



**ECHIM Core Group meeting, 22–23.9., ISS, Rome
Minutes**

Present:

Arpo Aromaa (THL; chair), Pedro Arias Bohigas (ES), Patsy Bailey (UK), Grainne Cosgrove (IE), Rita Gaidelyte (HI), Silvia Ghirini (ISS), Mika Gissler (THL), Maartje Harbers (RIVM), Sigurlaug Hauksdottir (DG SANCO), Jiri Holub (CZ), Nils Kirsch (RKI), Jari Kirsilä (THL), Pieter Kramers (RIVM), Kari Kuulasmaa (THL), Kristina Köhler (EE), Marja Lampola (THL), Neringa Madeikyte (HI), Sonia Martire (ISS), Remigijus Prochorskas (HI), Francoise Renard (BE), Livia Ryl (RKI), Ari-Pekka Sihvonen (THL), Jürgen Thelen (RKI), Antti Tuomi-Nikula (THL; secretary), Marieke Verschuuren (RIVM)

Observers:

Lorenzo Spizzichino (MOH Italy), Stefania Vasselli (MOH Italy), Lidia Gargiulo (ISTAT), Marzia Loghi (ISTAT), Gabriella Sebastiani (ISTAT), Alessandra Burgio (ISS), Lucia Galluzzo (ISS), Claudia Gandin (ISS), Nicola Parisi (ISS), Alessandra Rossi (ISS)

Apologies:

John K. Davies (UK), Bart Denorre (Eurostat), Susanne Holland (SE), John Kyriopoulos (GR), Gaetan Lafortune (OECD), Enrique Loyola (WHO), Hugh Magee (IE), Liis Roováli (EE), Emanuele Scafato (IT), Aris Sissouras (GR), Jean Tafforeau (B), Polonca Truden-Dobrin (SI)

1. Opening of the meeting – Arpo Aromaa

Aromaa opened the meeting and welcomed the participants. Director Stefania Salmaso also had a welcoming speech and introduced ISS and its position in Italy. The new ECHIM press release had been newly published on the main page of the ISS website: <http://www.iss.it/pres/prim/cont.php?id=1195&lang=1&tipo=6>

2.–3. Agenda, Minutes of the previous meeting – Arpo Aromaa

The agenda was adopted with no amendments. Minutes of the previous meeting were also accepted unchanged.

4. Recent developments in the Health Information activities of DG SANCO/HEIDI – Sigurlaug Hauksdottir

Hauksdottir stated that considering ECHIM, DG SANCO's basic aim is encouragement; the ECHI shortlist represents the core indicators for DG SANCO. They are well defined and expectations for future are high. The ECHI shortlist is being used by several EU data dissemination tools, such as HEIDI Wiki and HEIDI Data Tool. The full version of HEIDI Wiki will be online during the first half of 2012. After that its contents can be added by the editors. The HEIDI Data Tool is currently being further developed. The data tool, however, was considered to be quite difficult to find on the DG SANCO website, and should be made easier.

After the Joint Action, the future of ECHIM is unclear; there will not be a new joint action in any case. Possible solutions include incorporation of ECHIM into the European Statistical System, shifting the tasks to ECDC or some special health information structure. Moreover, the future depends on the interest of MS's, the very results of the Joint Action and the results of its impending evaluation in 2012. Finally, all depends on the financial situation.

Starting DG SANCO Joint Actions include EHLEIS (The European Life and Health Expectancy Information System) and JAMIE (Joint Action on Monitoring Injuries in Europe). Recent reports are e.g. Measurement of Health Inequalities and Health of People at Working Age.

5. Status of EHIS – Arpo Aromaa

Aromaa presented the latest news about EHIS. He also stressed the importance of EHIS, pointing out that most missing European health indicators (ECHI/ECHIM indicators) must be constructed from survey data (HIS or HES), which is extremely important to keep clearly in mind also if changes occur in ECHIM, EHIS, EHES or other joint surveys.

