



newsletter

Public Population Project
in Genomics

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I W G P R O G R E S S

1. New IWG leaders have been named! Congratulations to the two International Working Group (IWG) leaders, whose appointments were announced at the October 3rd Board Meeting. These individuals, leaders in their fields, will provide guidance and coordination at the international level for P3G activities. We look forward to hearing of their progress in setting priorities, identifying the scientific content, facilitating meetings and gathering international expertise for their IWGs.

The new leaders are:

- **Kurt Zatloukal**, Medical University of Graz, coordinator of the BBMRI
IWG1 - Social, Environmental and Biochemical Investigations
- **Samuli Ripatti**, FIMM: Institute for Molecular Medicine Finland
IWG2 - Information Curation and Information Technology

Best wishes also to **Alastair Kent**, who has been renewed as the IWG3 (Ethics, Governance and Public Engagement) leader.

We thank him for his previous dedication and welcome him again on board.

All IWG leaders, including IWG4 (Epidemiology and Biostatistics) leaders Muin Khoury, Director of the National Office of Public Health Genomics (Centers for Disease Control and Prevention, Atlanta), and Julian Little, Chair of the University of Ottawa's Department of Epidemiology and Community Medicine, will chair sessions during the P3G Annual Meeting in Philadelphia.

We thank the former IWG1 leader H. Erich Wichmann (2005-2008) for his leadership, sharing of expertise and generous contribution of time.

Erich has been:

- Indefatigable, in his contributions since the very inception of P3G.
- A hardworking leader of IWG1 and of the KORA project.
- A loyal member of the Steering Committee and constant in his insight.

Due to his outstanding contributions and his ongoing input, the P3G Steering Committee will continue to seek Erich's advice on strategic planning and key decisions.

2. CORES PROJECTS ON TARGET

The IWG Core Projects, which are the key independent research units of P3G, are expanding. A new IWG4 Core Project, GeneStat, has been formally accepted. Under the leadership of Samuli Ripatti, this project will provide a foundation for training in statistical genetics through an Internet-based series of tutorials and reviews. Links to key sites and computer programs for analysis of genetic data will also be available.

For a complete list of all ongoing Core Projects, please visit www.p3gobservatory.org/foundation-projects.htm.

3. RECENT PUBLICATIONS

- **Knoppers B.M., I. Fortier, D. Legault, P. Burton:** The Public Population Project in Genomics (P3G): A proof of concept?. *Eur J. Hum Genet* 2008; 16: 664 - 665. *This is the benchmark P3G publication.*
- **Wallace S., S. Lazor and B.M. Knoppers.** Consent and population genomics: The creation of generic tools. *IRB* (in press)
- **Gert Jan Van Omen.** "Population surveys and biobanking" ESF Publication, 2008 May 26
- **Wallace S., S. Lazor and B.M. Knoppers.** What is in a clause? A comparison of clauses from population biobank and disease biobank consent materials. In: Dabrock P. and Ried J. (eds) *Trust in Biobanking*. Springer:Heidelberg. (Book in preparation.)
- **Wallace S. and B.M. Knoppers.** The role of P3G in encouraging public trust in biobanks. In: Dabrock P. and Ried J. (eds) *Trust in Biobanking*. Springer:Heidelberg. (Book in preparation.)

Consortium members are encouraged to consider involving the P3G infrastructure in their proposed research projects. Advantages include input from international leaders, rapid and easy dissemination of results, formal technical support and nominal funding for integration of tools into the Observatory. For more information or to apply, please visit www.p3gconsortium.org/cores.cfm.

Save the Dates for Upcoming P³G Activities:

- **March 25, 2009: P3G Consortium Meeting 2009.** Brussels, Belgium. (Running in parallel to the BBMRI Meeting, also held March 25.) This full day meeting will include one plenary session, International Working Group (IWG) meetings, and our Annual Member's meeting. Preliminary information will soon be available on the P3G website (<http://www.p3gconsortium.org/Uevents.cfm>).
- **March 25-27, 2009: Brussels, Belgium. P3G PHOEBE-BBMRI meeting.** *Harmonizing Biobank Research: Maximizing Value - Maximizing Use.* For your convenience, PHOEBE, P3G and the BBMRI are combining efforts and resources to create one major event in the field of biobanking.

