Kick-off Meeting

Deliverable 2: Workshop 1 – Report 1

Barcelona, 26-27th April 2010

A project conducted within the European Union’s 7th Framework Programme
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CHICOS Kick-off Meeting - 26-27 April 2010 - Barcelona

Present: Anne-Marie Nybo Andersen (AA), Maribel Casas (MC), Leda Chatzi (LC), Liesbeth Duijts (LD), Diana van Gent (DG), Elisabeth Hagen (EH), Vincent Jaddoe (VJ), Manolis Kogevinas (MK), Debbie Lawlor (DL), Patricia Lucas (PL), Per Magnus (PM), Marco Martuzzi (MM), Franco Merletti (FM), Mark Nieuwenhuijsen (MN), Emanuele Pivetta (EP), Hein Raat (HR), Lorenzo Richiardi (LR), Camilla Stoltenberg (CS), Jordi Sunyer (JS), Antoni Taradach Plasència (AP), Martine Vrijheid (MV).

Apologies: Kevin McCarthy (EU officer)

Day 1 – 26th April

Welcome and introduction

JS (CREAL co-director) welcomed participants to CREAL, and highlighted the importance of the project to the CREAL. The Scientific Advisory Committee of CREAL had recommend that CREAL play a larger role in coordination of child health research at European level.

MV (CHICOS coordinator) introduced the project and explained the concept and main objectives of the project, and the strategy for accomplishing these objectives. It was highlighted that research is not part of this coordination project, but that case studies may be needed to evaluate specific issues. CHICOS will focus on main European child health policy issues. Eastern European issues need to be tackled in each WP. As emphasized by our EU Officer, Kevin McCarthy, the objective is to clarify where investment in birth cohort research should be focussed in future strategies.

Importantly, CHICOS will build on existing projects in the field of birth cohort and child health research such as ENRIECO, RICHE, EUCONNET, and more EC topic-specific projects (Gaalen, ESCAPE, EARNEST, etc).

The Kick-Off meeting has as main aim to discuss the protocols and workplans of each WP, so that protocols can be delivered to the EC in month 6. The first session of the meeting will discuss the needs of policy makers with input from outside speakers familiar with the policy field.
Policy-Research Interface: "What do policy makers need from child cohort researchers?"

Local View - Antoni Taradach Plasència

Antoni Plasencia (Public Health Director, Ministry of Health, Catalonia) outlined strategies for health policy making in Catalonia. “Health” is key to many policies, also outside the public health field. The contribution of cohorts in policy making are to identify new emerging problems and measurement, problem surveillance, providing hypothesis, testing, health impactasses, evaluation and improving information systems. The best information is used to take action, which may also mean that no action is taken.

International View - Marco Martuzzi

Marco Martuzzi (WHO Europe Office) introduced the efforts WHO has been making to develop the Children's Environment and Health Action Plan for Europe (CEHAPE). Specifically, the WHO has been at the forefront in engaging policy makers in this field. The Fifth Ministerial Conference in Parma that has just been held in Parma for this purpose. The Parma declaration is the first time-bound outcome of the environment and health process, yet it is not legally binding but by consensus which proves commitment to equality in access to basic life needs and strengthening eastern/southern EU relations.

Policy-Research interface in the CHICOS context - Patricia Lucas

Research has to be policy focussed, but the problem is that the needed answers may not come for decades due to the timescale of research projects. Project coordinators should engage with stakeholders, reflect on added-value of work and prepare easily readable findings. For policy relevance we need to look at the current impact of cohort studies to date. Lessons for CHICOS:

- Big enough datasets enable cohorts to recommend significantly: pan European and within nations
- Instrumental change suggestions
- Conceptual changes: causal relationships where randomised control data are not available.

Panel Discussion

Q: How does stakeholder involvement materialise?

(AP) Methodological, e.g. injuries, domestic violence are issues for concern – women groups are involved and contribute some close intervention. On air pollution issues: engage NGOs experienced in approaching policy making.

(VJ) There are two different directions in cohorts and policy: how results can inform policy and how policy addresses these findings; how cohorts can assess the policy questions.

(HR) Outcomes of cohort studies are informative of health problems and the effect.

(AA) Points out the example of an alcohol cohort which changed the public advice from ‘do not drink during pregnancy at all’ to ‘do not, but if you can’t leave, drink a little’, made no difference to actual drinking during pregnancy.

(AP) Politicians will look at what issues they have been voted in for, and may already have decided where the problem is and will be looking for the evidence. Policy needs research to make the decisions more consistent. Science adds rationalisation, not necessarily sophisticated information.

(CS) Embedding cohorts in registries would be useful, more evident.
e.g. MMR vaccine, what could cohort have added? Current cohorts are too young, small and thin. There are no biological samples. We should review successes (in the research policy link) but not base them only on current cohorts, but also on what may be possible with better infrastructure.

(MK) The cohort is a dominant study design in child health, we should look at other designs to make recommendations.

(MV) We need to raise awareness to policy makers, look at cohorts and other study design together.

(JS) Cohort studies can be very influential. Example in air pollution: 35000 papers, but for risk assessment, only few studies weighted with strong evidence and these were the cohort studies.

(MN) We also need to look at the failures: why are things not happening? Are things not happening because there is lack of scientific evidence? Failures are as important as successes.

(DL) Look at UK drug law, teenage pregnancy, etc, the attitude is to avoid policy makers as they won’t hear the evidence. It seems sometimes bets to stay away from the policy makers as they will try to influence the research evaluation process.

(PM) There are some decisions that research cannot response to easily in short time (for example vaccination of pregnant women against H1N1). However, we can evaluate these issues afterwards so that more evidence is available in the future.

(AP) Communication challenges: important to make CHICOS clearly visible. Research visibility is made difficult by the uncertainties.

**WP1 Cohort inventory – Anne-Marie Nybo Andersen**

AA provided an overview of aims and objectives and introduced the WP team. Close collaboration with WPs 2&3 are required. Deliverables: Searchable database M24 and scientific paper: M30. Cohort identification will use existing EC projects, CELSE meeting (most of the cohorts will attend), EUCCONET (more sociological) and contacts with cohorts where necessary. Pan-European registries will also be identified: IDB (injuries) EUROCAT- DNBC link (congenital malformations). Cohort definition of inclusion in the inventory needs to be decided; criteria may include: start latest at birth, more than 1000 children, more than one data collection point after birth.

(MV) Not the same level of information is necessary for each type of study, and not all need to be included in the web-based inventory. Information on outcome data has already been obtained through ENRIECO for 35 cohorts (see inventory questionnaire in meeting book). Are we including only birth or also child cohorts? Millennium cohort is a child cohort (start in first year of life). We may restrict population-based cohorts.

(AA) It is possible to identify 400 cohorts if we include small cohorts, patient cohorts, clinical trials, but it is difficult to manage all these data in a website.

(CS) We should focus on known cohorts and obtain contact details to invite all to future meetings.

(MK) The project description needs to be followed, areas can be added based on that. Birth and mother-child cohorts are the focus of the project and data collection for those should be more detailed. For other study types we may only need basic information. We can’t be seen not to reach beyond child health cohorts. Many hospital based collections, but not very helpful (too small or not following standards of research).

(FM) Start with constructing a list and check what information we need.

(LR) We cannot decide on the recruitment criteria at this moments as we need to know what is available.

(MC) ENRIECO: started with criteria, but flexible. Cohorts to be approached were defined at start, all interested cohorts happy to consider afterwards.

(AA) We have to make sure that cohorts don’t get contacted by all WGs – WP1 should be responsible for management of data collection.
**WP2 Research priorities - Camilla Stoltenberg**

CS provided an overview of the WP objectives, WG definitions and leads, and deliverables: protocol M6, report M36.

A large difference exists between the focus on EU region or EU countries, e.g. large differences in child mortality rate between 53 countries, and only half of the 53 WHO countries have a national registry in child health. We need to decide where CHICOS will focus. The current WGs cover 6 of 7 priority areas for EU context. The question here is how can cohort research contribute to policy making in these areas?

[CS] Links to relevant policy documents should be centrally coordinated as these are useful for the entire project. The intranet of the website can be used for this.

