EUROPEAN SCIENCE FOUNDATION
SETTING SCIENCE AGENDAS FOR EUROPE

RESEARCH NETWORKING PROGRAMME

EUROPEAN CHILD COHORT NETWORK (EUCCONET)

Standing Committee for the Medical Sciences
(European Medical Research Councils, EMRC)

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Introduction

EUROPEAN CHILD
EUCCONET
COHORT NETWORK

Despite its cost, the ethical and methodological issues it raises and time constraints on analysis, the cohort study is of strong interest to decision-makers and researchers in quest of new behaviours. Whereas longitudinal retrospective studies can reconstruct the past histories of individuals, they can only do so in a way that is subject to memory lapse. The *prospective* approach of cohort studies is more directly adapted to the information needs on current and future trends in population and can capture a variety of information that cannot be recalled. *Longitudinal* studies of children constitute a unique source of data to analyse human development in its context. They permit the study of the various factors all interacting during the life course up to adulthood: family structure, social and physical environment, schooling, health and nutritional behaviour, etc. They also clarify the impact of the experience lived during infancy on the individual's physical, psychological, social and professional development and therefore help the progress of research in many different disciplines.

While offering very valuable sets of data, cohort-type studies demand a very complex organisation and often raise important discussions on methodology issues as regards sampling, methods of data collection and storage, types of data collected, etc. Mostly, they also require the collaboration of many actors as well as the assent of various committees. All these factors make the cohort study a very ambitious venture. Despite this, many such studies, most of which focus on very specific issues, are conducted throughout Europe and are concentrated in specialist networks. However, there is no network for birth and child cohort studies, which assess the physical and psychological development of children in a multidisciplinary light.

This is why teams in Europe gathered to request support from the ESF in order to create the European Child Cohort Network (EUCCONET). The aim of this Research Networking Programme will be to offer an opportunity to several research teams in Europe to share knowledge and experience, and to enter into international collaborations. The ESF funding will also be used to create a web portal linking several cohorts and networks together, and to provide an international inventory of child cohorts as well as a database of available tools and literature.

The running period of the ESF EUCCONET Research Networking Programme is 5 years from May 2008 to May 2013.

Background

Whatever the field, be it health or social sciences, the analysis of longitudinal data on children is the best way to understand relations of cause and effect and to examine child development in the round, from the different perspectives of family, social and economic backgrounds, social interactions and health. The ESF interdisciplinary programme on Social Variations in Health Expectancy in Europe has stressed the importance of life-course analyses to be able to explain (and not only describe) variations in the health of individuals belonging to various groups. The value of this approach has been shown, e.g. in Kuh's[1] book or in a special issue of the *International Journal of Epidemiology*[2]. At each age the behaviour and the health status of an individual depends on his whole previous history, not only on his current situation. To assess properly the major steps in this history it is necessary to adopt a *life-course approach* based on the continuous collection of data that could otherwise not be reconstructed retrospectively. This is even truer for events occurring during childhood which may remain unknown or be poorly remembered by the adults involved with the child.

In September 2006, an international conference on child cohort studies took place in Oxford, organised by the Centre for Longitudinal Studies and funded mainly by the Economic and Social Research Council (ESRC). It attracted more than 200 participants from around the world and was an opportunity for European research teams to discuss their own experience, the design of cohorts and related methodological issues. This conference was the first of its kind, and, given its success, could form the first of a series, as yet unfunded. The Oxford conference was also an opportunity to observe the gap at European level, as no forum for discussion exists for researchers to exchange on the methodologies adopted by each of the national teams in the longitudinal studies. Building on the Oxford conference, leaders of child cohort studies felt that the moment had come to fill this gap, by organising a forum which will provide support for common methodological issues, while working towards a possible convergence and a better comparability of child cohort studies in Europe.

The European Child Cohort Network gathers cohorts of regional and national size with a population-based sample and an initial focus on children. The stress is on birth and child cohorts that study multiple aspects of the child's development, ranging from its psychological development and biological changes, to its social environment and environmental exposure, and this at several stages of its childhood. Therefore these studies deal with a lot of data, including biological samples, and require the cooperation of several teams in several institutions. The multidisciplinary aspect adds some difficulty to the task. These are all characteristics that justify the need for such a network.

These 13-14-year-old members of the Avon Children of the 90s cohort study based in Bristol, UK, have gathered at the study's clinical centre for physical measurements which will provide data on fitness, growth and body fat, along with blood samples.

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[1] D. Kuh and Y. Ben-Shlomo (eds), *A Life Course Approach to Chronic Disease Epidemiology*. Oxford, Oxford University Press, 1997; D. Kuh and R. Hardy (eds), *A Life Course Approach to Women's Health*. Oxford, Oxford University Press, 2002.

[2] *International J. of Epidemiology*, 31 (2), April 2002, p. 285-420.

