

# Scientists Are Hoarding Data And It's Ruining Medical Research

Posted on July 26, 2015 by [Stefaan Verhulstin](#) [GovLab Digest](#)

Ben Goldacre at [Buzzfeed](#): “We like to imagine that science is a world of clean answers, with priestly personnel in white coats, emitting perfect outputs, from glass and metal buildings full of blinking lights.

The reality is a mess. A [collection](#) of [papers published](#) on Wednesday – on one of the most commonly used medical treatments in the world – show just how bad things have become. But they also give hope.

The papers are about deworming pills that kill parasites in the gut, at extremely low cost. In developing countries, battles over the usefulness of these drugs have become so contentious that some people call them “The Worm Wars.”...

This “deworm everybody” approach has been driven by a single, hugely influential [trial](#) published in 2004 by two economists, Edward Miguel and Michael Kremer. This trial, done in Kenya, found that deworming whole schools improved children’s health, school performance, and school attendance. What’s more, these benefits apparently extended to children in schools several miles away, even when those children didn’t get any deworming tablets (presumably, people assumed, by interrupting worm transmission from one child to the next).

A decade later, in 2013, these two economists did something that very few researchers have ever done. They handed over their entire dataset to independent researchers on the other side of the world, so that their analyses could be checked in public. What happened next has every right to kick through a revolution in science and medicine....

This kind of statistical replication is almost vanishingly rare. A recent [study](#) set out to find all well-documented cases in which the raw data from a randomized trial had been reanalysed. It found just 37, out of many thousands. What’s more, only five were conducted by entirely independent researchers, people not involved in the original trial.

These reanalyses were more than mere academic fun and games. The ultimate outcomes of the trials changed, with terrifying frequency: One-third of them were so different that the take-home message of the trial shifted.

This matters. Medical trials aren’t conducted out of an abstract philosophical interest, for the intellectual benefit of some rarefied class in ivory towers. Researchers do trials as a [service](#), to find out what works, because they intend to act on the results. It matters that trials get an answer that is not just accurate, but also reliable.

So here we have an odd situation. Independent reanalysis can improve the results of clinical trials, and help us not go down blind alleys, or give the wrong treatment to the wrong people. It's pretty cheap, compared to the phenomenal administrative cost of conducting a trial. And it spots problems at an alarmingly high rate.

And yet, this kind of independent check is almost never done. Why not? Partly, it's resources. But more than that, when people do request raw data, all too often the original researchers duck, dive, or simply ignore requests....

Two years ago I published a [book](#) on problems in medicine. Front and center in this howl was "publication bias," the problem of clinical trial results being routinely and legally withheld from doctors, researchers, and patients. The best available evidence – from [dozens of studies](#) chasing results for completed trials – shows that [around half](#) of all clinical trials fail to report their results. The same is true of industry trials, and academic trials. What's more, trials with positive results are about twice as likely to post results, so we see a biased half of the literature.

This is a cancer at the core of evidence-based medicine. When half the evidence is withheld, doctors and patients [cannot make informed decisions](#) about which treatment is best. When I wrote about this, various people from the pharmaceutical industry cropped up to claim that the problem was all in the past. So I befriended some campaigners, we assembled a group of senior academics, and started the [AllTrials.net](#) campaign with one clear message: "All trials must be registered, with their full methods and results reported."

Dozens of academic studies had been published on the issue, and that alone clearly wasn't enough. So we started collecting signatures, and we now have more than 85,000 supporters. At the same time we sought out institutional support. Eighty patient groups signed up in the first month, with hundreds more since then. Some of the biggest research funders, and even government bodies, have now signed up.

This week we're [announcing](#) support from a group of 85 pension funds and asset managers, representing more than 3.5 trillion euros in funds, who will be asking the pharma companies they invest in to make plans to ensure that all trials – past, present, and future – report their results properly. Next week, after two years of activity in Europe, we launch our campaign in the U.S....([More](#))"

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