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Comparison of Drug Information on Consumer Drug Review Sites Versus Authoritative Health Information Websites

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Abstract

Huge amounts of health-related information of different types are available on the Web. In addition to authoritative health information sites maintained by government health departments and healthcare institutions, there are many social media sites carrying user-contributed information. This study sought to identify the types of drug information available on consumer-contributed drug review sites compared to authoritative drug information websites—what types of drug information are common and unique, and how they differ in nature, detail and usefulness.

Content analysis was carried out on the information available for nine drugs on three authoritative sites (RxList, eMC and PDRhealth), as well as three drug review sites (WebMD, RateADrug and PatientsLikeMe). The types of information found on authoritative sites but rarely on drug review sites include pharmacology, special population considerations, contraindications and drug interactions. Types of information found only on drug review sites include drug efficacy, drug resistance experienced by long-term users, cost of drug in relation to insurance coverage, availability of generic forms, comparison with other similar drugs and with other versions of the drug, difficulty in using the drug, and advice on coping with side effects. Drug efficacy ratings by users were found to be different across the three sites. Side effects reported on drug review sites are vividly described in context, with user assessment of severity based on discomfort and effect on their lives. Users also report side effects not found on authoritative sites.

INTRODUCTION

There is a huge amount of health-related information of various types on the Internet that is relevant to both health professionals and laypersons, including patients and caregivers. Medical information that would have been available only to health professionals in the pre-World Wide Web era is now available to everyone with a mobile device and Internet connection. Health-related organizations are also putting out a lot of information tailored for patients and laypersons. An example is the *Patient Care and Health Information* section of the Mayo Clinic website (<http://www.mayoclinic.org/patient-care-and-health-information>). In addition, there is tremendous growth in user-contributed content on different kinds of social media platforms, including:

- health discussion forums, for example HealthBoards.com (<http://www.healthboards.com/boards/index.php>)
- drug review sites, for example the *Drugs and Medications* section of WebMD, (<http://www.webmd.com/drugs/index-drugs.aspx>)
- health blogs, for example the University of Michigan Health Blogs (<http://uofmhealthblogs.org/>), and
- social networking sites, for example PatientsLikeMe (<http://www.patientslikeme.com/>) and Inspire (<http://www.inspire.com/>)

Searching for health information on the Web has become a common activity. A nationwide telephone survey in 2012 by the Pew Research Center's Internet & American Life Project found that 81% of adults in the U.S. used the Internet, and of these 72% had accessed health information online in the previous year (Fox & Duggan, 2013). 18% of Internet users had also consulted online reviews of particular drugs or treatments. An earlier survey in 2008 found that Internet users with one or more chronic diseases were more likely to consult online reviews of prescription or over-the-counter drugs (48%) compared to Internet users with no chronic disease (43%) (Fox & Purcell, 2010).

Generally, health information can be obtained from two types of Web sources: authoritative websites and social media websites. Authoritative websites provide information from official or expert sources such as government health departments and regulatory bodies, healthcare institutions (e.g., hospitals),

pharmaceutical companies, and medical and pharmaceutical associations. On the other hand, social media sites which are equipped with Web 2.0 technologies have enabled patients to contribute and share health-related information based on their personal experiences. With the growing use of social media platforms such as discussion forums, blogs and microblogs, review sites, Q&A sites, and social networking sites, the information flow is no longer just one way where users passively consume factual information from websites (Chou, Hunt, Beckjord, Moser, & Hesse, 2009). In addition, they also make use of social media platforms to form online support communities to share and discuss with other patients with similar conditions and treatments (Farmer, Bruckner Holt, Cook, & Hearing, 2009).

Health professionals and medical librarians have a fairly good idea of the types of health information published on authoritative websites, but it is not clear what new kinds of health information are contributed by patients and caregivers to social media sites, how trustworthy they are and what they can be used for. Earlier studies of online health information have focused on the quality of information, including credibility, readability and accuracy (e.g., Eysenbach, Powell, Kuss, & Sa, 2002; Soobrah & Clark, 2012; Thompson & Graydon, 2009). In addition to differences in quality, there are differences in the types of information on social media sites, as well as their nature, context, details provided, purpose, potential use and presentation style of information. Few studies have attempted to identify and compare the types of information available on authoritative sites and social media sites. Such a study will help health professionals, information professionals and laypersons to understand the value of user-contributed health information, their potential use and usefulness, and whether it is worthwhile to actively search for health information on social media sites.

Recent studies that have analyzed the content of online health information have focused on particular diseases, for example diabetes (Greene, Choudhry, Kilabuk, & Shrank, 2011; Zrebiec & Jacobson, 2001), dementia (Farrow, 2013) and cancer (Hartzler & Pratt, 2011; Huang & Penson, 2008). However, very few studies have analyzed and compared the content of drug information on authoritative websites and social media sites.

The objective of this study was to identify the types of drug information provided on consumer-contributed drug review sites compared to authoritative drug information websites. In

particular, we wanted to find out what types of drug information are common to both authoritative and drug review sites, and what types of information are unique to drug review sites. For the types of information that are common to both types of sites, we sought to identify the differences in nature, detail and usefulness.

The results of this study will be of interest to medical librarians who would want to know whether social media sites are worth searching for health/medical information to respond to user queries. It will also be of interest to health professionals to know whether social media content provide more insights on the effect of diseases and treatments, issues encountered by patients, and patient behavior that affects their recovery. Finally, patients and caregivers will be interested to know what kinds of useful information they can expect to find on social media sites, and how they should interpret the information in the context of their own condition.

PREVIOUS STUDIES

Before social networking sites became popular, the studies that investigated user-generated content had focused on communication platforms such as email mailing lists (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007), chat rooms (Coleman et al., 2005; Macias, Lewis, & Smith, 2005), and blogs (Chung & Kim, 2008). In recent years when the use of social networking sites have become prevalent, more studies have focussed on the content shared in health communities formed on popular social networking tools such as Facebook (Farmer et al., 2009; Greene et al., 2011) and Twitter (Robillard, Johnson, Hennessey, Beattie, & Illes, 2013).

