

Correspondence

Open Access to Trials Register

Susanne McCabe

I find the arguments raised by the *PLoS Medicine* editors very useful [1] as I had not considered that a scientific community would tolerate barring access to registers of trials. It leaves huge gaps for exploitation by privileged groups.

It is not only colleagues in research and allied professions who need access but the global community, including members of the public wherever they live, those who participate in trials and those who will be on the receiving end of their outcomes.

The annual reports of research ethics committees (RECs) are supposedly in the public domain after approval by Strategic Health Authorities in the UK. But very few members of the public know of their existence or how to access them. Approaches to individual committees even now can meet with varied reactions, from suspicious, defensive, or hostile—reluctantly sending one report, quizzing as to which organisation the enquirer belongs to and why they should want one—to extremely welcoming of interest and discussion.

The annual reports should be easily accessible online by now, surely, but they are not. The activities of RECs and information on what research is being carried out in the name of society as a whole largely remain hidden from public view.

There is no information about public access on COREC (Central Office for Research Ethics Committees; www.corec.org.uk) or OREC (Office for Research Ethics Committees; www.orecni.org.uk). COREC has not been open about dealing with issues of concern raised with them in the past. They do state that public interest is welcome now, so it would show a real commitment to making research activity more open if they would show support for totally open access to a register and to promote that through their Web site. ■

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Unregistered Trials Are Unethical

Eswar Krishnan

Current journal requirements forcing clinical trials to be registered [1] are insufficient and are unlikely to solve the problem of negative trials never even making it to a journal. Most of the patients consenting to clinical trials do so out of altruism. It is a great betrayal of their trust to suppress clinical

trial data. I suggest that institutional review boards refuse to allow human experimentation unless the protocol is filed in a central (online) repository. The primary data should also be required to be in the public domain (say, within 1–2 years after completion). Data obtained by appealing to altruistic instincts, similar to money in public charities, are not proprietary information, nor can physicians cash out the trust of their patients. In reality, it is the pharmaceutical industry that stands to gain the most if data are made public as such data inform future research and help smaller, innovative companies avoid redundancy. Voluntarily sticking to higher standards of ethics will raise societal respect for the industry (currently being battered for greed) and attract a more talented workforce, and may even help the current efforts to reform the tort law. ■

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Competing Interests: I continue to work with the pharmaceutical industry in developing clinical protocols and enrolling patients for clinical trials. I have received monetary compensation for consulting for this activity.

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Free Community Science and the Free Development of Science

Richard Stallman

In free community science, where large numbers of scientists participate as volunteers in a single project, the ideal of scientific cooperation finds a new expression. Free community science was inspired by the free software movement, which itself was inspired by the application of the ideal of scientific cooperation, as it was applied to software development by the operating system developers of the Massachusetts Institute of Technology Artificial Intelligence Lab in the 1970s. This ideal has suffered for two decades from corporate pressure to privatize science, so it is very gratifying to see that the free software movement can today help reinvigorate the principle that inspired it.

The ideal of scientific cooperation goes beyond the conduct of individual projects. Scientific cooperation is also being reinvigorated today through the open-access movement, which promotes the public's freedom to redistribute scientific and scholarly articles. In the age of the computer networks, the best way to disseminate scientific writing is by making it freely accessible to all and letting everyone redistribute it. I give a vote of thanks to the Public Library of Science for leading the campaign that is now gaining momentum. When research funding agencies

pressure journals to allow free redistribution of new articles they fund, they should apply this demand to the old articles “owned” by the same publishers—not just to papers published starting today.

Journal editors can promote scientific cooperation by adopting standards requiring internet publication of the supporting data and software for the articles they publish. The software and the data will be useful for other research. Moreover, research carried out using software cannot be checked or evaluated properly by other scientists unless they can read the source code that was used.

A significant impediment to publication and cooperation comes from university patent policies. Many universities hope to strike it rich with patents, but this is as foolish as playing the lottery, since most “technology licensing offices” don’t even cover their operating costs. Like the Red Queen, these universities are running hard to stay in the same place. Society should recognize that funding university research through patents is folly, and should fund it directly, as in the past. Meanwhile, laws that encourage universities to seek patents at the expense of cooperation in research should be changed.

Another impediment comes from strings attached to corporate research funding. Universities or their public funding agencies should ensure private sponsors cannot block research they do not like. These sponsors must never have the power to veto or delay publication of results—or to intimidate the researchers. Thus, sponsors whose interests could be hurt by publication of certain possible results must never be in a position to cut the funding for a specific research group.

The free software movement, the free redistribution policy of this journal, and the practice of free community science for developing diagnostic disease classifications [1] are all based on the same fundamental principle: knowledge contributes to society when it can be shared and developed by communities. All three face opposition from those who would like to privatize knowledge and charge tolls for its use. In the free software movement we have 20 years’ experience in resisting this opposition, and we have built up considerable strength and momentum. We can give the other two movements a boost, so they can advance more quickly. ■

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Competing Interests: I own stocks through mutual funds that are rather general, and I don’t know what companies they invest in. My only professional relationships are with the Free Software Foundation (FSF) and the Union for the Public Domain. A list of the FSF’s corporate donors can be found at <http://www.fsf.org>. I have received probably 60 different travel grants and honoraria this year. Most were from universities, conferences, and government bodies, but included also Google and OSDL.

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