

Indicators for Monitoring COPD and asthma in the EU

NEW WORK PLAN PROPOSAL

October – November 2003

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1. BACKGROUND

In 1977 the European Commission established the Health Monitoring Programme (hereafter called HMP) seeking to produce comparable information on the health and health related behaviour of the population, on health promotion and health systems. The activities under the HMP were set out under three headings or "Pillars": A: Establishment of Community Health Indicators; B: Development of a Community-wide network for sharing health data; and C: analysis and reporting reporting^{1,2}. The three Pillars served different functions. ***Pillar A*** asks the question ***which*** data and indicators should be included in a Community health data exchange system. ***Pillar B*** addresses the question ***how*** this system should, technically, be made to operate. ***Pillar C*** refers to the ***use*** of the data for policy decision makers.

Under Pillar A, over the past years, around 47 projects have been funded to develop indicators in many areas of public health and produce recommendations on how to collect these indicators to be incorporated to the future European Union Public Health Information Network (EUPHIN)³ developed under Pillar B. Most projects covered a wide spectrum of health issues (i.e. child-health indicators, perinatal health indicators, work related health, etc.). However, since it is not possible to monitor all relevant areas of chronic diseases using just one indicator (i.e. prevalence, treatment, mortality, etc.) some projects had a focus on acute or chronic diseases and with the objective of recommending a set of indicators for monitoring these conditions: cancer^{4,5} musculoskeletal⁶, cardiovascular⁷ and diabetes mellitus⁸. Although the ECHI project had already recommended some indicators for monitoring respiratory diseases no previous project had a specific focus on indicators for COPD and asthma.

These two conditions are affecting a large proportion of the population, and have an important impact on the quality of life of those suffering them and on costs of health services. The asthma prevalence among children is about 13% and in adults 8.4%^{10,11}. The prevalence of chronic obstructive pulmonary disease (COPD) ranges from 4 to 8%^{12,13}. Although asthma may cause death, the impact of COPD on mortality is higher. The World Health Organisation (WHO) estimates that COPD is currently the twelfth most common cause of morbidity and sixth leading cause of death in the world ¹⁴.

The routine data currently available to monitor these two conditions, their risk factors, and their impact of health services and clinical care on outcomes is extremely limited.

Mortality and hospital discharge data are routinely collected in most countries and they may allow to monitor trends and geographical variations between and within countries. However, these data sources have important limitations in terms of the accuracy of data¹⁵ and also with regard to the level of information they provide about the epidemiology or clinical management of the disease.

Health interview/examination surveys are other important sources of information, which could provide better information on both, the epidemiology and the process of clinical care of these two conditions. However, the reality is extremely disappointing, during the period 1998-2002, 60 health interview surveys were carried out at national/international level and 49 collected information about chronic conditions. However, only 12 carried out clinical examinations and only 5 of them collected information on respiratory function (spirometry)¹⁶.

The limited information available (in terms of quality and quantity) contrasts with the large number of aspects identified by the international clinical guidelines such as GINA¹⁷ or GOLD¹⁸ that could be monitored in order to have a full picture of the epidemiology (prevalence and risk factors), the process of care (diagnosis, treatment, exacerbations), interventions for prevention (avoidance of specific risk factors) and the main outcomes (quality of life, use of health services, mortality etc.) for these two conditions.

Using the guidelines standards, an important number of research studies have been able to investigate specific issues of these two conditions but in most cases, results may not be considered representative at national or even regional level. Some examples are the identification of under-diagnosis and under-treatment in both conditions and its determinants^{13,19,20} or the impact of different forms of health care organisation on clinical outcomes²⁰. In contrast with this view at national level, there are specific projects (I would say exceptional) focused on small geographical areas that have developed a comprehensive surveillance systems based on several surveys carried out in different setting and target populations. We can use the Chicago Asthma Surveillance Initiative (CASI)²¹ as an example. Although they are extremely interesting, they may not be cost-effective for national or international surveillance systems.

The implementation of a community-wide surveillance system that describes the epidemiology, characterize health care for asthma and COPD and its impact on outcomes its a complex task, and probably even more difficult at international level. It requires careful thinking in terms of either the issues to be covered, the potential users of the information at different geographical levels, the relevance of the information for either

prevention or strategies to improve clinical management and the feasibility and costs associated to the methods to be used.

