

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

CHARTER MEMBERS

An international, national or regional non-for-profit organization that is conducting, or which will be conducting, a large population genomics project such as a biobank or a large-scale cohort study (N > 10,000 samples).

Avon Longitudinal Study of Parents and Children **UK**
Biobank Popgen **Germany**
CARTaGENE **Canada**
Centre for Integrated Genomic Medical Research **Manchester, UK**
Danubian Biobank Foundation **Central Europe**
Estonian Genome Project of University of Tartu **Estonia**
Generation Scotland **UK**
GenomeEUtwin **Helsinki**
INMEGEN **Mexico**
INSERM **France**
King Abdullah Inter national Medical Research Center **Saudi Arabia**
KORA-Gen **Germany**

LifeGene **Sweden**
LifeLines Cohort **Netherlands**
National Cancer Institute (NIH) **USA**
National DNA Bank **Spain**
National Heart, Lung and Blood Institute (NIH) **USA**
Norwegian Institute of Public Health **Norway**
NUgene **USA**
Ontario Cancer Consortium **Canada**
Singapore Tissue Network **Singapore**
String of Pearls Initiative **Netherlands**
Taiwan Biobank Institute of Biomedical Sciences, Academia Sinica **Taiwan**
UK Biobank **UK**
Western Australia Genome Health Project **Australia**

ASSOCIATE MEMBERS

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 de Recherche en Droit Public **Canada**
CIHR-Canadian Institute of Genetics **Canada**
European Collection of Cell Cultures **UK**
Genetics Resource Center **Faroe Island**
Genoma España **Spain**
Génome Québec **Canada**
German Center for Public Health Genomics **Germany**
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**

INDIVIDUAL MEMBERS

An individual from an academic, public or private organization committed to complying with the objectives of P³G and to providing P³G with the benefit of their knowledge.

P³G works with biobankers and other subject-matter experts from around the world to

Foster collaboration between researchers and biobankers

Promote harmonization of information

Optimize the design, set-up and research activities of population-based biobanks

Facilitate the transfer of knowledge and provide training to those working in the field

P³G brings the genomics community closer together in person – at conferences and meetings held around the world, and online through the Observatory – a publicly accessible knowledge database. Principles of transparency and collaboration are integral to the P³G approach.

P³G 3333 Queen Mary Road, Suite 590, Montréal, Québec, Canada H3V 1A2
T 514-343-7001 F 514-343-2270 E secretariat@p3g.org
www.p3g.org



»» **Public Population Project in Genomics**
Building a Harmonized Synergy



www.p3g.org

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Membership

Membership in P³G is open to all individuals committed to upholding P³G objectives and to contributing their expertise to the P³G community under applicable legal and ethical obligations of P³G. The three categories of P³G membership are:

Charter International, national or regional not-for-profit organizations who are or who will be conducting a large population genomics project, such as a biobank or a large-scale cohort study (N > 10,000 samples).

Associate Not-for-profit organizations, such as research institutions, charitable organizations or funding agencies whose activities are devoted to scientific, ethical, legal or societal research related to population genomics and genetics.

Individual Individuals from academic, public or private sectors committed to sharing their knowledge and dedicated to P³G objectives.

Becoming a member offers a number of benefits, including invitations to participate in all P³G activities and member meetings, as well as access to networking and informal scientific exchanges with leading researchers in the field of population genomics. All members are eligible for office. Charter and Associate members are entitled to vote on all matters submitted to a vote. Only Charter members can elect the Directors of P³G.

TO BECOME A MEMBER, VISIT
www.p3g.org

The Public Population Project in Genomics

The study of complex diseases is a major challenge to modern biomedical science. The scientific community recognizes that to better understand disease, it is essential to study how genes interact with each other, the environment and lifestyle.

The Public Population Project in Genomics (P³G) is a not-for-profit international consortium that provides easy access to expertise, resources, innovative tools and the most up-to-date information from all areas of public population genomics to biobankers, scientists and researchers.

