PUBLIC HEALTH INDICATORS FOR EUROPE:

Context, selection, definition

FINAL REPORT BY THE **ECHI** PROJECT PHASE II

June 20, 2005

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EXECUTIVE SUMMARY

1. Technical information

Area of activities / working party: WP7 on indicators.						
Title of project: European Community Health Indicators, Phase 2 (ECHI-2).						
Start	Start date of the project: 01-10-2001.					
Dura	Duration of the project: 38 months.					
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Proje	ect number: SI2.325304 (2001 CVG 3	+ 506)				
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Coun	ntries involved:	1				
Member states:		Cand	lidate countries:			
[x]	a (austria) b (belgium)	[]	bg (bulgaria) tr (turkey)			
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[x]	d (germany)	Efta/	eea countries:			
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[x]	el (greece)	[x]	(NO) Norway			

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2. content related information

Context/introduction:

ECHI-2 is the continuation of the ECHI-1 report, which ran from 1998 to 2000. It started in the frame of the EU Health Monitoring Programme (HMP) and addressed one of the Programme's core issues: the establishment of a list of health indicators for the European Union. This task was approached with close consideration of already existing work by the Commission Services at Eurostat, by WHO-Europe and OECD on data and indicators in an international context.

Aims and objectives of the project:

- (1) the further development of the indicator list established by the ECHI-1 project, by implementing the results of forthcoming HMP projects and other relevant sources;
- (2) the further implementation of the 'user-window' concept, i.e. the establishment of interest-oriented subsets of indicators;
- (3) the establishment of a shortlist of indicators for priority implementation and presentation of actual data;
- (4) the building of a web-based application for the comparable presentation of the definitions of ECHI indicators and indicators used by Eurostat, WHO-Europe and OECD, as a follow-up of WHO-Europe's ICHI (International Compendium of Health Indicators); and
- (5) promoting the use of the ECHI frame as a common conceptual structure for the work on public health information both in the EU context and in the Member States.

Keywords:

Indicators; Health status; Health determinants; Health systems.

Performance process (activities / design / instruments):

The work was performed by seven meetings of the project team, in the period between October 2001 and October 2004. Three of these meetings were held together with a larger group of HMP project co-ordinators. The ECHI project co-ordinator has maintained frequent contact with many of these projects, as well as with the Working Party leaders, e.g. by joining meetings of all six Working Parties running under the 2003-2008 Public Health Programme. For the establisment of the shortlist, a rigid protocol was devised by the ECHI team, in close communication with DG Sanco C2.

Outcomes of the project / key health messages / added value for reaching the goals of the EU public health programme:

As a follow-up of ECHI-1, the ECHI-2 project has expanded the indicator list, with input from many projects under the Health Monitoring Programme and more recently the Public Health Programme. This has resulted in

- (1) the ECHI 'long list', which is above all an inventory of indicators proposed by the various projects, arranged according to a robust conceptual frame;
- (2) the concept of 'user-windows' which allows for the interest-oriented selection of subsets of indicators;
- (3) the ECHI shortlist, which is selected as a subset from the long list for first priority implementation; and
- (4) a web-based application (ICHI-2, International Compendium of Health Indicators) in which the ECHI indicators are listed, with their definitions, along with the indicators used by Eurostat (rather as 'statistical indicators'), WHO-Europe (the HFA database) and the OECD (OECD health data).

Thus, the project has served two functions: first to develop a list of items and indicators for more comparable data collection among EU Member States; second, to act as a co-ordinating momentum or 'umbrella' for the activities and results of the variety of projects. This has contributed to a common structure within the EU programmes, as well as to a structure for the establishment of the EU Health Information System.

Conclusions:

ECHI-1 and ECHI-2 have shown that a broad consensus can be reached among public health professionals representing a large range of expertise, on a basic logical frame for the organisation of information, and on the selection of a list of priority topics. This does not imply that there are not many issues of debate remaining, but the outcomes of the project provide a reference for these discussions and therefore a starting point for the further development of concepts, indicators, comparable data collection and presentation of public health information.

Plan of dissemination of results:

The results of ECHI-2 will be available by the written report, also presented on the Europa website. The indicator lists will be available on the ICHI website: www.healthindicators.org. A publication in a scientific journal will be considered. A pamphlet for wide distribution will be prepared.

Needs for future policy development:

First of all, the ECHI list should be used and implemented, especially the shortlist. At the same time, the development of indicators is an ongoing process, and should be continued. Several Member States use ECHI as a guideline for the development of national health information systems. Eurostat is using it as a frame for setting up new systems of comparable data collection. DG Sanco C2 is building a database application for the shortlist. Several new projects use the shortlist as a starting frame. As one of these, the EUPHIX project will build a information system based on the ECHI structure. As the closest follow-up of the ECHI-2 project, the ECHIM/WP7 project (Working Party 7 on indicators) will work on the implementation of the indicators and will continue the development of the shortlist and the long list, together with representatives of all Working Parties under the Information Strand of the Public Health Programme. All of this work will help to identify areas of importance for which good indicators are lacking, and thus give guidance to prioritize issues in the yearly Work Programme of the Public Health Programme.

