ScienceOnline09: Providing public health and medical information to all

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This Sunday I will moderate a session called Providing public health and medical information to all at ScienceOnline09. I didn't pick the title, but it is a topic I care a lot about. Because the session is intended as an open discussion, I thought that a blog post would be good way to organize my thoughts and ideas that I have for this session[1]. And even though there are only two days left, I might even get some valuable feedback.

We science bloggers have many recurring themes, and this session is again about access to information and filtering out the important information.

Access

The traditional format to provide important medical information is the peer-reviewed journal article. Unless you work at a large research institution or university hospital, only part of these papers will be available as full-text articles. Notable examples of journals with immediate open access to peer reviewed research are the British Medical Journal, PLoS Medicine, BMC Medicine and Open Medicine. Many other medical journals provide free fulltext access 6-12 months after publication, and this is now a requirement for research funded by many funding agencies, including the NIH, the Wellcome Trust, Howard Hughes Medical Institute.

Clinical trials are essential to improve the prevention, diagnosis and treatment of many medical conditions. Since 2005 all clinical trials have to registered in one of several central databases (e.g. clinicaltrials.gov) before the first patient is treated. The information in these publicly accessible databases includes the trial design and participating centers. Since September 2008, clinicaltrials.gov started to also report key results, as required by the Federal Drug Administration Amendment Act. It is important to remember that not all clinical trials eventually will be published, so that looking just at the published literature will not give a complete picture.

Filtering

Access to important medical information is only the first step. The filtering of this information is at least as important. With filtering I mean both finding the important research papers and evaluating them in a larger context. A meta-analysis is a systematic review that follows a standard set of rules for finding and evaluating research papers, a format championed by the Cochrane Collaboration. A meta-analysis can not only summarize published research papers, but sometimes also uses the raw data of the published research (the so-called individual patient data meta-analysis). I would wish that the meta-analysis receives the same kind of attention in the blogosphere as the open access to research papers.

Whereas a positive outcome in a good meta-analysis is the best evidence for the usefulness of a healthcare intervention, most filtering of biomedical research papers comes to us in different ways:

- Review articles
- Journal editorials
- Science blogging
- Articles by science journalists
- Direct to consumer advertising (United States and New Zealand only)
- Social networking sites such as Connotea, CiteULike or FriendFeed

I would argue that science articles in traditional media (e.g. newspapers) and direct to consumer advertising may work in drawing your attention to a research paper, but they are usually useless in evaluating biomedical research. And obviously I believe that science blogging has great potential to help in both the finding and evaluation of important biomedical research. Meta-analyses take a very long time and review articles take a long time. A thoughtful blog post on a recently published paper can provide an important service. Research Blogging and Nature Blogs are two services to help find these blog posts. Social networking sites for scientists are a great tool to find interesting research papers, but I don't know how they can help evaluate a research paper. Faculty of 1000 Medicine is a very interesting approach to the filtering problem, but I haven't used the service enough to comment on it here.

Addendum (01/18/09)
It can be a good thing to have your presentation on the second day of a conference. You come up with new ideas. I changed the title to better convey what I would like to talk about in this session: Reporting medical research: specific problems and specific solutions. And I've added another topic besides access and filtering:

Motivation

There are many reasons why people are interested in reporting or learning about medical research. But betroffenheit and financial interests are two very strong reasons that should always be kept in mind. Betroffenheit is a German word

that means something that is directly affecting your life. If you are a patient with a serious medical condition, or have a sick friend or relative, you obviously have very different needs than someone who just wants to catch up on the latest research on the release of calcium from intracellular stores. Betroffenheit is not confined to medical research, climate change is another example.
Obviously there are often important financial interests behind the outcome of medical research. And this not only means the interests of drug companies or device manufacturers. Most presentations of medical research in larger meetings now begin with a financial disclosure slide.

I've updated the Slideshare Presentation that I want to give as an introduction to the session. And the conference Wiki page for the session is here.

fn1. Yet another argument for the usefulness of science blogging.