



European Union Health Surveys Information Database Project (EUHSID)

Advisory Board Meeting Helsinki 14–15 September 2009

Participants (16)

Sanna Ahonen, National Institute for Health and Welfare (THL), Finland
 Arpo Aromaa, National Institute for Health and Welfare (THL), Finland
 Girts Brigis, Riga Stradina Universitate, Riga, Latvia
 Anne Fagot, Campagna Institut de Veille Sanitaire, Paris, France
 Simona Giampaoli, Istituto Superiore di Sanita (ISS), Rome, Italy
 Jiří Holub, Ústav zdravotnických informací a statistiky, Praha, Czech Republic
 Kati Karelson, National Institute for Health Development, Tallinn, Estonia
 Paivikki Koponen, National Institute for Health and Welfare (THL), Finland
 Kari Kuulasmaa, National Institute for Health and Welfare (THL), Finland
 Cornelia Lange, Robert Koch Institute, Berlin, Germany
 Jennifer Mindell, University College of London, United Kingdom
 Johanna Mäki-Opas, National Institute for Health and Welfare (THL), Finland
 Jean Tafforeau, Scientific Institute of Public Health (IPH), Brussels, Belgium
 Alessandra Tinto, Istituto Nazionale de Statistica (ISTAT), Rome, Italy
 Hanna Tolonen, National Institute for Health and Welfare (THL), Finland
 Antti Tuomi-Nikula, National Institute for Health and Welfare (THL), Finland

Not able to attend (6)

Lucian Agafitei, Eurostat
 Grazyna Broda, National Institute of Cardiology, Warsaw, Poland
 Enric Duran, Institut Municipal d'Investigació Mèdica (IMIM), Barcelona, Spain
 Jaason Haapakoski, National Institute for Health and Welfare (THL), Finland
 Ari Haukijarvi, National Institute for Health and Welfare (THL), Finland
 Monique Verschuren, Rijksinstituut Volksgezondheid en Milieu (RIVM), Bilthoven, The Netherlands

Item 0. Opening of the meeting: Aims of the project and tasks of the Scientific Advisory Board

The aims of the EUHSID project are to reinforce public health statistics in Member States (MS) and at EU level and harmonize and improve comparability by maintaining and developing the Health Survey database. The database is one part of the European Health Survey System along with EHIS (European Health Interview Surveys), EHES (European Health Examination Surveys) and other population surveys (e.g. SILC, Survey on Income and Living Conditions). The aims of the project are to update the HIS/HES database with surveys and reference tools, to reinforce collaboration at EU level, to promote best practices and to make comparisons of surveys easier. The tasks of the advisory board members are to share their expertise when the project team needs help in developing the database and solving problems, or needs scientific advice.

Item 1. Recent developments in health indicators (ECHIM) and health surveys (EHES) in the framework of the Public Health Programme of DG Sanco

The ECHIM (European Community Health Indicators Monitoring) project (2005-2008) laid foundation for indicator implementation with the ECHI shortlist of indicators. The purpose of ECHIM Joint Action (ECHIM JA 2009-2011) is to implement the indicators in all MSs.

ECHIM JA is one of the few practical development and implementation actions in the Health Information Strand. Recently it has been identified that many projects funded by the Commission are not well

coordinated and their results are not fully implemented in the Member States. These problems are highlighted e.g. in the evaluation report by the European Court of Auditors on the Public Health Programme by DG Sanco. This report is available at: <http://eca.europa.eu/portal/pls/portal/docs/1/2838313.PDF>

The three-year period of the ECHIM JA is not enough to implement indicators in all MSs. Plans for implementation have been prepared in a few countries. The current problem is how to finance a meeting of all MSs to keep all countries actively involved. As this financing has not been available, the implementation will start in countries represented in the core group.

It was emphasized that approximately 50% of the ECHI indicators rely on health surveys to be implemented. It was also reminded that the structure of the topic codes used in the HIS/HES database is in line with the structure of the ECHI list.

The main steps of setting up the European Health Examination Survey (EHES) include planning and preparing a national HES and carrying out a pilot survey in 14 countries (Czech Republic, England, Finland, Germany, Greece, Hungary, Italy, Malta, Netherlands, Norway, Poland, Slovakia, Spain and Portugal). The coordination and international support is being funded through a Tender covering the EHES Reference Centre activities. Negotiations for a Joint Action to support the pilot countries for 2 years are ongoing. Core examinations include height, weight, waist circumference, blood pressure and blood samples.

