



Science Activities and Updates

Observatory 9
DataSHaPER 9
Workshop 9
Core Funding Update 10
Member Updates 11
Summer School 13
Conferences 14
Collaborations 14

Features

Global Biobanking: Voices from around the World 2
IBBL Interview with Patrizia Luchetta 7

Events

Brussels March 2009 14
Québec City April 2010 15
Luxembourg Agenda September 2009 16

From the P3G Desk

Last May, P3G celebrated its fifth anniversary! Since our incorporation, P3G has grown to include 278 members from over 40 countries, including 28 Charter Members (and we're still growing). We are looking forward to welcoming India's Institute of Genomics and Integrative Biology as the newest Charter Member this September.

Since our launch as an international consortium dedicated to supporting emerging and existing biobanks, and providing tools for the harmonization of data and samples for pooling between researchers working in the area of population-based genomics, we have brought together hundreds of international biobanking experts. P3G's free, open-access Observatory website of tools and resources related to biobanking has expanded to include 12 networks and 138 studies from all over the world and several comprehensive tools such as the DataSchema. P3G's commitment to information shar-

ing between biobankers around the world has been a huge success. It has benefited scientists and ethicists thanks to the direct involvement and generosity from members and other dedicated researchers around the world. We look forward to many more years facilitating collabora-

tions and finding innovative ways of promoting harmonization. In this issue, we are delighted to introduce a new feature entitled Global Biobanking: Voices from around the World that takes a closer look at the people, regions and issues in biobanking and genomics that often go underreported. In the first of this series, we speak to Dr. Jamal Rahman of The Malaysia Cohort, Dr. Meral Ozcug from Turkey and Professor Mârcia Santana Fernandes of Brazil. In upcoming issues, you can look forward to reading more in-depth biobank profiles and issues-related articles.

Also in this issue, we look at recent and upcoming P3G meetings and events, including the March 2009 Brussels gathering, the September meeting in Luxembourg, and a peek at the 2010 meeting in Québec City. We also have a report on the first P3G-Wellcome Trust Summer School that took place in July.

The upcoming Luxembourg meeting is a highlight for all our members, and we've included the full agenda. In a related interview with Patrizia Luchetta, Deputy Director of Luxembourg's Board of Economic Development, we take a look at how the Integrated Biobank of Luxembourg (IBBL) got off the ground.

All the regular features are still here, including member updates, updates on our scientific activities, and more.

We enjoy hearing from you and invite you to send us your thoughts, feedback and ideas. Email us at secretariat@p3g.org. We look forward to seeing you at the next P3G Event!



The P3G video launched earlier this year at the Brussels meeting is now available in English, French and Spanish and can be viewed on our website.

All the best,

The P3G team in Canada

Introduction

Welcome to a new P³G newsletter feature that shines a spotlight on a broad range of biobanking experiences and issues around the world. We hope this feature will familiarize the community with the successes and challenges faced by different biobanks – and, perhaps, identify opportunities for the community to connect.

In this issue, we spotlight three very different voices in biobanking: Dr. Rahman Jamal who has been heading a study of 100,000 participants with The Malaysian Cohort; Dr. M^árcia Santana Fernandes who is working on the development of legal and ethical standards for biobanking in Brazil's Hospital de

Clinicas de Porto Alegre; and Dr. Meral Ozguc of Turkey's Hacettepe University, who has been leveraging her position on the Turkish National Executive Committee of UNESCO's Bioethics Committee to implement more stringent consent procedures as well as identify international collaborations. <<<

The Malaysian Cohort

with Professor Rahman A. Jamal

Professor Rahman A. Jamal is a professor of pediatric hematology, oncology and molecular biology at the Faculty of Medicine, Universiti Kebangsaan Malaysia (UKM). He is currently the Director of the UKM Medical Molecular Biology Institute (UMBI) and is project leader for The Malaysian Cohort.

Launched in 2003, the UKM Medical Molecular Biology Institute (UMBI) was a modest laboratory that has since grown to accommodate equipment that supports research in genomics, transcriptomics and proteomics. UMBI now leads three national initiatives including the Malaysia Cohort project, the Space Science programme, and the Cancer Epigenome project.

Can you describe the kinds of challenges you faced setting up your study?

One of our biggest challenges was trying to find a way to preserve the integrity of the biospecimens given we are in a tropical climate and would be travelling to some very

remote areas, and sometimes with limited access to electricity. When we started, there weren't many guidelines or SOPs on how to manage biospecimens in tropical climates as most of the larger biobanks are working in more temperate or colder climates. So we were innovative in devising ways to ensure our samples reached our processing centre within 24 hours, at a temperature that would keep the samples from degrading.

We built a customized mobile lab with coolers where we can store the samples until we can get them to our central storage facility. Unlike most western European biobanks, we don't use commercial courier services. Instead, we have our own fleet of transport vehicles – as it's less expensive and faster.

Can you describe how you got your funding?

We were lucky because the Malaysian government was fully supportive of the project and our request for the first five years of funding was approved very quickly. We are now working on securing funding for the next five years which, in light of the

economic recession, is a bit more challenging. So we will have to work harder to justify the project by showing the results of the project so far.

How do you anticipate it will go?

I think we have a good chance because this is the first time a project this big has been attempted, as well as looking at the broader issues of gene and biomarker discovery for early detection of various diseases. Our study protocols have allowed us to obtain comprehensive data from our participants on diet, lifestyle and physical activity, but we have also been very successful in collecting biospecimens which is extremely important. We believe that with a study this size and with this many samples, it is a way to put Malaysia on the global map. Another benefit of building such a large study is that it gets the attention of researchers around the world, so we have been able to benefit from a lot of international collaborators.

For example, we are one of the members of the Asia Cohort Consortium initiated by the Fred Hutchinson Cancer Research Center under

Professor John Porter. As we are the most recent entry into the consortium, we have benefited from the expert advice and protocols. We have been able to select the best approach, work with protocols established by older members of the consortium and learn from mistakes, while coming up with innovative ways to meet our challenges. One example is how we've implemented a paperless e-questionnaire as well as an electronic quality control system. We verify and validate every questionnaire against an MP3 recording of the interview. This is done by a dedicated team of trained personnel. The questionnaires themselves are downloaded onto a laptop computer with touch screen features. There are also pop-up windows with data definitions that the interviewer may not be familiar with. We found that our quality control system was a very successful way to catch data-entry errors made during the interview process.

How far along are you in the recruitment process of 100,000 people?

