EUROPEAN COMMISSION
HEALTH & CONSUMERS DIRECTORATE-GENERAL

Directorate C - Public Health and Risk Assessment
C2 - Health information

Luxembourg, 13 July, 2009

Summary Record of Meeting of the Health Information Committee
8 July, 2009
Jean Monnet Building (JMO M1)
European Commission
Kirchberg, Luxembourg

Participants: Please refer to Annex 1.

WELCOME AND ADOPTION OF DRAFT AGENDA

CHAIR welcomed the participants and outlined the agenda, which was agreed by all participants.

MINUTES OF PREVIOUS HIC MEETING

ECDC and **FI** added comments to the circulated minutes of the meeting on 28 April 2009, which will be integrated.

DISCUSSION

A.1. Revision Process of the ICD

COM briefly outlined the current developments of the ICD revision, particularly in the field of rare diseases. In this context, it was highlighted that the organisation of a workshop on rare diseases and the ICD in early 2010 is envisaged, on which more information would be available soon.

Orphanet gave a presentation on 'rare diseases in the ICD revision process' for the preparation of the coming ICD 11. The main points presented were the lack of a systematic approach in the classification of rare diseases within the actual ICD 10, which relates to the chapter organisation. It was highlighted that 'malformations' represents a difficult chapter due to semantic ambiguity. Further, it was described how, in a laborious process, a dossier for each single disease is prepared and transmitted to WHO.

In the following brief discussion, it was pointed out that a poly-hierarchy (one disease classified in several chapters) will allow to minimize, but not to exclude statistical discontinuity. It was further stressed that the classification of rare diseases has to be coherent with the classification of common diseases, and that this objective is integrated in the work of the group. The alpha-draft of the new rare diseases classification will tentatively be ready by March 2010.

WHO gave a presentation on the ICD 11, which was focused on describing the foreseen multidimensional nature of the revised classification. This is based on assigning several interlinked characteristics to a disease (body part, aetiology, etc.) in addition to its title and definition.

In the discussion, the following issues were raised:

- Many participants were concerned about the implications for users/coders and the way that data collection may be affected. **WHO** pointed out that the coding procedure as well as the data collection will by and large not change, and that the increased resolution of information is supposed to represent an offer rather than a constraint.
- Each disease in the actual ICD 10 will be assigned a unique identifier, which will allow the link with the same disease in ICD 11. This should minimise problems of statistical discontinuity.
- Further, the distinction between the ICD and SNOMED was made. The latter concerns terminology and is complementary to the ICD.
- It was highlighted that the translation and the meaningful linguistic transformation are challenges, which can however build upon existing data.
- Likewise, the importance of linkage with the International Classification of Functioning, Disability and Health (ICF) as well as the International Classification of Health Interventions (ICHI) was pointed out.
- It was made clear that comorbidity related to mortality would be difficult to assess, as coding of a single leading cause of death is at the moment widely established. The importance of harmonization in this field was emphasized, and it was agreed to take this issue into the Eurostat Technical Group on Causes of Death.
- **SE** suggested matching statistical indicators such as ECHI with the proposed ICD content.

CHAIR asked the participants for their sustained input on the revision process in terms of their expectations and propositions.

A.2. Healthy Life Years

A member of the Task Force on Health Expectancies gave a presentation on the current work of the Task Force by emphasizing the dissemination of the group's reports, the need to harmonize the wording in SILC, and the issue of the international diversity in summary measures.

In the following discussion,

- **DE** pointed out its discontent with the quality of the 2006 data, the fact that the HLY were a sensitive issue, and that there has been irritation concerning the Lancet article. **COM** and member from Task Force commented that there have been consultations for

the values used for the article, and that the article merely was an extract of the existing Task Force report.