The results of these studies on different social media platforms indicated that disease management and emotional support were common themes in the postings of social media users. In a study of an alcoholism community on the MedHelp social networking site, Chuang and Yang (2012) found two types of social support in the user postings:

- informational support, including facts, advice, information referral, personal stories and opinion
- nurturant support, including esteem support, network support and emotional support.

They found that the relative proportion of each type of support depended on the communication medium, with a higher proportion of informational support on the discussion forum. Among the three

subtypes of nurturant support, expressions of emotional support were the most common. Expressions of emotional support include stressing the relationship the recipient has with others, physical affection, assurance of confidentiality, sympathy, indication of listening or attention, understanding and empathy, encouragement and prayers.

Most studies that have analysed the types of health-related information on social media sites have focused on the patients' management and perception of the disease, rather than on the experience with the drugs prescribed for their conditions (Greene et al., 2011; Zrebiec & Jacobson, 2001). Greene et al. (2011) found that information exchanged on an online social networking community can contain blatant advertisements of non-FDA approved drugs and information with questionable intent.

Nevertheless, two studies have focused on comparing the side effects of specific drugs reported on drug review sites, with the side effects stated on authoritative websites.

Hughes and Cohen (2011) investigated the commonly reported side effects of two psychotropic medication—escitaloprom (an antidepressant) and quetiapine (an antipsychotic)—on four consumer drug review sites, and compared these side effects to the ones presented on two authoritative websites. They found that the side effects mentioned in the drug reviews were similar to the ones stated on authoritative websites. The differences lay in how the side effects were described and the relative frequencies of mentions of the side effects. Side effects that were more apparent and had a direct effect on patients' daily lives such as drowsiness and weight gain were mentioned more often on drug reviews. While authoritative websites provided concise and comprehensive lists of side effects of the drugs, the reviews provided “richer descriptions of effects in context” and “situational examples of how effects may manifest in various combinations and to varying degrees.” The consumer reviews also reported off-label uses of the drugs such as as a sleeping aid.

In addition, the perceived importance and severity of side effects reported in the reviews were incongruent with how the authoritative websites categorized the side effects. For example, drowsiness was listed as a less severe side effect of quetiapine on the authoritative website; however reviewers reported having to miss work because they couldn't stay awake. The sexual effects of escitalopram were labelled in the authoritative sites as less serious, less severe or severe; whereas reviewers used

the expressions “the absolute worst,” “extremely frustrating” and “can’t perform sexually so you get depressed and anxious.”

In another study, Schroder, Zollner and Schaefer (2007) compared the side effects of Parkinson drugs mentioned on online forums with the side effects listed on a Parkinson database. The results of this study were similar to the study by Hughes and Cohen (2011). The side effects mentioned on the online forums were similar to the ones stated in the Parkinson database. Side effects that were more obvious and caused more immediate distress to patients were more frequently mentioned on online forums compared to the side effects reported in clinical trials of the drugs. For instance, the percentage of skin reactions caused by anti-Parkinson’s drugs mentioned on forums (23%) was much higher than the percentage reported in the clinical trials (0.8%). On the other hand, side effects related to the cardiovascular system and general well-being, which were more insidious and unnoticeable, were seldom mentioned.

These studies have focused on only a few drugs for a specific disease and one type of information—side effects. Our study sought to identify and compare other types of health-related information on social media and authoritative sites for nine drugs used to treat three chronic diseases.

Fox (2007) had found that patients with chronic conditions (54%) were more likely to search for answers to their health concerns online as compared to people with acute conditions (7%). Fox further found that a majority of patients with chronic conditions had reported to gain positive feelings after searching online for health information such as reassurance, comfort, and confidence in querying their doctors about their condition. Patients with chronic conditions were also more likely to share health information with other fellow patients (55%) as they felt that it would benefit those who were in the same boat as they were. Given that chronic disease patients are more altruistic with information sharing and more likely to look for health information online, this study will focus on drugs used to treat chronic diseases.

RESEARCH METHOD

Selection of Drug Information Sites

Authoritative drug information websites can be characterised as those with content written and reviewed by a team of physicians and pharmacists, who strive to provide high quality, accurate and useful information for their target audience, based on peer-reviewed research reports, systematic reviews, reports of clinical trials, and information from pharmaceutical companies.

The Pharmacy and Drug Information Section of the Medical Libraries Association maintains PharmGuide, a guide to the "best free drug information resources on the web" (MLA Pharmacy and Drug Information Section, 2014). The drug information websites listed can be considered to be authoritative sources. They are mainly associated with reputable healthcare institutions, medical and pharmaceutical associations, government health departments and regulatory bodies, medical/pharmacy schools, and medical publishers. They can be categorized into primary, secondary and tertiary information sites.

Primary drug information sites include the Drugs section of the U.S. Food and Drug Administration (FDA) website (<http://www.fda.gov/Drugs/default.htm>) which provides access to drug information provided by pharmaceutical companies, as well as information on adverse events reported, drug safety and drug recalls. Secondary drug information sites offer "drug monographs" that are based mainly on primary sources. For example, the Cerner Multum website (<http://www.multum.com/>) asserts that "our researchers rely on the manufacturer's package labeling and FDA announcements. The content is also supplemented by analysis of primary medical literature, prominent review articles, standards guidelines, and textbook sources." Tertiary drug information sites either license drug monographs from the secondary drug information sources, repackage the information for a lay audience, or offer a Web portal to search primary and secondary information sources. For example, the Drugs.com website (http://www.drugs.com/support/editorial_policy.html) states that "for our drug-database information, we rely on the solid reputation of our suppliers: Cerner Multum, Micromedex and Wolters Kluwer Health. Drugs.com does not alter the drug information supplied by these companies."

