

WEBINAR 26 June 2019

Introduction to the ICTRP

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ICTRP Webinar list

Webinar – Introduction to the ICTRP: 26th of June 2019

Webinar - ICTRP Standards

Webinar – ICTRP Search Portal and Web services

Webinar – ICTRP Primary Registries

Webinar – ICTRP filters – Rare disease

Guest speakers will be invited in next Webinars

Dates of the next Webinars will be announced

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Webinar Outline Introduction to the ICTRP

I. What is ICTRP?
What does it do?
What are its
values?

II. ICTRP Network

- Primary registries
- Data providers
- 24 items TRDS

III. ICTRP Search Portal

- Search pages
- UMLS
- Bridging
- UTN
- web service
- xml download





What is ICTRP?

- The International Clinical Trials
 Registry Platform (ICTRP) is a global
 initiative that aims to make information
 about all clinical trials involving human
 beings publicly available.
- It was established in 2006 in response to demand from countries through the World Health Assembly Resolution WHA58.22
- It is the position of the ICTRP that the registration of all interventional trials is a scientific and ethical responsibility.





"a voluntary platform to link clinical trials registers in order to ensure a single point of access and the unambiguous identification of trials with a view to enhancing access to information by patients, families, patient groups and others"





Clinical Trials Transparency Flow

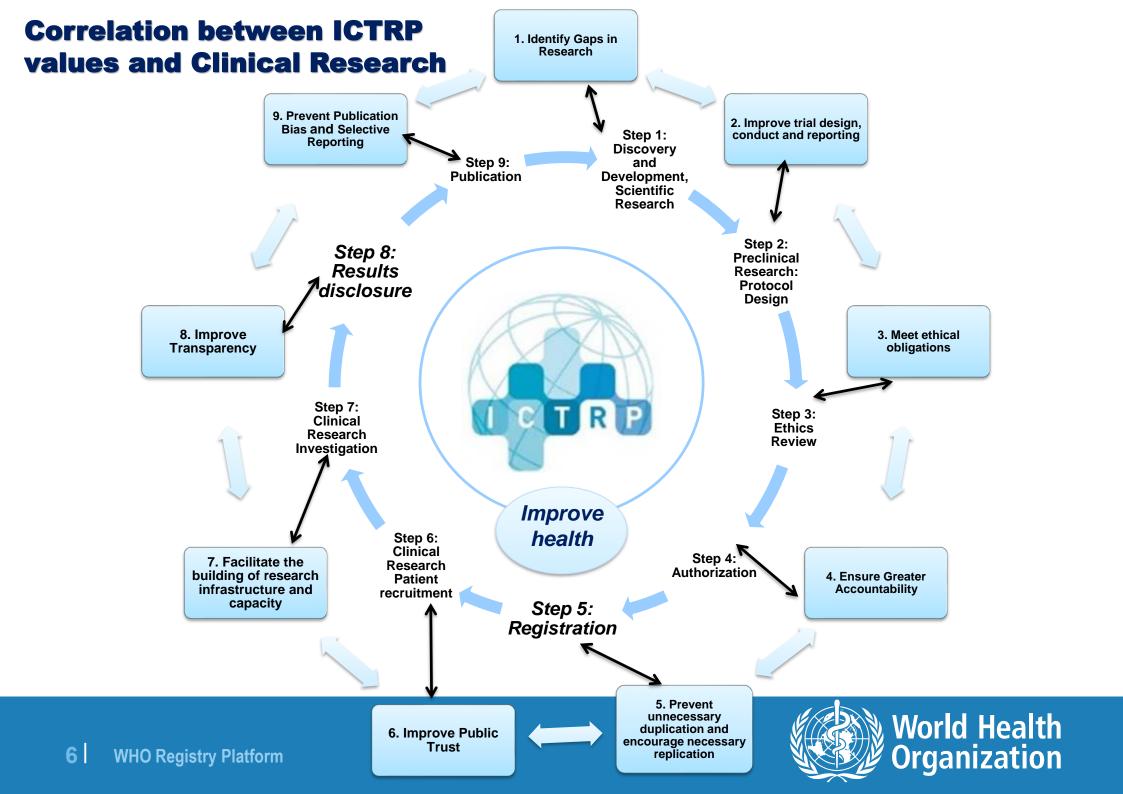
Registration

Results reporting | Individual Patient Data Sharing (IPD)

- 2006: WHO calls for the registration of all interventional trial and defines the 20 elements data set (TRDS)
- 2015 : WHO calls for the reporting of the results of past and new trials
- 2017: The TRDS is expanded to 24 elements







What does it do?

International Clinical Trials Registry Platform

Publishes the ICTRP Search Portal

Search for free, data provided by clinical trial registries

Supports the WHO Registry Network

a forum for Registries

Supports countries and regions

wanting to establish clinical trial registries or policies on trial registration





ICTRP Registry Network

WHO ICTRP Registry Network

• 17 Primary Registries & Data Providers:

Australia (ANZCTR), Brazil, China, Republic of Korea, India, Cuba, EU, Germany, Iran, ISRCTN (UK), Japan, Netherlands, South Africa, Sri Lanka, Thailand, USA, Peru

2 Partner Registries (China)

Primary registry **Primary Primary** ICTRP Registry registry registry Network **Partner** registry **Primary** registry



What is a Primary Registry?

