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1. From the WHO Registry Platform

Welcome to the second issue of the WHO Registry Platform *e-Note*.

In this *e-Note* we share with you the latest achievements made since our last issue.

The next WHO Registry Platform *e-Note* is scheduled for circulation on Friday, 27th April 2007.

We hope that you find the information provided in each *e-Note* to be useful.

Best wishes,

The Secretariat of the WHO Registry Platform

2. The WHO Search Portal

Over the last month, beta testing of the Search Portal continued using the small test datasets provided by 3 registers. Input has also been sought from the Scientific Advisory Group which has led to some refinements being made to the Search Portal site and some of the functionality.

The beta testing is now complete and we are now in the process of uploading the 20 item data sets for all trials provided by the 3 registers contributing to phase 1 of the Search Portal. These registers are the ACTR (Australia), ClinicalTrials.gov (United States of America) and ISRCTN (United Kingdom).

Phase 1 of the Search Portal will be launched on the 1st May 2007.

3. The WHO Network of Collaborating Clinical Trial Registers

The number of Collaborating Registers in The International Clinical Trials Registry Platform has now reached 16, of which 14 will eventually contribute data for inclusion in the Search Portal. The identity of these registers will be formally announced on the 1st May 2007.

4. Study Group on the Reporting of Findings of Clinical Trials

The WHO Registry Platform has established “*The Study Group on the Reporting of Findings of Clinical Trials*”. The Group will provide advice to the WHO Registry Platform Secretariat, Scientific Advisory Group (SAG) and International Advisory Board (IAB) on matters related to the reporting of the findings of clinical trials. The initial priorities of the group are:

- To define the nature and scope of the problem
 - To describe what the "results" (i.e. the findings) of a clinical trial are (which may be broader than the statistical results of the trial)
 - To describe the ways in which a result can be reported
- To identify stakeholders (including target audiences) in the reporting of the results of clinical trials

The inaugural meeting of the group was held on 23rd March 2007.

5. Communication tool: LISTSERV

To ease the management of the Newsletter and *e-Note* lists, the Secretariat of the WHO Registry Platform has put in place a new communication tool called LISTSERV.

As from now on, if you want to keep on receiving this e-Note and the Newsletter of the WHO Registry Platform, please register yourself to the new distribution list using LISTSERV. The next issues of the Newsletter and *e-Note* will be sent using LISTSERV exclusively.

For you to remain registered with us, please send a mail to:

LISTSERV@who.int with the following command in the body of the message:

subscribe ictrpnews John Smith

(-- please replace “John Smith” by your own name).

You will received an automated message asking to confirm your subscription to the list. Please do confirm it. Some explanations on how to use the LISTSERV functions will be automatically shared with you.

Relevant news regarding the WHO Registry Platform activities will also be sent to all registered e-mail addresses using LISTSERV.

If any problem using this new communication tool, please send us a mail at: ictrpinfo@who.int.

6. Web Site Review

Work on revising the web site continues. The revamped site should be publicly available by the middle of April 2007.

7. Translation of *e-Note*

Anyone interested in translating *e-Note* issues (in full or partially) into other languages please contact the Secretariat for approval.

The *e-Note* is translated into Chinese.

8. Presentations & Events

Presentation:

Prof. Kay Dickersin, Co-Chair of the Scientific Advisory Group for the WHO Registry Platform, is going to give a presentation on behalf of the Secretariat at the following conference organized by the Center for Business Intelligence:

- 2nd Annual Clinical Trial Registries and Results Databases, Compliant Clinical Data Transparency and Disclosure Strategies to Enhance Public Perception and Increase Patient Participation. Washington, DC, The United States of America. April 30 - May 1, 2007

http://www.cbnet.com/show_conference.cfm?confCode=HB735&field=summary

Events:

Event: Studi Clinici di nuove terapie contro il cancro: una guida per I pazienti. Clinical

Trials: what cancer patients need to know.

Dates: April 20, 2007

Venue: Rome, Italy

Web: <http://www.aimac.it/download/studiclinici.pdf>

Event: CDISC Interchange
Dates: April 25-26, 2007
Venue: Montreux, Switzerland
Web: <http://www.cdisc.org/events/index.html>

Event: Society for Clinical Trials
Dates: May 20-23, 2007
Venue: Montreal, Canada
Web: <http://www.sctweb.org/meeting2.cfm>

9. Contact Us

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e-Note is scheduled for publication on the last Friday of the month. Suggestions and/or comments should be addressed to ictrpinfo@who.int with “e-Note” in the subject line.

Subscription via LISTSERV: Please send an e-mail to listserv@who.int with “subscribe ictrpnews first_name last_name” in the body of the message (without any “”). The subject line can be left blank.

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