More than 100,000 trials

On International Clinical Trials Day 2010 there were 110,899 records on the ICTRP Search Portal for an estimated 108,702 registered trials (after bridging).

Figure 1: Records on the ICTRP Search Portal by WHO region

Table 1: Data provision

<table>
<thead>
<tr>
<th>Data Provider</th>
<th>Number of records</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANZCTR</td>
<td>4074</td>
</tr>
<tr>
<td>NCT</td>
<td>89686</td>
</tr>
<tr>
<td>ISRCTN</td>
<td>8682</td>
</tr>
<tr>
<td>ChiCTR</td>
<td>839</td>
</tr>
<tr>
<td>CTRI</td>
<td>942</td>
</tr>
<tr>
<td>DRKS</td>
<td>221</td>
</tr>
<tr>
<td>IRCT</td>
<td>344</td>
</tr>
<tr>
<td>JPRN</td>
<td>3893</td>
</tr>
<tr>
<td>NTR</td>
<td>2173</td>
</tr>
<tr>
<td>SLCTR</td>
<td>45</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>110,899</strong></td>
</tr>
</tbody>
</table>

Of the 110,899 records:
- Country information is not available for 9493 records.
- 48% of all records (53,522) are for trials recruiting in the AMRO region (Figure 1).
- Countries in the AFRO and EMRO regions are involved in less that 2% of all registered trial records, and in the SEARO region in less than 3%.
The ICTRP launched its search portal in May 2007, and on International Clinical Trials Day that year there were 62 sessions and 257 hits. On the same day in 2009 this had risen to 244 visitors and 4,648 hits. On 20th May 2010 there were 1033 visitors to the ICTRP Search Portal with 14,565 hits - a 200% increase in the space of a year.

The desire of individuals to learn more about clinical trial registration continues, particularly in countries where English is not the first language. So far this year, 25% of the almost 30,000 visitors to the main ICTRP web page were accessing information in languages other than English. That is, the pages in Arabic, Chinese, French, Russian and Spanish.

**News**

**Search the ICTRP from your phone**

Have you always wanted to search the ICTRP Search Portal from your mobile phone? Well now you can! Go to [http://apps.who.int/trialsearch/ictrpmob.aspx](http://apps.who.int/trialsearch/ictrpmob.aspx)

The link can be opened from any smartphone with an internet connection and works best on Nokia, iPhone and Google phones.

**Evidence of registration a reporting standard: the CONSORT Statement**

"Authors should provide the name of the register and the trial’s unique registration number. If authors had not registered their trial they should explicitly state this and give the reason."

For more go to [http://www.consort-statement.org/](http://www.consort-statement.org/) or [http://www.bmj.com/cgi/reprint/340/mar23_1/c869](http://www.bmj.com/cgi/reprint/340/mar23_1/c869)

**Upgrading the ICTRP Search Portal database**

Over the coming months, the database driving the Search Portal will be updated. This should improve search response time and other aspects of the portal. During the upgrade process, it may be necessary for the Search Portal to have some downtime. If this should occur, a note will be put on the site to inform users.

**New data providers**

**JPRN:** Since late February 2010 the data of the Japanese Primary Registry network (JPRN) have been included in the ICTRP Search Portal. The JPRN is hosted by the National Institute of Public Health, Japan and is composed of 3 registries Japanese:

- Japan Pharmaceutical Information Center - Clinical Trials Information (JapicCTI)
- Japan Medical Association - Center for Clinical Trials (JMACCT)
- University Hospital Medical Information Network (UMIN)

**PACTR:** Data from the Pan African Clinical Trials Registry (PACTR) will be included in the ICTRP Search Portal from 1st June 2010.
ICTRP Americas: a network of registries in Latin America and the Caribbean

A meeting to discuss a potential Clinical Trials Registry Network for Latin America and the Caribbean (LAC) was held in Washington DC, 27-28 April 2010. The overall aim was to discuss the potential development of a cooperative network of interoperable national and regional clinical trials registries in the region. Specific aims were:

1. To share the current state of development of the ICTRP and the participation of LAC
2. To develop a strategy for achieving clinical trial registration in LAC, including:
   a. A strategy for developing a cooperative network of primary and partner registries meeting WHO criteria and a single regional registration platform
   b. A strategy for developing common and interoperable software platform
   c. Sharing the experience of LAC and other regions developing strategies for clinical trial registration
   d. Identifying key partners and potential advisers to the implementation

Advisory Group on Clinical Trial Registration and Reporting (AGCTRR)

