Pharma Marketing News

www.pharmamarketingnews.com

26 July 2012
Vol. 11, No. 7
•
Published by
VirSci Corp.
www.virsci.com

Crowd Sourced "Creative Commons" Drug Information

Pitfalls & Opportunities for Pharma

Author: John Mack

PMN117-02

Find resources cited this article online at:
http://tinyurl.com/5hgxra

This article is part of the July 26, 2012 issue of *Pharma Marketing News*.

For other articles in this issue, see (after July 31, 2012):
http://www.news.pharma-mkting.com/PMNissue117Jul2012archive.htm

Published by:
VirSci Corporation
PO Box 760
Newtown, PA 18940
infovirsci@virsci.com

Like other industries, the pharmaceutical industry faces an onslaught of crowd sourced information about its products on the Internet. Sometimes, drug companies actively seek input and insights from the "crowd" online. An example of this is the "Lilly Clinical Open Innovation" venture, which Lilly hopes "can transform clinical research and development" by engaging "in the open for insight, innovation, talent and wisdom to drive new capabilities to fight disease and meet patient needs" (see page 3).

Open Innovation

"Open Innovation promises that we can all play bigger than we are, and enables greater innovation than any individual or organization can accomplish on it's own," says Jerry Matczak, Community Manager, Lilly Clinical Open Innovation, Eli Lilly and Company. Clearly, Lilly sees a benefit and opportunity in crowd sourcing and information "creative commons."

Matt Todd, Senior Lecturer in Chemistry at University of Sydney, points to other "open source drug discovery efforts" such as his "open source drug discovery for malaria project," which was built on some "pioneering open data from GSK Tres Cantos who deposited anti-malarial data in the open, then invited people to do what they will with the data - an astonishing and inspiring move that can be used as a catalyst for more open work, whether OI or OS" (see http://bit.ly/MhEZZn).

Beneficial Creative Commons Drug Information

Brad Pendergraph (@bradatpharma), former Senior Manager, Consumer Digital and Social Engagement at Novartis, posted an audio commentary, in which he touched upon how pharma deals with proprietary information. "Is pharma really going to let some of its information 'go general'?," Brad asked. He mentioned "creative commons" and "taking a look at what material you [pharma] have and figuring out how you can distribute it to people in the social media space in ways that they can understand and work with that are still compliant." Listen to Brad's comments on Audioboo here: http://bit.ly/NQ02oT

Brad suggested that pharma use creative commons license rather than the more restrictive copyright when distributing information. According to the Creative Commons organization, "If you want to give people the right to share, use, and even build upon a work you've created, you should consider publishing it under a Creative Commons license. CC gives you flexibility (for example, you can choose to allow only non-commercial uses) and protects the people who use your work, so they don't have to worry about copyright infringement, as long as they abide by the conditions you have specified."

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Terms Defined

Crowdsourcing: Crowdsourcing is a distributed problem-solving and production model.

In the classic use of the term, problems are broadcast to an unknown group of solvers in the form of an open call for solutions. Users—also known as the crowd—submit solutions. Solutions are then owned by the entity that broadcast the problem in the first place—the crowdsourcer. The contributor of the solution is, in some cases, compensated either monetarily, with prizes, or with recognition. In other cases, the only rewards may be kudos or intellectual satisfaction.

Crowdsourcing may produce solutions from amateurs or volunteers working in their spare time, or from experts or small businesses which were unknown to the initiating organization. Source: Wikipedia

Open Source: Open source is a development method for software that harnesses the power of distributed peer review and transparency of process.

The promise of open source is better quality, higher reliability, more flexibility, lower cost, and an end to predatory vendor lock-in. Source: Open Source Initiative (http://opensource.org/).

Creative Commons: Creative Commons (CC) is a non-profit organization headquartered in Mountain View, California, United States devoted to expanding the range of creative works available for others to build upon legally and to share.

The organization has released several copyright-licenses known as Creative Commons licenses free of charge to the public. These licenses allow creators to communicate which rights they reserve, and which rights they waive for the benefit of recipients or other creators. Source: Wikipedia

Introducing Clinical Open Innovation

(source: http://bit.ly/MwLWsq)

There's plenty of evidence that drug development is broken. The estimated efficacy rate of drugs for many common illnesses comes in at 50% or below, and a recent Forbes article by Matt Herper suggests the cost of bringing a new drug to patients is twice the already-big-number commonly used – over $4 billion per drug.