In some countries the economic crisis and the swine flu problem are threatening the possibility to find funding for HESs.

Item 2. Recent developments in the framework of the partnership health of Eurostat

Current EHIS activities include: development of a template for reporting technical and methodological aspects of the surveys hosting the EHIS module, development of the indicators to be obtained from EHIS and three Task Forces on: sampling, inclusion of institutionalized people in health surveys and migrants' health.

It was mentioned that it could be a problem if the use of the exact wording of the EHIS source questions is not mentioned in the future EU regulation on the organisation of the EHIS.

Health variables in EU-SILC were presented and the work on the improvement of the comparability. Quality assessment on the 2007 and 2008 national EU-SILC health questions was launched by Eurostat in August 2009. It was asked if it would be possible to get feed back on the previous assessment(s) of the comparability of the health questions in SILC.

The European Disability and Social Integration Module (EDSIM) has been developed on social life participation of disabled people. Also the Labor force survey ad-hoc module on employment of disabled people will be conducted in the near future (2011). Final report of the EDSIM development and a draft commission regulation and questionnaire of the Labor force survey are available in the public part of Circa: <http://circa.europa.eu/Public/irc/dsis/Home/main>

Item 3. Progress report

IPH - HIS progress report

WP1

Update the HIS/HES DB with recent surveys. List of 2007 health surveys (70) is available at the EUHSID website. The list also shows which surveys meet the inclusion criteria. 17 surveys are already included in the database or are in process and 24 need to be included later. EHIS surveys in 2008: 10 surveys were identified; for 7 of them some documents were already received but it is still needed to get the back-translations of the questionnaires to English. Multi-country surveys: need to evaluate whether or not to be included in the DB.

WP2

Update HIS/ HES DB with reference tools. Cleaning of the list of the frequently used HIS instrument in progress (e.g. verifying instruments).

WP3

Upgrade of HIS/HES database: analysis of new format of multi-country surveys MQ (item 6). Analysis of a possible new coding system for EHIS questions (item 7). Update HIS topic code list (item 8).

THL - HES progress report**WP1**

Update of the HIS/HES DB: 5 surveys entered (combined HIS/HES), 5 surveys in process. MQs and request letters updated. Participation rates and multi-country surveys evaluated.

WP2

Reference tools will be updated after a new format for them has been developed in the DB. Definitions and inclusion criteria revised. Also, a protocol for evaluating the correspondence of survey questions/examinations to EHIS questionnaire and FEHES recommendations will be developed.

WP3

DB and the EUHSID website: User survey has been finalized and the report is in the website. HES topic codes need to be revised (in progress). Technical development needs of the DB have been listed. Website updated with inclusion criteria for surveys and reference tools and a list of identified surveys.

WP4

An Extranet has been used to share documents between IPH and THL. The first issue of the newsletter was mailed; a short introduction of the project was included in the EUPHA newsletter. Presentations were held in the ESRA Conference in July.

Item 4. HIS/HES Database User Survey 2009

The survey was conducted to receive feedback from the users of the HIS/HES database. The user survey enables to develop the database according to the needs of the "clients". The survey was sent to 604 users; 113 replies were received from 27 countries. Respondents were pleased to find a large amount of surveys in one database, also the comprehensiveness and the possibility to compare surveys received credit. The users were hoping e.g. for more user friendliness, better search methods and more up to date information.

Questions were raised during the meeting about the potential bias in the survey's respondents. Their comments were more kind of wishful thinking; some proposals were however quite concrete such as the definition of topic codes and a web link to survey data. The discussion also raised another issue: more people need to be informed of the existence of the database. We need to identify organizations that could disseminate information on the DB to the possible users (also possible future users).

Item 5. Reference tools

The aim was to discuss the needs to develop a new format for reference tools in the DB.

Reference tools are standard methods developed for health surveys (recommendation or consensus from projects, methodology, survey instruments, questionnaires, examination protocols or fieldwork manuals). Presenting those reference tools in the database is serving the purpose to promote standardization for the data collection methods. We think that this could be reinforced by allowing an easy access to those tools when experts are in the process of making decisions about their national survey methods.

A new structure/format is needed for including the reference tools in the DB since using the current survey format is not functional as key information of feasibility, validity and reliability of the tool is missing.

