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P^{3}G — 10 years of toolbuilding: From the population biobank to the clinic

Sylvie Ouellette *, Anne Marie Tassé

Public Population Project in Genomics and Society (P^{3}G), 740 Dr. Penfield Avenue, 5th Floor, Montreal, Quebec H3A 0G1, Canada

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ABSTRACT

Over the past ten years, the Public Population Project in Genomics and Society ("P^{3}G") has grown as a consortium. It has expanded its range of services and resources to adapt to the ever-evolving needs of the research community. From its outset – when P^{3}G first tackled the building of biobanks as resources as well as data cataloguing and harmonization for data integration – to its new mission and vision, it has continually developed the tools for the conceptualization and design of population biobanks from their inception to their use to their closure. In so doing, P^{3}G has become key in fostering research infrastructures to facilitate transition to the clinic. The consortium has become a crucial stakeholder in the international scientific, ethical, legal, and social research communities.

1. Introduction

The Public Population Project in Genomics and Society (P^{3}G), established in 2004, is a non-profit international consortium focusing on genomics and biobanking. Originally, P^{3}G served four different but complementary population genomics research projects: CARTaGENE (Quebec); GenomEUtwin (FP5 (EC) project involving 8 countries); Estonia's genome project (Estonia); and the U.K. Biobank (U.K.). Dedicated to the development and management of multi-disciplinary research infrastructures, it sought to facilitate translational research via tools for prospective harmonization.

P^{3}G quickly established itself as a key resource for biobanking (in particular, for large cohort biobanking), and for the genomics research community at large. The importance of P^{3}G was illustrated in a major paper in the European Journal of Human Genetics, in which the consortium and its early achievements were introduced and discussed (Knoppers et al., 2008). For instance, at the time of its inception, one of the major issues with which genomic researchers had to contend was the disparities in the type and quantity of data available (Collins et al., 2003). This was compounded by the fact that both policy compatibility between studies and the ability to compare and use data (e.g. socioeconomic status, behaviours, diet, lifestyle, etc.) were lacking, thus limiting statistical significance (Burton et al., 2009). P^{3}G began to address the harmonization of questionnaires (Fortier et al., 2010), the issues surrounding population data and access (Fortin et al., 2011), as well as the need for templates that could be used to prospectively ensure the future interoperability of large biobanks (Wallace et al., 2009).

Through the years, P^{3}G's mission has been to lead, catalyse, and coordinate international efforts and expertise relating to policy and data harmonization for studies, biobanks, research databases and other health and social research infrastructures, in order to improve the health of individuals and populations. P^{3}G's tools, support and network help the international research community to use health and social data for health care strategies aimed at disease prevention and tailored treatments. Finally, P^{3}G is committed to:

- maintaining a global vision of the scientific, technical, ethical, legal, social environmental, economic and behavioural issues;
- promoting pre-competitive data sharing whilst respecting all applicable legal and ethical obligations; and
- supporting and enabling wide access to research tools and expertise.

P^{3}G comprises over 450 individual and institutional members. It was founded on a common shared philosophy of data harmonization and sharing under a common ethical framework, as expressed in a Charter of Principles:

Charter of Principles (adopted by P^{3}G Board of Directors: March 23, 2007)
P^{3}G aspires to the highest standards of ethical comportment and research integrity. The fundamental principles that underpin its activities are:

- Promotion of the common good: P^{3}G will optimise 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 P^{3}G is based on responsibility, collaboration, co-operation, trust and mutual respect for others, which

* Corresponding author. Tel.: +1 514 398 1648.
E-mail address: souellette@p3g.org (S. Ouellette).

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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, whilst at the same time allowing and promoting the free exchange of ideas, datasharing and openness for the benefit of all.

In Phase I (2004–2012), the goal of P^{3}G was to ensure the future interoperability of large population cohorts by providing expertise and fostering interoperability. Now in Phase II (2013–), the focus of P^{3}G is on access and use of genomic research and clinical databases, so as to move towards genomic medicine and address the issues that arise during this translation.

