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P³G EVENTS

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P³G Annual Meeting
April 26-27, 2010
Montreal



Public Population Project in Genomics

January 2010

e-update

From the P³G Desk

It's been a few months since our last newsletter, so we wanted to touch base and bring you up-to-date on several P³G happenings. Our next full-length newsletter will come out in March and will contain a number of interesting features, including the full agenda for the upcoming P³G meeting which will be held April 26 and 27th, 2010 in Montreal. Please note the change of location, originally Quebec City.

We'd also like to take this opportunity to send our warmest wishes to all for a peaceful and happy New Year. As always, your feedback is invited and welcome. Please share your thoughts by emailing us at secretariat@p3g.org.

Events

P³G Annual Meeting Montreal (April 26-27, 2010)

» P³G General Meeting
Sept 29-30, 2009
Luxembourg

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"Harmonization in Practice: A Platform Based on 50 Studies from 18 Countries"

Among the array of biobanking topics that will be addressed over the two-day period, the meeting will feature a report and special sessions on the process, benefits and future of harmonization. The report will describe the first completed harmonization process done in collaboration with 50 studies from 18 countries and will illustrate the potential of pooling data, and how and why this process can benefit biobankers around the world.

By identifying and analyzing scientific questions and drawing on the results of the report, participants will be able to contribute to the next stage of advances in the harmonization process. Challenges and opportunities in achieving the concrete harmonization of data and samples collected as well as access thereto will also be addressed, leading to an action plan for practical solutions.

View the [draft agenda](#). The final agenda will be included in the March newsletter.

Should you wish to extend your stay in Montreal and enjoy some organized tourist and social activities you will be able to indicate your interest during the [registration process](#).

P³G General Meeting Luxembourg (September 29-30, 2009)

Last September, P³G members met in Luxembourg for two days of presentations, discussions and workshops designed around the theme "Challenges in Life-course Projects: From Conception to Aging" (Day 1) as well as ELSI issues, a special session on Global Voices in Biobanking and presentations and discussions on evidenced-based standards, data-pooling and other topics.

Registration and Hotel Reservation Deadline: March 22, 2010

[Fairmount Queen Elizabeth Hotel](#)
900 Rene-Levesque Blvd. W
Montreal, Quebec Canada H3B 4A5

To benefit from the preferred rate, please book your hotel reservation before March 22, 2010, [online](#), or by [phone](#) using the promo code "P3GQE".

Audio and PowerPoint versions of many of the Luxembourg presentations and discussions may be referenced on [the P³G website](#). We've also posted session summaries and reports from the IWG meetings.

Science Activities & Updates

DataSHaPER

In September, the DataSHaPER left the nest. It can now be found under the new domain name www.datashaper.org. In addition to housing the existing DataSchemas, the DataSHaPER is now structured under an ontological approach so that the new DataSchemas platform interface lets users add their own DataSchema, sharing a same vocabulary and variable structure.

Three "modules" on biosamples in the DataSchemas platform will be posted online soon on; (1) collection, (2) sampling and handling and (3) warehouse and banking). The modules will define the core sets of information collected by the [five Canadian cohorts](#) on biosamples.

P³G Observatory



The recently launched [Partner Catalogues](#) section of the Observatory continues to evolve and grow with the addition of the Governmental Database Catalogue from the Canadian Partnership for Tomorrow (CPT) project. The Catalogue lists relevant data sources that are useful for longitudinal follow-up of CPT cohorts.

P³G is working on a radical upgrading of the Repository of Information and Tools, a central element currently on the P³G Observatory. This will include development a new web-based suite of tools that will serve as a central reference and deliver structured support to biobanks, funding agencies, governmental agencies, universities, partners, etc.

[Join us at the P³G meeting](#) to learn more about and contribute to the development of this upgrade.

50-Study Harmonization Initiative

In the fall of 2009, P³G embarked on a harmonization project to explore the data-sharing potential of 50 studies from around the world using the DataSHaPER tool. Studies included in the project represent 18 different countries from North America, Europe, Asia and Australia, and range in size from ten thousand to over half a million participants.

The harmonization exercise used the DataSHaPER's harmonization platform to determine the ability to generate Generic DataSchema (GenDS) variables from the assessment items found in each study's baseline questionnaires and physical measures. For each study, each GenDS variable is classified as either a 'complete match' (the variable can be generated with no information loss), a 'partial match' (partial information loss unavoidable), or an 'impossible match' (no information or no sufficient information to allow the construction of the variable). As an example, preliminary results show that over 75% of the studies have the potential to share the Occurrence of cancer, Occurrence of diabetes, Body mass index, and Some elements of post-secondary education variables. Type of Cancer, Diabetes onset, and Quantity of cigarettes smoked can be constructed by over 60% of studies. The data sharing potential demonstrated by the 50-study initiative will serve as a platform to explore further collaborations between the world's major population biobanks. The final results from this initiative will be reported in detail to P³G Members at the upcoming [P³G Annual Meeting](#) in Montreal, April 26-27, 2010.

International Questionnaire on Access Policies

The 50-Study Harmonization Initiative was used as the pilot phase for a new questionnaire on biobank access policies and covering aspects relevant to ELSI. Following feedback received during the P³G Luxembourg meeting, the questionnaire was developed and issued with the goal of taking a

snapshot of practices around the world and determining what informal mechanisms of harmonization might be possible. Preliminary results of the questionnaire - the first of its kind - will be presented at the [Montreal P³G Meeting in April 2010](#).

Summer Institute "Genetics, Ethics and Clinical Translation"

June 22-25, 2010, Hotel Zuiderduin, Egmond aan Zee, The Netherlands

P³G is delighted to be partnering with The ENGAGE Consortium (European Network for Genetic and Genomic Epidemiology) and The Centre for Society and Genomics in offering a four-day intensive course designed for professionals actively involved in biobanking who want to learn more about ethical, legal and societal implications related to the translation of epidemiological results from genetic and genomic research to clinical practice. The Summer Institute offers insight about issues and solutions and gives participants the opportunity to interact with the lecturers through discussions and working group sessions. For curriculum and registration information please visit [ENGAGE](#) or contact isabelle.budin.ljosne@fhi.no.

OBiBa



[OBiBa](#) is a P³G core project that produces a suite of open-source software for biobanks. OBiBa developers are currently working on three projects.

- Onyx, a web application for conducting, managing, and exporting baseline interviews at assessment centres
- Opal, a central data repository for research centres that will facilitate data sharing and harmonization among biobanks

- Enrolment and Tracking Application (ETA), a web application that will manage subject recruitment, track consent and communication with subjects, and provide a scheduling system for staff and other resources.

Onyx is already being widely used for the major Canadian genomics research initiative known as the Canadian Partnership for Tomorrow (CPT). The five cohort studies that comprise the CPT use Onyx in 15 assessment centres. Whenever a new assessment centre opens up, Onyx is easily deployed by local system administrators, and staff are trained and interviewing participants within days. The BC Generation Project's mobile assessment unit is a testimony to Onyx's ease of deployment and use: the mobile assessment unit is a van that travels to outlying communities.

A major new version of Onyx (1.6.0) will be released in December 2009. It includes expanded data export and extensive groundwork in preparation for future export to Opal. Look for an article in the upcoming P³G newsletter to learn more.

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