IMCA

Indicators for Monitoring COPD and Asthma in the EU

Minutes of the 1st IMCA General Meeting

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Present:

Josep Mª Antó (co-chair), Enric Duran (co-chair), Hanns Moshammer (Austria), Paul A Vermeire (Belgium), Pekka Jousilahti (Finland), Denis Charpin (France), Mina Gaga (Greece), Deborah Jarvis (United Kingdom), Romain Nati (Luxembourg), Henriette A. Smit (Netherlands), Mario Morais (Portugal), Per S. Bakke (Norway), Nikolai Khaltaev (WHO, Geneva) and Giovanni Viegi (ERS- Italy).

Appologies:

Christer Janson (Sweden), Stephan Weiland (Germany), Francesco Forastiere (Italy), Charlotte Supply Ulrik (Denmark), Luke Clancy (Ireland), Antoni Montserrat (DG-SANCO) and Frédéric Sicard (DG-SANCO).

Introduction and welcome.

Professor Josep Mª Antó welcomed all participants and acknowledged the valuable co-operation and support to the IMCA project of all participants and initiated the meeting with a self-introduction of all participants.

The context of the IMCA project: the health monitoring initiatives at the DG-SANCO.

Enric Duran explained to all participants that Frédéric Sicard and Antoni Montserrat could not attend the meeting to explain all new developments at DG-SANCO relevant to the IMCA participants. He also explained that the project was funded under the Health Monitoring Programme (HMP), which ended in 2002 when a New Public Health Programme was set up. To clearly inform all participants about the context of the IMCA project within DG-SANCO and also in relation to other previous HMP projects two documents were distributed. First, the "Community action in the field of public health (2003-2008), Work Plan 2003" was used to provide an overview of the general aims, policy context and priority areas of the New Public Health Programme for 2003 but stressing that this is a five years programme in which the IMCA project is expected to contribute in the field of respiratory diseases.

It was explained that the main areas of health information as defined in the ECHI project have been organized in working parties (WP) and the IMCA project has been included in the Morbidity and Mortality Working Party (MMWP). The document "Draft mandate Morbidity and Mortality Working Party" was distributed and the purpose, the dimensions of morbidity and mortality to deal with, the duration of the members, the organization and the tasks of the MMWP were presented and discussed.

Since the MMWP is expected to contribute to the development of a precisely defined indicators list via the European Community Health Indicators (ECHI-1 and ECHI-2), several questions were raised. What was the role of ECHI project? All indicators were already defined? Which was the contribution expected from the IMCA project?.

To answer all these questions the final report of the ECHI was distributed and Enric Duran explained the development of the ECHI project over the past years, the main areas of information established and the gaps of information still existing in which the IMCA project may contribute specially in the indicators precise definition, tools and measurements of data collection.

Participants acknowledged the value of the ECHI project but several participants were concerned about the limitations of the indicators included in the ECHI project to cover all relevant aspects of respiratory diseases. Enric Duran suggested that the project should contribute to the ECHI indicators but at the same time propose all indicators that the group agrees on its importance for a public health strategy in respiratory diseases. However all these issues will be further clarified with a more close involvement of DG-SANCO in the project in the near future.

The IMCA new work plan: description and discussion.

The coordinating center, in order to overcome the delays experienced by the project and reach a successful end of the project reaching the aims expected in the initial proposal, developed a new work plan proposal according to the

new deadlines agreed with DG-SANCO. The proposal was explained to all participants with special focus on clarifying possible misunderstandings on the project aims and tasks described.

Several questions were raised with regard to the tasks and timing related to all objectives. For instance, what information we need to collect on mortality and hospital discharges? What we should understand by large research studies? Why not to include more than those described? Is it useful to identify clinical guidelines? How many and at which level? Why to decide priorities for the indicators? To answer all these questions and clarify the tasks and final timetable, it was agreed to clarify them when discussing objective by objective and agree a final timetable in the last session.