This event will bring together key people from the international biobanking community and is the biobanking meeting you can't afford to miss in 2009!
- **July 1-5, 2009: P3G-Wellcome Trust Biobank Course.** Hinxton, UK. This session will also include a one-day course organized by CIGMR/UKDBN, specifically focused on tissue banking.

P³G E V E N T S

1. Barcelona P³G Meeting (May 30 to 31, 2008)

P3G welcomed its largest crowd ever to the Barcelona meeting. More than 100 delegates from 20 countries participated in productive scientific meetings. Highlights included the “Guidelines session”, that will be followed-up in Philadelphia, and the “Problem Solving session”, which received the greatest feedback and provided a useful forum for emerging organizations. The table on page 6 outlines a complete list of the sessions and outcomes.

Members were once again entertained by their peers during the P3G celebration dinner. Among the many performers was singer **Renate Gertz**, from the University of Glasgow, who demonstrated remarkable talent. Both her voice and lyrics were exceptional. The celebration cocktail was made possible through the generosity of GenVault Corporation.

2. P³G Participation at the European Society of Human Genetics

For the first time, P3G hosted a workshop during the European Society of Human Genetics (ESHG) entitled “Optimizing biobank tools: from silos to networks.” Bartha Maria Knoppers and Helena Kääriäinen moderated and speakers included:

- Tim Peakman, *Establishing a large biobank: major issues approaches. Experience from a UK Biobank.*
- Gert-Jan B. van Ommen, *Integrating molecular phenotyping of rare and common disease using ‘omics’ technology”*
- Bartha Maria Knoppers, *Researcher access to population biobanks: the final frontier?*

The topic was particularly timely and the session was so well received that P3G was invited to present at the next ESHG meeting.

CONFERENCE OF INTEREST

The **58th Annual Meeting of the American Society of Human Genetics** will be held at the Pennsylvania Convention Center in Philadelphia, November 11-15, 2008. For registration info, please visit www.ashg.org/2008meeting.

Governance of New Technologies: The Transformation of Medicine, IT and IP. Speakers: Francis Gurry, Dan Hunter and Bartha Maria Knoppers, March 29-31, 2009. University of Edinburgh. www.law.ed.ac.uk/ahrc/conference09.

Thank you to
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and Genome Canada,
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institution.



WELCOME TO THE NEW P³G SCIENTIFIC DIRECTOR

We are pleased to introduce P3G's new Scientific Director, Paul Burton, who was unanimously endorsed at the May 2008 Board Meeting. We wish to thank former Scientific Director Tom Hudson for his insight, enthusiasm and direction. Dr. Hudson remains firmly committed to P3G as a member of the Board and continues to be a pivotal leader in the organization.

Professor Paul Burton holds the Chair in Genetic Epidemiology at the University of Leicester (UK), and is a Chartered Statistician (Royal Statistical Society), a member of the Royal College of Physicians (UK), and a member of the Faculties of Public Health in both the UK and Australia. His main areas of scientific work include methods research in biostatistics and genetic epidemiology, and applied research in complex disease epidemiology.

Recently, Paul has focused on the promotion and con-

struction of major infrastructure research projects in population bioscience. He has worked with both the UK Medical Research Council (MRC) and Wellcome Trust (WT) on a number of committees focusing on strategic developments in population science. He has been newly appointed by MRC, WT and the Economic and Social Research Council (ESRC) as Chair Designate of the Oversight Committee for the 1958 Birth Cohort, which provides a set of more than 8,000 national controls for genetic association studies in Great Britain. He also sits on the Basic Science Interview Committee and the Study Design Expert Group at WT.



