



Infiltrating on-line patient forums for profit

On-line patient forums provide people affected by neurological and other conditions a place to find information, support, and a voice. Signing up is easy—but does that make these sites easy targets to be exploited for profit? Adrian Burton investigates.

For more on **counterfeit medicines** see <https://www.fda.gov/drugs/buying-using-medicine-safely/counterfeit-medicine>

For a **recent case of executive racketeering** see <https://www.nytimes.com/2019/05/02/health/insys-trial-verdict-kapoor-may/02/john-kapoor-opioids-billionaire-founder-guilty-of-bribing-doctors-to-prescribe>

For the **STAT article on social media influencers** see <https://www.statnews.com/2018/11/13/patient-influencers-get-a-voice-and-pharma-is-ready-to-pay-up>

For more on **information sharing policies of PatientsLikeMe.com** see <https://support.patientslikeme.com/hc/en-us/articles/201245750>

For the **PharmaTimes article** see http://www.pharmatimes.com/web_exclusives/harnessing_patient_communities_1209061

From snake-oil touts to clinics offering dubious treatments, from counterfeit medicines and fake doctors to racketeering pharmaceutical company executives, the history of medicine and healthcare is littered with examples of how the less scrupulous have tried to make unfair profit out of patients. In our current on-line world, with all its information harvesting, scams, purported alternative facts, and attempts to manipulate our behaviour, the bad guys can reach more patients than ever. What, for example, is to stop them signing up to a forum for patients with multiple sclerosis, Parkinson's disease, or Alzheimer's disease and attempting to steer information exchanges in directions leading towards their financial benefit? Or for a private clinic to casually diffuse its supposedly very promising results, for a fraudulent pharmacy to sell worthless medications, or for an unprincipled manufacturer to promote off-label

sales of its drugs? Once a buzz is created around a product's alleged benefits, it won't be long before patients are buying it or asking their neurologist to prescribe it. It's a front-line problem that independent patient websites must deal with every day.

And they should be wary: online engagement with patients has become of great interest to vendors of drugs and medical services (the following examples imply no illegal activity). A recent STAT article reports how some companies now pay so-called social media influencers when they mention their brands. The text states: "Patient influencers can be paid both for posting about a drug or a device, but also for bringing the opinions of people like them to the companies developing those products". Some companies buy information left by participants in community forums on websites such as PatientsLikeMe.com. With abundant transparency, the site states "We take the information patients like you share about your experience with the disease and sell it to our partners". Similarly, ParkinsonsDisease.net, one of over 20 patient sites owned by Health Union, also brings patients and corporate partners into close contact. "The people we serve via our 22 (and growing) condition-specific online health communities are our utmost priority", explains Health Union's Chief Operating Officer Lauren Lawhon. "This includes providing safe, supportive environments where people can engage with others who share their experiences and find the information, support, and validation they want. [Health Union] enables companies to connect, interact, and engage with our patient communities through paid relationships—with the biopharma

brands most relevant to the needs of the people within our individual communities—for media, market research, and clinical trial services. We strive to be open and honest within our communities regarding advertising, corporate partnerships, and sponsor relationships and always clearly disclose these relationships within the context of those communications." Companies may even choose to run their own patient community websites. A 2017 article in *PharmaTimes* online entitled *Harnessing patient communities* highlights the value of such activity: *Making online health communities work for your brand*, runs one subheading, *Whether called online health communities, treatment communities, or disease-state communities, these groups are a smart way for pharmaceutical companies to connect with their patients and consumers. Link all this with the knowledge that even legitimate pharmaceutical companies have been fined (sometimes heavily) for illegally (and creatively) promoting the off-label use of their products (off-label promotion is widely prohibited by law, but off-label prescribing by doctors is not; the trick is to get them to do it) and it's no big jump to see how independent patient forums could be targeted by unscrupulous agents for non-consensual information gathering or marketing purposes.*

And things do happen. "We have not come across any examples where we believe pharmaceutical companies have been trying to exert influence on forum users, but we do very regularly receive posts from people attempting to sell or promote unlicensed products", says Sarah Jarvis, Clinical Director of Patient, a website that aims to provide reliable information on different health conditions, treatments, and resources



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etc. "We are very aware that there are parties who would like to exploit people in our online community", adds Reah Brown, Community Manager for Parkinson's UK. "Currently we spot around five such posts a week. The majority tend to promote natural remedies that are on sale, or mobility products, rather than off-label drugs."

The UK Alzheimer's Society report similar attempts: "Quite a lot of 'spammy' content doesn't make it past the controls, but we have occasionally had an issue like that", explains Online Community Manager, Serena Snoad.