Patients need better.

The Lilly Clinical Open Innovation team exists to make it better. We believe that Open Innovation models – focused on clinical drug development – can result in transformational gains in value-to-patients and efficiency.

We also believe that open data, linked, crowdsourced, consumed and curated by experts outside (as well as inside) the walls of pharma will bring innovative insights and wisdom. And that open communities will set and meet objectives to reduce costs and improve outcomes.

We'll explore challenge driven innovation and gamification to tap into expertise which might otherwise be missed. We embrace open source development to maximize technical contribution and benefit, and will Work Out Loud to assure transparency on our projects. To manage rights in a distributed digital age we leverage Creative Commons licensing. In the open, with no strings attached.

That's a lot of buzzwords, and even more to actually try to do. Too much for the smallish Lilly COI group for sure – but that's kind of the point. Open Innovation promises that we can all play bigger than we are, and enables greater innovation than any individual or organization can accomplish on it's own.

To start, Clinical Collections is a tool to make personal collections of clinical trials. You can search and filter data served up from Clinicaltrial.gov and save a resulting collection. Collections are presented in multiple views focused on summary, outcomes, timeline and location.

Near term plans include more flexibility to add trials to a collection, as well as a "follow" feature to notify you and others of changes to your collection. Feedback is most welcomed, both on Clinical Collections today as well as how to evolve the tool to meet additional needs.

We've bundled Clinical Collections with an open source Q&A tool, and offer up what we call a "disease commons," focused on Tuberculosis. TB Commons enables sharing of clinical objects – in this case clinical trial collections – and encourages open scientific and operational collaboration focused on disease.

Does the notion of disease commons make sense? We don't know for sure, and look to understand through experience whether it does. Take a look and share what you think.

Finally, we invite you to join in the journey. We promise honesty, transparency and a passion to make drug development better. We ask the same of you and welcome your participation.

The Wikipedia Conundrum

The most visible and most accessed example of crowd sourced "creative commons" information is Wikipedia where "wikipedians"—i.e., people who write and edit the Wikipedia pages—create drug information pages such as the one about rosuvastatin.

"Nearly 75% of US physicians going online for professional purposes are visiting Wikipedia for medical information according to Manhattan Research," says Eileen O'Brien, Director, Search & Innovation at Siren Interactive. "And 36% of US consumers searched for health info on Wikipedia according to Rodale's DTC Study. This is because Wikipedia dominates the search results for health. As Wikipedia plays such a key role, I think it's essential that pharma help to provide accurate information." O'Brien made her comment in response to the survey "Should Pharma Edit Wikipedia Articles?" (see page 6 for survey results and more comments).

There may in fact be several "wikipedians" responsible for a single page of drug information on Wikipedia. The rosuvastatin page, for example, was edited by over 175 people as of 21 July 2012. The top three "editors" were:

1. "Ceyockey" (who made 35 edits),
2. "Jfdwolff" (who made 29 edits), and
3. "MALvis" (who made 23 edits).

The person who is number 4 on the list with 15 edits is "anon."

"Ceyockey"

Wikipedians

Who are these "wikipedians" and what credentials do they have as credible sources of drug information? We may never know who "anon" is, but we have some information about identified contributors.

"Jfdwolff" is a a "Dutch doctor living and working in the United Kingdom." "MALvis" is a US physician, "specializing in preventive, non-invasive and invasive cardiology and internal medicine in San Antonio." Both seem to be well qualified to write about rosuvastatin, but their Wikipedia profiles tell us nothing about possible conflicts of interest (COI).

"Ceyockey," however, does have a COI. He is Courtland Yockey, an "informatics scientist" who lives in Delaware and works for a "top-10 multi-national pharmaceutical company," according to his profile on Wikipedia.

User-Generated Content Transparency

Yockey has nothing to hide. You can find his Wikipedia profile here (http://bit.ly/OTYy9c), his LinkedIn page here (http://linkd.in/OTYAhb), his Twitter account here (http://bit.ly/OTYExq), and his Facebook page here (http://on.fb.me/OTYIxd).

