3.5 BIOBANKING FOR EPIDEMIOLOGY

Chair: Prof. Gerhard A Zielhuis, The Netherlands

03-5.1 BIOBANKING RESEARCH AND INFRASTRUCTURE DEVELOPMENT: A FUTURE FOR MERGING MOLECULAR STUDIES AND EPIDEMIOLOGY

doi:10.1136/jech.2011.142976b.1

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Biobanks are a key resource in unravelling the association between genetic background, life style and environmental risk factors for various diseases and their trait components.

Throughout Europe, and worldwide as well, major activity has started to connect the dispersed arena of existing and newly established population and clinical biobanks. In Europe, this initiative, BBMRI for Biobanking and BioMedical Resources Research Infrastructure, has just completed its "preparatory phase" led by Kurt Zatloukal (Graz), involves ca 50 participants and 200 associated participants, and is in the process of establish a legal European entity, BBMRI-ERIC. BBMRI aims to improve biobank accessibility and interoperability by harmonising similar biobanks in different locations, enriching the genotypic and phenotypic informational content and wherever possible achieve a more even ethical framework. This will greatly facilitate the development of public-private partnerships in merging molecular research and epidemiology, a prerequisite to improve future medicine. In many European countries national BBMRI's have emerged, often funded by the national governments. Examples will be given of the programme to develop research-based infrastructure improvement by initiating and enhancing joint research.

03-5.2 UK BIOBANK: THE NEED FOR LARGE PROSPECTIVE EPIDEMIOLOGICAL STUDIES

doi:10.1136/jech.2011.142976b.2

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Scientists have known for many years that our risks of developing different diseases are due to the complex interplay of different factors: our lifestyle and environment; our personal susceptibility; and the play of chance. But, despite this longstanding awareness, a clear picture of the combined effects of different factors on the risks of different diseases in different circumstances is yet to emerge. For the comprehensive and reliable quantification of the combined effects of lifestyle, environment, genotype and other exposures, prospective studies have a number of advantages. As well as allowing effects on a wide range of different conditions to be studied, exposures can be assessed prior to disease development, which avoids recall bias and allows investigation of factors that might be affected by disease processes and treatments, or an individual's response to developing some condition. Prospective studies are also able to assess those conditions that cannot readily be investigated retrospectively and can include all cases that have high fatality rates. Cohorts to date have typically been characterised by small numbers of disease cases (which may yield unstable estimates due to random variations), incomplete or inadequate measures of potential risk factors (which may yield systematic under-estimates of disease associations) and incomplete or inadequate measures of confounding factors (which may yield over- or under-estimates). Consequently, to help assess the main causes of various chronic diseases quantitatively, there is a strategic need to establish some large blood-based prospective studies of well phenotyped individuals, with prolonged and detailed follow-up of cause-specific morbidity and mortality.

03-5.3 STRING OF PEARLS, A SUCCESSFUL EXAMPLE OF A CONSORTIUM OF CLINICAL BIOBANKS

doi:10.1136/jech.2011.142976b.3

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The eight Dutch university hospitals in the Netherlands have joined forces to create a national research infrastructure for translational research. Initially eight national patient cohorts (the "pearls" are created, with DNA and other biomaterials stored in a biobank and clinical data available in one central database.

In the future, activities will be expanded to include additional patient cohorts. Since 2007, on a national level, specialists agreed on phenotypes to include, minimal datasets and use of standardised procedures to collect high-quality data in the setting of routine clinical care. Legal and ethical procedures were put down, sample processing and biobanking procedures were harmonised between the university laboratories, and data harmonisation models were created.

This is an example of how, through collaboration, a larger scale can be obtained to allow clinical research. These clinical biobanks are expected to contribute to more rapid evaluation of the effectiveness of therapies and the development of personalised treatment strategies.

03-5.4 DATASHIELD: INDIVIDUAL-LEVEL META-ANALYSIS WITHOUT SHARING THE DATA

doi:10.1136/jech.2011.142976b.4

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Contemporary research in biosocial science can demand vast sample sizes. Often, data must be aggregated across several studies or data sources to provide adequate power. When a pooled analysis is required, analytic efficiency and flexibility are typically best served by combining the *individual-level data* from all sources and analysing them as a single large data set. But valid ethico-legal constraints can prohibit or discourage the sharing of individual-level data, particularly across jurisdictional boundaries. This leads to a fundamental conflict between competing public goods. DataSHIELD (*Data Aggregation Through Anonymous Summary-statistics from Harmonised Individual-levEL Databases*) provides a simple approach to analysing pooled data that circumvents this conflict. Modern distributed computing is used and advantage taken of the properties of the algorithm that iteratively updates parameter estimates in generalised linear modelling. The presentation will cover the need for DataSHIELD, its theoretic basis, opportunities and challenges, and how to find out more.

03-5.5 LEGAL-ETHICAL ISSUES RELATED TO ACCESS TO BIOBANKING AT INTERNATIONAL LEVEL

doi:10.1136/jech.2011.142976b.5

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Significant amounts of resources, often public, are invested to setup large research infrastructures (biobanks) and cohorts.

The technical challenges of connecting these research infrastructures are increasingly being met by new IT solutions. Harmonisation tools—like the one developed at P3G- enhance our capacity to synthesise data. As this opens new opportunities for research and increase statistical power, these research infrastructures hold enormous potential for epidemiological research.