2. P^{3}G Phase I (2004–2012) — fostering interoperability of large population cohorts

At the outset, P^{3}G created five International Working Groups (IWGs) on:

1) socio-demographic health;
2) physical/physiological/biochemical measurements;
3) storage, logistics and security;
4) governance and ethical clearance; and
5) public engagement.

The IWGs focused on the similarities and differences amongst projects; key areas of collaboration; emerging issues; next steps; and harmonization. In order to keep the community informed of their progress, the results of the IWG's findings were discussed and presented to the membership at regular meetings.

One of P^{3}G's first major achievements was the creation of the Observatory. The P^{3}G Observatory was launched at a meeting in Salt Lake City in October 2005. Its main objectives were to provide support tools for researchers in the harmonization, development, and implementation of epidemiological and genomic studies; to disseminate scientific and technical information developed and collected by P^{3}G Cores and IWGs; and to make feasible the comparison and sharing of information and data between studies. The P^{3}G Observatory quickly became a valuable tool amongst the biobanking community; not only did it contain information from worldwide, large population-based biobanks (>10,000 participants) (such that the number of cohorts listed soon amounted to over 160), but also the information gathered was also made readily available as cohorts emerged. This effectively ensured a large degree of prospective harmonization and interoperability.

The P^{3}G Catalogues in the Observatory comprised a wide range of study descriptions, and many of them also linked to questionnaires, physical/cognitive measurements, DNA analysis, etc. The Catalogues provided access to both standard and detailed information on population projects in genomics; facilitated the selection of projects by specific criteria (study design, number of cases, etc.), and expedited the generation of synthesis tables.

Through compiling such information, disparities between cohorts, the accumulated data, and different variables became readily apparent. In response, P^{3}G sought to harmonize such variables by developing tools that would ease the integration of data across biological studies (Fortier et al., 2010). In point of fact, one of these tools, DataSHaPER, demonstrated that harmonization was possible (Fortier et al., 2011) by retrospectively assessing 53 cohorts from 21 countries, which resulted in a harmonization rate of 62% of essential variables. This made possible the "virtual" aggregation of 6.9 million individuals on any of the 148 variables, thereby creating the necessary statistical significance (power).

In short, the P^{3}G Observatory provided the community with the resources, tools and know-how to perfect data management and improve methods of transfer and sharing. This result was consonant with P^{3}G's main objective — the creation of open, public and accessible datasets. P^{3}G's emphasis on transparency and collaboration not only enabled its members (and any other entity that abided by its policies, and used its tools) to enjoy horizontal access to data, but also legitimized the works of P^{3}G.

P^{3}G became a much sought-after resource for establishing ground rules and policies for the worldwide biobanking community. For instance, several tools were developed by P^{3}G and its partners to facilitate the development of population research projects, including model frameworks for the governance of biobanks, generic models of consent forms or information pamphlets, and core elements and clauses for samples and data access agreements (www.p3g.org/resources/biobank-toolkit, accessed 24 Sept. 2013).

These endeavours enabled P^{3}G members to keep abreast of new development, and to respond to community-based needs. P^{3}G subsequently engaged in the conceptualization and publication of statements. For example, P^{3}G prepared the principles for the elaboration of a data sharing code of conduct (Knoppers et al., 2011), and a policy statement framing the return of research results and incidental findings particular to population studies (Knoppers et al., 2012).

On the international scene, P^{3}G quickly established itself as a major player, able to address issues and needs. For instance, P^{3}G proposed a roadmap for biobanks to enhance data pooling, so as to ease and accelerate international collaborations (Harris et al., 2012).