EHIS wave I: 17 countries participated prior to 2009 and data are on Eurostat's website. For the access to the microdata the anonymisation rules are being finalised with the feedback of the Member States and will afterwards be discussed for approval in the appropriate ESS (European Statistical System) bodies by the end of 2012. Afterwards Eurostat can create the anonymised microdata set.

The ESSnet (Public Health Statistics) finishes at the end of September 2011. Recent ESSC (ESS Committee) decisions concern the definition of negative priorities, reduction in the number of meetings, the inclusion of a sunset clause in new regulations and rationalising the social surveys. An EHIS Technical Group meeting will be organised in January 2012. The Working Group Public Health Statistics of June 2011 emphasised that EHIS is to remain a standalone survey and insists that the implementing regulation is to cover the next two waves of EHIS (2014 and 2019).

EHIS wave II: the Working Group Public Health Statistics confirmed that the implementing regulation is to use an input harmonisation approach, meaning that it should include the exact wording of the questions, but this seems problematic as six

countries have already voiced concerns. The major element is the model questionnaire, which contains 4 elements: health status, health care, health determinants and socioeconomic information.

Recent detail-level amendments to the model questionnaire include e.g. integration of some Budapest Initiative questions for functional limitations, introduction of the PHQ8 instrument for mental health (giving priority to depression) and dropping the drug use module. Some changes stirred up discussion about rationality of the changes, especially concerning that of mental health. Detailed changes are listed in Presentation 5, and the recent version of the wave II questionnaire is included in Attachment 5. Please note that those changes will most likely not be final, and some details may have already been changed after the Core Group HIS meeting in Malta, right after the ECHIM meeting.

6. Where are we now in ECHIM? – Mika Gissler

Gissler had an overview of ECHIM achievements so far, and concentrated on the remaining time, that is, until June 2012. Although the final approval of the extension for the project duration is still pending, but we assume that there should be no problem with that.

Based on the ECHIM work plan, the prospective outputs for the remaining time are:

- A new release of ECHI shortlist, updates of the Documentation Sheets
- Updated description of the method for improving the ECHI shortlist
- Member State and EU specific guidelines and plans for ECHI shortlist indicator implementation
- An ongoing process for implementing health indicators have been installed in most Member States and progress has been documented
- Improved data and data flow for comparable health indicators in Europe with documented description
- Update of the website www.healthindicators.eu, containing all relevant meta-information on ECHI Indicators
- The electronic representation of the health data based on the ECHI shortlist
- The first joint analyses and reports on data based on ECHI shortlist indicators
- The Final Report of the Joint Action for ECHIM on health indicators and progress in their implementation, promotion and dissemination.

There was discussion about the progress of implementation in different countries. There are big differences, mainly due to financial issues, but as a whole lots of progress has already been done. An overview of the situation had been prepared (Agenda item 10) and it is meant to be updated to be used in the future plans. Other recent progress include carrying out the the PiCo (Agenda item 14) and the ECHI shortlist development (Agenda item 7).

7. Status of the ECHI Indicators – Marieke Verschuuren

Verschuuren introduced the current update procedure and the proposed amendments to the ECHI shortlist, aiming for finalisation of the 2011 version. All working papers about the proposal can be found in the attachments (7a–d).

Even though the ECHI shortlist should be kept as stable as possible, revisions are necessary every 3–5 years, in order to keep the indicator definitions up-to-date in the changing environment of today's Europe.

Key points concerning the new version are that its focus is on implementation and stability, and that it is based on MS consultation. It should show the added value of ECHI to policy makers, and ensure as smooth as possible implementation in the MS. Therefore, a new division into three sections (Implementation, Work in progress & Development) instead of two was proposed. That would reflect implementation readiness of the indicators better than the current 2-level division. Some shifts between sections were also proposed, but there will be no additions or deletions of indicators in the new version.

The new version of the shortlist was approved by the Core Group, though it has to be noted that the final division of the indicators over the three new ECHI shortlist sections can only be made once the EHIS questionnaire for wave II has been finalised (probably early 2012). Verschuuren asked the Core Group members to send any comments on a set of new Documentation Sheets, that was prepared as background material for this item on the agenda, within the next 3 weeks. These comments will be processed and after that the documentation sheets will be published at www.healthindicators.eu.

