



Harmonising Biobank Research: *Maximising Value - Maximising Use*

March 25 - 27, 2009
Brussels, Belgium

Co-organized by:

PROMOTING
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PHOEBE
EPIDEMIOLOGICAL
BIOBANKS IN EUROPE

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Preface

The science of biobanking is rapidly changing the face and pace of biomedicine. Several countries have made substantial investments in biobanking, and intense activities are underway toward building an international network of biobanks that will support large-scale genomics and biomedical research. An impressive number of initiatives have been funded to help biobanks and researchers collaborate in cutting-edge science. Activities include the development of standard operating procedures, tools, compatible informatics, analytic approaches, and ethico-legal frameworks. An important result is the emergence of a new reservoir of knowledge, experience, and expertise that will benefit the biobanking community at large.

On March 25-27, 2009, more than 250 people from over 35 countries attended a conference in Brussels to exchange information and engage



Dr. Anne Cambon-Thomsen, France

in renewed thinking about building and sustaining biobanking infrastructures and ways to maximise their scientific value and international usage.

The content of the sessions clearly reflected that international biobanking has moved beyond the initial stages of laying the groundwork to a highly interactive, ever-evolving and multidisciplinary science. This report highlights the progress discussed, including phenotype harmonisation, Internet biobanking, and data sharing. Meeting participants underscored the symbiotic relationship between biobanking science and information technology. Specifically:

- (1) 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.
- (2) Research progress has brought into sharp relief the evolving scientific landscape and its impact on biobanking and ultimately on public health.

(3) 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.

We must now move forward in a joint and collaborative manner to address the challenges ahead. 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 health care infrastructure, to rationalise incentives along the continuum from data collection to data sharing, to track the impact of advances, and to realise economies from international collaborations.

This meeting helped to elevate the 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.

Jennifer R. Harris, PhD, Coordinator of PHOEBE

Division of Epidemiology, The Norwegian Institute of Public Health, Oslo Norway

Bartha Maria Knoppers, Ph.D., Chair of the Board of Directors, P³G Consortium

Centre of Genomics and Policy, Department of Human Genetics,

McGill University, Montreal, Canada

Kurt Zatloukal, M.D., Coordinator of BBMRI

Institute for Pathology, Medical University of Graz, Austria

Accelerating Scientific Discovery by Harmonising Biobanks Worldwide

Modern health research relies heavily on access to large-scale biobanks containing an array of information (genotypic, clinical, exposure, lifestyle, biomarkers) and biospecimens. Real progress in unraveling the



Dr. Jennifer Harris, Norway

causes of disease and developing translational applications will derive from pooling and harmonising resources across populations, and by making investigations more robust, more personalised, and

more economical. Indeed, the popular press ([Time Magazine](#)) has christened biobanks as one of 2009's top 10 ideas changing the world today. International biobanking will enable

new technologies and new knowledge to have clinical and public health impact. Biobanks could help screen for serious but treatable diseases, feeding information into an efficient public health system where results could help individuals, physicians, and policymakers make more informed health decisions.

Given the enormous progress already achieved, what are the challenges ahead and how can they best be overcome? What steps will advance collaborations across national borders on a larger scale and will promote cross-talk on issues that permeate distinct components of the biobanking enterprise? Discussion at the international biobanking meeting held in Brussels in March 2009 reflected the recognition that biobank quality, interoperability, and sustainability are critical to accelerating scientific discovery.

