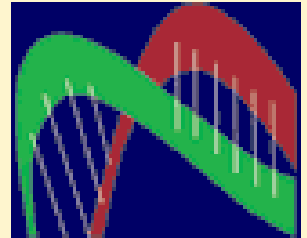


COGENE - a structured European approach in population genetics

Paul Burton

Dept of Health Sciences
Institute of Genetics



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COGENE Inaugural Workshop

"The coordination of European population databases for investigating genetic susceptibility to disease"

**Limassol, Cyprus
October 17-19, 2002**

A consensus

- We have a unique opportunity to ensure that Europe possesses a world class suite of coordinated studies that bring together appropriate demographic, social, life-style, environmental, clinical, physiological, and genetic information in a large enough number of individuals throughout the continent in order to undertake meaningful genomic epidemiological analysis for a wide range of common and important complex diseases.
- Target: $\geq 5,000$ cases per phenotype

Key questions

- What data (and of what quality) are available on how many individuals in what geographical locations?
- Can one define a "common minimum dataset" (information, measurements and samples) that is extensive enough for meaningful genomic epidemiological analysis?
- If so, how many individuals throughout all of these major studies possess all of these data?

Data collection proforma

- Data custodianship
 - OK to Proceed?
- Study Design
- Information availability
 - Questionnaire data
 - Bioclinical specimens
- Monitoring of outcomes
- Special features
- Status of the study

BIOBANKS FOR HEALTH



Optimising the Use of
European Biobanks
and
Health Registries for
Research
Relevant to Public
Health and
Combating Disease

Report and recommendations
from an EU workshop held at
Voksenåsen Hotel, Oslo 28-31
January 2003

Oslo Workshop - January 2003

- Optimizing the use of European biobanks and health registries for research relevant to public health and combating disease (Biobanks for Health).
- Organizing Committee
 - Anne Husebekk, Ole-Jan Iversen, Frøydis Langmark,
 - Ole Didrik Lærum, Ole Petter Ottersen, Camilla Stoltenberg

Post-Oslo COGENE Satellite Meeting

- **Camilla Stoltenberg, Per Magnus - Norway**
- **Andres Metspalu, Jaanus Pikani - Estonia**
- **Eero Vuorio, Iiro Eerola, Siru Oksa - Finland**
- **Thomas Meitinger - Germany**
- **Thorgeir Thorgeirsson - Iceland**
- **Paul Burton, George Davey Smith - UK**
- **Leena Peltonen - Finland**

Two types of Biobank

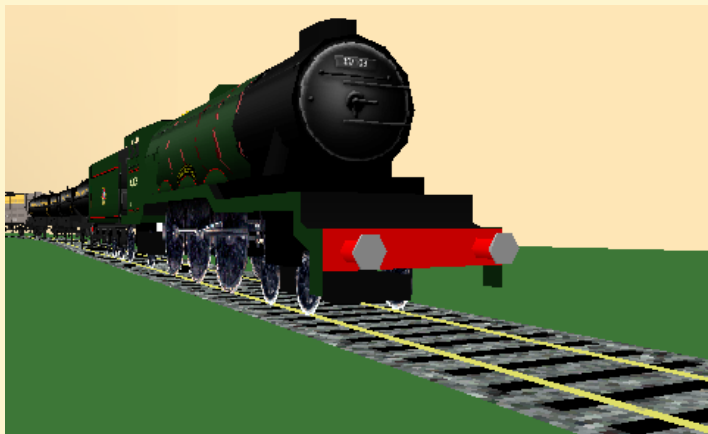
- Biobanks based primarily on pathological samples
 - Diagnostic
 - Research-based
- Population-based Biobanks based on large cohort studies
 - Common to these studies are a wealth of health information and data on nutrition, environmental risk factors, demographic, socioeconomic and lifestyle variables, combined with collections of blood samples (biobanks).



Primary objective

The harmonization of large population-based cohort studies and Biobanks across Europe

Harmonization not regimentation



Analogue: **Bill Ollier**

Not Regimentation



Studies involved from the start

- GenomEUtwin
 - Leena Peltonen
- UK Biobank
 - John Newton, Paul Burton
- Estonian Genome Project
 - Jaanus Pikani, Andres Metspalu
- BioHealth Norway
 - Camilla Stoltenberg, Per Magnus

Coordination Actions

Aims and Objectives:	They aim to promote and support the networking and coordination of research and innovation activities.
Project components:	<p>Coordination actions should cover:</p> <ul style="list-style-type: none"> ▪ definition ▪ organization ▪ management <p>of joint or common initiatives.</p> <p>They will cover activities such as:</p> <ul style="list-style-type: none"> ▪ the organization of conferences ▪ meetings ▪ the performance of studies ▪ exchange of personnel ▪ the exchange and dissemination of good practices ▪ setting up common information systems and expert groups.
Research spectrum:	A single project may span over the whole research spectrum (i.e. from to applied research).
Expected funding:	Up to several hundreds of thousands of euros
Type of funding:	Grant to the budget up 100% of actual costs.

A further issue

- None of the FP6 calls ideally appropriate
 - Our concerns about this fed back to EU
 - Bill Baig, David Coles: Directorate General Research, The European Commission

Detailed text

LSH-2003-1.1.0-2

Topics for CA in the area of Fundamental knowledge and basic tools for functional genomics in all organisms (see call text for more details)

LSH-2003-1.1.0-2

CA proposals should focus on structuring European research in mouse genomics, in models complementary to mouse, and in systems biology. Proposals aimed at developing a coherent European policy for management and maintenance of essential resources for all model organisms important in functional genomics research are also encouraged. **Actions for harmonising and optimising management and experimental use of important human biobanks in epidemiological research will also be considered.**

Links with P³G

- The Post-COGENE Population-based Biobanks initiative is now an "orphan" without a formal home or name
- Our basic objectives and plans as outlined in our CA are so similar to those of P³G, it seems only sensible that the our initiative should be subsumed within P³G - to be discussed further this afternoon

Amalgamation with P³G

- Shared focus on population-based rather than disease-based Biobanks
- Shared recognition of need to harmonize rather than to “force” regimentation and identical designs
 - Data richness enhanced by complementary designs
- Complete overlap of founder studies from Europe

Amalgamation with P³G

- Need to spread collaborative net as widely as possible
 - Sample size
 - Optimise choice of populations to study
 - Diversity of study designs
 - Maximise the input of good ideas
 - Avoid "reinvention of the wheel"
 - Share international investment as widely as possible

Amalgamation with P^3G

- Need to maintain identified "European" and "Canadian" components
- This will help to optimize future opportunities for funding