EUROCISS II Meeting

FINAL MINUTES

Place: Barcelona
   Institute of Health Studies
   Department of Health

Date: 4-6 October 2005

Participants in the meeting:

Konrad K. STEINBACH (Austria); Jiri HOLUB (Czech Republic); Mette MADSEN (Denmark); Veikko SALOMAA (Finland); Anne FAGOT-Campagna (France), replacing Juliette BLOCH; Angela DORING (Germany); Dimitra KONTOPOULOU (Greece), replacing Antonia TRICHOPOULOU; Roza ADANY (Hungary); Simona GIAMPAOLI (Italy); Diego VANUZZO (Italy); Luigi PALMIERI (Italy); Paola CICCARELLI (Italy); WM Monique VERSCHUREN (The Netherlands); Sidsel GRAFF-IVERSEN (Norway); Andrzej PAJAK (Poland); Evangelista Casimiro ROCHA (Portugal); Susana SANS (Spain); Nicklas HAMMAR (Sweden); Paola PRIMATESTA (UK); Steven ALLENDER (European Hearth Network)

4th OCTOBER 2005
2.00p.m. – 7.00p.m.

AGENDA

1. Welcome and overview of previous meetings
2. Short review on main points to be discussed around the three Manuals of Operations
3. Splitting of participants in three working groups: each of the following Writing Groups gathers in one meeting room for separate discussion:
• Writing group of the Manual of Operations of Cardiovascular Surveys: P. Primastega (coordinator), A. Doring, S. Graff-Iversen, S. Allender (successor to S. Petersen), WM M. Verschuren, D. Kondopoulou, J. Holub


• Writing group of the Manual of Operations of Stroke register: S. Giampaoli (coordinator), R. Adany, N. Hammar, A. Fagot-Campagna (successor to R. Morello)

4. Presentation of draft Manual prepared by coordinator and selection of a presenting rapporteur

1. Welcome words by Dr Juli de Nadal, Director of the host Institution (Institute of Health Studies), opened the meeting.

2. A brief summary of the main points discussed during previous meetings and of results obtained until now was made by Simona.

3. Before splitting into groups, members discussed about how to conduct the separate session and organize the list of contents of the three manuals in a similar way. Each group was asked to clarify intentions and proposals in order to avoid different directions in structuring the Manuals, especially as for Registers.

Mette presented the following list of questions for discussion prepared with Niklas:

Purpose of the manual
Organization of the manual
How to summarize the questionnaires and which registers are to be included (ongoing/MONICA)
What to include in the recommendations:
- for countries with existing registers
- for countries without existing registers
- validation procedures (they can be very different for different kinds of registers and for those registers starting now and for those existing since years)
- cost-utility considerations for different countries (cost of monitoring to be considered).

Niklas wondered whether Manuals should focus on surveillance or also include treatment and follow up of treatment.

It was highlighted by Veikko that, even though the main purpose is monitoring, there is no valid surveillance without research, so data obtained must be used for research and publications are the only way results can be spread.

After debate, all members agreed that Manuals should focus on surveillance but without totally excluding treatment. Susana suggested to set a minimum core of indicators regarding treatment. Also other sources of information need to be taken into account since they can help Writing Groups of Manuals reach the main goal, that is to set up a minimum package of Manuals of Operations which can be implemented in the greatest number of countries for CVD surveillance.
4. After the preliminary plenary discussion, each group gathered into a meeting room to draft the Manual and decide how to structure the final version and which topics need to be further developed. A rapporteur from each group to present results in the plenary session was elected in each group.

5th October 2005
09.00 a.m. - 7.00 p.m.

AGENDA

1. Continuation of Writing groups sessions

Plenary session:

1. Presentation of results by the rapporteur of each Writing Group:

2. Comments and debate of proposals under discussion in order to agree on a final structure of each Manual

1. During the plenary session, each rapporteur summarized the main points of separate discussion and presented the final results.

