

3.5 BIOBANKING FOR EPIDEMIOLOGY

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

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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

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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

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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

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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

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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.