



**ICC Meeting Minutes
Thursday June 3, 2010
12:00pm to 1:00pm
COPD Evidence-Based Resource Center Project**

Participants:

Larry Grouse, Youssef Mohammad, Dmitry Nonikov, Steve Prete, Laura Brockwell, Keith Allan, Novartis, Judy Robertson, Novartis, Derrick Geick, Boehringer Ingelheim, Yvonne Leonard, Nonin

Introductions:

- The group introduced themselves to each other.
- Dr. Grouse gave an overview of the meeting agenda and asked for feedback throughout the meeting.
- Dr. Grouse reviewed the overall concept for the Resource Center Project and asked for feedback on the circulated description of the project and the time and event schedule.
- Dr. Grouse indicated that in addition to the partners participating in today's meeting, GlaxoSmithKline, Almirall, and other GOLD and ICC sponsors will be reviewing this project for possible participation.

Initial Response on Project Description:

Mr. Geick indicated that there are several parts to this project: consolidation of existing databases, identifying other relevant medical and health economic data, and identifying the need for doing more economic research to obtain needed information. This discovery/research phase of the project needs to decide if more robust cases around indirect and direct costs of COPD are needed and share this with the stakeholders. For instance Novartis' "COPD Uncovered" has useful information, but further research may be needed.

Dr. Mohammad suggested that we need to also look at behavioural research. For instance, why are COPD patients not taking medications so that compliance and therapeutic benefits can be increased. Each country and member organization will need to help us with this research in their regions to understand the behavioural phenomena since there are major differences between countries and regions.

Mr. Allan agreed with the content portion and development, but felt it was important to acknowledge and recognize how we will use this Resource Center tool. He pointed out that statistics at a scientific session suggested that COPD prevalence will double over the next decade, so this project must respond to such an urgent and emerging health care problem with the Resource Center needs to be tailored to be an advocacy tool. ICC needs to focus on how the stakeholders will get the information that will be convincing for health ministries, regulatory organizations, and other health care policy decision makers, not just to convince academia. Taxpayers will need to understand and support key medical decisions as well. The project needs to be issue driven. What issues are we trying to tackle? Perhaps we need a detailed survey of all stakeholders in COPD and advice from an expert panel on the hot topics in different parts of the world.

Dr. Mohammad indicated that the EU is currently funding economic and behavioural research that could be included and is relevant to the COPD Patients' rights to diagnosis, therapy, and care.

Mr. Allan emphasized that COPD will have a huge economic impact for governments across the world and that an issue-oriented Resource Center could have the beneficial effect of guiding governments as they cope with the economic impact.

Dr. Grouse acknowledged the points that were made and indicated that he would liaise with key groups that would collaborate in the project and contribute to the database and identify the key, hot topics and issues that need to be focused on immediately. Since ICC will be taking the lead on the development and using their funding and resources to achieve the timelines proposed, he indicated that he would report back on the commitments from the stakeholders and would prepare an ICC proposal for sponsorship as a follow-up of this meeting.

Mr. Allan indicated that we need to structure access to this information easily and on an issue-oriented basis so that a wide audience of stakeholders will find it useful.

Dr. Mohammad said that patients very much need stakeholders to be talking for them. This project would help with popular impact and widespread information through media.

Ms. Leonard suggested that we need to think about a range of countries and issues as well as a continuum of needs for different stakeholders. There will be unique challenges for each country and region with the Bill of Rights and hopefully the ICC survey will reveal what they are. We should ask patients about their hot topics and figure out what stages countries and regions fall into for the Bill of Rights because this will inform the Resource Center's approach.

Dr. Grouse indicated that we have had about 28 responses for the ICC Survey so far from all over the world including the BRICS countries as well as developed and developing countries. The surveys will outline the needs of different regions and a committee of ICC and the stakeholders will be chosen to teleconference and meet to prioritize the issues to research and present in the Resource Center.

Mr. Allan emphasized that the Resource Center has to be a useful and actionable tool.