We passed the 32,000 mark and we are ahead of schedule by a year. We are recruiting at a rate of 100-120 people per day and are on track to recruit 50,000 by June 2010 and expect to have the complete 100,000 by September 2012.

How have you been managing recruitment since you launched the study?

We had some problems at the beginning with long waiting-lines of recruits, so we took a step back to see how we could relieve the bottle neck and minimize waiting times. We added more staff, bought more biophysical measurement equipment, simulated the recruitment process on a computer, and fine-tuned the process so that participants would leave our recruitment centres feeling like they got what they wanted and be willing to participate when we called them for follow-ups.

How have you gone about publicizing for recruits?

We have a dedicated and very organized team. They go out to pre-selected communities to meet and work with community leaders. Then we hold information sessions at local community and shopping centres where potential participants are briefed about the project and can volunteer to participate. Appointments are scheduled with phone calls made prior to the appointment to ensure they are still interested. When the recruits arrive at the remote sites we review the information sheet and complete the forms. At the main recruitment centre, we reach out mainly to an urban population. We hang posters and

hold information sessions there and at hospitals. Two particularly effective publicity efforts have been a free information phone line as well as word-of-mouth from those previously recruited.

How have you addressed concerns about privacy?

We anticipated that, but so far we haven't really faced that kind of problem in Malaysia. I think that on this side of the world people are quite happy to help. We explain that their blood will be stored and that further genetic testing will be done. They are also interested in getting screened and getting the results of their screenings because we offer a full roster of tests, including cholesterol, blood sugar, blood pressure, BMI, electrocardiogram and lung function tests. The recruits know it's not a full medical check-up, but when there is something out of the ordinary that might appear we will advise them to follow-up with their doctor. We used multi-layered informed consent from each participant at recruitment. This includes participation in the interview, the biophysical examination, the biospecimen collection and future research. Participants can give approval for one or a combination of those four aspects. So far, all our recruits have agreed to participate at all levels. <<<

FEATURE >>> Global Biobanking: Voices from around the World

The DNA/Cell Bank in Ankara, Turkey

with Professor Meral Ozguc

Professor Meral Ozguc

is based at the Hacettepe University, Faculty of Medicine, Department of Medical Biology, Ankara, Turkey.

In 1995, the Technology Development Fund of Turkey set up the DNA/Cell Bank in Ankara, Tur-

key with a World Bank grant. The Biobank was established to create a biological resource centre and database for rare genetic disorder in support of biomedical research. It was later funded by the Scientific and Technical Research Council of Turkey (TUBITAK) until 2006

as is presently under the administration of the Faculty of Medicine Hacettepe University. The biobank repository is used to map new disease genes and association studies, the development of new genetic tests, and contributes to functional studies through its cell and tissue collections.

How has the biobank progressed since its launch?

We have collected over 20,000 samples from approximately 6,000 families. There has been an increase in volume and we recently expanded with an entire floor and new laboratory in the medical school dedicated to the DNA bank. We have also secured two full-time biologists responsible for collection, DNA isolation and quality assurance.

We are looking at increasing our capacity for cryo-preservation with a state planning agency grant that we hope will come through in 2010. At the moment we have potential for 180,000 for minus 80, and over 10,000 for liquid nitrogen. Our initial scientific policy was to focus on rare disorders – which are actually not so rare in Turkey. We have a 21 % consanguinity rate in the general population, which makes rare genetic disorders appear at a higher frequency than in western countries. Turkey’s social structure of large families with longer child-bearing periods creates a high number of siblings and the cohabitation of multiple generations. These aspects make it valuable for family collections with rare diseases where, in particular, homozygosity mapping can be employed to look for new disease genes. We do have plans

to collaborate in the collection for common disorders with the Medical Genetics Department, but that will likely be after we have established a new grant for the bank.

Where is Turkey in developing its regulations?

Research on human subjects is regulated by various international guidelines such as WMA Helsinki Declaration, the OVIEDO Convention on Human Rights and Biomedicine, which Turkey ratified. The Turkish penal code – which was amended in 2004 – also contains clauses on this subject. While there is no specific law on biobanking yet, the Ministry of Health has established mandates for local ethics committees to oversee all research involving human subjects. Accordingly, new applications for an ethical review must be submitted if the biobank samples will be used for a new project.

What have been the challenges?

We face several challenges; the first was getting an understanding that if we call something a biobank, regulations have to be set and followed on sample collection, quality-assurance

and the length of time the samples could be kept in the bank. Also, we have been addressing a situation where people who conduct routine analysis were referring to themselves as biobanks, which can be very mis-

leading. So we’ve been working on creating awareness that samples obtained without consent are not to be regarded as biobank specimens.

I have been able to leverage my experience as a member of the Bioethics Committee of the UNESCO National Commission to talk to people, give lectures and organize meetings on how to build a biobank with an emphasis on informed consent. And while we don’t yet have a national biobanking law we are proceeding at a good pace in areas related to ethical guidance.

Another challenge is that we cannot recruit samples at the biobank – only clinicians who see patients can obtain and deposit them. (We don’t charge for the deposit or the processing of the samples.) This creates a question of proprietary rights: Is it the bank or the clinicians who own the samples? This is important because we have to ensure agreement among the stakeholders on the format of a project using the samples. On the other hand, the involvement of the clinicians is an advantage because we have all the personal and clinical data from the patients and which is encoded at the bank.

If someone wants to use the deposits in the bank, I have to go to the patients and the clinicians for consent. It’s not like in a private bank where one can say, “This is our DNA.” It is always the clinician who has to give us permission for the use of biological material.

Finally, we face certain challenges in international collaborations. We have devised material transfer agreements, as we must get official agreement between institutes about the format of a project before I can get the signatures to send out our samples.

Is it easy for the clinicians to gather samples?

They don’t have that much difficulty because, sociologically speaking, people in Turkey trust in medical doctors. When families understand that their contribution will help in diagnosis, as well as benefit future

“I have been able to leverage my experience as a member of the Bioethics Committee of the UNESCO National Commission to talk to people, give lectures and organize meetings on how to build a biobank with an emphasis on informed consent.”
– Professor Meral Ozguc

generations and in finding new therapies, they are quite collaborative.

Are you affiliated with other biobanks?

At the local level, we received a grant (2006-2008) from a state planning organization to create a network for rare disease collections in Turkey. We have also been trying to become part of some European projects. We see this as a way to facilitate our efforts in developing new guidelines, especially for over-the-border use of samples. We will learn a lot from collaborating and how people share samples, etc. But it has not been easy as biobanks are usually set-up for common disorders research.