Concerning single indicators, special emphasis is now on EHIS-based indicators, which comprise ca. 20 of the 88 ECHI shortlist indicators. As the EHIS questionnaire is being revised, ECHIM must follow the revisions and strive to adapt ECHI indicator metadata details accordingly. For most of the EHIS-based indicators changes will be minimal, but for physical activity, mental health and alcohol use the changes will be more substantial. Details are listed in Presentation 7 and the attachments.

Maartje Harbers introduced the consequences that the EHIS revision will have for operationalisation of the ECHI shortlist indicators. There was lots of discussion on the changes, especially concerning hazardous alcohol consumption and mental health indicators. Some proposed changes were seen as not reflecting the original ideas of ECHI Indicators. However, ECHIM must wait for the results of national assessments of the EHIS wave II proposal, and the wave II questionnaire establishment itself, before any decisions about possible amendments to the ECHI shortlist indicator definitions can be made.

The upcoming work of Wp1 includes adapting the new structure of the ECHI shortlist on www.healthindicators.eu, processing comments from the ECHIM Core Group on the new documentation sheets, adapting the list of operational indicators according to the new documentation sheets and 2011 version shortlist, and processing all resulting adaptations in documentation sheets after EHIS questionnaire revisions. All the

resulting materials, including all materials related to the updating procedure, will be published on www.healthindicators.eu

Wp2 will work on meta-information sheets on comparability for the indicators in the implementation section. If CG members would be willing to review some of that work, it would be greatly appreciated.

8. Status of implementation of the indicators in Europe – Ari-Pekka Sihvonen

Sihvonen briefly went through the implementation activities during the whole Joint Action for ECHIM, and concentrated on the most recent activities, including an overview of the implementation progress per country. The implementation progress had been recently surveyed in all MS (attachments 8a–c), and possible means about speeding up the implementation were debated.

It was realised that the main reason for the recent slowing down of implementation progress all over Europe is the difficult financial situation that has become even worse recently. Because of all that, it is very difficult to motivate the National Implementation Teams, especially now that the end of the project is approaching. Still, much progress has been made since the Berlin Partners meeting, e.g. the Pilot Data Collection (later on in this document: PiCo) and establishing contacts in new countries.

The PiCo, however, suffered from ECHIM's lack of official mandate and low support from the Commission. It was compared with the WHO HfA data collection, which is trouble-free especially thanks to its official mandate.

Suggestions to make implementation more effective in countries included dissemination of examples from countries, international comparisons, information on availability and use of ECHI Indicators, and policy briefs. The knowledge of ECHIM seems to be low on political level, so more lobbying is needed to get support. Commitment by ministries or even a permanent ECHIM structure would naturally be optimal, to secure future actions and also to eliminate possible turf problems with MoH's. Sharing experiences, possibly a survey of ideas within ECHIM Core Group members about speeding up implementation might be useful.

9. Example of national health indicator database – Remigijus Prochorskas

Prochorskas introduced one of the planned key outcomes of the national ECHIM implementation – integration of ECHI in a national health indicator system.

The Lithuanian Health Indicator Database, which is technically based on the same software as the WHO Health for All Database, has been up for ca. 20 years. The latest version of 2009 includes over 2000 operational indicators. The list has been revised and about a hundred first level operational ECHI indicators have been identified or newly included, resulting in the total list of about 2500 indicators. The ECHI shortlist indicators are tagged among them. The ECHIM logo is added to the database front

page and reference to ECHIM included in the Help text. The database also contains indicator metadata and different graphical data presentation tools.

The new 2011 version of the database is not yet completed, as the data for some indicators are still being processed. The provisional, incomplete off-line version of the database in English (srs_new_a.zip) has been temporarily placed on Internet and can be downloaded from sic.hi.lt/html/zsrs.htm. The database is expected to be finalised by the end of 2011.