His work on the power calculations for UK Biobank led him to recognize how important it is that we harmonize and integrate biobanks internationally. Consequently, he helped set up, and is the Scientific Coordinator, of the EU-funded PHOEBE project (Promoting Harmonization of Epidemiological Biobanks in Europe).

Professor Burton shares his thoughts and vision for P³G

Why did you join P3G, and what do you see as its strengths?

Understanding the myriad causes of the complex diseases and the factors that determine whether an individual patient recovers, stabilizes, deteriorates or dies is a central goal of modern biomedical science. But, this task is not unlike trying to find small dim objects in outer space. By focusing a large amount of information in one place, a biobank may be viewed as a biomedical "telescope." P3G is the international organization that is not only helping us to design the best possible telescopes, but also to work together to focus our telescope array on the most important, and often most difficult, problems that bioscience must face.

I first encountered P3G in Manchester in 2003 and was immediately impressed by the vision of its leaders

including Bartha Maria Knoppers, Tom Hudson, Andres Metspalu and Leena Peltonen. But the triggers that persuaded me to join were two presentations by Mylene Deschenes and Isabel Fortier at a Wellcome Trust biobanking meeting held in September 2005, in Hinxton, Cambridge. Although many groups had been "talking the talk," it was clear that P3G had actually started to "walk the walk." I was astounded by the speed with which Mylene Deschenes and the P3G leaders had been able to build an active consortium and by the progress that Isabel Fortier had already made in beginning to construct the P3G Observatory. It seemed obvious to me that theirs was the necessary "big science" approach: the approach that can ensure that our "biomedical telescope array" is powerful enough to meet the needs of contemporary bioscience.

What are some of your short-term goals for the organization?

I have both science and non-science goals.

Science goals

To work alongside the P3G science team, led by Isabel Fortier, and in collaboration with the broader consortium to:

- Develop and extend the Observatory and to encourage the widespread use of Observatory tools.
- Develop and extend the DataSHaPER as a tool for harmonizing questionnaires and physical measures, in order to promote both prospective and retrospective harmonization.
- Develop a suite of specialized DataSHaPERs to accompany the generic-DataSHaPER that currently focuses on baseline information gathering in cohorts recruiting middle-aged participants.
- Apply Observatory tools to real-world projects to undertake applied harmonization in a scientific setting, and to formally evaluate the effectiveness of that harmonization.
- Publish as much of our work as possible to ensure that P3G remains clearly “on the scientific map” and to demonstrate proof of principle.

Non-science goals

- To extend and strengthen links with sister organizations, particularly with BBMRI and PHOEBE in Europe and with ISBER. As a biobanking community, we must make a coordinated global effort to generate long-term international funding to secure ongoing infrastructural development for biobanks and biobank harmonization.
- To help promote convergence of research activity with groups focusing on disease-based (case-control) and tissue-based biobanking.

What is your long-term vision for P3G?

I can realistically see a world in which there is a global network of harmonized biobanks that are linked electronically, but with control remaining distributed: each biobank will remain responsible for its own samples, data, distinctive scientific flavour and development strategy. Potential users will be able to access federated IT systems via a central portal (e.g. the P3G Observatory) to identify where data and samples exist that might be used to answer

particular scientific questions. The harmonization of ethico-legal issues (local, national and transnational) will be such that routine systems will enable users to submit straightforward applications to obtain and pool data, samples, or both.

The potential roadblocks to this vision are not scientific, technical or ethical - I am therefore convinced that this can and should be realized. Furthermore, I believe it will take less time to develop the necessary technology and methods than to accumulate the data and samples. Thus, the only real potential obstruction is “human nature.” We all need to be open to shared efforts and collective rewards rather than maintaining individual control and optimizing individual return.

P3G is already helping to advance the development, cataloguing and dissemination of information, guidance, methods and tools advancing the vision I have described. It also provides a wonderful environment in which biobanking scientists from around the world are able to meet, get to know one other, share ideas and launch research programs. I have personally never worked in a setting where there is greater trust, true sharing and real academic generosity between scientists. My personal confidence in the long-term vision I outlined is based therefore on the academic philosophy of cooperation and sharing that is so evident within P3G.

