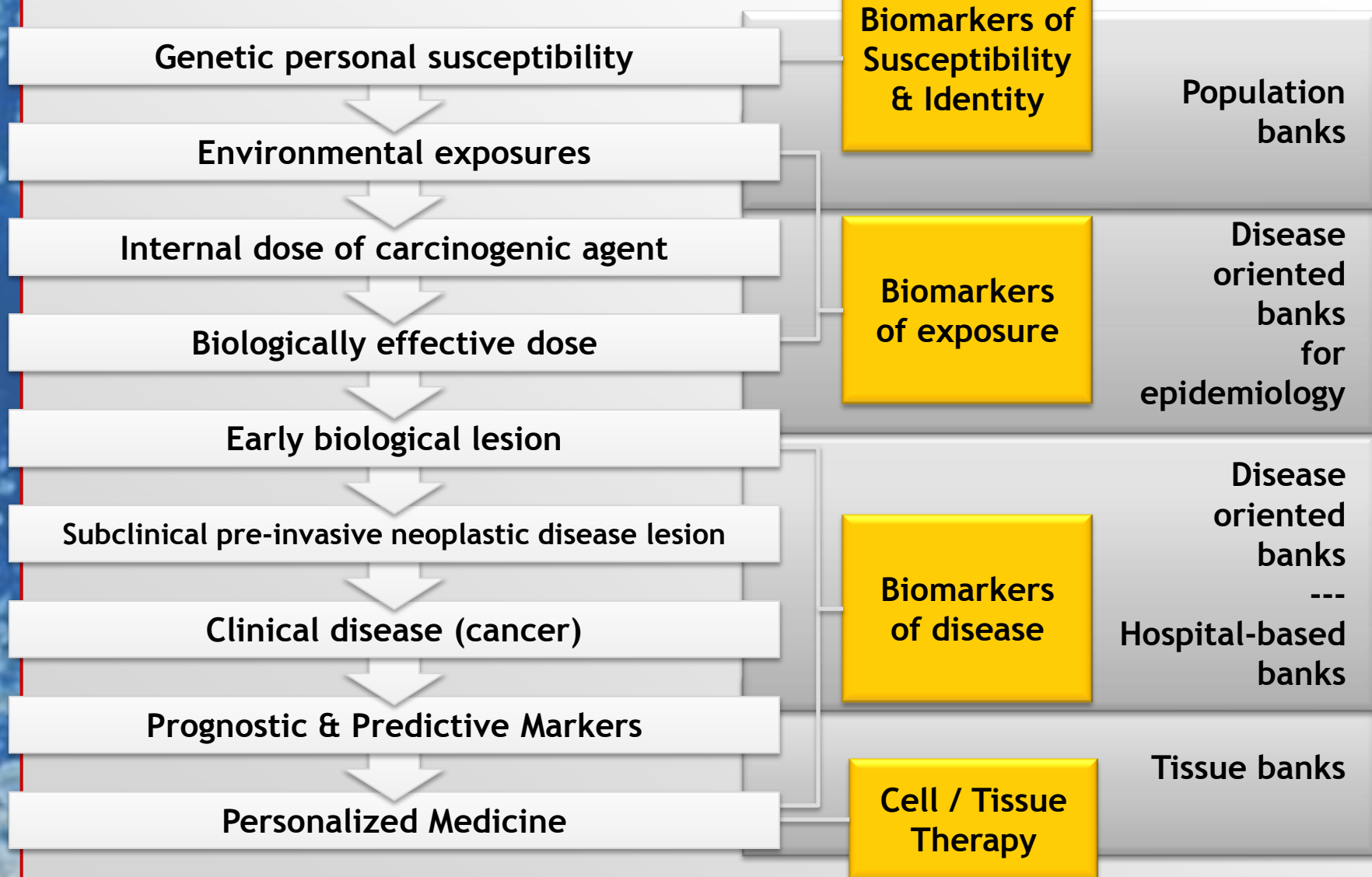
## Biobanks : what are we talking about?

