



ANNUAL REPORT 2010

HARMONIZATION IN PRACTICE





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 P³G Principal Investigator and 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. The P³G co-Principal Investigator is Dr. Thomas J. Hudson, President and Scientific Director of the Ontario Institute for Cancer Research. P³G is under the Scientific Direction of Dr. Paul Burton, University of Leicester; United Kingdom.

P³G MISSION AND OBJECTIVES

P³G creates a platform where scientists working in population studies can meet and exchange knowledge and expertise. It focuses on developing and sharing information, methods, and tools needed to optimize the design of population biobanks, and to facilitate their harmonization. We seek to enable our members to plan future large-scale collaborations. We believe this is the best route to realizing the full potential of those research resources and deliver on improving health. To support these goals, P³G has built the P³G Observatory, a growing and dynamic web-based repository of tools, information and resources that disseminates this knowledge freely throughout the international scientific

community. Through its broad network of leading international experts from the biomedical and social sciences, P³G has bridged the biobanking and the large-scale research data base world. Innovative channels of collaboration will continue to shape the landscape of future research in biomedical science. P³G's membership is comprised of large-scale population studies

with at least 10,000 participants, and we continually reach out to potential new members. Longitudinal studies require various forms of expertise to support the development and management of their biobanks. P³G members share their knowledge, tools and methodologies, but each study has its distinctive traits and retains control over its data and samples.

P³G CHARTER OF FUNDAMENTAL PRINCIPLES

The Public Population Project in Genomics (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 the Chair and the Co-Principal Investigator

P³G - WHAT DOES THE FUTURE HOLD?

Professor Bartha Maria Knoppers
Principal Investigator and Chair of the Board

The initial phase of the Public Population Project in Genomics (P³G) has been marked with numerous achievements, including the launching of many new international cohorts using P³G-enabled questionnaires, guidelines for consent, data management tools, the P³G Observatory. This has enabled P³G to attract new sources of funding from Canada and the European Commission to support further development.

From a network which included only three founding Charter members, P³G now proudly boasts a membership of 31 Charter members, 16 Associate members and more than 300 Individual members. Forty-nine countries are taking part in our activities: a testimony to the idiom that from humble beginnings, great things will come.

A NEW DECADE, A NEW FUTURE

Phase two of P³G will bring a move of its headquarters over the mountain from the Université de Montréal to McGill University.

This change not only signals the closing of P³G's first chapter, but also inspires reflection and realignment of priorities for the next phase. Harmonization is the core of P³G; it necessitates collaboration and leverages the full potential of genomics technologies. We have built a great foundation of tools and applications to fulfill this goal; our next steps should be testing and refinement for translational purposes.

FOCUSING OUR OUTLOOK

Our early years required the creation of international networks and collaborations within and across disciplines, including genetics, epidemiology, information technology, ethics and policy. Now that our partners are on board, the next three years will focus on optimizing the uses of our large scale epidemiological and ELSI resources that include standardized description of over 160 biobanks represented over 12.7 million study participants. Moreover, to uphold P³G's international mission of promoting and developing tools for efficient and open sharing to generate maximum genomic value, we now aim to foster disease-specific studies and consortia that translate knowledge into the clinic.

SUSTAINING DATA AND BIORESOURCES

As noted in a recent *Science*¹ forum, one of the challenges identified was adequately recognizing the translational nature of data and bioresources for funding agencies and another was developing structures for sustaining core international resources when funding sources remain predominantly national. We need to acknowledge this challenge.

RESTRUCTURING THE FIELD

The fragmented nature of research and lack of harmonization between common interests and



Dr. Thomas Hudson
Co-Principal Investigator and Board Director

goals is now proving to be a major obstacle to the search for clinically relevant biomarkers. According to a recent *Nature*² commentary from more than 150 000 manuscripts documenting thousands of biomarkers, only less than 100 have been validated for routine clinical practice. This dismal record reflects the failure of researchers to embrace a coordinated systems-based approach. Only through collaborative networks, which adopt common approaches and cross-disciplinary methods can we hope to achieve clinically meaningful results. It is time to restructure and mobilize the field to operate more like large international entities focused on delivering tangible advances in health care.

There is no doubt that the successful progress of P³G would not have been possible without the support of Genome Canada and Génome Québec through the mechanism of the International Consortium Initiative. This support is not just a matter of funding, but rather that of a shared vision.