According to his LinkedIn page, the pharmaceutical company that Yockey works for is Astrazeneca, which markets rosuvastatin as CRESTOR.

"I believe that my editing of Wikipedia is generally beneficial," says Yockey in his Wikipedia profile, "and I have no regrets or concerns about anything that I have or will create or revise here, which is why I am willing to provide my real name."

Whether or not it is "beneficial" for individual pharma company employees such as Yockey to be editing Wikipedia information about their own company's products is difficult to know for certain.

Transparency, however, is crucial for judging credibility of drug information on Wikipedia. Yockey addressed transparency head on in a straight-forward fashion, although he failed to state unambiguously in his Wikipedia profile that he works for Astrazeneca.

Official Pharma Wikipedians?

Did Astrazeneca empower Yockey or give him permission to edit Wikipedia pages about AZ drugs? That is, is Yockey an "official" Wikipedia spokesperson appointed by Astrazeneca to perform all Wikipedia article edits on behalf of the company? I doubt it. Yockey's profile specifies that he works on edits from home.

Official pharma employee Wikipedia editors and related issues were discussed during a recent Pharma Marketing Talk podcast titled "Pharma Wikipedians: The Pros and Cons of Pharma Employees Editing Wikipedia Articles" (turn to page 7 for an edited transcript).

It's possible to determine the exact edits Yockey has made to the Wikipedia rosuvastatin page, but I do not have the time or resources to find that needle in a haystack of thousands of edits Yockey has made to Wikipedia articles over the years. Wikipedia is not user-friendly enough to allow ordinary citizens to ferret out that kind of information, IMHO.

Consumer Unfriendly Wikipedia

Another problem with Wikipedia drug information pages is that they are not consumer-friendly—i.e., not written at a level that is understandable by non-physicians. The Wikipedia rosuvastatin page, for example, says "as with

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all statins, there is a concern of rhabdomyolysis, a severe undesired side effect." Unfortunately, the article does not explain what rhabdomyolysis is in layperson terms.

Survey: Should Pharma Edit Wikipedia Articles?

To get a broader view of pharma Wikipedia editing issues, *Pharma Marketing News* hosted a survey that asked under what circumstances should pharma edit Wikipedia articles. This survey was inspired by Bertalan Meskó, MD, founder and managing director of Webicina.com. Meskó wrote an open letter to pharmaceutical companies, inviting them to "employ a Wikipedia editor if you want to make sure only evidence-based information is included in entries about your own products."

Dr. Meskó is a Wikipedia "administrator," which means he has "been granted the technical ability to perform certain special actions on English Wikipedia, including the ability to block and unblock user accounts and IP addresses from editing, protect and unprotect pages from editing, delete and undelete pages, effectively to rename pages without restriction, and use certain other tools." Read Meskó's opinions about pharma editing Wikipedia articles starting on page 8.

Respondents to the survey were asked how strongly they agreed or disagreed with several statements regarding the pros and cons of pharmaceutical companies editing Wikipedia articles that include "misinformation" about their drugs. The survey did not define what was meant by "misinformation," leaving it up to respondents to interpret that as they saw fit (see PhRMA's viewpoint on page 6).

The statements were:

1. Pharma should NOT correct Wikipedia "misinformation" under any circumstances.
2. Pharma should appoint employees or hire outside "Wikipedians" (ie, trained specialists) to edit "misinformation" on Wikipedia.
3. When pharmaceutical company employees or agents correct "misinformation" on Wikipedia, they must reveal their ties to the company.
4. When pharma corrects Wikipedia "misinformation" about Rx products, FDA should NOT consider this promotional labeling subject to regulation.
5. If pharma edits Rx information on Wikipedia and this information is later re-edited by others, pharma should not be held responsible for any resulting misinformation.

