Why research should be hacked

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Australian researchers are calling for the open sharing of clinical trial data in the medical research community, saying it would be instrumental in eliminating bottlenecks and duplication, and lead to faster and more trustworthy evidence for many of our most pressing health problems.

Moreover, hackers should be role models for freeing up access to the "source code" of clinical trials – patient-level data – the researchers from the University of New South Wales (UNSW) in Sydney argue in a commentary published in the journal *Science Translational Medicine*.

Hackers revolutionised the software industry by countering the economic and cultural motivations that drove closed source software and disengagement from user needs.

"Similar roadblocks plague the clinical evidence domain where, despite a rapid increase in the volume of published research, physicians still make decisions without access to the synthesised evidence they need," said paper co-author, UNSW Australian Institute of Health Innovation Research Fellow, Dr Adam Dunn.

The call follows a wider push for free, open access to academic publications and intellectual property rights designed to turn more university research into real-world applications.

Open source communities often out-perform their closed source counterparts, most notably in the software community where millions of programmers contribute code that can be used for free, by anyone.

"If the same principles were applied to medical research, bottlenecks, biases and self-interest would be largely removed," said Professor Enrico Coiera, a co-author on the paper along with UNSW Professor Ric Day, and Professor Kenneth Mandl from Harvard Medical School.

"Clinical trial data is a potential goldmine. If researchers, doctors and patients were able to re-analyse and pool this data, there would be a host of questions that could start to be answered. But these meta-analyses are very uncommon because researchers and companies don't like to share data," Professor Coiera said.

"One solution, which has no support, is for data to be pirated. No one would win in that scenario. But everyone could be a winner if clinical research data went open source."

While there are technical challenges around building an open source community for clinical trials, including important considerations around privacy and data quality, "these could be easily overcome", Dr Dunn said.

Less easy to overcome are the social and financial barriers. "Most researchers want to hold their data as long as they can as the basis for publications," Dr Dunn said. "And unfortunately, pharmaceutical companies want to control the messages that are delivered to doctors and maximise profits rather than facilitate the cost-effective delivery of care."

Provided by University of New South Wales