The data come from different national sources. Compulsory health insurance database SVEIDRA is the main source for incidence, prevalence, hospital discharges and related indicators. It is a huge database covering over 99% of hospital discharges and about 90% of outpatient contacts. Its use for producing statistical data for indicators requires rather sophisticated data processing.

In case of some indicators the national definitions, mostly age groups, somewhat differ from ECHI definitions. This will cause comparability issues in international comparisons, which was noted by some participants. In some of such cases additional indicators have been added to follow ECHI definitions precisely.

All in all, the database was seen as a very positive and encouraging example, yet a challenging task to do. But it is something that could be the end result for the whole Europe some day. Czech Republic, Estonia and Latvia have similar national health indicator databases and also plans of integration of ECHI indicators.

10. Status and plans of HEIDI – Sigurlaug Hauksdottir

Only technical details were presented. The technical personnel working on HEIDI are “in the house” in DG SANCO. There were some concerns about how to reach them, but Hauksdottir assured that they should be quite well accessible. It was noted that direct contacts would be good.

Outside the original agenda, Kari Kuulasmaa (THL) had a short presentation about the latest news from EHES (European Health Examination Survey) project (www.ehes.info). The EHES consists of standardised national HESs with a small questions part in selected European countries. It is meant for planning and evaluation of health policies and health care, and for research. It is complementary to EHIS; some countries even conduct EHES in pursuance of EHIS.

Kuulasmaa highlighted the quality of HES’s over HIS’s, especially when it comes to subjects that are delicate in nature. For example, measured prevalence of obesity tends to be higher than self-reported.

The ongoing pilot phase of EHES includes a full-size HES in 4 countries and a pilot survey in 12 countries. 7 countries have decided to carry out a national HES in the next two years. Many others have plans but no decisions yet. The long-time goal is a development to a sustainable HES system. EHES works in collaboration with e.g. ECDC, EFSA, Environment and WHO.

11. ECHI data flow to the HEIDI system – Jürgen Thelen

RKI had gone through the HEIDI functionalities in detail, and found the following usability issues (with proposed changes):

- Selection of indicators in need of improvement; Indicator names too long – enlarge selection window
- Grouping of Indicators to be established; only one indicator can be selected – enable multi-selection
- Connectivity to be expanded; links lead to main page – enable for deep linking to specific indicators, not only html-tags/embedded objects
- Download; only single indicator download – enable complete download

The detailed overview (Presentation 11) also revealed broken links and missing metadata.

The EHIS wave I data has now been calculated and published by Eurostat for 17 countries. The Eurostat calculations follow slightly different rules compared to ECHI (mainly different age groups). The ECHI Indicators from EHIS were provided by Eurostat (with age groups). They are being combined with PiCo Data and prepared for integration in HEIDI data tool. The future data flow for ECHI indicators from EHIS (Eurostat) will follow the PH Statistics framework and implementing regulation. The changes that will happen in EHIS and consequences for ECHI are a challenge for the future.

In many cases, the ECHI Indicator definitions in HEIDI differ from those of ECHI presentations of national public health institutes (e.g. national HIS vs. EHIS). In those cases, it is recommended to use data provided by HEIDI for cross country comparisons and analyses. Also estimates by international organisations (e.g. IARC data on Cancer prevalence and incidence estimates) tend to differ from national estimates due to different post-harmonising procedures. In discussion it was pointed out that notes on comparability should be added in the metadata.

12. Quality and aims of analyses for the Pilot Data – Nils Kirsch

Kirsch gave an overview of the PiCo. Data have been gathered from 22 countries for 21 indicators, out of which 17 are derived from EHIS. The volume of data is large, but the quality varies; some data might not be useful, and even some EHIS data seem dubious. Especially problematic are register-based data, which may not be suitable for international comparisons but only for within-country comparisons.

Kirsch presented an idea of a format in which the data should be analysed, the “Data Documentation Sheets” with descriptions, definitions, calculations, interpretations and methodological considerations, in a format close to the Documentation Sheets of the ECHI Indicators. The Health at a Glance report by OECD also could be a role model for it. It could include correlation analysis and maybe also other analyses of indicator data. Comparisons with other data reports could also be possible. The idea was widely accepted.