- **WHO** suggested in this context to pre-present future results to politicians.
- It was clarified that the confidence intervals have indeed been computed.
- There was a consensus that a significant improvement of data quality is expected with the 2008 SILC.
- It was highlighted that a refinement of the broad indicator would be a benefit to target specific questions, and that work on decomposition techniques was under way.
- It was suggested to further address the dimensions 'inequalities' and 'socioeconomic status'.
- The question was raised whether the work of the Task Force could be organised as a joint action.

CHAIR concluded that the communication of the initially politically requested instrument HLY constituted a delicate task. Further, the evaluation of the use of the information conveyed would be an interesting prospective step to see to what extent it facilitates the decisions for action.

A.3. Updates on ongoing Health Information Work

A member from ECHIM presented the joint action by outlining its foreseen structure, objectives and outputs. A total of 24 involved Member States will aim to consolidate and expand the ECHI indicator system. It was pointed out that the ECHIM implementation process in Member States does not take place at a similar speed, and it was suggested that **COM** send a letter recommending the initiation of a national ECHIM implementation process in all countries.

In the following discussion, participants generally endorsed this suggestion.

COM acknowledged the proposition and underlined that interested Member States still had the opportunity to actively join the work of the ECHIM joint action. It further pointed out that – in case that data from Eurostat or other sources such as PERISTAT was available – the implementation of ECHIM basically implied the use of this data. Wherever such data was not available, the implementation would then require further action.

Eurostat informed the participants about the latest developments in **Eurostat**, which included the SILC 2007 data, updates regarding the implementation of EHIS and EDSIM, morbidity statistics, and the causes-of-death regulations implementation. It was pointed out that workshops on EHIS are planned to identify problems concerning the implementation.

The Executive Agency for Health and Consumers (EAHC) presented the funding for conferences, projects and operating grants that was allocated in 2008. It also outlined the state of play in 2009 and agreed to update the HIC twice a year on ongoing projects.

COM announced that the workplan 2010 of C2 was to be presented during the next meeting, but already outlined some foreseen key points:

1. Joint action on Alzheimer.
2. Call for proposal for Multiple Sclerosis registry.

3. Exchange of information on added value of orphan medicines.
4. Joint action on HLY.
5. Continuation of the work of PERISTAT.

Further, the priorities of the next Commissioner may become part of the unit's agenda, as well as work on the effects of the financial crisis on health expenditures in terms of politicians' responses to budgetary pressure.

A.4. Health Information Knowledge Management

CHAIR briefly outlined the state of play of the EUGLOREH report, stating its usefulness but also the fact that is too long for effective use. As a basis for discussion, a 20 pages summary as well as a "living report" in form of a Wiki (to be edited by networks of experts) was proposed.

In the following brief discussion several issues were raised:

- The question of eligibility for becoming an editor.
- The balance between quality of information and effective use of limited resources.
- The issue of how to balance the content.
- The question how this could affect the workload of the Committee and the need for future health reports.

CHAIR thanked the participants for their input and suggested to continue the discussion during upcoming meetings.

A.5. Any other Business

CHAIR announced the countries for which nominations for the HIC were still missing:

AT, CY, DE, IT, LU, MT, PT, RO, LV, SI, ES, UK, TR, IS, NO, MK.

CHAIR raised the question whether the current level of participation in this meeting (17/27) was sufficient and useful for the envisaged purposes. An evaluation and discussion about the meaningfulness was deemed necessary.
Further, a discussion paper will be circulated, on the basis of which the scope and mandate of the HIC is to be further discussed.

COM announced that it will soon be an official partner of the European Observatory on Health Systems and Policies, and that it welcomes the Committee's input on prospective areas of work.

CHAIR acknowledged that the sending of preparatory materials for the meetings was not optimal, and agreed to improve it.

On a request by **FR**, **CHAIR** noted that the consultation for the discussion paper on Health Information Strategy and Structure was planned to stay open until the October 2009 meeting.

The next Health Information Committee meeting will be a one day meeting on **14 October 2009** and will be linked to a wider meeting with neighbouring countries on 15 October 2009.