**Action: DG to coordinate central deposition of policy documents with WP4**

**WG Respiratory health - Liesbeth Duijts**

LD summarised the possible factors that contribute to asthma development. Existing international collaborations: ENRIECO, GA2LEN, EAGLE, GABRIEL (adult cohorts).

(MV) As the WG each encompass very broad areas of research we may not be able to answer all questions through literature reviews only. Each WG will have to make a broad report, but case studies may be required to give more relevant information on specific issues, to give answers on a specific set of questions.

(JS) Medal is a new project about Allergy but is under development. Objective: to collect new samples from cohorts.

**WG Obesity, and vascular and metabolic health - Debbie Lawlor**

DL introduced the WP and emphasised the need to characterise data and identify research priorities that benefit from collaboration. Existing collaborations: Pelotas, Raine, MUSP, Earnes, ENRIECO, GALEN, Metropolit, Young Finns, Raine, EYHS. The use of case studies may attract other cohorts to work with us. For this, there are two approaches to consider: cohorts can provide data and the WG performs the analysis or the WG provides a protocol/programme and the cohorts perform the analysis themselves.

(MK) Presented is a life course approach, focus on outcome for adults. What about the effect on children?

(CS) There may not be enough time or material for 1 or 2 papers in each WG, we should combine WGs and produce less but better papers to include the whole project.

(DL) Experiencing difficulty employing new staff due to the short contract (10 months) and lack of research focus.

(VJ) Possible to combine the 2x10 month posts to work in Rotterdam and Bristol/Copenhagen/Oslo?

**Action: DL to send job advert to DG for distribution across the ENRIECO network.**

**WG Neuro-cognitive and behavioural development – Jordi Sunyer**

JS introduced the WG and highlighted the very broad range of topics within neurocognitive and behavioural studies. (see presentation annex) Some existing reviews have already covered the different neuropsychological testing methods available for cohort research. This WG covers a very broad range of topics and would need case study(s) to examine specific issues. For
example an ADHD case study would be useful to highlight issues in data comparison across Europe. This is a topic of great current policy interest.

(MK) We have to start by defining what the important research questions are, and what the important policy questions are.

(CS) A case study has been done on ADHD (refers to Danish & Finnish studies), what about motor development, mental disability? We should figure out what the policy concern is and how to answer these questions.

(PM) Risk assessment and management are used in other areas, but not possible here. Cancer risk assessment is possible. Creating a link between science and politics through risk assessment as this is more recognisable.

(MM) Behavioural (as opposed to cognitive) studies are very important to policy demand. This is a very good case to focus on.

**WG accident and injuries – Martine Vrijheid**

This WG was added because of the great importance of injuries in the childhood disease burden, not because there is a great role of cohorts currently. We have not yet identified experts on this. *Who can we approach?* There could be a potential roles of (birth?) cohorts, but currently the area is heavily reliant on registries.

(HR) Generation R also includes questions on unintentional injuries, very important for public health, but prevalence (of serious injuries) low and highly diverse – limited funding. Suggests to move to behavioural approach but it is difficult to measure in the cohorts.

**Action: CHICOS and Generation R to work together on this topic**

**WG Childhood cancer – Manolis Kogevinas**

Childhood cancer is a rare but major cause of mortality, which has been on the increase in last decades. Large cohort numbers are needed (more than the 250,000 available in Europe). The I4C consortium is considering on genetic and non-genetic factors in birth cohorts world-wide. NewGeneris works on food contaminants and biomarkers for genotoxicity in maternal and cord blood. CHICOS will evaluate the work of these and other projects in this area.

(CS) I4C: initial phase, cohorts, genetics working group and environmental, lifestyle working group. First paper anticipated on paternal age.

**WG Infectious diseases – Camilla Stoltenberg**

*European health report 2009* – infant mortality has fallen with 50% in 90s. A great variance in rates exist and the causes of birth defects are largely unknown. Perinatal outcomes are closely related to future health outcomes. Limited knowledge about minority populations. Policy areas include (in)equity, etc. Existing registries contribute importantly in this area. Possible focus areas: preterm birth? Congenital anomalies - collaboration with EUROCAT? (MV is part of EUROCAT and leads WP in new joint action).

(CS) The Rome network focuses on minorities, what about a focus on pre-term birth and study variabilities?

**WG Communicable disease and immunisation – Camilla Stoltenberg**

This WG needs experts. Focus on vaccination issues – use of cohort data to evaluate immunisation effects? Interesting: NorFlu study – follow-up of 4,000 pregnant women and children after flu vaccination. Guidelines for when one should establish or add on to cohorts? Do countries have existing strategies?

(DL) Contact Andy Hall at London School for Hygiene and Tropical Medicine. He works on this with the BiB cohort.
**WP3 Research priorities for child health determinants - Vincent Jaddoe**

VJ provided an overview of the WP objectives, WG definitions and leads, and deliverables: protocol M6, report M36. This WP considers a very large range of risk factors. Reviews will have to focus on some topics. WP2 and 3 will work together to develop protocols, reviews, case studies, and will hold meetings together.

**WG Social and cultural conditions - Hein Raat**

Inequalities in health persist in all countries. Existing projects that consider child health inequalities include the International Research Network on Child Health Inequalities and RICHE. (MV) This is a WG with large policy interest – CHICOS was asked to strengthen this area. Strong work (case studies?) needed to highlight cohort contribution in this area.

**WG Nutrition and physical activity – Leda Chatzi**

As part of the EARNEST project some cohorts are already pooling data health outcomes and nutrition. Interesting policy topics include breastfeeding, pregnancy diet. Not much data of European cohorts on physical activity. (MV) Does WP1 need to collect new information from the cohorts on these topics? Through questionnaires? (LC) Data from EARNEST does not include breastfeeding. Their strategy is not clear, we should contact the key person from each cohort and collect some basic information for the inventory. (LR) We need to decide which topics to approach (mother, child, adolescent?), maternal seems key to CHICOS.

**WG Life-style and substance exposures – Per Magnus**

PM discussed alcohol drinking and tobacco: comparisons between countries; opposite effects for social and cultural determinants (alcohol high level in older, higher educated women with several children, smoking more in lower social classes), influence of family background on teenage drinking and smoking behaviour. Moderate alcohol intake is an important policy issue, a case study might consider moderate alcohol intake and behavioural problems. Paradoxical effects: alcohol v preterm birth, v cardiovascular disease, tobacco v preeclampsia. (CS) Risk estimates changed in literature over time, will it be interesting to assess comparison?

**WG Other environmental exposures incl ETS - Mark Nieuwenhuijsen**

MN outlined major exposures (see annex) and European collaborations, especially the ENRIECO project. As the ENRIECO project is already conducting basic reviews of many topics, it will be interesting for CHICOS to go further into topics of harmonisation and pooling. Case studies may include occupational exposure and birth outcomes, or persistent organic pollutant and ADHD. The ENRIECO inventory is available, so easy to check which cohorts have information.

**WG Biological and genetic factors - Vincent Jaddoe**

Biomarkers to analyse molecular basis of disease (see presentation). Existing collaborations include: BBMRI – similar to CHICOS focus; WP2 lead Markus Perola suggested to approach for information. P3G – large data inventory (p3gobservatory.org). EAGLE – start 2009, genome wide association studies – design similar to CHICOS, cohorts involved but not in core team (12 cohorts). CHICOS approach: develop inventory, review protocols, review recommendations for genetic and non-genetic biobanks.

**WG Multiple determinants, health impact assessment - Martine Vrijheid**
Strength of cohorts is wide ranging data on effects, confounders, at multiple time points. Traditionally research has focused on single exposure-outcome associations. But policy is shifting towards multiple factors (i.e. through integrated impact assessments) and cohort may have a role in this. CHICOS approach: review what has been done, review needs of tools used by policy makers in this area. For selling cohort research to the outside world it is important to show that we can integrate different topics.

(MM) Good idea to use cohort data to have a go a multiple exposures, this is high on the list of priorities (in environmental health policy). Childhood cancer is the best candidate, looking at combination of exposure and risk factors.

Integrated impact assessment is less clear. Families of complicated models to carry out impact assessment. A review of basic needs of these models would be enough, no need for case studies.

(MN) Epidemiologists are supposed to provide data but policy makers think in more practical terms about how one policy may influence different health outcomes and behaviours (cycling: physical activity, pollution, traffic injuries).

