

# Objectives

## To provide a high level overview of:

- 1. The Canadian Partnership for Tomorrow Project (CPTP)
- 2. Types of data and biosamples available for request from CPTP
- 3. The CPTP Portal that provides detailed descriptions of available data
- 4. The CPTP access process, and what CPTP can do to help you create an application to CIHR





# ■ Population Health in Canada: Cancer and Chronic Disease

- Incidence of cancer and chronic diseases in Canada differs from other countries, and across the country
- Modifiable (e.g., diet, exercise, environmental exposure) and non-modifiable (e.g., genetic) risk factors likely contribute synergistically to disease, but how not fully known
- Understanding the complex interplay among risk factors requires access to large datasets, and is expected to lead to better prevention strategies, more effective treatments, and improved outcomes for Canadians





# Vision & Mission of the Canadian Partnership for Tomorrow Project (CPTP)



**Vision**: Improve population health through a better understanding of the causes of cancer and other chronic diseases.



**Mission**: To create and sustain a pan-Canadian population health platform that promotes and supports high quality, innovative population and health research.





# The Canadian Partnership for Tomorrow Project (CPTP)

- CPTP is Canada's largest cohort for health research
  - >300,000 participants aged 30-74 years
  - A variety of biological samples
  - Longitudinal data collection strategy
- It will continue to add depth over time through planned enrichment:
  - Passive (e.g., linkage to administrative data)
  - Active (e.g., additional questionnaires, data derived from biosamples)





## **CPTP: Regional Cohorts**









## **CPTP:** Resources

# CPTP is a versatile and powerful research platform that is poised to *grow* in value.

### Its resources include:

- A collection of harmonized data and biosamples
- Participant consent for use by bona fide researchers
- Participant consent for linkage with health administrative data
- Participant consent for re-contact and follow-up
- Access infrastructure to facilitate research





# **CPTP:** Data & Biosamples











Questionnaire data	DNA containing samples	Physical measures	Urine samples	Toenail clippings
<ul> <li>303,432 participants</li> <li>Demographics</li> <li>Lifestyle</li> <li>Risk factors</li> <li>Health history</li> <li>Follow-up questionnaires in progress</li> </ul>	<ul> <li>Venous blood (144,264)</li> <li>Blood spots (31,597)</li> <li>Saliva (18,064)</li> </ul>	<ul> <li>90,954 participants</li> <li>Height</li> <li>Weight</li> <li>Waist &amp; hip circumferences</li> <li>Grip strength</li> </ul>	• 101,379 participants	• 30,418 participants of Atlantic PaTH





## **CPTP: Baseline Questionnaire Domains**

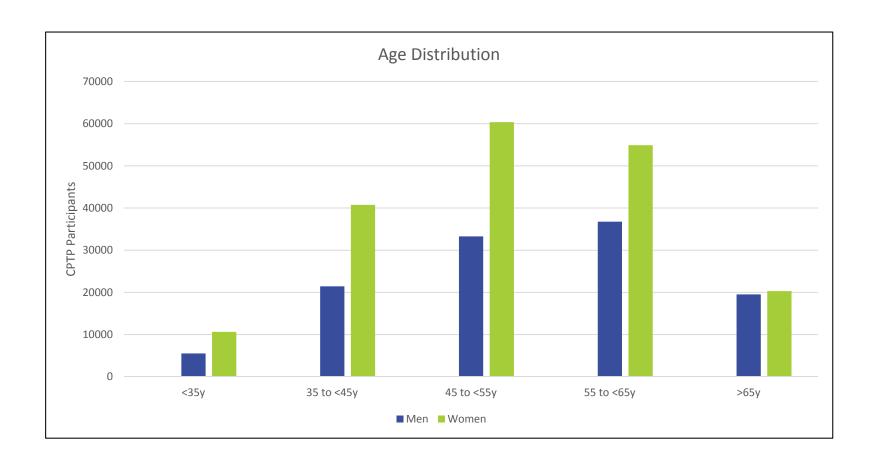
- Demographics (incl postal code)
- Education
- Medical check ups and screening
- Women's reproductive health
- Personal medical history
- Use of prescribed medication (past year)
- Family health history
- Sleep
- Sun exposure
- Alcohol use

- Tobacco use and second hand smoke exposure
- Physical activity
- Ethnicity, country of birth (participant, parents, grandparents) and first language
- Employment status, job title, business type, working schedule (shifts)
- Income
- Height, weight & waist/hip circumferences