The 1st Meeting of the Advisory Group on Clinical Trial Registration and Reporting (AGCTRR) was held 4-5 November 2009 in Geneva. Some of the recommendations of the group include:

- Improvements in the explanatory text for some items in the trial registration data set (including intervention and study type)
- That the "contact for scientific queries" has two elements: scientific leadership and scientific contact details, and that both elements should be reported when the trial is registered.
  - Scientific leadership should always be identified in registered records of clinical trials, for reasons of accountability and transparency. There should therefore be clearly assigned responsibility for scientific leadership to a named Principal Investigator (PI).
- Registered information should be updated at least once a year.
- At this point in time, mandatory registration of observational studies is not warranted. The possible exception is protocols for systematic reviews.

The meeting report can be viewed on the ICTRP web site.

Middle East Clinical Research Association Conference and Exhibition 2010

The first annual meeting of the Middle East Clinical Research Association (MECRA) was held in Beirut, Lebanon 12-13 February 2010, starting with a session dedicated to registering clinical trials in the Middle East. The meeting was opened by Dr. Mohamad Jawad Khalifeh, Minister of Health, Lebanon and was followed by presentations by the ICTRP and the Iranian Registry of Clinical Trials.

The International Standards for Clinical Trial Registries

It is expected that the International Standards for Clinical Trial Registries will be finalized and ready for implementation by registries by July 2010. All Primary Registries in the WHO Registry Network, and their partners, will be expected to comply with these standards.
Registration of systematic reviews

The Centre for Reviews and Dissemination (of the UK's National Institute for Health Research, University of York) is building a registry of ongoing systematic reviews and will soon be undertaking a Delphi exercise to identify a registration data set. Those interested might like to visit:

http://www.york.ac.uk/inst/crd/projects/register.htm

"Support is growing for prospective registration of systematic review protocols, as exemplified in the recent PRISMA statement. As for clinical trials, registration could be an important means of combating publication and selective outcome reporting biases associated with systematic reviews. Registration could also help avoid unnecessary duplication; encourage collaboration; and create opportunities for methodological and other research."

PDQ: End of an Era

The database of the US National Cancer Institute known as PDQ (Physician Data Query - previously known as the International Cancer Research Data Bank) has 30 years of experience in the business of registering clinical trials. This historic database will shortly stop functioning as a clinical trial registry. For more information please visit the PDQ web site.

PDQ is no longer a Partner Registry in the ICTRP. Our web site therefore now displays the following message:

"As a result of changes in US Federal law and NIH policies, PDQ is no longer a clinical trial registry. Please note that all clinical trials on the PDQ database have also been registered in ClinicalTrials.gov."

Welcome to new staff

The ICTRP welcomes Maribel Gomez to the ICTRP Secretariat. Maribel has more than 20 years experience in the conduct of clinical trials in Latin America, and a special interest and expertise in the ethical aspects of clinical trials. She will primarily be responsible for supporting the registries in the Registry Network and working with them to implement the International Standards for Clinical Trial Registries.

Strategic Plan

The early work of the ICTRP focused on meeting the immediate need for a platform to link clinical trial registries and provide a single point of access. Now that this initial need has been met the focus needs to shift to tackling the significant gaps that still remain, particularly the lack of information about clinical trials recruiting participants in low and middle income countries. The ICTRP has therefore developed a strategic plan to help focus the future development of the platform.

The vision of the ICTRP is to achieve:

- A significant reduction in the gap between what we do and do not know about clinical trials, particularly those conducted in low and middle income countries
- An increase in the number of countries with either their own national clinical trial registry (meeting WHO standards) or an enforceable policy that clinical trials be registered in a Primary Registry in the WHO Registry Network
- An improvement in the quality of registered data
Recent publications of interest

The following list of publications is provided for the information of interested readers. Listing of a publication does not imply WHO endorsement.


Publicity material

Help us to raise awareness of trial registration and of the WHO International Clinical Trials Registry Platform (ICTRP). Please contact us if you are organizing a meeting and would like to distribute material about the ICTRP to delegates.

Contact us

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Department of Research Policy and Cooperation (IER/RPC)
World Health Organization
20, Avenue Appia,
CH-1211 Geneva 27,
Switzerland

http://www.who.int/ictrp

The WHO Registry Platform e-Note is scheduled for publication on the last Friday of every second month. The next e-Note is scheduled for circulation on Friday 30th July 2010. Suggestions for the next edition can be sent to via http://www.who.int/trialsearch/Contact.aspx.

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.

Previous issues of the eNote are available at http://www.who.int/ictrp/news/enote/en/index.html