Over the past decades, large international research studies such as ECRHS²² or ISAAC²³ have developed methods and tools that could be incorporated in the routine information systems for monitoring COPD and asthma across the EU. This project, will identify the most relevant areas of these two conditions for monitoring, and by **consensus among project participants will recommend a set of indicators appropriate for monitoring asthma and COPD in the EU, and the methods and tools that should be used for data collection.**

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2. AIMS

2.1 General:

- To get a consensus among participants of all EU countries about a set of indicators relevant for monitoring asthma and COPD across the EU.

2.2 Specific:

- To identify all routinely and research (large studies) sources of data providing useful information for monitoring COPD and asthma in the EU and assess their comparability (within and between countries), and their strengths and limitations.
- Explore to what extent international databases such as OCDE, WHO, EUROSTAT could be improved based on the information available for these two conditions.

- To identify the best scientific evidence on risk factors (exposures), prevalence, clinical management and policy interventions and explore to what extent the evidence is (or could be incorporated to the information systems).
- To identify the most important protocol or clinical guidelines recommend by national or international scientific societies implemented in each EU country and assess their comparability.
- To identify a set of indicators useful for monitoring and covering several aspects of these two conditions such as risk factors, prevalence, clinical management, and outcomes.

3. ORGANIZATION AND MANAGEMENT

3.1 Steering Committee

The Steering Committee (SC) will be integrated by the “core group” as it was established in the proposal submitted to DG-SANCO. The role of the SC will be to advice on specific methodological issues of the project, advice on links with other international organizations or scientific societies and to monitor the overall project development. The SC will be integrated by the project co-ordinator, Enric Duran (Spain), Josep M^a Antó (Spain), Christer Janson (Sweden), Debhora Jarvis (UK), Stephen Weiland (Germany) and Francesco Forastiere (Italy) and Giovanni Viegi in representation of the European Respiratory Society (ERS). The SC will decide the number of meetings to have over the project development.

3.2 Study co-ordinating Centre

The study co-ordinating centre will be established at the Fundació IMIM in Barcelona and co-ordinated by Enric Duran. The centre will be responsible for the ongoing administrative and financial management task, organization of meetings and will take care of the overall project development according to the decisions taken by the Steering Committee and suggestions from other partners.

The centre will guarantee the communication between partners, DG-SANCO representatives, other DG-SANCO project co-ordinators and representatives of international organisations and scientific societies. Initially the communication will be

established through e-mail but in order to facilitate communication and debate a web site will be established.

Over the past years, the Health Monitoring Programme (DG-SANCO) funded several projects aiming to contribute to the development of a new EU health information system. Although each project studies specific areas of information or diseases, there are issues that are common to our project. In order to get good interaction between projects, the co-ordinating centre and according to the SC advice, will identify projects with common links and establish appropriate ways of communication and collaboration. Some of these projects may be: European Community Health Indicators (ECHI), Environment and Health Indicators, European Health Risk Monitoring, Hospital Data Project and Health Surveys in the EU.

