THE PUBLIC POPULATION PROJECT IN GENOMICS (P³G) AT A GLANCE

Founded in 2003 to respond to the growing needs and demands of the population genomics community, the Public Population Project in Genomics (P³G) is a not-for-profit international consortium with its head office in Montreal. The Chair of the Board is Professor Bartha Maria Knoppers, PhD, Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University. P³G is under the Scientific Direction of Dr. Paul Burton, University of Leicester, United Kingdom.

P³G MISSION AND OBJECTIVES

P³G’s mission is to lead, catalyze, and coordinate international efforts and expertise so as to optimize access and the use of large cohort studies, biobanks, research databases and other similar health and social research infrastructures for the improvement of the health of individuals and populations.

To achieve this, the Consortium is committed to the following objectives:

1. Providing global perspectives and strategic approaches to the optimization of data access and use.
2. Catalyzing multidisciplinary and international scientific expert input.
3. Engaging studies, cohort and biobank resources/infrastructures and their users in a dynamic knowledge-based exchange.
4. Disseminating and valorizing knowledge relevant to the mission of P³G.
5. Serving the needs of the P³G Programmes and Platforms.

P³G brings the genomics, epidemiology, social science, ELSI/policy-making and information technology communities together. Through its network of experts and platforms, P³G offers policy direction and other services to large-scale research infrastructures.

P³G CHARTER OF FUNDAMENTAL PRINCIPLES

P³G aspires to the highest standards of ethical comportment and research integrity. The fundamental principles that underpin its activities are:

- **PROMOTION OF THE COMMON GOOD** P³G will optimize the benefits of collaborative research for the benefit of all.
- **RESPONSIBILITY** Protection of the interests of all affected stakeholders including families, groups, populations, researchers and research sponsors is the highest priority. Every effort will be made to respond to the concerns of stakeholders in a timely and appropriate manner.
- **MUTUAL RESPECT** The development and sustainability of P³G is based on responsibility, collaboration, co-operation, trust and mutual respect for others, which includes recognition of cultural diversity and the scientific specificity of the projects involved.
- **ACCOUNTABILITY** All standards, processes and procedures will be transparent and clear, developed on the basis of consensus, and aim to create best practice in the networking of population genomics resources.
- **PROPORTIONALITY** All research materials (such as data and samples) must be protected to the highest standards of privacy and propriety, while at the same time allowing and promoting the free exchange of ideas, data-sharing and openness for the benefit of all.

Adopted by P³G Board of Directors: March 23, 2007
MESSAGE FROM CHAIR – BARTHA MARIA KNOPPERS

Building on solid ground always proves to be the best way to proceed. As a case in point, following the receipt of bridge funding from Genome Canada, Genome Quebec and CIHR (Institute of Genetics), P³G entered its Phase II. This includes re-organizing its structure, expanding the services offered to members, revamping its website, and planning for future activities on the access and use of data and samples. Since September, the launch of the newly redesigned website with its innovative tools www.p3g.org has attracted a lot of attention and positive comments. We are pleased to see that it has proven to be a highly regarded resource.

In the midst of all these changes, the Board of Directors held its Annual Meeting of the members on June 8th, 2012. For the second consecutive year, this meeting was achieved by electronic means. This proved to be convenient and enhanced the participation of the attendees. In September 2012, the Board officially approved the change to “Public Population Project in Genomics and Society”. Thus 2013 will see the launch of a new name for P³G – the Public Population Project in Genomics and Society – so as to better reflect its important policy work.

For the coming year, we are striving to add more members to our already-growing list, and work on improving our range of initiatives so as to meet the use and access needs of the research community across all disciplines.

MESSAGE FROM THE EXECUTIVE DIRECTOR - ANNE MARIE TASSÉ

In order to empower researchers with tools, expertise and networking activities, we supported the development of three research programmes: the Maelstrom Research Programme (led by Drs Isabel Fortier and Vincent Ferretti), the Policy Research Programme (led by Dr Bartha M. Knoppers) and the International Paediatric Research Programme (led by Dr Denise Avard) (see reports on page 6).