# **CPTP:** Participant age and sex







# CPTP: Self-reported history of cancer and chronic disease

Individual Disease History	Total Reported (n, %)	
Cancer	29228 (9.6%)	
Diabetes	21949 (7.2%)	
Hypertension	68697 (22.6%)	
Stroke	3126 (1.0%)	
Myocardial infarction	5993 (2.0%)	
Arthritis	67588 (22.3%)	
Asthma	36709 (12.1%)	
Chronic hepatitis	1798 (0.6%)	
Multiple sclerosis	1743 (0.6%)	





## CPTP: Current enhancement initiatives

- Follow-up questionnaire (planned for early 2017)
  - updates on health history, use of prescribed medications, screening, alcohol, tobacco, e-cigarettes, demographics, weight, waist and hip circumferences
- MRI and additional environmental data on a subset (see Anand et al, BMC Public Health 2016)
- Genotyping on a subset
  - Affymetrix Axiom
- Sample analysis on a subset
  - Lipid panels, HbA1c, plus other markers





# **Examples of large grants obtained for research using CPTP data & biosamples**

- Two large CIHR grants awarded in 2015-16:
  - Determining the genetic and environmental factors associated with metabolic phenotypes across Canada; \$1.93 million over 5 years (PIs: Awadalla P, Dummer T, Spinelli JJ)
  - 2. CANadian Urban Environmental (CANUE) Health Research Consortium; **\$4.16 million over 5 years** (Pls: Brook JR, Steib DM, Awadalla P, Brauer M, McGrail KM, Subbarao P)





# CPTP: Linkage with administrative health data

- Currently managed at the level of regional cohorts
- Working towards a CPTP wide strategy in the longer term
- CPTP Access Office can coordinate contact with regions to determine feasibility of studies using linked data (e.g. health services utilization, health outcomes etc.)





## **CPTP Portal**



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The Canadian Partnership for Tomorrow Project (CPTP) Portal provides information to help the research community identify data and biosamples of interest to answer innovative research questions and request access to the CPTP resources.

#### Cohort design



Find out more about the five regional cohorts of the Read more

### Datasets



Find out more about the CPTP datasets and data harmonization approach.

#### Read more

#### Biosamples



Find out more about the CPTP biosamples collection and its upcoming availability.

#### Read more

#### Access



Find out more about the CPTP Access policies and procedures.

Read more

Welcome to CPTP Portal! The portal includes comprehensive information on the cohort design, data harmonized across the five regional cohorts, collected biosamples, and CPTP access procedures.

#### More information

Visit the CPTP web site to learn more about the Project.

For inquiries about data, biosamples and access, create a CPTP Portal User account to contact the Access Office.

#### Data available (April 1, 2015)

Researchers can request access to CPTP Health and Risk Factor questionnaire data (202.404 participants). Click here for more information on the CPTP harmonized datasets.

#### Future data releases

Data for additional participants, physical measures and other types of data, as well as information related to biosamples, will be made available to the research community in 2015 - 2016 and as more data is collected and harmonized.

## https://portal.partnershipfortomorrow.ca/





## **CPTP Portal: Browse Datasets**



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### **Datasets**



This first release of CPTP harmonized data includes information from Health and Risk Factor Questionnaires collected at baseline (307,830 participants) and comprises a total of 709 variables.

Additional data releases will include physical measures data and biosamples data.

#### **Data Harmonization**

The CPTP datasets are generated using a rigorous harmonization process achieved in collaboration with Maelstrom Research. To learn about the harmonization methods and software used to harmonize data across the CPTP cohorts, click here.

#### Health and Risk Factor Questionnaire Data

CoreQx Release 1 questionnaire data collected at baseline (709 variables) - Currently available

#### **Physical Measures Data**

Physical measures collected at baseline in evaluation clinics, including height, weight, waist and hip circumference, blood pressure and resting heart rate, body mass index (BMI), body composition, and grip strength – Accessible at a later date in 2015-2016