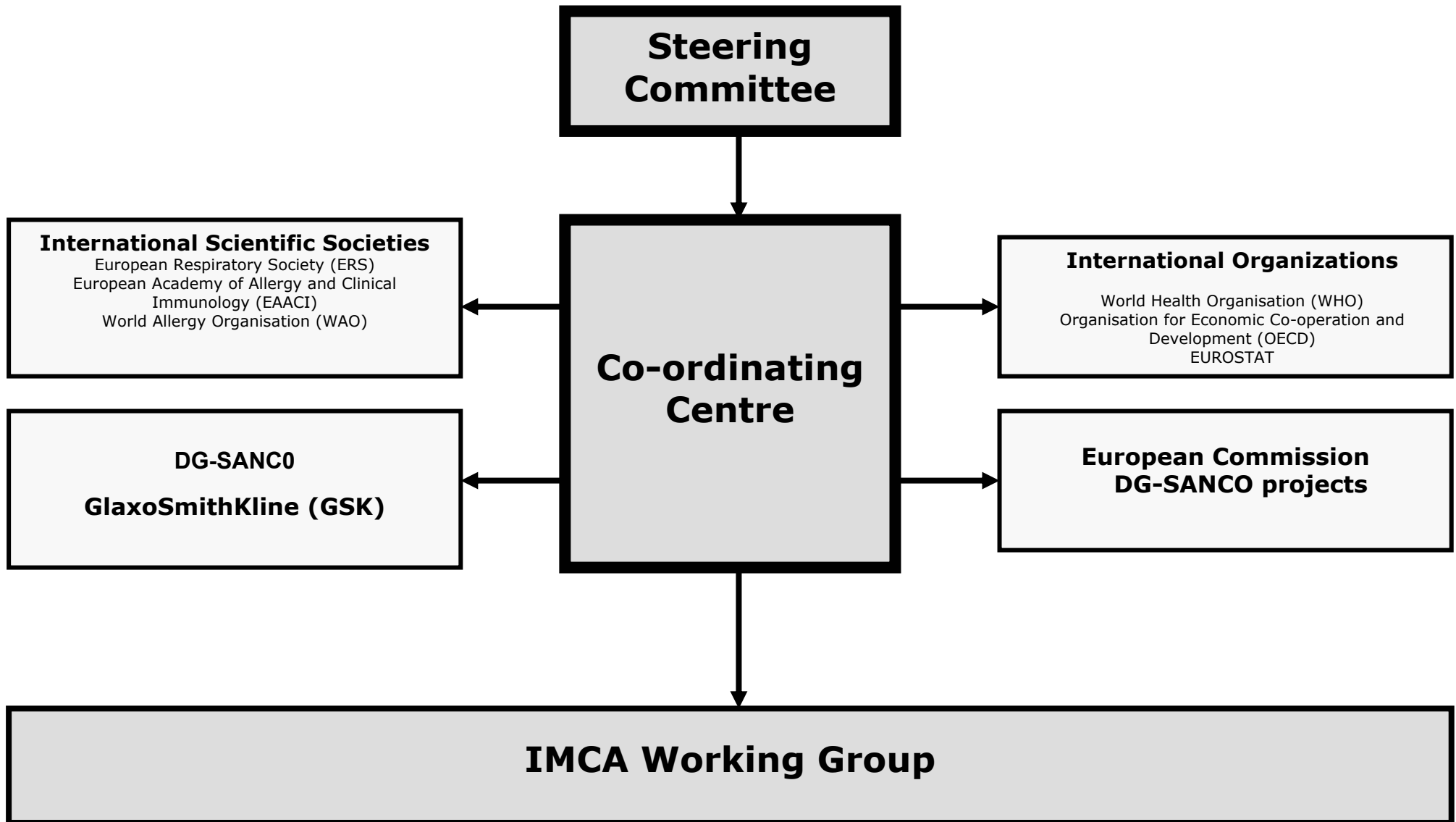
International organisations such as Eurostat, OECD, and WHO have been collecting data from MS for a long period of time and they have large experience in data collection and reporting. In addition, some of these organisations, such as WHO, are developing specific programmes to prevent and monitor respiratory diseases. The project through the co-ordinating centre will establish appropriate links and identify areas of collaboration. As well as with the previous organizations, the co-ordinating centre will seek ways of collaboration with international scientific societies not already involved with the project such as ERS.

3.3 IMCA Working Group

All IMCA participants representing most EU Member States (MS) will integrate the group. There will be two general meetings of two days and according to the project needs additional intermediate meetings through teleconference will be organized.

During the first meeting, will be decided which DG-SANCO project co-ordinators, experts, or representatives of international organizations or scientific societies will be invited to participate in the project and general meetings. The IMCA group will decide if invited people have a vote in the general meetings or just an advisory role.