› P³G is dedicated to supporting existing and emerging biobanks and facilitating large-scale collaborations. P³G develops and shares expertise, methods and the tools necessary to help optimize the design of population biobanks and facilitate their harmonization.

› P³G brings together world-renowned experts in the areas of biobanking, ethics, health and law both in person, online and in scientific research collaborations to address the issues facing population-based genomics research.

› P³G's ever-growing platform of tools and resources has been developed by and for scientists working predominantly in population-based studies. Members of P³G share their knowledge,

tools and methodologies, but each study has its distinctive traits and retains control over its data and samples.

› P³G encourages scientific input and contributions of information from all biobankers – whether or not they are members of P³G.

› Knowledge Transfer In addition to P³G Meetings, working groups, publications and the Observatory, P³G supports additional means of knowledge transfer such as providing ongoing education of biobanking professionals around the world through partnering with institutions such as The Wellcome Trust in building educational programs.

P³G SECRETARIAT

Mylène Deschênes Executive Director
Isabel Fortier Research & Development Director
Denis Legault Administrative Director

SCIENTIFIC DIRECTION

Paul Burton Chief Scientific Officer and Steering Committee Leader

P³G FUNDERS

Genome Canada
Génome Québec

HOST INSTITUTION

Université de Montréal (Canada)

The P³G Observatory

The P³G Observatory is a free, online repository of information, open-access tools and resources designed to facilitate harmonization in biobanking. The site provides information about biobanking activities around the world and supports investigators and biobank administrators in the development and realization of their activities. In the spirit of information sharing much of the information on the site has been supplied by biobankers from all over the world.

The P³G Observatory is divided in the following sections:

Catalogues As a window to biobanks around the world, the Catalogue section is comprised of nearly 140 studies from 43 countries and representing studies that range in size from 2166 to 1,300,000 that offers easy access to information related predominantly to large population-based biobanks, as well as an overview of the similarities and differences and the potential for harmonization between participating biobanks. There is also a special partner catalogue related to disease-based studies.

Network Provides an overview of selected networks of population-based biobanks, and includes contact information, objectives and member studies.

Study Provides an overview of the large population-based biobanks worldwide, including: contact information, design, and current status of the studies.

Questionnaire Provides access to questionnaires, method of administration and an interactive tool that displays similarities and differences in content from participating study questionnaires.

Information Technologies Provides an overview of the application software used by participating biobanks.

Physical and Cognitive Measures Provides access to the series of physical and cognitive measures and, if available, to standard operation procedures in use by participating studies. It also includes an interactive tool displaying similarities and differences between the measures collected.

DNA Processing Provides access to the type of samples collected and the DNA processing and storage conditions. It also includes a tool displaying the similarities and differences between processes.

Ethics and Governance Provides an overview of the ethics and governance strategies of a resource/biobank and allows researchers to assess the potential for collaboration and future use.

DataSHaPER (Data Schema and Harmonization Platform for Epidemiological Research)



is both a scientific approach and a suite of practical tools designed to facilitate prospective harmonization of emerging biobanks, provide templates for retrospective pooling and support the development of questionnaires and information-collection devices, even when pooling data with other biobanks is not planned. The basic structure reflects a four-step adapted for each new harmonization action as it arises:

- 1 Identify and document the set of core variables to be shared
- 2 Formally assess the potential to share each variable between participating studies
- 3 Define appropriate data-processing algorithms
- 4 Process and pool real data

REPOSITORY OF INFORMATION AND TOOLS

brings biobank science theory and practice together by providing access to technical and scientific information in the different domains of biobanking.

P³G is a collaborative work-in-progress and welcomes all researchers working in the area of population-based genomics to submit their ideas, tools, studies and expertise to the P³G Observatory. Your contribution is vital in helping advance our shared goal of harmonization. Please email us at secretariat@p3g.org or visit www.p3g.org.