



Aims and Structure

Coordination Action Application to the EU-FP6

Camilla Stoltenberg
MD, PhD
Director, Division of epidemiology

POPULATION BIOBANKS

Harmonising population-based biobanks and cohort studies to strengthen the foundation of European biomedical science in the post-genome era



World-leading cohorts that already exist and exciting new initiatives

- GenomEUtwin (1.6 mill twins+MORGAM)
- UK Biobank (500,000)
- CARTaGENE (60,000)
- The German National Research Network (20,000+)
- Biobanks for Health in Norway (450,000 - >250,000 already incl)
- The Estonian Genome Project (1 mill individuals)
- International Agency for Research on Cancer (EPIC) (520,000)
- Public Population Projects in Genomics (P3G)
- COGENE working group on population-based biobanks= CA application structure



Participants

Max Baur

Dorret Boomsma

Paul Burton

George Davey Smith

Mary Dixon-Woods

Paolo Gasparini

Jennifer R Harris

Thomas Hudson

Bartha-Maria Knoppers

Jan-Eric Litton

Per Magnus

John Newton

Leena Peltonen

Jaanus Piikani

Elio Riboli

Camilla Stoltenberg

University of Bonn

Vrije Universiteit, Amsterdam

University of Leicester

University of Bristol

University of Leicester

University of Naples

Norwegian institute of public health, Oslo

McGill University, Montreal

Université de Montreal

Karolinska Institutet, Stockholm

Norwegian institute of public health, Oslo

UK Biobank, Manchester

National public health institute in Finland, Helsinki

Estonian Genome Project, Tartu

EPIC, Lyon

Norwegian institute of public health, Oslo



Aims

Ultimate aim

Establish and maintain a cost-effective and “harmonised” network of population-based biobanks and longitudinal cohort studies across Europe and Canada



Specific aims



1 COHORTS (Davey Smith & Baur)

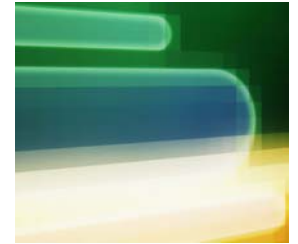
- To identify and describe, in a standardized form, large population-based biobanks and longitudinal cohorts in Europe.
- Particular emphasis is placed on studies that can contribute substantially to coordinated investigations of genetic and environmental determinants of complex diseases.

2 ISOLATES (Gasparini & Riboli)

- To identify new biobanking opportunities within Europe.
- This will include a particular focus on genetically isolated populations, and we will establish standard criteria for selection and collection of data and samples from these populations.



Specific aims



3 INFORMATION and DATABASE MANAGEMENT (Litton, Newton, Magnus)

- To review best practice for Biobank Information Management Systems.
- Key issues of harmonisation in relation to the management of large and complex databases for biobanks will be explored with a focus on efficient technologies, high level programming and the development of flexible communication engines that support reliable, efficient and secure communication between biobanks.



Specific aims



4 GENOTYPING (Peltonen & Hudson)

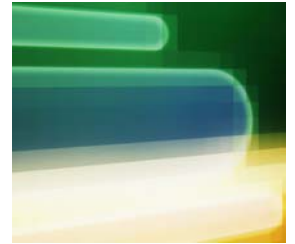
- To create an operational infrastructure for the evaluation of ongoing large-scale genotyping efforts in population cohorts.
- This will provide a natural forum for expert opinions regarding marker selection, genotyping methods.

5 PHENOTYPING (Burton, Boomsma, Harris)

- To lay the groundwork for the harmonised approach for the assessment of complex phenotypes and life-style exposures.
- Major unipolar depression will be worked up in full



Specific aims



6 ETHICS and GOVERNANCE

(Harris, Knoppers, Pikani, Dixon-Woods)

- To establish ethical-legal and governance criteria consistent with the international norms and European practices.



Practical aims

Web-pages

Meetings

Pre-registration of analysis?

Publish all (negative) results

- Promote communication between major biobank initiatives
- Enhance effective sharing and synthesis of information
- Avoid expensive mistakes that can arise when individual initiatives “re-invent the wheel”



Structure

Workpackages (WP)

- WP1 Identification of potentially informative population biobanks in Europe
- WP2 Opportunities for future biobanking in Europe
- WP3 Databases and biobank information management systems
- WP4 Strategies for genotyping in large-scale biobanks
- WP5 Harmonising the assessment of phenotypes and life-style exposures
- WP6 Ethical, legal and social issues in population biobanks and in data sharing



Meetings



36 MONTHS

- Initial conference on population biobanks for health
- Concluding conference on population biobanks for health



Status

A technical problem arose during submission

We contacted the help-desk three times during the last hour before deadline

The proposal was finally delivered by e-mail 6 minutes past 17:00

The help-desk says that the special committee for eligibility of proposals will consider our application in January??



BIOBANKS for HEALTH NORWAY

The Norwegian Network of
Human Research Biobanks and
Health Studies



Components

CONOR

Cohort of Norway - 200 000 adults
167 000 to date with blood samples

MOBA

The Norwegian mother and child cohort study
a cohort of 100 000 pregnant women,
100 000 children and 70 000 fathers = 270 000
>75 000 to date with DNA

Genealogy database

- Builds on existing and ongoing studies
- Includes biological samples and standardised health and exposure data