Professor Paul Burton, who, similar to Professor Kurt Zatloukal (interviewed for the Spring 2008 Newsletter), is a keen skier and sailor. But, unlike Professor Zatloukal, Professor Burton is not (he maintains) very good at either, and so consoles himself with the knowledge that he is more youthful, even if it is only by one week!

P³G Barcelona Meeting Sessions and Outcomes

SESSION	OUTCOMES
Observatory update	Update of Observatory development.
IP / Ownership of biomaterial / MTA s	Model MTA under construction.
Governance	Primer: Ready for Philadelphia.
Problem solving	Overview of challenges faced by nascent organizations and input from more experienced agencies. A new Observatory catalogue will compare current practices.
Guidelines: Genotype storage	Analysis of the similarities and discrepancies of major guidelines in biobanking will be conducted and the results will be presented in Philadelphia.
DNA quantity and quality control initiative	A paper on the first set of analyses (submitted). A new project will compare genotypes generated between biobanks.
Access to data/material	Cooperative research results to be published at a later date.
DataSHaPER	Launch of the DataSHaPER. Validation is ongoing and an updated version will be available before 2009.

The next P³G General Meeting (see following page for agenda) will be held at the Marriot Courtyard Philadelphia Downtown Hotel November 10-11, 2008 in Philadelphia, Pennsylvania, just before the American Society of Human Genetics meeting. Multiple Topic Sessions will be held. Participants are welcome to attend any session and all P3G members are invited to take part in this exciting scientific event (see table for details). Please join us for the Cocktail/Poster viewing session that was made possible thanks to the generosity of GenVault.

POSTERS FOR P³G MEETING

All members are invited to present posters describing the progress of their biobanks, or relevant issues or tools addressing these projects. If you plan on displaying your poster at ASHG, and the information meets these criteria, you may consider presenting it at P3G as well. All posters are welcome. The preference is that they not exceed 2'10" (86.36 cm) wide x 3'8" (111.76 cm) high. The Poster Session will be held during the Cocktail, reception November 10.

If you would like to display your poster, please confirm by e-mail at dlegault@p3g.org under the subject heading: POSTER.



P³G General Meeting Schedule
Marriot Courtyard Philadelphia Downtown Hotel

Monday, November 10

Time	Room	Activity
08:45-9:15	1	Welcome and brief update
09:15-10:00		Ethics in Genome Wide Studies
10:00-10:30		Break
10:30-12:00	1	Identifiability of individuals from genome wide association scans
12:00-13:00		Lunch
13:00-14:45	1	New tools for collecting, disseminating and integrating research data in biobanks
	2	Models for governance
	3	A road map for biobanking guidelines
14:45-15:15		Break
15:15-17:00	1	Nutritional Biomarkers
	2	Open source software: What's mine is yours, but please show it some respect!
18:00		Cocktail reception

Tuesday, November 11

Time	Room	Activity
08:45-10:15	1	Sharing core information sets: Let's share what matters most
	2	Gaining and regulating access to biobanked samples: practical aspects
10:15-10:30		Break
10:30-11:30	1	IWG 1 (Social, Environmental and Biochemical Investigations) meeting
	2	IWG 2 (Information Curation and Information Technology) meeting
	3	IWG 3 (Ethics, Governance and Public Engagement) meeting
	4	IWG 4 (Epidemiology and Biostatistics) meeting
11:30-12:30	1	Population-based and tissue-based biobanking
12:30-13:00		Wrap-up session
13:00-14:00		Buffet
14:00-15:30	1	Steering committee meeting - Invitation only

UPDATE FROM MEMBERS

1. The Spanish Banco Nacional de ADN (BancoADN) will be collaborating with the National Medical Association to collect new disease-oriented samples, expand its healthy individual sample collection to 3,000 subjects and to support various projects of different working groups.