The organization framework was presented and discussed. Participants agreed that the Steering Committee (SC) would be integrated by: Enric Duran (Spain), Josep Mª Antó (Spain), Christer Janson (Sweden), Deborah Jarvis (UK), Stephan Weiland (Germany), Francesco Forastiere (Italy) and Giovanni Viegi (Italy) in representation of the European Respiratory Society (ERS).

It was considered important to establish formal links between the IMCA project and international organizations and scientific societies. From the World Health Organization Nikolai Khaltaev is already participating in the project. In relation to the OECD, Enric informed that Gaetan Lafortune will be very happy to have the final report but he does not have the time to actively participate in the project. In relation to Eurostat contacts have been established with Pierre Didier.

With regard to international scientific societies, Giovanni Viegi is already participating in the project and representing the European Respiratory Society. It was agreed that Mario Morais Almeida or Denis Charpin, since they are members of the EAACI they would establish the links with the society.

It was also considered important to establish formal contact with project leaders of other DG-SANCO projects participating in the MMWP and others from other WP which may be relevant to the IMCA project.

In this occasion, Frédéric Sicard and Antoni Montserrat were not able to participate in the meeting. Participants felt that in the future arrangements should be made to make sure their participation and involvement with the project.

Objective 1 and 2: routine, research data sources and international databases: what information on asthma and COPD is available?

The information available and how it is presented in the international databases such as WHO, OECD, and Eurostat was presented by Enric Duran. The group agreed that immediate improvements could be suggested for these databases: 1) mortality indicators should separate asthma and COPD, 2) rates should be presented by age specific death rates and in 10 years age groups, 3) should be able to separate "young" death from those more than 45. It was agreed the these recommendations should be reported to the Eurostat Mortality Task Force, to the WHO, OECD and to the ECHI project for a better definition of these indicators.

Deborah Jarvis stressed the need to know the effects of changes in the new rules of coding death certificates on future trends. It was agreed to ask Mary Hennue about any initiative in this field.

The definitions of respiratory diseases on health interview and examination surveys was explored from the HIS/HES database by the coordinating center. There was high variability on the definitions making impossible to carry out comparisons between countries. The only risk factor available was smoking and information was collected in many different ways.

Henriette Smit suggested that although some database may be very specific for one country, not only mortality and hospital discharges should be reported. Routine data collected by general practitioners should be considered as a relevant target for future information systems. Its importance will increase with increasing computerization of diagnostic and treatment data as well as because its importance in terms of burden of morbidity at the population level.

In some countries large population based treatment databases for reimbursement or administrative purposes have been proven useful for the epidemiological investigation of respiratory diseases and its role as routine data sources need more attention.

Regarding the hospital admissions, despite its large availability more information is needed to assess its contribution (its justification) in the routine data systems.

Regarding to the existing routine data sources the following issues were raised:

- The need of narrower age stratification (10 years groups).
- The need to separate asthma and COPD.
- The need to include multiple causes of death.
- The assessment of its validity and quality (the coordinating centre was asked to review recent papers on validity of death certificates for respirator diseases.
- The difficulties in its interpretation due to the influences of patterns of care and health structures. Trends within countries may be more easy to get but international comparisons my lack validity.

Its was clear to most of participants that taking into account the prospects for health examination surveys in Europe the experience gathered by large international surveys of asthma, ICSAAC and ECRHS is extremely important and useful.

In addition, it was pointed out by several participants that other research studies at the national levels are as well important, This could be specially the case for COPD and for elderly population.

Giovanni Viegi contributed with an initial list of research studies that should be considered as potentially useful and the coordinating centre was in charge of completing and circulating this list. He also distributed the ERS White Book

and the ERR Supplement with the outcomes of the BIOMED1 Concerted Action on COPD.

Which criteria should we use in the process of selecting indicators for its classification?

Enric Duran presented a review of the ECHI and other HMP projects criteria and prerequisites for classifying indicators. The group decided to take the criteria proposed by the ECHI project (9-10) for the development of an initial wide and comprehensive list of indicators on respiratory disease.