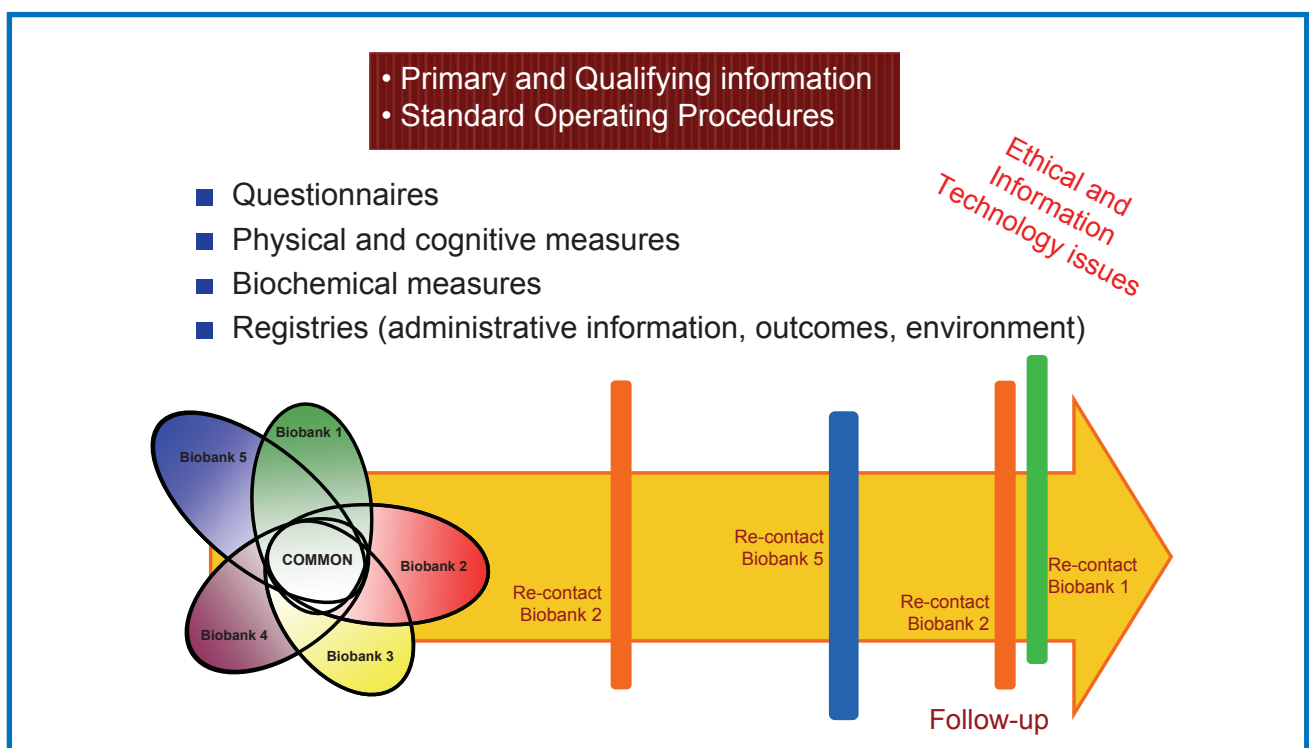


Figure 1 – What to Harmonize? (Dr. Isabel Fortier, P³G, Canada)

Striving for Harmony Across Platforms

Better understanding of the biology underlying complex and rare diseases depends upon measuring variables (or “phenotypes”) consistently across individuals. These variables may include, for instance, physical, cognitive, and biochemical measures. Agreeing on which variables to collect remains a prominent challenge in biobank harmonisation efforts.

Many ongoing international research projects are already rich in collaboration, and they actively solicit input from the research community and generate scientific results by using readily available tools and technologies that facilitate phenotype harmonisation. As an example, DataSHaPER (Data Schema and Harmonisation Platform for Epidemiological Research), developed through P³G and PHOEBE, involves more than 25 biobanks worldwide, has defined a core set of variables across research domains, and has been adopted by multiple research projects. A specialized DataSHaPER also has been developed with the Canadian Partnership of Tomorrow. Other examples include

Harmonisation is best understood as a process and not an end point.

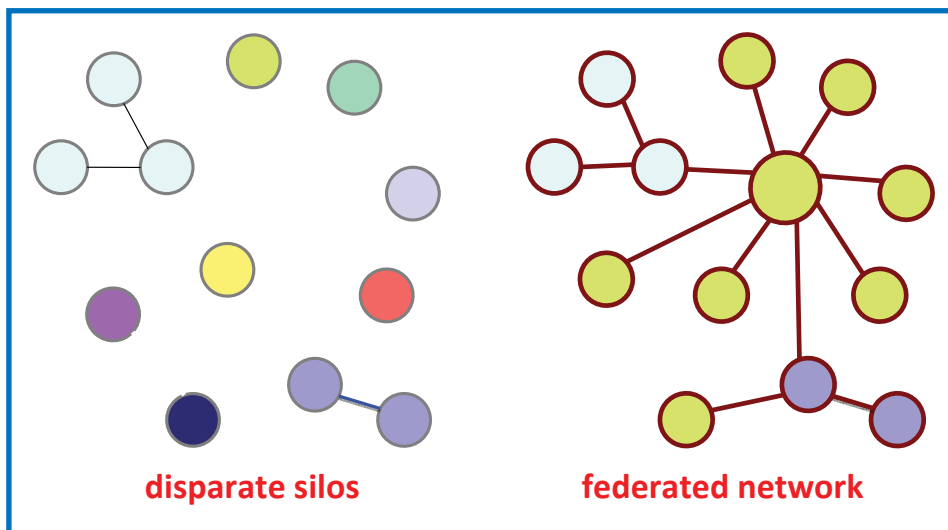


Figure 2 – Bridging the “Internet-Biobanking” Gap (Prof. Anthony J. Brookes, University of Leicester, UK)

(1) a U.S.-led collaborative project called PhenX (Phenotypes and eXposures), which is identifying a limited number of high-priority variables for 20 research domains so that studies can be better integrated, and (2) a consortium of provincial tumor banks in Canada that is developing a data repository with common tools and data standards.

These collaborative projects are actively seeking to pool their efforts in order to enhance standardisation and promote interoperability. One possibility is using “concept Web technologies” to promote semantic integration of biological resources. The goal is to better connect biobanks and biospecimens research to the broader scientific enterprise. Linking to biobanking concepts rather than mere words can enrich Internet searches, enhance the relevance of findings, and map them to wiki-type entries. In Europe, the need to translate measures into multiple languages adds a layer of complexity that can easily benefit from the use of related concepts.