3. Phase II (2013–) — promoting access and use of research and clinical databases

P^{3}G developed as a fluid and flexible organisation, able to modify its trajectory and adapt according to the needs of its community. In order to better serve the research community, P^{3}G prepared Phase II in 2012. As P^{3}G had already built a foundation for biobanks, it soon began to address the needs arising from the usage of and access to biobanks. This shift necessitated major changes in the focus, mission and structure of P^{3}G. Thus, P^{3}G changed its name to Public Population Project in Genomics and Society to better reflect the societal aims of the consortium, and its optimization of access to and use of population studies. P^{3}G also broadened its mission to include social science databases and linkage with administrative and personal health records and databases, for incorporation into societal health systems the creation of diverse research programmes with distinct platforms and a new suite of tools.

3.1. Mission

In early 2012, P^{3}G began to prepare Phase II, having achieved the critical mass needed to become the principal international body for the harmonization of public population studies in genomics and society. Structural changes and new tools were needed to meet the challenge of optimising the use of and access to biobanks and cohort studies, together with a new emphasis on integrating social science, administration, and clinical data.

3.2. Structure

P^{3}G remains governed by its Assembly of Members, and operates pursuant to its Board of Directors as a non-profit international consortium. The Board is itself composed of a Finance Sub-Committee and a Member's Sub-Committee. Scientific guidance is provided by an International Steering Committee (ISC), and the P^{3}G's secretariat works in collaboration with three research programmes to promote the realisation of research endeavours for the benefit of the entire research community (www.p3g.org/about-p3g/glance — accessed 24 Sept. 2013).

Through the years, P3G has developed and fostered relationships with many research groups that have benefited from the organisation's expertise, networks and support. In particular, in its early years, various IWCs sought to identify and keep track of trends and issues in the biobanking community. In this new phase, P3G fostered the development and activity of affiliated programmes to replace the IWCs by re-centering its support for these programmes. At present, three such research programmes are officially affiliated with P3G: the Centre of Genomics and Policy Programme; the Maelstrom Research Programme; and the P3G International Paediatric Research Platform.

The Centre of Genomics and Policy Programme (Director: Bartha M. Knoppers) includes an international policy database (www.humgen.com) and research platforms that provide ELSI toolkits and policy advice for projects, as well as templates for researchers and for ethics and access review committees. Currently, the CGP's research covers five areas of genomics and policy: procreation and reproductive genetics, paediatric health, privacy, public health, and, personalized medicine.

The Maelstrom Research Programme (Directors: Drs Isabel Fortier and Vincent Ferretti) is an epi-IT research programme that seeks to optimise the use of study data and to facilitate collaboration amongst networks or study consortia. The Maelstrom Research Programme provides the research community with methods, open-source software, and expert advice to support valid data comparison and harmonization across studies.

The P3G International Paediatric Research Programme (Director: Ellen Wright Clayton) builds a common approach to the tools and resources for the facilitation, harmonization and management of ELSI issues in international paediatric research biobanking through the international expertise of its members. Its first policy statement centred on the issue of whole genome sequencing and the return of incidental findings of medical significance considered to be in the best interests of the child (Knoppers et al., 2013a, 2013b). Similar efforts also resulted in a generic access agreement to ensure uniformity of legal and ethical access, in terms of both data and materials (Knoppers et al., 2013a, 2013b).

3.3. Services to the research community

P3G supports activities relating to meeting, events and knowledge development and transfer by promoting innovation, valorisation, and the implementation of knowledge.

3.3.1. Support for innovation — P3G meetings and events

P3G regularly organises and co-organises meetings and networking opportunities for its members. Whether stand-alone or part of a larger event, these events are always specifically tailored to specific issues, and allow for a constant re-alignment of priorities. P3G is committed to finding solutions that benefit its many partnerships. As a result, it fosters and supports collaborations with its institutional members.