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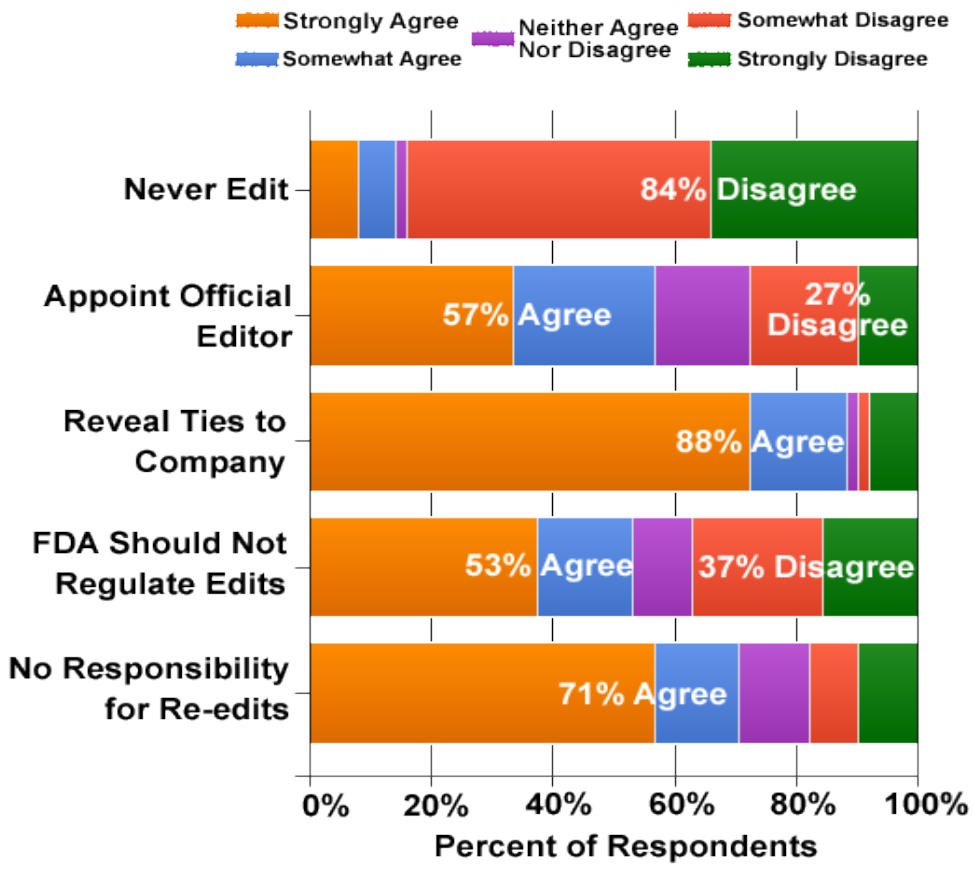

Figure 1. "Should Pharma Edit Wikipedia Articles?" Survey Results. All Respondents (N=51). The survey is still running. Complete the survey and see more detailed up-to-date results: http://svy.mk/MCPskT

According to a majority of survey respondents—50% of whom work for FDA-regulated life science companies (22%) or for companies that have such companies as clients (28%)—pharma companies should correct "misinformation" about their products on Wikipedia, but should designate someone who is trained to do it properly and transparently (see Figure 1, pg 5). Most respondents (53%) agree that the FDA should not consider pharma edits of Wikipedia drug information as promotional and therefore subject to regulation (37% disagree). A large majority (71%) of respondents agree that pharma companies should not be held responsible for any misinformation resulting from re-edits by others.

Comments from Survey Respondents

What is "Misinformation"?

Defining "misinformation " is critical in understanding this survey. Disagreement is part of progress. Transparency in debating disagreement is critical. Wikipedia ideally should foster transparent debate in a subsection of anything controversial. – Anon., non-pharma respondent (healthcare professional), somewhat supportive of pharma industry

Their "misinformation" is usually lies. Therefore completely independent sources INCLUDING patients who have been affected by the drugs and lies should have an opportunity to weigh in. All information on the Web should be taken with a grain of salt so people's experiences and opinions should stand. Consumers need to make their own final decision and take the responsibility. Sadly, their are so many lies and fraudulent "studies" handed out by the drug companies and the FDA is corrupt. So we are on our own. – Anon., non-pharma respondent (healthcare professional), very unsupportive of pharma industry

FDA as Referee?