We selected for analysis three authoritative drug information websites that provided information in a form that is understandable to consumers:

1. **RxList** (<http://www.rxlist.com/>). This website is owned and operated by WebMD. It provides "articles written by pharmacists and physicians and data provided by credible and reliable sources like the FDA, Cerner Multum, and First Data Bank, Inc. to ensure the most accurate and beneficial information is provided" (RxList Inc., 2013).
2. **Electronic Medicines Compendium (eMC)** (<http://www.medicines.org.uk/emc/>). This website is owned by Datapharm and contains information about medicines licensed for use in the U.K. The drugs present in the website are approved by the U.K. Medicines and Healthcare products Regulatory Agency (MHRA) or the European Medicines Agency (EMA) (Datapharm Communications Ltd., 2013). All the drug information on the site is provided by pharmaceutical companies.
3. **PDRhealth** (<http://www.pdrhealth.com/drugs>). This website is a consumer Web portal of PDR (Physicians' Desk Reference) Network (www.pdrnetwork.net). It is U.S. based with content based on information from pharmaceutical companies and the FDA (PDRhealth, 2013).

These three websites were selected to represent different countries (the U.S. and U.K.), as well as different information sources and presentation styles. RxList can be considered a tertiary information source as the information is derived from other secondary sources. The U.K.-based eMC offers information directly from pharmaceutical companies. The PDRhealth website targets mainly consumers, and the drug information is packaged in a patient-friendly form. In contrast, the drug monographs on RxList and eMC can also be used by physicians.

Social media websites are fundamentally different from the normal websites as they are equipped with additional functions that enable users to interact, communicate, and share information with other users. Users can choose to contribute information and communicate on social media sites anonymously or under a pseudonym. The social media triangle framework proposed by Ahlqvist, Bäck, Heinonen and Halonen (2010) specify three criteria that social media sites must fulfil:

1. Provides Web 2.0 capabilities to enable users to share information and form virtual communities

2. Carries user-created content, which can be of various form—reviews, images, videos, etc.
3. Provides support for groups and online social interaction.

The three social media websites that were chosen for this study were:

1. **WebMD** (<http://exchanges.webmd.com/default.htm>), owned by WebMD. It has both a reference content section and a user-review section for drug information. Only the user-review section was analyzed in this study.
2. **RateADrug** (<http://www.rateadrug.com>), owned by RateADrug.com, an independent company. It provides a platform for discussion of health topics and tools for self-evaluation (RateADrug, 2009). RateADrug has a drug review section called “Evaluate Your Treatment” and drug reviews from this section were downloaded for analysis.
3. **PatientsLikeMe** (<http://www.patientslikeme.com/>), a health data-sharing platform that was co-founded in 2004 by Benjamin and James Heywood, and Jeff Cole. It aims to help patients manage their own condition and to provide user-generated data for the pharmaceutical industry and healthcare researchers (PatientsLikeMe, 2013).

These social media websites were chosen because they had at least one review for all the drugs selected for the study. They had distinctly different layouts and structure of the reviews, which reflected different types and amounts of information available.

Of the three social media websites, WebMD had the most number of reviews for most of the drugs, followed by PatientsLikeMe and then RateADrug (see Table 1). Since WebMD and PatientsLikeMe had a larger user base, the reviews on WebMD and PatientsLikeMe were much more current than the ones on RateADrug. For WebMD and RateADrug, reviewers did not have to create an account to contribute drug reviews. On the other hand, reviewers had to create an account detailing their medical and drug history on PatientsLikeMe to contribute a review. Hence, PatientsLikeMe also had additional functions for keeping a record of the reviewers’ condition and tracking their progress.

Selection of Diseases and Drugs

The 2012 telephone survey by the Pew Research Center mentioned earlier had found that the most prevalent chronic diseases in the U.S. were hypertension (25% of U.S. adults), asthma and other lung

conditions (13%), diabetes (11%), heart disease (7%), and cancer (3%) (Pew Research Center, 2013).

Hence, three chronic diseases were selected for this study:

1. Diabetes
2. Hypertension
3. Asthma.

The prevalence of diabetes globally was estimated to be 2.8% in 2000 for all age-groups (Wild, Roglic, Green, Sicree & King, 2004). For high blood pressure, the overall prevalence in adults aged 25 and over was around 40% in 2008 worldwide (World Health Organization, 2013). The prevalence of asthma varies across developed and developing countries. An estimated 235 million people are suffering from asthma worldwide (World Health Organization, 2011b). Cancer was not included in this study due to the complex nature of cancer therapy.

Drug selection for the selected chronic diseases was done with reference to the common drugs and treatment procedures recommended by guidelines obtained from the National Guideline Clearinghouse (<http://www.guideline.gov/>) and PubMed Health (<https://www.ncbi.nlm.nih.gov/pubmedhealth/>). The drugs selected for the study were:

- for diabetes: Pioglitazone, Metformin and Glyburide (Type 2 Diabetes, 2013)
- for hypertension: Hydrochlorothiazide, Furosemide (Lasix) and Spironolactone (Chobanian et al, 2003)
- for asthma: Singulair, Beclomethasone HFA (Qvar) (inhaled steroids) and Ventolin (short-acting bronchodilators) (Asthma, 2013).

These drugs were selected based on two rudimentary factors:

1. availability of reviews on these drugs on the selected social media sites (drugs with more reviews were chosen)
2. wherever possible, the drugs chosen for each disease were from different classes of drug or had a different mode of delivery.

Data Collection

The drug reviews for the nine selected drugs were collected from the three social media websites during the period of 28 March to 22 April 2013. Most of the reviews were posted in 2008 or later. The oldest post was in Aug 2007 for WebMD, Oct 2008 for RateADrug, and Jan 2000 for PatientsLikeMe. The Web pages for the nine selected drugs were also collected from the three authoritative websites in the same period.