We also embarked on new collaborations, be it through our support of the ELSI 2.0 Collaboratory, the launch of the P³G International Pediatric Research Programme, or organization of international events, such as the Translational Genomics Pipeline: From Populations to Individuals, held in Hinxton, UK (June 18th-21st, 2012), the ELSI 2.0: Planning an International Collaboratory for Genomics and Society Research held in Rotterdam, The Netherlands (June 26th, 2012), as well as the International Biobanking Summit, held in Uppsala, Sweden (September 19th, 2012).

These activities were a great success, exceeding our registration expectations and including vibrant discussions. Follow up activities and initiatives in 2013 are foreseen for the ELSI 2.0 Collaboratory, the P³G International Pediatric Research Programme and the International Biobank Summit. The momentum generated by these initiatives remains strong.

P³G and its research programmes not only contributed to more than 35 publications and presentations, but were among the key authors of a high profile paper published in Science: J. Kaye [...] B.M. Knoppers, et al., (2012) “ELSI 2.0 for Genomics and Society”, Science, 336(6082): 673-674.

For the coming year, P³G will most certainly keep moving at the same pace. First, the name change to Public Population Project in Genomics and Society will be more than the addition of a word. It highlights how the organization can best serve the entire infra-structure research community. To that end, we aim to offer a policy screening and access authorization service so as to support, co-ordinate, and, facilitate international collaboration between and within research consortia, academia and industry.

This new focus will shape the framework for the upcoming P³G meetings, such as the Privacy Summit on Datasharing and Cloud Computing, to be held in Paris on May 3rd 2013, as well as the workshops for both the ELSI 2.0 Collaboratory and the International Pediatric Research Programme, taking place subsequently in Montréal in September 2013.
This year has seen many changes for P3G, as we moved to our Phase II with a new organizational chart, new research programmes, new membership and new services. The bulk of our efforts have converged towards bringing the research community a revamped website, with easier to navigate functionalities. Built as an open access web platform, the new P³G website www.p3g.org now includes a:

**TOOLKIT:** Providing epidemiological ethical, statistical and IT instruments for the access and use of biobanks;

**LIFESPAN:** Providing an open access web platform offering users a step by step approach for the development and maintenance of a biobank;

**CATALOGUES:** Providing information about large population-based biobanks;

**TRAINING:** Providing tutorials and information sessions;

**HUB:** Providing an online agora for all those interested in biobanking, discussion, exchange and collaboration; and

**BRIF:** (BioSHaRE Pilot Study): Providing a unique identifier associated with a single bioresource to be cited in scientific publications using the bioresource.

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**UPDATE FROM THE SCIENTIFIC DIRECTORS**

**RESEARCH PROGRAMMES:**

**THE POLICY RESEARCH PROGRAMME**

(led by Professor Bartha Knoppers)

Led by Bartha Maria Knoppers, the Policy Research Programme at the Centre of Genomics and Policy (CGP) of McGill University is one of the independently funded research pillars of P³G. Thanks to an international collaborative effort in 2012, the Policy Research Programme led the development of the P³G Return of Research Results and Incidental Findings Policy Statement (see BM Knoppers et al., Population Studies: Return of Research Results and Incidental Findings Policy Statement, Eur J Hum Genet. 2012: 21(3): 245-7). This Policy Statement considers the issue of research results and incidental findings in the specific context of population genomics and addresses possible modalities for such return.

The year 2012 also saw the development of a roadmap in global health biobanking (see JR Harris et al., Towards a Roadmap in Global Health Biobanking, Eur J Hum Genet. 2012: 20(11):1105-11). The purpose of this white paper is to articulate a vision for global biobanking that calls for improved sharing and pooling of data from biobanks in order to promote and facilitate health research and translation. In the same vein, the Policy Research Programme collaborated in the publication of MJ Murtagh et al., Navigating The Perfect [Data] Storm, Norsk Epidemiologi 2012: 21(2): 203-209, which highlighted solutions and additional endeavours that could change how we manage future data, not only in bioscience or -omics research, but across domains using large-scale potentially shareable data.

