IMCA

Indicators for Monitoring COPD and Asthma in the EU

Interim report

Barcelona, 31 January 2004

European Commission
Directorate for Public Health and Safety Work
DG-SANCO
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1. BACKGROUND.

1.1 The original IMCA project.

As stated in the outline (Agreement no.SI2.328106 (2001CVG3-513)), the project *Indicators for monitoring COPD and asthma in the EU* aims to support the initiatives in health monitoring developed by DG-SANCO by providing scientific advice on a set of indicators relevant for monitoring asthma and COPD in the EU.

The project was recommended for funding by Health Monitoring Programme and according to the project protocol and timetable, the project was supposed to be carried out during the period 2002-2003. Unfortunately, despite the early excitement for the success of the application, the project did not have an appropriate start and development.

From the coordinating centre several activities were carried out for the project development. These activities can be summarized in three groups: i) a literature search to identify the most relevant scientific papers in relation to the validity of the information produced form death certificates and hospital discharge data on asthma and COPD, ii) and assessment of the information available at international databases from OECD, WHO, and Eurostat on respiratory diseases, iii) identification and review of the most relevant clinical guidelines for asthma and COPD and the international research large studies. However, the coordinating centre fail in getting all international participants fully involved. The difficulties and activities carried out are reflected on the interim report that the project coordinator submitted to DG-SANCO in July 2003 and later made available to all participants.

1.2 Establishment of a new IMCA work plan.

The interim report submitted to DG-SANCO was not accepted. At the end of September 2003, the coordinating centre received a letter from John Ryan requiring to submit a new interim report by October 15th. After a careful thought and discussions with Frédéric Sicard and my colleagues from the Environmental Health Research Unit I come to the conclusion that two actions were necessary to overcome all difficulties experienced in the past and have the capacity to achieve the outcomes expected: i) it was absolutely necessary to have an extension of the project in order to have the opportunity to have an

appropriate re-start of the project and ii) it was crucial to achieve full involvement of all international participants.

After some conversations with Frédéric Sicard, we agreed to amend the contract and have a reasonable extension of the contract. According to this new agreement, the project coordinator should submit an interim report by 31/01/2004 and a final report by 31/12/2004.

Following this agreement, a letter was send to all participants explaining the situation of the project and asking them if they still were interested in participating in the project and prepared to attend a 1st IMCA meeting in Barcelona in order to discuss the new work plan proposal prepared by the coordinating centre **(Annex I)** as a way to make progress and achieve the outcomes expected from the project. Fortunately, all expressed their interest in continuing and in participating in the 1st IMCA General meeting in Barcelona.

2. 1st IMCA GENERAL MEETING IN BARCELONA

2.1 Introduction.

Since the project was funded, due to the difficulties previously mentioned, although the coordinating centre established contacts with some of the participants individually and discussed specific issues related to the project, no general meeting had been arranged to discuss the aims, work plan and timetable of the project. From the coordinating centre we felt it was absolutely necessary to arrange a general meeting with the following objectives:

- To update all participants about the project situation and have the opportunity to have a plenary discussion and agree a new work plan **(Annex I)** to develop and finish the project successfully according to the new deadlines established by DG-SANCO.

- To explain to all participants the initiatives in the field of health monitoring that have been developed during the past year by DG-SANCO and help them to understand the context of the IMCA project.

- To agree on the criteria and methods to select a preliminary list of issues/indicators useful for monitoring COPD and asthma.

- In order to fulfil these objectives, all participants considered important to have this meeting and it was organised to be held in Barcelona on the 26-27 January 2004. The agenda and minutes of the meeting can be found in the **Annex II and III**.

2.2 Development of a preliminary list of indicators.

The general aim of the project is to get a consensus among participants on all EU countries about a set of indicators relevant for monitoring COPD and asthma in the EU. In order to reach this objective, in the original proposal several steps were considered important. For instance, the assessment of routine data sources (international and national), the identification and comparison of clinical guidelines (international and national) and the identification of research large studies. However, after the plenary discussion on the new work plan, it was considered very important to start with the identification of the main issues or indicators for monitoring asthma and COPD and in a later stage to proceed to the assessment of routine sources of information and consistency with clinical guidelines. In order to select the first list of indicators, during the meeting, two different panels were set up:

The Asthma panel included : Deborah Jarvis (Chair), Enric Duran (Rapporteur), Roman Nati, Henriette Smit, Mario Morais, Denis Charpin, Hans Moshammer.

The COPD panel included : Giovanni Viegi (Chair), Josep Mª Antó (Rapporteur), Mina Gaga, Per Bakke, Pekka Jousilahti, Paul Vermeire, Nikolai Khaltaev.

The two groups were asked to provide the first list of indicators related to the main areas described in the new work plan (Annex I) on risk factors, measures of disease frequency and clinical management for the two conditions that the project is focused on. For each group of indicators, the sources of information available or desirable to be set up were identified. The lists provided by the asthma and COPD panels are described in the following two pages. Both lists of indicators, specifications and possible sources of data were discussed in a plenary session and further work was agreed.

