

A sustained future for ECHI

Proposal on how to maintain a health indicator system for the EU after the Joint Action for ECHIM

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Executive summary

Health Policy needs a system for health monitoring. The ultimate perspective underlying 13 years of ECHI work is having a sustainable health monitoring and reporting system in place. Starting from the current status, a transition period is needed to safeguard what has been accomplished and to develop it into a viable permanent arrangement. This future system should be jointly operated by DG SANCO, Eurostat and the Member States, in close collaboration with WHO and OECD, to serve health policies and professionals at Member State and EU level.

The Joint Action for ECHIM is expected to run until June 30th 2012. Therefore, a plan is needed for the future maintenance and development of the health indicator system. This document contains the recommendations from the ECHIM Joint Action to DG SANCO on the future of the ECHI indicator system, which is the core of EU health monitoring and reporting.

After 13 years of work, ECHI and ECHIM have generated EU added value by defining a common indicator set, the ECHI shortlist. In recent years, work has focused on the implementation of the indicators in the Member States and on the improved comparability of health data across countries. Work by WHO, OECD and Eurostat as well as by EU public health projects has been taken into account. By mid-2012, half of the Member States will have incorporated ECHI into their national health information systems. The EU Parliament and Council have defined in a regulation that health statistics shall provide data according to ECHI. DG SANCO has taken further steps towards a sustained activity by developing the HEIDI tool, filled with data according to the ECHI shortlist, by stating repeatedly that ECHI work should shift from projects to permanent financing, and by developing EHIS and EHES. Finally, Eurostat prepared its regulation on data delivery.

In this document, the ECHIM Joint Action team presents a vision on how the ECHI work should be continued. Starting from current results and discussions, the team gives an outline of the tasks to be performed, the expertise needed, and organisational options for the work to be carried on in a professionally acceptable manner.

The continuation involves the following tasks:

- The ECHI indicator system should be maintained and improved.
- The central health indicator database and data presentation tool should be further developed.
- The ECHIM network should be maintained.
- The implementation of data sources and indicators in Member States should be continued.
- Collaboration with other international organisations should be enhanced.
- In the longer term, health reporting as well as analysis and interpretation of health data should become priorities.

Performing these tasks will require a small central team of public health professionals and other experts, of outstanding qualification. The activity could be organised either as an actual central unit or as a virtual capacity comprising of both experts placed centrally and others working in national public health institutes.

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1. Background, history

1.1. *ECHIM focuses on the main goal of the Commission's Public Health Programmes.*

The Joint Action for ECHIM (2009–2012,) is the fourth project phase of the ECHI(M) initiative. In 1998, the first ECHI project started from the Commission's new mandate in health monitoring, more specifically from its main goal "to establish of a set of health indicators for the EU". The first two ECHI projects focused on the selection and definition of indicators, and established the ECHI shortlist in 2005. The 3rd and the current 4th phase shifted the focus towards the implementation of the ECHI indicators in the Member States and at EU level. [ECHI stands for "European Community Health Indicators". ECHIM is the project name after 2005, for "ECHI Monitoring"].

1.2. *The ECHI shortlist is one of ECHIM's main outcomes*

By 2009, the ECHI shortlist comprised 88 indicators selected by panels of experts as (1) covering the entire public health field (including mortality, health status, health determinants, aspects of health services), (2) using many results of related international work (WHO, etc.), and (3) serving health policy needs of the EU and Member States, at the level of a general overview, or "cockpit" function. The list was divided into an "implementation section" (ready for use) and a "development section" (still some problems to be solved). It was discussed and approved in several Committees with all Member States represented.

1.3. *ECHI work is supported by DG SANCO and Member States*

The central position of the ECHI work has been appreciated by the Commission right from the start. This was apparent, e.g., from (1) the intense cooperation between DG SANCO and ECHI, (2) the uptake of many results of EU-funded projects on indicators, (3) the early orientation of Eurostat towards the ECHI shortlist, for its data collection developments, (4) the publication of shortlist data on the DG SANCO website, and (5) the Parliament and Council regulation of 2008 stating that "The statistics shall provide data for ... and European Community Health Indicators (ECHI)". The recent development of the HEIDI tool for the presentation of ECHI data marks the move towards sustainability of ECHI at Commission level. Other developments adding to sustainability are the development of the European Health Interview Survey (EHIS), and of the Eurostat regulation on statistics on public health and health and safety at work, which all refer to the ECHI shortlist. All of this supports the improved comparability of data across countries, in support of evidence-based health policies. Finally, the Member States have been involved in all the development steps of ECHI(M), and they increasingly use the ECHI shortlist for their own health information strategies.