Internet Banking: The Future of Biobanking?

An attractive vision for the future is an Internet-based “knowledge environment” that supports direct submission of data, seamless data integration, and holistic searching capabilities. Of all the challenges of biobank harmonisation, Internet biobanking is among the biggest and certainly the timeliest, given the widespread use of online information tools. Prominent challenges include concerns about contributors losing publication rights if information, particularly unpublished data, is posted immediately on the Internet and also ensuring proper credit when there are multiple contributors. One creative solution is to develop a database that tracks contributions to all facets of data production. Another solution would be to develop unique identifiers for each contributor. While such approaches would reassure users that data are authentic and reputable, they pose problems for those researchers concerned about privacy.

Despite the numerous challenges of making data available online, exciting efforts are

already underway to coordinate biological data resources throughout Europe. (1) The Gen2Phen project, which involves 19 organisations throughout Europe, is supporting efforts to build genetic databases more quickly and easily and in a more standardised fashion. (2) The collaborative European project ENGAGE is translating biobank records and vocabulary into a common set of terms, giving users

An attractive vision for the future is an Internet-based “knowledge environment.”

a broad view of data availability across different data repositories using a Web application. (3) Finally, BioBank-Info is a compendium of studies on such variables as infrastructure, population, and environment, all accessible through a common database and biobank.

Ultimately, the success of tomorrow’s online biobanking activities will depend upon creative

problem solving and will require a fundamental shift from working in disparate “silos” isolated from other research efforts to working collaboratively to build infrastructure and access.

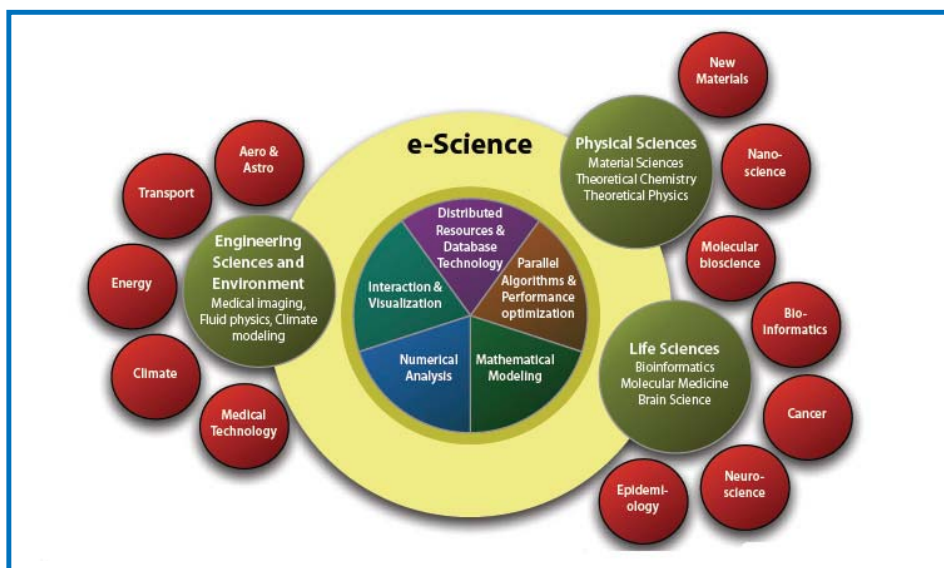


Figure 3 – Integration of Technologies Required (Prof. Juni Palmgren, Karolinska Institutet and Stockholm University, Sweden)

Lessons From Isolated Populations

Isolated populations of people, which tend to be small, inbred populations, present a special challenge in biobanking. Their homogeneity is of great value in research because genetic and environmental risk factors for complex traits can be more readily identified. Further, the incidence of rare mutations is magnified in these populations, offering opportunities to advance our knowledge of disease genetics. Greater harmonisation between studies on isolated populations would certainly be enriching, although it faces many of the same challenges seen in other types of biobanks. Study design in these

populations needs to be population specific with study results validated in outbred populations.

One ongoing study on isolated populations, the Italian Network of Genetic Isolates, has

collected data from approximately 10,000 people from 6 villages in Italy. More than 400 traits have been tracked, including physical traits, disease history, drug and alcohol consumption, blood and urine clinical chemistry, and psychological characteristics. The study is

Studies of isolated populations offer opportunities for deep sequencing, making them extremely powerful for exploring recessive mutations for complex diseases.



Dr. Iiro Eerola, European Commission, Belgium

pursuing greater data harmonisation and data sharing, as well as collaborations for assistance with data analysis. In a separate effort, several researchers have collaborated to compare genetic maps of 21 isolated populations, comprising nearly 4,000 individuals from throughout Europe. The genetic map reflects the geography of the continent, corresponding to its long history of migration.

Studies of isolated populations also raise unique consenting issues. Because these studies tend to involve people who are related to each other, one individual's decision to participate may reveal information about extended family members who may not have agreed to participate. To address this concern, some isolated populations may require community consent for research, as is the case in aboriginal populations in Canada.