Most of the drugs had fewer than 200 reviews in each drug review site and all were collected for analysis. For two drugs with more than 200 reviews on WebMD (i.e. Metformin and Hydrochlorothiazide), the latest 200 reviews were analyzed. An examination of the next 30 reviews beyond the 200 did not uncover new types of information.

Table 1 shows the total number of reviews collected for each drug from the three drug review sites and also the corresponding number of reviews with comments. In WebMD and PatientsLikeMe, the reviewers can choose not to write any comments after providing the ratings for the drug on the structured component of the review. Hence, the corresponding number of reviews with comments for PatientsLikeMe and WebMD were usually less than the total number of reviews. On the other hand, RateADrug consolidates the ratings and comments section of the reviews separately. While RateADrug only states the number of comments made by the reviewers, it does not explicitly state the number of ratings which can be either more or less than the number of reviews. For simplicity, the total number of reviews is assumed to be the same as the number of comments consolidated.

Table 1. No. of reviews collected and analyzed for each drug and drug review site.

Disease	Drug Name	Websites	No. of reviews	
			Total	With comments
Diabetes	Glyburide	PatientsLikeMe	10	6
		RateADrug	5	5
		WebMD	89	72
	Metformin	PatientsLikeMe	193	79
		RateADrug	51	51
		WebMD	200 (out of 968)	188
	Pioglitazone	PatientsLikeMe	21	16

		RateADrug	1	1
		WebMD	27	23
Asthma	Qvar	PatientsLikeMe	4	0
		RateADrug	1	1
		WebMD	84	77
	Singulair	PatientsLikeMe	20	8
		RateADrug	26	26
		WebMD	139	124
	Ventolin	PatientsLikeMe	3	2
		RateADrug	11	11
		WebMD	12	11
High Blood Pressure	Furosemide	PatientsLikeMe	90	50
		RateADrug	8	8
		WebMD	33	24
	Hydrochlorothiazide	PatientsLikeMe	127	63
		RateADrug	12	12
		WebMD	200 (out of 537)	230
	Spirolactone	PatientsLikeMe	30	15
		RateADrug	7	7
		WebMD	54	44

Content Analysis

The Web pages containing information on the nine selected drugs were analyzed for the types of information presented in these webpages. The following steps were carried out to derive the types of information presented in the webpages:

1. The section headings of the Web pages were extracted.
2. The section headings were compared and conflated to form the initial types of information.
3. The content of different sections was reviewed to find out if there are any sub-types of information.
4. The content of webpages were reviewed against the initial list of types of information to check if some information are stated within the texts of the content rather than in the section heading.

After collecting the drug reviews from the three drug review sites, content analysis was done on the unstructured part, i.e. comments sections of the drug reviews. Content analysis software, NVivo 10, was used during the coding process to help organize and develop the coding scheme.

Grounded theory methodology (Strauss & Corbin, 1990) was adopted in deriving the coding scheme and subsequently the types of information. Open coding was done to derive a preliminary coding scheme. The drug reviews from the different social media sites were first grouped according to the different drugs. Next, the comment text in the reviews were coded sentence-by-sentence for different types of information conveyed. Interesting keywords or phrases used to describe the reviewers' experiences with the drugs were tagged. After reading through all the review comments, an initial coding scheme was developed by grouping identical and similar words and phrases together to form the initial categories. Each category was associated with a set of keywords and keyphrases.

After performing open coding, axial coding was done to summarize and construct themes that explained the major and most frequent codes derived from the open coding. In the axial coding process, the constant comparative method of comparing data to data, data to code, and codes to other codes was used to improve consistency and reliability of the coding. This means that sentences containing the identified keywords and keyphrases were examined to check whether they could be assigned to the associated category of information. Co-occurrences and associations between pairs of categories were identified, and became candidates for forming larger themes. Some themes with overlapping concepts were merged. For example, "drug switching" and "termination of drug use" were grouped under the same theme as both involved a change in the reviewer's drug prescription. For descriptions of drug side effects, the phrases used by the reviewers were coded literally and with minimal interpretation. For example, "sleepy" and "constantly tired" were coded as "drowsiness". Layman terms were used for the code labels, rather than medical terms.

Sentiment conveyed in a review can be direct or indirect, requiring some inference from the reviewer's context. It is sometimes difficult to distinguish between types of sentiments from the text, for example anger versus frustration. The sentiments in the reviews were coded simply as positive or negative polarity. Positive sentiment includes a sense of happiness, contentment, optimism,

hopefulness and helpfulness. Negative sentiment includes anger, frustration, anxiety, hopelessness, confusion and trauma.

TYPES OF INFORMATION FOUND ON AUTHORITATIVE AS WELL AS DRUG REVIEW SITES

Drug information on authoritative Websites is usually divided into sections and sub-sections, with headings indicating the type of information. Within each section or sub-section, more specific types of information may be signalled by keyphrases at the beginning of paragraphs. Table 2 presents the types of information that were found on the three selected authoritative websites. They include the purpose of the drug, storage, form, dosage, considerations for particular groups of patients (e.g., children, pregnant women and the aged), contraindications, warnings and precautions, side effects and drug interactions.

Table 2. Types of information available on authoritative websites.

	Section Headings and Keyphrases		
Types of information	RxList	eMC	PDRhealth
Drug Name	Given in the title header	Given in the title header <"Name of the medicinal product">	Given in the title header
Purpose/Uses	"Drug Description"	"Therapeutic indications"	"What is <Drug X>?"
Other Names	Chemical name and generic name given in the "Drug Description" section	-	"Generic Name"
Description	"Drug Description"	-	"What is the most important information I should know about <Drug X>?"
Storage	"Storage" under "How supplied section"	"Special precautions for storage"	"How should I store <Drug X>?"
Form	"How supplied"	"Pharmaceutical form"	-
Intake / Application	"Indications & Dosage"	"Posology and method of administration"	"How should I take <Drug X>?"