1.4. *The ECHI system has added value*

The ECHI indicator system adds to the value of other international databases (Eurostat, WHO, OECD), for its:

- stricter focus on the most relevant health issues, at the level of the EU and its Member States;
- putting increased efforts on improved comparability between countries;
- highlighting new data collection developments on the basis of policy needs, including the monitoring of socio-economic health differences;
- supporting the data flow between the Commission and the Member States;
- providing an intermediary presentation tool between the primary databases (notably Eurostat and the Member States) and the end users;
- thereby optimising the evidence base for policy makers;
- profiting greatly from the extensive network of national experts and EU-funded projects.

1.5. *More cooperation is needed between international organisations*

From the point of view of the Member States, there is the urgent need to reduce obligations for data delivery instead of expanding them. On the other hand, further harmonisation in data gathering and health information systems call for additional efforts. Therefore, it is crucial that the intention, announced in 2010 by the European Commission, the WHO Regional Office for Europe and OECD to work towards a common European health information system is followed up by concrete steps. The ECHI indicator system is expected to play a useful part in these developments.

1.6. *ECHIM's views on a sustained health monitoring system*

For more information on the ECHI(M) projects, see Kramers (2005), Kilpeläinen et al. (2008, 2011) and Verschuuren et al. (2010), and the websites www.echim.org and www.healthindicators.eu. From all this, it becomes clear how much developmental and coordinating work has been invested since 1998, by many experts from all Member States, DG SANCO, Eurostat and others, and what has been accomplished. We anticipate that by mid-2012 the ECHIM work will provide a firm basis for taking further the development of a European public health monitoring and reporting system with the ECHI shortlist at its core. Nevertheless, substantial efforts are still needed, at Commission and Member State level, to arrive at a really sustainable situation. This document sets out the views of the ECHIM Joint Action Core Group team on what needs to be done to ensure the continuation of ECHI(M) work.

2. Starting situation by July 1st 2012

The results of the Joint Action for ECHIM by mid-2012 will be the starting point for the further development and maintenance of the ECHI work. Other important building blocks include the work that is actually going on in the Member States, and a variety of contributions from experts in the ECHIM Core Group, the Member States and DG SANCO. All these are briefly outlined below.

2.1. Results of the Joint Action for ECHIM

It is foreseen that by the end of the current Joint Action the following concrete results will be attained (being the Joint Action's deliverables):

- An updated and fully documented shortlist of ECHI indicators, including guidelines for its further maintenance and for the solution of the remaining problems on "difficult" indicators; integration of this documentation into the HEIDI data presentation tool of the Commission (work by ECHIM and DG SANCO).
- To serve this indicator development: a network of experts on specific subject areas, and close connection with important parallel developments, e.g. on EHIS, EHES, HLY.
- An up-to-date presentation of data and metadata in the HEIDI tool; checks and validation of contents and data integration processes (work by DG SANCO and ECHIM).
- A network of contact persons for ECHIM involving 32 countries; guidelines for ECHI implementation.
- At country level: the establishment of National Implementation Teams (NITs) and implementation plans, to further develop ECHI's implementation, in most Member States and some other countries. See below under 2.2 for details.
- The pilot data collection made accessible by the HEIDI tool. This pilot was focused on data that are not available from international databases (work by ECHIM, the MS and DG SANCO).
- An analysis of the collected data, from the pilot collection and the international sources.
- A full documentation of all experiences and lessons learned.