- What material/data is being collected, how and for how long?
  - existing material or new biobank?
  - Snapshot or follow up?
- Are we talking about a research project (the biobank is an ‘accessory’) or a research infrastructure?
- Is it a population based biobank or a disease-based biobank? What type of research purposes can it serve?

# The importance of the design:

Source: Dr. Manuel Morentes

*Tumor Bank Unit, Molecular Pathology Program, Spanish National Cancer Centre – CNIO/ Marble Arch Group*



## 2. GLOBALITY

- Major investments in biobanks all around the world
- E.g. UK Biobank
  - Recruit 500 000 participants between 40-69 and follow them for at least 30 years.
  - 58.3£ million over 8 years.
  - Source: Report and Financial Statement 2007 – UK Biobank

## 2. GLOBALITY

- WHY?
  - Rapid evolution of technologies : *enabling high exploitation at low costs*
  - Serves the scientific challenges raised by today's research on complex disease
  - Strategic scientific/economic pre-competitive asset

## 2. GLOBALITY

- Trends
  - Build large biobanking infrastructures / networks
  - Increase accessibility
  - Improve quality – best practices (biobanking as a science.)
  - Harmonize to enable Collaboration
    - Accelerate research and the return of results to participants

## 2. Globality

The need for collaboration: increasing the statistical power

How long does it take to reach 10,000 cases in a cohort study with 500,000 cases?

- **Alzheimer's disease: 18 years**
- **...With 2.5 M. participants: 9 years**

## 2. GLOBALITY

In order to collaborate need to know:

- Who has a biobank?
- What does it contains? (material/ data?)
- What could I do with this material/data?
- Can I collaborate ? (i.e. ..have access)

## 2. GLOBALITY

Attempts to assess how important are the biobanking resources:

- 1999 RAND study in the USA:
  - ‘conservatively estimated that there were more than 307 million human biospecimens from more than 178 million cases stored in the United States, accumulating at a rate of more than 20 million specimens per year.’

## 2. GLOBALITY

- P3G:
  - Members in more than 40 countries
  - Offers a free online access to information about biobanking activities especially in the field of population based biobanks.
  - Build tools to improve the quality of biobanks and to support harmonization so as to enable future collaboration

# P3G Study Catalogue

## 138 studies

DataSHaPER

### P<sup>3</sup>G Catalogues

- Network
- Study
- Questionnaire
- Physical and Cognitive Measures
- DNA Processing
- Ethics and Governance
- Information Technologies

### Partner Catalogues

- BBMRI
- CPT project
- Diabetes Biobank
- INGI
- Renal Biobank

### Repository of Information and Tools

- Epidemiology and Biostatistics
- Sample Collection and Processing
- Data Collection and Processing
- Ethics, Governance and Public Engagement
- Project Administration

Home > P<sup>3</sup>G Catalogues > Study Catalogue

## STUDY CATALOGUE

This Catalogue is a repository of standard information describing population-based studies in genomics.

To be included in the Catalogue, a study should:

- Collect or plan to collect DNA samples or biological material from which DNA can be extracted.
- Have recruited or plan to recruit more than 10 000 healthy individuals (some smaller studies are also included occasionally).
- Studies must collect minimal information on health status and socioeconomic status.

The descriptive information is collected in a two-steps process: (1) The summary information is initially gathered by our team through websites and/or publications and (2) Complete information is provided by study investigators using the P<sup>3</sup>G study description form. For studies with only a summary description, the scope and quality of information collected is limited, and the search form provides fewer data.

If you would like your study to be included in the catalogue, please complete the [study description form](#) and send it back to us by [email](#) .

Do not hesitate to contact us to update the information related to your study!