Because RKI have no resources to handle and analyse all data, it was agreed that other Partners take on some indicators. In addition to that, data for the alcohol and smoking related indicators will be dropped because of their obvious quality and validity problems. Thus, there will be data for 19 indicators to be analysed. The exact share between partners will be agreed upon later.

Kirsch reminded that the PiCo is terminated for good – no further data submissions, revisions or updates are taken into account. The next steps in the work on the PiCo data are finalisation of a compiled PiCo and EHIS data file and an export file for import into HEIDI.

13. Future of the indicator work after the Joint Action for ECHIM – Pieter Kramers

Kramers briefly reviewed the history of ECHIM before concentrating on the future. As ECHIM in its current form will come to an end, every effort must be taken to ensure the continuity of the European health indicator work. Core tasks for keeping the ECHI system running in a professionally and acceptable way include above all:

- Maintaining the ECHI shortlist: Update when needed, e.g. every 3–4 years and maintaining/updating the indicator documentation, solving remaining problems of definition or data availability, and coordinating with related indicator work;
- Supporting the HEIDI Tool: checking, validating and updating data and metadata in presentation tool; IT development of database and presentation tool;
- Promoting the use of ECHI; supporting MS in ECHI implementation: continuous support and advice in data improvement;
- Collaborating with WHO and OECD to increase synergy in indicator work.

A long term vision would be a sustained central health monitoring and reporting capacity, supporting EU and MS health policies. Minimally, it could consist of a group of experts at DG SANCO, and a network of experts in national PH institutes. It would handle the data collection, organise data flow and perform data analyses and presentations for EC reports. Remaining key questions include its position, minimal set of tasks, SANCO's vision and financing. As many details are open and will take time to be solved, a plan for an interim solution should also be created.

The MS have a major role in the indicator work, yet it is problematic as ECHIM currently lacks an official mandate. Therefore, permanent structure with an official position, and sustained financing would be essential.

The work toward a document (attachment 13) about the future of ECHIM started in September 2010 in the Berlin meeting, and continued in March 2011 in the group discussions in the Extended Core Group meeting in Luxembourg. Kramers had collected the views of the ECHIM Core Group in a document, which has been in process since. Up to this day it is quite good, but some things still have to be discussed and agreed upon. These include:

- Clarifying the added value: why continue ECHIM?
- More precise numbers, budgets, timetables etc.
- Organisational scheme

- Overview of countries that use ECHI shortlist to be included
- Answering concerns from MS's about our future role

The above questions stirred lively discussion. The added value seemed to be seen as higher in MS than in DG SANCO. It was emphasised that information about resources used in MS implementation work would be important in planning the future. Concrete answers from DG SANCO were called for, as it is difficult to make any plans for budgets and timetables before that.

It was agreed that the paper will go out on the commenting round after the meeting, to be finalised in 3–4 weeks and then submitted to DG SANCO, as high up as possible. Numerous past statements by DG SANCO officials show that our work is greatly appreciated and that it is recognised that the work must be based on a permanent structure, not a project.

14. Indicator work in the future from the DG SANCO's point of view – Sigurlaug Hauksdottir

Hauksdottir first presented the legal base of DG SANCO, and then the Work Plan for 2012. Basically, it only includes evaluation of the Joint Action for ECHIM.

About the future of ECHIM or the European health indicator work in general, Hauksdottir presented some possible options. A special health information structure as in Kramers's presentation is possible, and so are incorporation into e.g. ECDC or ESS.

Any further plans are impossible at the moment, as making decisions depends on so many things: MS's interests, ECHIM's results and products, results of the evaluation, and financing, which in turn depends on the new work plan. Preparation of the work plan is very bureaucratic; DG SANCO will be consulted but will not make any decisions.

The only thing that's clear at the moment is that there's no money for ECHIM as it is now. Still, sustainability of ECHI Indicators is of high EC priority.