Objectives

Reconcile through one survey, social, health and environmental aspects of child development

Some specialised thematic networks already exist and the objective of EUCCONET is not to replicate what has successfully been done elsewhere. The focus of this network is on large-scale and generalist cohorts, and its originality will lie in the interdisciplinarity of the themes to be covered: researchers involved in these studies tend to find ways to reconcile through *one survey* social, health and environmental aspects of child development.

Within this context the objectives of EUCCONET are to:

- **Enhance the visibility and the synergy between child cohorts** and among the different European teams involved.
- **Identify the best expertise in Europe** on cohort methodology. Links between large-scale and generalist cohorts will be strengthened, but the objective is also to call on the experience of limited-scale, regional cohorts, or very specific epidemiology and medical cohorts which may have already encountered similar methodological issues.
- **Perform a mapping exercise at the European level** of the diversity and similarities in methodology in order to identify common methodological, scientific and ethical questions.
- Making the network **a single access point** of expertise for Child Cohorts in Europe, able to gather a scientific community of interested stakeholders and to diffuse methodology advice to potential newcomers.
- **Initiate new and in-depth collaborations** between scientific teams which could lead to comparative analysis, using common questionnaire modules, develop standardised questionnaires, and identify potential issues where comparative analysis could be undertaken.

The objectives of the network will be to increase awareness and knowledge, by providing a forum for discussion and an easy access to world-class expertise in the field. It will create and consolidate a scientific community working in a very specific field and producing data. It will also participate in the convergence of cohort studies in Europe and on the comparability of data at the European level on a policy-relevant issue: child development.

Activities

Sharing experience and best practice

Through its main partners, the programme benefits from the experience and skills acquired by leading European, American, Canadian and Australian scientists in this field. A wide range of expertise will be mobilised for the programme, ranging from demography, sociology, epidemiology, or medicine, as well as methodology skills in conducting surveys.

The partners involved in the network are leaders of major national or regional child cohort studies which are at different stages of advancement. This makes it very beneficial for those studies which are just starting as they will benefit from the expertise of more experienced cohorts. The desires and needs expressed by these new teams will lead the way to organising science meetings that we know to be of great interest to many scientists. These meetings will be an opportunity for all to present their different experiences and practices in specific fields, opening an unprecedented forum for exchange. Apart from setting targets and standards in the methodology of cohort studies, these meetings will help new teams to avoid making mistakes, thus giving more chance of success to their study.

In order to do this, *interest groups* will be created to study specific themes. One important point is that these *interest groups* are open to cohort leaders and team members so that everyone can benefit from the opportunities given by the network to learn and share. For example, a specific working group will be created to discuss *data management*, i.e. all the computer systems used to store, secure and anonymise the data, whereas data managers mostly do not get to meet their international counterparts. Expertise and the synergies with existing specialised cohorts and networks will also be sought in order to develop sound discussions on specific methodology issues.

Several themes have already been defined to be studied during the first two years of the programme. The first theme was discussed at the opening workshop:

- **Securing consent from parents and children –** Consent is a very important issue since the participant's consent is needed for the cohort study to start in the first place. This raises a lot of questions such as: whose consent is required? At what point should the child's personal consent be asked? What form should the consent have? Should the participant be informed upfront of the long-term aspect of the study? Consent is also linked to the different national legislations which may have specific requirements.
- **Specific instruments for measuring child development –** This group will cover the measurement of health outcomes alongside cognitive and socio-emotional development of children.

- **Designing specific materials for child interviews –** Obviously children are an audience which requires very specific material adapted to their age and level of perception and understanding. It is important to know from what point the children can be personally interviewed, what questions can be asked at what age and how the study should be presented to them so as to ensure their willingness to fully participate. This requires specific materials and techniques to communicate with children.
- **Different modes of data collection –** There are different ways of collecting data: face-to-face interviews, phone interviews, questionnaires sent by post; should the participant be met at school, at home or in a specific place? Although this greatly depends on various factors such as the type of data being collected, from whom and at what stage, this interest group will try to define the pros and cons for each mode of data collection.
- **The role of fathers in child cohorts –** At the early stage, most cohorts interview the parents in order to have information on the child's environment and behaviour. In most cases mothers are more involved in the study, which raises the issue of the role of fathers in cohort studies. Certainly they would bring another view of their child than mothers do. But the issue of fathers raises the question whether the biological father or the everyday-caring father should be taken into account (this depends whether the focus is on genetic follow-up or day-to-day social environment and exposure). How should fathers be included in the studies? How should cohort studies deal with a couple's break-up, new unions and non-resident fathers, etc.?
- **The maintenance of large cohorts –** The European Child Cohort Network focuses on studies having a sample size of a minimum of 1 000 children, but most cohorts represented deal with much bigger samples. A lot of questions are linked to this factor: How do we ensure the participation of the families in follow-up surveys and into the long term? What means are used to keep track of respondents and retain their consent to participate? Another aspect of cohort maintenance is the problem of assuring funding from short-term sources for a long-term enterprise.
- **Record linkage –** It is very interesting for cohort studies to be able to link the data collected to other existing data, for example, in police or social security files, about the people being followed. This can be very easily done such as in Norway where each person gets one single identity number at birth which is used in all aspects of his/her administrative life, but can be very difficult when all administrations use different numbers, which is mostly the case in European countries. Which information is relevant? Does this linkage require another specific consent from participants? How should the linkage be technically managed?
- **Methods for data analysis –** Analysing longitudinal data requires specific tools, to take into account the succession and repetition of events, attrition, missing data, etc.
- **Acceptability, feasibility, and ethics of collecting biological samplings from children –** In addition to the questions raised when biological samples are taken from adults (e.g. not exposing the donors to any significant negative side-effect), taking samples from children have specific aspects, such as the limitation on volumes sampled, the indirect consent (given by parents) and 'ownership' of samples stored, etc.