1. Content (prospective, TRDS 24 items)

2. Quality and Validity (SOP, public audit trail)

3. Accessibility (24/7 registration and search, local language)

4. Unambiguous Identification (use sec ids for bridging)

5. Technical Capacity (xml transfer, IT)

6. Administration & Governance (national remit, Not-for profit)





Meet criteria for:

24 Items dataset

- 1. Primary registry / Trial ID
- 2. Date of registration
- 3. Secondary ID
- 4. Source of support
- 5. Primary sponsor
- 6. Secondary sponsor
- 7. Contact (public)
- 8. Contact (scientific)
- 9. Public Title
- 10. Scientific Title
- 11. Countries of recruitment
- 12. Health Conditions

- 13. Interventions
- 14. Inclusion/Exclusion criteria
- 15. Study type
- 16. Date of first enrolment
- 17. Target & final* sample size
- 18. Recruitment status
- 19. Primary outcomes
- 20. Secondary outcomes
- 21. Ethics approval*
- 22. Date of study completion*
- 23. Summary results*
- 24. IPD sharing*

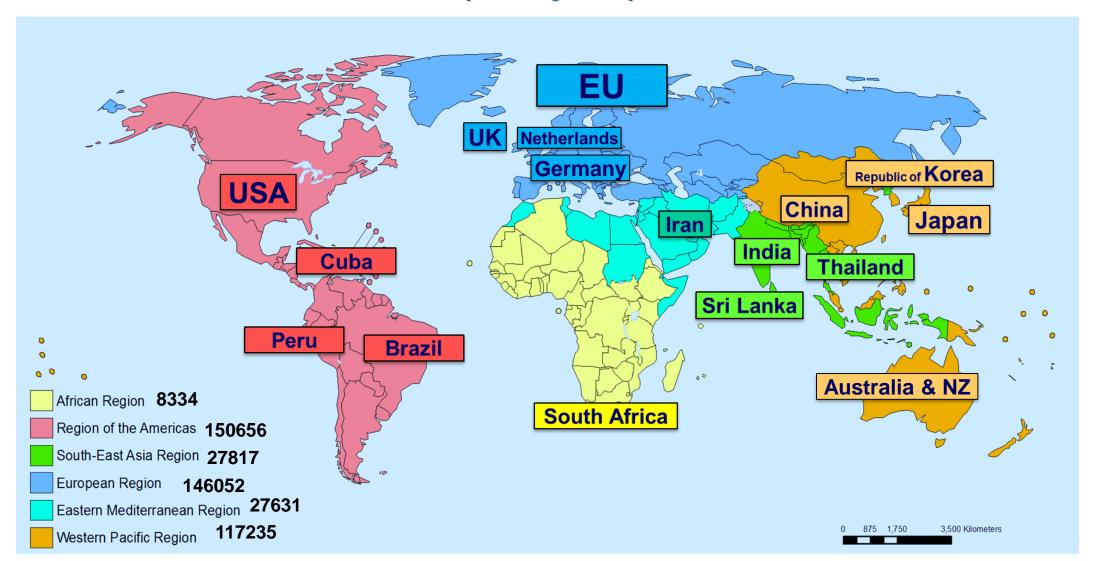
^{*} New data elements added





ICTRP Registry Network and Data by WHO regions

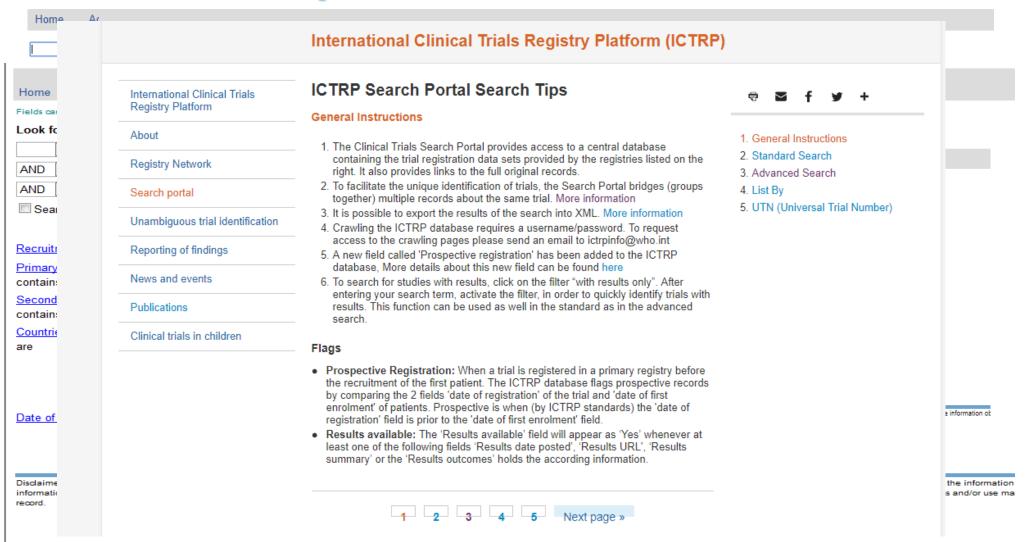
(January 2019)





ICTRP Search Portal

http://www.who.int/trialsearch





ICTRP website

- http://www.who.int/ictrp
- The ICTRP website is in all 6 official WHO languages: English, French, Spanish, Arabic, Chinese, Russian





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