INITIAL LIST OF INDICATORS FOR ASTHMA		
Indicator	**Specifications**	**Sources of data**
Mortality	• Age and sex specific death rates. • Crude death rate may be also important. • 10 years age group or 5 years? • Paediatric, adulthood, late death, elderly? • Must be able to separate "young" death from those more than 45 (minimum). • The characteristics of death certificates should be taken into account. • Validity of death certificates should be considered.	**Mortality registries**
Prevalence	• Should be based on symptoms in the last 12 months. • Should be dependent on age. • Diagnosed asthma. • Treatment for asthma yes/no? • Chronic cough, presence of symptoms. • Exacerbations	**Health Interview Survey (ISAAC/ECRHS)**
	• FEV1/FVC • Metacholine? Bronchodilator? What information add? • Atopy (house dust mites, grass, cat) • Skin prick test / serum IgE	**Health Examination Survey (ISAAC/ECRHS)**
Severity	• Severity • FEV1 FVC or PEF according to GINA • Symptoms shorter time frame • Life threatening in bed days	**HIS/HES**
Risk factors for prevalence	• Proportion in high-risk occupations or proportion exposed to specific agents. • Proportion living in homes with damp. • Maternal smoking during pregnancy. • Exposure to environmental tobacco smoke. • Outdoor pollutants – ozone, PM diesel exhaust, allergens for incidence of attacks. • Birth weight • Obesity • Nutrition – antioxidants and fat intake • Social class • Genetic susceptibility? • Serious infection?	**Health Interview Survey**
Treatment	• Beta agonists – Inhaled/oral. • Steroids inhaled/oral. • Age dependent, <45? Beta agonist steroid ratio and dose of steroid inhaled. • Desensitisation therapy?.	**Health Interview Survey**
	• Proportion of patients attending for care treated. • Proportion of patients attending for acute care treated. • Incidence of acute episodes.	
	• Beta agonist – inhaled/oral age specific rates. • Steroids – inhaled/oral age specific rates.	**Drug sales prescribing**
Health Service utilization	• Inpatient – age and sex specific rates. • 10 years age groups - <5 separated. • Length of stay - % > than two days. • GP attendances – age dependent.	**Hospital discharge data**
	• Place of regular care. • Outpatients, ER, nights in hospital. • Facilities – chest physician specialist, allergists.	**Health Interview Survey**
Outcomes	• Quality of life – working or school days lost • GINA asthma control questions. • Generic versus disease specific	**Health Interview Survey**
Costs	• Direct cost – to patient and to society.	**Administrative data**

INITIAL LIST OF INDICATORS FOR COPD		
Indicator	**Specifications**	**Sources of data**
Background	• Definition (clinical / lung function). • Distinction from asthma. • Chronic bronchitis.	
Population & sociodemographic	• Age groups: paediatric, young, adult elderly (young, old elderly) fine stratification is important. • Universal stratification by gender. • Sociodemographic: education (highest level achieved: including parents education), income, migration history, family history (?).	
Mortality	• Age and sex specific death rates. • Crude death rate as well as standardized. • Age groups: paediatric, infant, young, adult, elderly (young, old elderly) fine stratification is important. • Universal stratification by gender. • Poor quality of mortality data in death certificates (review literature?). • Multiple cause of death should be considered.	**Mortality registries**
Morbidity	• Symptoms: presence, intensity (?). • Sob, cough, expectoration. • Exacerbations (standardized instrument needed). • Lung function at all ages (ATS/ERS recommendations for wider assessment residual volumes). • Specific quality of life.	**Health Interview Survey** **Health Examination Survey**
Determinants	• Susceptibility: age, gender, BMI, family history, antecedents of serious infections (including tbc.) atopy, BHR, ATT. • Health behaviours: smoking (inc. cannabis), diet, physical activity. • Living conditions: passive smoking (pregnancy, childhood, home, work), indoor/outdoor pollution, occupation; importance of simple questions like exposure to vapours, gas, fumes or living near to highways.	**Health Interview Survey** **Health Examination Survey** **Health Examination Survey**
Health systems: **prevention and treatment**	• Influenza and pnumococal vaccinations (patients & health personnel). • Smoking cessation (general population & patients). • Professionals: specialist (pneumologists, Physiotherapists), geographical distribution. • GPs, hospital admissions (length of stay & readmissions), prescriptions, long term oxygen therapy, non invasive ventilation, cpap rehabilitation, self-reported use of medication, nebulizers.	**Health Interview Survey** **Routine data**

2.3 Development of a new Work Plan

The new Work Plan proposal **(Annex I)** prepared by the coordinating centre was extensively discussed during the 1st IMCA meeting and the group agreed to develop the project in five steps.