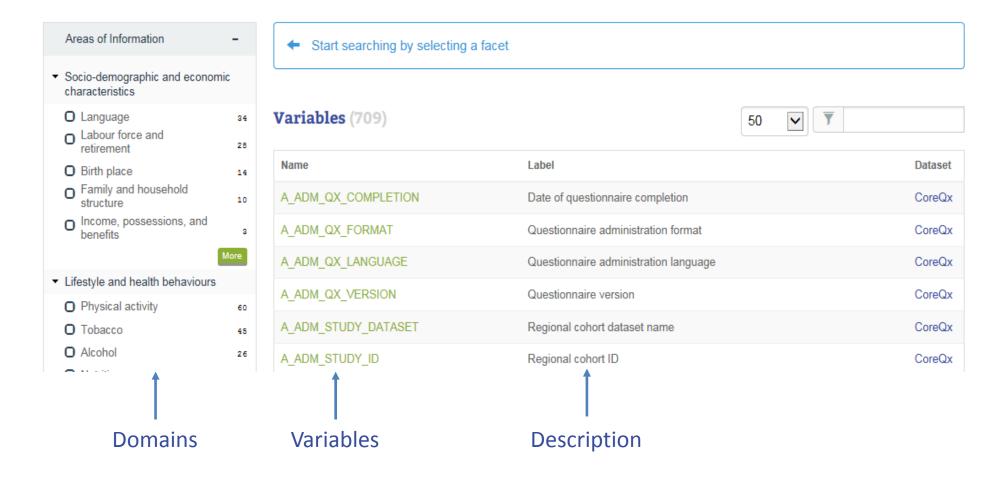
#### **Biological Samples Data**

Data related to biosamples collected at baseline - Accessible at a later date in 2015-2016





## **CPTP Portal: Browse Data**

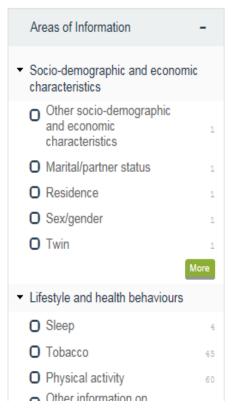


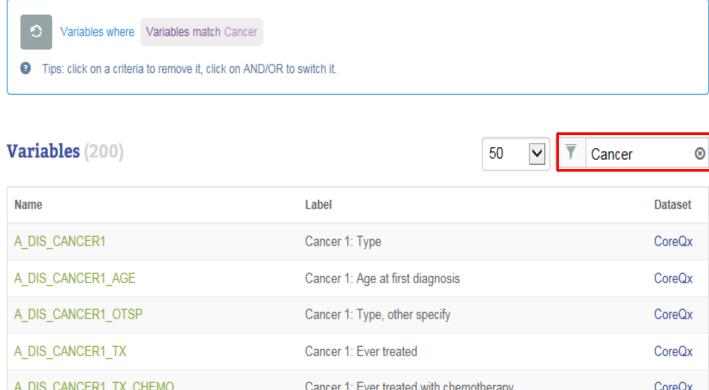




## CPTP Portal: Keyword Search







### Search pulls up all variables tagged with cancer



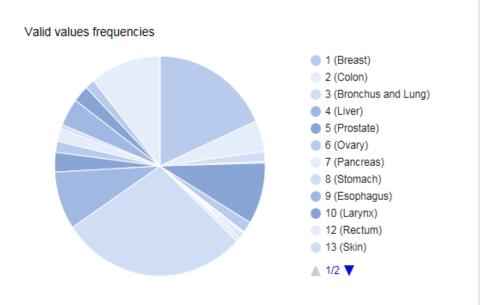


## ■ CPTP Portal: Variable Information

#### **Statistics**

Cumulative summary of all studies:

Value	Frequency
Valid Values	
1 Breast	5116 1.7% (18.3%)
2 Colon	1285 0.4% (4.6%)
3 Bronchus and Lung	407 0.1% (1.5%)
4 Liver	61 0.0% (0.2%)