These criteria were mainly: selection guided by scientific principles, selection should be based on quality including validity and type of indicators should be guided by flexibility in terms of large variety of potential users. However, it was also stressed that indicators suggested should not only be based on available data sources or technologies but also considering the future trends in research and the need of developing new tools.

The group recognized that was important to provide input to the indicators of different categories of the ECHI project but we should have freedom to select the relevant indicators independently of categories.

Objective 3: Which indicators of risk factors, disease frequency and clinical management should be selected? Asthma and COPD panels: group discussion.

To select the first list of indicators two different panels were set up:

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

COPD panel : 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 on risk factors, measures of disease frequency and clinical management to be discussed in a plenary session.

Objective 3 continuation: Defining the initial list of indicators for monitoring COPD and asthma.

The asthma and COPD panels in a plenary session agreed the first list of relevant indicators to monitor asthma and COPD. To see the full list, please see the interim report (pages 3-4). The list needs to be further specified and reviewed according to the most updated scientific evidence.

Objective 4: I) Identification and comparison of national clinical guidelines: ii) Description of health care delivery for asthma and COPD: what we know from each country?

The participants discussed the proposal made by Enric Duran in the working plan. It was agreed that the guidelines are relevant for the purposes of the project because they may identify important needs of indicators as well as to provide valuable information for the definition of both asthma and COPD, grading of severity as well as other several purposes.

In contrast it was considered that taking into account the large number of guidelines developed at national level and its large variability mainly addressing different clinical patterns and traditions it would of little value to undertake a comparison and synthesis of the information contained in these guidelines.

Taking into account the previous points it was agreed that after having an initial list of indicators as agreed by the group it would worth to assess its consistency with the clinical guidelines first international levels (by the coordinating centre) and second at the national levels by the participants. It was agreed that based on the assessment at the international levels a checklist should be prepared to standardise the review of the national guidelines.

Objective 5: Deciding priorities for a set of indicators: which criteria should be used?

The discussion of this objective was postpone for a later stage when the precise list of indicators and we could get some feed back form other groups and DG-SANCO.

The European Health Survey System: what should be the IMCA project contribution?

The document "Building a European Health survey system: Improving information on self-perceived morbidity and chronic conditions" was distributed. All participants welcomed the initiative but some concerns about the methods and implemenntation process were expressed. Participants stressed that special expertise is required in HES and expressed that the IMCA project should contribute to this development as soon as possible.

Other issues related to the organization and project administration.

Some participants expressed their concern with regard to the co-funding of the project by GlaxoSmithKline (GSK) to cover the 30% not covered by DG-SANCO. It was explained that GSK will not have any influence on the project results and a conflict of interest is very unlikely. Also, although by a contract two payments were established, the second payment was cancelled by GSK. So its influence is very limited. The only think that GSK requires is the acknowledgement that GSK has co-funded this project in all documents.

Some participants asked if the payments received through the sub-contracts were considered allowance costs. It was agreed that Enric Duran would clarify this.

A sub-contract model was send to all participants in order to be to check all details with their administration. At present contracts have been completed and signed by both parts with Manfred Neuberger, Pekka Jousilhati, Denis Charpin, Stephan Weiland, Mina Gaga, Francesco Forastiere, Henriette Smit and Giovanni Viegi. Some sub-contracts have been signed by the Fundació IMIM but we are still expecting the signature of the corresponding

administration for the following participants: Paul A Vermeire Charlotte Supply Ulrik, Mario Morais, Christer Janson, Deborah Jarvis, and Per Bakke.

What will happen in the forthcoming 12 months?

The group discussed the tasks to be done and the importance of fitting the close deadlines for the delivery of the final report. The following sequential work plan was agreed:

Step 1: The initial matrix list of indicators.

Step 2: An annotated list of indicators.

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

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.

Please, for further details see the interim report (pages 8-9).

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 center. Once the final steps are completed a 2nd plenary meeting will be organized.