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1. Information on WHO Registry Platform *e-Note*

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

e-Note is a monthly information notice (issued on the last Friday of the month) which is sent by email to individuals who have registered their interest in the activities of the WHO Registry Platform. The intention is to provide a concise summary of current and upcoming activities and events of relevance to the WHO Registry Platform and the world of trial registration.

You are receiving this *e-Note* because your email address has been registered on our mailing list. If you do not wish to receive future editions, please refer to the instructions at the end of this notice.

Please note that we are planning to establish a mailing list based on LISTSERV in the near future. Subscriptions to the Newsletter and *e-Notes* will become automated. We will give you more information on this in the issue no. 2 of the WHO Registry Platform *e-Note*, which is scheduled for circulation on Friday, 30th March 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 Model for the WHO Registry Platform

The International Clinical Trials Registry Platform (ICTRP) currently has 2 key elements: the WHO Network of Collaborating Clinical Trial Registers (the Register Network) and the Search Portal. The Register Network will provide a forum for the exchange of information across registers, and the Search Portal will provide a single point of access for the identification of trials.

The Search Portal will **not** be a clinical trials register. It will simply be a conduit via which trials can be identified. The Search Portal will be a web site that enables users to search a central database (the Central Repository). This Central Repository will contain the trial registration data sets provided by Contributing Registers and will exist for searching purposes only. When a search is conducted, and a trial identified, users will click on a hyperlink that will direct them to the relevant record in the source register from which the trial came.

3. WHO/WKC Meeting, Kobe, Japan

The Secretariat of the WHO Registry Platform and the WHO Kobe Center jointly held the 3rd meeting of the Scientific Advisory Group (SAG), and the 1st meeting Registers Working Group (RWG) in Kobe, Japan between 29 November and 1 December 2006. The Secretariat would like to acknowledge and sincerely thank the Ministry of Health, Labour and Welfare, Japan and the WHO Kobe Center for their respective contribution and support in the organization of the two meetings.

A. SAG Meeting

The 3rd SAG Meeting took place on 29th-30th November 2006. Those present reviewed the progress made during the previous year and then considered the year ahead. Time was spent on developing 1, 2 and 5 year goals for that would ultimately form the basis of a strategic plan for the project.

B. Registers Working Group

The first RWG Meeting took place on 1st December 2006. As this was the first meeting each participant introduced themselves and briefly discussed the key aspects of the register they represented. The first steps were taken towards developing guidelines for the practice of clinical trial registration. The topics discussed included the various models that exist for registering trials, the minimum a register should do to make sure a trial exists and that the person registering the trial exists, and how to handle trials submitted with incomplete information.



4. The Register Network

The purpose of the WHO Network of Collaborating Clinical Trial Registers (the Register Network) is to provide a forum for registers to exchange information and work together to establish best practice for clinical trial registration.

There are 2 types of Collaborating Register in the Register Network: those that contribute data to the Central Repository, and those that do not. Contributing Registers are identified as being either Primary or Partner Registers based on the route via which they contribute data to the Central Repository. Non-Contributing Registers do not submit data to the Central Repository, either directly or indirectly. This is in recognition of the fact that some registers may wish to be part of the Register Network, but do not meet one or more of the criteria for a Contributing Register.

The Secretariat of the WHO Registry Platform is in the process of sending out invitation letters for Registers to collaborate in the Register Network.

- At the time of writing this *e-Note*, ten registers have agreed to join the Register Network.

We encourage the administrators of clinical trials registers that register trials prospectively (-- that is, before the first participant is recruited) to contact us at: ictinfo@who.int. We are looking forward to counting you as a member of the WHO Register Network.

5. Search Portal: Pilot Testing

Data has been provided by a sample of Collaborating Registers so it can be uploaded to the Registry Platform database (Central Repository) for the purposes of the pilot testing phase. A beta Search Portal is under construction and is expected to become public in April 2007. The Search Portal will be searching the data received from the Contributing Registers in the Register Network and uploaded onto the Central Repository.

6. Web Site Review

The Project has now entered its implementation phase. We would like to keep visitors informed on the many ongoing activities implemented by the Registry Platform and to do so, the Web site of the WHO Registry Platform (www.who.int/ictpr) is currently under revision.



We are also working on how to ease navigation throughout the Web site. The new version of our Web Site should be online by the April 2007.

7. Presentations & Events

- Ghersi D. “European Form for Good Clinical Practice (EFGCP) Annual Conference 2007. Ethics Committees in Europe – How to Work with Diversity? Brussels, Belgium. 30-31 January 2007”. Panel member for forum discussion on "Conflicts of interest in clinical research: ethical responsibilities to publish".
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8. Contact Us

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