Minimum feasibility criteria and at least one reliability and validity criteria should be met before including new reference tools in the DB. Those tools also need to be culturally adaptable. i.e. valid in different countries and/or different cultures. Tools only tested in one setting should not be included, or at least the limitations in testing should be pointed out.

Most relevant items (as far as development, feasibility, reliability, validity, references, web link etc.) need to be shown/included in the DB.

The group agreed that it is important to include reference tools in the DB. THL will evaluate which features are needed in the new format in the DB, based on the feedback from the advisory board members. The key issues that the user would like to know and to find in the DB, were discussed:

- Links to published reports, and to the original source instrument/tool
- Information on countries currently using the tool
- Information on feasibility, validity, reliability, purpose/aims of the tool, time and cost to implement
- Provide contact details to the institution which developed the tool (not individual persons)
- Warnings about any potential problems identified while using the tool.

It is important to remember, that the aim is not to recommend which tools to choose, but to provide information on potential tools and to follow up which tools have been used in the field.

Some reference tools developed outside Europe could be included in the database also, if there is a note saying that it has not been further tested in EU.

Some reference tools have a copyright protection. One solution is that there could be some background information with a link to further information on the reference tool even if it is not included to the DB. Another solution would be to effectively include the instrument (with permission from the copyright owners) but to clearly warn the users that they have to request permission before using the tool.

For the HESs included in the DB, the corresponding reference tools are already shown for each HES measurement. But for HIS, there is no link between HIS questions and the corresponding reference tool (if the question used is effectively corresponding to a reference tool). The feasibility of developing this link between questions and standard instruments/questionnaires will be evaluated.

Questions were raised about the inclusion of instruments developed by the Budapest initiative and by the Washington city group, but the development is still ongoing.

It was suggested also to keep at the EUHSID website a list of reference tools that do not meet the inclusion criteria in the HIS/HES database.

Item 6. Multi-country surveys: definition, inclusion criteria and adaptations in the database format

Including multi-country surveys (MCS) in the database is problematic because the current format in the DB is not planned to include surveys conducted in more than one country (with different sample sizes etc). Also, it would require too much work to include all of them separately and would not be very informative. A solution could be to enter them only once with a link to every national survey.

A list of potential MCS's was distributed to the participants and some of them were discussed:

CINDI: it is a multicountry programme including surveys, but only the purpose of those surveys is common between the countries

DHS: too specific

ECHP: survey implemented in the past in EU countries

EQLS: there is a need for more information

ESS: no health items included

ESWT: no health items included

EUROHIS: survey implemented in the past

EB: too specific

EPIC: specific and regional surveys but could be interesting to evaluate if there are relevant reference tools developed in this study

EU-SILC: good candidate for inclusion but would be interesting to show the difference in translations in the different countries

SHARE: limited to elderly people

The discussion on each of the specific MCS was discontinued but it was recommended to finalise the evaluation of the remaining surveys in the list (EWCS, FINBALT, HBSC, HETUS/MUTUS, HBS, LFS, LSMS, MHES, WHS, WHMCSS, WMHS).

As very few of these MCS's need effectively to be included in the DB for the moment, it was decided that the development of a new format for MCS is not a priority for the time being in the technical development of the DB. Anyway, all the national surveys using the EHIS source questions need to be entered separately, since the Eurostat requests information on all of them.

Some countries may modify the instrument and use different data collection methods, which is why MCSs may vary between countries. This may be a problem if entering only one MCS. And even when the same methodology is supposed to be used, like in the SILC, we still see differences in the implementation at the national level (in the wording of the questions)

It was pointed out that the methodological information at country level is very important.

Item 7. Identifying national EHIS questions and assessment of correspondence with EHIS source questionnaire

There is a need to identify the questions used at national level for the implementation of the EHIS questionnaire. The solution proposed is to develop a new parallel topic code classification and searching procedure in the DB. Two level classifications would probably be enough. There is also an alternative way by adding EHIS codes to current classification system, but this would not be an exact link from EHIS source to national question.

The final aim is to evaluate the comparability of the national questions and the EHIS source. National questions need first to be back-translated into English and then compared to original EHIS questions. The similarity should be scored according to the differences found. Also the differences should be coded.

The evaluation procedures will be described in a protocol and test first tested with a few surveys in order to test the feasibility of the procedures, estimate resources needed and evaluate if the scores and codes are functional.