We are a collaborating partner in a European project coordinated by the National Center for Rare Diseases Italy; EUROPLAN (European Project for Rare Diseases National Plan Development – Program of Community Action – Public Health). This project started in April 2008 and will continue for three years. It will allow us to review our policies, which will also involve biobanking and we will be in close collaboration with the Ministry of Health. This may be a good vehicle for the establishment of normative actions that may eventually lead us more easily into collections from healthy population samples.

Is that one of the reasons you're looking at broadening the scope of your studies?

Yes. Now that we have been successful in using the rare-disorder depository for identification of new genes and single-gene disorders are excellent models to build on for the molecular pathologies of common disorders. As a part of the Mediterranean region, Turkey would be an interesting population to study in terms of common disorders. However, we need to learn much more about how to organize and implement follow-up, and so on. That's why we want to become part of a collaborative biobanking project. <<<

FEATURE >>> Global Biobanking: Voices from around the World

Hospital de Clinicas de Porto Alegre, Brazil

with Professor Márcia Santana Fernandes

Professor Márcia Santana Fernandes is a Law professor and post-doctoral fellow in Bioethics and Science Ethics at the Research Laboratory of Hospital de Clinicas de Porto Alegre.

What is the biobanking situation in Brazil?

Presently, there are numerous biorepositories throughout Brazil. Sample collection is being done for research projects and those projects must get approval from the ethical committee of the research institution. Most are individual research projects, but the materials are not shared between researchers of different projects. There are some cancer study initiatives in São Paulo, such as Hospital A.C. Camargo, about which we can talk about biobanking properly. In genetic studies, some samples have been collected for clinical purposes, but there is no national research project coordinated by the government. It is something we are trying to address. There are some concerns regarding the protection of the ethnic populations, indigenous people and other communities. In this area, there are some individual gene-related projects such as a multi-disciplinary study on indigenous populations led by doctor Francisco Mauro Solzano but these projects are not administered by the federal government. We are really at the beginning of that road. We are trying to verify what has already been collected because, while local ethical committees know what's in storage, some of the hospitals don't really know. It's not centralized.

What is HCPA and what is its connection to biobanking in Brazil?

Hospital de Clinicas de Porto Alegre (HCPA) is a public teaching hospital in southern Brazil that is indirectly affiliated with the federally-run University of Brazil. HCPA is also the coordinating institution of the National Network of Clinical Research and hosts four of Brazil's national science and technol-

ogy institutes in population genetics, women's endocrinology, translational medicine, and health. HCPA facilities currently host at least 13 different biological sample repositories connected to clinical research trials and collaborative research networks.

With such a diverse population spread out across such a large territory, the HCPA is looking to develop a solid and more centralized foundation that will standardize some aspects of population-based genomics research. Our advantage is that we have an institutional willingness to do it and to do it right. We also have 20 years of experience and an organized patient database that has maintained questionnaires and clinician notes, and all our research is digitized and well-protected for privacy.

How are biobanking activities regulated in Brazil?

Currently, there is no legal framework for the implementation and maintenance of biobanks in Brazil,

although storage of biological samples is regulated by two documents: (1) guidelines from the National Health Council, which contain minimal regulatory information about the maintenance of research sample repositories, and (2) a resolution from the National Health Surveillance Agency which specifically regulates the technical and ethical aspects of cell and tissue biobanks only. Detailed standard operating procedures (SOPs) and guidelines for sample collection, transport, annotation, storage, retrieval and distribution are not available.

While our biobank project is used for clinical research and is not population-based, we have been working to establish an institutional biobank that incorporates best practices, and which could positively influence other public health care institutions in Brazil – either by example or, preferably, through the introduction of federal laws. Accordingly, we are addressing aspects such as informed consent procedures, IP regulations, how to manage the sharing of samples within Brazil and abroad, etc.

How have you gone about doing this?

We’ve established a broad task-force that includes researchers, physicians, pathologists, biologists, bioethicists, engineers, managers, lawyers, geneticists, epidemiologists, nurses and patient advocates. We also set up a focus group to formulate institutional guidelines for biobanking activities in clinical and

basic research, as well as healthcare, and which could be adapted by other public hospitals and institutions affiliated with the National Clinical

Research Network. We are also working with Brazil’s Ministry of Health to work out norms for the whole country.

Our group drafted preliminary biobank norms to protect and annotate human biological materials, including DNA, tumors and others biological samples, including clinical information contained in patient medical records. We consulted national and international norms and regulatory issues in preparing this draft, which includes SOPs for specific technical, ethical and legal issues. The draft is undergoing evaluation by the HCPA Research Ethics Commit-

tee. Our working group will also be proposing the establishment of federal regulations in the set up and maintenance of integrated research biobanks in Brazil.

How is it working with people from so many different fields and perspectives?

Our group is amazing. Usually, it’s not very easy to work in an interdisciplinary environment but we are so willing to get it right so we try to understand each other. While I am coordinating the writing of the norms, it’s very interesting to have someone like a geneticist or pathologist nearby because they offer a different perspective. I incorporate their points with my legal expertise and the ethical aspects. It does require patience as sometimes they

have to explain things which are very basic to them but for which I require a detailed explanation.

How has HCPA addressed issues of consent?

Our lab has been studying this subject for almost 15 years. And since we began collecting biobspecimens in 1990, we have taken care as to how we ask people to donate their biomaterials for research. All human biospecimen research conducted at HCPA first must be approved by our ethics committee. As informed consent is a priority here, we are committed to making it clear and addressing issues of legal or psychological incompetence. We contact and re-contact should we need to reuse materials. We make every effort to ensure donors are aware that they can withdraw their consent at any time. We have begun a large study about coercion and how the consent process can be coercive, and in what situations. We want to determine the degree of autonomy patients have when they consent. We know that in many situations patients don’t really have full autonomy and that the freedom to say yes or no can be relative. We are working on three projects in that area including projects focusing on children, the elderly and women. Also, we would like to verify how researchers feel when asking patients if they can use their samples. These studies are helping us as we build our own norms. We’ve drafted 37 articles so far and expect to be finished by the end of September.

How committed is the government?