3.4 ORGANIZATION FRAMEWORK



3.5 List of participants

Country	Partner Name	Institution
Austria	Manfred Neuberger	Abteilung für Allgemeine Präventivmedizin Institut Für Umwelthygiene der Universität Wien
Belgium	Paul A Vermeire	Dienst Longzickten Universitaire Instelling Antwerpen
Denmark	Charlotte Supply Ulrik	Department of Respiratory Diseases Hvidovre Hospital
Finland	Pekka Jousilahki	Department of Epidemiology and Health Promotion National Public Health Institut
France	Denis Charpin	Service of Pneumologie – Allergologie Centre Hospitalier Régional et Universitaire de Marseille
Germany	Stephen Weiland	Department of Epidemiology Ulm University
Greece	Mina Gaga	Department of Respiratory Medicine Medical School of Athens University
Ireland	Luke Clancy	University Teaching Hospital of Trinity College Dublin St James’s Hospital
Italy	Francesco Forastiere	Department of Epidemiology Agency for Public Health
Luxembourg	Romain Nati	Service de Neumologie Centre Hospitalier de Luxembourg
Netherlands	Henritte A Smit	Department of Chronic Diseases Epidemiology National Institut of Public Health and Environment
Portugal	Mario Morais	Servicio de Inmuno Alergologia Hospital de Doña Estefania
Sweden	Christer Janson	Department of Medical Sciences, Respiratory Medicine and Allergology Uppsala University
Spain	Enric Duran	Respiratory end Environmental Research Unit Municipal Medical Research Institute
United Kingdom	Deborah Jarvis	Department of Public Health Sciences Guy’s Hospital, King’s College London
Norway	Per Bakke	Department of Thoracic Medicine University of Bergen
ERS	Giovani Viegi	CNR Institute of Clinical Physiology and European Respiratory Society
WHO	Nikolai Khaltaev	Chronic Respiratory Diseases and Arthritis Management of Noncommunicable Diseases Department World Health Organisation
EUROSTAT	Didier Dupré	Eurostat Unit E3 Education, health and other social domains
OECD	Manfred Huber	Organisation for Economic Co-operation and Development

4. WORK PLAN

In the original proposal there was a brief description of the tasks and timetable for the project development. This was supposed to be discussed and expanded in more detail but unfortunately due to the problems you already know we never discussed. In order to facilitate the discussion of the new work plan and according to the new deadlines I have written this document which describes for each objective of the project the tasks and responsibilities. For each objective I have also tried to clarify issues of interpretation that will help to clarify the tasks to be done in relation to each objective. However, we have to incorporate your views on the interpretation once you have had the chance to look at this document.

4.1 Objective 1

To identify all routinely and research (large studies) sources of data providing useful information for monitoring COPD and asthma in the EU and assess their comparability (within and between countries), and their strengths and limitations.

The identification of routine and research data sources on COPD and asthma was established as the first step of the project. The knowledge of what information is available, what is the quality and comparability, which are the gaps and how is it collected should be the basic information in the process of selecting indicators. As it was written in the first proposal the words "all" "large studies" and "useful information" may be quite ambiguous or led to the identification of a large number of studies without any benefit for the final outcome of the project.

As a group, we have to decide which sources of data the project have to identify and assess their comparability. However, as starting point for discussion and after some interaction with other HMP I propose the following work to be done.

4.1.1 Identification of routine sources of data.

The information systems collecting routine data in each country may differ substantially and in some countries it may be possible to identify a relatively large number of databases containing some information on respiratory diseases. However, databases collected in all countries and at national level are much more limited. In an attempt to classify them we can define three groups: 1) mortality registries, 2) hospital discharge

databases and 3) health interview (HIS) and health examination surveys (HES). In addition to this three groups we may find specific databases such as: GP prescribing databases, occupational health registries or insurance companies databases.

I suggest to compare databases and the information that they contain **only** for mortality registries, hospital discharges and HIS/HES surveys and using simple questionnaires but with relevant information or databases already available set up by other groups.

For mortality and hospital discharges, based on the experience from other projects "Comparability and Quality Improvement of European Causes of Death Statistics, 2001" and "Hospital Data Project, 2003", the co-ordinating centre will design a brief questionnaire to collect information on the main characteristics of these databases in each country. Each partner will complete the questionnaire for his country. This information could be complemented by other reports and suggestions from the EUROSTAT Mortality Task Force that we have already established communication and collaboration and also from the other international organisations such as OECD and WHO.

To complement this information with published papers on mortality and hospital discharges trends in Europe and on the quality of the information of these databases, a Medline search should be carried out and the most relevant papers identified. The co-ordinating centre has already done this work and all relevant papers have been collected.