Of course, to strengthen the objectivity of information/data, FDA might follow Wikipedia entries by the pharma companies - they might act as sort of referee certificating pharma based submissions. By building on certified submissions a pharma company could gain trust perceptions! In fact, entries on meds could best be certified through certifying bodies. The question of course would be how those certifying bodies would work. [t]heir procedures would be the basis of the certification..;-) – Rob Halkes (@rohal), agency having pharma clients, somewhat supportive of pharma industry

The general public uses Wikipedia as their main source of information. I'm not saying this is the best source to go to when performing Internet searches, but it is one of the most common information sources for the public. It would be wise for pharma to edit and monitor Wikipedia entries regarding their drugs, both to make sure false information isn't being posted, and to fulfill an ethical obligation to ensure the searcher (most likely, patient) is being correctly informed.

With the Internet and social media being such an integrated part of our lives, it only makes sense that pharma keeps up. However, I think the FDA should be more lenient on what is posted to Wikipedia, keeping in mind that it is a publicly edited source. – Anon., agency having pharma clients, neutral

From my experience it can be somewhat difficult to update/change a Wikipedia page - why would Wikipedia support additional resources, outside of Pharma, in further

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PhRMA's Views on Correcting "Misinformation"

(Source: "Accountability for Pharma Content on Social Media Sites'; PMN93-03; http://bit.ly/NHRvDf, pdf)

In comments to the FDA, PhRMA suggested that manufacturers would welcome correcting misinformation about their products posted to sites like wikipedia if these corrections 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."

PhRMA acknowledges, however, the futility of correcting misinformation on sites like wikipedia and sidewiki.

"Even when manufacturers take corrective measures," said PhRMA, "there is no guarantee that the company's alterations or posted information will remain in a correct state; users of Wikipedia, for example, may simply edit or delete the sponsor's corrective post. For such independent sites, manufacturers cannot be held responsible for all content. By definition, manufacturers cannot control the content of most independent blogs (including Sidewiki) and therefore cannot be held responsible for them."

changing what has been posted from the maker/company itself? How often does this happen on other pages? The information is up there regardless, let's get those who follow guidelines - Pharma - making the updates to the Wikipedia page, since the public is seeking information [from] there regardless. – Anon., employee at agency having pharma clients, very supportive of pharma industry

The same ethics should apply to updating "information" (ie, not promotional marketing copy) on Wikipedia as for any pharma company website. It is important that communications professionals take responsibility for these updates with the full backing of the management. – Pharma employee, somewhat supportive of pharma industry

Creation of a trusted arms length broker organization having medical information librarians to edit Wikipedia pages (even if funded by Pharma companies) should aim to allow balanced non-DTC drug information to be brought into the light of day for public use and dissemination. It may be also worth investigating the creation of some kind of page "Wikilock" mechanism for such pages to ensure patient safety is not compromised and a factual balance is maintained. The information for such a "Drugpedia" would be derived from the hidden vaults of non-marketing product information held by manufacturers and licence holders that are currently only available via, for example, formal documents such as SPCs and PILs, or (and only in some countries) through specific non-promotional answers generated by Pharma medical information departments in response to unsolicited questions from HCPs and patients. – Anon., pharma employee, very supportive of pharma industry

Role of FDA, PhRMA, and Wikipedia Itself

Wikipedia has become a major source for health information and misinformation regarding medicines can be dangerous. Someone needs to be accountable for endeavoring to insure the most accurate information is available through Wikipedia and logically that party should be the manufacturers. If the FDA would provide the guidance that pharma can only used pre-approved labeling information to correct Wikipedia misinformation, would that not solve the issue? Am I oversimplifying? – Anon., pharma employee, neutral

Phrma could partner with WP to come up with guidelines e.g. how to report efficacy. – Anon., employee at agency having pharma clients, somewhat supportive of pharma industry

Podcast Discussion

The following is an edited/shortened transcript of a Pharma Marketing Talk podcast recorded live on July 17, 2012. The topic of discussion was: The Pros and Cons of Pharma Employees Editing Wikipedia Articles: Should pharmaceutical companies appoint employees as Wikipedia "spokespeople" to perform all edits on behalf of the company? The guests were Bertalan Meskó, MD, founder and managing director of Webicina.com, Michael Spitz, SVP and Managing Director at Zemoga, and Silja Chouquet, owner and CEO of whydot GmbH. To listen to full audio podcast, go here: http://bit.ly/PMT170a

John Mack [JM]: Bertalan Meskó's open letter to pharma urging the industry to "employ a Wikipedia editor" was the inspiration for the survey just mentioned. The first question asked in that survey is: Should pharma companies go into Wikipedia and correct "misinformation" under any circumstance? Michael Spitz, tell us your opinion.