Beyond the development and improvement of indicator definition, the development and sustained existence of appropriate data collection systems at the Member State level, is the ultimate basis of any health information system. Therefore, it is important that the Member States feel committed to safeguard long-term investments into these activities, instead of embarking on ad hoc decisions inspired by short-term political views. It is also important that databases which originate from the public domain, i.e. the citizen, do not become subject to power plays of private organizations.

All of this indicates the need, at EU level, for an organized structure (center) of public health expertise employing a critical mass of experienced professionals. This center should take care of the analysis and dissemination of information for policy support, and take a lead on the implementation and continuous improvement of an EU-wide health information system. The European Center for Diseases Prevention and Control has realized this model for the area of communicable diseases and one possible development route is for it to be expanded to the broad Public Health Area. These tasks should be performed together with Eurostat, with WHO-Europe, with OECD-health, and with the Member States' public health and statistical agencies.

THE FULL REPORT

1. Preface, acknowledgements

This is the final report of the project 'ECHI-2' (European Community Health Indicators, phase 2). This project was started under the EU Health Monitoring Programme (HMP) and has run from October 1st, 2001 to December 1st, 2004. Like its predecessor, ECHI-1, the project was co-ordinated by RIVM, the Dutch National Institute of Public Health and the Environment, in Bilthoven, The Netherlands. The ECHI team consisted of participants from the EU-15, plus Hungary and Norway, and representatives or observers from Eurostat, WHO-Europe and OECD.

Paragraph 2 gives the objectives of ECHI-2. In paragraphs 3 and 4, the report gives background and definitions on what 'public health' is, and on how public health information can be structured, for the support of health policies. Paragraph 5 gives an outline of how the goals of ECHI were approached. Next, paragraphs 6 to 9 discuss the results, i.e., the indicator lists, the concept of 'user-windows' and the ICHI internet database. The lists themselves and further details are given in Annexes 5 to 9. Paragraphs 10 and 11 give conclusions and perspectives for the future. The indicator lists are also accessible by internet under: www.healthindicators.org.

The project team of ECHI-2 consisted of the following persons (full affiliations are given in *Annex 12*):

- Austria: Mr. Richard Gisser, Statistics Austria, Vienna.
- Belgium: Prof. Herman van Oyen, Scientific Institute of Public Health, Brussels (replacements: Ms. Nathalie Bossuyt, Mr. Pieter-Jan Miermans).
- Denmark: Ms. Eva Hammerby, National Board of Health, Copenhagen (early phase: Ms. Christina Ecklon).
- Finland: Prof. Arpo Aromaa, National Public Health Institute, Helsinki.
- France: Mr. Gérard Badéyan, Haut Comité de Santé Publique.
- Germany: Mr. Thomas Ziese, Rober Koch Institute, Berlin.
- Greece: Prof. Aris Sissouras, University of Patras, Patras.
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- Ireland: Mr. Hugh Magee, Department of Health and Children, Dublin.
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- Luxembourg: Mr. Raymond Wagener, General Inspectorate of Social Security.
- Netherlands: Dr. Pieter Kramers (project co-ordinator), Dr. Peter Achterberg, Mr. Rutger Nugteren, Ms. Eveline van der Wilk, National Institute of Public Health and the Environment, Bilthoven.

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- Portugal: Mr. Paulo Ferrinho, Mr. Rui Calado, Directorate General of Health, Lissabon (replacement: Ms. Judite Catarino).
- Spain: Dr. Enric Duran, Municipal Research Institute, Barcelona.
- Sweden: Ms. Susanne Holland, Dr. Mans Rosén, National Board of Health and Wefare, Stockholm (replacement: Dr. Magnus Stenbeck).
- United Kingdom: Dr. Hugh Markowe, Department of Health, London (replacement, Mr. Richard Willmer).
- WHO-Europe: Mr. Remigijus Prochorskas.
- OECD: Mr. G. Lafortune (observer).

The project co-ordinator thanks all these colleagues for their invaluable and continuous participation and support. In addition, he wants to acknowledge the very constructive communication, over the entire period of the project, with the project officials at Sanco C2, dr. Henriette Chamouillet and dr. Frédéric Sicard, as well as all other Sanco C2 staff and the staff of Eurostat's unit on health statistics.

We are happy to see that the results of ECHI-2 are being picked up and used. At the same time, indicator development is being continued, and will particularly be carried on by the ECHIM project which also covers the secretariat of Working Party 7 on Indicators. Whenever readers of this report want to comment on its contents or other issues of indicator development, they can get in touch with the WP7 secretariat: katri.hakulinen@ktl.fi. For more information on this, see paragraph11.

2. Objectives of ECHI-2, as a follow-up of ECHI-1.

ECHI-2 has been the follow-up of ECHI-1, of which the final report was produced by February 15, 2001. The main result of ECHI-1 was a list of indicators for the public health field, arranged according to a robust conceptual frame of public health and health determinants (cf. *paragraph 4*). In addition, the concept of 'User-windows' was devised. This means that from the overall set of indicators which is arranged following the standard conceptual frame, subsets of indicators can be defined from the viewpoint of specific interests or perspectives. The abridged version of the ECHI-1 report has been added to the present report as *Annex 1*.

