Open Data and Better Quality HealthCare

Doctors need to see results as well as regulators! (taken from briefing document on Open Data)

There is a critical campaign, being spearheaded by sense about science, about the need for all trials to be registered and all results reported. The more signatures the better as it is all about research accountability and transparency. A medical professional can’t participate in shred decision making when they themselves do not had access to data. This surely impacts health care information for all because all are not being informed. You can sign at http://www.alltrials.net/ 3866 signatures already!

If your organisation supports this aim, contact Michael Stacey: mstacey@senseaboutscience.org, Want more background check out the BMJ article here http://www.bmj.com/content/346/bmj.f105

“Thousands of clinical trials have not reported their results; some have not even been registered. Information on what was done and what was found in these trials could be lost forever to doctors and researchers,
leading to bad treatment decisions, missed opportunities for good medicine, and trials being repeated unnecessarily on people and animals. All trials past and present should be registered, and the full methods and the results reported. We call on governments, regulators and research bodies to put in place measures to achieve this.

An editorial in the BMJ today spells out that academics as well as companies need to report the results of their trials. Editor in Chief Fiona Godlee calls on both industry and academia to clean up their act and invites BMJ readers to add their voice to the petition at www.alltrials.net: “The evidence that much research goes unreported is overwhelming”,

“A medicine does not simply “work” or “not work”. Some drugs work very well, some work less well than other drugs, but are still better than nothing. A medicines regulator decides if a drug should go on the market at all, and they have a low bar for approval. This is good: we need some less effective drugs to come on the market. For example, a patient may have idiosyncratic side effects from the best available drug for their condition, in which case it is useful to have a less effective drug to try next.

Doctors and patients need all the information about all the clinical trials that have been conducted on drugs (and other treatments) in order to make informed decisions. A clinical decision (“should this patient receive this drug?”) is very different to a regulator’s decision (“overall, is it in the interests of society that this drug should be on the market for use at all?”).

Furthermore, regulators can sometimes miss important problems with medicines. For example, as with Tamiflu, the problems with the drugs Vioxx and Rosiglitazone -- both now taken off the market -- were spotted by academics and clinicians rather than regulators. This is not because regulators are incompetent: these are difficult problems, so it is good to have many eyes working on them. It is also good for patients
if the evidence behind regulators’ decisions can be independently assessed, to ensure regulators have made good decisions.”

**ThinkWell** joins the signing of this petition for better reporting, open data and quality health care.

The information above was provided from a joint effort by: Carl Heneghan (CEBM), Ben Goldacre (Bad Science), Iain Chalmers (James Lind Foundation), Fiona Godlee (BMJ), Sile Lane, Michael Stacey and Tracey Brown (Sense about Science).