

Should Pharma Correct “Misinformation” on Wikipedia?

There’s a Right Way and a Wrong Way

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It is a well-known fact that Wikipedia is the leading single source of healthcare information for patients and healthcare professionals. The top 100 English Wikipedia pages for healthcare topics were accessed, on average, 1.9 million times during the past year, noted the IMS Institute for Healthcare Informatics in a recent report (find it here: <http://bit.ly/IMSreport>).

Wikipedia Health Access Factoids

IMS also revealed other, perhaps less well-known, facts about Wikipedia health information:

- Visits to Wikipedia pages are higher for rarer diseases than for common diseases.
- Wikipedia is used throughout the entire patient journey, not just at the point of treatment initiation or change in therapy.
- Correlation between Wikipedia use and medicine use can be identified for a large number of disease areas.
- Younger people tend to investigate conditions and treatment options online before treatment is started whereas patients of age 50+ tend to start their treatment first and then seek information online thereafter.
- Content incorporated or changed at healthcare related Wikipedia pages is subject to constant change, often overseen by informal or formal working groups.
- At least half of all healthcare related changes on assessed Wikipedia disease articles are changes to patient relevant information.

IMS noted that "information gathering occurs not only at time-points where treatments are started or changed, but rather throughout the entire patient journey, including adherence to the medication." IMS said this finding "should encourage providers of online information, as it indicates that patients not only focus on the treatment initiation or the dynamic treatment phase within the patient journey, but require information, tools and insights that relate to the entirety of the treatment process."

Finally, IMS reminded us that Wikipedia articles on health issues are "in flux" and that there is a need for "knowledgeable editors" to keep the information as current and unbiased as possible.

Who Currently Edits Wikipedia Drug Info?

Gary Monk, Director of Strategy and Innovation at HAVAS LYNX (previously Product Manager at Janssen Cilag), analyzed the Wikipedia pages of the

top 20 pharmaceutical products to see exactly how often these pages are edited and who does the editing. He found that there are a lot of editors but a small number have a major influence over the content. While a total of 129 users have edited the top 20 brands, five editors were responsible for over 18% of the top ten edits (see <http://bit.ly/MonkWiki>).

Monk's analysis demonstrates the power that a few knowledgeable editors could have to correct or influence content on Wikipedia. Which begs the question:

What if the pharmaceutical industry or agents of the industry stepped up and edited content on Wikipedia?

According to IMS, this is not yet happening. "There is yet to be established a broad approach to funneling the vast resources of healthcare institutions, the pharmaceutical industry, regulators and patient groups into the information that is being used by millions of patients," said IMS.

The Right Way

Recall that back in June, 2012, Dr. Bertalan Meskó (@Berci), in an open letter to pharma, urged the pharmaceutical industry to employ Wikipedia editors and thus "funnel [their] vast resources" to help.

"Based on the pretty negative past encounters between pharma employees and Wikipedia editors (pharma employees trying to edit entries about their own products in a quite non-neutral way; see "ABBOTT CAUGHT ALTERING ENTRIES TO WIKIPEDIA," page 2), we advise you to employ a Wikipedia editor if you want to make sure only evidence-based information is included in entries about your own products," said Berci in 2012 (see <http://bit.ly/pmn11602>).

"Appointing someone from within your company as a 'spokesperson' in Wikipedia who would perform all edits on behalf of the company is an excellent way to update those entries," said Berci.

You would think that the pharmaceutical industry would have jumped at the chance to establish a liaison with Wikipedia to help edit articles about their products. At least one pharma company, in fact, did seem to endorse the idea, at least in principle.

Boehringer Ingelheim (BI) responded to Berci via Twitter: "We look for patient safety issues & react. Its important to stick to Wikipedia policies too, so all

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transparent." But when asked by Berci if BI had posted anything online about this, BI responded "No at this point in time we have not....yet," seemingly leaving the door open.

In a PMN survey, 57% of respondents agreed that pharma companies should appoint an official Wikipedia editor (see Figure 1, below and survey summary here: <http://bit.ly/pgdaily012914-2A>).