2. The Canadian Health Measures Survey (CHMS) is currently collecting data and biospecimens from 5,000 Canadians aged 6 to 79 and aims to complete collection by March 2009. While the CHMS was originally funded as a one-time only survey, interest in the survey's potential and the initial success have resulted in funding from the Canadian government. Cycle 2 of the CHMS will collect data and biospecimens from an additional 5,000 Canadians starting in fall 2009 and continuing for two years. For this cycle, recruited participants will be aged 3 to 79.

3. In June 2007, the **Canadian Partnership Against Cancer (CPAC)** launched the Canadian Partnership for Tomorrow Project (CPTP), a study with 300,000 Canadians that will explore how genetics, environment, lifestyle and behaviour contribute to health and to the development of cancer and other chronic diseases. Bartha M. Knoppers will be chairing the project's ELSI Taskforce in proposing instruments to harmonize recruitment methods, consent form requirements and access policies among the five regional cohorts involved. The ELSI Taskforce will also be proposing a governance framework for the project.

4. The CARTaGENE Project is finalizing its methods and tools and preparing for the launch of its Phase A in 2009. CARTaGENE harmonizes certain of its epidemiological questionnaires, physical mea-

surements and computer tools with the Canadian Partnership for Tomorrow Project (<http://www.partnershipagainstcancer.ca/inside.php?lang=EN&ID=127>). To do so, CARTaGENE has organized a knowledge-transfer workshop and frequent joint work sessions.

5. The Estonian Genome Project (EGP) is a research venture of the University of Tartu. In 2008, the EGP became part of a Centre of Excellence along with the Estonian Biocentre and three University of Tartu laboratories from the IMCB. As a consequence, the EGP will receive additional funding for the next six years. The EGP started collecting tissue samples from gene donors in October 2002 and currently has 22,000 samples.

6. The next **GenEdit** entitled "Building a Future for Trust: Governance Mechanisms and Population Databanks" (by Susan Wallace et al.) was published on www.humgen.umontreal.ca in September 2008.

7. The Genome Database of Latvian Population (Latvian Biobank) is run by the Latvian Biomedical Research and Study Center. Since its official promotion in November 1, 2006, the Latvian Biobank has received government funding and is recruiting participants in both disease- and population-based groups. This biobank has recruited 7,000 of its 60,000 participant target.

8. KORA-gen is starting the new research project "Whole Genome and Transcriptome amplification in large biobanks," which is funded by the German National Genome Research Network (NGFN). In collaboration with Qiagen, new techniques will be developed and standardized, and the usage of the new WGA and WTA products will be evaluated in a large number of biosamples. Another task will be to



transfer the results to international biobanking organizations. Members of P3G will be invited to participate at a later stage.

9. **The Norwegian Mother and Child Cohort Study** (MoBa www.fhi.no) recently reached an important milestone: the 100,000th child to be included in the study was born. Recruitment will continue until the end of 2008 to support ongoing subprojects. The estimated number of final participants will be 108,000 children, 100,000 mothers, and 70,000 fathers. Approximately 100 subprojects have been initiated and 40 papers have been published since release of the study data in 2006. Papers based on analyses of samples from the biobank are expected to be ready for publication in early 2009.

10. **The National Institute of Genomic Medicine of Mexico** (www.inmegen.gob.mx) has released the first set of genotype data from the Mexican Genomic Diversity Project led by Dr. Gerardo Jimenez-Sanchez. Genotypes in the Mexican Mestizo population obtained using the Affymetrix 100,000 SNP array were released to the public in a report of major milestones in genomics in that country (Jimenez-Sanchez G., et al. *Genomic Medicine in Mexico: Initial steps and the road ahead.* /Genome Res/. 2008. Aug18(8):1191). These represent the first genome-wide genotyping results available in the public domain which refer to a recently mixed Latin American population

11a. **The US National Human Genome Research Institute (NHGRI)**, National Institutes of Health (NIH) awarded RTI International with a three-year cooperative agreement. The goal is to develop a toolkit of standardized measures for use in genome-wide association studies (GWAS) and related research so as to facilitate future cross-study analysis in the future. This project, named the Consensus Measures for Phenotypes and Exposures (PhenX, www.phenx.org) will focus on twenty research domains. Expert working groups comprising both NIH and non-NIH scientists have been convened for the Demographics, Anthropometric Measures, and Substance Use research domains.