Co-founder of the ELSI 2.0 initiative (see J Kaye et al., Research Priorities: ELSI 2.0 For Genomics and Society, Science 2012: 336(6082): 673–4), members of the Policy Research Programme were involved in developing a proposal to establish dynamic international collaboration for the ethical, social and legal issues (ELSI) related to genomics research. The paper outlines how the establishment of a “collaboratory” for ELSI research will enable it to become more organized, responsive to societal needs, and better able to apply the research knowledge it generates at a global level. The Canadian Institutes for Health Research has provided funding for the hosting of an ELSI 2.0 Collaboratory meeting in September 2013.
THE MAELstrom RESEARCH PROGRAMME
(led by Drs Isabel Fortier and Vincent Ferretti)

In early 2012, the Maelstrom Research program was officially launched. Bringing together data harmonization expertise and the tools developed by the DataSHaPER (Data Schema and Harmonization Platform for Epidemiological Research), OBiBa (Open Source Software for Biobanks) and DataSHIELD (Data aggregation through anonymous summary-statistics from harmonized individual-level databases) teams, this new research program aims to optimize the use of existing study data and facilitate collaboration amongst networks or consortia of studies. To achieve this, Maelstrom Research conducts applied and methodological research and develops open-source software to support retrospective data harmonization and integration of individual study datasets. Core funding of the Maelstrom Research program comes from the BioSHaRE-EU project (Biobank Standardization and Harmonization for Research in Excellence in the European Union), Quebec’s Ministère du Développement économique, de l’Innovation et de l’Exportation (MDEIE), and the Canadian Longitudinal Study on Aging (CLSA). In partnership with Canadian and international research projects, the Maelstrom Research program is currently piloting and assembling a suite of tools which will offer a structured resource to support data harmonization and database federation projects and to promote collaborative research in epidemiology, public health and the social sciences.

THE INTERNATIONAL PAEDIATRIC RESEARCH PROGRAMME
(led by Dr Denise Avard)

The first International Pediatric Research Programme meeting was hosted by P3G and the Centre of Genomics and Policy on June 26th, 2012 in Rotterdam (Netherlands). A specially convened group of experts on pediatric research was invited to discuss the need to build a common programme regrouping the tools and resources for the facilitation, harmonization, and management of ELSI issues in pediatric research. Participants discussed the immediate needs of researchers for such a programme, how to best articulate and meet these needs, and how to proceed in coordinating funding to develop new ELSI tools for pediatric research. The Programme is developing a policy statement specific to the return of results and incidental findings in the pediatric context.
Knowledge development, valorization and transfer are fundamental components of P3G activities. In 2013, the International Steering Committee (ISC) undertook to integrate the current P3G repository of information and tools into one “user-oriented” kit. From its inception, the concept of this open access web platform focused on offering users a step by step approach for the development and maintenance of a biobank, following the different stages of its life cycle, (e.g. data collection tools and relevant software and ELSI resources (consent, information pamphlets, access policies, MTA’s, IP and governance)).

Under the leadership of the ISC, the P3G Secretariat has developed what has ultimately become the revamped P3G website. As a result, researchers who wish to build a biobank now have the expertise, tools (or links to these tools) and know-how, all in one place and at their fingertips. The website also provides a description of the challenges and elements to consider at each stage of development. Building on our network of international experts, it links experts/teams in the field to the tools that have been developed by P3G or are being offered by our Programmes and Partners.

The building of this kit required a thorough mapping of the current efforts in the field (showing gaps, strengths, and overlap at the international level). In time, it will be brought to another level by including new components customized for the needs of researchers in different countries. In addition, future plans include linkage of resources such as other summer schools and/or web tutorials (webcast, webinars, etc.) at a global level. In summary, it can be customized and translated to meet various needs.

In a few short months, this new website has become tremendously useful for biobank managers, research/clinician teams seeking to develop a biobank, funders, and groups or countries anywhere in the world seeking assistance in the development of such research infrastructures. It now constitutes a very important legacy and visible output of the initial Canadian investments in P3G.

Parallel to that effort, the ISC has also reviewed the P3G organizational chart, to better explain the role of programmes it supports, such as the Maelstrom Research programme, the Policy Research Programme, as well as its own role. The P3G Secretariat is now considered as the hub for all activities, so as to avoid duplication of effort and to achieve effective communication between members.

In keeping with its scientific role, the ISC has kept in close contact with its affiliated programmes as mentioned above. It has also added a new International Paediatric Research Programme to the list. Details on the developments and recent activities of these groups can be found on pages 4 and 5.

As for 2013, the ISC has plans that include raising the visibility of P3G, along with the enhancement of the services it offers to best meet the needs of the community.
INSTITUTIONAL MEMBERS:

Organizations conducting, using or collaborating with or planning to be involved in with health studies, biobanks, research databases and other similar health research infrastructures committed to complying with the P3G Mission and to providing P3G with relevant knowledge and expertise. Institutional members have voting rights.