For instance, following a workshop co-organised by P3G at the Brocher Foundation in Geneva, Switzerland (2011), it became clear that ELSI research in genomics had achieved global expansion over the last 20 years, and had promoted scholarship on the implications of genomic information for communities, societies, and cultures. Discussions included consideration of the scholarly needs of those around the world who study genomic issues; strategies for improving communication and collaboration across national research groups and centres; and, approaches for engaging communities, policy-makers, and patient groups in genomics and society research. The workshop concluded that there was a need to stimulate creativity, communication and collaboration on genomic research and policy. This conclusion resulted in the creation of the ELSI 2.0 Collaboratory (Kaye et al., 2012), an initiative which focuses on fostering international collaboration in ELSI genomics, in order for researchers to better assess the impact and dynamics of global genome research. To accommodate the ELSI 2.0 Collaboratory, P3G built an online workspace for all potential users that provided opportunities to be involved in and to contribute to local, regional, and international policy and practice. In 2014, ELSI 2.0 became the fourth P3G research programme.

3.3.2. Support for knowledge development — P3G HUBs

Another aspect of P3G services is the implementation of specific modules or HUBs as the need arises amongst P3G partners. A network of online agoras was created for close contact between researchers interested in discussion, exchange and collaboration. An expanded search function has been established on P3G's website, and HUBs are dedicated and designed per the specifications of the groups that wish to use them (www.p3g.org/resources/biobank-hub — accessed Sept. 24 2013). Recent developments, news and publications are updated regularly. The HUB can also include features such as discussion forums and portals for the exchange of documents and other files. HUBs are emblematic of P3G's ability to harness the expertise of its members, and thereby encourage the development of the organisation in unique ways with human-to-human connections. With its logistical aspects being managed by P3G, any HUB can provide information on research resources and prospective projects, and workspaces for online collaboration. A HUB can also include educational webinars and workshops, and can support strategic activities including reviews and meta-analyses of ELSI research and policy; development of foresight papers; rapid response action teams to advise on specific issues; international memos for identifying emerging policy issues and priorities; and modelling exercises for the construction of international frameworks and approaches.

In terms of knowledge development, P3G also hosts the Bioresource Research Impact Factor (BRIF) pilot project (Cambon-Thomsen et al., 2011). Currently set up as a pilot project within BioSHaRE.EU (Biobank Standardisation and Harmonisation for Research Excellence (FP7 European Union)), the BRIF initiative is developing a framework for creating a tool to provide a unique digital resource identifier to calculate the research impact of bioresources, and to trace citation and attribution of bioresources in research. Each cohort/collection/database used in the project can obtain a unique identifier from P3G for their bioresource; this identifier will then be used to identify the bioresource in its broadest form.

3.3.3. Support for knowledge valorisation and implementation — P3G website and the IPAC

P3G also offers support for knowledge valorisation and implementation using two main sources: the P3G website and the IPAC.

3.3.3.1. The P3G website. Perhaps the most remarkable resource that P3G offers is its website, which contains a wealth of information (www.p3g.org — accessed 24 Sept. 2013). The website, which has been completely revamped, is an easy-to-navigate compendium of tools and resources. It was redesigned with a view to the needs of biobanks and other entities involved in health and social research, and is especially suited to infrastructures that work towards improving the health of individuals and populations.

The website's main frame is divided, using an easy-to-access toolbar, into six sections, each pertaining to a different aspect of biobanking. Each resource can be used by the international research community and stakeholders, such as biobank managers, bioethicists, research/clinician teams, funders, lawyers, policymakers, groups seeking assistance in the development of biobank infrastructures, and any other party as they see fit. In addition to the HUB and the BRIF as described above, the website also offers the TOOLKIT, the LIFESPAN, the CATALOGUES and the TRAINING modules.

i) TOOLKIT
The TOOLKIT is a one-stop shop for epidemiological, ethical, statistical and IT tools for the access and use of biobanks (www.p3g.org/resources/biobank-toolkit — accessed 24 Sept. 2013). These tools include relevant websites, documents and software.

Under specific conditions, members of the community are also allowed to add their own tools to those already present and either customize the tools themselves, or ask P^{3}G to customize them.

