

EUCCONET seminar

International access to cohort data

Date : 8th July 2013

Location : Institut National d'Etudes Démographiques (INED) – 133 boulevard
Davout – 75020 Paris – France

The ambition of the European Child Cohort Network is to bring together leaders of national or regional major child cohorts in order to compare practices, exchange experience, share questionnaires and other tools, and encourage comparative analyses. The focus of this network is on generalist cohorts that combine health and social sciences.

Many countries in Europe and beyond have invested large amounts of resources, time and research commitment into large scale generalist cohorts, as they believe they represent an invaluable tool to understand the development of the individual in a dynamic perspective. These cohorts represent a very promising source for future understanding of child and adult well-being, especially if comparative analysis between cohorts could be developed.

However, if one is to promote the cross-country comparison of cohort data as a tool to enrich research findings, organizing transnational access to the data collected is a concern that should be tackled explicitly by cohort organizers. Cohort studies are complex projects that generate vast amounts of data over long periods of time, and cohort data are complex to handle. They raise specific ethical issues as they gather large amounts of data on the participants and they must keep their identities for the follow-ups.

This workshop intends to build on recent work carried out since the beginning of the EUCCONET network on the main issues identified with regards to international access to data. The objective is to gather several interesting initiatives rather than going into the technical issues of cohort data access organization.

Draft programme

10.00 – 10.45

Welcome and introduction (Henri Leridon and Heather Joshi)

10.45 – 11.15

How the French cohort prepared its dissemination tool. Insights into the ELFE PANDORA system – Ando Rokotonirina, ELFE cohort

PANDORA is the data management system of the Elfe cohort. It manages a highly secure storage of survey data in the study while it is able to automatically provide specific anonymised data sets on request. The longitudinal nature of the data led to enforce special arrangements to organize the provision of data. Ensuring a good understanding of the data structure, a good readability of the data to be selected but also complying with the safety requirements imposed by the data control authorities were the major objectives taken on board in the preparation of the platform. This presentation will focus on the progress of work towards the establishment of the PANDORA information system and how satisfying all

the actors involved (collector, researchers, authority control data) has been thought in the management of a huge number of data collected at various time in a large longitudinal cohort.

11.15 – 11.45

The CLOSER initiative - Jane Elliott, Director of the Centre for Longitudinal Studies

This presentation will provide an overview of the new CLOSER initiative. CLOSER aims to maximize the use, value and impact of the UK's cohort and longitudinal studies. Bringing together nine leading studies, CLOSER works to stimulate interdisciplinary research, develop shared resources, provide training, and share expertise. In this way CLOSER is helping to build the body of knowledge on how life in the UK is changing – both across generations and in comparison to the rest of the world. CLOSER is funded by the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC). Visit www.closer.ac.uk. The presentation will also provide some exemplars of previous research based on cross-cohort comparisons and will discuss the specific ways in which CLOSER is working to facilitate more comparative analysis.

11.45 – 12.15

Pregnancy and birth cohorts in Europe - an opportunity for etiological child health research – Pernille Stemann Larsen (University of Copenhagen, Department of Public Health)

The many pregnancy and birth cohorts in Europe provide unique opportunities for examining associations of intrauterine and early-life exposures with child development and health. To exploit the large amount of available resources, it is necessary to have accessible information regarding these cohorts and their individual characteristics. As part of the pan-European CHICOS-project a web-based database, www.birthcohorts.net, has been updated in order to provide an overview of the European pregnancy and birth cohorts. Experiences from this work will be presented.

12.15 – 12.45

Questions and reactions

12.45 – 14.00 – Lunch

14.00 – 14.30

Use of data from two or more European birth cohorts – is it worth it? - Katrine Strandberg-Larsen(University of Copenhagen, Department of Public Health)

Combining data from European birth cohorts increases statistical power, address European diversity, and permits replication of findings. Together, this can ideally improve causal inference and makes it possible to study rare outcomes. The wide range of data collection methods that have been used across European cohorts poses a great challenge when combining data from these cohorts. Experiences from two CHICOS-studies (one still in progress), and experiences from the three largest Scandinavian cohorts will be presented.

14.30 – 15.00

Sample and Data sharing in the era of "big data" in biology - Anne Cambon-Thomsen, (CNRSUMR U 1027, Inserm, Univ Toulouse III - Paul Sabatier)

Data as well as biological sample international sharing is paramount in a growing part of health research. While policy declarations encourage such sharing a number of difficulties and needs are identified in practice to "make it happen". Considerations about the evolving legal framework regarding exchanges of biological samples (no unified legal EU framework for research, but heterogeneous national legal systems) and personal data protection (Directive in revision) will be exposed as well as initiatives to facilitate sharing. In particular examples will be taken in various

consortia and projects: the P3G consortium (Public population projects in genomics and society, <http://p3g.org/>), the international consortium on cancer genomics (ICGC <http://icgc.org/>), European infrastructures such as BBMRI : (Biobanking and Biomolecular Resources Research Infrastructure <http://www.bbmri.eu/>) or ESGI (European sequencing and genotyping infrastructure <http://www.esgi-infrastructure.eu>) and other EU FP7 projects (GEN2PHEN, www.gen2phen.org : Genotype to phenotype databases: a holistic solution, BioSHaRe : Biobank Standardization and Harmonization for Research Excellence in the European Union www.bioshare.eu). The focus will on tools to foster sharing at various levels, especially hSERN (human sample exchange regulation navigator: <http://www.hsern.eu/>) that gives information on theoretical and practical legal aspects for exchanging biological samples across borders and the initiative on BRIF (Bioresource research impact factor : <http://www.gen2phen.org/groups/brif-bio-resource-impact-factor>) that aims at providing ways to recognise the efforts to make available valid bioresources and at measuring their use. Thus from policy willingness to incentives in practice a whole culture of samples and data sharing is on its move, but not without difficulties.

15.00 – 15.15 – Coffee break

15.15 - 15.45

International access to official micro-data. Insights into the DwB project - Roxane Silberman, Data without Boundaries (DWB) project coordinator

The Data without Boundaries – DwB – project exists to support equal and easy access to official microdata for the European Research Area, within a structured framework where responsibilities and liability are equally shared. Europe needs a comprehensive and easy-to-access research data infrastructure to be able to continuously produce cutting-edge research and reliable policy evaluations. DwB enhances researchers' transnational access to official micro data through coordination of existing infrastructures, Council of European Social Science Data Archives ([CESSDA](http://www.CESSDA.org)) and the European Statistical System ([ESS](http://ec.europa.eu/eurostat)).

15.45 – 16.30

Discussions

16.30

End of meeting