Annexes to the document "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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Annex 1: Input from the ECHIM extended Core Group and from DG SANCO on the future of ECHI

During the ECHIM Core Group meeting of September 2010, the future maintenance of ECHIM work was on the agenda for the first time. After some exchange of views, this issue was discussed more extensively during the Extended Core Group of March 2011. Also, DG SANCO received quite a few responses from Member States on its encouragement letter of February 2011. Finally, on several occasions, DG SANCO gave its own views on the issue. Below we give a list of the points raised. All of these have been incorporated in sections 3 and 4.

Issues reported from the Extended Core Group discussions:

- General issues:
  - The future system has to be sustainable, and worth keeping. Therefore it is essential to ensure good quality;
  - The (moral) support from DG SANCO for MS is important.
  - Improve the visibility of the shortlist status as *the* core set for the EU; make clear the added value already already achieved;
  - At national level, political commitment must be strengthened; we should remember that ECHI has already brought about many improvements in MS;
  - Avoid increasing data delivery load in the MS;
  - Long-term scenario: one European Health Information System, an umbrella under which EU, WHO, OECD would work together;

- On the tasks to be performed in the sustained structure:
  - Maintain the shortlist properly; give special attention to the developmental work that is still needed;
  - Support adequate data flow from international and national sources;
  - Further develop the HEIDI presentation tool;
  - Develop analysis and reporting tools connected to HEIDI;
  - Maintain and improve the MS contact network and the National Implementation Teams; support Member States in their national implementation of ECHI; help MS in problem solving;
  - Improve and further clarify the synergy with WHO, OECD and other EU indicator systems;
  - Improve comparability of data and indicators: this is the added value of ECHI;
  - Continuously assess data quality at entry into the database and ask MSs to check their data at gathering; check for unexplained discrepancies;

- On issues of structure and organisation:
  - Build a permanent function at DG SANCO C2: public health experts with statistical/IT assistance;
  - Maintain a network of experts;
  - The EGHI (Expert Group on Health Information) can function as an advisory board representing all MS; nevertheless it is quite general and advice also needs to be obtained from health monitoring and survey experts;
  - A minimal requirement is to organise “brains” and network coordination at central level, have implementation teams in MS;
  - Make sure to maintain involvement of technical data skills (Eurostat, ECDC);
  - At MS level there are sometimes several players with conflicting interests: promote uptake of indicators in the Eurostat regulation;
  - The Eurostat regulation on statistics on public health and safety at work will be most helpful for Member States, by stimulating political commitment and financing;

- *MS replies to the February 2011 DG SANCO letter to MS (as presented by DG SANCO during the extended Core Group meeting):*
  - Ensure a sustainable approach to health monitoring after the end of the Joint Action;
  - Improve political marketing of ECHI at national and EU levels;
  - Create a user-friendly presentation system;
  - Include adequate information on precise data collection (meta-data), to enable the assessment of comparability issues;
  - Compile analytical reports at EU level, with ECHI as the core, tailored to target audiences: primarily policy makers;
  - Indicators must be of practical value to MS;
  - Harmonisation of primary data collection is important;
  - Keep the shortlist short, build on existing work;
  - Ensure that further developments are in line with constrained resources in MS; avoid unnecessary additional burden of work in MS.
  - Promote data collection that allows to stratify according to socio-economic inequalities;

- *Remarks from DG SANCO (letter from Andrzej Rys, presentations by Stefan Schreck, Nick Fahy)*
  - ECHI is much appreciated by DG SANCO, and seen as reference point in health monitoring; it is supported by the MS;
  - There is a need to shift from project-based to more permanent financing;
  - The current Health Programme cannot be used for permanent funding;
  - The system and the data provided should be useful for experts as well as for policy makers;
  - Restrict innovations; take stock of (i.e. evaluate) what we have; do ECHI indicators make a difference in health policy decisions-making?
  - We need a permanent structure, but also professionally specialised; in view of the latter, is DG SANCO C2 the right place being a policy unit? Can we involve a specialised Agency?
  - How can MS contribute to a sustained system?
  - Nick Fahy at EUPHA November 2010: ECHI has made structure in chaos; ECHI shortlist is dashboard for policy makers; we have to move to a sustained structure.