Michael Spitz [MS]: I would venture to say unequivocally, yes, pharma companies should edit misinformation about their products on Wikipedia. I believe pharma companies are the experts about their own molecules whether they did the actual research and development and ushered them through clinical trials and launch or whether they purchased the molecules. I think the pharmaceutical industry is ultimately responsible for the dissemination of accurate, FDA-approved information, whether it's on crowd sourced channels such as Wikipedia or even on third-party sites.

There is a boundary to pharma's capacity to publish certain information, but they're the keepers of the data and should be its policemen in a sense.

Who Determines What is "Misinformation"

JM: I guess everybody realizes that obviously, pharma companies have the information, but sometimes they don't quite report the full information or they twist it a little bit. One of the questions people were asking in the survey is: What do we mean by "misinformation?" Obviously, there are all kinds of misinformation—who determines what is misinformation and what's not misinformation?

MS: The ultimate bible for a particular treatment option produced or distributed by a pharmaceutical company is the prescribing information, which goes back ultimately to the clinical trial data. It's possible for someone [editing Wikipedia drug information] to make a false claim about efficacy or contraindications, or state errors with regard to administration, and even the side effect profile. In these cases, the pharmaceutical company could and should go into that source and make corrections.

JM: I just viewed the Wikipedia entry for Brilinta (ticagrelor), a drug marketed by AstraZeneca (AZ). The information for this drug looks like the official package insert, but it's not the complete FDA-approved

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package insert. When you look at the editing history you find that someone called "Anypodetos" is the probable author of the original page. This person's Wikipedia profile is very sparse with regard to credentials and possible conflicts of interest. So it's still somewhat anonymous.

Sole Pharma Authorship on Wikipedia

MS: I think you're bringing up a secondary question, which is: Should pharmaceutical companies create a Wikipedia article from scratch and ultimately be the owner?

Personally, I think that pharmaceutical companies should **not** do this and the reason I think that they shouldn't is because ultimately they're able to communicate about their brand only within the boundaries of the approved prescribing information. When you're dealing with a legacy molecule, one that might have gone generic, there's a treasure trove of information that often goes beyond what the generic or the brand has been indicated for, what's in the package insert.

Many pharmaceutical companies, within password-protected physician portals, make available research information that would be considered off label in other contexts. This is outside the boundary of what we consider marketing information. It's a value-added resource that pharmaceutical companies will provide to physicians and again it has nothing to do with the marketing and communications aspect of the drug.

The reason I bring that up is because a Wikipedia article about a drug should probably be as comprehensive as possible. In order for that article to be as comprehensive as possible from a pharmacological point of view, it de facto will go beyond the regulated indication of the molecule as approved by the FDA. So, what I'm saying is that the pharmaceutical company really can't be the sole author of a Wikipedia drug article because from a communications standpoint, the information that they can share is limited and based solely upon the FDA-approved package insert.

Therefore, I think the responsibility for authorship should lie outside the pharmaceutical industry. The pharmaceutical industry should provide error checking for any and all information that's within the approved indication. For any kind of off-label discussion, any kind of discussion of the drug and its potential outside the boundary of that indication, edits have to be handled by somebody else.

In a nutshell, a pharmaceutical company cannot own a Wikipedia article or any crowd sourced article. A pharmaceutical company needs to rely on a third-party creator of this content, a third party that could be more comprehensive in the scientific description and analysis of the treatment options. The pharmaceutical company, however, can weigh in and say that within the boundaries of prescribing information, the information that you are sharing is or is not accurate and provide corrections as necessary.

Dr. **Bertalan Meskó** [BM]: I have to say that I represent two points of views. First, I'm a social media consultant for many pharma companies and in many cases I have to help them regarding Wikipedia. I have been a Wikipedia administrator since 2006 and for six years I've been quite active. I have been working on medical projects in Wikipedia and that's why I also represent the Wikipedian point of view.