(DL) We should first define the research question.

(MK) Cohorts been successful at single factors, but not multiple interactions. Possibly at high toxicity levels, but not at low levels. CHICOS shouldn’t go into details. CHICOS can identify problems but not further. Gene-gene and gene-environment interactions are few and far in between.

General discussion WP2 and 3 focus

(AA) Would like to raise awareness of importance of life course research and data needs. Often funding for start of cohorts is available, but continuation is problematic. There are no ages in life where you are healthier than 11 years old, so difficult to get funding for continued follow-up. Priority to build an infrastructure. Can CHICOS show examples of why it is important to set up the infrastructure, to be the background for the 15 year continuation?

(DL) The extend to which we are trying to say what the benefit is of all the cohorts together rather than people continuing with separate cohort work. Is this part of the CHICOS remit?

(MV) This is an important question that CHICOS needs to tackle: Do we need coordination and infrastructure? what is the benefit? Does every WG have to discuss this separately? WGs could tackle this for specific health outcomes and behaviours but we as a group need to write an overall, integrated, strategy together. All WGs need to conduct the reviews to identify the gaps in research and geographical spread. But some topics will require case studies in order to answer more detailed questions about the benefits and problems with European coordination. Such case studies will have to be chosen strategically across Europe - if there is no strategic advantage of coordination on a particular topic, this could also be an outcome of the project.

MK - How much coordination is needed for which area? Cancer needs it but others may not.

CS – we want to approach cohorts at later stage when we know what we want.

MV – day 2 will be needed to decide on the focus of the WG reviews.

Action: WP leaders (with project coordinator) to prepare WP2 and 3 protocols outlining the steps to be followed for each WG. (see further day 2 and Annex 3)
Day 2 – 27th April

Summary of decisions taken for WP1, WP2, WP3 Protocols
(led by Martine) - see also Annex 3 for summary list of protocol decisions.

Criteria for inclusion of studies in the inventory

Although criteria for inclusion of cohorts in the project should be flexible and multi-level, i.e. different study types can be evaluated in different levels of detail, clear criteria are needed for the inventory of WP1.

1) Birth and mother-child cohorts will form the main focus of WP1 inventory and the entire project. For these studies, WP1 will collect details about study design, main variables, etc, from the study investigators directly, from websites, and from publications. Criteria for inclusion in this group are:
   - birth and mother-child cohorts,
   - population-based,
   - recruitment at the latest during the first year of life (if data on outcome of pregnancy available, e.g. Millenium cohort)
   - at least one follow-up point during first years of life
   - sample size: at least 1000
   - start year: 1990 onwards
   - located in one of the EU member states

These criteria will be applied with some level of flexibility - to be discussed within the project group when exceptions arise (e.g. a smaller cohort in a country not well covered)

2) Registries with information on child health outcomes or determinants. A list of pan-European registries will be created by WP1 for use within the project. This list can take the form of a simple spreadsheet describing the geographical coverage and data collected in the respective registry. Data can be collected mainly from websites but in some cases PIs may need to be contacted to clarify specific issues. National registries will not be identified by WP1. If relevant, WGs may choose to include national registries in their reviews.

3) Child cohorts, historical cohorts, patient cohorts. These studies will not be identified by WP1 and will not be part of the inventory. WGs can decide to include them in their reviews (i.e. as background material and for comparison with birth cohort contribution to a topic) and collect the relevant information from existing publications and websites.

4) Other study designs. To be included in reviews of WGs where relevant to discuss added value of birth cohorts.

Workplans for the WGs

1) Focus of the evaluations:
   - The focus will be on pre and postnatal period up to 18 years of age and on the EU member countries
   - In general, the focus will be broad, with particular emphasis on:
     o the added value of a cohort approach
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- the European perspective
- the added value of coordination between the cohorts
- the research priorities that could benefit from collaboration
- the study of inequalities
- the life-course approach

2) Evaluations will consist of **three** tasks. (max length of reports: approx 10 pages).

**Task 1: review of existing cohort data**

1) description of **current state of scientific knowledge**. Note: this does not need to be a comprehensive review, reviews of reviews should be used if available (maximum length of 1-2 pages).

2) description of the **contribution of (European) birth cohort research** to scientific knowledge (against other study designs). Highlight most influential birth cohort research in the area.

3) brief description of the **contribution of other study designs** and data sources (including registries) if relevant.

4) description of **data currently available/being collected** by the cohorts (Note: based on WP1 inventory, other existing inventories or projects - e.g. ENRIECO. If needed, however, cohorts should be contacted through WP1 to collect more data). Particular emphasis should be on: geographical distribution; comparison of methods and tools used by the cohorts.

5) Identification of **gaps**, particularly in: methods; data; geographical and cultural coverage, harmonisation, coordination.

**Task 2: Case studies on specific topics if needed to tackle specific issues**

The aim is to analyse data from cohorts in different European countries to illustrate specific issues of relevance for the main CHICOS objectives (i.e. in order to develop recommendations we need detailed evaluation of data comparability, data sharing, geographical differences, etc.). **Criteria for selecting case-studies** were decided:

1. Interest for research (gap in information in specific scientific area, i.e. moderate alcohol), with priority for causal evidence analyses. (topics to cut across WGs, ideally at least one for each post-doc working on the project)
2. Relevance for policy making
3. Benefit from pooling (e.g. rare outcomes, rare exposures, international comparison)
4. Topics that highlight added value of a cohort approach (e.g. repeated measurements, life-course analysis)
5. Evaluation across a range of European cohorts (small/large, North/South, young/old, many follow-up points vs few follow-up points)
6. Topics that cut across CHICOS working groups
7. Publishable as papers (and report with add-on for specific CHICOS issues)

Some ideas for case studies were tabled during the first day of the meeting:

- Prevalence of behavioural and learning problems across Europe (as little prevalence data in general population – role of cohorts? NB cohort are selective)
- Asthma?
- Obesity?
**Task 3: Recommendations**

Recommendations should:

1. **Identify research priorities for European cohort research for each topic area.** These recommendations will need to include: need for harmonisation of methods between cohorts; need for EU comparisons and pooling (using case-studies to highlight the problems); need for targeted research in specific regions; criteria for conducting future follow-ups; need for new follow-ups and cohort studies. As described in the DoW.

2. **Identify a general strategy for cohort research in Europe.** This will include: infrastructure for cohort research; research framework (mix of smaller and larger...
The final set of recommendations will be produced at the end of the project. However, a draft version of the recommendations in form of a policy document (2-5 pages) should be produced at an early stage and discussed throughout the project. This draft version will be used for discussion with the EC officers and presentation at relevant meetings. An early publication of this general framework should also be prepared.

**ACTIONS**

i. draft outline of policy document (*Martine*)

ii. draft outline for publication with general vision (*Martine*)

### Data collection

1) **data collection for the inventory and the WGs’ evaluations**

WGs should consider soon if they need to collect more information for their topic area than is available in existing inventories (such as birthcohorts.net and ENRIECO). For example we may need to contact the cohorts to get more information on breastfeeding, diet, physical activity. Data will be collected through WP1.

2) **data collection for the case-studies**

This should be organized by the responsible persons for each case-study according to a general set of rules that will be prepared by Martine, Vincent and Camila

**ACTIONS**

i. Identify soon needs for further data collection through WP1 – first list of data needs by end of June, draft of questionnaire to cohorts by 1 September, discussion at CELSE meeting (all WGs).

ii. draft a strategy plan on how data for the case-studies should be collected (contact with the PIs, etc.). After ideas for case studies have been finalised (*Martine, Vincent and Camila*)

### Involvement of other cohorts and experts in the CHICOS project

Involvement of the cohorts is very important and will be achieved through the following means:

- A newsletter to communicate about CHICOS and invite participation, presentation of CHICOS plans at relevant meetings (ENRIECO, CELSE, etc)
- Invitation of cohort researchers as WG members
- Invitation to join in the case-studies
- Invitation of the cohort representatives in the CHICOS workshops
Experts will be identified by each WG (1-2 per WG). Preference should be given to experts from within the partners and from cohorts. We need to make a particular effort to involve experts from Eastern Europe.