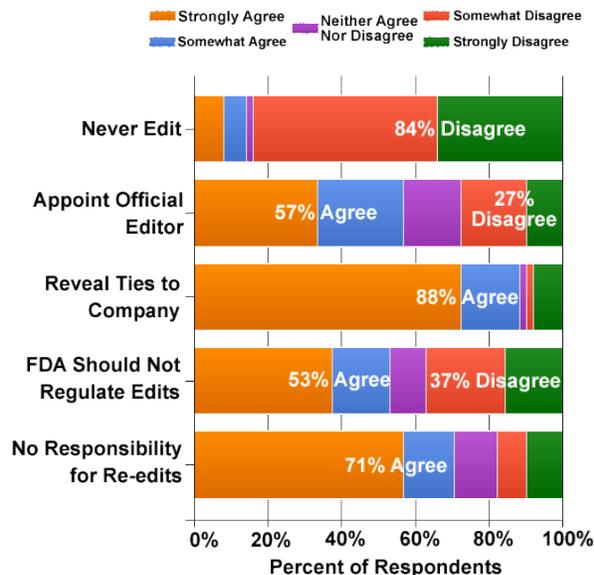


Figure 1. PMN Survey Results. Respondents were asked xxxxx

Berci, however, in a personal communication, indicated that no pharma company has yet taken him up on his offer, but he remains optimistic.

Wikipedia's Pharma Vacuum

"Since I announced my open letter for pharma companies," said Berci, "I've been in touch with several international pharmaceutical companies and while they all agreed my proposal was the perfect method for them about editing Wikipedia in a proper way, none of them seemed to be able to make the final required step for that. I'm still optimistic though I know how much time it takes to run through such ideas in large companies."

This lack of commitment by the industry was confirmed by IMS: "none of the traditional stakeholders for patient information—such as regulators and pharmaceutical companies—is actively engaged in the development of information or in ensuring its correctness."

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ABBOTT CAUGHT ALTERING ENTRIES TO WIKIPEDIA

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<http://bit.ly/1lrsHT9>

Several drug companies have now been caught deleting important information from Wikipedia, in order to downplay the risk of their drugs.

The first drug company caught messing with the Wikipedia was AstraZeneca. References to claims that Seroquel allegedly made teenagers "more likely to think about harming or killing themselves" were deleted by a user of a computer registered to the drug company, according to Times.

According to Patients not Patents, now it is Abbott Laboratories who've been caught doing the same thing. The group alleges that "employees of Abbott Laboratories have been altering entries to Wikipedia, the popular online encyclopedia, to eliminate information questioning the safety of its top-selling drugs."

The tool used to catch these corporate erasers is the WikiScanner, which was developed by Virgil Griffith, a researcher at the California Institute of Technology, and it reveals changes to the online encyclopaedia by linking edits back to the computers from which they were done, using each computer's unique IP address. The scanner has wreaked havoc in news media, politics and among corporations caught redhanded "improving" articles.

Patients not Patents found that in July of 2007, a computer at Abbott Laboratories' Chicago office was used to delete a reference to a Mayo Clinic study that revealed that patients taking the arthritis drug Humira faced triple the risk of developing certain kinds of cancers and twice the risk of developing serious infections. The study was published in the *Journal of the American Medical Association* in 2006.

The same computer was used to remove articles describing public interest groups' attempt to have Abbott's weight-loss drug Meridia banned after the drug was found to increase the risk of heart attack and stroke in some patients.

The site's editors restored the deleted information, but Patients not Patents claim that Abbott's activities illustrate drug companies' eagerness to suppress safety concerns.

Jeffrey Light, Executive Director of the Washington, D.C.-based advocacy group said, "The argument that drug companies can be trusted to provide adequate safety information on their own products has been used by the pharmaceutical industry to fight against government regulation of consumer advertising. Clearly such trust is misplaced. As Abbott's actions have demonstrated, drug companies will attempt to hide unfavorable safety information when they think nobody is watching."

Berci thinks it's organizational inertia holding back pharma. It could also be the high cost of hiring FTEs to be Wikipedia editors. But there is another more likely reason why pharma is holding back: lack of clear guidelines from the FDA that pharma Wikipedia editors can follow to make edits.

According to the recently published "Guidance Agenda: New & Revised Draft Guidances CDER is Planning to Publish During Calendar Year 2014," FDA promises to publish guidance related to "Correcting Independent-Third Party Misinformation About Prescription Drugs and Medical Devices." The biggest, most influential independent third-party source of information (or misinformation, depending on your POV) on the Internet is, of course, Wikipedia.