**Authorization** from contributors to post information on the P<sup>3</sup>G Observatory catalogues.

### Catalogue current content

Number of Studies	138
With Summary information (to be validated)	59
With Complete information (validated by study investigators)	79

All 0-9 A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Results 1 to 25 of 138 studies found

[First/Prev] 1, 2, 3, 4, 5, 6[Next/Last]

Name	Acronym	Target or final number of participants	Study design	Country of residence	Format
45 and Up Study (The)		250000	Cohort	Australia	Complete
Agincourt Health and Demographic Surveillance System, South Africa	AHDSA	85000	Longitudinal demographic surveillance	South Africa	Summary
Agricultural Health Study	AHS	89658	Cohort	United States	Summary
Airwave Health Monitoring Study	AWHMS	60000	Cohort	United Kingdom	Complete

SEARCH /  
ADVANCED SEARCH

COMPARISON TABLE

STATISTICS



## **P<sup>3</sup>G Observatory**

**138 large population-based studies identified  
( >10 000 healthy participants )**

**Over 40 countries have recruited  
11 million participants so far !**

**29 biobanks of more than 100 000  
participants**

**[www.p3gobservatory.org](http://www.p3gobservatory.org)**

## 2. GLOBALITY

**10K participants/public  
(N = 135)**

		Number of studies	Number of participants TARGETED
<b>Single-country studies</b>	EUROPE	60	4,597,000
	AMERICA	44	3,420,000
	OCEANIA	7	431,000
	AFRICA	1	85,000
	ASIA	15	1,319,000
<b>Multiple-countries studies</b>	EUROPE, AMERICA, OCEANIA	8	837,832

**November 2009**

**[www.p3gobservatory.org](http://www.p3gobservatory.org)**

# P3G Statistics

## Collected biological samples (N = 68)

What type of Biological samples are collected?

Collected biological samples		Number of studies
Blood		63
Cord blood		5
Buccal cells		19
Tissues		12
Saliva		8
Urine		16
Others		10

		Blood		Buccal cells		Saliva	
		Total nb studies N = 16	Coverage** (Percent bar indicator)	Total nb studies N = 6	Coverage** (Percent bar indicator)	Total nb studies N = 8	Coverage** (Percent bar indicator)
<b>PRE-EXTRACTION SAMPLE STORAGE FORMAT</b>							
Substrate storage condition	Fresh	15		5		8	
	Frozen	12		5		6	
	Dried (paper)	5		0		0	
	Other	0		0		1	

## DNA EXTRACTION

DNA extraction method	Salting out	16	
	Phenol-chloroform	3	
	Columnary-extraction	3	
	Magnetic beads	1	
	Oragene (saliva)	0	
	Others	0	
Automation of handling	Manual	10	
	Automated	9	

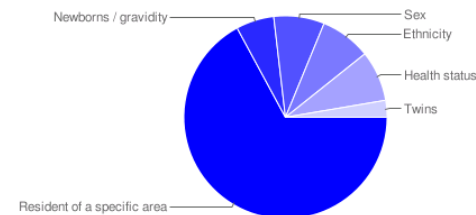
## Access to data and samples (N = 53)

Is access to data and samples to external researchers or third parties provided or foreseen?

Access given to:	Number of studies
Data (Questionnaire-derived, measured...)	47
Biological samples	45

## Selection criteria (N = 124)

Selection criteria (independent factors)	% of studies
Newborn / Gravidity	9 %
Sex	12 %
Ethnicity	12 %
Health status	12 %
Twins	4 %



## Questionnaire administration mode (N=20)

Administration mode	Number of studies
Auto Administered	12
Auto Administrated With Face To Face	
Administrated By Trainee	
Other	

## Administration environment (N = 19)

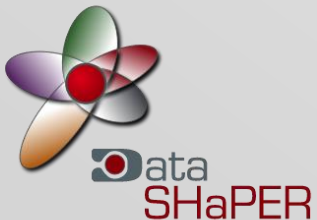
Where were the physical and cognitive tests and measures performed?