**ACTIONS**

i) identify experts (*all WGs*)  
ii) identify cohorts willing to participate in the selected case-studies (this will start after the identification of the case-studies) (*responsible persons for the case-studies*)  
iii) prepare CHICOS abstract for submission to CELSE meeting (Martine and Maribel)

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### WP4 – Improving the contribution of cohorts to policy - Patricia Lucas and Hein Raat

PL and HR presented the objectives of WP4 (see slides – *Annex 1*). This WP will review the extent to which cohort studies have been influential in current policies at national and European level. A Delphi study will then identify the research needs of policy makers. And case studies will evaluate how policy makers have influenced decisions on birth cohort studies. All this will result in a set of recommendations for improving the cohort impact on policy.

(MM) Important for case studies also to evaluate also whether cohort research has been relevant for other policies than those on public health, e.g. housing, energy efficiency. Health should be an important factor in these also and there are many knowledge gaps here. Do not focus just on public health.

(FM) There is an overlap with WP5 as both WPs will need to identify the right stakeholders and target audience. These WPs should work together and join efforts to put together a comprehensive stakeholders list, which can then be used in the Delphi study and for dissemination.

(MV) A key factor in the Delphi study will be the identification of the right stakeholders. The policy makers are notoriously difficult to identify and involve. There is no point getting cohort researchers to be on the Delphi panels. Stakeholders should also involve NGOs and professional organisations (MV: European Public Health Association. JS: European Pediatric Society).

(HR) Spoke to Kevin McCarthy (project officer) about this. Kevin has promised to help direct us to the key stakeholders at European level.

**ACTIONS**

i. Production of a protocol by month 6  
ii. Choice of the case-studies  
iii. Identification of the stakeholders/policy makers to be involved in the Delphi study (*WP4 in connection with WP5 and other partners*)
**WP5 – Dissemination**
*Franco Merletti, Emanuele Pivetta and Lorenzo Richiardi*

LR presented the CHICOS logo, the CHICOS website and a project for the stakeholder forum. The group approved the proposed logo and the outline for the website. The following decisions were taken about the website:

a) to add a section listing the WGs,

b) to have news from the single cohorts participating in CHICOS (WP5 will search for relevant news in the six participating cohort websites)

c) to divide the stakeholders section into different sections according to the typology of stakeholder (international organizations, scientific societies, etc.)

d) change “dissemination” with “communication”

e) the contact emails will be received by the coordinator of the project

f) to pilot in Turin the involvement of the women participating in the cohorts as CHICOS stakeholders

g) to add an intranet area where we can post the working documents, slides, etc.

h) to add a mail signature in CHICOS emails as follows: “Visit the CHICOS project website: [www.chicosproject.eu](http://www.chicosproject.eu) And feel free to subscribe to the CHICOS newsletter: [www.chicosproject.eu/dissemination/newsletter/](http://www.chicosproject.eu/dissemination/newsletter/)

**ACTIONS:**

i. the website should be reviewed according to the suggestions made during the meeting

ii. prepare a report describing the logo and the website

iii. prepare the study brochure by June

iv. prepare an “official” layout for the power point presentations

v. identify and contact potential stakeholders (*WP5 in connection with WP4 and other partners*)

**WP6 – Management - Martine Vrijheid and Diana van Gent**

DG reviewed the project management, deliverables, responsibilities (PEC, scientific advisory board, coordinator, WP leaders, WG leaders), finance, meetings, financial justification, etc.

**Note:**

- The advisory board will be formed soon. Potential candidates have been contacted.
- The project plan is being drafted and will be circulated after the meeting.
- Quarterly progress report will be circulated every 4 months.
- Participation to conferences relevant to CHICOS should be reported to the coordinator and included in the report.
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- All deliverables should be submitted to Martine and Diana who will submit them to the EC.
- Justifications for expenditures should be kept for 5 years after the end of the project.
- For subcontracts it is enough to show that there has been a search for different options or to provide justification for a direct choice.
- Intellectual property: Any publication dissemination activity should include the following sentence: “The research leading to these results has received funding from the [European Community's] [European Atomic Energy Community's] Seventh Framework Programme ([FP7/2007-2013] [FP7/2007-2011]) under grant agreement nº [xxxxxx]”.

Next CHICOS meetings:

- The schedule should be re-arranged according to the 3-year duration of the project.
- WP meetings (planned at M9 and M18 according to the 2-year duration) will be combined in one larger meeting including WPs 1, 2 and 3. The first of these WP1,2,3 meetings will take place in Cyprus during the CELSE conference scheduled to be held from October 13th to 15th 2010 (day before: 12 May).
- Larger CHICOS project meeting will be held on an yearly basis. Next meeting is scheduled for the last week of April 2011 (Diana will circulate the exact dates). Currently the suggested place for the meeting is Barcelona but this can be changed later on. This meeting will invite experts and cohort representatives. Drafts of the WG evaluation will be presented and case studies will be discussed.
- Smaller meetings will be needed to start the case studies – these will be planned as and when needed.
- PEC meetings (by phone) will be held every 3 months throughout the project.

**ACTIONS:**

i. Diana/Martine to circulate meeting plan and dates for the next year, including PEC phone conferences. *(Annex 2)*

ii. Diana/Martine to circulate deadlines for work in the next 6 months. *(Annex 2)*

**MISCELLANEOUS AND END OF THE MEETING**

The group agreed that an (editorial) paper should be drafted early in the project about the use of the existing virtual European megacohort and the need to ensure follow-up and maintenance. Vision for European infrastructure should be presented.

**ACTIONS:**

Martine to start drafting outline for such a paper.
**Meeting Programme**

**Day 1, 26 April**

**CHAIR – Franco Merletti**

**9:00-9:30  Welcome and introduction**

Welcome (Jordi Sunyer – Co-Director CREAL)

Project aims and objectives (Martine Vrijheid)

**9:30-11:00  Policy-research interface**

“What do policy makers need from child cohort researchers?”

- **Local view** (Dr Antoni Plasència Taradach, Public Health Director, Ministry of Health of the Generalitat of Catalunya)
  - Examples of recent policy initiatives in child health and use of research results in these.

- **International view** (Dr Marco Martuzzi – WHO-Europe)
  - European Child Health Action Plans, Parma Ministerial Conference, other examples of how international policy may use cohort research.

- **CHICOS context** (Dr Patricia Lucas – Bristol University)
  - Examples of areas where child cohort research has influenced policy

- Panel discussion

**11:00-11:30  Coffee**

**11:30-12:15  WP1 – Cohort inventory (Anne-Marie Nybo Andersen)**

- Objectives
- Overview of existing inventories
- Definition of cohorts for inclusion in CHICOS
- Inclusion of Registries
- Work plan for CHICOS
- Discussion

**12.15-13.00  WP2 – Research Priorities for Childhood Diseases**

General overview (Camilla Stoltenberg)

Presentation by **WG leaders**, including:

- Current knowledge and role of cohort research
- Identification of broad policy areas where cohort
research could make an impact
- Existing international collaborations
- Ideas for focus of CHICOS reviews

- Perinatal outcomes (Camilla Stoltenberg)
- Respiratory health (Liesbeth Duijts)
- Obesity, and vascular and metabolic health (Debby Lawlor)
- Neuro-cognitive and behavioural development (Jordi Sunyer)
- Accidents and injuries (Martine Vrijheid)
- Infectious diseases (Camilla Stoltenberg)
- Childhood cancer (Manolis Kogevinas)

13:00-14:00 Lunch

CHAIR : Debby Lawlor

14.00-15.00 WP2 – Research Priorities for Childhood Diseases - continued
15:00-16.00 WP3 – Research Priorities for Child Health Determinants

General overview (Vincent Jaddoe)

Presentation by WG leaders, including:
- Current knowledge and role of cohort research
- Identification of broad policy areas where cohort research could make an impact
- Existing international collaborations
- Ideas for focus of CHICOS reviews
- Social and cultural conditions (Hein Raat)
- Nutrition and physical activity (Leda Chatzi)
- Life-style and substance exposures (Per Magnus)
- Other environmental exposures incl ETS (Mark Nieuwenhuijsen)
- Biological and genetic factors (Vincent Jaddoe)
- Multiple determinants, helath impact assessment (Martine Vrijheid/Mark Nieuwenhuijsen).