The impending evaluation of the results of the Joint Action for ECHIM was discussed vividly. The evaluation criteria are not known, and that raised concern by many. Hauksdottir promised to have a word with Stefan Schreck (C2) about the possibility to organise a negotiation about the issue. That there will most probably be a "gap" between the project finale and the evaluation results was seen as a problem, because during that time no decisions are anticipated, and the indicator work will probably stagnate. Trying to influence MS so that they would impress their aspiration to continue ECHIM through the Programme Committee was seen as one way to contain that.

15. Final Report – Antti Tuomi-Nikula

Tuomi-Nikula presented the preliminary table of contents and division of work for the Final Report (attachment 15). The big idea is to make the Final Report a textbook, so that readers could actually learn from it. Also it will be a sequel to the previous ECHIM book, so that there is no need to rewrite all history of ECHIM, or include much process information.

There was some discussion on some concepts and emphases, but in general all necessary elements were found in the paper. Some introductory chapters may even be unnecessary, while the importance of data analysis should perhaps be emphasised. That data exist and can be used should be clear, along with the “instructions” parts. A possibility to write a separate report on the data and their analyses was discussed, but no decisions were made. The agreement on the table of contents is aimed to be reached in 3–4 weeks, after which the writers can begin their work with full steam.

Concern about possibilities of receiving any information from some countries was raised. It was acknowledged that from some countries there will be no information, especially because some countries have announced that they are not taking any part in the Joint Action for ECHIM.

A draft version of the Final Report will be prepared by January 2012. The Final version should be ready in May, and the book will be printed and ready for distribution by July 2012.

Tuomi-Nikula also reminded the participants that ECHIM leaflets, books, pens and ECHIM Extranet user rights can be asked from him.

16. Next steps in ECHIM – Arpo Aromaa

Aromaa emphasised the main elements of the remaining work of ECHIM. In short term, implementation must be continued, future plans further prepared, and indicator definitions further developed. MS's and EU must be supported in data gathering and analyses, and ECHIM and DG SANCO must make joint efforts to maintain experienced personnel after the end of Joint Action for ECHIM. He also stressed the importance of a Draft Final Report for the future work.

Longer term tasks include:

- Continuing development of indicators and the health information system
- DG SANCO to seek commitment from MS administrations – with ECHIM support
- DG SANCO and MSs to preserve the momentum gained
- Resources permitting ECHIM to work closely with SANCO in creating the longer term future
- SANCO together with WHO, OECD and ECHIM to develop a concise action for the development and maintenance of the Health Information System for Europe
- ECHI and ECHIM during more than a decade have created a roadmap for the future

The keys to success were seen to be vision and will, clear aims and action plans, experience, expertise, continuity, collaboration (EU, WHO, OECD, MSs, ECHIM, and other EU projects), resources, and visibility.

17. Financial issues – Marja Lampola

Lampola reminded participants of the travel invoice practices, and presented the current administrative and financial situation of both the previous and recent ECHIM. The previous ECHIM is currently being audited, and Lampola will contact every partner in case there is need to submit more documents to THL than already requested.

The final OK for the 6 months extension of the Joint Action for ECHIM from EAHC is still missing, but anticipated.

18.–19. Next meeting/any other issues/concluding the meeting – Arpo Aromaa

The next meeting of the Extended ECHIM Core Group will most probably be held in mid-March 2012 in Luxembourg. It was suggested that the main focus of the meeting would be on what has been achieved in the implementation work, highlighting countries that have done especially well. Short future plans could be asked from the MS's, and also the Final Report can be reviewed with them. Other important subjects will be the continuation of the European health indicator work and strengthening the cooperation between ECHIM, Eurostat, DG SANCO, WHO and OECD.

Marieke Verschuuren reminded the participants about the upcoming EUPHA conference in Copenhagen, 10.–12.11.2011, where ECHIM will have a workshop. Its focus will be on EHIS and PiCo data, in collaboration with Eurostat and DG SANCO.

Aromaa thanked the participants and closed the meeting at 14:10.