The Brazilian government is very involved. The Ministries of Technology and Education have provided financial support through the National Council of Technological and Scientific Development and the Coordination of Improvement of Higher Education. Some large institutions are benefitting from federal money – not for biobanking so far but for individual projects. Our hope is that they will draw on our work in the introduction of federal regulations. <<<

“Our group is amazing. Usually, it’s not very easy to work in an interdisciplinary environment but we are so willing to get it right so we try to understand each other.”
– Prof. Márcia Santana Fernandes

FEATURE >>> Profile

The Integrated Biobank of Luxembourg

with Patrizia Luchetta

What does it take to get a biobank off the ground and how do you stand apart from what's already out there? In this interview with Patrizia Luchetta, Deputy Director of Luxembourg's Board of Economic Development, we find out that a challenge from the EU can inspire vision, strategic planning, and broad collaboration to bring a successful biobank to the fore.

The Integrated BioBank of Luxembourg (IBBL) was conceived following a challenge issued in the Lisbon Strategy that asked EU member countries to find ways to become the most dynamic and competitive knowledge-based economy in the world.

What was the driver behind Luxembourg decision to launch a biobank?

In 2004, Luxembourg decided to look into medical biotechnology to see if we could carve out a niche. As Luxembourg doesn't have a pharma industry and our research institutions and university are relatively young we wanted to find out if we could play a role in that area. So we first asked ourselves, "Do we stand any chance?"

Then in 2007, a couple of studies came out that inspired the Luxembourg ministers of Economy, Research, and Health to get together and adopt a strategic approach that looked specifically at niche areas where there was some activity but where, if we did something, we wouldn't run the risk of duplication. They determined that molecular diagnostics was the way to go as it is heavily reliant on well-documented and well-preserved samples and is,

to a certain extent, revolutionizing the pharma industry with companion diagnostics. They also recognized that there are researchers and pharmas in need of good samples, especially tissue, and while there are a lot of bio-repositories in Europe, most belong to universities or research institutes, so the samples are not accessible to outside partners. In addition – and as has been discussed in meetings like P³G and BBMRI – in the past, patients had not provided proper consent because the samples being used were for the research purposes of the institutions. Another problem has been that corresponding clinical data are not available, or the samples have not been



Patrizia Luchetta

stored under ideal conditions. And that's how we came to the decision to open a biobank. The next question was "If we open a biobank, in what context will it exist?"

Within the strategic proposal, T-Gen in Phoenix expressed interest in helping us build a state-of-the-art biobank that would be open for research institutions and pharma

around the world. In addition, there were other compelling opportunities that met our overall initiative objectives, including a research project on lung cancer that needed samples, and another research project looking at setting up a centre with the Institute for Systems Biology (ISB) that would also need samples. We then saw that our new biobank would be able to provide the necessary samples which would make it a sort of pilot project and which would also help to kick-start attraction from other projects.

Did you intentionally seek out American collaborators?

I wouldn't say that it was intentional. One of our requirements was that we were looking for strategic partners following a 2006 OECD review of Luxembourg's innovation system. There was a recommendation to identify three areas of excellence where we would want to grow and then arrange strategic partnerships with institutes or industries outside Luxembourg. The reasoning was that we could grow more quickly with external partners than if we tried to do it all indigenously.

In addition, we knew that we might not be able to attract researchers if we didn't have a project that had some credibility, as money is not enough. These are people who have careers and who want to participate in state-of-the-art projects, so in talking specifically about biomedical sciences we knew we had to find people who were prepared to work and grow with us, and contribute to knowledge transfer. It just so happened these three Americans who, for reasons which were meaningful to them, too, were prepared to work with a "junior" partner and build something together. As

it happened, at least two of these partners, T-Gen and ISB, also had strong proven track records in translational medicine in terms of applying research projects to medicine – which we were looking for – and were interested in commercializing the research results.

“One of our requirements was that we were looking for strategic partners following a 2006 OECD review of Luxembourg’s innovation system. There was a recommendation to identify three areas of excellence where we would want to grow and then arrange strategic partnerships with institutes or industries outside Luxembourg.”

– Patrizia Luchetta

This was important to us because while the government was ready to put money into it, we really needed to be able to prove the value to the economy at large. This kind of valorizing or translating research into commercial opportunities is probably stronger in the U.S. than it is in Europe presently.

How does that balance with the not-for-profit aspect?

The legal entity of the biobank is not-for-profit, which doesn’t mean we won’t charge, but it is not a commercial company. The biobank will provide services and will, of course, be paid for those services, at least to the extent of covering our costs. There are a lot of bioethical issues around biobanking and patient consent and we felt that by being a not-for-profit entity – and where the ministry of health is represented on the board – we could offer greater credibility to people who want to work with us.

This means IBBL will be paid enough to cover costs for whatever it provides if it works for other public reserve centres. In the case of pharma, we will charge higher costs, but the aim is not to make a profit. We will never be able to cover all our costs, but whatever money we will be able to make from our activities will be directly reinvested into machines and making our services better.

What makes IBBL unique?

Usually biobanks are disease-based or population-based. IBBL has the mission of providing both services. While there is a strong focus on disease-based because it started with oncology, our project with Dr. Leroy Hood and ISB will require samples from healthy populations and will be followed over time. Within that context, there is a challenging of the notion of the distinction between population- and disease-based research because the farther one goes with the concept of personalized medicine, at the end of the day each person becomes its own control. If we go farther and say that everyone is unique, the groups become so small that one cannot compare a whole population in a way

that gives a rough breakdown. The individual patient has to be examined because, for example, we know that some patients will respond to one form of chemotherapy, whereas others will not, so the concept of a clear-cut distinction between disease- and population-based is fading. As a biobank that started in this interesting period of time, we would like to head in new directions.

Do you have to manage donor expectations for any results that may be found?

We are still discussing it, but at this time and from a regulatory framework, our stance is that the results will not be given. Samples will be coded so researchers are able to go back if need be, because if you want to collect clinical data about people, you need to have some kind of link, but generally speaking, results will not go back to patients.

How have you communicated the establishment of IBBL to Luxembourgers?

The process started before launching the project by getting the medical community and ethical boards outside. The management of IBBL is putting a communications strategy in place to work with patients-at-large, associations like the cancer foundation and individual medical doctors outside hospitals. It’s a very important aspect not only so that we can get patients and donors, but because we want to be a portal for people to find out what is happening with samples overall and what researchers are doing with the biological samples.

Do you see IBBL as being accessible to or mentoring emerging biobanks?