16:00-16:30 Coffee

16:30-17.00 WP3 – Research Priorities for Child Health Determinants – continued
17:00-18:00 WP2 and WP3 discussion
   Plenary discussion of draft protocols (Camilla/Vincent)
   - WG divisions/overlaps, leadership, members, experts
   - Involvement of cohorts
   - Identify general steps/tasks to be followed for each WG
   - Methods: data sources to be used as basis for review, etc
   - Inclusion of case studies
   - Interaction with other international projects

20.30 Conference Dinner at Restaurant Posit (see Maps and Directions)

Day 2, 27 April

CHAIR: Camilla Stoltenberg

9:30-10:30 WP4 – Improving the Contribution of Cohorts to Policy
   Presentation of draft protocol (Patricia Lucas and Hein Raat)
   - Cohort contribution to current policies: review and case studies
   - Inventory of information needs of policy makers (European and national level) – Delphi study
   - Role of policy makers in cohort design
   Discussion of WP4 protocol

10:30-11:00 Coffee

11:00-13:00 General discussion of work plans for WP 1-4
   (moderator: Martine Vrijheid)
   - Links between WP 1 and WP2/3 – information needs, data collection, contacts with cohorts, etc
   - Links between WP4 and WP2/3
   - Workplans and timing
   - Workshops and meetings

13:00-14:00 Lunch
Kick-off Meeting 26-27 April 2010

**CHAIR: Anne-Marie Nybo Andersen**

**14:00-15:00 WP5 – Dissemination** *(Franco Merletti/ Lorenzo Richiardi)*
- logo, website
- newsletters
- stakeholders forum
- publication plan
- meetings

**15:00-16:00 WP6 – Management** *(Martine Vrijheid, Diana van Gent)*
- Project planning, including plan of upcoming meetings
- Responsibilities
- aob

**16.00** *End meeting - Coffee*

**16:30-18:00 WP meetings**
- WP4
Delegate information

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Public Health Director

WHO-Europe
Dr Marco Martuzzi
Scientific Officer

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National School of Public Health
196 Alexandras Avenue
Athens 115 21, Greece
### Annex 2 - WP Activities up to April 2011

<table>
<thead>
<tr>
<th>Action</th>
<th>Responsible</th>
<th>Completion date</th>
<th>Format</th>
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<tbody>
<tr>
<td><strong>WP1, 2, 3</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Develop WP 2 &amp; 3 protocols (details of case studies to be added at later stage)</td>
<td>WP 2 &amp; 3 leaders with MV</td>
<td>30th June</td>
<td>Deliverables D3 &amp; D4 – submit to EC in July</td>
</tr>
<tr>
<td>Submit ideas for case studies (use template form – annex 5)</td>
<td>All</td>
<td>30th June</td>
<td>Suggestions to Camilla, Vincent &amp; Martine</td>
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<tr>
<td>Submit list of questions to WP1 for inclusion in inventory questionnaire</td>
<td>WG leaders</td>
<td>30th June</td>
<td>Suggestions to Anne-Marie</td>
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<tr>
<td>Draft WP1 questionnaire for data collection from cohorts</td>
<td>WP1 with relevant WG leaders</td>
<td>Mid Sept</td>
<td>Questionnaire</td>
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<tr>
<td>Draft protocols for case studies</td>
<td>WP 1, 2 &amp; 3 – relevant WGs</td>
<td>Mid Sept</td>
<td>Draft protocols for discussion at CELSE</td>
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<td><strong>WP 1, 2, 3 meeting:</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>- Discuss case study protocols</td>
<td>WP 1, 2 &amp; 3</td>
<td>12/13th October, CELSE</td>
<td>Minutes</td>
</tr>
<tr>
<td>- Discuss ongoing WG review work</td>
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<tr>
<td>- Finalise inventory questionnaire (WP1)</td>
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<tr>
<td><strong>Protocols case studies</strong></td>
<td>WP 1, 2 &amp; 3 – relevant WGs</td>
<td>1st November</td>
<td>Case study protocols</td>
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<tr>
<td><strong>Data collection from cohorts with questionnaires</strong></td>
<td>WP1</td>
<td>Oct 2010 - March 2011</td>
<td>Completed questionnaires from cohorts</td>
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<tr>
<td><strong>Perform case studies</strong></td>
<td>WP1, 2 &amp; 3 – relevant WGs</td>
<td>Nov 2010 – March 2012</td>
<td>Reviewed at WG/WP meetings, reporting updates to PEC</td>
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<tr>
<td><strong>First draft WG review of cohort contribution and existing cohort data</strong></td>
<td>WG leaders</td>
<td>Oct 2010 - March 2011</td>
<td>Draft reviews</td>
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<tr>
<td><strong>Draft policy document with general recommendations</strong></td>
<td>All</td>
<td>March 2011</td>
<td>First draft</td>
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<td><strong>WP 4</strong></td>
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<td>Develop WP 4 protocol (with detailed protocol for review, case study 1 and Delphi study; less detail for future case studies)</td>
<td>WP 4 leaders</td>
<td>30th June</td>
<td>Deliverable D5 – submit to EC in July</td>
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<tr>
<td>Perform WP 4 case study 1 and information gathering Delphi</td>
<td>WP 4</td>
<td>April 2011</td>
<td>Review at project meeting</td>
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<tr>
<td>Prepare draft protocol for WP 4 case study 2 and 3</td>
<td>WP 4 leaders</td>
<td>April 2011</td>
<td>Draft protocol</td>
</tr>
<tr>
<td><strong>WP 5</strong></td>
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<td>Revising website according to suggestions made during the kick-off meeting</td>
<td>WP5</td>
<td>31st May</td>
<td>Website</td>
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<tr>
<td>Prepare a report describing the logo and website</td>
<td>WP5</td>
<td>31st May</td>
<td>Deliverable 1 – Project website</td>
</tr>
<tr>
<td>Prepare Workshop I Report</td>
<td>WP5</td>
<td>31st May</td>
<td>Deliverable 2 – Workshop I Report I</td>
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www.chicosproject.eu
### Meetings

<table>
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<tr>
<th>Event Description</th>
<th>Responsible Parties</th>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PEC meeting</strong></td>
<td>PEC members</td>
<td>June</td>
<td>Suggestion – 5 July 2010, Teleconference, minutes</td>
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<tr>
<td>- review draft protocols WP1-4</td>
<td>PEC members</td>
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<tr>
<td>- review case study ideas</td>
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<tr>
<td>- review inventory data needs</td>
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<tr>
<td><strong>PEC meeting</strong></td>
<td>PEC members</td>
<td>Mid September</td>
<td>Teleconference, minutes</td>
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<tr>
<td>- review case study short list and protocols</td>
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<tr>
<td>- review WP1 questionnaire</td>
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<tr>
<td>- prepare CELSE meeting</td>
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<tr>
<td><strong>WP 1, 2, 3 meeting:</strong></td>
<td>WP 1, 2 &amp; 3</td>
<td>12/13th October 2010, CELSE</td>
<td>Minutes</td>
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<td>- Discuss case study protocols</td>
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<tr>
<td>- Finalise inventory questionnaire (WP1)</td>
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<tr>
<td><strong>PEC meeting</strong></td>
<td>PEC members</td>
<td>December</td>
<td>Teleconference, minutes</td>
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<td><strong>PEC meeting</strong></td>
<td>PEC members</td>
<td>Feb/March 2011</td>
<td>Teleconference, minutes</td>
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<td><strong>CHICOS Project meeting</strong></td>
<td>WP 1-6</td>
<td>4-5 or 11-12 April 2011</td>
<td>Meeting in Barcelona</td>
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<td>- including experts and cohort representatives</td>
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<tr>
<td>- discussion of draft WG reviews</td>
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<tr>
<td>- discussion of case study progress</td>
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</table>
Annex 3: Protocol issues WP 1, 2, 3 - decisions taken during the kick-off meeting which should feed into the WP protocols

**Cohort inclusion criteria (WP1 and whole project)**

Criteria for inclusion of cohorts in the project should be flexible and multi-level, i.e. different study types can be evaluated with different level of detail, depending on the topic. However, clear criteria are needed for the work of WP1 (inventory), otherwise this work could be infinite. It was therefore decided to group studies and base data collection on these groups:

1. **Birth and mother-child cohorts** that will form the main focus of WP1 inventory and the entire project. For these studies, WP1 will collect details about study design, main variables, etc, from the study investigators directly, from websites, and from publications. Criteria for inclusion in this group are:
   - birth and mother-child cohorts,
   - population-based
   - recruitment at latest during first year of life (but with collection of data on outcome of pregnancy) (including Millenium cohort, etc)
   - at least one follow-up point during first years of life
   - sample size: 1000 or more
   - start year: 1990 onwards
   - located in one of the EU member states

   (these criteria will be applied with some level of flexibility - to be discussed within the project group when exceptions arise)

2. **Registries** with information on child health outcomes or determinants. A list of pan-European registries will be created by WP1 for use within the project. This list can take the form of a simple spreadsheet describing the geographical coverage and data collected in the respective registry. Data can be collected mainly from websites of these projects, in some cases PIs of the projects may need to be contacted to clarify specific issues. National registries will not be identified by WP1. If relevant, specific WGs may choose to include national registries in their reviews.