In the future, there will be greater integration between the various biobank typologies (e.g., population, clinic, disease, tissue), making data exchange more fluid between studies from isolated populations and from population-based and clinical-based biobanks.

From Data to Statistical Analysis and Beyond

Advances in biobank data harmonisation create a need for higher level modeling and statistical analyses. However, these analyses become more challenging given complex information structures that integrate large quantities of diverse data. An analysis pipeline is needed to handle the growing complexity surrounding the phenotypic data, the analytic strategies, and the larger quantities of data being generated. Substantial infrastructure and greater integration of technologies—from mathematical modeling to database technology—is needed to achieve high-quality statistical analyses in a harmonised environment. Considerable investments in the biomedical and life sciences are aimed at generating important pieces of this pipeline. “E-Infrastructures,” for example, allow researchers to share resources electronically and to strengthen collaboration using an integrated system with many independent components that function in a consistent manner. At the European level, a common

Collaborations among genomic studies have increased the ability to detect genetic factors with small effect because of greater statistical power.

policy for e-Infrastructure is being developed. A consistent pipeline from raw data via low-level filtering to complex statistical analyses must also consider the educational aspects of future challenges.

Genome-wide association studies (GWAS), which seek to identify common genetic factors that influence health and disease, have made critical strides that could only be realised through collaborations that increased the ability to detect genetic



Prof. Paul Burton, UK

factors with small effects. Increasingly, however, attention is turning to more complex and developmentally plausible models involving, for example, gene-environment and gene-gene interactions, rare variants, and imprinting effects. This will present greater challenges, such as integrating increasing amounts of information and harmonising statistical analyses across studies, coordinating efforts, and necessitating collaborations to test more complicated models of etiology.

Recontact and Reconsent Ethical and Legal Considerations

Respect for study participants imbues all aspects of biomedical research. For this reason, two issues of critical concern in biobanking are recontacting study participants with research results and getting participants' reconsent to use their specimens in further studies, including for previously unforeseen purposes. Both of these issues highlight the importance of balancing the needs of patients with those of scientists. The changing landscape with respect to these and other ethical and legal considerations can have long-term implications for health care and disease. Further, differences between countries in handling these issues can pose challenges for international harmonisation.



*Prof. Bartha Maria Knoppers,
Canada*

Seeking reconsent from participants, while often viewed as burdensome, is nevertheless explicitly required in many cases. In France, for instance, researchers have a legal obligation to renew consent before reusing donors' samples for a new purpose, and an effort in Canada to advance population genomics research must renew consent for participants every 5 years. Generally, public preferences for consent depend on the context, including the country or region, the tissue type (e.g., cancer, brain), and the situation (treatment versus death), to name only a few.

While some studies recontact participants in cases of abnormal results, most do not provide participants with specific information but instead

may offer aggregate feedback on the progress of the study via Web sites and newsletters. This presents both ethical and legal concerns in known cases of serious, treatable conditions and thus has been a topic of ongoing discussion. Some contend that recontacting participants with individual results would promote public trust while offering meaningful return for individuals' participation. New governance structures would be required to incorporate this option into the informed consent process and to define what information would be fed back, by whom, and how. Others argue that sharing individual results is unduly burdensome and thus impractical. They further contend that

Discussions about recontact and reconsent highlight the importance of balancing the needs of patients with those of scientists and the changing scientific landscape that can challenge ethical and legal norms.

participants are most interested in knowing simply that their involvement has enhanced scientific knowledge and served the public good.

In the case of both recontact and reconsent, it is important to recognise that ethical and legal considerations can evolve over time as our knowledge and science progresses. The challenge is to avoid outdated ethical norms that stymie productive research without compromising public trust.

The Power of Data Sharing

Striking advances in genome-wide association studies underscore the power of consortia and data sharing. The 1000 Genomes Project, for instance, aims to identify and make publicly available a deep catalog of human genetic variants from the genomes of more than 1,000 individuals to support medical



Dr. Camilla Stoltenberg, Norway

genetics and population genetics research. The project relies on an international consortium that includes sequencing centers, technology companies, statistical and population geneticists, ethicists, and funders. The study of Type 2 diabetes (T2D) offers another compelling example of the tremendous power of collaboration and meta-analysis. In this case, the advent of larger datasets and routine sharing of summary data have amplified small but significant signals in predicting T2D, furthering research in this area.

While data sharing is essential to accelerating scientific discovery, it presents a number of challenges, one of which is balancing the interests of science, the scientist, and the donor. For example, when researchers want to use samples for new purposes, the onerous task of seeking reconsent from donors may slow the process of scientific discovery, yet it is critically important to maintaining public trust. The use of summary statistics published in one study for a distinctly different study for which consent was not requested presents yet another challenge to “informed” consent. A more practical approach—one that recognises donors’ rights while

simultaneously advancing science—is to relegate oversight to an ethics committee that could approve research uses on behalf of the donors. It might also be helpful to include donors on ethics committees, which could result in much broader consents than those in place today. Clearly, the future of biobanking depends on creative solutions to this and other challenges as they materialise.