2.2. Implementation status in the Member States and other countries

The ECHIM project (2005–2008) assessed the availability of data for ECHI indicators in 31 countries. It appeared that the variation between countries was large (Kilpeläinen et al., 2008, 2011). By September 2011, ECHIM was updated by the participating countries about their progress in implementing the ECHI shortlist indicators. Almost all Member States are working with the ECHI shortlist indicators or are preparing for it, as well as seven countries outside the EU. However, the countries vary a lot in their stage of development. By September 2011, seven EU countries and one EFTA country have included ECHI indicators in their national monitoring and/or reporting activities at least in part (Austria, Denmark, Germany, Ireland, Lithuania, The Netherlands, Spain, and Norway). An additional six MSs expect to do so by mid 2012 (Czech Republic, Estonia, Finland, France, Italy, Latvia; of non-EU countries also Serbia). 20 EU Member States and 5 other countries delivered data for the pilot collection in 2011. 19 EU countries have a National Implementation Team in place or an equivalent structure. 16 MS made up an implementation plan and 19 participated in a second inventory of their data availability according to ECHI. Only three Member States were not able to join into any of these activities. In one of those cases, ECHIM was not able to identify a contact person (Slovakia). See *table 1* below for the details by country.

In their reports, countries mentioned several obstacles that hampered the implementation progress. These include: lack of resources; scattered responsibilities in health information; discrepancies between national indicator definitions and ECHIM definitions needed for international comparability (this applies to data for WHO and OECD as well); problems with register linkages or data protection. Member States welcome and sometimes need formal support from DG SANCO or Eurostat as helping them to create political mandate.

2.3. Input from the Member States and from DG SANCO on the future of ECHI

The future maintenance of ECHIM work was on the agenda for the first time during the ECHIM Core Group meeting of September 2010, and was discussed extensively during the Extended Core Group meeting of March 2011. In February 2011, DG SANCO sent its supporting letter to the Member States, on which it received quite a few responses. On several occasions, DG SANCO gave its own views on the issue. *Annex 1* gives an overview of all the points that were raised. The main ones are summarised below. In *sections 3 and 4* of this document, on the future tasks and their organisation, all of these have been taken into account.

Table 1. Implementation of ECHI shortlist indicators in national monitoring and reporting, by five different features. A coloured cell indicates an accomplished task / an action in place.

Core group countries EU	Implementation plan / team	Data availability inventory	Pilot data collection 2010-2011	ECHI implemented in national activities by 9/2011	ECHI implemented in national activities by 6/2012
Belgium					
Czech Rep.					
Estonia					
Finland					
Germany					
Greece					
Ireland					
Italy					
Lithuania					
Netherlands					
Slovenia					
Spain					
Sweden					
UK					
Other EU MS's (started later)					
Austria					
Bulgaria					
Cyprus					
Denmark					
France					
Hungary					
Latvia					
Luxemburg					
Malta					
Poland					
Portugal					
Romania					
Slovakia					
Non-EU countries					
Croatia					
Turkey					
Iceland					
Norway					
Switzerland					
Moldova					
Serbia					

First, there was the shared vision of preferring a sustained way of financing instead of project-type financing. DG SANCO restated its views of ECHI being a reference point in EU health monitoring. Its status as *the* core set for health information in the EU should be made clearer, and political commitment should be strengthened at EU and national levels. The ECHI(M) work has already stimulated quite a few improvements in harmonised data collection and use of comparable health indicators.

There was also a call for consolidation and evaluation. The ECHI shortlist should not grow, innovations should be limited, and additional workloads to the MS in data deliveries should be minimised. As to the latter, increased cooperation with WHO and OECD is highly recommended. Also, the forthcoming Eurostat regulation on statistics on public health and safety at work is seen as potentially helpful for Member States. It was indicated that the collected data should indeed be of practical value to MS policy makers. Making a difference in policy making is the most fundamental demonstration of the value of health monitoring. In daily practice, however, factual information often plays a role among other influences, which makes it difficult to separately assess its impact on policies and actions.

There was much agreement on the tasks to be performed in a sustained structure of health monitoring with ECHI at the core. These tasks are shown in detail in *section 3* and *annex 2*. There were useful suggestions, such as to focus on the continued improvement of data comparability. This is the main added value of ECHI for EU health information and calls for a continuous assessment of data quality.