I’d be happy if we reached that stage. We are actively participating in this initiative in Europe and with BBMRI. I hope we will be able to benefit from biobanks in that network and share our experience as a new biobank that started from scratch but which has also had the advantage that we haven’t had to cope with existing situations. <<<

Science Activities & Updates

Observatory

Partner Catalogues
BBMRI
CPT project
INGI
Diabetes Biobank
Renal Biobank



DataSHaPER has undergone some significant improvements. An ontological approach was implemented for the DataSchemas and a new web interface has been developed (www.datashaper.org). Both the Generic DataSchema and the CPT DataSchema have been adapted into an ontological structure that should increase potential compatibility with other projects and models.

Comparison Charts are now centralized in the Repository of the P³G Comparison Charts at <http://www.p3gobservatory.org/repository/comparisonCharts.htm>. Four new charts have been added, giving access to a larger set of domains of interest.

Partner Catalogues A separate section has been built on the Observatory that houses partner study catalogues, making it easier to access them. Three new partner catalogues have been added, bringing the total to five. <<<

Catalogues	Updates
Network	12 networks
Partner Network Catalogues of Studies	BBMRI: 54 studies CPT Project: 5 studies INGI (Isolated population): 2 studies Renal Biobank: 12 studies Diabetes biobank: 1 study
Study	138 studies (65 with summary information / 72 with Complete information validated by study investigators)
Questionnaire	33 Questionnaires from 21 studies
Physical and Cognitive Measures	25 studies
DNA Processing	17 studies
Ethics and Governance	5 studies
Information Technologies	11 studies

Science Activities & Updates

DataSHaPER Workshop

The most recent DataSHaPER Workshop was held in Edinburgh, Scotland on May 11 – 14, 2009. Presented by the Public Population Project in Genomics (P³G), PHOEBE (Promoting Harmonization of Epidemiological Biobanks in Europe) and the Generation Scotland Project, the workshop focused on two aspects of biobank harmonization: calibration of variables and data-pooling across biobanks. The objective of the workshop was two-fold: develop an action plan

for conducting future calibration studies, and begin the development of a new “DataSchema” focusing on obesity, including the selection of variables and preparation of an action plan for real data-pooling using a subset of cohorts.

The workshop was divided into two parts – the first two days exam-

ined the key scientific and practical challenges of calibration, including statistical models for calibration, exposure domains to be considered for calibration sub-studies, and potential study designs. The last two days were allocated for discussions about current and future DataSHaPER activities, specific-

ally opportunities and challenges related to the development of a new DataSchema focusing on the diseases, phenotypes and exposures associated with obesity. The discussion considered the key scientific and practical questions relevant to potential pooling of obesity-related data across cohorts. <<<

Science Activities & Updates

Core Funding Update

A one-time Core Financing Program was established to support P³G Cores to get through the final stages of their projects so that they may be disseminated in a joint P³G publication or on the P³G Observatory. The grant offered up to CDN \$5000. All three proposals, including one joint proposal, were accepted.

Centre for Integrated Genomic Medical Research

Principal Investigators Erich Wichmann, Bill Ollier and Martin Yuille

The Project “DNA Quantity and Quality”

Project Description A pilot study with 13 participants to establish the feasibility of comparing different biobank estimates of DNA concentration made on the same source of DNA. The pilot provided evidence that both academic and commercial labs would participate. It also provided the first experimental evidence supporting anecdotal variation in the consistency of DNA concentration estimation.

How the Grant Will Be Used Advance from the pilot stage to a larger scale study of this variation. An earlier attempt to do this resulted in a poor response by potential participants when we included a cost-recovery element in the plan of work. Support from P³G will allow us to exclude a cost-recovery element. We believe this will ensure participation by many biobanks. Eighty-two participants have been recruited.

The proposed study comprises the following steps

- 1** Extraction of DNA from volunteered blood and estimation of its concentration.
- 2** Dilution and distribution of DNA into 96-well plates. Dispatch to participants.
- 3** DNA concentration estimation and return of data and protocols by participants.
- 4** Data analysis. This may provide evidence on factors that minimize variation is estimation.

How Conclusions Will Be Shared

- 1** Invite participation by P³G members.
- 2** Report results to P³G in general and IWG1 in particular.
- 3** Submit results for publication in a refereed journal.

Data Sharing in Genomics (ELSI Issues)

Principal Investigator Dr. Jane Kaye, Wellcome Trust Research Fellow, Ethox Centre, University of Oxford; Director of the Research Programme in Law, Health and Emerging Technologies,

Collaborators Dr. Paula Boddington, Dr. Cate Heeney, Dr. Nadja Kanellopoulou, Dr. Karen Melham, Jantina De Vries, Naomi Hawkins, Liam Curren

The Project Explore the ethical, legal and social issues surrounding data-sharing between biobanks Research Programme in Law, Health and Emerging Technologies, Ethox Centre, University of Oxford.

As part of the Law, Health and Emerging Technologies research programme located in the Ethox Centre, our research is focussed on issues raised by data-sharing at a global level between biobanks and within large collaborative projects, and which may create and use repositories of information. Of particular interest, is the use of GWAS and moving to next generation sequencing, and the twist that the use of these methodologies gives to perennial issues such as feedback.

How the Grant Will be Used To fund a research assistant to help complete work on papers to be delivered over the next 6 - 12 months. Our research will use legal and ethical analytical tools, draw on sociological approaches and some of our findings from our empirical research in the Governing Genetic Databases Project (2006-9) as well as our on-going work in the ADLS, ENCORE, PROCARDIS and MALARIAGEN projects. Examples of some of the issues we will explore include:

- 1 How biobanks will be acknowledged in publications;
- 2 Protecting the privacy of participants using GWAS technology;
- 3 Consent for data sharing;
- 4 Whether to give feedback on incidental findings;
- 5 The development of appropriate governance mechanisms regarding access to biobanks;
- 6 The challenges faced by global research for national legal and regulatory frameworks;
- 7 The tension between data sharing and IP protection and how we develop appropriate structures and partnerships for translation, and;
- 8 The issues that emerge when collaborative projects are carried out in developing countries

Funding will allow us to focus on these issues, write them up, and test some of our findings and analysis within the international forum of biobanking.

How Conclusions Will Be Shared Our aim is to publish a number of papers, with the intention that this work could form a basis for the development of tools within P³G. We will organize an international conference in Oxford in June 2010 which will focus on Data Sharing in Genomics to further develop thinking in this area.

DataSHaPER and OBiBa

Principal Investigators Vincent Ferretti, Isabel Fortier

The Project The DataSHaPER and OBiBa cores have produced software, tools and methodologies which are currently used by several biobanks and biobank networks. Both cores are facing increasing demands from investigators looking to adapt the tools to their specific research activities or to contribute to the projects.