Another consideration regarding data sharing is whether to institute local or centralised oversight and access to data. While a local approach offers high quality and timely curation, a more centralised approach offers increased sample size and standardisation. Probably some mixture of these features, informed by country context, would be ideal. This could include virtual or networked biobanks, such as EuroBiobank, that exemplify patient organisation efforts. Other challenges related to data sharing involve protecting the privacy of donors, controlling access to data, and rewarding researchers not only for publishing results but also for sharing data.

The principal rewards for good science have traditionally been directed at researchers on the cutting edge of new science rather than at those who have provided the raw material for that research. can challenge ethical and legal norms.

Practical Experience With Clinical Biobanks

Different types of biobanks provide different raw materials depending on the scientific questions under consideration. Clinical biobanks, for instance, are much more diverse than population-based biobanks. Generally, samples in clinical biobanks were collected mainly to assure correct diagnosis of the samples, not for population-based research.

Many countries recognise that national and international networks can bring discipline and credibility to biobanking, helping projects



Prof. Lyle Palmer, Australia

operate under a similar framework so that precious biospecimens are not isolated. The Swedish National Biobanking Program, for instance, involves comprehensive participation of seven major

Swedish biobanks, all committed to using common quality standards and to providing access to samples. Similarly, the Canadian Tumour Repository Network is a consortium of the country's leading tumour banks that provides an online pan-Canadian network of tissue banks

and clinical data accessible to all members.

Clinical biobanks in Belgium and The Netherlands also serve as enviable models, with linkages

to other data sources, rich collaborations across research domains, and national infrastructures that support biobanking efforts.

Many countries now recognise

that basic biobanking infrastructure is an essential component of modern clinical care. In

Western Australia, for example, biospecimen banking is part of standard clinical medical practice. Patients complete a scannable questionnaire that they review with their physician, and an open-source application allows data management to reside with the clinician.

Harnessing the capacity of clinical laboratory medicine for research

more widely around the world will require a broad biobanking consent system in routine medical care as well as enhanced educational and networking opportunities.

Biobanks should be treated as public goods and not forced into a business model that requires them to break even.

Building an International Biobanking Community

Biobanks worldwide face similar strategic issues. A number of efforts have already begun to lay the groundwork for a more coordinated approach that can inform a much needed overarching research strategy. For instance, 25

EU-funded biobanking projects convened in 2008 to identify strategic priorities, including improved synergy between major

Biobanks are embedded within communities and the world and can play a more visible role in the scientific enterprise and in educating the public.

sources of health information.¹ PHOEBE has established a collaborative research network laying the harmonisation groundwork in five key biobanking platforms. BBMRI emphasizes integration of European biobanks and expects its members to comply with evidence-based standards. P³G is working to build tools and create a network that supports harmonisation efforts and contribute to building an international community. The International Society for Biological and Environmental Repositories (ISBER) publishes [Biopreservation and Biobanking](#) and produced [2008 Best Practices for Repositories: Collection, Storage, Retrieval and Distribution of Biological Materials for Research](#), which reflect the collective experience of its 500-some members. To focus on specific targets for coordinated actions, the Forum on International Biobanking

Organizations (FIBO) has effectively acted through its member organisations, which include BBMRI, ISBER, P³G, the International Agency for Research on Cancer, and the U.S. National Cancer Institute Office of Biorepositories and Biospecimen Research.

Harmonisation between biobanks is essential and must be done in coordination with efforts by the World Health Organization (WHO), government entities, funding organisations, industry, and the general research community. Further, there needs to be more emphasis on building a truly global biobanking community that reaches beyond the United States and Europe to engage participation by individuals in Africa, India, China, and developing countries. This will enable new technologies and knowledge to have widespread clinical and public health impact.

Like harmonisation, sustainability is also of critical importance to biobanks of the future. Typically, biobanks require outside funding for support and steady contributions from scientists and subjects—in other words, resources that are not assured. Among ideas for better ensuring the sustainability of biobanks:

Embed biobanks in healthcare systems.

Biobanks are just as essential to medical research as hospital beds are to treatment. Embedding biobanks in healthcare systems would help ensure reliable long-term funding and establish biobanks as a key component of the public health infrastructure.

¹ ftp://ftp.cordis.europa.eu/pub/fp7/docs/report-meeting-eu-funded-biobanks_en.pdf

Impose conditions to incentivize behavior.

Funders should consider requiring grantees to contribute to infrastructure building or requiring that requests for building infrastructure



Prof. Kurt Zatloukal, Austria

demonstrate linkages to research efforts and to serving undefined research foci. Funders might also consider requiring applicants to justify collection of new samples and address plans for analyses.

Raise awareness about the importance of biobanks.

An educational component is essential to help explain to potential sample donors and the public, as well as potential funders, the benefits of biobanks and biobanking research, how personal health information is used in research, and contributions to public health. It is also critical to engage the broader scientific community, reinforcing the message that biobank collections are for the benefit of the larger research community, and to articulate the ways in which biobanking can contribute to the loftier ideals of a civil society—e.g., justice, public good, and scientific investment.