11b. **The Electronic Medical Records and Genomics Network** (eMERGE, www.gwas.net) is a four-year project initiated through NHGRI's RFA HG-07-005 "Genome-Wide Studies in Biorepositories with Electronic Medical Record Data." Its goal is to combine data from five existing DNA biorepositories linked with medical records to conduct large-scale, genome-wide association studies on a number of complex phenotypes. Genotyping is expected to begin in early 2009. The Network is also looking at ELSI issues, such as privacy and confidentiality, surrounding genomic research linked to biorepositories.

12. **NUgene** is a participant of the eMERGE Network. As such, they are developing computational algorithms to identify participants with type-2 diabetes and asthma based on EHR data. NUgene has also recently completed focus group meetings to better understand people's attitudes toward collecting, analyzing and sharing genetic research data.

13. The coordinating centre of the **Public Health Genomics European Network (PHGEN)** has moved from the German Center for Public Health Genomics (DZPHG) in Bielefeld, Germany, to the newly established European Centre for Public Health Genomics (ECPHG) in Maastricht, the Netherlands (Director Prof. Dr. Angela Brand, MPH). There will be continuous funding from the European Commission (DG SANCO) until the end of 2011.

14. **The Tomorrow Project** in Alberta, Canada plans to enroll 5,000 participants before the end of March 2009, bringing the total enrolled to approximately 35,000. In addition, the Tomorrow Project has joined with other planned and existing cohorts in British Columbia, Ontario, Quebec and a coalition of the Atlantic Provinces to build a pan-Canadian cohort of approximately 300,000 participants.

Charter Members

ALSPAC (UK)
Biobank PopGen (Germany)
BancoADN (Spain)
CARTaGENE (Canada)
Centre for Integrated Genomic Medical Research (United Kingdom)
Danubian Biobank Foundation (Germany)
Estonian Genome Project (Estonia)
Generation Scotland (UK)
GenomEUtwin (Finland)
INMEGEN (Mexico)
INSERM (France)
KORA-gen (Germany)
LifeGene (Sweden)
LifeLines Cohort (Netherlands)
National Cancer Institute (USA)
National Guard Health Affairs Biobank (Saudi Arabia)
National Heart, Lung and Blood Institute (USA)
National Institute of Genomic Medicine (Mexico)
NUgene Project (Northwestern University, USA)
Norwegian Institute of Public Health (Norway)
Ontario Cohort Consortium (Canada)
Singapore Tissue Network (Singapore)
String of Pearls Initiative (Netherlands)
Taiwan Biobank Institute of Biomedical Sciences, Academia Sinica (Taiwan)
UK BioBank (UK)
Western Australian Genome Health Project (Australia)

Associate Members

Alberta Cancer Board (Canada)
Centers for Disease Control (Office of Genomics and Disease Prevention; Atlanta, USA)
Centre de Recherche en Droit Public (Canada)
CIHR: Canadian Institute of Genetics (Canada)
European Collection of Cell Cultures (UK)
Genetics Resource Centre (Faroe Islands)
Genoma Espana (Spain)
Genome Québec (Canada)
German Center for Public Health Genomics (Germany)
Hans Mak Institute (Netherlands)
Latvian Biomedical Research and Study Center (Latvia)
Marshfield Clinic Research Foundation (USA)
McGill University and Genome Quebec Innovation Centre (Canada)
Medical University of Graz (Austria)
National Human Genome Research Institute (NIH, USA)
Ontario Institute for Cancer Research (Canada)
Statistics Canada (Canada)