Message from Mylène Deschênes, Isabel Fortier and Paul Burton

P³G - CELEBRATING COLLABORATION THAT YIELDS RESULTS



Mylène Deschênes
Executive Director



Isabel Fortier
Director, Research and Development



Paul Burton
Scientific Director

Three years ago, Genome Canada and Genome Québec funded an International Consortium Initiative grant aimed at enhancing individual and population health by creating a multi-disciplinary network of international scientists and other expert professionals working in human population genomics and related fields. P³G subsequently evolved from this original concept to become a globe-spanning consortium involving members from 49 countries. This critical mass of experts and biobank leaders is working to ensure that large scale population genomic resources are of high quality and well harmonized with the ultimate aim of developing effective healthcare strategies aimed at enhancing clinical care, public health, and ultimately to underpin the concept of “personalized medicine”. This research community is tightly knit and characterized by enthusiastic collaborations. In reality we have surpassed our

initial hopes and expectations and we applaud the vision and hard work of all of our consortium members who have collectively enabled this success.

2010: A YEAR OF PUTTING HARMONIZATION TO PRACTICE

P³G’s commitment to fostering collaboration between researchers and projects in the field of population genomics was evident at this year’s Annual Meeting held in Montreal. More than 120 participants attended as we announced the creation of P³G’s first international harmonization project at this forum. This collaborative initiative involves 53 large studies from 18 countries representing more than five million participants. This is the culmination of our efforts over the last years, and demonstrates the benefits of community-based information sharing.

ACTIVITY REPORT 2010

Meeting: Montreal annual members meeting.

■ **Landmark Publication** : The manuscript *Quality, quantity and harmony: the DataSHaPER approach to integrating data across bioclinical* was recently published in the International Journal of Epidemiology.

Stay tuned for manuscripts about the demonstration of the DataSHaPER approach to generate harmonized variables in 53 studies.

■ **P³G Observatory Catalogue maintenance and improvement.**

■ **P³G pilot and test of tools and methods, including the 53 studies project and the OBiBa actual implementation of their software at biobank sites.**

■ **P³G establishment of new collaborations that are actually making use of the tools developed (in Canada and internationally) to generate research leading to novel scientific discoveries.**

P³G - ALWAYS LOOKING FORWARD

LOOKING FORWARD

As high quality, harmonized data and material are rapidly accumulating in the world's biobanks – with the assistance of P³G's tools - the next big challenge is to ensure that these resources are optimally exploited to generate new science. This demands the development of effective and secure approaches to data management and access. The need to be able to work with an international pool of harmonized open access biobanks is clearer than ever before. Contemporary biomedical research relating to the complex diseases often demands data from huge numbers of well measured study participants – and the resources required regularly exceed what can be provided by any single study. For example, large consortium-based analyses have underpinned the identification and confirmation of many of the hundreds of gene-disease associations that are now known to exist. As we move forward to explore how genes interact with environment, sample sizes demands will increase yet further, and the need to harmonize non-genomic factors will become ever more crucial. P³G is leading efforts to achieve this goal and our research tools are converging toward the creation of a Harmonization Platform. This platform, a one-stop shop for the management of the harmonization process, and for the harmonization of datasets to enable information sharing, will accelerate human health research involving significant samples size and information from a broad range of sources.

P³G is “evolving with the needs of its members”. When P³G was created, most biobanks were a mere concept on papers and our focus was necessarily on supporting their conceptualization, design, and realization. An increasing number of our member biobanks have now completed initial data collection. The next phase of P³G will therefore focus on meeting our members' needs in relation to the challenges of sustainability, increasing the use of their resources and ultimately ensuring effective exploitation. Streamlined yet secure access to the data and samples held in large scale biobanks is a goal shared by many stakeholders including

funders, biobankers, research users and also the participants who wish to see their own contribution in terms of time, effort and generosity. In its next phase, P³G will focus on the development and implementation of solutions to the ethico-legal and scientific challenges presented by the need to ensure effective data access. This will include an “International Code of Conduct” for data-sharing in collaboration with ENGAGE and HeLEX and the development, implementation and enhancement of tools such as DataSHIELD and the concept of electronic researcher IDs. Optimal use of research infrastructures is our next mission!