Niklas presented an updated list of contents of the Manual of Operations of Stroke Register covering the following topics:

- Background:
  Burden of stroke in Europe: incidence, mortality, number of subjects affected, disability, health costs. Future projections.
  History of surveillance (briefly); MONICA, local initiatives (Dijon, Orebro, GP network, Italy, NORDAMI etc).
  Needs for surveillance activities and international comparisons

Strategies for surveillance:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital records or mortality records</td>
<td>Hosp rec mort rec linkable (national or</td>
<td>Regional stroke register including</td>
<td>GP network and/or health survey</td>
</tr>
<tr>
<td>not linkable (national with sample</td>
<td>regional; sample validated)</td>
<td>non-fatal cases out of hospital</td>
<td></td>
</tr>
<tr>
<td>validated)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalization /death</td>
<td>Attack rate / incidence / prevalence /</td>
<td>Attack rate / incidence / case fatality</td>
<td></td>
</tr>
<tr>
<td></td>
<td>case fatality</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4 strategies (A, B, C, D) have been set up taking into account differences among countries. A and B strategies can be applied in all countries as first step.

- **Definition of Stroke event:**
  Diagnostic criteria according to MONICA including subtype (duration of event 28 days)
  Measures of stroke occurrence, case fatality and disability:
  - Hospitalization rate per 100,000 pop
  - Mortality rate
  - Attack rate (first and recurrent)
  - Incidence rate (first events; wash out period (7 y?))
  - Case fatality 28 days and 365 days
  - Prevalence
  - Disability (Rankin scale) ; suggested if possible

- **Strategy for quality evaluation and measures of diagnostic quality**
  Strategies:
  - Examination of medical records, autopsy records etc random samples of cases
  - Linkage to more refined registers (e.g. regional stroke register or a population based study)
  Measures of diagnostic quality:
  - Sensitivity, specificity, positive predictive value

**Basic information needed for evaluation of diagnostic quality**
- Clinical signs from the medical record
- Report from CT scan or MRI
- Death certificate and if available autopsy report

**Strategy for evaluation of A and B strategies**

<table>
<thead>
<tr>
<th></th>
<th>National or regional</th>
<th>Local evaluation vs C</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step I Stroke</td>
<td>Step II Stroke by subtype</td>
</tr>
<tr>
<td>ICD code</td>
<td>ICD-9 430-8</td>
<td>430-32, 434,436</td>
</tr>
<tr>
<td></td>
<td>ICD-10 I60-9</td>
<td>I60-64, I66 (or more detailed)</td>
</tr>
<tr>
<td>Age group</td>
<td>30+; age specific; priority 35-74</td>
<td>35-74 (typically)</td>
</tr>
<tr>
<td>Sample for validation</td>
<td>Random sample from defined case population</td>
<td>All cases for pop covered by C</td>
</tr>
<tr>
<td>Measures of validity</td>
<td>PPV</td>
<td>Sensitivity, specificity, PPV</td>
</tr>
<tr>
<td>Quality indicators</td>
<td>% hospitalized or dead, % CT scan or MRI, % autopsy</td>
<td></td>
</tr>
</tbody>
</table>
**Quality control of C and D**
Included in the protocol for establishing C and D.

**Recommendations**
- All countries should do at least A and step I
- This could be a basis for international comparisons of hospitalization and mortality and could indicate possibilities to move to step II (stroke subtype)
- Possibilities to do B regionally or nationally should be investigated at least in a long term perspective
- Where B is not possible C or D should be seriously considered

Fruitful and positive comments followed.

Veikko, as rapporteur of the Writing Group for the manual of Operations of AMI Register presented a reorganization of the draft manual list of contents as well:

1. **INTRODUCTION AND RATIONALE**
   - Burden of disease (populations are ageing rapidly, the cost is increasing, survival rates are improving)
   - Summary of existing AMI registers in Europe and Existing surveillance (WHO, OECD)
   - Types of registers
   - Purposes of the project

2. **OBJECTIVES**
   - develop a protocol for the minimum data set for monitoring AMI and a step-wise procedure for those countries who have no registers and for those who have only hospital-based registers in order to produce as much comparable data as possible.