The indicator list and its underlying structure were taken up by the Commission Services at DG Sanco, unit C2 (hereafter called: Sanco) as a useful frame of reference for much of the work within the Health Monitoring Programme (HMP), and later on in the 2003-2008 Public Health Programme (Strand 1 on information). During 2001 and 2002, many of the HMP project reports produced recommendations of indicators, quite often following the ECHI frame. There were many presentations by the project

co-ordinator, and many discussions between the respective projects and the ECHI co-ordinator. Stimulated by this ongoing debate, a proposal was submitted for ECHI-2.

The goals of ECHI-2 were formulated as follows:

- (1) The further development of the indicator list established by the ECHI-1 project, by implementing the results of forthcoming HMP projects and other relevant sources.
- (2) The further implementation of the 'user-window' concept, i.e. the establishment of interest-oriented subsets of indicators.
- (3) The establishment of a shortlist of indicators for priority implementation and presentation of actual data (this goal became prominent in 2003).
- (4) The building of a web-based application for the comparable presentation of the definitions of ECHI indicators and indicators used by Eurostat, WHO-Europe and OECD, as a follow-up of WHO-Europe's ICHI (International Compendium of Health Indicators).
- (5) Promoting the use of the ECHI frame as a common conceptual structure for the work on public health information both in the EU context and in the Member States.

The work towards realization of these goals is described in the further paragraphs of this report, with many details in the Annexes. At the beginning of the project, comments were made on the high ambitions and high expectations from the project. It was agreed that the establishment of an indicator list is a crucial step towards the actual collection of data, but that data collection was not among the goals of ECHI-2. For more details on working procedures in ECHI-2, see *Annex 3*.

3. On public health information and indicators

Public health policies aim at improving the health of the citizen, including the reduction of health inequalities. In order to be effective, these policies must be based on factual information. Such information can effectively be summarized and presented in the form of 'indicators'. This area: health data, information and indicators, is the core business of Strand 1 (on information) of the European Commission's Public Health Programme 2003-2008.

The crucial next question is *which* information is needed for *whom*, and *when*, or *how often*. Here, we come to questions such as (1): what belongs to the public health field? (2): how do we arrange issues in a logical structure? and (3): how are we setting priorities for selecting topics. Examples of such topics are: occurrence of certain diseases, health behaviours, health care quality, etc. Addressing these questions has been the subject of the ECHI project. The approach has been to select policy-relevant public health topics, to arrange these topics in a logical structure, and where possible

to define the topics in terms of 'indicators'. Therefore the project was named: European Community Health Indicators (ECHI).

What is an indicator? In the ECHI-1 report, it was described as 'A concise definition of a concept meant to provide maximal information on an area of interest'. This implies a few things: (1) an indicator should tell us something about an area of interest for (policy) action, sometimes defined as a concrete policy target (e.g., reduce the percentage of smokers to less than 20%); (2) an indicator should do this in a maximally efficient way, i.e. provide the simplest possible numerical presentation, calculated from basic data, to give a robust view of the situation (e.g. life expectancy as a measure for the overall age-specific mortality). One could also say that indicators are at the crossroads of policy questions and data sets. Their selection and definition will be directed, on the one hand, by the needs of health policies and actions, and on the other hand by the availability of data. The recently fashionable term 'performance indicators' does not refer to a basically different concept. Rather it implies a more explicit link to a specified objective of an activity or policy.

In the ECHI context, the word indicator has been used in a rather broad way, sometimes referring to 'topics' or 'issues' ('generic indicators'), and sometimes to precisely defined 'operational indicators'. The term 'alcohol use' is an example of the former. Specifications like 'percent of the male population over age 16 drinking 4 glasses per day or more', or 'percent of 14-18 year old drinking alcohol', are examples of operational indicators.

4. What belongs to the public health field? Conceptual models.

The first criterion for selecting indicators was that, as a set, they should comprehensively cover the field of public health (see also *paragraph 5*). Already in 1997, Annex 2 to the Health Monitoring Programme (European Commission, 1997), gave a list of the main areas which should be included:

- Health status
- Lifestyle and health habits
- Living and working conditions
- Health protection (meant to include health services)
- Demographic and social factors
- Miscellaneous.

This was not a haphazard series of issues but reflects a logical grouping. Basically, it goes back to the public health model connected to the name of the Canadian health minister Marc Lalonde (1974). This model (see *figure 1*) says that health is determined by four domains, i.e., biological and genetic factors, lifestyle, the environment and the health care system. These four domains have later been called

'determinants of health'. The implication of this is twofold: (1) Health is viewed as more than the absence of diseases, and has components of functioning and wellbeing (cf. WHO definition of 1948), (2) public health policies and interventions try to improve health by acting on those four groups of 'health determinants'. One could make this explicit by turning *figure 1* around into *figure 2*. Then the model more clearly appears as a causal chain: (1) health is influenced by the set of health determinants, (2) many activities (prevention, health promotion) help to improve health by acting on the determinants, and (3) health (and health-related) policies create conditions in which these activities can work. These figures are simplified, of course, but they help to focus on the basic concepts.