The issue of "access" is central to epidemiological research. Once a set of "interesting" data has been targeted, the researcher must overcome the ethical, legal and other conditions to actually access the data and samples of interest. In addition, study specific conditions (eg, access to aggregate data only) may limit the choice of methodologies to analyse synthesizable data.

A more "open access" culture for research data requires properly managing and accessing the massive amount of potentially sensitive information in a way that will be of optimal use for the scientific community while also ensuring proper protection and respect of participants (including their privacy and confidentiality). The "law" is often blamed for creating "undue hurdles" to international access to research data, but are we focusing on the real problem?

We will discuss some *ethical, legal and social issues* challenges faced by researchers who wish to access multiple research infrastructures to conduct epidemiological research. We also identify avenues of innovative solutions being proposed to meet some of these challenges.

03-5.6 STANDARDISATION OF CLINICAL AND PERSONAL CHARACTERISTICS USING INTERNATIONAL STANDARD NOMENCLATURE AND ICT SOLUTIONS

doi:10.1136/jech.2011.142976b.6

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The compilation, retrieval, use, storage, and distribution of genotypic and phenotypic data associated with the collection, storage, processing, and distribution of biomaterials managed by biobanks is insatiable. Clinical trials, observational studies, and fundamental basic science research is "pre-qualifying" biomaterials sought and used in research based on the quality of data submitted with a biomaterial as well as the quantifiable data associated with its processing. Additionally, longitudinal designs to study the course of disease may require multiple specimen submissions tied with its time specific associated phenotypic data. Furthermore, significant attention is being given to defining "clinical data elements" or CDE's to assure that data with the most significant clinical relevance are collected at each time interval. Clearly, it is no trivial task to define a CDE and correlate its potential relevance to the research enterprise. This presentation will discuss how said data are collected, evaluated for its relevance (power), and how it is made available to the scientific community using the Coriell Personalised Medicine Collaborative and Coriell's biobanking models as case presentations.

3.6 EARLY CAREER RESEARCHERS SESSION

03-6.1 PUTTING EMERGING EPIDEMIOLOGIST'S VOICES ON THE MAP

doi:10.1136/jech.2011.142976b.7

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This Early Career Researcher (ECR) session will be the first such session at an IEA World Congress of Epidemiology. The session is being held in order to build on the work of an ad hoc ECR Committee which has prepared a report to the IEA Council recommending the creation of a formal IEA ECR group. The session will report on what the ad hoc committee has been doing, and get feedback and suggestions on how to proceed, as well as have a discussion with Professor Cesar Victora and Professor Shah Ebrahim about how to make health research work towards development. It is hoped, and intended, that the incoming IEA Council will then formally establish an ECR group within IEA. This group would aim to develop a network of emerging epidemiologists to enhance global scientific collaboration. We look forward to the active participation of early career epidemiologists from across the world in this session as it will be an extraordinary opportunity to establish a global dialogue among early career health professionals engaged in research and teaching of epidemiology.

Wednesday 10 August 2011
Parallel session 4
4.1 SPECIFIC CHALLENGES TO GLOBAL HEALTH

Chair: Dr. Vinod K Srivastava, India

04-1.1 NEONATAL CONDITIONS AND AUTISM SPECTRUM DISORDERS

doi:10.1136/jech.2011.142976b.8

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Background Autism spectrum disorders (ASDs) are disorders of neural development characterised by impaired social interaction and communication, and by restricted and repetitive behaviour. Only few previous studies have investigated neonatal conditions and the risk for ASDs.

Objectives To use Danish population based sample and register based information to investigate whether neonatal conditions are associated to the later development of ASD.

Methods A Danish population based cohort study, including all singletons born in Denmark from 1994, through 2005, a total of 581 493 children. Data were retrieved from the Danish National Hospital Register and the Danish Psychiatric Central Register. Data were analysed using Cox proportional hazards regression. All analyses were stratified by gestational age (term vs preterm birth).

Results A total of 4846 children were diagnosed with ASD during the follow-up time. We found an increased risk of ASD after exposure to a variety of neonatal conditions. For children born at term, we found an increased risk of ASD after perinatal hypoxia: HR 5.0 (95% CI 2.1 to 11.9), neonatal seizures: 2.2 (1.4 to 3.5), intracranial haemorrhage: HR 3.0 (1.4 to 6.2), neonatal hypoglycemia: HR 1.5 (1.3 to 1.8), and neonatal septicaemia or meningitis: HR 1.8 (1.5 to 2.2). The results for children born preterm were similar as for children born at term.

Conclusions Different neonatal conditions are likely to cause neurological damage and alter brain development, and hence increase the risk of ASDs. This effect seems to be mediated through different pathways including lack of oxygen, glucose, and possibly through activated immune function during early neonatal life.

04-1.2 IDENTIFYING AN OPTIMAL EXPOSURE METRIC FOR MEASURING THE SHORT-TERM EFFECTS OF LOW INDOOR TEMPERATURES ON ASTHMATIC CHILDREN'S LUNG FUNCTION

doi:10.1136/jech.2011.142976b.9

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Introduction Many epidemiological studies have shown that low outdoor temperatures lead to increased mortality and