NEW MEMBERS

Welcome to the three new Charter Members who have joined P3G:

- **Biobank PopGen** (Germany). An arm of Germany's National Genome Research Network that provides samples and data for collaborative genetic epidemiological research projects.
- **BancoADN** (Spain, www.bancoadn.org). A service provided by the University of Salamanca that receives, processes and stores DNA, plasma and cell samples from voluntary donors along with relevant information on health and lifestyle habits related to the samples.
- **String of Pearls Initiative** (Netherlands, www.erasmusmc.nl/research/subsidies/investeren/parelsnoer/?lang=en). A collaboration of university medical centres in the Netherlands whose goal is to set up an infrastructure for collecting clinical data and biomaterial in the Netherlands.

The **Hans Mak Institute** (Netherlands, www.hansmakinstituut.nl) and the **Latvian Biomedical Research and Study Center** (Latvia, bmc.biomed.lu.lv/site/main/cgi/YaBB.cgi?action=lo) have recently joined P3G as associate members.

We are proud to have more than 40 Charter and Associate Members.



P³G IN THE SPOTLIGHT

In order to better protect and keep track of P3G's contribution (and also the contribution of all researchers actively participating in P3G) the P3G Board and General Assembly have endorsed a new Authorship Policy. This will clarify when contributions from P3G should be formally acknowledged in papers and presentations and will support the fundamental P3G principles of transparency, openness, collaboration and knowledge-transfer. This is a living document that will be modified over time following member input.

For more information, clarification and to read the entire policy, please visit www.p3gconsortium.org.

Following is the P3G Standard Acknowledgement:

The author(s) wish (es) to acknowledge the Public Population Project in Genomics (P3G), hosted by the University of Montreal and supported by Genome Canada and Genome Quebec. The [tool, work, presentation, paper, etc.] presented herein was made possible using [methods/tools/open software] from [P3G Observatory website/ or developed by P3G].

P³G OBSERVATORY www.p3gobservatory.org

There has been a flurry of activity at the Observatory, thanks to your input there has been a steady stream of new developments. The "What's new" section of the website is a great resource for updates. Listed are the most recent Observatory additions.

1 . Partner Network Catalogue

This Catalogue lists and describes networks of population-based studies in genomics. To be included in the Catalogue, a Network must:

- Be a structured organization (already active or under development).
- Have at least two individual entities, across one or several countries.
- Comprise population-based studies.

2 . DataSHaPER- A harmonization tool

Data Schema and Harmonization Platform for Epidemiological Research (DataSHaPER) is a suite of tools aimed at assisting biobanks to harmonize projects and to design questionnaires and other information-collection devices. It also promotes and facilitates the pooling of information between biobanks. The first tool is the Generic-DataSHaPER, which supports the construction of cross-sectional baseline questionnaires for general-purpose biobanks enrolling middle-aged participants. The creation of the Generic-



DataSHaPER was a collaborative venture involving experts from more than 25 international biobanks. P3G, PHOEBE and Generation Scotland jointly funded its development. An updated version will be available soon.

3. Guidelines Comparison Chart

This document compares selected referenced guidelines and best practices for biological sample collection and processing. It covers all biobanking steps including biological sample collection, labeling, processing and storage, for a wide range of sample types.

4. Information Technology Catalogue

This catalogue provides an overview of the application software used by participating biobanks. Other comparison charts will be available soon.

5. Ethics and Governance Catalogue

This catalogue provides both an overview of the ethics and governance strategies of a resource/biobank and allows researchers to assess the potential for collaboration and future use.

As of early November, the Observatory listed 123 biobanks in the Study Catalogue and 27 questionnaires from 20 studies in the Questionnaires Catalogue. This dramatic increase in numbers is a reflection of P3G's reputation of integrity and resourcefulness.

We are listening. In response to your requests we have developed new Observatory elements, including new tools and repositories. Thank you to all who contributed. Many of our newer tools are in development and your continuing input is key. We invite you to add your studies, data or comments.