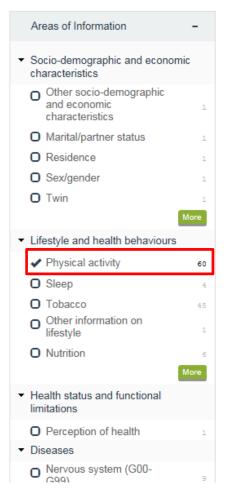


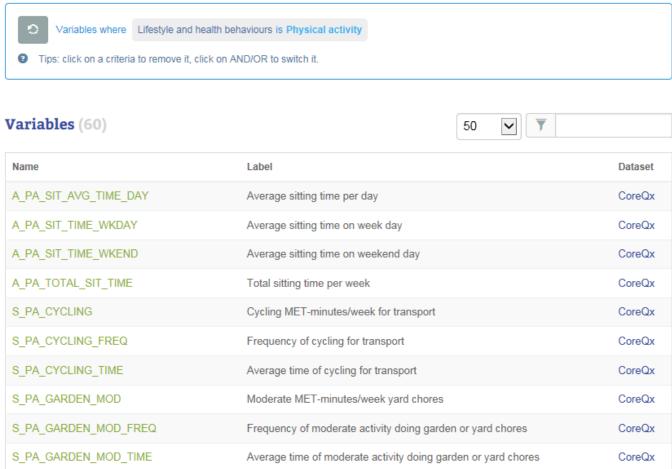
...including its relative representation in the cohort





## **CPTP Portal: Area of information search**





### Variables can be searched by theme





## CIHR Grant

### Call has three areas of focus:

- 1. Targeting High Fatality Cancers (cancers with a mortality rate/incidence rate of >75%)
- Health Economics and Health Services Research in Cancer Control
- 3. Redressing Cancer Risk Factor Disparities and Prevention Service Inequities





## High Fatality Cancers

## Based on 2015 Canadian Cancer Society Estimates\*:

Cancer Type	Incidence Rate (I)	Mortality Rate (M)	M/I
Pancreas	9.3	8.7	93.5
Esophagus	4.2	3.9	92.9
Lung	51.9	40.2	77.5
Brain/CNS	6.9	4.4	63.8
Stomach	6.6	3.9	59.1
Ovary	10.8	6.2	57.4
Multiple myeloma	5.1	2.6	51.0
Liver	4.4	2.2	50.0

\*Computed by G. Lockwood





# Health economics & health services research



 Participant consent permits linkage with administrative health data

• CPTP Access Office can coordinate contact with regions to determine feasibility of studies using linked data (e.g. health services utilization, health outcomes etc.)





# Risk factor disparities/prevention service inequities

- CPTP captures a range of data related to risk factors and screening behaviours
- Data could be paired with pre-existing indices of deprivation/socioeconomic inequality (6 digit postal codes allow geocoding)





## The Access Process

- National Access Infrastructure
- Starting off
- How the process works
  - Feasibility/Queries
  - Access Application Process
- Placing an access request
- Supporting the CIHR grant





# Access Infrastructure to Facilitate Research

## National Access Infrastructure:

- Access Office:
  - Single point of contact for access requests
  - Aims to facilitate access while respecting the participants consent
  - Implements approved Access Policies and Procedures
- Independent Access Committee:
  - Accountable for requests approvals and oversight on access activities





# Starting off

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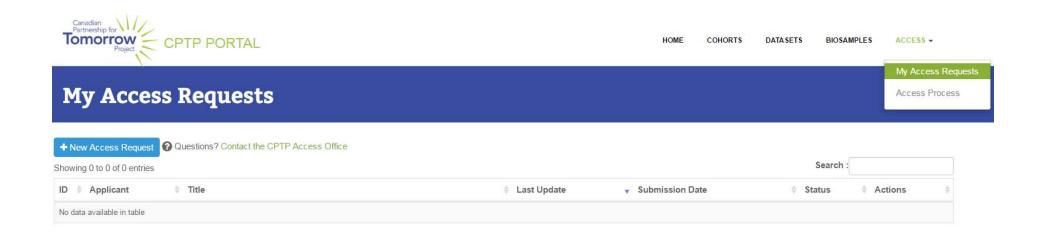
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#### Create an account





# Starting off



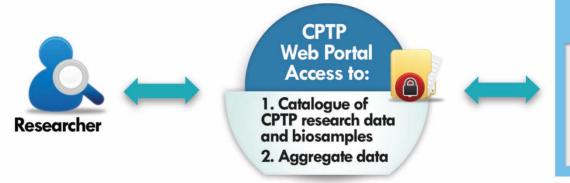
### **Initiate Access Requests directly online**