Figure 1. Basic health field model, after Lalonde (1974).

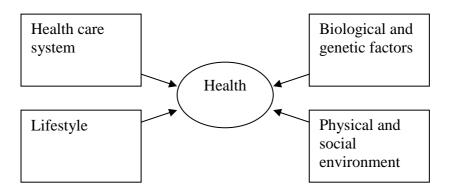
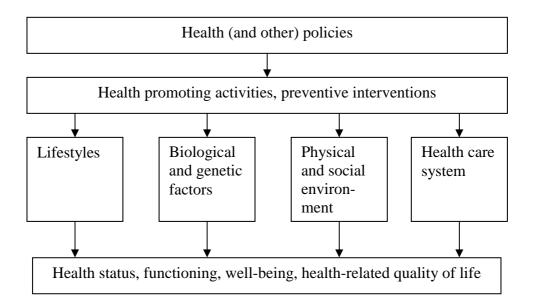


Figure 2. The basic health field model transformed to show the simplified causal chain.



Annex 2 gives additional examples and explanations of such models. The idea behind all of them is (1) that the ensemble of blocks and arrows represents the comprehensive public health field as we want to approach it, including the various issues and the relationships between them; and (2) that within each block, one can define topics and indicators on which data can be collected and indicators defined.

At the start of ECHI-1, it was clear that we needed a model like this to ensure that we would adequately cover the public health field, and to take care of a proper arrangement of indicators. During the first phase of ECHI-1, intensive discussions led to the arrangement of public health domains as shown in *Box 1*. Roughly, classes 2, 3 and 4 (on health status, health determinants and health systems) correspond with the layers in *figure 2*, except for the inclusion of health care in the chapter on health systems, and the merging of 'health promoting/preventive activities' with 'policies'. Also, class 1 was added to account for population and socio-economic variables. These are considered as important background variables in public health, although some of them can be seen as health determinants as well (e.g. income level, educational level, household status). It was decided that this arrangement was a rather robust average of existing models and sometimes conflicting considerations.

Box 1: Main categories for the ECHI indicator set

1 Demographic and socio-economic situation

- 1.1 Population
- 1.2 Socio-economic factors

2 Health status

- 2.1 Mortality
- 2.2 Morbidity, disease-specific
- 2.3 Generic health status
- 2.4 Composite health status measures

3 Determinants of health

- 3.1 Personal and biological factors
- 3.2 Health behaviours
- 3.3 Living and working conditions

4 Health systems

- 4.1 Prevention, health protection and health promotion
- 4.2 Health care resources
- 4.3 Health care utilisation
- 4.4 Health expenditures and financing
- 4.5 Health care quality/performance

During ECHI-2, discussions have taken place with the EUHPID project team (EU Health Promotion Indicator Development). In the EUHPID report, a different conceptual model was proposed, implying a broad and dynamic view on health-promoting activities (also called 'salutogenic' approach) rather than focusing on aspects of ill-health. *Annex 2* shows how the two models can be reconciled. These discussions also led to a change of the ECHI frame. Basic to this was the recognition that in the present Class 4 on health systems, it would be useful to discriminate between health promoting activities within the health services system (the areas of cure, care and classical disease prevention) and outside this system (health promotion in settings, health in other policies, etc.). Also, this would provide more weight to the broad area of health promotion that is explicitly within the mandate of the European Commission. The change was implemented as a split of Class 4, health systems, as follows:

- Class 4: Health interventions: health services (including the 'medical' parts of 4.1, plus 4.2-4.5);
- Class 5: Health interventions: health promotion (including the non-medical parts of 4.1).

5. Selecting public health topics, defining indicators

Having chosen the boundaries and logical arrangement of the various domains in the public health field, the next step is the more precise selection of topics and indicators. This calls for a set of explicit criteria. The ECHI-1 final report has outlined and

discussed these criteria quite extensively. They are recalled below, with short comments (see also *Annex 1*).

- The set of indicators should cover the comprehensive field of public health. This was dealt with in the paragraph above.
- The selection should take account of earlier work by international organisations. Consequently, many indicators defined and used by WHO-Euro (HFA database) and OECD (OECD health data), as well as variables used by Eurostat have been adopted in the ECHI list. In the indicator lists given in the *Annexes 5* and *6*, these links are mentioned.
- The indicator set should meet the needs of Member States' and the Commission's public health policy priorities. To account for this, policy documents were collected from the Member States and screened for priority topics. It was not meant to do this in an exhaustive manner, rather to identify main issues and directions. *Annex 4* gives an overview of such targets and issues for 13 Member States. *Box 2* gives a short overview of the main trends and differences that could be identified.
- The selection of topics and indicators should not only be data driven but also exploit possibilities for innovation. These could be based both on new scientific insights and new policy needs. It is here that many of the projects under the Health Monitoring Programme have made valuable contributions.
- The selection of topics and indicators should be guided by quantitative principles such as the size of a health problem at population level, or the degree of preventability of the problem.
- At the level of their precise definition, indicators should meet methodological criteria such as validity (does the indicator measure what it is intended to measure?), reliability (is the measurement reproducible?) and sensitivity (is the measurement sufficiently discriminative in space or time?).
- Finally, the set of indicators should allow for flexible use. This means that the underlying data collection which can only be a sustained effort should at the same time allow queries that vary rather quickly based on shifts in policy interests.

