

Policy Brief

Consent Options for Biobanks: Perspective and commentary

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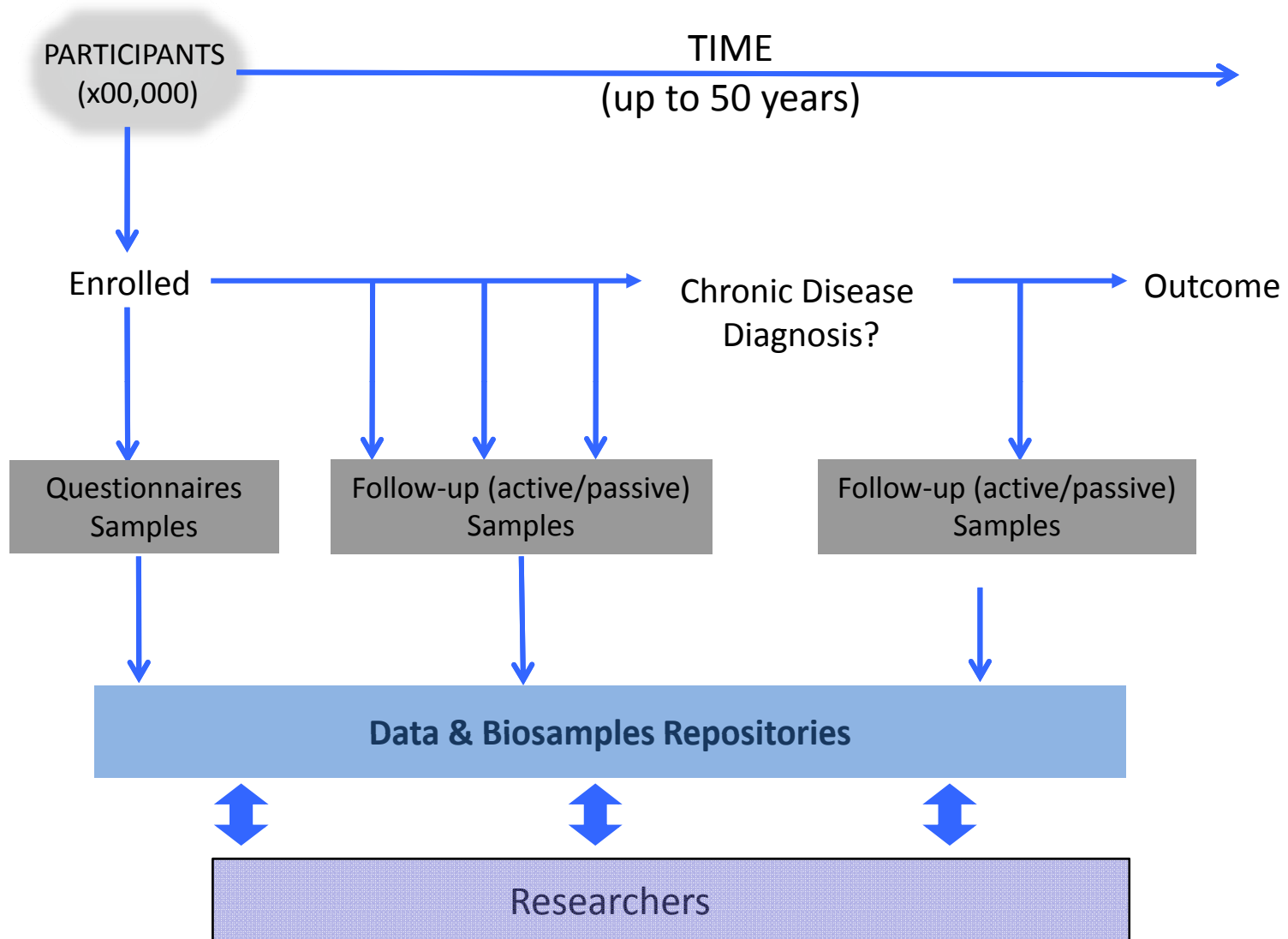
On behalf of the CPT Project Investigator Team

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Cancer burden

- Cancer imposes a substantial burden on individuals and society
- Between one third and one half of cancers may be preventable...
- BUT effective prevention (or risk reduction) means that we need to understand much more about the causes

Design: prospective cohort for research in cancer etiology



Adapted from Potter, 2005

Aims of the Canadian Partnership for Tomorrow Project

- To establish a pan-Canadian cohort of approximately 300,000 participants, aged 35-69 years, using a federated model
 - Alberta, Ontario, Quebec, Atlantic Consortium, British Columbia
- To collect health & lifestyle **data**, physical **measures**, and biological **samples** from all participants
- To obtain permission from participants for **active** and **passive** follow-up for up to 50 years
- To **harmonize** with other large international initiatives (e.g. UK Biobank) to increase probability of successful future pooling of data and samples

Federated model for the Canadian Partnership for Tomorrow Project

Cohorts

Alberta (*The Tomorrow Project*) n=50,000
Atlantic Canada (Partnership for Tomorrow's Health) n=30,000
British Columbia (BC Generations Project) n=40,000
Ontario (Ontario Health Study) n=150,000
Quebec (CARTaGENE) n=20,000

National coordinating centre

Task Forces & Working groups

ELSI and Privacy Task Force
Information Technology Task Force
Harmonization Task Force
Environment & Occupation Advisory group
Physical measures working group
Biological samples working group

**Canadian
Partnership for
Tomorrow
Project**

'Core' consent elements in CPT Project

- complete questionnaires, measurements, biological samples
- receive follow-up invitations to provide additional data and samples
- allow researchers with REB approval to access administrative 'health-related' databases for use in future research studies
- allow long-term storage of data and samples ready for use in future research studies
- permit transfer of data and biological samples to pan-Canadian repositories
- allow Canadian and international researchers with the necessary approvals to access de-identified data and samples for defined research studies

Additional challenges

- 300,000 may not be enough for less common cancers – may need to ‘share’ data and/or samples internationally
- CPT Project is primarily a platform for cancer etiology – data/samples could be of equal (or greater!) value for research in other areas
- Should those who consent to contribute to a ‘research platform’ be given options? “My blood can be used for cancer research, but nothing else...”
- Re-consent is not an option following death – can we still use data/samples?

Additional challenges

- Definition of ‘informed’?
- Biobanks are moving towards harmonization – will we ever see ‘harmonization’ of REBs?

CPT Partners and Supporters

- Alberta Health Services and Alberta Cancer Foundation
- Dalhousie University and Cancer Care Nova Scotia
- CARTaGENE and Genome Canada
- Cancer Care Ontario and the Ontario Institute for Cancer Research
- British Columbia Cancer Agency
- P3G (Public Population Project in Genomics)