Review of Mind Map:

- Dr. Nonikov reviewed the circulated "Mind Map" for the Resource Center Project in detail and asked for feedback.

Feedback to the "Mind Map":

Dr. Mohammad suggested that we can reach all the different regions and local people and their challenges and needs through GARD.

Dr. Grouse felt that having this information available, focusing on the hot topics, and taking the data forward rapidly to be useful soon to stakeholders will be important. Active issues like advocacy for access to treatment and focusing on the biggest patient complaints will be important.

Mr. Allan said that we must be sure that the Resource Center is issue-driven, that it will predict and prepare for the likely issues and structure the resources around those topics. He agreed that we also need to make sure that regulatory agencies would be a target audience.

Mr. Geick indicated that there are a lot of different stakeholders and strategies relating to different chronic respiratory diseases and we need to figure out what is most effective for COPD. We need governments and policy makers to form strategies to manage COPD as they are currently doing for cancer and diabetes, food labelling for dietary and public awareness, etc. These things are missing for COPD. This Resource Center could be accessed by advocates and by coalitions, but we need to remember that at a local level, in one given country, they may have different issues. Stakeholders need to be able to access this Resource center and be able to say "how can I use this data in my country from

a cost and care perspective?” We should also be careful of the scope of this project in the end. Tactical execution and lobbying should be a second level, but we need to develop this library of resources in able to be able to do this. One other point is that it would be good if we could identify gaps in data identification. We should do this early from the list of resources we put together so that these gaps may be addressed.

Dr. Grouse reviewed WHO's activities in NCDs to confirm what Mr. Geick had said. There is no reason why we can't proceed in developing the database along the lines of what has been discussed so long as we make sure that it is open and responsive to stakeholders. He reviewed his plan to develop with Dr. Nonikov and others a proposal and budget and to schedule talks with all stakeholders and assess their commitment levels, although ICC can't make progress on the Center dependent on the consent of each collaborator. He proposed further discussions with GOLD and suggested that a press release and background on the Resource Center could be made a part of World COPD Day 2010.

Mr. Allan said that the key to the plan is in the dialogue with the experts to get a feel of the burning issues and then get together a list of 3 to 5 hot topics from the leaders, keeping in mind that this is will be a political minefield to navigate.

Dr. Grouse indicated that we have worked with these leaders for many years and have good relationships with them, so we are likely to get a good operational coalition organized, and having this Resource Center be the mandate of all the world's COPD patients is the most credible format for the effort.

Dr. Mohammad suggested that we prioritize the Bill of Rights, from short-term to long-term issues to deal with various gaps in knowledge and gaps in practice.

Dr. Nonikov summarized. This was a very fruitful discussion on WHY and WHAT this project will be and was helpful to summarize where we should focus our planning. We need to focus carefully on selected topics and focus on gap analysis. We should come up with suggestions on where research is needed. It would be helpful to make a name list for each country on who is the contact dealing with the Resource Center and what their country or region is doing. The key will be to put together arguments to support advocacy.

Dr. Grouse said that Professor Zhong and Professor Chen, the ICC leaders from China (and Prof. Zhong as ICC Co-Chair with Dr. Mohammad) would like to have this new Resource Center as a highlighted part of the Second World Conference of COPD patients in Shanghai, China in November 2011. EFA has also been very supportive as Dr. Fink-Wagner had indicated to Dr. Mohammad, as well as APSR and the Australian Lung Foundation. He will contact the various groups and continue to provide feedback.

Dr. Mohammad suggested that we should incorporate both public and private partnerships in the Resource Center.

Mr. Allan and Ms. Robertson summarized the following points:
The Resource Center should be a proactive tool for advocacy, it should be predominantly issue driven; it should navigate through all the stakeholders; if we have agreement on proceeding then a follow-up meeting should be held at ERS in the planned ICC meeting.

Dr. Grouse closed the meeting by offering to send follow-up details, a proposal, and to provide information on the next meeting time and place during ERS to all the attendees and to the sponsors who participated at the ICC meeting and wish to be updated.