3. **Child cohorts, historical cohorts, patient cohorts.** These studies will not be identified by WP1 and no information will be collected directly from these cohort. WGs can decide to include them in their reviews (i.e. as background material and for comparison with birth cohort contribution to a topic) and collect the relevant information from existing publications and websites.

4. **Other study designs.** To be included in reviews of WGs where relevant to discuss added value of birth cohorts.

Data collection from cohorts should go through WP1 – **each WG needs to let WP1 know what information should be collected directly from the cohorts** (NB this refer to protocol information not to individual data – see for example the ENRIECO questionnaire).
Workplans for WG evaluations (WP2 and 3)

Focus for each WG:
- The focus will be on pre and the postnatal period up to 18 years of age and on the EU member countries
- In general, the focus will be broad, with particular emphasis on:
  - the added value of a cohort approach
  - the European perspective
  - the added value of coordination between the cohorts
  - the research priorities that could benefit from collaboration
  - the study of inequalities
  - the life-course approach

Task 1) Review of cohort contribution and existing cohort data (max 10 pages + tables)
1. Description of current state of scientific knowledge. Note: this does not need to be a comprehensive review, reviews of reviews and existing projects should be used if available (maximum length of 1-2 pages).
2. Description of the contribution of (European) birth cohort research to scientific knowledge (against other study designs). Highlight most influential birth cohort research in the area.
3. Brief description of the contribution of other study designs and data sources (including registries) if relevant.
4. Description of data currently available/being collected by the cohorts (Note: based on WP1 inventory, other existing inventories or projects - e.g. ENRIECO. If needed, however, cohorts should be contacted through WP1 to collect more data). Particular emphasis should be on: geographical distribution; comparison of methods and tools used by the cohorts.
5. Identification of gaps, particularly in: methods; data; geographical and cultural coverage, harmonisation, coordination.

Task 2) Conduct case studies on specific topics if desirable (specially for WGs already further advanced on Task 1):
Aim: Analyse data from cohorts in different European countries to illustrate specific issues of relevance for the main CHICOS objectives (i.e. in order to develop recommendations we need detailed evaluation of data comparability, data sharing, geographical differences, etc)

Criteria for defining case studies:
1. Interest for research (gap in information in specific scientific area, i.e. moderate alcohol), with priority for causal evidence analyses. (topics to cut across WGs, ideally at least one for each post-doc working on the project)
2. Relevance for policy making
3. Benefit from pooling (e.g. rare outcomes, rare exposures, international comparison)
4. Topics that highlight added value of a cohort approach (e.g. repeated measurements, life-course analysis)
5. Evaluation across a range of European cohorts (small/large, North/South, young/old, many follow-up points vs few follow-up points)
6. Publishable as papers (and report with add-on for specific CHICOS issues)

WP2 and 3 will coordinate the development of these case studies, together with the project coordinator. All partners should participate, not just WG leaders.

Task 3) Recommendations

1. **Identify priorities for European cohort research by topic area (see DoW):**
   - need for harmonisation of methods between cohorts
   - need for European comparisons and pooling (use case studies to highlight problems)
   - need for targeted research in specific regions
   - criteria for conducting future follow-ups and new cohort studies

2. **Identify general strategy for cohort research in Europe:**
   - infrastructure for cohort research
   - research framework – mix of smaller and larger cohort studies and registries.
   - focus on the existing (virtual) mega cohort – maintenance important.
   - continuous discussions throughout the project – drafting as we go along.
   - in the form of a policy document (2-5 pages) (discuss with EC Officer)
   - and early publication with general vision
Annex 4: Relevant Parts of the ENRIECO Access Database – Inventory Questionnaire

This questionnaire is a shortened version of the original designed for the FP7 funded ENRIECO project (2009-2011). It complements the ENRIECO Access Database, of which parts relevant to CHICOS are available through the CHICOS intranet for project partners.

Due to the format of the database, we are unable to submit it as part of this Annex. If you wish to obtain a copy, please contact Diana van Gent either by email: dvangent@creal.cat or phone 0034 932 14 7354.
ENRIECO Inventory of birth cohorts with data on environmental exposures (WP1)

**Aim**
To make an inventory of all existing pregnancy and birth cohorts in Europe that have data which can be used to explore environment and health relationships.

**Background**
There are many pregnancy and birth cohorts in Europe, with sample sizes ranging from a few hundred to tens of thousands. A number of these aim to examine environment and health relationships. ENRIECO has as aim to support the exploitation, at European level, of data generated by past and ongoing birth cohort studies. The development of an inventory is a **first and important prerequisite** for such exploitation.

**Who will use the inventory?**
1) Researchers, to enable more effective exploitation of existing studies. For example researchers looking to pool their data with other European cohorts will be able to assess easily which cohorts may be suitable for such pooling.
2) Policy makers, to enable them to identify birth cohorts that can provide certain types of information, specifically on environmental exposures.

**How will information be collected?**
All information to be included in the inventory will be collected from the cohorts using the attached *Inventory Questionnaire*. All cohorts are invited to comment on the draft of this questionnaire. The final questionnaire will be completed through personal contact with each cohort, it is not meant to be a purely self-administered questionnaire. The PI of each cohort will be asked to distribute appropriate sections to the appropriate researchers in the cohort first. WP1 will then contact these researchers (usually by phone) and complete the questionnaires with them.

**How will the information collected for the inventory be used?**
The inventory will be stored in a searchable web database. We will link this inventory to the already existing website www.birthcohorts.net, which currently holds basic protocol information on a large number of European cohorts and will be expanded to include modules relating to “exposure data”, “outcome data”, etc. Users will be able to search for specific exposures and outcomes, and extract information on the cohorts that have data for the specific topic as well as basic information on the methods used to collect data. For example, users interested in air pollution will be able to search the database on air pollution and/or specific pollutants and extract a list of cohorts that collect these exposures with some basic details about the exposure assessment method used (timing, type of modelling).

At the end of the project, a publication will be prepared with an overview and description of European birth cohorts. All cohorts included in the inventory will be invited to participate in this publication.

**Which cohorts will be included in the inventory?**
Inclusion criteria will be flexible. The main focus of the inventory will be on cohorts that:

1. collect data on at least one environmental exposure topic (see questionnaire);
2. start enrolment during pregnancy or at birth (or during first year of life if data on birth outcomes is collected from medical records);
3. have at least one follow-up point after birth;
4. include at least 200-300 mother-child pairs.

Cohorts that do not fit these criteria entirely can be included on request, but data collection will be passive rather than active.
INVENTORY QUESTIONNAIRE

IMPORTANT:
- This questionnaire will be completed through personal contact with cohort researchers, it is not meant to be administered as a purely postal or email questionnaire. We will discuss with you the best ways of completing the questionnaire.
- This questionnaire aims to collect information needed for the web-based inventory. ENRIECO working groups may need additional information for their reviews. Such information will be collected separately.
- Please add more space where needed for description and comments and copy sections/pages where multiple pollutants are concerned.