3. **STRATEGY FOR MONITORING**
   - Population under surveillance (size)
   - Datasources (Hospitalised Discharge Lists and Records; Deaths Certificate; other sources)
   - Types of registers (Populationbased (Monica-like or based on administrative registers, Hospital-based)
   - Ethical issues

4. **METHODS FOR MONITORING**
   - Definition of events: Type of pursuit
   - Record linkage

5. **QUALITY CONTROL**
   - Coverage of events (fatal/non-fatal; hospitalized/non-hospitalized)
   - Completeness of information
   - Internal validity
   - Representativeness
   - Validity of population data
   - Validation methods
6. COST-UTILITY OF DIFFERENT REGISTERS (hospital vs population, administrative vs MONICA-like)

- Methods to reduce costs of registration

7. RECOMMENDATIONS

- Existing registers (validation)
- New registers (validation)
- Implementation – a stepwise procedure

APPENDIX 1: OVERVIEW OF AMI REGISTERS IN EUROPE AND EXISTING SURVEILLANCE

APPENDIX 2: MONICA CRITERIA OF MYOCARDIAL INFARCTION

Veikko presented the Stepwise Approach recommended for the implementation of AMI Register.

STEPWISE APPROACH

STEP 1

- select a geographical administrative area with a population big enough to provide stable estimates
- analyze population demographic data
- analyze existing Hospital Discharge and Mortality data
- identify problems with these data (coverage, ICD version, ICD codes, procedures, DRG, unit of analysis [discharges and/or patients], personal ID, coherence with previous studies, etc.)

STEP 2

- perform validation studies on available data (in order of importance)
  - coverage (comparison of different routine data sets [electronic or manual], number of patients treated in- or out-of area, hospital/mortality ratios, age and gender ratios, principal vs secondary and/or procedure diagnoses)
  - discharge diagnoses according to a standard method (including revision and abstraction of medical records) in a random sample or in all the cases (including check of other related diagnoses)
  - mortality causes according to a standard method in a random sample or in all the cases
  - demography and representativeness of the area in comparison to the region or country
  - residency and other individual data
STEP 3
- explore the feasibility of record linkage within Hospital Records (probabilistic or deterministic approach or using personal ID code) [within the same hospital, among hospitals of the area, among hospitals at regional or national level]
- explore the feasibility of record linkage between Hospital Records and Mortality Register (probabilistic or deterministic approach or using personal ID code)
- evaluate the feasibility of linkage with other sources of information (e.g. GPs)

STEP 4
- if feasible set up record linkage system
- validate the linkage procedure
- validate diagnostic information at least in a random sample of sufficient size
- estimate sensitivity and specificity and positive predictive value of record linkage
- estimate incidence, recurrence, attack rate, case fatality and mortality rates
If sensitivity, specificity and positive predictive value are representative for region or country and they are acceptable then
  - perform periodic validations
If not
  - follow STEP 5 and STEP 6

STEP 5
- set up a pilot population-based register with proven standardized protocol for Acute Coronary Syndromes
- evaluate the pilot study results (coverage, completeness of information and diagnostic validity, cost considerations)

STEP 6
- select one or more populations representative for the region or the country
- for each selected population set up a population-based register with approved standardized protocol for Acute Coronary Syndromes
- use the results from the register to validate the attack rate, incidence and case fatality obtained from the administrative data
- evaluate the representativeness and coverage, completeness of information and diagnostic validity and costs

Fruitful and positive comments followed

Finally, Paola Primatesta, the rapporteur of the Writing Group of Manual of Operations of CVD Survey presented the following updated list of contents:
INTRODUCTION
- Relationship between Registers and CVD Surveys
- Pros and Cons of the Surveys
- Relationship with other EU funded Projects in terms of content, recommendations.
- CVD modules as part of the National Health Surveys

HISTORICAL BACKGROUND
- Seven country study
- Old MI to be removed

HIS\ HES

MINIMUM SET OF QUESTIONS FOR Health Interview Survey
- Diseases: AMI, HF, AP, Stroke and CABG, PTCA
- Risk factors (smoking, drinking, physical activity, diabetes, blood pressure, lipids, height and weight if no HES)
- Questions on use of medications (name of medications currently used ATC)
- General questions on age, sex, education, occupation, ethnicity, self-reported health

MINIMUM SET OF EXAMINATIONS FOR Health Examination Survey
- Height, weight, waist, hip, blood pressure, blood sampling (no fasting), total and HDL cholesterol

EXTRA EXAMINATIONS FOR HES (in sub-samples?)
- ECG, ECHO-cardiography, ABI (Ankle Brachial Index), blood sample (additional laboratory analyses).