Open Access Guidelines

An adhoc editorial board of social media advocates organized by Webicina—a website owned by Berci—developed a set of "open access" social media guidelines for pharma. These guidelines, which you can find here <http://bit.ly/pgdaily102913-2>, include suggestions for how pharma companies can edit Wikipedia articles.

"We'd love every article about a drug to contain information about its regulatory status around the world, its development, its manufacturing process, and its commercial history, such as the companies that developed it and the annual sales," state the guidelines' authors. "We believe that you can freely edit Wikipedia articles about your medicines if you follow the following principles."

Consider how to:

- Be transparent. Clearly state who you are and what your intent is.
- Clarify your intent. Make the rationale for the edit clear in the Edit history or on the Discussion page.
- Do not promote. Do not edit an article to promote your medicine.
- Speak plainly. No jargon, no technical words. Keep in mind you are talking to people outside your industry.
- Select your audience. Ensure we know who the edit is for clarify which country license applies where appropriate.
- Understand your medicine's licence. Care needs to be taken when referring to off-licence data to ensure that information is balanced, informative and non-promotional.

You may also wish to:

- Suggest edits. Suggest edits on the Discussion page for other editors to make. But you still need to be transparent about who you are and explain your rationale.
- Appoint a specific company spokesperson. To be the point of contact for your medicine.

Waiting for FDA Guidelines

In comments submitted to the FDA, PhRMA—the industry trade association—suggested that manufacturers would welcome correcting misinformation about their products posted to sites like Wikipedia (see "Accountability for Pharma Content on Social Media Sites"; <http://bit.ly/fdasmAcct>). In comments submitted to the FDA in response to issues raised at the 2009 public hearing on social media, PhRMA suggested that manufacturers would make corrections if they were not subject to FDA regulation.

"FDA," said PhRMA, "should confirm formally that, while it is not possible for manufacturers to monitor or correct all inaccurate information about their products on the Internet, such corrections by manufacturers in response to inaccurate postings will not be considered promotional labeling. FDA's adoption of such a policy would thereby allow manufacturers to correct inaccurate information about their medicines on the Internet or social media (e.g., Wikipedia, Sidewiki, blogs, or other websites) if they should become aware of such information."

Is the pharmaceutical industry waiting for guidance from the FDA before it gets involved with Wikipedia or is it currently engaging agents to do the deed secretly?

The Wrong Way

On March 24, 2014, Gary Monk started a Twitter conversation regarding a Wikipedia "group" called WikiCorrect-Health (WCH), which claims to train "pharma companies on how to use Wikipedia ethically and also legally." On his blog, Monk asks, "Who are WikiCorrect-Health?"

So far, WCH hasn't fully answered that question, but this is how the group describes its intentions on Wikipedia:

"We typically stay away from editing the pages to avoid conflict of interests unless there is no response"

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from the main contributors,” says WCH. “We get paid for consulting and training we provide hospitals, universities and pharma companies on how to use Wikipedia ethically and also legally. We get in touch with experts like you (i.e., Doc James – one of those Top 5 drug information editors cited by Monk in his analysis) if a healthcare related page needs correction. So you might not see us editing pages. The reason we formed the group is to provide a bridge to the entities to ETHICALLY fix legitimate errors on healthcare pages. As you know hospitals and companies do not get involved in providing the wealth of information they have about some major topics, notably pharmaceutical products, fearing backlash. Some are paying unknown agencies to promote marketing material, which is not good for the Wikipedia community.”

Despite claims of being ETHICAL, the group is not behaving ethically. They have so far not revealed who they are but claim to be "a team of 5." It is against Wikipedia policy for multiple people to use a

single account. Therefore, whoever they are, WikiCorrect-Health lacks transparency and is NOT operating "legally" by Wikipedia standards.

Monk suggested that "one or more of them [WikiCorrect-Health] may work for IMS Health, in which case there is again a serious lack of transparency."

I think Gary Monk is correct about this group being IMS. As already pointed out above, IMS has chastised the industry for failing to "funnel" its vast resources into "the information that is being used by millions of patients" and for not being "actively engaged in ... ensuring its correctness."

Could it be that PhRMA and/or several pharma companies hired IMS to be its "eyes and ears" and sometimes its "editor" on Wikipedia? If so, the fact that they are doing this in stealth mode, however, is not cool.

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