Document the evolving body of knowledge related to biobanks. Cataloging is the first step to documenting the current body of knowledge. The next step is to more formally integrate activities into action. Journals that accept

articles related to biobanking science might be persuaded to expand their scope to encompass a broader base of relevant topics.

Institutionalise reward systems for community-building behavior. Authors should acknowledge the source of material and all contributors in published articles or forums.

Support efforts to measure the impact of biobanks. Demonstrating measurable impact is critical to the credibility of the field. A robust system will require a systemized way to cite bioresources so that usage can be easily traced. This information could then help construct indices that capture impact factors.

Find ways to efficiently manage and link vast quantities of data generated by biobanks.

To address these and other challenges that lie ahead, continued engagement and collaboration are critical. Next steps include preparation of a white paper that provides a blueprint or common strategy for the way forward. This white paper should reflect international consensus to clarify the issues that are of priority concern, mitigate misunderstanding and misimpression, and give direction about biobanking funding strategies and policy. It should advance progress in the field and help sponsors justify their investments in this area. Continuing to share insights and enhance coordination, as was done in the international meeting described in this report, is certain to raise the quality of biobanking to enable revolutionary science.

Harmonising Biobank Research: *Maximising Value – Maximising Use* Programme

Wednesday 25th of March 2009

18.30 Conference Opening with Refreshments

19.00 **Harmonisation: What Does it Mean in Ethics?**

Dr. Ruth Chadwick, *Director of the ESRC, Cesagen, Cardiff University, UK*

19.45 Reception with Poster Session

Thursday 26th of March 2009

08.45 **Welcome**

Dr. Jennifer Harris, *PHOEBE Coordinator, Norwegian Institute of Public Health, Norway*
Professor Kurt Zatloukal, *BBMRI Coordinator, Institute for Pathology, Medical University of Graz, Austria*
Professor Bartha Maria Knoppers, *P³G, University of Montreal, Canada*

09.00 **Session I – Phenotype Harmonisation**

CHAIR: Professor and Chairman Julian Little, *University of Ottawa, Canada Research Chair in Human Genome Epidemiology, Canada*

From Harmonization to Standardization, Just a Step?

Dr. Isabel Fortier, *Director Research and Development, P³G, Canada*

Accelerating and Improving Research through Standardization

Peter Geary, *Chief Executive Officer, Canadian Tumour Repository Network and Chair of the Marble Arch International Working Group on Human Specimen Biobanking for Research Purposes, Canada*

PhenX Measures

Dr. Carol M. Hamilton, *Director of Bioinformatics, RTI International, PhenX Principal Investigator, USA*

Concept Web Technologies to Harmonize Dispersed and Ambiguous Information

Dr. Barend Mons, *Biosemantics Group, Department of Medical Informatics, Erasmus Medical Center, Rotterdam and Department of Human Genetics, Leiden University Medical Center, The Netherlands*

10.30 **Break**

11.00 **Session II – Making the Most of Biobank Data via the Internet**

CHAIR: Professor Rex Chisholm, *Dean for Research, Feinberg School of Medicine, Northwestern University, USA*

Bridging the 'Internet-Biobanking' Gap: Modular Resources and Researcher IDs

Professor Anthony J. Brookes, *Department of Genetics, University of Leicester, UK*

Anonymous Bosh: Identity, Authority and Reputation in a Mashed-Up World

Geoffrey Bilder, *Director of Strategic Initiatives, CrossRef, UK*

Tools for Multi-Center Data Harmonisation and Analyses

Dr. Maria Krestyaninova, *European Bioinformatics Institute, EMBL-EBI, Hinxton, UK*

Tracing Biological Collections: an Incentive for Collaboration

Dr. Francine Kauffmann, *Inserm U780, Epidemiology and Biostatistics, France*

12.30 **Lunch – Cap Nord Restaurant**

13.30 **Pooling Data of Isolated Populations: Prospects and Limitations**

Professor Cornelia van Duijn, *Department of Epidemiology & Biostatistics, Erasmus University Medical School, The Netherlands*

14.15 **Session III – Isolated Populations**

CHAIR: Professor Thomas Meitinger, *Head of the Institute of Human Genetics, Helmholtz Zentrum Munich and Head of the Institute of Human Genetics, Technical University Munich, Germany*

Complex and Quantitative Traits: Definition of a General Picture from The Study of a Network of Isolated Populations

Professor Paolo Gasparini, *University of Trieste/IRCCS-Burlo Garofolo, Italy*

Consenting in Isolated Population Biobanks: Individual Autonomy vs. Intersubjective Responsibility

Deborah Mascalzoni, *EURAC Bolzano, Italy*

Genetic Structure of Some of the Isolated and Non-Isolated Populations in Europe

Professor Andres Metspalu, *Director of the Estonian Genome Project of the University of Tartu, Estonia*

15.15 **Break**

15.45 **Sequencing 1000 Genomes to Provide a Deep Catalogue of Human Genetic Variation**