Dosage	"Indications & Dosage"	"Posology and method of administration"	"What is the usual dosage?" "What should I do if I miss a dose of <Drug X>?"
Special Population Considerations	"Nursing Mothers" "Pediatric Use" "Geriatric Use"	"Pregnancy and lactation"	"Can I receive <Drug X> if I am pregnant or breastfeeding?"
Contraindications	"Overdosage & Contraindications"	"Contraindications"	-
Warnings / Precautions	"Warning & Precautions"	"Special warnings and precautions for use"	"Who should not take <Drug X>?" "What should I avoid while taking <Drug X>?"
Side Effects	"Side effects centre" "Side effects & Drug interactions"	" Effects on ability to drive and use machines" "Undesirable effects"	"What are the possible side effects of <Drug X>?"
Drug Interactions	"Side effects & Drug interactions"	"Interaction with other medicinal products and other forms of interaction"	"What are possible food and drug interactions associated with <Drug X>?"
Pharmacology	"Clinical Pharmacology"	"Pharmacological properties"	-
Others	"Patient" "Consumer" "Medication Guide"	"Shelf life" "Marketing authorisation holder" "Nature and contents of container" "Special precautions for disposal and other handling"	-

However, the level and structure of information varied across these three websites:

- Rxlist and eMC quoted statistics and figures from clinical studies on the possible side effects of the drug
- Rxlist and eMC provided drug pharmacology information, but not PDRhealth.
- Chemical structure and images of drugs were available on Rxlist but not on eMC and PDRhealth.
- Rxlist merged some of the sections together (e.g., side effects & drug interactions) which resulted in lengthy pages.

- eMC provided a table of contents for each drug at the top of the page which linked to each individual section.
- PDRhealth used the Q&A approach to present information and there were fewer sections.

Out of the three selected authoritative websites, PDRhealth provided the least comprehensive information as it lacked information on drug pharmacology and results from clinical studies. Nonetheless, PDRhealth was the easiest website to navigate as there were fewer sections and the information were presented in a more concise form compared to the other two websites.

Using the types of information listed in Table 2, the postings from the drug review sites were analyzed to determine whether they carried those types of information, and if so how the information was different in content. A summary of the comparison is given in Table 3.

The types of drug information listed in Table 2 and 3 are clearly the strength of authoritative websites: users can expect to find comprehensive, objective and verified information for these categories of information. Nevertheless, user postings on drug review sites can provide additional useful information and insights for patients and health professionals especially in the areas of drug dosage, side effects and warnings/precautions. These types of information are discussed in more detail below.

Table 3. Comparison of types of information on authoritative and drug review sites.

Types of information	Authoritative Websites	Drug review sites
Drug Name	<ul style="list-style-type: none"> • Brand names • Generic names 	<ul style="list-style-type: none"> • Reviews are usually consolidated under the drug's generic name • Brand names are not available unless mentioned by reviewers
Purpose/Uses	<ul style="list-style-type: none"> • Information on the condition(s) which the drug is used to treat 	<ul style="list-style-type: none"> • Reviewers state the conditions which they are taking the drug for
Description	<ul style="list-style-type: none"> • Short introduction on the drug is usually available 	<ul style="list-style-type: none"> • Reviewers rarely introduce the drug
Storage	<ul style="list-style-type: none"> • Storage recommendations given by the manufacturer 	Not available
Form	<ul style="list-style-type: none"> • Available forms (i.e. tablet or solution) and available dosages 	Not available unless reviewer states the form of drug taken

Intake/Application	<ul style="list-style-type: none"> • Recommended time and method to consume the drug 	Not available unless reviewer states his drug consumption habits
Dosage	<ul style="list-style-type: none"> • General starting dosage guidelines • Maximum possible dosage 	<ul style="list-style-type: none"> • Reviewers' own prescriptions • May state changes in dosage and reasons for the change
Special Population Considerations	<ul style="list-style-type: none"> • Specific information for pediatric, geriatric, pregnant or lactating patients 	Not available
Contraindications	Available	Not available
Warnings/Precautions	<ul style="list-style-type: none"> • Detailed explanation and description on the side effects and health complications that could be caused by the drug • Advice on what other substances to avoid when taking the drug • Related to other sections such as drug interactions & contraindications 	<ul style="list-style-type: none"> • Depends on whether the drug works on the reviewer and whether the reviewer suffered from severe side effects
Side Effects	<ul style="list-style-type: none"> • Concise • Objective—based on clinical trial results • Side effects listed are the more common ones 	<ul style="list-style-type: none"> • Subjective—based on the reviewer's experience with the drug • Vivid description • Severity of side effect is often stated • Queries on less common side effects
Drug Interactions	Available	Not available
Pharmacology	Available in more detailed authoritative sites	Not available

Drug Dosage

Drug dosage information is available on both authoritative sites and drug review sites. However, the nature of drug dosage information on these two types of websites was quite different. Drug dosage information on authoritative websites usually included the following information:

- Recommended starting dosages
- The maximum daily dosage
- Special population considerations, i.e. whether different dosage is needed for geriatric, pediatric or pregnant patients

- Drug dosage information obtained from drug companies

On social media websites, reviewers stated the drug dosage prescribed to them and sometimes mentioned the changes in their dosage and the reasons for it.

The drug dosage information on drug review sites were more subjective as they were personal drug prescriptions based on the patients' condition. However, readers can get a sense of the common drug dosages prescribed. Drug dosage information provided by reviewers can give other users a context to evaluate and anticipate the possibility and severity of side effects, and also to compare their conditions with reviewers who are prescribed with the same dosage.

Figure 1 gives an example of a user review for Glyburide obtained from WebMD. The reviewer stated the drug dosage that was prescribed to him and queried about his bouts of low blood sugar after taking the drug. In this review, the drug dosage provides a reference and context for other patients who are taking identical dosages to offer advice or answer the query posed.