CONTACT for questions: Martine Vrijheid (mvrijheid@creal.cat), Maribel Casas (micasas@creal.cat)

CONTENT
A. Basic Protocol Description
   A1. Identification
   A2. Basic Description
   A3. Basic Data Collection Scheme

B. Exposure Assessment
   B1. Outdoor air pollution
   B2. Indoor contaminants
   B3. Water contamination
   B4. Allergens and biological organisms
   B5. Heavy metals
   B6. Pesticides
   B7. Radiations
   B8. Smoking and Second-hand Smoke (SHS)
   B9. Noise
   B10. Persistent organic pollutants (POPs)
   B11. Occupation
   B12. Other and emerging chemical exposures: e.g. BPA, phthalates, etc.

C. Outcome Assessment
   C1. Reproduction and birth outcomes
   C2. Neurodevelopment
   C3. Allergies and asthma
   C4. Cancer
   C5. Growth, obesity, metabolic and endocrine disorders, puberty
   C6. Other outcomes

D. Other Information
   D1. Genotyping
   D2. Residential history
   D3. Time-activity
   D3. Sociodemographic variables
   D4. Breastfeeding
   D5. Diet and physical exercise
   D6. Medical history
   D7. Parental anthropometry
A. Basic Protocol Description (update of www.birthcohorts.net)

A1. Identification

- Cohort name:

- Principal investigator:

- Contact(s) for environmental exposures:

- Cohort website:

- Key publication(s) of cohort protocol/methods/description:

A2. Basic Description

- Main aim/objectives/focus of cohort:

- Source population
  - nation-based
  - region-based
  - hospital-based
  - selected (high-risk, exposure etc.), describe:
  - other:

- Geographical coverage, please describe: ______________

- Calendar period of enrolment – calendar years of start and finish: ____________

- Enrolment - status:
  - completed
  - ongoing
  - planned

- Developmental period of enrolment – give developmental period of start of enrolment:
  - pre-pregnancy
  - pregnancy, give pregnancy week(s) ________ weeks of pregnancy
  - at birth
  - postnatal, give month(s) ________ months of age

- Enrolment criteria, please describe in and exclusion criteria:

- Expected number of participants at enrolment when enrolment completed:
  - _____ mothers
  - _____ fathers
  - _____ children

- Expected duration of follow-up: ________ years
### A3. Basic Data Collection Scheme

<table>
<thead>
<tr>
<th>Type of data collection</th>
<th>Pregnancy</th>
<th>Birth</th>
<th>Post natal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st trimester</td>
<td>2nd trimester</td>
<td>3rd trimester</td>
</tr>
<tr>
<td>Questionnaires:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>maternal exposures</td>
<td></td>
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<tr>
<td>paternal exposures</td>
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<td></td>
<td></td>
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<tr>
<td>offspring exposures</td>
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<tr>
<td>maternal outcomes</td>
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<tr>
<td>paternal outcomes</td>
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<td>offspring outcomes</td>
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<tr>
<td>Biological samples:</td>
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<tr>
<td>maternal blood</td>
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<td>paternal blood</td>
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<td></td>
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<tr>
<td>cord blood</td>
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<tr>
<td>offspring blood</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>maternal urine</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>paternal urine</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>offspring urine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>maternal other (hair, nails, saliva, breast milk, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>paternal other (hair, nails, saliva etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>offspring other (hair, nails, saliva, etc.)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
C. Health Outcome Assessment

C1. Reproduction and Birth outcomes

- Was data on reproductive and birth outcomes collected for the members of your cohort?
  - yes
  - not yet, but planned. Please give predicted year of completion: 20____
  - no (proceed to part C2)

- Use of a contraceptive method at the start of a pregnancy:
  - yes
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- Time to pregnancy:
  - yes
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- Infertility treatment before the index pregnancy:
  - yes
  - not yet, but planned. Please give predicted year of completion: 20____
  - no
  If yes, was the duration of the pregnancy attempt until the start of the infertility treatment recorded?
    - yes
    - no

- Congenital anomalies:
  - yes. Please give %/number of subjects for whom this information was collected: ______
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- Specific anomalies of the male reproductive system:
  - yes.
    - cryptorchidism (if planned, year _____)
    - hypospadias (if planned, year _____)
    - anogenital distance (if planned, year _____)
  - no

- Spontaneous abortions (until 21 weeks of amenorrhea)
  - yes. Please give %/number of subjects for whom this information was collected: ______
  - not yet, but planned. Please give predicted year of completion: 20____
  - no
- **Stillbirths (after 22 weeks of amenorrhea)**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- **Medical termination of pregnancy**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

  If yes, please indicate if information on the reason of the termination of the pregnancy is known, and if the presence of congenital malformations has been recorded.

- **Birth weight**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

  If yes, please indicate how the data were collected:
  - Self-reported from mothers
  - Medical record, midwife or doctor reported
  - Other, specify__________________________

- **Gestational Duration**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

  If yes, what is the origin for the calculation of gestational duration?
  - self-reported last menstrual period (by study subject)
  - Medical record: midwife or physician assessed last menstrual period (on basis of self-report, but assessed and recorded by medically qualified person)
  - ultrasound
  - other:

- **Premature Rupture of Membranes**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- **Onset of labour (spontaneous, induced, caesarean section before onset, ...)**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no

- **Mode of delivery (spontaneous vaginal birth, operative vaginal birth, caesarean section)**
  - yes. Please give %/number of subjects for whom this information was collected: ____
  - not yet, but planned. Please give predicted year of completion: 20____
  - no
• **Ultrasound measurements**
  - yes. Please give %/number of subjects for whom this information was collected: _____
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no
  If yes, describe how many ultrasounds, which gestational weeks:

• **Doppler measurements (of uterine, umbilical, fetal cervical arteries, or other)**
  - yes. Please give %/number of subjects for whom this information was collected: _____
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no
  If yes, describe the arteries concerned, which gestational weeks, how many (or percentage of) women:

C2. **Neurodevelopment**

• **Was data on neurodevelopmental and behavioural outcomes collected for the members of your cohort?**
  - yes
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no (proceed to part C3)

• **Which of the following outcomes were assessed in the children:**
  - neuropsychological assessment (e.g. developmental tests for executive function, memory, language, IQ)
  - behaviour (ADHD symptoms, etc)
  - autism symptoms
  - school achievements/performance
  - neurophysiology/neuroimaging: _______________
  - other:_________________________________

• **Details of neurobehavioural and cognitive development assessment of child (number completed or planned)**

<table>
<thead>
<tr>
<th>Name of test/assessment and year (Bayley, McCarthy, Griffith, ...)</th>
<th>Birth</th>
<th>Post natal (give months/years of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>e.g. 14 months</td>
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<tr>
<td></td>
<td></td>
<td>4 years</td>
</tr>
</tbody>
</table>

- **Dubowitz**
  - Bayley scales of infant development (BSID)
- **Griffiths** Mental Development scales
- **McCarthy** scales of children’s abilities (MSCA)
- Wechsler Preschool and Primary scale of Intelligence (WPPSI)
- Others:
• Which of the following assessments were completed in *mothers and fathers*:

<table>
<thead>
<tr>
<th>Type of assessment</th>
<th>Name of test</th>
<th>Timing</th>
<th>Number/% of cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>maternal IQ</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>paternal IQ</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>maternal mental health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>paternal mental health</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>maternal stress</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Paternal stress</td>
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<td></td>
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<tr>
<td>maternal attachment</td>
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<td></td>
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<tr>
<td>paternal attachment</td>
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<td></td>
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<tr>
<td>Other</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
C3. Allergies and Asthma

- Was data on asthma and allergies collected for the members of your cohort?
  - yes
  - not yet, but planned. Please give predicted year of completion: 20____
  - no (proceed to part C4)

- Which of the following outcomes were assessed in the children:
  - asthma
  - allergies (other than allergic rhinitis)
  - allergic rhinitis (indoor/outdoor)
  - eczema
  - respiratory infections (upper/lower)
  - food allergies

Asthma

- Which of the following methods to assess asthma were used?
  - parental questionnaires / interview (wheezing, asthma symptoms)
  - doctor’s diagnosis of asthma (by study doctor or parent-reported doctor’s diagnosis)
  - lung function tests
    - oscilometry
    - spirometry
    - bronchial challenge test
    - tested reversibility (bronchodilators)
    - interrupter technique (Rint)
    - exhaled NO