Dr. Richard Durbin, *Principal Investigator, Wellcome Trust Sanger Institute, UK*

16.30

Parallel Sessions

Session IV: From Data to Statistical Analysis

CHAIR: Professor Paul Burton, *Department of Health Sciences and Department of Genetics, University of Leicester, UK*

Infrastructures in the Updated ESFRI Roadmap

Professor Juni Palmgren, *Department of Medical Epidemiology and Biostatistics, Karolinska Institutet and Department of Mathematical Statistics, Stockholm University, Sweden*

From Data to Statistical Analyses: A Lesson and a Vision from the Domain of Lipids and CHD in ENGAGE

Dr. Samuli Ripatti, *Institute for Molecular Medicine, University of Helsinki, Finland*

Statistical and Bioinformatical Challenges in the Analysis of Genome-Wide Association Data

Dr. Yurii Aulchenko, *Department of Epidemiology and Biostatistics, Erasmus MC, University Medical Center, Rotterdam, The Netherlands*

From Data to Statistical Analysis: Explaining Genetic Heritability by Interaction Analysis?

Dr. Kristel Van Steen, *Montefiore Institute, Bioinformatics, Biometry and Statistics, University of Liège, Belgium*

EUROGENE – The First Pan-European Learning Service Dedicated to Genetic Medicine

Professor Heike Bickeböller, *Department of Genetic Epidemiology, University of Göttingen, Medical School, Germany and Petr Knoth, Researcher and Doctoral Student, Knowledge Media Institute, The Open University, UK*

Session V: Recontact and Reconsent

CHAIR: Dr. Ruth Chadwick, *Director of the ESRC, Centre for Economic and Social Aspects of Genomics (Cesagen), Cardiff University, UK*

Deconstructing and Reconstructing a Terminology

Dr. Anne Cambon-Thomsen, *Director of Research, CNRS, INSERM U558, France and Professor Bartha Maria Knoppers, University of Montreal, Canada*

UK Biobank's Recontact and Reconsent Policy

Dr. Jane Kaye, *Wellcome Trust Fellow, Ethox Centre, University of Oxford, UK*

Recontact and Reconsent in Estonia

Professor Andres Metspalu, *Director of the Estonian Genome Project of the University of Tartu, Estonia*

French Policies and Examples Regarding Re-Contact and Re-Consent

Mrs. Emmanuelle Rial-Sebbag, *INSERM, France*
Recontact and Reconsent in CARTaGENE
Ms. Karine Bédard, *CaRTaGENE, Canada*

Public Perspectives on Recontact and Reconsent

Dr. Klaus Hoeyer, *Institute of Public Health, University of Copenhagen, Denmark*

20.00 **Dinner – Cap Nord Restaurant**

Friday 27th of March 2009

- 09.00 **Thinking Big: Collaboration and Data-Sharing, The New Genetics, and Genes Influencing Diabetes and Obesity**
Professor Mark McCarthy, *Oxford Centre for Diabetes, Endocrinology and Metabolism, UK*
- 09.45 **Session VI – Data Sharing: Various Models - Same Science?**
CHAIR: Professor Paul Burton, *Department of Health Sciences and Department of Genetics, University of Leicester, UK*
- The European Genotype Archive Data Access Model**
Dr. Mario Caccamo, *European Genotype Archive, EMBL-EBI, UK*
- dbGaP as a Model for Sharing GWAS Data**
Dr. Rebekah Rasooly, *Program Director for the Genetics and Genomics Program, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health, USA*
- Data Sharing: Can We Align The Needs of Science and the Needs of Individual Scientists?**
Professor Paul Burton, *University of Leicester, UK*
- Panel Discussion:**
Professor Anthony J. Brookes, *University of Leicester, UK*
Professor Paul Burton, *University of Leicester, UK*
Dr. Mario Caccamo, *European Genotype Archive, UK*
Dr. Jennifer Harris, *Norwegian Institute of Public Health, Norway*
Professor Mark McCarthy, *Oxford Centre for Diabetes, UK*
Dr. Rebekah Rasooly, *National Institute of Health, USA*
Professor Cornelia van Duijn, *ERASMUS MC, The Netherlands*
- 10.45 **Break**
- 11.15 **Session VII – Practical Experiences with Clinical Biobanks**
CHAIR: Dr. Peter Riegman, *ERASMUS MC, The Netherlands*
- Clinical Population-Based Biobanks: Experiences of Building and Scientific Use**
Professor Joakim Dillner, *Department of Laboratory Medicine, Lund University, Sweden*
- Building a Tissue Bank Network**
Peter Geary, *Chief Executive Officer, Canadian Tumour Repository Network and Chair of the Marble Arch International Working Group on Human Specimen Biobanking for Research Purposes, Canada*
- Practical Experiences with Clinical Biobanks: Lessons from Down Under**
Professor Lyle Palmer, *Foundation Chair in Genetic Epidemiology and Director of the Centre for Genetic Epidemiology and Biostatistics, University of Western Australia, Australia*
- Cervical Cytology Biobanks as a Resource for Molecular Epidemiology**
Dr. Marc Arbyn, *National Centre for Cancer Control, Scientific Institute of Public Health, Belgium*
- Bridging Population Biobanks and Disease Based Post-Mortem Biobanks - Yes, We Can**
Dr. Rivka Ravid, *Netherlands Institute for Neurosciences, Dutch Royal Academy of Sciences, The Netherlands*
- 13.15 **Lunch**

14.15 **Session VIII – Building an International Biobanking Community**

CHAIR: Professor Lyle Palmer, *University of Western Australia, Australia*

This structured discussion aims to stimulate our thinking about the reasons and approaches for building an international biobanking community. The panelists will identify and discuss important next steps that could help move forward this agenda through international biobanking initiatives.