If comparability problems are found, they need to be identified and solved in collaboration with the MSs and when developing the EHIS questions for the second wave.

Discussion: The back-translation procedure raised a few comments. First of all, people tend to translate differently to English in the different countries. This is why back-translation may show a lot of differences between the questions. On the other hand, only the meaning of the question needs to be similar, a few differences in the wording are not a problem. Still it is important to distinguish if the problem is real or only a translation problem.

It will also be necessary to verify if the back translation was performed properly. Would it be possible by example to give to the translator the conceptual translation card (in national language)?

It was mentioned that some countries may have different questions or the questions are in a different order but they may still be able to deliver comparable data. Some countries may even include the questions in other surveys than the HIS.

Item 8 and 9. HES topic codes (definitions, need for new, recoding)

The codes have been developed during the database development. The topic codes need some re-evaluation. It was decided that the ICF (International classification of functioning, Disability and Health, <http://www.who.int/classifications/icf/en/>) will be used as a support source when modifying the HES topic codes. However, major modifications are not possible due to technical restrictions of the database.

There was discussion about renaming some codes e.g. walking speed renamed as walking. Stair mounting ability could be functional ability, because the first one can also include the measurement of cardiovascular ability/function. The idea is also to use wider headings for the topic codes, in order to place more examinations under the topics. Adding a few new codes e.g. environmental exposure and bioimpedance was also discussed.

It was mentioned that it would be beneficial for the database users to be able to search also by health area and not only by topic codes.

HIS topic codes (definitions, need for new, recoding)

Members of the Scientific Advisory Board were asked to read later at least a few definitions for the codes and to give some feedback.

Definitions and contents of a few topic codes were discussed:

- Pregnancy status needs to be clarified and perhaps a new code is needed to describe problems during pregnancy
- What is the right area for a new code “Use of technology”. We should try to identify, what is the purpose of the question and what might be logical for the users. For example in some countries the use of television is a matter of money (for area 1) and in other countries it is a question of how many hours per day a person is not moving when watching the television. It could this be coded under both areas
- Mobility - 208 is on physical limitations (with impact on mobility but also in other domains) – 211 is a specific concept (moving from one location to an other) referring to physical limitation in mobility : both codes could be used. The use of ICF to better phrase the title of the codes will be evaluated.
- 417 is typically related to behavior in contrast with 416, which is limited to knowledge.
- Condom use can be both 418 (sexual behavior) and 604 (contraception)
- “Have you had the menopause?” cannot be coded 418 : delete it from the examples of questions
- Passive smoking at workplace could be coded 403 but also 504 (workplace exposure): change the definition of this last code
- 607 code and following could include the concept of being aware of programmes but also to participate.
- 717 : could be interesting to discriminate between medical and social care, but also informal help; the problem is however that sometimes the type of help is specified in the answer category and not in the question
- The concept of needing help due to limitation could also be coded under area 2
- 720 recognition of handicap would rather be in area 2
- Brushing the teeth in area 6 (prevention)

Topic codes for Mental Health raised a lot of discussion. Under the code 217 will be coded in the future the questions that cover general mental health and also the series of questions/instruments related to general mental health (e.g. GHQ). If some questions of those tools are investigating specific positive or negative mental health domains, they could be coded with both the general (217) mental health code as well as with the corresponding specific code. It is however still not possible to identify which questions are part of a broad instrument and to have the link between a specific question and the corresponding reference tool.

The possibility to have only one code for all questions related to mental health was also mentioned, but in that case there would be too many questions under the same topic code.

Area 3 was also considered as problematic: only measurements are mentioned (glucose should be added) but nothing on the purpose: it is however sometimes difficult to discriminate if it is done for screening purpose (to be then also included in area 6) or not.

Area 7 is a mixture of different concepts. Health insurance could be in area 1 as a socio economic indicator, but also in area 7 as an indicator of accessibility to health care.

Some new topics are needed, like blood glucose, religion, language, use of technology, day hospitalization, gambling and violence, quality of care (split by type of care?). The work with the topic code definitions will be finalised by the end of this year.

Item 10. Technical development of the database: prioritization

Technical developments are proposed to make the database more user-friendly. A ranking of the priorities needs to be made.