Recently, the DataSHaPER and OBiBa teams undertook the integration of ontological approaches in their respective work. Ontologies allow a comprehensive and flexible description of information that cannot be readily achieved through traditional data models. Employing an ontological approach will permit the formalization of the DataSHaPER harmonization and pairing rules – an essential condition for the effective pooling of data between biobanks. A first ontological version of two DataSchemas (Generic and Canadian Partnership for Tomorrow (CPT) DataSchemas) was drafted by the DataSHaPER team and the OBiBa group is working on its implementation into the CPT central database software currently under construction.

How the Grant Will Be Used

To ensure the long-term quality, improvement and dissemination of the P³G tools, the two Cores are seeking to establish new collaborations with key experts that will support the development of those respective approaches and to exchange expertise and knowledge. The principal objective of the collaboration is to promote the compatibility and the interoperability of data models under construction by organizations developing biobank information systems worldwide.

How Conclusions Will Be Shared An initial workshop on data modeling, integration and ontologies in October 2009 will bring together IT experts and epidemiologists. The goal is to explore potential for collaboration and integration of work currently being done by investigators interested in ontological approaches and database models to support the creation of individual and integrated databases between biobanks.

Workshop deliverables

- 1 Development of a common web discussion portal
- 2 Paper on phenotype and integration models
- 3 Action plan for future collaboration. <<<

Science Activities & Updates

Member Updates

New Member

We are pleased to announce that the **Institute of Genomics and Integrative Biology in India** has presented a complete application to become a Charter Member. Funded by the Indian government, the Indian Genome Variation (IGV) Consortium was launched in 2002 and tenured for five years by six constituent laboratories of the Council of Scientific and Industrial Research (CSIR).

The commitment was to develop a database of variations in over 1000 biomedically-important genes from the Indian population for predictive medicine – at 1/20th the cost of the HapMap project. This would provide an excellent opportunity for mapping genes associated with common and complex diseases and for understanding the genetic predisposition to complex medical disorders and adverse drug reactions.

The first phase of the project referenced populations representing

the genetic diversity of India. Samples were collected from 55 contrasting ethnic populations (classified on the basis of size) derived from four major linguistic lineages viz Indo-European, Dravidian, Austroasiatic and Tibeto- Burman. The number of populations selected and their sizes as estimated from various surveys represent nearly a quarter of the Indian population. The project is unique from other global and national endeavours in two aspects: so far no other study has attempted

to study diversity in functional variations in such a large number of diverse populations.

Indian Genome Variation incorporates a public health approach identifying genetically protected populations, as well as populations at-risk from major threats such as HIV infection, diabetes, hypertension, susceptibility to malaria, etc. This will help in setting strategies to manage these diseases and reduce the total financial burden on the society.

It is anticipated that the Indian Genome Variation data along with epidemiological and associated phenotype data will help in the construction of specific drug response/disease predisposition maps to aid policy level decision making for drug dosage interventions and disease risk management, especially for complex and infectious diseases.

Updates

Generation Scotland (GS) is continuing development on a range of resources to support research into common complex diseases in the Scottish population. The Scottish Family Health Study (GS:SFHS), which aims to follow the health of thousands of families, passed an important milestone in August 2009 with the collection of biological samples and phenotype data from 10,000 participants. GS:SFHS samples recently contributed to a major consortium replication study. Genetic Health in the 21st Century (GS:21CGH), which is building up a picture of the genetic profile of Scotland, has collected samples and phenotypes from 1,300 participants with Scottish ancestry. The Donor DNA Databank (GS:3D) has processed around 5000 DNA samples from blood donors which can be used as controls in a variety of genetic association studies. GS is also developing policies and procedures for efficient handling of applications to use GS resources.

CARTaGENE in Québec Having successfully completed its pilot in 2008, CARTaGENE has begun

recruitment of 20,000 participants in four of its eight sites.

The National DNA Bank of Spain The Spanish Government granted the Central Node of the National DNA Bank of Spain (BancoADN) at the University of Salamanca funding for a project to develop a Biological Resources Centre. This grant was made to support activities recognizing the Eighth Centenary of the university's founding. Currently, BancoADN stores samples and data from over 25,000 healthy donors and patients and has joined the international "1000 Genomes Project" (www.1000genomes.org) to recruit samples from 70 trios (adult child plus father and mother) representing the Spanish population, and which will contribute to the overall European population".

Lifegene Project LifeGene's pilot is set to begin in October 2009. They are currently working on final preparations for the study. Successful pre-pilots were performed May-June, 2009.

Kaiser Permanente Division of Research As of August 2009, more than 100,000 biospecimens (saliva samples) have been received by the Kaiser Permanente Research Program on Genes, Environment, and Health (RPGEH), a developing biobank and resource for scientific research. The RPGEH started enrolling participants in Northern California in 2007 and plans to collect biospecimens from 500,000 participants by 2013. The Program plans to begin collecting blood samples in addition to saliva in the coming months. For more information: www.dor.kaiser.org/rpgeh.

The RPGEH is also collecting information from participants from health surveys (almost 400,000 Kaiser Permanente members have completed the survey to date, including those who have provided saliva samples) and clinical data from the Kaiser Permanente electronic health record. The program also offers researchers environmental data, mapped to participants' addresses, such as information about air pollution, water qual-

ity, and neighborhood characteristics such as proximity to parks, grocery stores, and healthy foods.

Integrated Biobank of Luxembourg (IBBL) will be an independent, not-for-profit biobanking, biotechnology and biomedical informatics organisation. Its temporary building with 1000 square meters of floor space will be completed in October 2009. The IBBL will have advanced technology platforms for genomic and proteomic analysis as a resource to foster collaboration in biomedical research.

Canadian Health Measures Survey (CHMS) The CHMS completed cycle 1 data collection in March 2009 with 5,600 respondents. Permanent funding for a continuous survey was secured from the Government of Canada and the survey will begin cycle 2 collection in Sept 2009. Initial results on such topics as anthropometry, physical fitness, blood pressure and oral health will be available in January 2010. Results from laboratory analyses related to nutrition and cardiovascular health will be available in March 2010, followed by environmental contaminants in July. The CHMS biobank will be operational in the fall 2010 for additional study.