Panel Discussion:

Professor Paul Burton, *University of Leicester, UK*

Professor Rex Chisholm, *Northwestern University, USA*

Mrs. Mylène Deschênes, *Executive Director, P³G Consortium, Canada*

Dr. Jennifer Harris, *PHOEBE Coordinator, Norwegian Institute of Public Health, Norway*

Dr. Robert Hewitt, *President ISBER, National University Hospital, Singapore*

Professor Gerardo Jimenez-Sanchez, *National Institute of Genomic Medicine, Mexico*

Dr. Jane Kaye, *University of Oxford, UK*

Dr. Jan-Eric Litton, *Karolinska Institutet Biobank, Stockholm, Sweden*

Professor Lyle Palmer, *University of Western Australia, Australia*

Mr. Markus Pasterk, *International Agency for Research on Cancer, France*

Dr. Camilla Stoltenberg, *Deputy Director, Norwegian Institute of Public Health, Norway*

Professor Gert Jan B. van Ommen, *Leiden University Medical Center, The Netherlands*

Professor Kurt Zatloukal, *BBMRI Coordinator, Medical University of Graz, Austria*

16.00 **Adjourn**

Dr. Jennifer Harris, *PHOEBE Coordinator, Norwegian Institute of Public Health, Norway*

Programme Committee

<i>Jennifer Harris, Norway Isabel Fortier, Canada Kazuto Kato, Japan Gerardo Jimenez-Sanchez, Mexico Jan-Eric Litton, Sweden Paul Burton, Great Britain Mylène Deschênes, Canada</i>	<i>Leena Peltonen, Finland Anne Cambon-Thomsen, France Paolo Gasparini, Italy Kurt Zatloukal, Austria Erich Wichmann, Germany Camilla Stoltenberg, Norway Bartha-Maria Knoppers, Canada</i>	<i>Juni Palmgren, Sweden Heli Salminen, Finland Gertjan J.B van Ommen, The Netherlands Michaela Mayrhofer, Austria Elisabeth Shaw, Norway Isabelle Budin Ljøsne, Norway</i>
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About The Organisers

The conference was co-organised by three interrelated initiatives—PHOEBE, P³G, BBMRI—working in tandem to further biobank science and research.



Promoting Harmonisation of Epidemiological Biobanks in Europe (PHOEBE) is a coordination action funded by the Sixth Framework Program of the European Commission. With 18 partners in 13 countries, PHOEBE identifies and explores key issues to help ensure that Europe makes the best use of its rich array of population-based biobanks and longitudinal cohort studies. The ultimate aim is to harmonise those features that will help to (1) promote communication between major biobanking initiatives, (2) enhance the effective sharing and synthesis of information and data, and (3) avoid the expensive mistakes and inefficiencies that can arise when individual initiatives repeatedly “re-invent the wheel.” PHOEBE work is broadly focused around five main themes: epidemiology and biostatistics, opportunities for future biobanking in Europe, database and biobank information management systems, strategies for genotyping in large-scale studies, and ethical and societal issues.



The Public Population Project in Genomics (P³G) is a not-for-profit international consortium that promotes collaboration between researchers in the field of population genomics. With support from GenomeCanada and GenomeQuébec, P³G was launched to provide the international population genomics community with the resources, tools, and know-how to facilitate data management for improved methods of knowledge transfer and sharing. Its motto is transparency and collaboration, with its main objective to create an open, public, and accessible knowledge database—the P³G Observatory. P³G has developed a strong international collaborative network of biobanks (including more than 40 member countries) and is developing mechanisms to include partnership projects. The Observatory features a number of catalogs mapping the biobanks and their content as well as harmonisation tools for biobanks.



The pan-European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) is a project funded by the Seventh Framework Program of the European Commission and by the European Strategy Forum on Research Infrastructures. Its mission is to establish a pan-European research infrastructure with innovative components, and properly embedded into European ethical, legal, and societal frameworks, to support biomedical and biological research and to build on existing biobanks, resources, and technologies. BBMRI has a hub-and-spoke structure, with a small central coordinating unit that integrates solutions for activities of its members. It adheres to the philosophy that research infrastructures should facilitate access; should require coordination of different programs; may provide services, education, and training; and must build on scientific excellence. Although BBMRI members are mostly European, the project emphasizes global integration.