The TOOLKIT was built from resources gleaned and/or created by P^{3}G, and aims to provide useful tools relating to studies, biobanks, research databases and other similar health and social research infrastructure. These tools are relevant at every stage of the biobank lifecycle — i.e., conception, building, use or closure of a biobank. Tools that are distantly related to biobanking are also included if they address specific needs of the community.

As with any other work-in-progress, members can suggest and propose new tools for inclusion to the P^{3}G International Steering Committee. To be considered suitable for the P^{3}G web platform, tools must satisfy the following four criteria:

- they must be relevant to studies, biobanks, research databases and other similar health and social research infrastructure aimed at improving the health of individuals and populations;
- they must be useful across different projects (i.e. tools must be standardised and useful to a large number of users);
- any website/document/software must have been recently updated; and
- they must be open access.

For ease of use, the TOOLKIT module of the P^{3}G website consists of a searchable platform through which users can not only search by specific tool name, but also select tools using different criteria in order to seek crucial, to-the-point information. These criteria include choice by category (i.e. epidemiology and biostatistics, sample collection and processing, data collection and processing, ELSI, etc.), and/or type of tool (i.e. documents vs. software vs. websites). The user also has the option of narrowing his or her search, thereby limiting results to P^{3}G-developed tools.

The TOOLKIT was designed to simplify the search for relevant tools for the biobank community. As P^{3}G continues to test and survey the needs of website users, several components of the TOOLKIT will become increasingly interactive.

ii) LIFESPAN

The biobank LIFESPAN module provides an open access web module offering users a step-by-step approach to the development and maintenance of biobanks; this module is a complete map of the biobank lifecycle, from building and maintenance, to use and closure. Appropriate tools were identified and mapped onto the biobank lifecycle (www.p3g.org/resources/biobank-lifespan — accessed Sept. 24 2013).

Tools are assigned in chronological order of use, considering the four different phases of the biobank lifecycle:

1 — conceptualization and design of biobanks: this first phase includes planning, design and creation, and provides governance tools, funding mechanisms, ethics tools, and public engagement tools;
2 — construction of biobanks: this phase is the most intensive in a biobank's lifespan, as it consists of set-up and operations (data collection and handling, questionnaires, physical and cognitive measures, software and IT tools, consent tools, and privacy tools);
3 — biobank usage: this third phase is the essence of biobanking it concerns how data is used and accessed (data analysis tools, harmonization tools, biostatistics tools, data access policies and procedures, intellectual property management, return of results tools, and public communication of research); and
4 — biobank closure: this phase is the decommissioning phase, which occurs once the resource has reached its conclusion (seeking approvals and other such implications).

At each of these phases, users are offered a variety of 'Steps' that link to relevant tools (documents, software and/or websites) to better orient their activities, as well as a chart of 'Tasks and Needs', that was developed by P^{3}G experts.

iii) CATALOGUES

The P^{3}G Partner CATALOGUES provide easy access to information about large population-based biobanks (www.p3g.org/resources/biobank-catalogues — accessed 24 Sept. 2013). They describe, index and present information about various technical aspects of studies; their aim is to support the development and harmonization of epidemiological projects in genomics by providing an overview of a range of biobanking aspects.

The P^{3}G Catalogues contain information obtained by P^{3}G during data collection, via websites and other open access resources, or compiled following close interaction with the partner team that set up each of the given research studies. The study description is constantly updated as the research project develops, with information supplied by relevant resources. In addition to a study description, complementary elements are often also made available, such as:

1 — Questionnaire Catalogue, including reference questionnaires from large population-based studies; these aim to facilitate the development and harmonization of questionnaires. The catalogue gives access to questionnaires administered at the recruitment of the participant; their methods of administration; and an overview of the similarities and differences of the information;
2 — Physical and Cognitive Measures Catalogue, providing an overview of the physical and cognitive measures;
3 — DNA Processing Catalogue, offering an overview from sample storage to DNA quality control including DNA storage and extraction; and
4 — Access Catalogue, which provides an overview of information relating to access of study data and samples.