Annex 2: Full description of tasks to be undertaken by the (interim and final) "central health monitoring capacity"

a. Maintaining and improving the ECHI indicators shortlist

a.1. Updating the ECHI shortlist

The shortlist is intended to remain rather stable. Nevertheless, changing policy needs and advancing scientific insights may be a reason for updating the ECHI list. This updating can imply adding or deleting indicators, but also a reconsideration of whether an indicator should stay in the implementation section (ready for use) or development section (still some problems to be solved) of the shortlist. The review and updating of the ECHI shortlist should take place at regular intervals, e.g. every three years, and it should follow the ECHIM guidelines.

a.2. Maintaining the indicator documentation

ECHI indicator meta-data (definition, calculation, sub-group definitions, data sources etc.) have been documented according to a structured format in the ECHI documentation sheets. These sheets must be updated when there have been changes in data collection, or when indicators are added. This applies similarly to the list of operational indicators. This is the list specifying all the required subdivisions, mostly those by sex, age, and socioeconomic status.

a.3. Solving remaining problems

By the end of the Joint Action, several indicators will not yet be completely ready for full implementation in the MS. These indicators are placed in the 'development section' of the shortlist. There may be remaining questions on the appropriate definition, or problems with the regular availability of data. The actions to solve these problems vary from consulting experts to communicating with data providers on improved methods. Such actions will remain necessary.

a.4. Ensuring coherence with other indicator initiatives

Next to ECHIM work, other initiatives exist which produce indicators for different purposes. Examples are the indicators developed by the Social Protection Committee, the EU structural indicators, OECD Health Care Quality Indicators, or the indicators identified by DG SANCO Committees. Whilst the 88 ECHI shortlist indicators are a manageable core set to describe health in general terms, the other indicator sets reflect additional data needs from different, mostly more specific scopes. There is, however, a natural overlap, e.g. in the sense that ECHI has often selected one or two indicators from any specific area for presentation in the shortlist. In these cases, the indicators should be harmonised, and ECHI should utilise development work done in these specified fields.

a.5. Utilising EU-funded projects

Collaboration with many DG SANCO funded projects has been very fruitful during the previous ECHI and ECHIM project periods. Some current DG SANCO funded projects and Joint Actions (but also other projects, e.g. funded by DG research) are engaged in indicator development and or data collection. ECHI(M) and Member State experts should assess these for new information on possible improvement of existing indicators, or even on the usefulness of introducing new indicators into the ECHI shortlist. The reverse is just as important: Needs and problems in some

ECHI indicators (notably in the development section) may be taken up in DG SANCO annual work programs and subsequently dealt with in new projects.

b. Central health indicator database and data presentation tool

b.1. Data handling with content expertise

An important task is to fill the central database. This implies the responsibility to initiate and control the continuous process of introducing the appropriate data, preferentially from international sources, but sometimes also from national sources. More specifically, this includes the validation of the correct breakdown of data by background variables such as sex, age and socioeconomic group according to ECHIM standards, and of the inclusion of the required meta-data. A quality check of data coming from international sources is not always easy, but a continuous effort is needed to improve the comparability of data, e.g. by checking for unexplained discrepancies. For this, profound knowledge is needed of the various primary sources used (e.g. mortality statistics, population surveys, health care registers). Notes should be taken on data deficiencies in any respect, in order to improve for the next round. Finally, the task includes a check on whether the data are presented in the data presentation tool correctly.

b.2. IT development of the database

An equally important task is the IT-development of the database and the connected data presentation tool. This includes the design and maintenance of the proper data flows from international databases and Member States to the central database, as well as the desired functionalities of the data presentations. Here we require IT-expertise, in good and frequent coordination with public health content expertise.

