

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

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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

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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

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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

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