Richard Bedlack, Professor of Neurology at Duke University (Durham, NC, USA), recounts a problem his group faced with its *ALSuntangled.com* website. Recent winner of the American Academy of Neurology's Brainstorm Competition, the site helps patients determine the value of alternative and off-label treatments for amyotrophic lateral sclerosis (ALS). Users propose drugs and treatments for the site's scientific team to review and vote for the proposals they would most like to see reach the review stage. Voting occurs by simply clicking on a proposal's link. Once written, reviews are submitted for publication to the journal *Amyotrophic Lateral Sclerosis and Frontal Degeneration*. But what stops a malicious agent signing up, making a proposal, and voting it into the review process by simply clicking the appropriate link many times? "In 2009, when we first started, some of my colleagues had the exact same concern", says Bedlack. "But we could find no other similar program on any disease, so we were not sure [what to do]. On behalf of our patients, we decided to move forward with it anyway and see what happened." And something did happen, although via an unexpected route. "So far as I am aware, one commercial group has, what I would say, 'capitalized' on what we are doing", he explains. "Some independent distributors within a multi-level marketing company were selling a product called [X] that we

wrote about and eventually did a trial on. I woke up one morning to find a large number of Facebook messages from people with ALS asking why I did not just tell them directly to start taking this product. I learned that one of the distributors had gone into my Facebook account, found the patients with ALS, and told them that I was recommending [X] for them. Some of these distributors continue to advertise [X] as being under study at Duke University, but that study was completed over a year ago, and the negative results were presented publicly multiple times and even published. However, I continue to have patients with ALS around the world e-mail me to tell me they are considering starting [X]. There may be other examples of this kind of thing that I do not know about."

To protect themselves, sites often rely on forum moderation helped by automated word flagging. "Patient.info has a very strict moderation process that includes over 2700 words that are immediately flagged to our moderator if they come up", explains Jarvis. "If brand names are used specifically, and especially if they are used repeatedly, these will also be flagged. If there is any suggestion that a user is trying to influence others to use disreputable or unproven products, or if the moderator believes there is any reason to be suspicious that they are trying to influence others dishonestly, the post will be deleted. In the case of repeat offenders we will blacklist the user. We will also be more vigilant [in future] about any attempts they make to return by making a different user account."

"In addition to our 24/7 team of moderators, we use an algorithm to identify suspicious activity, and forum members can also flag any concerns", explains Brown. "[And although] we do not want to discourage people from joining the forum by asking for intrusive levels of personal information, we [try to reduce the risk of people setting up fake accounts

by requiring new members create] a profile and write a post introducing themselves to the forum, rather than just entering a name and e-mail address, and every new sign-up is reviewed. But of course, we know it is possible to create a fake profile and then attempt to promote products, goods, or services."

"We set terms and conditions that we ask all members to agree to when joining, [which] includes not promoting products or companies and also not giving medical advice to others", says Collins. "In addition, new members are not permitted to post links until they have posted ten times. We also have a system within the software that will flag [and can put on hold content with] specific keywords. Most importantly, we have three trained teams working on the community—two teams of volunteers and one team of staff, and they work together to manually review new members, identify and report issues, and edit/remove/ban if necessary."

"Websites can increase security by trying to identify fake accounts. One way to do this is requiring a unique email address, which can be difficult to set up in bulk", explains Alice Hutchings of the Computer Laboratory Security Group, University of Cambridge (Cambridge, UK). "While they could block IP addresses from VPNs (virtual private networks) and anonymity networks, these may also be used by patients for privacy purposes. Any voting could be limited by account or IP address. A more effective method to prevent rogue advertisers may be to disrupt how they receive payments, by blocking their payment networks."

But in the end, patient website users need to be aware of what they consent to, and remember that there are parties out there eager to make money out of their misfortune. There's still nothing quite so likely to spoil a snake-oil salesman's day.

Adrian Burton

For an example of a pharmaceutical company being fined see <https://www.justice.gov/opa/pr/glaxosmithkline-plead-guilty-and-pay-3-billion-resolve-fraud-allegations-and-failure-report>

For the Patient website see <https://patient.info>

For more on off-label promotion and regulation see <https://www.whistleblowersinternational.com/types-of-fraud/pharmaceutical/off-label-marketing> and <https://www.tandfonline.com/doi/full/10.1080/14740338.2016.1186642>

For more on the Alzheimer's Society see www.alzheimers.org.uk

For more on ALS Untangled and AAN's Brainstorm Competition see <https://neurology.duke.edu/about/news/highlights-aan-brainstorm-award-parkinsons-and-exercise-ulysses-s-grants-headaches-and>