The Ontario Health Study has reached its pilot goal of 1,500 completed participants and has established three assessment centres. The Scientific Advisory Board will meet in Toronto in September 2009 to review the conclusions from the pilot evaluation. An international peer review panel is scheduled for December 2009. Subsequently, we expect to launch province-wide in early 2010, with a rolling schedule of six assessment centres operating concurrently across 16 communities.

The National Cancer Institute (NCI) Office of Biorepositories and Biospecimen Research (OBBR) presented the 2nd Annual Biospecimen Research Network (BRN) Symposium: Advancing Cancer Research through Biospecimen Science last March 16-18, 2009. The OBBR recently awarded four research con-

tracts which will (1) systematically define the impact of key pre-analytical variables in human biospecimens on downstream molecular data and (2) develop innovative approaches to the control, monitoring and assessment of biospecimen quality. The OBBR is also in the process of awarding research contracts to collect and process well-annotated and differentially preserved cancer and normal tissues as part of a research project to systematically assess the effects of human biospecimen pre-analytical variables on the outcome of genomic and proteomic studies to provide the basis for evidence-based biospecimen protocols.

The NCI Best Practices for Biospecimen Resources are currently being revised and will be available on the OBBR website for public comment in late 2009. Finally, the NCI has recently launched an effort to plan the cancer Human Biobank (caHUB) a national biospecimen resource which would serve as a unique, centralized, public resource, the primary mission of which will be to ensure the adequate and continuous supply of high-quality human biospecimens for the research community.

The Marshfield Clinic Personalized Medicine Research Project (PMRP) will enroll its 20,000th participant in October 2009. As a

member of the eMERGE consortium, more than 4000 subjects aged 50 years and older will have whole genome scans on the Illumina 600 platform. Samples were initially selected for GWAS studies of cataract and HDL, and will be analyzed for other outcomes available from the electronic medical records.

The Tomorrow Project (Alberta) Continuing with support from the Alberta Cancer Foundation, Alberta Health Services and the Canadian Partnership Against Cancer, the Tomorrow Project in Alberta is currently enrolling new participants to join the existing 31,000. The goal is to reach 50,000 by the end of 2012. <<<

Science Activities & Updates

P³G-Wellcome Trust Biobank Summer School

The P³G-Wellcome Trust Biobank Summer School took place July 1-5th, 2009, at the Wellcome Trust Genome campus in Hinxton, UK. The jointly organized and sponsored programme brought together 16 internationally renowned experts and 27 students from around the world to address in practical terms the scientific, legal and ethical challenges in setting up and maintaining a biobank, and the tools available to meet those challenges.



Training sessions included Introductory Issues in Biobanking; Epidemiology; Information Management and Technology; Ethical, Legal and Social Implications; Samples and Laboratory Science; Tissue Bank-

ing (organized by CIGMR/UDBN); and Communication. Each session incorporated theory and practical experience.

Networking opportunities were built into the programme providing participants a forum in which they could educate the international community about their biobank and foster opportunities for future collaborations and partnerships.

Four students were awarded travel bursaries made possible by contributions from the European Network of Genetic and Genomic Epidemiology (ENGAGE), Genetics Education Networking for Innovation and Excellence (GENIE), and P³G. These travel bursaries served to attract interest from applicants who might otherwise have been discouraged by the cost of attending, advancing P³G's



commitment to bringing together professionals from a diversity of academic and cultural backgrounds.

The summer school was an enjoyable, instructive and rewarding experience, and served to forge new working relationships and inspire ideas for joint projects in the future. We were delighted to receive tremendously positive feedback from all participants. In light of this success, we are pleased to announce that P³G and WellcomeTrust have decided to make the summer school an annual event, with the 2010 session scheduled for June 30th – July 4th. <<<

Science Activities & Updates

Conferences

P³G Secretariat & Observatory

Over the last six months, P³G staff, principal investigators and members delivered presentations at biobanking conferences around the world. The gatherings included events organized by ISBER, Gen2Phen, MarbleArch, Alberta Cancer Board and addressed topics such as DataSHaPER, ELSI in biobanking, privacy and data-sharing, access to biobanks, and future developments. Conferences took place in the US, Canada, Belgium, Scotland, Switzerland and the UK. <<<

Science Activities & Updates

Collaborations

FIBO Mylène Deschênes presented at the ISBER meeting Portland (May 2009). An official deck of presentations currently used by members and a common text to be included on member websites is under review.

GenCure Collaboration Collaboration between P³G and the GenCure study progressed. Data-entry is continuing. Marion Verdujin, a senior researcher with GenCure, spent eight weeks at the Montreal offices this summer working on the creation of the renal DataSHaPER. A new partner catalogue documenting studies recruiting diabetic cases was also developed.

BBMRI Collaboration Collaboration between P³G and BBMRI continued and information on studies affiliated to BBMRI, as collected by the Observatory team, is now available online.

ENGAGE Collaboration A collaborative program of harmonization in the ENGAGE project continued over the spring. The P³G team continues to work with ENGAGE on the primary “pilot” of retrospective harmonization based on the DataSHaPER.

CPT Collaboration The harmonization process of the CPT cohorts continued. A series of modules were developed that

document sample collection, processing and banking. They are currently under validation. Also, a catalog documenting relevant governmental and health database registries was developed. Quality assurance of common sets of information will be achieved through a series of different initiatives such as a periodic report on recruitment status, and the consistency of the information collected by the provincial cohorts. Ongoing support has been given to the harmonization between the “Core” and the cohorts regarding questionnaires, physical measures and biosamples. <<<

Events

Brussels – March 25-27, 2009

P³G/BBMRI/PHOEBE Joint Meeting

PHOEBE, P³G and BBMRI combined efforts and resources to create a major event in the field of biobanking entitled “Harmonised Biobank Research: Maximising Value-Maximising Use”. The event brought together 250 key experts from the

international biobanking community and demonstrated the benefits of combining efforts and leadership in the field of population-based biobanks.

Forty presentations were delivered and covered a diverse array of issues facing the biobanking community, including phenotype harmonization, increased usability of biobanks, improved statistical analy-

sis, and follow-up contact and consent. Lively discussions took place between attendees and presenters on the broader issues related to data-sharing and building an international biobanking community. The content of the sessions reflected that international biobanking has moved beyond the initial stages of laying the groundwork to a highly interactive,

ever-evolving and multidisciplinary science. Meeting participants underscored the symbiotic relationship between biobanking science and information technology, specifically:

Technological solutions are allowing biobanks to reach new levels of integration and activity, while advances in the science of biobanking and the need to manage massive amounts of data have driven innovations in information technology.