The Catalogues have proven very useful to many stakeholders in the research community; the wide-ranging database of resources can provide highly valued information to be applied to a variety of different projects. This suite of catalogues is at the core of the P^{3}G mission, as it constitutes a solid scientific foundation on which the members and partners can rely.

iv) TRAINING

The TRAINING module links users to tutorials and information sessions on how to use the P^{3}G website, as well as specific tools (www.p3g.org/resources/biobank-training — accessed 24 Sept. 2013).

With a view to complementing and enhancing the TOOLKIT and the LIFESPAN modules, the TRAINING module accompanies the user in the learning process via contact with experts. This can take many different forms, such as web tutorials/webcasts or expert mentoring.

3.3.3.2. Promoting access and use: the International Policy interoperability and data Access Clearinghouse (IPAC). In order to complement P^{3}G's Phase II objectives, in particular the facilitation of access to and effective utilization of the data and samples that exist in large cohorts, P^{3}G has developed new services to meet the changing needs of the research community.

The International Policy interoperability and data Access Clearinghouse (IPAC) (www.p3g.org/ipac — accessed Sept. 24 2013) is a collaboration between P^{3}G and the Centre of Genomics and Policy (CGP) at McGill University, whereby expertise services for ELSI screening and data access compliance will be offered to researchers/consortia/industry and biobanks. The goal is to provide a "one stop" screening service for policy interoperability and access authorization so as to support, coordinate, and, facilitate access and use of research data. One of the first

examples of the services that can be offered is a generic access agreement prepared by P^{3}G's International Scientific Committee. It seeks to ensure uniformity of legal and ethical access, in terms of both data and materials.

Both policy interoperability and access authorization to data require the development of policies and procedures and the examination of conformity of requests with national laws. Also, narrow consent and the failure to notify research participants of possible or eventual commercialization and international datasharing can block actual and future collaboration. Legacy collections that seemingly fail to meet modern ethics requirements are not used. The creation of the IPAC will be the first step to fostering and facilitating data sharing via international interoperability mechanisms. It would also raise levels of assurance and accountability. As an independent, third-party access broker with requisite expertise, credibility and international legitimacy, IPAC will provide an "ethical safe harbour" environment by authorizing requests for access in accordance with harmonized principles and tools. The added value of IPAC's intervention as both a policy interoperability tool provider and an intermediary data access broker would be to alleviate resistance to data sharing, promote interoperability, and facilitate preparation for successful ethics/privacy/access review, thereby reducing unnecessary bureaucracy and delays. IPAC proposes a range of services in four languages (English, French, Spanish and Arabic):

1 — policy interoperability services such as international comparative analysis of consents (legacy collections); preparation of policies and consents for de novo projects or preparation of templates for customized access agreements; and preparation of international codes of conduct, policies and procedures, ongoing monitoring and governance mechanisms;
2 — access services that include the review of data and samples access request/authorization and compliance e.g. creation of a project-personalized Data Access Compliance Office ("DACO"); reception and review of applications for access to controlled datasets, in conformity with the goals and policies of the project; development or assessment for prospective and retrospective harmonization; and serving as the depository, ensuring the confidentiality of paper copies of applications/confidentiality agreements and other DACO material of sensitive nature.

4. Conclusion

As its mission and range of activities expand, P^{3}G will continue to keep abreast of developments in the global world of biobanking and related aspects to evolve and redefine itself. As P^{3}G embarks on collaborations with a wider range of projects, including the nascent Global Alliance for Genomics and Health (http://www.humanvariomeproject.org/index.php/news/237-a-global-alliance-to-enable-responsible-sharing-of-genomic-and-clinical-data — accessed 17 November 2013), the consortium and its secretariat continue to be an enabler and provider of services at the very heart of international genetic research. P^{3}G will endeavour to lead, catalyse, and coordinate international efforts and expertise to optimise the use of studies, biobanks, research databases and other similar health and social research infrastructure with a view to improving the health of individuals and populations and easing the translation to clinical research.

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