



FOOD-CT-2005-007036

EARNest

EARly Nutrition programming- long term follow up of Efficacy and Safety Trials and integrated epidemiological, genetic, animal, consumer and economic research

Instrument: Integrated Project

Thematic Priority 5.4.3.1: Food Quality and Safety

Final public report on activity: 2.1.1.

Title of activity: Identification of birth cohort databases in Europe

Period covered from 15.04.2005 to 14.10.2010

Start date of project: 15.04.2005

Duration: 5,5 Years

Organisation Name of Lead Contractor for this report: FIMIM

Identification of birth cohort databases in Europe

The identification of birth cohort databases in Europe followed different approaches. There are numerous mother-child cohorts (prospective studies of pregnant mothers and their children) in Europe. Some of them are well known long term cohorts that are easily identifiable, while other are new cohorts, sometimes of small size that are less easily identifiable. A first list of cohorts was created by researchers participating in EARNEST through personal knowledge of research in the area of mother child cohorts. This list was supplemented through PubMed searches and personal contacts.

At a first stage, we identified 32 ongoing pregnancy cohorts in Europe. Basic information for each cohort was recovered. Of those, only approximately half fulfilled basic criteria particularly size of the cohort, collection of exposure and outcome and biological samples and start of follow up during pregnancy.

The quality of information is widely different when examining overall the cohorts both concerning the study design (type of population enrolled, contacts, type of epidemiologic instruments used) and hypotheses tested. However, several of the largest EU cohorts that are following very similar protocols regarding the evaluation of exposures and outcomes. This is particularly so for the evaluation of nutritional factors for which several cohorts have used a variation of a common food frequency questionnaire. Among the main aspects to be highlighted was the absence of relevant information for wide parts of the EU population particularly in Eastern Europe.

A second step was the development of a one page questionnaire (see last page of the report) that was easily completed and that included basic information for each cohort. This was developed in conjunction with the ChildrenGenoNetwork Concerted Action. The questionnaire has been on purpose limited to one page to have maximum coverage of as many cohorts as possible. Information was requested on basic design items (such as number of mothers recruited, follow-up time), contact information on the research team, information on time of contact and person contacted (e.g. mother 3 months), information on type of exposures and outcomes recorded and on biological samples. The completion of the questionnaire has been on purpose made as simple as possible to maximise participation. The questionnaire was completed by nearly all cohorts contacted at the first phase and this information was included in the website that was created on pregnancy /birth cohorts (www.birthcohorts.net). The questionnaire was subsequently sent to new cohorts identified or self identified and these cohorts were asked to register in the birthcohorts.net website and include the relevant information. At present the birth cohorts website includes information of practically all mother-child cohorts in Europe and is the main source of systematic essential information of these cohorts.

Identification								
Cohort Name				Principal Investigator				
Key reference				Cohort Website				
Basic description								
Main aim of cohort, please gives keywords on main exposures and main outcomes								
Year(s) of enrolment (for ex. 1980-2004)			Enrolment		Gestational age at enrolment			
to			<input type="checkbox"/> completed <input type="checkbox"/> ongoing		<input type="checkbox"/> week 1-12 <input type="checkbox"/> week 13-18 <input type="checkbox"/> week 19 - 28 <input type="checkbox"/> week 29+			
<input type="checkbox"/> planned								
Source population							Country	
<input type="checkbox"/> nation-based <input type="checkbox"/> region-based <input type="checkbox"/> hospital-based <input type="checkbox"/> selected (high-risk, exposure etc.) <input type="checkbox"/> other								
Expected No. of participants when enrolment completed				Expected time of follow-up				
mothers:				fathers:				children:
Type of data collection	Pregnancy			Birth	Post natal			
Tick if data for the actual period is available	1. trimester	2. trimester	3. trimester	birth	0-6 month	7-18 months	18-60 months	5+ years
Questionnaire data								
maternal exposures								
paternal exposures								
offspring exposures								
maternal outcomes								
paternal outcomes								
offspring outcomes								
Biological samples								
maternal blood								
paternal blood								
cord blood								
offspring blood								
maternal other (urine, hair etc.)								
paternal other (urine, hair etc.)								
offspring other (urine, hair etc.)								
Amount and storage of bio samples, please describe (example: 5 ml EDTA cord blood, separated in buffy coat (-80°C), full blood on filter paper (-20°C), 3 vials of plasma (-20°C). Placenta: 3 cotylones in - 20°C)								
Exposures and outcomes available in the cohort								
Exposures:			<input type="checkbox"/> medication		<input type="checkbox"/> environmental		<input type="checkbox"/> occupation	
<input type="checkbox"/> tobacco, alcohol			<input type="checkbox"/> social position		<input type="checkbox"/> psychological		<input type="checkbox"/> nutrition, pregnancy	
<input type="checkbox"/> health services			<input type="checkbox"/> other, specify		<input type="checkbox"/> nutrition child			
Outcomes:			<input type="checkbox"/> milestones		<input type="checkbox"/> birth defects		<input type="checkbox"/> infections	
growth/obesity			<input type="checkbox"/> neurodevelopment		<input type="checkbox"/> asthma/allergies		<input type="checkbox"/> pubertal development	
immunity			<input type="checkbox"/> other, specify					
Data planned to be collected								
Please describe plans that are funded or most likely to be funded								
Register-based follow-up								
Please describe types of registers (e.g. death, cancer)								