I wrote that open letter to pharma companies about using Wikipedia. In that letter, I said that we Wikipedians are more than open to starting a discussion about this whole issue with them.

Bad Pharma Wikipedians

The reason why I sent the open letter to the major pharma companies was that a few years ago, a certain pharma company—I won't say the name—started editing Wikipedia entries about their own products in a non-neutral way. It led to blocking of several user accounts from IP addresses owned by the company. They came back from different computers and made the same edits. Finally, after weeks of fighting, Wikipedia administrators decided that the accounts from that pharma company should be blocked. It was quite hard for us to deal with that situation.

Since then when a pharma company tries to edit or have been trying to edit a Wikipedia entry about their own product, it has been quite complicated for us to know how to deal with this. Because anyone can edit Wikipedia, they [pharma companies] should be able to add their own changes to those entries especially regarding their own products. But because of this controversy of years ago, it's been quite complicated.

That's why first we crowd sourced a social media guide for pharma companies last December in which we had a whole page dedicated to Wikipedia. When we created this page, I asked my fellow medical editors on Wikipedia about their opinion and based on those opinions and feedback, we created a list of suggestions or pieces of advice about what a pharma can do when they want to edit Wikipedia (see box on page 9).

Now a few weeks ago, I came up with this open letter suggesting that pharma companies should appoint one Wikipedia editor, a spokesperson from the pharma

Continues…

company who could make these edits, who could make his or her profile absolutely transparent on Wikipedia revealing any conflict of interest, being absolutely transparent and complete in every detail. I believe that will be the best solution to overcome the problem that has been out there for three or four years now.

Training, Certification of Pharma Wikipedia Editors

JM: The pharma Wikipedia editors that you're talking about, I assume these are specialists that either are employees of a pharmaceutical company or hired by a pharmaceutical company and they require special training on how to work with Wikipedia. Correct? Do you need to certify them, anything like that?

BM: The current Wikipedia drug article editors, the majority of them, have known each other for years now. I know that many of them are medical professionals. Some of them are even professors. Some of them are medical students. So this is the Wikipedia medical community. Although anyone can edit medical entries, only medical professionals and medical students are involved in medical projects such as the WikiProject Medicine.

> NOTE: WikiProject Medicine project aims to enable Wikipedians to cooperate, organize, make suggestions and share ideas on the improvement of the medicine and health-related articles of Wikipedia. According to Wikipedia, "everyone is welcome to join in this endeavor" (regardless of medical qualifications!).

BM: If someone from a pharma company would like to become the Wikipedia spokesperson for that company, I believe that with one or two hours of work, they can learn all the tips and tricks they have to know about editing Wikipedia. It's really easy. They have to be able to understand the basic concepts such as those listed in our social media guide and that's it.

MS: I think we're in agreement that the pharmaceutical company should be a fact checker, an error corrector. The pharmaceutical company could and should be empowered to edit and make comments about the treatment options that they ultimately develop and bring to market. But I think an important part of this conversation concerns the boundaries of the pharmaceutical company in terms of (a) creating some of these articles from scratch, (b) editing existing articles, and (c) selecting content for dissemination through crowd sourced channels like Wikipedia. How do we determine where these boundaries lie?

BM: That's a very good question and also a very complicated question. I don't believe that it is the responsibility of pharma companies to edit the entries about their own products on Wikipedia. If they want their customers to access only quality information, they have a chance to edit these entries. I'm not saying this is their responsibility. I'm saying there's a possibility for them to make those edits.

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Advice for Pharma Wikipedia Editors

(Source: "Open access social media guidelines for pharma"; http://bit.ly/MFzZm3)

Wikipedia is not a patient guide or drug formulary, it is an encyclopedia.

Companies are in a unique position to provide additional knowledge. 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.

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 you 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.

A Wikipedia Sandbox Just for Pharma to Play In?

Silja Chouquet [SC]: What I think from what I heard Michael and you say, the problem is that the FDA-approved pharmaceutical information is limited. I agree that there should be one pharma company social media/Wikipedia spokesperson, but I wish I had seen in your letter a request that pharma companies take whatever they can legally communicate and put it into Wikipedia. Take the content of their websites and have a page in Wikipedia saying this is the product information that pharmaceutical companies can provide at this moment and have that as a marked area in Wikipedia that can be referenced and have pharma responsible for keeping that updated. I think anything that goes outside of that scope is very difficult to monitor and as Michael said, very difficult to set the limits and boundaries.

