How will the platform work?

The planned International Clinical Trials Registry Platform will not be a register itself, but rather will provide a set of standards for registers to follow to be internationally acceptable.

The project has set down 20 aspects about a planned trial that should be reported prior to recruiting participants in order to register that trial. These 20 items must all be publicly disclosed upon registration.

The platform is also developing a global trial identification system that will assign to every qualified trial a unique reference number to cross-reference duplicate records across registers and information systems worldwide.

The platform will create an internet search portal where scientists, patients, doctors, donors and anyone else who is interested can search among participating registers for information about clinical trials taking place throughout the world.

Visitors will not be able to enrol in a trial directly through the site, but they will find contact information for the person who can assist them with enrolment or any other queries.

The 20 items to be submitted when registering a clinical trial are as follows:

1. Name of primary register, and unique ID number assigned by the primary register to this trial.
2. Date of registration in primary register.
3. Secondary ID: other identifying numbers and issuing authorities.
4. Source(s) of monetary or material support.
5. Primary sponsor: individual, organization, group or other legal person responsible for the trial.
6. Secondary sponsor(s).
7. Contact for public queries.
8. Contact for scientific queries.
9. Public title: intended for lay public in easily understood language.
10. Scientific title of the study, as it appears in the protocol.
11. Countries of recruitment.
12. Health condition(s) or problem(s) studied.
13. Intervention(s).
14. Key inclusion and exclusion criteria for participant selection, including age and sex.
15. Study type: for example, single arm or randomized trial.
16. Date of enrolment of first participant, anticipated or actual.
17. Target sample size: number of participants that trial plans to enrol.
18. Recruitment status of this trial. Pending: participants are not yet being recruited or enrolled at any site. Active: participants are currently being recruited and enrolled Temporary halt: there is a temporary halt in recruitment and enrolment. Closed: participants are no longer being recruited or enrolled.
19. Primary outcome(s).
20. Key secondary outcomes.

For full details please see: http://www.who.int/ictrp/data_set/en/index.html

by the state of available registries. "It's very hard for people in these circumstances, dealing with the terror of a fatal diagnosis, to trawl through the different sites and struggle with the scientific jargon only to find that the trial that seems to offer hope is no longer active," she says.

The internet is very good at bringing people and goods, or people and services together. Deborah Collyar, a two-times breast cancer survivor, now president of Patient Advocates in Research, believes that web services such as EmergingMed.com, have a great deal to offer. "You can put your profile into the system and the search engine seeks to match you with trials currently going forward," she says. "It's very simple and very effective."

Such a system would certainly have helped the Italian man Kathy Redmond tells a story about. "He was a leukaemia patient who began to develop resistance to the drug Gleevec," she says. "The prognosis was bad so he went on line and surfed his way into Clinicaltrials.gov, the registry run by the US National Library of Medicine." It was there that he discovered that a trial looking at precisely the problem he was experiencing was taking place in Toronto.

"He got on the plane and flew to Canada. When he arrived in Toronto he was told by one of the research staff that an identical trial was going forward in his home town, Rome. Italy has no clinical trial register. The man had no way of knowing what was happening on his doorstep."

If WHO's plan to bring together the world's clinical trials registries works, that brave traveller's doorstep is about to get a little closer to home. ■

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