Box 2: short overview of main health policy issues in EU Member States

In ECHI-1, the exercise to collect Member State health policy issues was carried out for the first time. At that time, a quite remarkable similarity was noted between Member States in their priority topics. High-ranking issues were:

- Increase the number of healthy years lived, by tackling the main causes of death, ill-health and functional limitations (including physical and mental health aspects).
- Reduce health inequalities, by means of health policies but also by social policies.
- Improve effective health promotion and disease prevention especially aiming at lifestyle and at young people.
- Improve the quality and accessibility of care, including community care
- Improve the quality of life and participation of the elderly.

This inventory has not changed in recent years. However, recent reports show a wider range of issues and approaches. On the one hand, we see an emphasis on medical diagnostic categories and their determinants (e.g. France, Netherlands). On the other, we also see an increasing emphasis on social conditions and health-promoting environments (e.g. Hungary, Sweden). Along this line, some topics emerge which were not so clearly present in the ECHI-l list shown above:

- Actions in health promotion and health promoting environments.
- Health system performance (effectiveness, safety, sustainability, efficiency).
- Involvement and empowerment of citizens/patients.

These issues are mentioned in the ECHI list, but there are not many reliable indicators yet, for which international comparisons can be made. Therefore, these are priority areas for indicator development.

The above criteria have been applied implicitly or explicitly throughout the selection procedure. For individual indicators, however, it is often not feasible to tell which criteria were especially important for their selection. To cover this point as much as possible, the long list (see *paragraph 6* below, and *Annex 5*) specifies criteria for each section, and the shortlist (*paragraph 7* below, *Annex 6*) gives specific justifications for each indicator. It should be noted here that in many cases the justification for selection of indicators was given by the original sources such as the respective HMP project reports.

6. The comprehensive ECHI list ('long list')

Ideally, the end product of ECHI would be a list of indicators, all clearly referring to an operational definition and a preferred data collection approach. As was said before, the ECHI list has not been intended to be a database by itself, only to serve as a consensus reference about which data would be needed.

The end product of ECHI-1 (ECHI, 2001) was a list of 192 topics and indicators. (class I: 28; class II: 28, not split for ICD codes; class III: 49; class IV: 87. ICD = WHO's International Classification of Diseases). This number is somewhat arbitrary because of the grouping and splitting of items. In the course of the work in ECHI-2, this list has been growing steadily by the addition of new recommendations from HMP projects. The present version has more than 400 topics and indicators. It is given in *Annex 5*. The list gives the following information:

- (1) Generic indicator or item.
- (2) Operational definition(s), as derived from HMP projects or existing international indicator bases (Eurostat, WHO-Euro, OECD); stratification by gender, age, region or SES (Socio-economic status); remarks.

- (3) An indication of the source type and data availability, often from the HMP project involved.
- (4) The HMP project or other source from which the recommendations came.

In the second phase of ECHI, the co-operation with and the input from the HMP projects has been of greater importance than in the first phase, since many of these projects have produced their final reports in the period 2000-2004. In most cases the projects were carried out by appropriate networks of experts in the respective fields, which makes their recommendations an important innovative stimulus in indicator development. The other side of the coin is that expert groups not infrequently lack the insight of how the newly developed concepts and measurements can be translated into routine data collection in the variety of practices of 25 Member States. The result is that the ECHI list contains quite a few items for which a regular and comparable data collection is still many steps away. Admittedly, it was one of the goals of ECHI to be innovative and not only data-driven, but a balance is needed.

Another point of (im)balance resides in the fact that for some topics there happened to be projects in the HMP, and for others not. For example, the projects on cancer, cardiovascular diseases, COPD (chronic obstructive lung disease) and asthma produced a wide range of indicators, whereas for other important diseases, there is nothing. From a disease-specific viewpoint the recommended indicators are definitely valid and relevant, and the work performed is highly valuable. However, for a workable list of indicators covering the entire field of public health, which ECHI is meant to be, the addition of such sets of indicators for all major diseases or diagnostic groups would not be an option. In some instances, we have chosen to mention sets of recommended indicators as a group, with reference to the project report where the full list and background are given (e.g. levels of specific serum cholesterol fractions, detailed nutritional status indicators, indicators on the quality of care for disease X).

The dilemma has become that, on one hand, ECHI has chosen the role of putting the wide range of recommended indicators and topics into a logical arrangement, thus keeping consistency with the ensemble of results from the public health projects. On the other hand, it is not in the competence of the ECHI team to decide whether certain recommended indicators can be taken on board and others cannot, except in cases where proposals are conflicting with each other or are evidently beyond the scope of public health.

