COPCORD POLICY BUSINESS MEETING:

14 JULY 2010, APLAR CONGRESS HONG KONG-

Agenda and Discussion Summary

The following delegates attended the meeting- RD Wigley (New Zealand), F Davatchi (Iran), Atiqul Haq (Bangladesh), Arvind Chopra (Indai), Nazrul Islam (Bangladesh), Ashish Mathews (India), Bhaskar Thakuria (India), Romi Singh (India), Asma (India), Deepak Songoji (India), Soosan Soroosh (Iran), Monica (Lebanon), Zeinab (Lebanon), Peter Brooks (Australia), Anthony Woolf (UK), D Hoi (Australia). Prof Davatchi and Dr A Chopra chaired the meeting.

1)Prof A Haq, APLAR Coordinator, welcomed the delegates and briefly reviewed the progress. OA knee risk questionnaire had been tested in pilot studies in Iran and Bangladesh and the results are to be published in Int J Rheumatology. A similar risk assessment questionnaire is being prepared for low back ache. An updated COPCORD Core Questionnaire have been validated in several recent Phase 1 population surveys in India and Guatemala. ILAR has sanctioned a project to set up a COPCORD website and database. Prof Davatchi has been nominated the new APLAR COPCORD coordinator in place of Prof Haq. Dr A Chopra continues to be the WHO ILAR COPCORD coordinator. Prof Haq stressed the need to follow COPCORD survey with follow up study wherein besides risk factor assessment, public health program to educate people and carry out preventive and control strategy could be undertaken. There was a need to validate outcome assessment questionnaires like HAQ, WOMAC, WHO QOL in regional languages. Dr Chopra added that HAQ and WOMAC had already been validated in several Indian languages, and that an Indian Version of HAQ has been used in over 12 COPCORD survey sites in India.

2) Dr Chopra introduced the COPCORD website and data base project which would be funded by ILAR, BJD India and ARCF-CRD (Pune, India). The World standard website is being launched at CRD (Center for Rheumatic Diseases), Pune. Mr Deepak Songoji, a soft ware programmer and consultant from CRD Pune India made a presentation on the proposed outline of the website, and explained the various interactive features. Mr Songoji showed how each World site would be shown and will be linked with its publications, photos and any other events. There will be a global link of all the sites. Each survey site will select the extent of data to be posted, and if required this will be protected for privacy, intellectual property and ownership rights etc . The website manager will work closely with all the survey site investigators (one per site). In time, the website will be used for data entry and stat analysis, and will link with other similar sites. Dr Chopra summed by stating that this will be a one stop hub for all information connected with COPCORD, and appealed to all delegates for support and active participation and hoped that the site would be launched in the last quarter of the year.

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Several delegates appreciated the project and acknowledged its need. Prof Davatchi (Iran) suggested that important domains of the proposed website be sent to each of the COPCORD investigators for review and comments, especially with reference to questionnaires. Prof Monica (Lebanon) suggested a multilingual ability of the website so that questionnaires in different languages can be posted.

3)Dr D Hoy presented an overview of the ongoing global disease burden program with reference to MSK, and distributed a questionnaire being used to collect data on common conditions. He stated that COPCORD data could be used for several painful disorders like back ache and neck pain. Several members discussed the need to include 'ill defined aches and pains' and 'soft tissue rheumatism' in the classification system which have been the predominant ailments in all COPCORD survey sites. Prof Woolf described the new ICD system that has been developed and emphasized inclusion of all these not so well defined MSK painful disorders, and that COPCORD data could look at the new system. Dr Chopra and DR Nazrul discussed in length the need to capture the clinical profile of pain as described by the patient which often is difficult using any ICD or currently advocated classification systems. Dr Chopra stated that COPCORD India has used a user friendly classification system that was developed based on the findings of the COPCORD Bhigwan, and that he would send this to all members. Prof Davatchi advised Dr Hoy to communicate with COPCORD members on the GDB.

4) Dr Wigley stressed the need for socio economic evaluation of COPCORD survey and programs. It would be useful to know how much the community benefits from COPCORD. He referred to the COPCORD Bhigwan (India) program which was in its 14th year and had continued with health education and free of cost community treatment advise. Dr Wigley stated that he will be submitting a research proposal on this subject to ILAR, and that a meeting on the same is being planned in Pune, India in the near future. Dr Chopra stated that the meeting is likely to be in early Sept and that the focus is on the several COPCORD surveys completed by BJD India in recent years and that members were welcome to attend.Prof Davatchi described the difficulties in following a COPCOR survey and evaluating the results, mainly because of non-validated COPCORD questionnaires. Prof HAQ, Dr Chopra and several members emphasized the need for a new strategy that can be used in COPCORD. Dr Wigley stated that this is what could be discussed with health economists in the Pune meeting.

5)Prof Haq summed up the agenda items that were to be followed from the above discussion. Prof Davatchi concluded the session by appealing to all COPCORD members to interact regularly especially with the new website being launched in near future. He said "talk, talk and talk' with each other so that all can make good progress and fulfill the community expectations from COPCORD.

The meeting concluded with members thanking the chair and the organizers of APLAR 2010.