Minor changes will be performed:

- Headings to be renamed
- Un-functional details to be corrected
- Add to the database a user name reminder
- Add survey inclusion criteria
- Add survey names to the list of survey codes
- Add the "AND" Boolean operator for searching the questions
- Add a glossary of terms used in the database and in the survey methodology
- Add a second link to survey website with the survey report/results (sometimes at a different place than the survey website).

One important modification is adding the link / additional coding system between survey questions and EHIS source in the database.

A key major change is the new structure of the reference tools that will be developed.

There was a lot of discussion about the modifications needed for the multi-country survey structure. It was decided this is not a priority

It was also decided that the definitions of the topic codes will be added to the database.

There should be an easy way for users to mention that there is a mistake or something is missing in the database, or at least a clear and easily identifiable "contact us" button in the main menu. This should open a user feedback box in a web form so that it will not be needed to open the email software of the local computer of the user.

There was also discussion about the use of the term methodology. It could be changed to methods.

The need to verify and update regularly the survey websites has also been emphasized.

Item 11. Pooling national HIS data: current situation and future potentials

EHIS data from different countries will be gathered at Eurostat. It will enable European level analysis and comparisons between countries. Eurostat is taking care of the procedures to allow an access to the EHIS database for the scientific institutions first by adding the EHIS in the list of databases that can be accessed and second by verifying with all the MSs what are the rules for privacy protection. This whole process would be done by the end of 2010. Each institution will have to be added to the list of admissible third parties that will be allowed to access to data. These institutions can then address a request to Eurostat to access the data.

Item 12. Dissemination of EUHSID: EUHSID website, newsletters, presentations and reports

The EUHSID website and also other disseminations plans for the project were presented. The purpose is to promote awareness of the existence of the database and to get more users for the database.

Newsletter

The EUHSID newsletter needs to be modified to raise more interest. In order to avoid spam filters it was suggested to include the newsletter in the mail (with short titles as links to the items included in the newsletter, and links to the full information). There was also discussion on the target group for the newsletter, e.g. more people involved in education could be reached.

User's experiences could be added in the newsletter to attract reader's interest.

Conferences

Kati Karelson provided information of organizations, which could be useful in disseminating information on the DB:

1. IUSSP –International Union for the Scientific Study of Population: <http://www.iussp.org/>. Main conference of the Union is once in every 4 years (<http://iussp2009.princeton.edu/>).
2. EAPS – European Association for Population Studies: <http://www.eaps.nl/>

It was also recommended to present the database at several future conferences in addition to EUPHA and IEA.

A short information leaflet and a power point presentation will be prepared. During conferences it would also be useful, whenever possible, to show directly on the Internet how to access and use the database. The Scientific Advisory Board members can use these materials to “market” the database, in addition to administrators at IPH and THL.

Specific networks

It was suggested to:

- Contact the ASPHER (EU association of schools of public health) to include the HIS/HES database in the education programme of the students
- Collect additional addresses for the newsletter’s mailing via the members of the advisory group.

It would also be useful to attend and present the database during the UK health surveys user’s day.

Item 13. Work plan for 2009–2010 and agreement on the tasks of the members of the advisory board

The updating of the database will continue for both HIS and HES parts.

The evaluation of the multicountry surveys will be finalised and a list of these will be added to the EUHSID website. An inquiry for the EHES contact persons about conducted and planned health examination surveys will be done by the end of October.

The procedure for assessment of correspondence of survey questions to EHIS questionnaire will be planned and tested at THL by the end of this year. Detailed instructions for the reference tools structure in the database will be prepared and the modifications will also be tested.

The EUHSID newsletters will be sent when adequate news are available. Awareness of the database will be promoted by many means (presentations at the conferences, PowerPoint presentation about the database and information leaflet).

Item 14. Future of the HIS/HES Database and the project

The members of the advisory board were in favor of the continuation of the database in the future. The database is actually one element of the European Health Survey System. There should be some kind of continuity in updating the database. It should be planned to be more stable than just with short project funding for two years at the time.

When planning the next project period and funding for it, good arguments for the necessity of the database will have to be developed: preparation and follow up of the EHIS wave II, development of the EHES. A possible way to ensure the continuity of the database could be to include it in the EU regulation on public health statistics.

Further development of the database could cover the assistance to the scientific community in the access to the EHIS pooled database and methodological guidelines for the analysis of those data.

Next meeting

It was decided that it is too soon to decide if there is a need for a second meeting of the EUHSID advisory group. This could be decided later depending on the decisions on the continuation of the project and the database.