The strength of the list remains that it provides a logical and conceptually solid frame in which all indicator proposals can be accommodated, and by which the relationships between them become apparent. In addition, the imbalances reveal the areas for which information collection and indicator development is lagging behind. These can then be taken up as priorities for the further activities within the Public Health Programme, as laid down in the Annual Work Programme.

In conclusion, the ECHI long list has become, in the first place, a structured inventory of indicators and draft indicators proposed by many. From this inventory, further selections can be made in the process towards harmonized data collection. The shortlist and also the user windows are examples of this.

7. The ECHI shortlist

The main goal of the ECHI list has always been to give guidance to harmonised data collection and presentation throughout the EU. For this purpose, the expanding long list (see above) gradually became less suitable. Therefore, the initiative was taken in 2003 to select a set of core indicators, as a subset from the comprehensive list. This so-called 'shortlist' should serve as a priority list for starting the collection and presentation of actual data and contents.

The selection of the shortlist from the long list was done by a panel of public health generalists, mostly consisting of the ECHI team, following an agreed procedure. The criteria used were:

- The indicator should be relevant from the point of view of the 'general public health official'.
- The indicator should be oriented towards the 'large public health problems', the 'large health inequalities' and the 'large possibilities for improvement', in terms of health impact and options of (cost-)effective intervention.

The availability of data was not taken as a primary selection criterion, in order to keep the innovative aspect on board. The assessment of data availability as a second step then would lead to a part of the list being ready for implementation and another part being the candidate list for further development work.

The first draft shortlist resulting from this selection round was issued in June 2003 and discussed in various Committees, and suggestions given by those were considered again by the ECHI team. By January 2005, the team released a version which it considered as final for the course of the ECHI-2 project, at the same time defining needs for further development. Further details of the procedures and subsequent evolution rounds of the shortlist are given in *Annex* 7.

The January 2005 final version of the shortlist includes 82 items, mostly defined as operational indicators. For 46 of these, data are considered relatively well available and comparable in the Member States. For 31 items, substantial developmental work is still needed because of problems with regular availability and/or comparability. Another 5 are items for which most developmental work still has to be done. The degree of data availability (assigned according to an assessment by Eurostat) is a gradual issue rather than a yes/no situation. Finally, the list has an Annex containing

32 items which have been proposed by various parties, but for which a balanced decision about inclusion has been postponed to later stages.

The list is added to this report as *Annex 6*, but given in *table 1* below in summary form. The two columns list the indicators by the degree of availability, as indicated above.

Table 1. The ECHI shortlist, divided by two grades of availability of data.

Indicator class	Regularly available,	Partly available,
	reasonably comparable.	sizeable comparability problems.
Demographic and socio-economic factors Health status	 Population by gender/age Birth rate Mother's age distribution (incl. teenage pregnancies) Fertility rate Population projections Population by education Population by occupation Total unemployment Population in poverty Life expectancies Infant mortality Perinatal mortality SDR Eurostat 65 causes, ages 0-64, 65+ Drug-related deaths HIV/AIDS incidence Lung cancer incidence Breast cancer incidence (low) birth weight Injuries road traffic Injuries workplace Perceived general health Prevalence of chronic illness Limitations of usual activities Related health expectancies 	 Smoking-related deaths Alcohol-related deaths Diabetes prevalence Dementia/Alzheimer prevalence Depression prevalence AMI incidence Stroke incidence Asthma prevalence COPD prevalence Injuries: home/leisure, violence Suicide attempt General musculoskeletal pain Limitations in physical functions Psychological distress Related health expectancies
Health determinants	 Regular smokers Total alcohol consumption Intake of fruit Intake of vegetables PM10 exposure 	 Body mass index Blood pressure Pregnant women smoking Hazardous alcohol consumption Use of illicit drugs Physical activity Breastfeeding Social support Work-related health risks
Health interventions: health services	 Vaccination coverage children Breast cancer screening Cervical cancer screening Hospital beds Physicians employed Nurses employed 	 Mobility of professionals Other outpatient visits (surveys, besides GP) Equity of access Medicine use Waiting times elective surgeries

	Technologies (MRI, CT)Hospital in-patient dischargesHospital daycases	Surgical wound infectionsCancer treatment qualityDiabetes control
	Daycase-discharge ratioALOSGP utilisation (surveys)	Patient mobility
	• Surgeries (PTCA, hip replacement, cataract)	
	Insurance coverageExpenditures on healthCancer survival rates	
Health interventions: health promotion	Policies against ETS exposure	 Policies on healthy nutrition Policies/practices on lifestyles etc. Integrated programmes in settings

An important note is that, where this is appropriate and possible, indicators should be presented by age group and gender, and also by socio-economic status and subnational region. For age-group stratification, it is proposed to take as a general starting point: 0-14, 15-44, 45-64, 65-84, 85+. This corresponds with the minimal recommendation included in the ICD-10, with deletion of the 1-year age cut-off and addition of the 85+ limit. Additional groups can be presented according to Eurostat standards. For some items, a more refined grouping in younger and old age will be needed. From the data side, there may be a problem of non-inclusion of certain age groups in interview surveys. For socio-economic status, the recommendation has been (project on monitoring of socio-economic difference in health, see Annex 11), on practical grounds, to stratify primarily by education and occupation, in the case of mortality data, and by education and income, in the case of interview surveys. For stratification by subnational region, the ISARE project has proposed regional subdivisions that would be relevant from the point of view of health responsibilities, for the EU-15 countries (ISARE-1 project, see Annex 11). In most countries, these subdivisions coincide with a 'NUTS'-level (territorial subdivisions for statistical use).