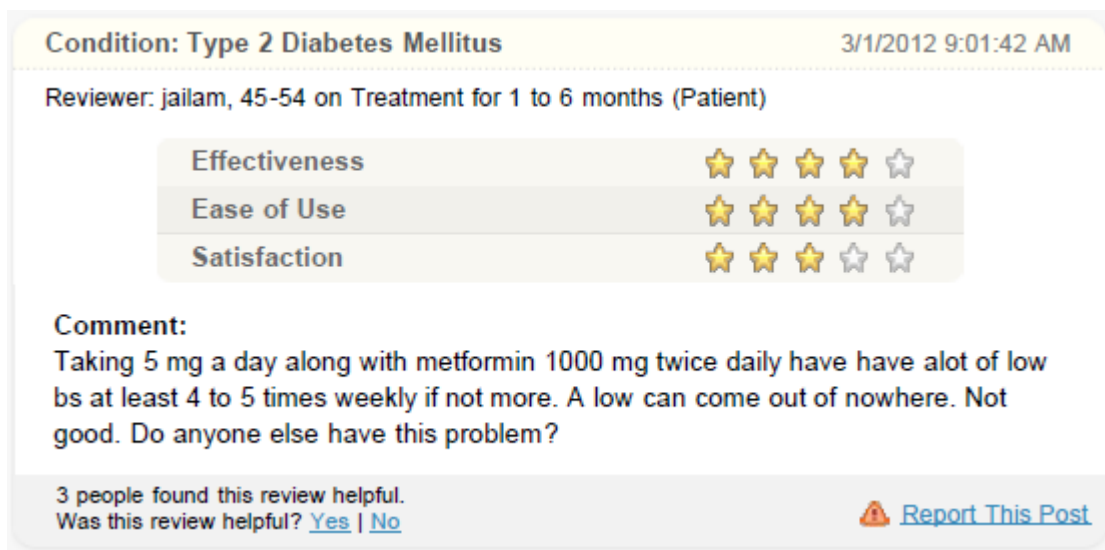


Figure 1. A user review for Glyburide with dosage information (source: WebMD).

Side Effects

All three authoritative websites included a section on the drug's side effects; however, comparing the side effects stated across the three authoritative website on the nine drugs revealed some differences in the quality and how the side effects were presented:

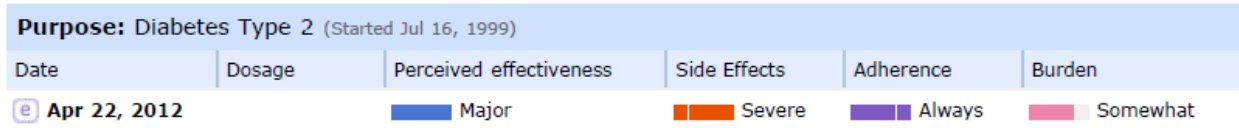
- The number of side effects listed varied across the three websites. Consistently for all the nine drugs, Rxlist provided the most comprehensive list of possible side effects followed by eMC and then PDRhealth.
- The websites had different ways of listing the side effects. Rxlist categorized the side effects according to their severity, whereas eMC categorized the side effects according to their frequency, i.e. how commonly the side effects were reported in the various clinical trials.
- Different terminologies were used to describe identical or similar side effects across the websites. Rxlist and PDRhealth tended to use layman terms (e.g., sore throat, hives, etc.) to describe the side effects, whereas, eMC tend to use medical terminologies (e.g., pharyngitis, urticarial, etc.). Using layman terms to describe the side effects makes it easier for patients to understand and match with their symptoms. On the other, using medical terminologies provide some consistency in listing the side effects, but patients without medical knowledge may find the terms hard to understand and need to perform an extra step of looking up the meanings of the terms.

At the same time, side effects information can also be found on social media postings. Side effects information on authoritative websites is concise and objective (i.e. based on clinical trial results), and reflects the more common side effects. The information on drug review sites:

- is subjective, based on the reviewer's experience with the drug
- is vividly described, with contextual information
- includes indication of the severity
- contains queries on less common side effects.

Figure 2 gives an example of a review containing a description of the severity of the drug's side effects and how the reviewer's life was affected. According to the three authoritative websites, diarrhea was listed as a common and less serious side effect of Metformin. However, the reviewer suffered from such a severe case of diarrhea that it inconvenienced her daily life to the point that she had to stop taking the drug. Authoritative websites consider mainly the clinical seriousness of the side

effects, whereas users also consider how “bad” the side effects feel or how much inconvenience they suffer.



Date: Apr 22, 2012

Advice & Tips: this medication worked well in helping to control my diabetes but the whole time I was taking it I had severe diarrhea which means if I had to go out I had to plan my trips around gas stations with a bathroom that I knew where the washrooms were at because there would be no time to look for one so my doctor put me on insulin.

Figure 2. A user review on Metformin with side effects information (source: PatientsLikeMe).

Table 4. Side effects reported more than once on drug review sites but not stated on the authoritative sites.

Disease	Drug Name	Side effects reported
Diabetes	Glyburide	<ul style="list-style-type: none"> Bad cough (3) Changes in blood pressure (2)
	Metformin	<ul style="list-style-type: none"> Dry mouth (3) Hair loss (3) Kidney damage (3) Constipation (3) Lack of libido (2) Hot flashes (2)
	Pioglitazone	None more than once
Asthma	Qvar	<ul style="list-style-type: none"> Mood swings (3)
	Singulair	None more than once
	Ventolin	None more than once
High Blood Pressure	Furosemide	None more than once
	Hydrochlorothiazide	<ul style="list-style-type: none"> Swelling (12) Low potassium level (8) Hair loss (5) Increase in perspiration (4) Chest pain (4) Breathing problems (4) Pain in joints (4) Gout (4) Nightmares (3) Weight gain (3) Memory loss (3) Sodium loss (2) Unable to urinate (2) Insomnia (2)
	Spironolactone	<ul style="list-style-type: none"> Dry mouth (3) Sweating (2)

		• Weight gain (2)
--	--	-------------------

Some patients reported side effects that were not stated on the authoritative websites. A list of side effects reported more than once on the drug review sites but not found on the authoritative websites are given in Table 4.

