

# P<sup>3</sup>G Meeting – Montréal April 2010

The Fairmont Queen Elizabeth Hotel

900 René-Lévesque Blvd. W, Montréal, Québec

## DAY 1 Monday April 26, 2010

08h00 BREAKFAST

09h00 Welcome  
Tribute to Leena Peltonen-Palotie

### 09h15 SESSION 1 BIOBANKING OF RESIDUAL SAMPLES: OPT-OUT? Chair Kurt Zatloukal (University of Graz)

In addition to prospective population archival pathology cohorts, the emergence of clinical-sampling biobanks raises new ethical issues. Based on patient notification and an opt-out possibility for the storage and research use of residual samples obtained during medical care, this approach challenges the hallmark ethical tenets of both informed consent and withdrawal.

09h15 Ellen Wright Clayton (Vanderbilt University)

09h45 Discussants Rex Chisholm (Northwestern University), Trudo Lemmens (University of Toronto)

09h55 Questions/Discussion

10h15 BREAK

### 10h45 SESSION 2 FROM HARMONIZATION TO RESEARCH FINDINGS – OPPORTUNITIES AND CHALLENGES Chair Paula Robson (Alberta Health Service-Cancer Care)

This session frames the focus for the remainder of the meeting starting with a brief introduction to current harmonization opportunities and challenges. Considerations include extending harmonization into new arenas and contexts beyond population-based studies and discuss the challenges of using harmonized building blocks (data and samples) to generate epidemiological and biomedical research.

10h45 Jennifer Harris (Norwegian Institute of Public Health)

11h15 Daniela Seminara (National Cancer Institute)

11h30 Paolo Boffetta (International Prevention Research Institute)

11h45 Questions/Discussion

12h00 LUNCH

### 13h00 SESSION 3 HARMONIZATION PLATFORM – SUCCESSES AND ONGOING DEVELOPMENTS Chair Tom Hudson (Ontario Institute for Cancer Research)

This session will feature the results of the 50 studies of the harmonization platform of P<sup>3</sup>G and its major Partner Projects. This session will identify the key tools available, their complementary and any strategic gaps that need to be filled.

13h00 DataSHaPER: The Mechanics of Achieving Results  
Isabel Fortier (P<sup>3</sup>G)

13h45 Access Catalogue  
Saminda Pathmasiri (P<sup>3</sup>G)

14h00 DataSHIELD : How to perform a pooled analysis of individual level data without sharing the data  
Paul Burton (University of Leicester)

14h30 OPAL: An open source platform for data integration  
Vincent Ferretti (Ontario Institute for Cancer Research)

14h45 Questions/Discussion

15h00 BREAK

15h30 Panel

Code of Conduct for data-based research Bartha Maria Knoppers (McGill University)

SAIL: Sample avAILability system Maria Krestyaninova (European Molecular Biology Laboratory - Outstation)

D<sup>3</sup>G in P<sup>3</sup>G: Digital Identifiers, Database Federation, and Data Publication in Genomics Anthony Brookes (University of Leicester)

Integrative analysis of longitudinal studies of aging (IALSA) Scott Hofer (University of Victoria)

Conclusions Isabel Fortier & Mylène Deschênes (P<sup>3</sup>G)

16h20 Questions/Discussion

### 16h50 – A Case Study Using the Harmonization Platform: Introduction to Session 4 17h00 Julian Little (University of Ottawa)

17h15 P<sup>3</sup>G ANNUAL MEMBERS' MEETING

18h15 POSTER SESSION and COCKTAIL

19h15 P<sup>3</sup>G MEMBERS' DINNER

## P<sup>3</sup>G Meeting – Montréal April 2010

The Fairmont Queen Elizabeth Hotel  
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### DAY 2 Tuesday April 27, 2010

08h00 International Working Groups (IWG) BREAKFAST

09h00 **SESSION 4: FROM CONCEPT TO REALIZATION – DEVELOPING A LARGE-SCALE CASE-STUDY TO PILOT AND EVALUATE HARMONIZATION TOOLS**  
Chair: Parminder Raina (McMaster University)

We will work collectively on a case-study with the aim of evaluating the tools available in the harmonization platform, and address a specific research question. The case-study will target a hypothesis related to a complex disease/trait and its etiological determinants, and which necessitates data pooling from several studies. The desirable characteristics of such a case-study will be outlined and multidisciplinary challenges, options and feasibility will be discussed in the first breakout session. In the second session, we will consider new research areas (e.g., aging) that highlight important harmonization gaps and which benefit from future targeted developments and applications of the DataSHaPER tools. After the P<sup>3</sup>G meeting, the DataSHaPER team will take the case-study forward with interested studies and researchers.

09h00 Isabel Fortier (P<sup>3</sup>G) and Paul Burton (University of Leicester)

09h20 **Break-out session Part 1: Steps necessary to enable the realization of the "case study"**

Group 1 Chair: Gert-Jan van Ommen (Leiden University)	Group 2 Chair: Bruce Wolffenbuttel (University Medical Center Groningen)	Group 3 Chair: Scott Hofer (University of Victoria)
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10h30 BREAK

11h00 **Break-out session Part 2: What are the major types of scientific questions to target and what scientific areas could benefit most from a suite of harmonization tools?**

Group 1 Chair: Gert-Jan van Ommen (Leiden University)	Group 2 Chair: Bruce Wolffenbuttel (University Medical Center Groningen)	Group 3 Chair: Scott Hofer (University of Victoria)
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12h00 LUNCH

13h00 Reports from breakout session Chairs  
13h30 General Discussion

14h00 **SESSION 5: ESTABLISHING COSTS FOR BIOBANK DATA AND SAMPLES ACCESS**  
Chair: Rex Chisholm (Northwestern University)

Pose and discuss general yet practical questions related to pricing of data and samples collected by biobanks (or studies).

14h10 Factors Affecting Cost Denis Bilodeau (Genome Quebec)  
14h20 Users Perspectives Lyle Palmer (University of Western Australia)  
14h30 Transnational / Trans-biobank Research George Dagher (Inserm)  
14h40 Long-term Sustainability Strategy (Speaker TBD)  
14h50 Questions/Discussion

15h30 BREAK

16h00 **SESSION 6: RETURN OF RESULTS**  
Chair: Alastair Kent (Genetic Interest Group)

We will look at return of 'results' (general research results, results from assessments as part of recruitment, and individual results) in the context of large-scale longitudinal population studies. P<sup>3</sup>G has developed a draft set of Core Elements for member studies advocating the return of general research results and critical values/results from tests at the time of the initial assessment. We will present and discuss emerging models for returning clinically validated results, general health results etc., against the background of the draft Core Elements, the pressures they create and potential implications.

16h00 Susan Wallace (McGill University)  
16h30 Questions/Discussion

17h00 CLOSING OF THE MEETING