STRATEGY FOR SURVEILLANCE
Used when validated questions’ questionnaires from EU Projects (European Health Risk Monitoring)

1. For Heart Attack, AMI; Angina Pectoris; Stroke, Cerebral Haemorrhage, TIA, ask:
   o Have you ever had any of them?

   (For each disease with a positive response, ASK)
   o [How old were you when you had the first attack?]
Interventions (CABG, PTCA):
  - Have you ever had ..........?
  - Have you had it in the past 12 months?
  - (How old were you when you had.....?)

Angina ROSE Questionnaire (optional)

2. Heart Failure:

   no validated set of questions exists.
   We recommend that an instrument should be developed.

SURVEYS IN THE EUROPEAN MEMBER STATES (to be updated)

POPULATION

  - Age-Range (it may vary according to CVD condition)
    Minimum requirement: 50-79 (extended age range: 35+)
    Inclusion/exclusion criteria:
      - inclusion of institutionalized people subject to available resources;
      - minority ethnic groups to be included;
      - people younger than 35 to be excluded.

  - Socio-Economic Characteristics

  - Ethnic Origin and Migration Level

POPULATION SAMPLING

   - Random national samples
   - Boost of group of interest (e.g. ethnic groups, regional groups.....)

RESPONSE RATE

   - Study of non-respondents
   - Weight for non-respondents
REPORTING

- By age-group of interest
- Age-standardized according to the European Standard

QUALITY CONTROL

Standardization of methods

- Piloting the study
- During data collection
- Validation of questionnaires
- Validation of measurements (intra- and inter-observer variability)
- Observer specific missing checks

After presentation, the debate mainly focused on the importance of validating HIS to get the prevalence. HES implementation should be a further step which need EU financial support since examinations are very much expensive and if performed only on sub-samples they might not be representative of whole population.

It was also stressed the importance of placing EUROCISS Surveys within the context of EU surveys which are being carried out to be aware of what is going on in Europe.

It was also suggested:
- to add obesity and diabetes to the list of risk factors since they are increasing throughout Europe;
- to perform fasting blood sampling at least in a sub-sample;
- to add disability to the list of questions;
- to perform HES at least in a sub-sample;
1. Overview of EUROCISS Project financing to single members countries

2. EUROCISS web site: advancements

3. Presentation of tabs summarizing data from Inventories

4. Participation to international meetings to disseminate project results

5. EUROCISS project activities plan for the next year

6. New EUROCISS meeting (time and place)

7. New Steering Committee meeting (time and place)

1. Members have been informed that all countries which had sent the Grant Agreement properly signed were paid the first tranche of payment. Those who have not sent the Agreement yet have been urged to do that as soon as possible. The table reported below clearly show the financial situation:

<table>
<thead>
<tr>
<th>Country</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUSTRIA</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>BELGIUM</td>
<td>missing</td>
</tr>
<tr>
<td>CZECH REPUBLIC</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>DENMARK</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>FINLAND</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>FRANCE</td>
<td>missing</td>
</tr>
<tr>
<td>GERMANY</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>GREECE</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>HUNGARY</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>ICELAND</td>
<td>missing</td>
</tr>
<tr>
<td>THE NETHERLANDS</td>
<td>missing</td>
</tr>
<tr>
<td>NORWAY</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>POLAND</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>PORTUGAL</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>SPAIN</td>
<td>missing</td>
</tr>
<tr>
<td>SWEDEN</td>
<td>sent (1st tranche paid)</td>
</tr>
<tr>
<td>UK</td>
<td>missing</td>
</tr>
</tbody>
</table>
2. Luigi presented the EUROCISS web-site advancements:

- a new picture representing an heart “flying toward Europe” has replaced the previous one
- under the section “Data at national level” tables summarising data about cardiovascular diseases by single country are now available in a more updated and completed version which takes into account data collected through the first questionnaires and those drawn from the new questionnaires.
- a forum for discussion recently set up has been presented to participants. This internal ‘working page’ can be accessed exclusively by EUROCISS partners through a personal user and password in order to store data and consult common documents. All comments and suggestions made by partners are necessary to keep the forum up to date.