There was also agreement on the need of a permanent structure, centred at DG SANCO, but not necessarily all located there. Sufficient professional expertise should be involved as well as adequate statistical/IT skills. Eurostat should be closely involved in the data collection work. A network of experts would be needed and the EGHI (Expert Group on Health Information) could function as an advisory board representing all MS.

It was recognised that the Member States have a major role to play. That is the level where the implementation of ECHIM data work has to be realised (see also above under 2.2). If at present the requirements set by the ECHI shortlist cannot always be met, the logical and viable perspective would be to integrate the work on ECHI-defined data with the delivery of data to other international databases such as WHO and OECD. This should be seen as one coherent investment of resources, aimed at constantly improving the availability and cross-national comparability of health data.

A long-term scenario was worded as: one European Health Information System, an umbrella under which EU, WHO, OECD would work together.

3. Tasks of the (interim and final) “central health monitoring capacity”

This section gives a list of the tasks to be performed for the maintenance of the ECHI work in a professionally acceptable manner. The input comes from the ECHIM experience and results as mentioned in *sections 1 and 2*. Besides these tasks, there is the issue of their organisation and financing. These are covered in *section 4*.

3.1. *Core versus additional tasks*

We consider some tasks as *core*. These are the ones that have to be performed as a minimum, and in a continuous manner, in order to keep the ECHI indicator system alive and working. For us, “alive and working” means that the system is actually accepted and used by the target groups, i.e. policy makers and public health professionals. Some other tasks can be considered as “*additional*” in the sense that they are essential for a full monitoring and reporting function, but they can be taken up ad hoc instead of being continuous. They are linked, e.g., to specific reporting activities which may be organised and financed separately. This section gives a summary of the tasks. *Annex 2* provides their full description.

3.2. *The core tasks*

The *core* tasks are listed below, (a–e) are mainly for the central unit, (f) is for the Member States.

A. Maintaining and improving the ECHI indicators shortlist.

This task includes (1) updating the ECHI shortlist when needed; (2) maintaining the indicator documentation, e.g. when data collections change; (3) solving remaining problems of definition or data availability; (4) ensuring coherence with other indicator initiatives that may be overlapping; (5) using EU-funded projects in indicator development and data collection.

B. Maintaining the central health indicator database and data presentation tool.

This includes (1) the handling of data and metadata with content expertise, i.e. validation of incoming data, checks for unexpected inconsistencies, and taking care of the correct presentation in the data tool; (2) IT development and maintenance of the health indicator database and presentation tool.

C. Promoting the use of ECHI; supporting the Member States in the implementation of ECHI.

This task involves the active promotion of the ECHI system to health professionals, policy makers, etc. It also implies the continuous encouragement and support of the Member States in gathering appropriate data and in improving their data collection practices. Feedback on existing differences and national experiences will further improve data comparability. Some data that are currently only available at national level could increasingly be shared with international data collections. When the Eurostat regulation will become operational, this task may gradually shift to them.

D. Increasing the collaboration with other international organisations.

The European Commission, WHO-Euro and OECD want to work towards a common European health information system. In the maintenance of the ECHI indicator system, there is a task to act in the forefront of these activities. This cooperation should ultimately lead to a reduction of data delivery obligations in the Member States.

E. Carrying out regular evaluations of how the system meets the needs of the users.

This implies the regular assessment of how and where ECHI data are used, to check whether indeed the goal of “supporting health policies by information” is sufficiently served.

F. Implementation work within the Member States.

The success in consolidating ECHI will rely on the implementation work in each of the Member States. The challenge is to develop data sources and data collection using experience of others, and to develop a perspective of data collection and delivery for ECHI and other international databases in an integrated manner. This should be mirrored by the increasing collaboration as indicated above under D.

3.3 . The additional tasks

G. Using ECHI indicators in health reporting.

This task includes assuring that all indicators and in particular ECHI information in various Commission products has been obtained according to the guidelines and that it is correct.

H. Analysing the data, creating their interpretations and jointly with Member States assessing their impact on health policy.

This is the long term goal of all health data collection and also the only way to improve on the quality of the data and development of the monitoring system. Therefore, as soon as possible, emphasis should be laid also on this task.