# How the Process Works: Feasibility/Queries

### CPTP FEASIBILITY QUERIES (PRIOR TO ACCESS APPLICATION)



### **Access Office**

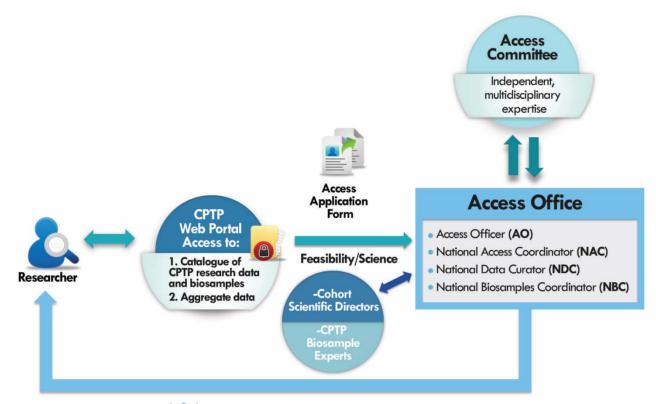
- Access Officer (AO)
- National Access Coordinator (NAC)
- National Data Curator (NDC)
- National Biosamples Coordinator (NBC)





# How the Process Works: Access Application Process

#### CPTP ACCESS APPLICATION PROCESS







# Placing an Access Request







# Placing an Access Request



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### **Access Request**







Validate

This application form is for requests for access to the controlled research data of the Canadian Partnership for Tomorrow Project (CPTP). To obtain access, applicants must complete this entire application form and attach the required documentation including: research protocol; proof of funding (e.g. decision letter from funding body), if available; proof of scientific peer-review, if available; decision letter from a Research Ethics Board and a 2-page CV of the principal applicant.

Upon approval of an access request by the Data Access Oversight Committee, access to CPTP research data will be granted for the timeframe agreed upon in the Data Access Agreement (starting from the date of signature of the Agreement). An Annual Report must be completed to access/use CPTP research data beyond a one-year period.

Moreover, the names, institutions, and lay summaries of the scientific abstracts of all Approved Users will be added to its publicly available access registry

Contact Access Office

#### I - Contact and Research Project Information

#### A. Name, institution, and contact details of the Applicant (Principal Applicant)

Please ensure that a full postal address and a valid institutional e-mail address are included. In case of more than one affiliation, applicants are asked to only provide their contact information pertaining to the institution they are affiliated with for the purpose of this research project.

Name *	Institutional E-mail Address *
Title *	Alternate E-mail Address
Position *	Telephone Number *
Institution *	Mailing Address *
Institution *	Mailing Address *





- The Access Office will review requests for Letters of Support to support grant applications.
- For submissions: <u>access@partnershipfortomorrow.ca</u>
- Documents needed: scientific background of your submission (extra information if biosamples will be needed).





- Elements that CPTP will be assessing:
  - Alignment with the Vision, Mission (slide 4) and Guiding Principles of CPTP;
  - The proposed study data variables and biosample type(s) are available from CPTP;
- A LoS does not guarantee access





- Guiding Principles of CPTP (from the Access Policy)
  - Promoting the common good by maximizing collaborative research for the benefit of all;
  - Ensuring the generation of high quality research;
  - Making data and biosamples available to the research community to advance scientific knowledge;
  - Respecting the legal rights and legitimate interests of all stakeholders involved (e.g. families, populations, researchers and funders);
  - Protecting the privacy of its Research Participants and the confidentiality of their data;





- Guiding Principles of CPTP (from the Access Policy) (continued):
  - Promoting transparency, responsibility, interoperability and fairness;
  - Ensuring accountability and oversight;
  - Enriching the content of the CPTP database, including through the return of quality derived data by researchers; and
  - Managing access to CPTP biosamples to balance current and future needs.





# Thank you

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Atlantic PATH Dr. Louise Parker

**Dr. Trevor Dummer** 

CARTaGENE Dr. Anne-Monique Nuyt

Dr. Sébastien Jacquemont

Centre

ELSI Dr. Bartha Knoppers

Biosamples Dr. Anne-Marie Mes-Masson

### **CPTP Sponsors**















## Questions?

Data, biosamples or access related questions: <a href="mailto:access@partnershipfortomorrow.ca">access@partnershipfortomorrow.ca</a>

CPTP Website: <a href="http://www.partnershipfortomorrow.ca/">http://www.partnershipfortomorrow.ca/</a>

CPTP Portal: <a href="https://portal.partnershipfortomorrow.ca/">https://portal.partnershipfortomorrow.ca/</a>

Twitter: <a href="mailto:occupation">occupation</a>