Partners accessing documents are not allowed to make changes themselves but should sent all their comments by e-mail to eurociss@iss.it.

All members will be sent by e-mail the password to access the forum.

At present the following documents are available in the forum:
tables, draft Manuals of Operations, minutes of previous meetings, interim report. It was suggested to provide a pdf format of these documents.

3. Simona showed the tables summarizing available data drawn from the Inventories on Registers (both at national and regional level) and Surveys.

Participants were informed that the tables are available on the EUROCISS web-site forum and were invited to check and eventually update information.

4. As concerning the dissemination of EUROCISS results and recommendations, members have been informed about the poster presented by Mette Madsen to the Sixth International Conference on Preventive Cardiology (May 21-25, 2005. Iguassu, Brasil), the presentation held during the Symposium on Cardiovascular surveillance in Europe at the ESC Congress 2005 (September 3-7, 2005. Stockholm, Sweden) and the abstract “European Cardiovascular Indicators Surveillance Set (EUROCISS) Project: Recommendations for Monitoring Cardiovascular Disease” presented by Diego Vanuzzo at the Workshop “A Canadian Best Practices System For Chronic Disease Prevention And Control” held in Toronto, Canada on March 10-11, 2005.

Future dissemination of project results on behalf of EUROCISS group:
- two abstracts will be presented at the EUPHA meeting which will be held in Austria next November 10-12, 2005
- a proposal for Symposium has been submitted to EUROPREVVENT which will be held in Athens, Greece, on May 11-13 2006. Deadline for proposals: 27th January 2006
- an abstract has been sent to the AHA 46th Annual Conference on Cardiovascular Disease Epidemiology and Prevention in association with the Council on Nutrition, Physical Activity, and Metabolism to be held in USA, Phoenix, March 2-5, 2006- a symposium on activities of EUROCISS Project will be held during the International Symposium on Stroke Surveillance (Rome, June 8-9 2006). Proposal must be sent by the end of October. In December the last version of the programme will be available.
- two proposals for symposium on surveillance have been submitted to the ESC which will be held in Barcelona, September 2-6, 2006. Deadline for proposals: 14th February 2006.

Diego suggested to place all the abstracts already sent on behalf of the EUROCISS group on the project web-site so that they can be accessed by members for consultation.
It has been also suggested to place on the project web-site the abstracts to be sent in the future so that comments can be made and abstracts can be revised and approved by members before submission.

Simona highlighted the fact that every author of abstracts can present the abstract at meetings but she/he should find funds himself since EU does not support participation at any international meeting.
Abstracts must be always sent on behalf of the group, giving the names of all authors.

Susana suggested that the deadlines for submission to approaching International Meetings should be available on project web site.

Niklas suggested to place the list of EUROCISS I and II publications on project web-site as well.

5. As for the activities for the next year, the main activity is to complete the three Manuals of Operations.
It was also stressed the importance of spreading project results at national level through publications on public health journals and local meetings.
Since manuals cannot be published before being completed, it was suggested to publish the list of available recommended indicators at national level.
Mette informed participants that she will do her best to mention EUROCISS, whenever possible, in the papers which are to be published in her country. She also suggested to place presentations from Northern Countries on web-site.

A brief overview of ECHI Project was provided:
ECHI Project had formally finished and the new project, called ECHIM, has been launched with the purpose of assessing availability, comparability and use of health indicators.
Next meeting of the MMWP (Morbidity Mortality Working Party) will be held in December and it is expected to focus on CVD, while last meeting focused on cancer.

6. As for the next meeting, the proposed places are:
   Amalfi
   Erice
   Florence
   Tentative date: 11-13 October 2006

7. It was unanimously decided to hold the next Steering Committee Meeting in Athens, Greece during the EUROPREVENT meeting (may, 11-13 2006).

The meeting rose at 12.00a.m.