4. Carrying out the tasks, minimal conditions, phased development

The above paragraphs clarified ECHIM's history, highlighted its recent achievements, and presented a shared view on the tasks to be performed for the successful continuation of the initiative. In this last section, the focus is on how these tasks could be organised in the future.

4.1. Recent European Commission initiatives

As noted earlier, DG SANCO has stated that the financing of the ECHI indicator work should shift from projects to permanent financing. Accordingly, the Commission has already made a start to take some of the tasks on board as sustained activities, such as the development of the HEIDI data tool and the connected HEIDI health information website, the development of the EHIS harmonised questionnaire, and the piloting of the European Health Examination Survey (EHES). In the more formal sense, we have the Regulation, published by the Parliament and Council in 2008, stating that EU statistics shall provide, a.o., data for the ECHI indicators, and the "Regulation on statistics on public health and safety at work" and EHIS implementation regulation currently under development by Eurostat.

4.2. Expertise needed

Before entering into more organisational issues, we must be aware of the types of expertise needed for adequately performing the tasks. First of all, it is essential to have a concise core team of first-grade public health professionals in place, in combination with up-to-date skills in IT and

data handling. These people need to work closely together and communicate informally, and they should be firmly anchored in a wider European expert network. Only then an “ECHI unit” can gain the level of professional authority needed to act as a credible partner in discussions with experts around Europe, and can it grow towards a status where it is respected and used by the community of European public health professionals and policy makers. The types of expertise needed in the team include at least public health, health services, epidemiology, health statistics and informatics. With the right people and the right setting, the critical mass, in terms of the number of people for the core team, may be fairly small.

4.3. A vision of a sustainable situation

The ECHIM long-term vision of the final sustainable situation is a permanent health monitoring and reporting (HMR) capacity, to carry out the tasks listed above. As outlined earlier by Aromaa (1998), this could be shaped as one central unit or as a “virtual capacity”, consisting of persons placed centrally plus experts located in national public health institutes. A central Agency for the overall function of health monitoring and reporting would by itself seem reasonable, since such agencies do exist for sub-areas of public health, e.g. ECDC and EMCDDA. This may not be realised within the next few years, however.

To place an HMR capacity entirely within DG SANCO C2 would perhaps not be the optimal choice, in view of the specialised professional character of the HMR work and SANCO’s primary function as a policy unit (a view also expressed by DG SANCO). A logical solution could be to host the capacity within an existing Agency. This could be ECDC, which has the advantage of offering a professional environment including the necessary infrastructure. The ECDC’s current mandate holds the option of broadening its activities into areas such as non-communicable diseases. However, having a small general health reporting unit within a much larger communicable disease unit might cause problems of balance and it might be necessary to “ring fence” resources in this area.

If none of these options would guarantee an adequate professional environment for a central HMR capacity, the solution has to be sought in the collaboration with national public health institutes, or specialised university departments. Perhaps the model of the WHO Collaborating Centres can be used. In all cases there should be a close connection with Eurostat where the technical data handling skills are located.

The tasks for this HMR capacity have been described above. If the collaboration with WHO and OECD on harmonising health information systems proceeds and develops in the future, it is this HMR unit that should represent the SANCO side, together with Eurostat. Also, DG SANCO has initiated the HEIDI wiki system which, like ECHI, needs professional input, particularly that of ECHIM-type experts. All of these developments could find a natural environment in the HMR capacity. In any of these organisational options, it should be possible to perform the ECHI tasks with some 10 experts, provided they are of the right expertise and professional level. They also should be able to flexibly employ other experts for limited tasks. Such a small size seems optimal for professional critical mass, efficiency by small overheads, flexibility, and openness towards expert circles around Europe.

Finally, the “ideal” sustainable situation implies to have a permanent structure in place in each Member State, coordinating all data deliveries from the country to international organisations, and serving as an active counterpart at MS level for the central HMR capacity, along with WHO and OECD.

4.4. The need of interim arrangements

The “ideal structure” is unlikely to be in place by mid-2012. Therefore, arrangements should be made for an interim period of several years, and for this short term we may rather speak of an “ECHI unit”, as opposed to the “HMR capacity” to emphasise the more restricted scope. We assume that in one way or another the needed expertise will be realised since otherwise the adequate maintenance of ECHI will not be possible. How to organise and how to finance the activities?