Progress in research has brought the evolving scientific landscape into sharp relief, its impact on biobanking and ultimately on public health.

With the advent of increasingly powerful data-collection tools, analytic techniques and results, the research is forcing a reconsideration of ethical and legal boundaries drawn from an earlier era that could not have anticipated the issues of today.

Biobanks have an increasingly important role to play in transferring

knowledge to health systems and to the public in an effort to stem increasing healthcare costs. As meeting participants observed, the sustainability of a biobank may ultimately depend on its ability to become embedded in the healthcare infrastructure, to rationalize incentives along the continuum from data collection to data sharing, to track the impact of advances, and to realize economies from international collaborations.

The meeting helped elevate dialogue by encouraging critical thinking about opportunities, challenges, and next steps. It is crucial that the biobanking community continue to interact as science advances and to share insights, continually raise the quality of biobanking science, question conventional thinking, and speak as one global voice when it counts.

Catching the Eye of the Media
This special gathering caught the attention of the BBC, who interviewed

Gert-Jan van Ommen, Ann Cambon-Thompson and Kurt Zatloukal.

P³G Members Meeting (March 25, 2009)

Approximately 115 participants attended the P³G Brussels meeting that included an opening plenary session, “Economics of Biobanking” led by Stephen Birch, Peter Geary, Markus Perola, and Gert-Jan van Ommen. The session addressed the actual costs of a running a biobank and the benefits. Financial aspects were discussed and parallels were examined against comparable undertakings, such as organ donation and blood banks, where more extensive economic research has been done.

P³G International Working Group (IWG) meetings and the Annual Member’s meeting were held later in the day. <<<

Events

P³G Annual Meeting Québec City 2010



Join us for the 2010 P³G meeting taking place April 26 and 27 in the heart of the UNESCO World Heritage Site, Québec City, where Old World charm envelopes the modern amenities and lifestyle of this 400-year-old city. The 2010 meeting will bring together biobanking experts from around the world to meet and address the challenges and opportunities in genomics research.

You may also consider attending the Genome Canada International

Conference (April 28-30) which follows the P³G gathering on the theme “2020 Vision: The Biology and Pathobiology of Aging”, with a keynote address by Dr. Peter H. Diamandis, founder of the X Prize Foundation.

Registration and Accommodations

Registration is free and open to P³G members only. Online registration will begin in early 2010. Participants are responsible for booking their own accommodations. For the convenience of our attendees, a preferred rate will be available at the historical Fairmount Le Château Frontenac. P³G will provide participants with meals and refreshments.



We understand that for some attendees this may be a long trip; accordingly, we invite you to extend your trip to enjoy the rich cultural and scenic beauty this region has to offer. We will do our best to provide you with information that may be helpful in planning an extended trip for yourself and guests.

For more information, please visit www.p3g.org under Events. <<<

Events

P³G Meeting Luxembourg September 2009

Day One September 29, 2009 Special day on life-course projects

Welcome and Introduction Bartha Maria Knoppers (P³G Chair)

Address from host country Robert Hewitt (CEO, Integrated Biobank of Luxembourg)

Challenges in life course projects – From Pregnancy to Aging: Integration Across the Life Course Using Population-Based Biobank and Cohort Studies

- i Taking advantage of a series of well-established birth cohorts
- ii Taking advantage of a varied portfolio of population-based studies
- iii Ethico-legal issues in studies recruiting in early life

Speakers **Chris Power** (1958 Birth Cohort), **Jennifer Harris** (CONOR and GENOMEUTWIN),

Jeantine E. Lunshof (European Centre for Public Health Genomics)

Conclusion Chaired by **Bartha Maria Knoppers**

Topic 1 Ethical and Public Health Challenges: Including Pregnancy/Newborns, Children and Minors in Population-based Studies: Challenges and Opportunities, chaired by **Alastair Kent** (Genetic Interest Group)

Topic 2 Epidemiological and Public Health Challenges: Including Pregnancy/Newborns, Children and Minors into Population-based Studies: Challenges and Opportunities, chaired by **Nancy Pederson** (Karolinska Institutet)

Panel Discussion and Conclusions Children's Studies

Chaired by **Bartha Maria Knoppers** (P³G Chair)

Opportunities and Challenges Presented by Studies Involving Older Participants: Aging Cohorts

- i Well-established birth cohorts and harmonization
- ii Studies recruiting in older age
- iii Ethico-legal Issues

Speakers **Parminder Raina** (Canadian Longitudinal Study of Aging), **Rebecca Hardy** (Halcyon Initiative),

Patricia Kosseim (Genome Canada)

Topic 3 Ethical and Public Health Challenges: Elderly participants in population-based studies: Challenges and opportunities, Chaired by **Jane Kaye** (Ethox)

Topic 4 Epidemiological and Public health Challenges: Elderly participants in population-based studies: Challenges and opportunities, Chaired by **Julian Little** (University of Ottawa)

Panel Discussion and Conclusion Aging Studies, Chaired by **Paul Burton** (P³G, CSO)

Steering Committee Meeting Next Steps for Biobanking Community and P³G

Update on Biobank Members of P³G

Poster Session

Day Two September 30, 2009

Topic 5 Evidence-based Standards for Pre-analytical Processes – Part I: Extraction and Storage

chaired by **Bill Ollier** (CIGMR/University of Manchester)

Part II: High-throughput Sequencing chaired by **Klaus Lindpaintner** (Roche Genetics)

Topic 6 Calibration and Use of the DataSHaPER: Case Study/Pooling of Data, **Julian Little** (University of Ottawa) and **Isabel Fortier** (P³G)

Topic 7 Presentation of New Core: Data Sharing in Genomics – ELSI Issues, **Jane Kaye** (Ethox)

Topic 8 Global Voices: Scientific and Socio-cultural Issues, **Paolo Boffetta** (IARC)

Commentator **Margaret Sleeboom-Faulkner** (University of Sussex)

International Working Groups Meetings (IWGs)

Topic 9 International Collaboration in Open Source Software for Biobanks: The OBiBa Project, **Vincent Ferretti** (OICR), **Philippe Laflamme** (McGill University/Genome Quebec Innovation Centre), **Paul White** (University of Western Australia)

Topic 10 Providing Access to a Biobank: A Practical Approach, **Saminda Pathmasiri** (P³G)

Update on the Observatory / Cores

Keynote Closing Address

David Galas (Institute for Systems Biology)