Administration environment	Number of studies
Hospital, clinic, university or recruitment center	15
Participant residence	3
Other	3



**P<sup>3</sup>G Harmonization Platform**  
**Now possible to identify WHAT information**  
**(physical measures, lifestyle, samples, etc.)**  
**can be shared between biobanks**

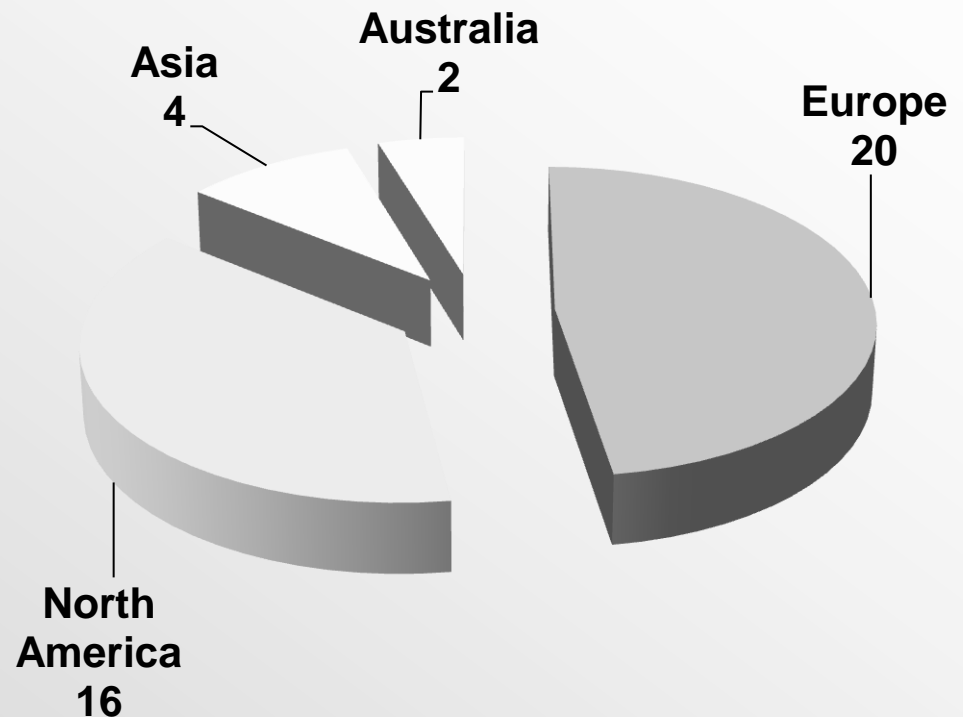
**Up to now, 40 participant biobanks**  
**More that 5 million participants targeted !**



[www.p3gobservatory.org](http://www.p3gobservatory.org)

# Participant studies (n=42)

Country	Number of Studies
USA	9
Canada	7
Sweden	6
UK	5
China	3
Australia	2
Norway	2
Estonia	1
France	1
Germany	1
Italy	1
Latvia	1
Netherlands	1
Singapore	1
Spain	1



### 3. COMPLEXITY

- New trends:
  - Harmonization
  - Collaboration
  - Opening access
  - Use of large scale research infrastructure  
biobanks
  
  - = ELSI challenges

### 3. COMPLEXITY

#### Research options

- Researcher/Biobanker collecting:
  - For his own project/biobank (traditional model)
  - For an alliance/collaborative network (private or public, virtual or real)
  - for another biobank (private or public)
  - ...In the same or another jurisdiction
- Researcher using:
  - From a biobank infrastructure
  - From an alliance/collaboration, private or public, virtual or real
  - ...in the same or another jurisdiction

## CONCLUSION

The world is building today research infrastructures/tools that should be able to serve the research projects of tomorrow.

Building our capacity to solve health problems!

MARCH 23, 2009

Annual Special Issue

# TIME

## 10 IDEAS CHANGING THE WORLD RIGHT NOW

The global economy is being remade before our eyes. Here's what's on the horizon

- WHY YOUR JOB IS YOUR MOST VALUABLE ASSET
- REPURPOSING THE SUBURBS
- SURVIVAL-STORE SHOPPING
- BIOBANKS: SAVING YOUR PARTS
- NEED LAND? RENT A COUNTRY
- THE NEW CALVINISM
- ECOLOGICAL INTELLIGENCE
- AMORTALITY: FOREVER YOUNG
- AFRICA: OPEN FOR BUSINESS
- REINVENTING THE HIGHWAY



www.time.com

## CONCLUSION

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