8. The concept of user-windows

At the start of ECHI-1, the wish was to have one list of 'core' indicators and another containing 'background' indicators. The group then considered that what could be considered as 'core', would depend a lot on one's point of view, which led to the creation of the 'user-window' concept. The principle of a 'user-window' is that it selects a *subset* of indicators from the full ECHI list, based on a particular perspective or interest. These particular perspectives can be manyfold, such as: 'health and health services for mother and child', 'health inequalities', 'cancer occurrence, prevention and care'. The subsets of indicators linked to such perspectives will normally be collected from most or all of the main groups of the ECHI hierarchy, which was made on the basis of the generalised conceptual scheme (see *paragraph 4*). The 'user-

window' concept was introduced in the final report of ECHI-1 (see *Annex 1*), with a series of examples. Apart from the rather specialized examples like the ones mentioned above, there were two generalised ones: 'cockpit information', and 'EU priority list'. The first one would provide a quick overview of the overall public health situation, the second one would do the same, but more specifically towards issues selected as policy focus by the Commission. These two seem very close to the original idea of a set of core indicators. In fact, the ECHI shortlist (see *paragraph 7*) is the realisation of a user window from this perspective.

Besides the shortlist, this report proposes a series of additional user-windows. Whereas in the ECHI-1 report, the various examples given were all 'invented' behind the desk, we have now chosen the following two approaches:

- 1. Many HMP projects represent specific expert areas. The set of indicators recommended by these projects can be taken as a user-window to cover the area in question. The same may apply to areas covered by Working Parties under the Public Health programme.
- 2. For some important areas or perspectives, no project has proposed indicators, although it seems useful to create a user-window for that area. In these cases a user-window was conceived by the ECHI team.

All user windows proposed by those two approaches are given in *Annex 8*, with their sources. Each user window has been given a number. In the long list, this number is shown with each indicator. In the ICHI-2 internet application (see below), these user windows can be selected from the full list and presented separately.

9. The ICHI-2 indicator database: comparison of indicator definitions

ICHI stands for 'International Compendium of Health Indicators'. Its basic goal is to allow for an easy comparison of the indicator definitions used by international organisations. The first version of ICHI was prepared by WHO-Euro (supported by the European Commission) in the form of a book and an Access database, and was received with much enthusiasm (ICHI, 1999). It included indicators used by WHO-Europe (for the HFA database), OECD (for OECD health data) and Eurostat (for the New Cronos database).

In the frame of ECHI-2, ICHI-2 was developed as a web-based application, to allow for easier updating. It was structured according to the hierarchical grouping of indicators as applied in the ECHI list, and all ECHI indicators were included as well. A mechanism was conceived for the easy updating of the system with the annual or otherwise regular updates of WHO-Euro, OECD and Eurostat. Although recent updates were received from these organisations, the ideal way of updating still needs some development.

The rationale for building ICHI was that the development of indicators in the frame of the EU Health Monitoring Programme would take the existing sets of indicators as a starting point. So, it was meant in the first place as a supporting tool for those involved in indicator development in HMP projects. Additional users could be those engaged in collecting national data for reporting to the international databases. This would facilitate the establishment of a single national data repository for various international users, thus reducing the burden of reporting and helping to ensure that the same values for the same indicator are reported to different organisations.

The ICHI-2 application offers the following entries:

- By the ECHI taxonomy: you enter the indicator list by the classes of the ECHI taxonomy; you can choose to have all indicators within a given group or only the ones coming from one of the four lists (WHO, OECD, Eurostat, ECHI).
- Search by the individual indicator name: this gives users the possibility to search for specific indicators and their respective definitions directly.
- Select a user-window: besides the above possibilities, the application allows the user to select user-windows. All user-windows mentioned in *Annex 8* have been implemented in the ICHI-2. In addition, there is the possibility to create one's own user-window.
- Hyperlink to organisations: this function provides hyperlinks to the websites of the participating organisations.

The web address of ICHI-2 is: <u>www.healthindicators.org</u>. Technical details are given in *Annex 9*.

10. Conclusions

As a follow-up of ECHI-1, the ECHI-2 project has expanded the indicator list, with input from many projects under the Health Monitoring Programme and recently the Public Health Programme. This has resulted in (1) the 'long list', which consists of an inventory of indicators structured within a robust conceptual frame, but with recognized imbalances reflecting specific areas covered by HMP projects; (2) the concept of 'user-windows' which allows for the interest-oriented selection of subsets of indicators; (3) the shortlist, which is selected as a subset from the long list for first priority implementation; and (4) a web-based application (ICHI-2, International Compendium of Health Indicators) in which the ECHI indicators are listed, with their definitions, along with the indicators used by Eurostat (rather as 'statistical indicators'), WHO-Europe (in the HFA database) and the OECD (OECD health data).