Sometimes, a side effect manifests gradually and can be mistakenly attributed to other reasons. Hence the patient or caregiver may not be aware that a condition is a side effect of a drug the patient is taking. Browsing through drug reviews by other patients can help the patient or caregiver to realize that a condition is caused by the drug. Figure 3 shows a posting by a reviewer who started to suspect that a condition is a drug's side effects after reading drug reviews.

Condition: High Blood Pressure 11/29/2010 12:15:14 AM

Reviewer: 55-64 Female on Treatment for 1 to 6 months (Patient)

Effectiveness	★ ★ ★ ★ ★
Ease of Use	★ ★ ★ ★ ★
Satisfaction	★ ★ ★ ★ ☆

Comment:
Some increase in urination, which I expected. I am tired, but I have been working 10-12 hour days for the past few months, so I didn't relate it to the drug side effects until I started reading the reviews on this site. My skin is dry, but with winter being here, I didn't give it a thought until I read these reviews. The worst problem I notice is a red and itchy rash on my neck in the "collar area". I thought it was an allergic reaction to something, or contact dermatitis, but believe it may be the medication. I also have noticed I am much more sensitive to the sun. Have been on the medication for almost 4 months. I need to discuss with my doctor to see if this is normal...what the solution might be...or if it's time to switch medication.

[Hide Full Comment](#)

11 people found this review helpful.
Was this review helpful? [Yes](#) | [No](#) [Report This Post](#)

Figure 3. Reviewer began to think that her conditions are side effects of Hydrochlorothiazide after reading reviews.

As demonstrated by the selected examples, side effects information obtained from drug review sites can complement information on authoritative sites by providing more context and details of the side effects, and their impact on the patients' lives. A patient who is experiencing a condition not listed on the authoritative websites may be alerted to the possibility that the condition is a side effect of the drug.

Warnings and Precautions

The *warnings and precautions* sections in the authoritative sites carry information on possible serious side effects and health complications that can be caused by the drug. The information provided is often related to other sections such as drug interactions and contraindications as they provide information on what other substances to avoid when taking the drug, and under what circumstances is it not advisable to take the drug.

In contrast, warnings and precautions stated in the drug reviews are largely based on the reviewers' experience with the drugs. How the reviewers phrase their warnings not only depends on the severity of the side effects experienced and but also on how traumatic is the patient's experience with the side effects. The sample review shown in Figure 4 was emotionally-charged and warned other parents against letting their children use the drug Singulair. Although the side effects were not life-threatening, the reviewer was strongly affected by the complications that his or her child experienced.

Condition: Allergic Asthma 3/19/2009 8:54:21 PM

Reviewer: ANGELA C., 35-44 Female on Treatment for 1 to 6 months (Caregiver)

Effectiveness	★ ★ ★ ☆ ☆
Ease of Use	★ ★ ★ ★ ★
Satisfaction	★ ☆ ☆ ☆ ☆

Comment:
 THIS MEDICINE SHOULD NOT BE USED ON CHILDREN!!! MY 5 YEAR OLD SON HAS BEEN ON THIS MEDICINE FOR 2 MONTHS AND NOW HE IS DEFIANT , CRIES ABOUT ANYTHING , IS ANGRY ALL THE TIME AND HAS NIGHT TERRORS. BASICALLY MY SWEET BOY NOW HAS COMPLETELY CHANGED . I WISH I HAD READ THESE REVIEWS AND NOT GIVEN HIM THIS MEDICINE. IT HAS BEEN 3 MONTHS AND WE NOW SEE MY SWEET BOY BACK , BUT IT WAS A HARD ROAD. PARENTS DO NOT GIVE THIS MEDICINE TO YOUR CHILDREN!!!!!! EVEN OUR PEDIATRICIAN AGREES WITH US.
[Hide Full Comment](#)

40 people found this review helpful.
 Was this review helpful? [Yes](#) | [No](#)  [Report This Post](#)

Figure 4. A drug review on Singulair warning others on the side effects (source: WebMD).

TYPES OF INFORMATION FOUND ONLY ON DRUG REVIEW SITES

In the three selected drug review sites, the information is generally presented in two forms: structured format and unstructured format. Information in structured format is in the form of pre-defined categories for reviewers to enter their ratings according to a scale provided by the website. The ratings are consolidated to provide an aggregate, usually mean, of all the ratings. The reviewers can provide more information in the unstructured part of the review, i.e. the comments or advice section, to elaborate on the reasons for their rating. Sentiment and information that is personal to the patient's condition (e.g., doctor's advice, personal advice and encouragement) can only be found in the unstructured part of the reviews as the information has to be expressed in text.

Of the three selected drug review sites, WebMD and PatientsLikeMe have both structured and unstructured information for each individual drug review. For RateADrug, the structured and unstructured information are separated, i.e. the ratings for the various categories are separated from the comments and not displayed together. Displaying both structured and unstructured information in a single review, as in WebMD and PatientsLikeMe, provides the readers with some context and

explanation for the reviewer’s rating. However, RateADrug has the most extensive list of categories for reviewer ratings.

Table 5 summarizes the types of information found only on drug review sites and the formats in which the information is presented. Examples of the structured information portion of the drug review sites can be seen in the screenshots given in Figures 1, 2, 5 and 6.