International collaborations

The network will also offer all partner research teams the opportunity to meet within the framework of exchange visits that can last from one day to six months. These visits should be used to start or deepen bi- or multilateral collaborations in order to create common tools, share data, compare data content and structure, derive comparable variables, understand contextual differences, conduct comparative analysis, etc.

All teams have already shown great interest in this possibility.

Website

One major milestone of the network will be the creation of a website that should become a single access point in Europe for information on child cohort studies.

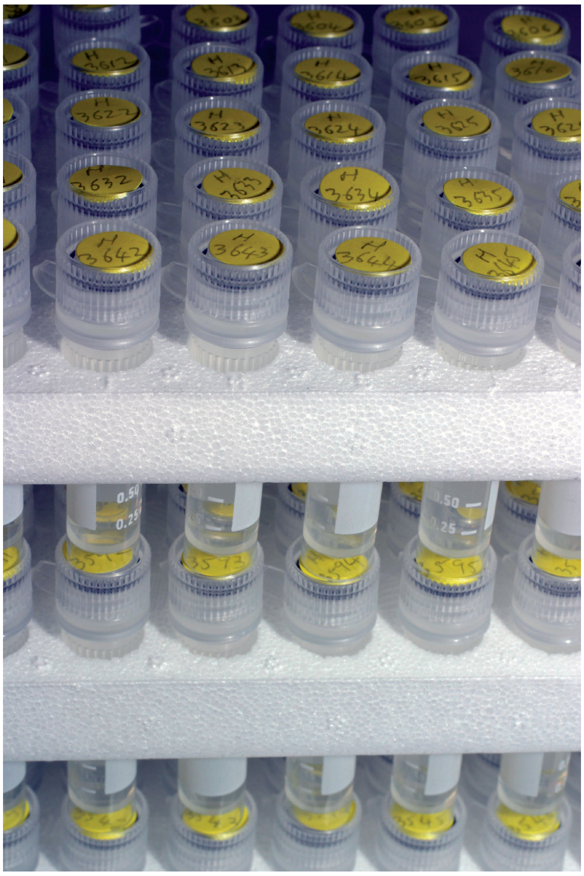
One mandate was to create an inventory of all child cohorts in Europe but it appears such an inventory already exists. The website **www.birthcohorts.net**, which was created and filled as part of several EC projects, presents an inventory of cohorts with specific focus (nutrition, genetics and environmental exposure). Since EUCCONET does not wish to create an overlap with these initiatives, it decided to collaborate with those projects and to complement the site, where needed, with information on cohorts not falling within the scope already covered. Therefore the inventory proposed on the EUCCONET website will list European and international child cohort studies, publishing only minimal information, and link them to their official website or/and to their description in **www.birthcohorts.net**. As such, the EUCCONET website will be a general portal, the first and only one to cover child cohorts from all disciplines (social sciences, health, environment etc.).

The EUCCONET website will thus focus primarily on making an inventory of methodological documents, such as publications or articles interesting to the field, as well as technical documents used in the various cohorts.

If some documents are already available on the Web (mostly on the cohorts’ official websites), EUCCONET will create direct links to them, according to the specific thematics they refer to. As a matter of fact, most cohort studies already put a lot of their tools online, but it will be the first time that these are linked together within a thematic database open to all. A forum should also be put in place in order to allow researchers around the world to freely discuss any specific issue related to child cohort studies.

Moreover, the website will compile news from different sources on child cohort studies around the world. It will also communicate on all network events and make all resulting outcomes available.

The existence of the website will be widely disseminated so as to ensure the visibility of the network as well as of the methodology toolbox to any research team planning, starting or conducting a cohort study. This again follows the network’s principle of not being reserved to a few people but to have anyone interested benefit from the work being achieved within its framework.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Example of sample storage for automatic retrieval systems.

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For the latest information on this Research Networking Programme consult the EUCCONET website: **www.esf.org/eucconet**

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