Thus, the project has served two functions: first to develop a list of items and indicators for more comparable data collection among EU Member States, and

second, to act as a sort of co-ordinating momentum or 'umbrella', integrating the results of a variety of projects into a common structure.

Clearly this is not a type of activity that is finished by any sort of deadline. Policy views on what is important in Public Health change over time and may also converge within the EU. In accordance with this, data needs will change. Therefore, the development and improvement of indicator definitions is an ongoing process. For all of this, the development *and* maintenance of data collection systems is the ultimate basis.

This point needs emphasis because not infrequently policy-makers who are faced with budget shortages tend to decide rather easily on cutting down basic data collection and statistical work. These are however long-term investments which do not always show immediate results towards their short-term goals. When their successor policy-makers suddenly need the data, it may be too late.

Another danger is that indicators are too much reduced to administrative control tools, whereas they always reflect a world behind them. This means that we should use indicators merely as 'signals', and always keep the connection with the basic data, and to the possibilities to analyze *why* a certain indicator is going up or down.

All this indicates the need, at EU level, for an organized structure (center) of public health expertise employing a critical mass of experienced professionals. This center should work on interpreting, analyzing and presenting data and information, and take a lead in the work towards improving the EU-wide health information system. The reason for having this center is that the establishment of a sustainable health information system can never be accomplished by series of two- or three-year contracts. In fact, the present European Center for Diseases Prevention and Control has realized this model for the area of communicable diseases and one possible solution could be the expansion of its role to the broad Public Health Area.

Needless to say but necessary to repeat again and again: These tasks should be performed together with, first of all, Eurostat, with WHO-Europe and OECD-health, and above all with the Member States' public health and statistical agencies. It is there where the basic work has to be carried out.

11. Follow-up of ECHI-2

First of all, the ECHI list should now be used and implemented, especially the shortlist. In terms of data presentation it should be mentioned that DG Sanco C2 is building a database application for the shortlist, using data available at Eurostat and other international data sources. The EUPHIX project (EU Public Health Information

and Knowledge and Data Management System, co-ordinator Peter Achterberg, the Netherlands) will expand on this idea by building a structured information base which uses the ECHI scheme as a starting frame.

Regarding data collection, we mentioned earlier that several Member States have used ECHI as a guideline for the development of national health information systems (e.g., Italy, Hungary, Greece and others, see *Annex 3*). At the EU level, Eurostat is using ECHI in developing several areas of data collection, for instance in the area of health interview surveys, the so-called European Health Survey System. Notably in this area, the issue of the proper definition of indicators and survey questions in all EU languages, to also cover cultural differences, is a major effort in data comparability.

As the closest follow-up of the ECHI-2 project, the ECHIM/WP7 project (ECHI-Monitoring/Working Party 7 on indicators, co-ordinator Arpo Aromaa, Finland) will (1) work on the implementation of the indicators, by e.g. focusing on the actual quality of data collected and presented by the Member States, (2) continue the development of the shortlist and the long list, in the web-based ICHI application, and (3) carry the secretariat of the Working Party 7 on indicators. In this WP, together with representatives of all Working Parties under the Information Strand of the Public Health Programme (see *Annex 11*) the new results from projects concerning indicator development will be discussed and adopted for the ECHI list. At the same time, the Working Party wants to identify areas of interest where good indicators are lacking, and thus give guidance to prioritize issues in the yearly Work Programme of the Public Health Programme.

Finally, all of this should find its place in the EU Public Health Portal. In fact, the portal could use both the conceptual ECHI scheme and the concept of user-windows. As well as other work the portal could, by its orientation towards a broad audience, be a platform for recognizing missing issues that could be picked up for indicator development.

12. List of Annexes

- 1. Abridged version of the ECHI-1 report of February 2001.
- 2. Examples and discussion of conceptual models of health.
- 3. From ECHI-1 to ECHI-2; procedures, meetings, dissemination of results.
- 4. Member State health policy issues.
- 5. The ECHI comprehensive list ('long list').
- 6. The ECHI shortlist, final version of April 30, 2005.
- 7. The ECHI shortlist, selection procedures.
- 8. List of user windows proposed.
- 9. Technical details of ICHI-2.

- 10. Reports of ECHI-2 meetings:
 - ECHI-morbidity, october 2001.
 - 1st, 7 February 2002.
 - 2nd, 12 September 2002.
 - 3rd, 20 March, 2003, attached to HMP project co-ordinators.
 - 4th, 19-20 June, 2003, especially on the shortlist.
 - 5th, 19-20 February 2004, with HMP project co-ordinators, Working Party Leaders and Eurostat Core group Leaders.
 - 6th, 28-29 October 2004.
- 11. List of HMP projects used.
- 12. Members of the ECHI-2 team, with affiliations.

13. References

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