



BC GENERATIONS PROJECT
Your time today, builds a healthier tomorrow.



Bridging Research Platforms-Opportunities and Challenges

Background

In 2007-8, three health research platforms were funded in British Columbia.

- 1) BC Generations Project – prospective cancer and chronic disease cohort in BC; part of the national cohort initiative
- 2) Population Data BC –Platform to link data generated through routine medical services programs in BC for health services and other research
- 3) BC BioLibrary – Platform to catalog and link bio-specimens and specimen banks, and promote research access throughout province

BC Generation Project

Recruit 40,000 BC adults age 40-69 into the 300,000 person Canadian Partnership for Tomorrow cohort

- 1) Questionnaire (lifestyle, environment, residence, occupational, and family health history, and other variables.
- 2) Physical measurements (BP, lung function, bone density, height, weight, body composition)
- 3) Biospecimens (DNA, plasma, serum, preserved cells + urine)

OUR VISION

Population Data BC is a multi-university, nationally active and recognised data and education resource that facilitates interdisciplinary research and teaching on the determinants of human health, well-being and development. While respecting and adhering to legislation and protocols governing access to sensitive information and protecting individual privacy, Population Data BC's work will strive to ensure that:

- researchers have timely access to data and training,
- researchers have access to data that address research questions on human health, well-being and development, and
- research using these data informs policy-making and leads to healthier communities.

Population Data BC

Resource for single-point research access to all routinely generated health data collected in BC

- 1) Hospital discharge summaries, physician visits, Rx, home, community, and mental health services, vital statistics data, cancer registry etc.
- 2) Data is linkable into anonymized longitudinal files on a project-by-project basis
- 3) Data from many sources dates back to 1985



The BC BioLibrary helps pathologists streamline and improve biobanking activities.

Creation of best practices enables pathologists to better manage volume and quality control of biospecimens collected for research and education.

About the BC BioLibrary

The BC BioLibrary is a Michael Smith Foundation for Health Research (MSFHR) funded Technology/Methodology Platform. This program supports a broad range of health research applications with a mandate to enhance health research across BC.

The BC BioLibrary is not a biobank and does not perform research. It is a network that complements current biobanks, maintains stakeholder trust, improves quality and access to human biospecimens for biobanks, research studies and clinical trials, and builds capacity for translational research in BC.

For additional information, please contact the [BioLibrarian](#).



News

May 12-15
The BC BioLibrary presented a poster at the [ISBER 2009 Annual Meeting](#) in Portland, OR. [Click here](#) to view the poster.

April 17/09
The BC BioLibrary hosted its 2nd Annual Workshop on Friday, April 17th, 2009. Please [click here](#) to read about the events of the day and view presentations

October 12-17/08
[The BC BioLibrary recently presented a poster](#) at the 27th Congress of the International Academy of Pathology held in Athens, Greece. [Click here](#) to view the poster.

[Click here](#) for archived news.

eNewsletter

Sign up for our eNewsletter!
To stay engaged in the activities of the BC BioLibrary please sign up for our eNewsletter. Submit your email address below.

[Click here](#) for the most current issue of *BioAccess*.

[Click here](#) to view past issues of *BioAccess*.



Events Calendar

Complete listings from the [Public & Researcher](#) event calendars.

June 2009						
Su	M	Tu	W	Th	F	Sa
24	25	26	27	28	29	30
31	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	1	2	3	4
5	6	7	8	9	10	11

Today Thu, Jun 18
No events on the 18th.

[Gadgets](#) powered by Google

BC BioLibrary

Platform to catalogue and facilitate research access to tissue and other bio-specimens held throughout the province. Operates primarily in conjunction with pathology units.

- ١) Catalogue, organize and help distribute human biospecimens (frozen and paraffin embedded tissue) for research
- ٢) Define and promote standardized criteria for collection, processing, and storage of material.
- ٣) Potential for provincial repository

The Opportunity?

The relatively recent and synchronous start up may allow creation of a unique population health laboratory:

By bridging these could create a research platform which combines the strengths of:

- a) a population-wide health care usage database,
- b) a prospective population-based cohort with pre-diagnostic bio-specimens,
- c) a province-wide cooperative tissue library.

10 Year Outcome

Integrated resource allowing population-based

- a) social epidemiology studies of health and disease trajectories,
- b) Studies of disease etiology, secondary prevention interventions,
- c) disease diagnosis, prognosis, treatment, side-effects, and outcomes
- d) all within a single well-characterized multi-ethnic population

Challenges (Technical)

- ١) Harmonized IT to allow linking of individual longitudinal records over 3 different platforms
- ٢) Harmonized data archiving practices, and data sharing agreements
- ٣) Tight physical and electronic security; single portal controlled data access and analysis point (VPNs?)
- ٤) Fair and transparent data access and usage policies

Challenges (Ethical and legal)

- ١) Approval from data and specimen stewards (MoH, DVS, regional health authorities, BC universities, CPT, etc.)
- ٢) Office of Information and Privacy Commissioner of BC approval and oversight
- ٣) Research Ethics Board buy-in across province
- ٤) Integrated legal charter; with harmonized privacy and confidentiality policies and practices

Challenges (Social—most important?)

- 1) Public buy in –through consultative process?
Deliberative democracy? ; continuing role in governance? W. Maurice Young Centre for Applied Ethics (UBC)
- 2) Harmonized (to the degree possible) participant consent, novel methods for ensuring tissue specimen collection at disease outcome
- 3) Many others

Challenges

- ١) Financial crisis –Several platforms have major financial concerns due to funding shortage brought about by declining gov't revenues and grant body money shortages
- ٢) Legislation changes regarding privacy, use of MoHS databases for secondary purposes (research), contact of potential participants
- ٣) Unease about health data (particularly among vulnerable groups) due to concerns about electronic medical record (government use rather than research uses!)

Collaborators

Population Data BC:

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BC Generations Project

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