Allergic Rhinitis

- Which of the following methods to assess allergies were used?
  - parental questionnaires/ interview (sneezing, runny nose, nasal congestion, itching of the nose, and post nasal drip)
  - doctor’s diagnosis of allergy (by study doctor or parent-reported doctor’s diagnosis)
  - sensitization assessment (blood samples, SPT (skin prick test), urine samples)

Eczema

- Which of the following methods to assess eczema were used?
  - parental questionnaires/ interview
  - doctor’s diagnosis of allergy (by study doctor or parent-reported doctor’s diagnosis)

Allergic Sensitization Assessment

- Were IgE-antibodies to common inhalant allergens analysed in biological samples?
  - yes
  - no
If yes, describe the specific IgE measured:
  - total IgE
  - IgE mite
  - IgE cat
  - IgE dog
  - IgE pollen
- IgE grass
- other, including food allergies

**Were skin prick tests (SPT) performed?**
- yes
- no

If yes, indicate the specific SPT performed:
- mite
- cat
- dog
- pollen
- mould
- others, including food allergens

**Details of asthma and allergy assessment of child (number completed or planned)**

<table>
<thead>
<tr>
<th>Type of assessment and timing</th>
<th>Birth</th>
<th>Post natal (give months/years of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>e.g. 14 months</td>
</tr>
<tr>
<td><strong>Examples:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>allergic rhinitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>eczema</td>
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<tr>
<td>asthma</td>
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</tbody>
</table>

- physiological measures
  - intermittent technique (Rint)
  - exhaled NO
- IgE/IgGs
  - Skin prick test

**Completed:**

**Planned:**
C4. Cancer

- **Is information on childhood cancers collected for your cohort**
  - yes
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no

- **Please describe how:**
  - linkage to cancer registry
  - other: ________________________________

- **What is the estimated annual number of childhood cancer cases in your cohort**
  0-1 years:  _________________
  1-2 years:  _________________
  2-5 years:  _________________
  5-10 years:  _________________
  10-15 years:  _________________
  15-18 years:  _________________
  *(or other, convenient, age categories)*

- **Are genotoxicity markers measured in your cohort?**
  - yes
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no

*Details?*
C5. Childhood growth and obesity, sexual maturation, other outcomes

- Is information on childhood growth, obesity, sexual maturation, or other metabolic and endocrine disorders, collected for your cohort?
  
  - yes
  - not yet, but planned. Please give predicted year of completion: 20_____
  - no, please go to section D

- Which of the following outcomes were assessed in the children:
  
  - childhood growth and obesity
  - indicators of metabolic syndrome
  - diabetes
  - sexual maturation
  - other:_____________________________________

- Details of childhood growth and obesity assessments (give number/% completed or planned)

<table>
<thead>
<tr>
<th>Measure of growth/ body composition</th>
<th>Type of assessment (self-report, medical record, measurement, etc)</th>
<th>Birth</th>
<th>Post natal (give months/years of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>e.g. 14 months</td>
</tr>
<tr>
<td>Weight</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Height</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Waist circumference</td>
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<td></td>
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<tr>
<td>Arm circumference</td>
<td></td>
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<td></td>
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<tr>
<td>Wrist circumference</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fat/fat free mass by bioimpedance</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other measure of body composition:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Details of metabolic syndrome indicator assessments in children (give number/% completed or planned)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Type of assessment (include whether fasting samples...)</th>
<th>Birth</th>
<th>Post natal (give months/years of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>e.g. 14 months</td>
</tr>
<tr>
<td>Blood pressure</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Triglycerides</td>
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<td></td>
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<tr>
<td>Glucose</td>
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<td></td>
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<tr>
<td>Insulin</td>
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<tr>
<td>Other:</td>
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</tbody>
</table>
### Details of sexual maturation assessments (give number/% completed or planned)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Type of assessment (self-reported child/mother, evaluated by doctor, etc.)</th>
<th>Birth</th>
<th>Post natal (give years of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tanner stage</td>
<td></td>
<td>N=</td>
<td></td>
</tr>
<tr>
<td>Puberal Development Stage</td>
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<tr>
<td>Age at menarche</td>
<td></td>
<td>N=</td>
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<tr>
<td>Age at voice change</td>
<td></td>
<td></td>
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<tr>
<td>Gonadal axis hormones</td>
<td></td>
<td></td>
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<tr>
<td>Other:</td>
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</tbody>
</table>

### Other outcome assessments, including other biomarkers of effect (e.g. thyroid hormones, CRP, etc)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Type of assessment</th>
<th>Prenatal (mother)</th>
<th>At birth</th>
<th>Post natal (give months/years of age)</th>
</tr>
</thead>
<tbody>
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<td>e.g. 14 months</td>
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<td>N=</td>
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</tr>
</tbody>
</table>
D. Other information – including genetic and important covariates - all please comment

D1. Genotyping:
• Have genetic analyses been performed
  □ yes, GWAS
  □ yes, specific genes: _____________________________
  □ not yet, but planned. Please give predicted year of completion: 20____
  □ no

D2. Residential history and time-activity (tick which are available)
• Home addresses available:
  □ only once:
    □ during pregnancy
    □ at birth
    □ during follow-up: week/month:_________________
  □ residential history

• Work addresses of mother during pregnancy:
  □ yes
  □ no

• School/daycare addresses of child
  □ yes
  □ no

• Were these addresses geocoded?
  □ yes, specify which _________
  □ not yet, but planned. Please give predicted year of completion: 20____
  □ no

D3. Time activity patterns
• Was information on time-activity patterns collected:
  □ for child
    □ questionnaire, specify when__________
    □ diary, specify when ____________
  □ for mother
    □ questionnaire, specify when__________
    □ diary, specify when ____________

D4. Sociodemographic variables
□ mother’s social class (coded from occupation), specify coding system ____________
□ father’s social class (coded from occupation), specify coding system ____________
□ household income
□ mother’s education
□ father’s education
□ mother’s ethnic origin/country of birth
□ father’s ethnic origin/country of birth
□ maternal age
□ paternal age
D5. Breastfeeding
☐ weeks of breastfeeding
☐ weeks of exclusive breastfeeding

D6. Diet and physical exercise
- Dietary assessments
  ☐ yes:
    ☐ FFQ
    ☐ 24 hour recall
    ☐ other: ______________________________
    person (child/mother): ______________________________
    timing (e.g. stage of pregnancy, age of child): ______________________________
  ☐ no

- Assessment of physical exercise:
  ☐ yes:
    ☐ questionnaire
    ☐ measurements
    person (child/mother): ______________________________
    timing: __________________________________________
  ☐ no

D7. Medical history
- Is the following information collected for the parents?
  ☐ family history
  ☐ pre-pregnancy medical history of mother
  ☐ pregnancy complications
    ☐ blood pressure measurements
    ☐ maternal hypertension
    ☐ preeclampsia
  ☐ maternal allergic history
  ☐ paternal allergic history

D8. Parental anthropometry
☐ maternal pre-pregnancy weight, height
☐ maternal pregnancy weight, height
☐ paternal weight/height

D9. Other/Comments
Annex 5 - Case study ideas
(mix of different settings needed – some case studies including as many cohorts as possible, others to illustrate more specific issues)

Criteria for defining case studies (as discussed at meeting):

1. Interest for research (gap in information in specific scientific area, i.e. moderate alcohol), with priority for causal evidence analyses. (topics to cut across WGs, ideally at least one for each post-doc working on the project)
2. Relevance for policy making
3. Benefit from pooling (e.g. rare outcomes, rare exposures, international comparison)
4. Topics that highlight added value of a cohort approach (e.g. repeated measurements, life-course analysis)
5. Evaluation across a range of European cohorts to demonstrate value of different settings (small/large, North/South, young/old, many follow-up points vs few follow-up points)
6. Publishable as papers (and report with add-on for specific CHICOS issues)

<table>
<thead>
<tr>
<th>First ideas:</th>
<th>WGs involved:</th>
<th>Cohorts included:</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal occupation (priority occupations, possibly JEMs) and birth outcomes</td>
<td>Environment; Birth outcomes</td>
<td>Many cohorts</td>
<td>Rare exposure - large benefit from pooling; includes many cohorts, smaller and larger, different parts of Europe. Continuation of Enrieco work. Could demonstrate whether topics such as this benefit from having smaller cohorts in many countries.</td>
</tr>
</tbody>
</table>

CHICOS project