EDITOR'S CHOICE

Open data: seize the moment

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One of the most popular videos on TED.com is a mini-lecture by the writer, doctor, and academic Ben Goldacre, called “What doctors don’t know about the drugs they prescribe” (<http://tinyurl.com/9y8chac>). In the video, Goldacre (whose latest book, *Bad Pharma*, does much to expose the damage caused by withheld and misreported data from clinical trials) says that in drug trials funded by pharmaceutical companies “positive findings are around twice as likely to be published as negative findings.” Since it was posted two months ago, the video has attracted over 387 000 views. Does this suggest that the public is waking up to one of the biggest scandals in clinical research: that big pharma does not make all the clinical trial data for all drugs in current use available for independent scrutiny?

Certainly *BMJ* editor Fiona Godlee, who has led an ongoing campaign for open data, hopes that we are on the brink of a “sea change in the public mood.” In an editorial this week (doi:10.1136/bmj.e7304) she asks, “Why aren’t all clinical trial data routinely available for independent scrutiny once a regulatory decision has been made? How have commercial companies been allowed to evaluate their own products and then to keep large and unknown amounts of the data secret even from the regulators? Why should it be up to the companies to decide who looks at the data and for what purpose?”

The past fortnight has seen a number of initiatives that might help to make this moment a tipping point in the United Kingdom. The first came from general practitioner and Conservative MP Sarah Wollaston, who last week raised in the House of Commons the issue of missing data affecting the medical evidence base (doi:10.1136/bmj.e7306). In response, Norman Lamb, the minister for care services, agreed that access to all data from clinical trials was a “really important issue.” He committed the government to a meeting with campaigners.

The second initiative was a letter to the *Times* this week, signed by 28 campaigners—including Fiona Godlee and Ben Goldacre. The letter called on the government to act to end “ongoing secrecy” surrounding the reporting of clinical trials (doi:10.1136/bmj.e7306). “We wish that drug companies truly were compelled to be transparent. In reality, vitally important information about drug trials continues to be withheld from doctors and the public, meaning that patients are harmed, and money is wasted,” they wrote.

The third initiative is part of the *BMJ*’s own open data campaign. As David Payne, editor of *bmj.com*, reports (doi:10.1136/bmj.e7303), the *BMJ* has this week launched a dedicated website aimed at persuading Roche, the manufacturers of oseltamivir (Tamiflu), to give doctors and patients access to the full data on the influenza drug. The site (www.bmj.com/tamiflu) displays emails and letters dating back to September 2009, when Cochrane researcher Tom Jefferson asked Roche for the unpublished dataset used in a 2003 analysis of oseltamivir. The site’s aim is to persuade Roche to fulfil a public promise it made in 2009 to release full clinical trial reports, in response to an investigation by the *BMJ*, Tom Jefferson, and his Cochrane colleague Peter Doshi. The latest addition to the site is a letter from Fiona Godlee to John Bell, regius professor of medicine at Oxford University and a Roche board member, urging the company to disclose the full data (doi:10.1136/bmj.e7305). Jefferson and Doshi explain more about the open data campaign in this week’s *BMJ* podcast (www.bmj.com/podcasts).

Can the momentum of the UK campaigners help push for change in Europe and beyond? As Fiona Godlee says at the end of her editorial, “We should seize this moment with both hands.”

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