



## Table of contents

1. From the ANZCTR Manager
2. Trial registration milestones in 2008
3. WHO ICTRP interactions continue
4. Current statistics
5. Survey of Australian HRECs
6. Australian Cancer Trials Online project
7. ANZCTR plans for 2009
8. Contact us

### 1. From the ANZCTR Manager

Welcome to the fifth issue of the ANZCTR newsletter. The past year has seen many events and achievements and we hope you enjoy this summary of our activities during 2009.

Lisa Askie

### 2. Trial registration milestones during 2009

There were several important milestones that occurred during 2009 that have highlighted the increasing recognition of the need for prospective trial registration.

- **10 Page Online Form**

The ANZCTR online registration form has been expanded from a 3 page to a 10 page form following user feedback asking for an improved layout.

### 3. WHO International Clinical Trial Registry Platform (ICTRP) - ongoing interactions

The ANZCTR continued its association with the WHO International Clinical Trials Registry Platform (ICTRP) in 2009 as a Primary Registry.

- **Data provider for the ICTRP Search Portal**

The ANZCTR provides an updated version of our registry's data to the [WHO's ICTRP](#) each week so that when the [ICTRP portal](#) is searched, up-to-date information is available. The ICTRP Search Portal now contains data from seven Primary Registries: see [www.who.int/ictcp/en/](http://www.who.int/ictcp/en/)

- **Improved linkage of records displayed on the ICTRP Search Portal**

On December 10<sup>th</sup> the ICTRP Search introduced a new method of displaying trials which allows records linked by common registration numbers from any of the participating Primary registries to be displayed in groups. This will make for easier identification of trials that have been registered more than once in different registries.

- **Universal Trial Number (UTN)**

The introduction of the UTN has helped to ensure

- **Establishing minimum standards for trial registries**

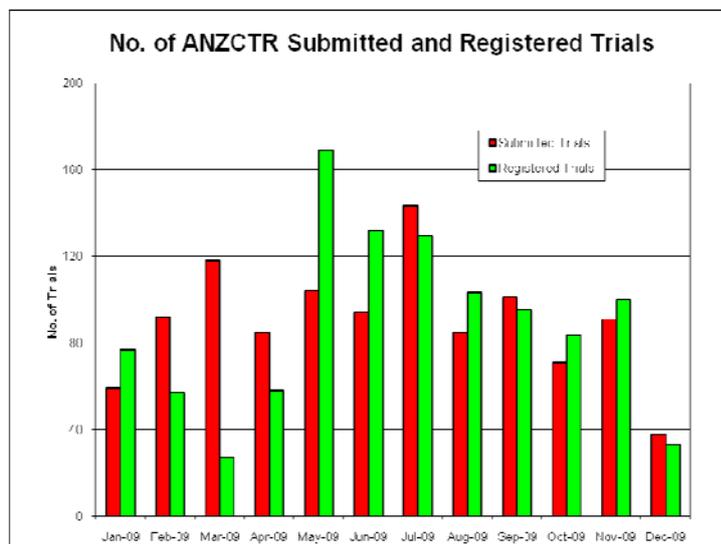
The ANZCTR Manager, Dr Lisa Askie, attended a meeting of the Best Practice Group (BPG) at the WHO in Geneva on 29-30<sup>th</sup> September 2008. Representatives from registries based in the USA, UK, South America, Germany, India, China, Japan, the Netherlands and Australia and New Zealand attended. Over two days the BPG members established several minimum standards to which registries should adhere.

- **Commentary published in the *Lancet***

A commentary on the role and importance of national registries was published in 2008: Grobler L, Siegfried N, Askie L, Hooft L, Tharyan P, Antes G. National and multinational prospective trial registers. *Lancet* 2008; 372: 1201-1202.

### 4. Current statistics

The past year has seen a sharp increase in the number of new trials submitted for registration with an average of 90 new trials being submitted each month - an increase from the 2007 average of 54 and the 2007 average of 73 per month.



Once submitted, trials are checked for data quality, accuracy and duplication before being registered.

Following a busy 2008 with a considerable backlog of submitted trials with a response time of 21 days, the waiting time for submitted trials to be responded to is now back to the ANZCTR's original target of 2 working days due to the hiring

of two additional staff members in April, with Kylie Hunter and Will Ooi joining the team and its culmination with a sharp jump in the number of registrations beginning that month. Nicole Holcroft, our former Senior Project Officer has since left her position in September.

Since our website counter commenced in September 2007, over 30,000 unique users have accessed the ANZCTR website. Since September 2008 we have been collecting information about the type of ANZCTR users and their satisfaction with the site. The Registry is being used for a wide variety of reasons including looking for trials to participate in, accessing information to include in a systematic review, as well as people looking for general information about clinical trials. This data collection is ongoing.

**5. Survey of Australian HRECs**

In 2008 we wrote to all Australian Human Research Ethics Committees (HRECs) to find out information about ways in which they promote prospective registration of clinical trials submitted for ethics approval. To date we have received 65 replies. In the new year we will be contacting the HRECs that have not yet responded to complete the data collection process.

**6. Australian Cancer Trials Online consumer website project**

Work commenced in 2008 on the Australian Cancer Trials Online (ACTO) consumer website project. We are collaborating with colleagues from Cancer Australia and the School of Public Health at the University of Sydney to assist in the development and evaluation of a consumer-focused website where all cancer trials being conducted in Australia can be easily accessed.

**Lastly and once again .....**

We would like to take this opportunity to thank all our stakeholders, funders and collaborators for your continued support during 2009 and wish you all a very happy holiday season & all the best for the New Year.



Davina Ghersi Director      Lisa Askie Manager      Jenny Chow Executive Officer      Kylie Hunter Project Officer      Will Ooi Project Officer      Fergus Tai Project Officer      Thuyen Vu IT Officer

*The ANZCTR Team*

The project involves extracting up-to-date cancer trials information from the ANZCTR, requesting some additional data items relevant to cancer consumers, and making this information available on a separate website. The project is being evaluated via a cluster randomised trial before making the website accessible to the general public. For more information about this project, please contact: + 61 (0)2 9351 6171 or [audiotrial@health.usyd.edu.au](mailto:audiotrial@health.usyd.edu.au)

**7. ANZCTR plans for 2010**

Major ANZCTR plans for 2010 include:

- taking steps to decrease the proportion of trials registered after the first participant is enrolled (as such trials do not fulfil the ICMJE requirement of *prospective* trial registration);
- undertaking comprehensive stakeholder consultations to assess our performance to date and plan for future needs; and
- establishing increased links and data transfer procedures with several partner registries.

**8. Contact us**

We welcome your questions, comments, suggestions and contributions on any matter relating to the Australian New Zealand Clinical Trials Registry.

Please send your message to: [info@actr.org.au](mailto:info@actr.org.au)

Alternatively, you can contact us on:

- Phone:** +61 2 9562 5333
- Fax:** +61 2 9565 1863
- Website:** [www.anzctr.org.au](http://www.anzctr.org.au)