Alberta Health Services - Cancer Care (Canada)  
Biobank Popgen (Germany)  
BioHealth Norway/Biobank Norway (Norway)  
CARTaGENE (Canada)  
Canadian Partnership for Tomorrow Project (Canada)  
Center For Integrated Genomic Medical Research (UK)  
Centre of Genomics and Policy, McGill University (Canada)  
Estonian Genome Project of the University of Tartu (Estonia)  
Generation Scotland (UK)  
Genome Quebec (Canada)  
IBBL (Luxembourg)  
INSERM (France)  
National Institute of Genomic Medicine (INMEGEN) (Mexico)  
Kaiser Permanente (USA)  
King Abdullah International Medical Research Center (Saudi Arabia)  
National DNA Biobank (Spain)  
National Heart, Lung and Blood Institute (USA)  
Malaysian Genome Institute & UKM Medical Molecular Biology Institute, National University of Malaysia (Malaysia)  
Ontario Health Study (Canada)  
UK BioBank (UK)  

INDIVIDUAL MEMBERS: More than 400 individual members

Individuals from academic, public or private organizations committed and capable of furthering the objectives of P3G and of providing P3G with the benefit of their knowledge and expertise.
## Corporate Information

### Board of Directors

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Bartha Maria Knoppers</td>
<td>Chair (Canada)</td>
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<tr>
<td>Jennifer Harris</td>
<td>Vice-Chair (Norway)</td>
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<tr>
<td>Thomas J. Hudson</td>
<td>Director (Canada)</td>
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<td>Claude Laberge</td>
<td>Director (Canada)</td>
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<tr>
<td>Gert-Jan B. van Ommen</td>
<td>Treasurer (Netherlands)</td>
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### Executive and Staff (2012)

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<tr>
<th>Name</th>
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<tr>
<td>Anne-Marie Tassé</td>
<td>Executive Director</td>
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<tr>
<td>François L’Heureux</td>
<td>Research Coordinator</td>
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<tr>
<td>Charles Rivard</td>
<td>Director of Operations</td>
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<tr>
<td>Dany Doiron</td>
<td>Research Coordinator</td>
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<tr>
<td>Sylvie Ouellette</td>
<td>Communication Officer</td>
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<tr>
<td>Camille Craig</td>
<td>Research Assistant</td>
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<tr>
<td>Irène S. Toffolo</td>
<td>Administrative Assistant</td>
<td></td>
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<tr>
<td>Massaud Kakkar</td>
<td>Research Assistant</td>
<td></td>
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<tr>
<td>Etienne Morency-Bachand</td>
<td>Senior Programmer</td>
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<tr>
<td>Cédric Thiebault</td>
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### Head Office

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H3H 2R9

www.p3g.org  
E-mail: secretariat@p3g.org  
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### Annual General Meeting

P³G Annual Meeting  
Date: May 21st, 2013  
Time: 9:00 am  
Web conference

### Auditors

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### Host/Home Institution

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Montreal, Quebec, CANADA H3A 0G4

Research Institute of the McGill University Health Centre  
2155 Guy St, Suite 460  
Montreal, Quebec, CANADA H3H 2R9
# 2012 Activity Report

## Meetings (Organized or Co-organized by P3G)

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## Presentations

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<tr>
<td>Fortier I., V. Ferretti. <em>From individual studies to collaborative research: How can we enable data harmonization and integration across studies?</em> Epidemiology Seminars of the Department of Epidemiology, Biostatistics and Occupational Health. McGill University, Montreal, Canada, February 12, 2012.</td>
<td><strong>Fortier I., <em>From individual studies to collaborative research: Maelstrom Research approach</em>. AP2012, De la connaissance à l’action, Arctic Monitoring Assessment Programme (AMAP) Sustaining arctic observing networks (SAON). Montreal, April 26, 2012.</strong></td>
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**PUBLICATIONS**

*(the following are papers published either as a result of P3G activities or in which P3G was mentioned, cited and/or acknowledged)*


### 2012 Activity Report (con’t)


### Posters


### Book Chapters


“Nothing in life is to be feared, it is only to be understood.”

— Marie Curie