4.5. Interim period: organisation

In regard of organisation, DG SANCO has stated that it might not be ideal to place all of the expertise functions directly within DG SANCO C2, due to their specialised professional character. It may be preferable to bring together expertise from different actors under a central “umbrella” as the “ECHI unit”. In this unit, we need to combine the policy-oriented input from SANCO with the professional expertise from a consortium of Member States’ public health institutes (or specialised university departments). For continuity it would be beneficial to have at least some of the current ECHIM partner institutes involved in this work, although the structure might differ from the present one. Also Eurostat needs to be included. We note that Eurostat has been actively involved in the ECHI(M) process from the start, and for a major part of ECHI shortlist indicators Eurostat data are being used. In the development of EHIS there is a close collaboration between ECHIM and Eurostat, which has to be continued. During the coming years, Eurostat’s role in the ECHI data collection will potentially be formalised through the Regulation on statistics for public health and health and safety at work.

We envisage the following structure:

- *ECHI unit* as the core team, consisting of a coordinator at DG SANCO C2, two or three IT experts at DG SANCO A4, one contact person at Eurostat, and three public health professionals in national institutes. They together carry out the tasks described in *section 3*.
- *ECHI advisory group* of about 8 national HMR specialists and representatives from Eurostat, WHO and OECD, for regular consultation by e-mail, meeting e.g. every 6 months, to discuss main issues. This group would be the steering group resembling the current ECHIM Core Group.
- *Health Information Committee* as the body where all Member States are represented. This body has a broader scope than ECHI, but it is the place where general issues and progress on ECHI and health monitoring are discussed and commented. At present, the EGHI Committee is the natural place for this, but it should then be strengthened to the position it held in the past.

- *Network of national contact persons* for the implementation. They coordinate the work within each country. They keep contact with the core team on their progress, and with their national representation in the EGHI meeting. Note that the gathering, production, analyses and reporting of national health data is a within-country task often shared by many actors in a complex manner. Therefore the national contact persons can only function by good contacts with the NITs (National Implementation Teams), and other experts in charge of national data.

This solution results in a “virtual public health monitoring capacity”, involving the triangle: Member States, DG SANCO and Eurostat. The ECHI unit should also think of improved ways to organise and host the work in the future. If for the more “final” solution (see under 4.3.), the “agency” option is not realised, this “virtual” capacity may need to persist for a longer time.

4.6. Interim period: financing

In regard of financing, it is difficult for ECHIM, or any affiliated expert group, to be fully aware of the various formal possibilities and constraints of financing sustained work by the Commission. ECHIM is aware of the view as stated by DG SANCO that the current Public Health Programme cannot finance permanent or frequently recurring costs for the same activity. This reflects the general and pressing problems that are encountered repeatedly when DG SANCO-funded projects produce results that all involved parties subsequently would want to become sustainable. In the ECHIM case, with the arrangements as described *in section 4.5*, DG SANCO and Eurostat could finance parts of the virtual capacity from their existing budgets, which they already do to some extent. For the necessary expert input from Member States’ institutes in the ECHI unit, a way needs to be found to generate some dedicated funding. Here it is important that there is no or minimal co-funding required from the participating Member States, since it is basically sustainable Commission work, also supported by formal Regulations (see 4.1.). Is a direct agreement with a consortium a viable option? As this is envisaged to be a transition situation, the financing could be arranged for a limited period, but linked to a view on a sustained solution for the future.

As to the financing of Member State activities rather linked to national data work than to the ECHI unit, the experience from the current Joint Action for ECHIM suggests that it would be desirable to have some emergency financial support to Member States for the development of incomplete national information systems, especially in these days of economic troubles. This could possibly be arranged via structural funds. On the other hand, it is logical as a long term perspective that Member States devote structural resources of their own to the sustained delivery of data according to ECHI, as an integrated part of the data flow to all international organisations that is current practice for years. In some countries, this is already happening, as shown in *table 1*.

Ultimately, the continued availability of good data that are comparable in time and between countries is, first of all, of interest not only for the EU but above all to the individual countries, in support of improved evidence-based health policies.

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