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

c.1. Increasing the visibility of the ECHI shortlist

In spite of the importance attached to the ECHI shortlist by DG SANCO and increasingly also the Member States, knowledge of its existence and added value should be further promoted in various EU circles, and especially in the Member States, at political level. This is a continuous task, like the others. Actions by DG SANCO and the “ECHI unit” should include an active promotion of ECHI towards other EU initiatives and towards Eurostat work, and regular (also moral) support towards the Member States. At national level, the national contact persons and national implementation teams should continuously involve policy makers and national parties in data collection.

c.2. Continued implementation of data sources and indicators in all Member States

This task implies encouragement and support to the Member States’ experts and organisations in developing and improving their data collection. Due to the existing variation in the available health information there is a need to work on further harmonisation, to achieve better comparability. The ECHIM experience (Kilpeläinen et al., 2008) shows that only part of important data and indicators, as selected by ECHIM, are available in international data sources (Eurostat, OECD, WHO). For quite a few indicators, the required data not present in international databases exist at national level. For some areas, like hospital data and especially interview surveys (EHIS), the

situation is improving, as after the full implementation of EHIS in 2014 a much larger share of ECHI indicators will be covered by Eurostat. However, the recently appearing lack of commitment for an appropriate continuation of EHIS after 2014 is definitely worrysome. Apart from these areas, there will probably remain a few issues where ECHI has to rely on national data sources. One example is the current lack of possibilities to partition many health data by socioeconomic variables.

When the Eurostat regulation will become operational, this task may be expected to gradually shift to Eurostat, being the natural partner for the national data deliveries. There will remain a task for ECHI, however, in feeding back to Eurostat and the Member States on issues of data improvement and comparability, e.g. on the issue of subdividing health data by socioeconomic background.

d. Collaboration with international organisations

As stated in the Introduction, the European Commission, WHO-Euro and OECD have announced that they intend to work towards a common European health information system. Already now, a large part of the data for the ECHI central database are derived, besides Eurostat, from sources such as ECDC, EMCDDA, WHO Regional Office for Europe, OECD, IARC, and others. It is clear that, in the maintenance of the ECHI indicator system and the associated data presentation, there is a task here to act in the forefront of the envisaged further harmonisation of health information in Europe.

A crucial issue here is that the perception of ECHI in the Member States is one of increasing data delivery obligations, not only from ECHI but also from the various other international organisations. The above-mentioned coordination aimed at further integration should ultimately lead to a reduction of this workload.

e. Regular evaluation of the system's meeting the needs of the users

Evaluation should be undertaken on a regular basis as to whether the ECHI indicator system still satisfies the users, and who the users are. This includes an assessment of the feedback from users, including policy makers and health professionals, and subsequently the development of views and plans on improvements in the organisation of health monitoring and reporting work.

f. Implementation work within the Member States.

Much of the success in consolidating ECHI will rely on the implementation work in each of the Member States. An important issue is that the actual work to implement the ECHI shortlist and to integrate it into the existing systems of data delivery to international organisations has to be done by the Member States themselves. During the current ECHIM project, NITs (National Implementation Teams) have been set up in quite a few participating countries. These NITs made an inventory of the problems encountered in implementation of ECHI, and the formulated corresponding solutions, unique for each country's specific situation. Often the NITs brought together the various actors involved in international data delivery, for each MS. The challenge at MS level is to develop data sources and data collection using experience of others, and to develop a perspective of sustained 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).

g. Using ECHI indicators in the Commission's health reporting products

This task includes ensuring that ECHI information in various Commission products has been obtained according to the guidelines and that it is correct. It could also include work on other indicators than the ECHI shortlist that are important for the Commission and that are used for different, more specific purposes. In this case, some of the tasks mentioned under (a–d) would need to be expanded to these adjacent indicator areas.

h. Analysing and interpreting the data, 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 the quality of the data and development of the monitoring system. Therefore, as soon as possible, emphasis should be laid also on this task.