2.3.1 Step 1: The initial matrix list of indicators.

The coordinating centre, based on the initial list of issues selected by the Asthma and COPD panels will prepare a matrix list of indicators in the same way of the one provided by the ECHI project including the indicator group, the operational definition and the availability and sources. The correspondence of this list with the one already proposed by the ECHI group should be established.

The coordinating centre will send the list to all participants for further comments, identification of possible gaps or new suggestions covering aspects not well covered during the meeting.

2.3.2 Step 2: An annotated list of indicators.

The coordinating centre will carry out a scientific literature review and produce a summary report of the relevant information to the indicators selected for each of the three major areas of classification: measures of disease frequency, risk factor and clinical management.

This review and summary should be useful for: a) better specification of the areas, b) justification of the indicator, c) scientific validity, d) data sources and e) validity. Based on this information and annotated list of indicators will be produced. The annotated list will be reviewed by the participants and a final document produced.

2.3.3 Step 3: Assessment of the consistency of the list of indicators at the international level.

This step should potentially contribute with additional indicators, improved information for some of the indicators already included, a wider perspective of the clinical needs of information from the ECHI perspective (user-window notion). The consistency should be assessed in routine data sources, international guidelines and research studies.

2.3.4 Step 4: Assessment of the consistency of the list of indicators at the national level.

All participants will check the consistency of the list of indicators at the national level. The consistency should be assessed like at international level in routine data sources, international guidelines and research studies. This review will be done after having it assessed at the international level. In order to make this process more efficient and standardized a checklist will be produced from the experience of the assessment at the international level.

2.3.5 Step 5: Final selection and prioritisation of the list of indicators.

The discussion on the methods to be used for the final selection of the indicators will take place during the 1st Steering Committee meeting. During the 1st IMCA meeting it was considered important to have some feed back form other groups and DG-SANCO.

3. OPERATIONAL DEVELOPMENT OF THE NEW WORK PLAN

3.1 Role of the Coordinating centre.

The study co-ordinating centre is 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 a web site with intranet have been set up at the following address: **www.imca.imim.es.** By the second week of February, the coordinating centre will distribute the individual passwords to all participants.

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, has identified projects with common links and after the 1st IMCA General meeting will establish appropriate ways of communication and collaboration with project leaders. 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 through representatives involved in the project.

The framework for the organization and management of the project can be seen in the Annex I, page 9).

3.2 Tasks of the coordinating centre.

- Based on the initial list of issues selected by the Asthma and COPD panels will prepare a matrix list of indicators in the same way of the one provided by the ECHI project.
- Send the list to all participants for further comments, identification of possible gaps or new suggestions covering aspects not well covered during the first meeting.
- Add possible new indicators suggested by participants.
- Check consistency of all indicators with all possible routine databases, international guidelines and research studies at international level.
- Prepare a first report for the 1st Steering Committee meeting in Barcelona.
- Update the list of indicators according to suggestions from the SC and participants.
- Taking into account all comments from participants after the exercise of checking consistency of all indicators at national level with routine databases, national guidelines and national research studies prepare a final list of indicators.

- According to the methods decided by the SC and participants the coordinating centre will prepare the process to decide priorities for indicators selection.
- Prepare the first draft of one or two scientific publications.
- Prepare the final report.

3.3 Tasks of the participants.

- To participate in the meetings organised by the coordinating centre according to established plans (Steering Committee or General meetings).
- Making suggestions for new indicators or improvements of those selected in the initial list.
- Check consistency of all indicators with all possible routine databases, international guidelines and research studies at national level after the task carried out by the coordinating centre at international level.
- Actively contribute with comments and suggestions to the scientific publications and final report.
- Participate in the process that will be established for the final selection of the indicators.

3.4 Meeting of the Steering Committee.

During the 1st General IMCA meeting it was agreed that a Steering Committee meeting would be organized once the work described in steps 1 and 2 had been prepared by the coordinating centre. Ideally the meeting should take place by the end of April.

3.5 Consultation to the ERS and EACCI.

In order to get a formal input from ERS and EACII, it was proposed to ask both societies the designation of a number of reviewers for the draft of the final report.

3.6 Final Timetable for the Work Plan agreed in 1st IMCA meeting in Barcelona.

A revised work plan timetable for the activities required to achieve all aims established in the project protocol and agreed during the 1st IMCA meeting is describe in the next page.

REVISED WORK PLAN TIMETABLE

YEAR 2003

Month 11	• 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	• 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	• **1ST IMCA General Meeting in Barcelona.** • **Step 1:** The initial list of indicators containing information on risk factors, measures of prevalence and areas of clinical management.
Month 2-4	• **Step 2:** An annotated list of indicators. • **Step 3:** assessment of the consistency of the list of indicators at the international level. • **1st IMCA Steering Committee Meeting.**
Month 5-9	• **Step 4:** Assessment of the consistency of the list of indicators at the national level. • **Step 5:** Final selection and prioritization of the list of indicators.
Month 09-10	• **2nd IMCA General Meeting in Barcelona.** • Project results dissemination. • Final report writing up.

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