For HIS/HES surveys I suggest to use the database already set up by the HMP project "HIS an HIS/HES evaluations and models" which have collected information and reviewed all national surveys across Europe. The web site of this database is currently under development but Arpo Aromaa from the Finland National Public Health Institute have already agreed to collaborate with the project and facilitate access to the most updated version of this database. From this database we will be able to identify all national HIS/HES surveys by country and asses the type of questions used for the estimation of prevalence rates for chronic diseases, possible risk factors, drugs prescribed or taken, sample sizes and methods used. This information, is being prepared at the co-ordinating centre and will be made available to participants for comments and discussions on specific issues and on the general meetings.

4.1.2 Identification of research large studies.

As I said before, the identification of research large studies providing useful information for monitoring COPD and asthma is quite ambiguous and may led to unnecessary work not relevant to the final outcome of the project. Over the past two decades a large number of research studies on the prevalence of asthma and perhaps (much less on COPD) studies have been carried out and some of them may contain information on clinical management issues and outcomes. However, due to the lack of a standardized methodology, in early 1990's the European Community Respiratory Health Survey (ECRHS) and the International Study on Asthma and Allergies in Childhood (ISAAC) have developed a common methodology and comparisons within and between countries are possible. More recently, other studies such as AIRE and the Confronting COPD survey have developed other methods useful for international comparison with some advantages respect to the previous mentioned studies but also with some disadvantages.

In my view, we should focus on these studies, and perhaps just include other studies that each participant may have identified in their own country and he/she feels it is relevant to include in the inventory of studies that will be used later for specific discussions on indicators.

4.1.3 Report on the strengths and limitations of routine and research databases for monitoring COPD and asthma.

Once all this information is collected and discussed with all partners the co-ordinating centre will prepare a report summarizing all information in relation to the strengths and limitations of routine and research databases. Once the report is reviewed and accepted by all partners it will be included in the final report.

Tasks	Responsibilities	
	Co-ordinating Centre	Partners
To develop a mortality and hospital discharges questionnaire	X	
To fill up the mortality and hospital discharges questionnaire		X
To carry out a literature search on data quality	X	
Identification of research large studies	X	X
Report on the strengths and limitations of actual routine and research databases	X	

4.2 Objective 2

Explore to what extent international databases such as OECD, WHO, EUROSTAT could be improved based on the information available for these two conditions.

The second aim of the project was to explore how the information collected from national databases is incorporated to international databases and review how information for COPD and asthma is reported. The databases to explore were EUROSTAT, OECD and WHO.

EUROSTAT was established in 1953 and it has key role to supply statistics to the Commission and other European institutions for identifying, implementing and evaluating Community policies. Usually, EUROSTAT collects data from EU Member States for its own databases and also provides data to the other two organisations OECD and WHO. All these three organizations have a web site from which is possible to explore all information available.

In order to accomplish this objective I suggest two activities: 1) review all information available in the database of each organization (including data available and ways of reporting) and 2) identify the key people responsible for these databases and check that all information we obtained is correct, discuss possibilities for improvement and prospects for future data development for these two conditions and 3) to suggest improvements on these databases.

The co-ordinating centre has already done the review of the information available. Also, if the group feels it is important we can get any data available from EUROSTAT database. As a group working for a DG-SANCO project EUROSTAT have given us a password to have full access to the database.

Tasks	Responsibilities	
	Co-ordinating Centre	Partners
To explore EUROSTAT, OECD and WHO databases	X	
To identify key people and check the information	X	

To identify gaps and suggest improvements on actual data available	X	X
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4.3 Objective 3

To identify the best scientific evidence on risk factors (exposures), prevalence clinical management and policy interventions and explore to what extent the evidence is (or could be incorporated to the information systems).

As it happens with the description of the first project aim, the translation of the third aim into specific tasks may also be a bit confusing and we have to discuss it and decide what to do. As it is written, one may interpret that we have to do a systematic review of the scientific evidence for each of the issues described (risk factors, prevalence, clinical management and policy interventions) and in fact it was written on page 20 of the proposal. However, it is clear that although we have to take decisions based on the scientific evidence, a systematic review on all this issues is clearly out of the scope of the project and certainly not necessary to reach the final outcome of the project.