JM: Are you suggesting that pharma companies reproduce what they have on their product websites?

SC: Yes, they should embed their product information on Wikipedia and make it clear that that's what they can communicate, period.

BM: It's a very special issue. If you're saying that there's a certain product on Wikipedia, for example an English one and it's the responsibility of that specific pharma company with that product to update that entry. I'm saying that they can do that, but other editors or even anonymous users can remove those changes at any time. That's why I believe it's impossible to do that. Just like reproducing the content, pharma companies have to know that they have to use the Creative Commons 3.0 license, which I don't believe they would like to use because I believe that the majority of their content is copyright content. That's why it's a very tricky issue.

Also, you cannot make such a deal with Wikipedia because it was founded by the Wikimedia Foundation, which is a nonprofit and the Wikipedia entries are edited by people from around the world, not just a group of editors who are in complete control of the process.

MS: I like the idea of a delineated area, but I understand that by definition a crowd sourced platform like Wikipedia can't allow that. So if this information can't be contained or separated, then it goes back to the pharmaceutical company's ultimate responsibility to fact check and correct obvious errors. I think everyone agrees with that.

Robots Enforce "Structured" Drug Information

BM: Of course, it's very complex to find a way to update these entries, but that's why for the last two years, Wikipedians have been working on a common structure for all these entries focusing on pharma products. We also created a pharmacology Wikiproject (http://bit.ly/LLiUFL) in which there are plenty of volunteers from pharma and from medicine who are trying to make this structure the best possible. Now if you take a look at any of these product Wikipedia entries, you will see the same exact structure. For the past year, robots have been trying to make the same structure or create the same structure for each entry.

We also have style guidance on Wikipedia for pharma products and other medical entries about diagnosis, treatments, and so on. Based on that quite long guidance plus this structure, we hope that only the best information will be included about each entry. Actually, I believe that that's the only way to make sure we do our best.

But that's why I wrote in my open letter that we are eager to start a discussion with pharma companies. At least they should tell us their opinion, what kind of structure they would like to use, what kind of studies they would like to include and then we can come up with an even more extended guidance and find out how we can work together to improve the entries. At the end of the day, the aim is to make better entries containing better information for consumers who want to access this information. That's the common goal of everyone involved.

SC: Also, I think it would be very helpful for the FDA to recognize that it's actually a hazard to patient safety to have misinformation on something as important as Wikipedia, right? FDA needs to clarify what is promotional and what is not when pharma companies edit Wikipedia pages.

MS: To Berci's point, just because you have a crowd sourced platform does not mean you have editorial chaos. There are editorial standards. Jimmy Wales [the co-founder of Wikipedia] from the beginning espoused the notion that although Wikipedia was crowd sourced, it has group approved standards. If you could realize a certain critical mass of standardizations for these products, these treatment option articles, structured in a way Berci has outlined right now, then in a sense the structure of the article themselves becomes proscriptive enough to preclude opportunism on the part of either pharmaceutical companies or their agents to "vandalize" the information,

Call for a Pharma Wikipedia Summit

BM: If I were a pharma company executive, I wouldn't want to wait for the FDA to come up with an extended detailed guideline about using Wikipedia, but I would love to discuss these issues first with Wikipedians. Let's get to a consensus and as soon as we get that, we can approach the FDA as well as the European Medicines

Agency just like we did when we published the social media guidelines a few months ago. Hopefully, based on the feedback and based on the guidance we provide, these agencies will come up with something we could use as soon as possible.

JM: Perhaps it would help to convene a high level summit of medical Wikipedians and pharma companies to discuss this issue?

MS: A summit is a good idea for reconciling this issue and pinpointing the role pharma should play, figuring it out structurally in terms of how to moderate the conversation, how to systematize it without limiting the freedom of the participants. It's an issue that's not going to go away. I think those solutions and recommendations are going to reverberate through digital health overall and it very well might even help some of the regulatory bodies better understand these new digital platforms and how the constituents are talking to each other and actually pave the way forward for embracing it in the future.

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