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**1. From the WHO Registry Platform**

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

First, our apologies for the slight delay in this *e-Note* which is being distributed on the eve of the launch of the Search Portal and Register Network.

The next WHO Registry Platform *e-Note* is scheduled for circulation on Friday, 25<sup>th</sup> May 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

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**2. The WHO Network of Collaborating Clinical Trial Registers**

The Collaborating Registers in the WHO Register Network will be announced on 4<sup>th</sup> May 2007.

The first 3 **Primary Registers** in the WHO Register Network are:

- Australian and New Zealand Clinical Trials Registry (ACTR)
- ClinicalTrials.gov
- International Standard Randomised Controlled Trial Number Register (ISRCTN )

**Partner Registers** are:

- ArQule, Inc (partnered with ClinicalTrials.gov)
- Dutch Trial Register (partnered with ISRCTN)
- Eli Lilly (partnered with ClinicalTrials.gov)
- Mitsubishi Pharma Corporation (partnered with ClinicalTrials.gov)
- Physician Data Query (partnered with ClinicalTrials.gov)

### **Other Collaborating Registers in the Register Network**

The following registers do not currently contribute data to the WHO Search Portal. The Registry Platform Secretariat is in the process of ascertaining whether or not each register meets the requirements necessary to be a Contributing Register.

- Centre for Clinical Trials, Chinese University of Hong Kong
- Chinese Clinical Trial Register (ChiCTR)
- Clinical Trial Database of the University Hospital Freiburg
- German Somatic Gene Transfer Clinical Trial Database
- HIV/AIDS, Tuberculosis and Malaria Clinical Trials Registry (ATM Registry)
- Latin American Clinical Trials Register (LatinRec)
- Clinical Trials Registry - India (in development: not yet open to registrants)
- National Swedish Competence Centre for Musculoskeletal Disorders (in development: not yet open to trial registrants)
- South African National Clinical Trial Register (SANCTR)
- University Hospital Medical Information Network (UMIN)

The South African Cochrane Centre (ATM Registry) will be officially launched on 22<sup>nd</sup> May 2007. For more information, please consult the Web site of the South African Cochrane Centre at: <http://www.mrc.ac.za/cochrane/cochrane.htm>

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### **3. The WHO Search Portal**

The WHO Search Portal will be launched on **4th May 2007** at the following Internet address:

<http://www.who.int/trialsearch>

The WHO Search Portal provides users with access to the Trial Registration Data Sets provided by the first three Primary Registers in the WHO Register Network (ACTR, ClinicalTrials.gov and ISRCTN). It is expected that other contributing registers will join in the future.

Those interested in reading the press release for the launch can do so by visiting the WHO web site on 4<sup>th</sup> May. <http://www.who.int/>

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### **4. Register Working Group**

Ms Lakshmi M. Grama, Branch Chief at the International Cancer Research Databank of the National Cancer Institute, National Institutes of Health has kindly agreed to chair the Register Working Group.

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### **5. Study Group on the Reporting of Findings of Clinical Trials**

*“The Study Group on the Reporting of Findings of Clinical Trials”* hold its second meeting on Thursday, 26<sup>th</sup> April 2007.

The work of the Study Group now focuses on the establishment of a matrix for the reporting of clinical trials findings. Examples are taken from the CONSORT and ICH-E3 matrix.

The first step is to work on the design of the matrix and then develop its content. Focusing on the design will add to the fluidity of the reported clinical trials.

The Study Group also came to an agreement regarding the WHO Registry Platform's Policy position, which is:

- **“That the findings of all clinical trials must be made publicly available.”**

Work on the identification of stakeholders (including target audiences) in the reporting of the results of clinical trials is still ongoing.

The next meeting of the Study Group will take place in the first half of June 2007 and the main discussion topic will be around the establishment of a reporting matrix for the reporting of findings of clinical trials.

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## **6. Web Site Review**

The Registry Platform web site has been updated (<http://www.who.int/ictrp/>). We hope the site is now easier to navigate. Suggestions for additional improvements are welcome.

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## **7. 60<sup>th</sup> World Health Assembly**

The 60<sup>th</sup> World Health Assembly will take place on 14-23 May 2007 in Geneva, Switzerland.

The achievements of the WHO Registry Platform will be presented in a dedicated stand located in the main hall at the United Nations' *Palais des Nations*, so that delegates will have the opportunity to collect information on the Project.

The WHO Search Portal will also be introduced.

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## **8. Presentations & Events**

### **Presentations:**

- Dr Tikki Pang, Director at the Department of Research Policy and Cooperation, WHO, presented WHO's Perspective at Clinical Trials: What Cancer Patients Need to Know held in Rome, Italy on 20<sup>th</sup> April 2007
- Dr Davina Ghersi, ICTRP Coordinator, updated the ICMJE on the status of the Register Network and Search Portal at their annual meeting held in Sydney, Australia on 13<sup>th</sup> April 2007

- Dr Tikki Pang, Director at the Department of Research Policy and Cooperation, WHO. Keynote presentation, CDISC Interchange: 4<sup>th</sup> European Interchange, 23<sup>rd</sup>-27<sup>th</sup> April 2007, Montreux, Switzerland
- Dr Davina Gheri, ICTRP Coordinator. Panel member: European Research and Standards: Statements & Roundtable, CDISC Interchange: 4<sup>th</sup> European Interchange, 23<sup>rd</sup>-27<sup>th</sup> April 2007, Montreux, Switzerland
- Prof. Kay Dickersin, Co-Chair of the Scientific Advisory Group for the WHO Registry Platform. 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

### **Upcoming Events:**

**Event:** Society for Clinical Trials.

Invited session: Global Clinical Trials Registration: Where we are and where we are heading

Chair/Discussant:

- Kay Dickersin, Johns Hopkins Bloomberg School of Public Health

Speakers:

- Davina Gheri, World Health Organization
- Karmela Krleza-Jeric, Canadian Institutes of Health Research
- Bill Vaughan, Consumers Union
- Ambujam Nair Kapoor, Indian Council of Medical Research & WHO Network of Collaborating Clinical Trial Registers

**Dates:** May 20-23, 2007

**Venue:** Montreal, Canada

**Web:** <http://www.sctweb.org/meeting2.cfm>

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## **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](mailto:ictrpinfo@who.int) with “e-Note” in the subject line.

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