In fact, the idea behind this objective was to carry out a selection of risk factors, measures of prevalence, areas of clinical management and possible effects of policy interventions that could be incorporated as indicators for monitoring different aspects of COPD and asthma taking into account the scientific evidence as main criteria.

We have to discuss this issue but I suggest to carry out the selection based on: 1) the reviews reported on the most important clinical guidelines which at present are based on the scientific evidence (GINA for asthma and GOLD for COPD), 2) possible additional information from published papers and 3) the personal expertise as investigators.

In order to accomplish this objective I suggest to carry out the following tasks:

4.3.1 Risk factors.

To produce selected list of risk factors clearly and consistently associated with each of the conditions under study, to describe the methods and tools available for its data collection (either questionnaires, specific tests or biological measurements).

4.3.2 Measures of disease frequency.

Although at present we have well validated questionnaires with specific questions useful for the measurement of asthma prevalence, not always the same questions or a combination of questions and measurements are used to measure the prevalence of asthma. This is even more complex when we want to measure the prevalence of different grades of severity of the condition. The group, have to agree on which measures of frequency (incidence or/and prevalence) to use for monitoring asthma and COPD and the methods and tools to be used.

4.3.2 Clinical management.

This may be a wide area and perhaps the work should be carried out in two stages. First, identify the most relevant areas of clinical management that should be monitored (under-diagnosis, under-treatment, avoidance of risk factors for exacerbations, control of asthma indicators or outcomes, etc.). Second, to clarify if the methods and tools available at present could be used for the development of indicators and there are methods and tools available.

Tasks	Responsibilities	
	Co-ordinating Centre	Partners
Initial proposal of indicators containing information on risk factors, measures of prevalence and areas of clinical management	X	
Final list of indicators with detailed description	X	X

4.4 Objective 4

To identify the most important protocol or clinical guidelines recommended by local or international scientific societies implemented in each EU country and assess their comparability.

Over the past decade there have been an exponential increase of the development and publication of clinical guidelines for the management of chronic conditions. Although one may have the feeling that the main objective of clinical guidelines is to provide

recommendations specifically on treatment, in general and especially international guidelines provide extremely valuable information on other aspects related to prevention, the process of health care, outcomes and in some cases recommendations for monitoring. In the most updated versions, recommendations are based on scientific evidence (GINA and GOLD).

The dissemination and the implementation of clinical guidelines is a complex process. In general from international guidelines, pocket or nationally adapted guidelines are published and implemented in different countries. However, it is possible to see that in this process, a substantial part of the information available in the original guideline may be dropped or even modified. Also it is possible to see contradictory recommendations in clinical guidelines published by different scientific societies.

Another important aspect of clinical guidelines is the degree to what extent they are used as a guide for health care planning and policy decision-making. It is clear that in some countries there are specific centres to promote the use of clinical guidelines and in others some clinicians in the clinical management process only use them. In general the incorporation of indicators into the routine information systems is very rare and the evaluation of its impact is in general carried out by specific research studies.

In my view, for the project, it is important to assess to what extent the indicators selected by the group may be in contradiction with recommendations of clinical guidelines provided by different scientific societies and also by different national guidelines. If we find important differences this would indicate possible difficulties in the acceptance of some indicators in some countries and specially its incorporation into the information systems. For some of the indicators selected, it may be interesting to produce estimates in relation to specific characteristics of the structure, organization and funding of primary and specialist health care for asthma and COPD that exist in each country. National clinical guidelines, although make several recommendations for different levels of health care structure do not describe the organization of health care. It would be interesting that each partner could describe this information for his or her own country. In order to identify the relevant clinical guidelines assess its comparability and also have a description of health care delivery for the two conditions under study I suggest the following tasks:

4.4.1 Identification and comparison of the most important international and national clinical guidelines.

Most international clinical guidelines can be identified through internet. National guidelines or national scientific societies guidelines may be more difficult to identify and will require the collaboration of each partner.

I suggest that each partner and for their own country identifies the scientific societies involved with asthma and COPD and also identifies if they have published any guideline. It may be the case that in some countries a guideline is promoted by health administration rather than a specific scientific society. These guidelines should also be identified.