A SNAPSHOT OF P³G MILESTONES ACHIEVED OVER THE PAST 3 YEARS

- P³G has brought the genomics, epidemiology, ethics/policy development, and information technology communities closer through novel communication strategies and via 12 international meetings. Growth and development of the P³G consortium has been rapid and dramatic. P³G now includes 30 Charter members, 16 Associate members and 316 Individual members from 49 different countries.
- P³G's Observatory includes a series of online catalogues that provide a comprehensive snapshot and overview of the current state of biobanking around the world. The catalogues currently include standardized descriptions of 160 biobanks/studies that, between them, have recruited or intend to recruit more than 12.4 million participants.
- Along with our partners, we have developed a series of scientific, ethico-legal and educational tools that promote optimal biobank design and facilitate information sharing. Amongst these tools is the DataSHaPER (Data Schema and Harmonization Platform for Epidemiological Research), which aims to facilitate harmonization of emerging biobanks, provide a template for retrospective synthesis and support the development of questionnaires and information-collection devices. Work on the DataSHaPER is complemented by the IT developments of OBiBa which is developing a full open source suite of information software for biobanks (including Onyx and Opal) into which the DataSHaPER can ultimately be integrated.

P³G - MEMBERSHIP



LIST OF CHARTER MEMBERS (30)

Avon Longitudinal Study of Parents and Children - UK	Estonian Genome Project of University of Tartu - Estonia	LifeLines Cohort - Netherlands
Biobank Popgen - Germany	Generation Scotland - UK	National Cancer Institute - USA
Bio-Bank (SBB) - Singapore	GenomeEUtwin - Finland	National DNA Bank - Spain
BioHealth Norway/Biobank Norway - Norway	IBBL - Luxembourg	National Heart, Lung and Blood Institute (NIH) - USA
Canadian Partnership for Tomorrow Project - Canada	INMEGEN - Mexico	NUgene - USA
CARTaGENE - Canada	INSERM - France	Ontario Cancer Consortium - Canada
Centre for Integrated Genomic Medical Research - Manchester, UK	Institute of Genomics and Integrative Biology - India	String of Pearls Initiative - Netherlands
Charles R. Bronfman Institute of Personalized Medicine - USA	Kaiser Permanente - USA	Taiwan Biobank Institute of Biomedical Sciences, Academia Sinica - Taiwan
Danubian Biobank Foundation - Germany	King Abdullah International Medical Research Center - Saudi Arabia	UK Biobank - UK
	KORA-Gen - Germany	Western Australia Genome Health Project - Australia
	LifeGene - Sweden	

INDIVIDUALS (319)

An international, national or regional not-for-profit organization that is conducting, or will be conducting a large population genomics project such as a biobank or a large-scale cohort study (n ≥ 10,000 samples).

Individuals from academic, public or private organizations committed to complying with the objectives of P³G and to providing P³G with the benefit of their knowledge.

LIST OF ASSOCIATES (16)

A not-for-profit organization whose activities are devoted to scientific, ethical, legal or societal research related to population genomics and genetics.

Alberta Cancer Board (Canada)
Centers for Disease Control (Office of Genomics & Disease Prevention, USA)
Centre of Genomics and Policy (Canada)
CIHR-Canadian Institute of Genetics (Canada)
European Center for Public Health Genomics (Netherlands)
European Collection of Cell Cultures (UK)
Genetics Resource Center (Faroe Island)
Genoma España (Spain)
Génome Québec (Canada)
Hans Mak Institute (Netherlands)
Latvian Biomedical Research and Study Center (Latvia)
McGill University and Génome Québec Innovation Centre (Canada)
Marshfield Clinic Research Foundation (USA)
Medical University of Graz (Austria)
National Human Genome Research Institute (NIH, USA)
Statistics Canada (Canada)

P³G - CORPORATE INFORMATION

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Gert-Jan B. van Ommen
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ANNUAL GENERAL MEETING

P³G Annual Meeting
April 8, 2011
Location: P³G Head Office - Web conference

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P³G - EXECUTIVE AND STAFF



Sitting from left : Isabel Fortier, Mylène Deschênes, Bartha Maria Knoppers and Paul Burton.

Standing from left : Cédric Thiebault, François L'Heureux , Etienne Morency-Bachand, Charles Rivard,
Irene S. Toffolo, Dany Doiron, Mayss Naccache and Clément Tamisier.

*“You must be the change
you wish to see in the world”*

- Mahatma Gandhi

**Thank you Consortium members,
Genome Canada and G nome Qu bec!**



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