Since some guidelines may not be published in English, the co-ordinating centre will develop a questionnaire to extract the specific information to compare and later on summarize the information.

4.4.2 Description of health care delivery organization for asthma and COPD.

Although this may be a task that does not fit under the heading of clinical guidelines, it is an issue that needs consideration and has to be discussed in relation to the indicators selected. It is clear that there are important differences in the delivery of health care either within or between countries and these differences may have an important impact on health outcomes. It is clear too that different professionals or specialists are involved in the clinical management and sometimes with a very strongly opposite views. I suggest that each partner provides a description of the delivery of health care for asthma and COPD for their own country and if it is possible with some indicators. The co-ordinating centre have already produced a summary of the main characteristics of the health care system of each country based on the Health Care Systems in Transition prepared by the European Observatory on Health Care Systems. This summary does not contain any information related specifically to respiratory conditions. However it provides a framework for a detailed description of health care issues in relation to asthma and COPD.

Tasks	Responsibilities	
	Co-ordinating Centre	Partners
Identification of the most relevant international clinical guidelines	X	
Identification of all national scientific societies related to asthma and COPD and also identify if they have produced any clinical guideline for these two conditions.		X
To develop a questionnaire to compare guidelines	X	

To complete the questionnaire on clinical guidelines		X
To describe the structure of health care delivery for asthma and COPD		X

4.5 Objective 5

To identify a set of indicators useful for monitoring and covering several aspects of these two conditions such as risk factors, prevalence, clinical management and outcomes.

Form the work carried out to accomplish objective 3, we will have a relatively long list of indicators covering risk factors, measures of prevalence, different areas of clinical management and outcomes. However, it may not be feasible to collect all of them at national level since the methods and tools required are not yet available or simply it may be too expensive. Certainly, as a group, we will need to define criteria for selecting indicators and also the methods that we are going to use in order to reach a consensus on the final list.

Once we have the final list, we will need to define the precise methods for its data collection (questionnaire, routine data or survey, test, biological assessment, etc) and justify the rational of each indicator with scientific evidence. This task has to be carried out in close collaboration between the co-ordinating centre and all partners.

Tasks	Responsibilities	
	Co-ordinating Centre	Partners
Define criteria for making the final selection of indicators	X	X
Define the methods and tools for data collection and justification of each indicator	X	X
To write a brief justification for each indicator based on the scientific evidence	X	X

5. PROJECT TIMETABLE

According to the new Work Plan and deadlines agreed with DG-SANCO I have written a new timetable. However, I understand that we have to discuss it with all of you and probably the best opportunity will be during the first general meeting in Barcelona.

PROJECT TIMETABLE ACCORDING TO THE NEW WORK PLAN

YEAR 2003

Month 11	<ul style="list-style-type: none"> • Literature search on mortality and hospital discharges data quality. • To explore EUROSTAT, OECD and WHO databases. • Identification of the most relevant international clinical guidelines.
Month 12	<ul style="list-style-type: none"> • Mortality and hospital discharges questionnaire development. • Identification of research large studies. • To identify key people and check the information. • Explore which specific questions on respiratory diseases exist in all surveys included in the HIS/HES database. • Development of a Web site.

YEAR 2004

Month 1	<ul style="list-style-type: none"> • To complete mortality and hospital discharges questionnaires. • Initial proposal of indicators containing information on risk factors, measures of prevalence and areas of clinical management. • 1ST IMCA General Meeting in Barcelona.
Month 2-4	<ul style="list-style-type: none"> • To suggest improvements to EUROSTAT, OECD and WHO mortality and hospital discharges indicators available at present. • Report on the strengths and limitations of actual routine and research databases. • Identification of all national scientific societies related to asthma and COPD and also identify if they have produced any clinical guideline for these two conditions. • To develop an complete a questionnaire to compare clinical guidelines. • To describe the structure of health care delivery for asthma and COPD.
Month 5-9	<ul style="list-style-type: none"> • Define criteria for making the final selection of indicators. • Produce a final list of indicators. • Define the methods and tools recommended for data collection. • To write a brief justification for each indicator based on the scientific evidence.
Month 10-12	<ul style="list-style-type: none"> • 2nd IMCA General Meeting in Barcelona. • Final report writing up. • Project results dissemination.

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