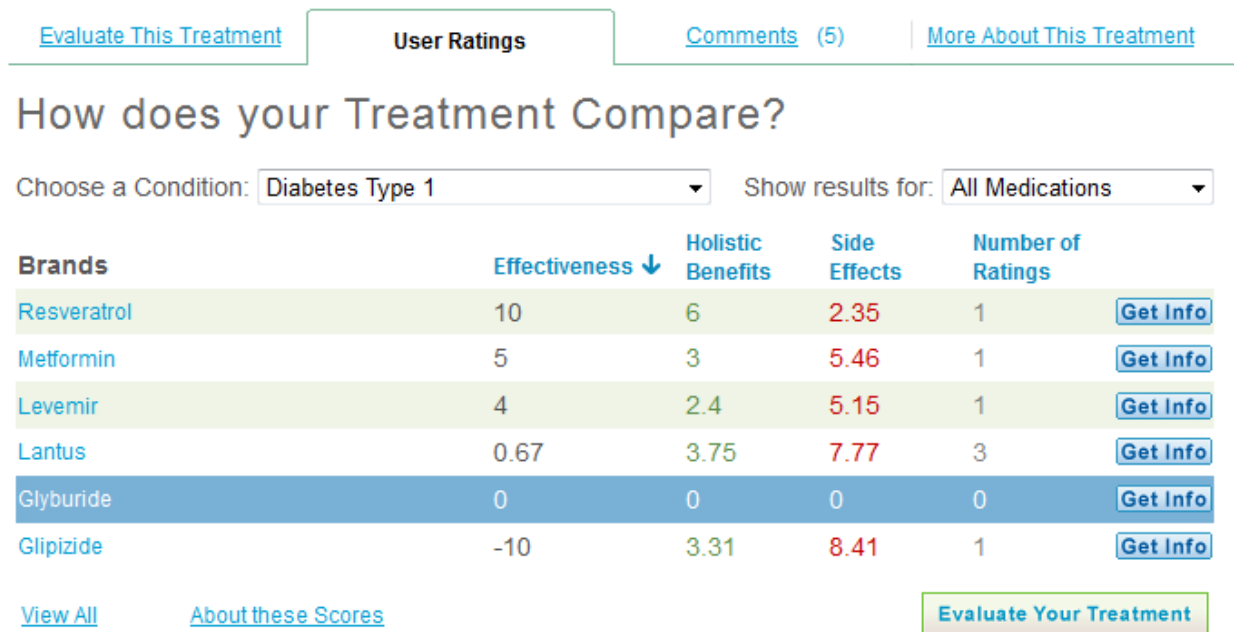


Figure 5. First structured section of RateADrug comparing different drug treatments.

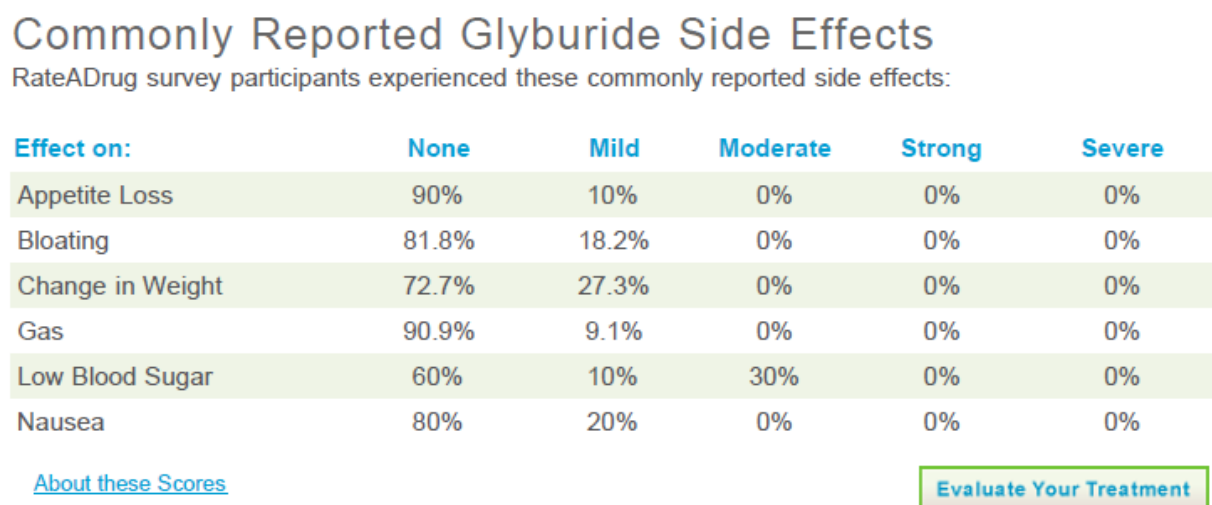


Figure 6. Structured section of RateADrug on commonly reported side effects after taking the drug.

Table 5. Types of information found only on drug review sites.

	Types of information that are found only on drug review sites	Available in structured form	Available in unstructured form
Drug-related	Drug efficacy	√	√
	Cost of drug	√	√
	Difficulty/Ease in using the drug	√	√
	Comparison with other similar drugs	√	√
Patient-related	Change in prescription	X	√
	Doctor’s advice	X	√
	Personal advice and encouragement	X	√
	Sentiment	X	√

Drug Efficacy

Information on drug efficacies can be said to be the essence of drug review websites. There are usually two components for drug efficacy information:

1. rating scales provided by the websites
2. reviewers’ feedback on drug efficacy in the comments section.

The rating scales used by the three drug review sites were quite different. WebMD used a quantitative 5 point scale, while PatientsLikeMe and RateADrug used a 5-optioned qualitative scale. For PatientsLikeMe, the options were “Major”, “Moderate”, “Slight”, “None” and “Can’t tell”, whereas RateADrug offered the options “Extremely”, “Very”, “Moderately”, “Mildly” and “Not at all”.

We wanted to know whether the three sites were consistent in their efficacy rating of drugs. As the scales were different, we couldn’t compare the ratings directly. Our approach was to derive an aggregate rating score for each drug, and rank the nine drugs in efficacy within each social media site. Since WebMD already used a quantitative scale, the overall average user rating provided could be used directly. For PatientsLikeMe and RateADrug, a numerical score was assigned to each qualitative option as shown in Table 6. The overall average score was then calculated for each drug.

For each social media site, the nine drugs were ranked by their average rating. The ranks for the drugs within each social media site are given in Table 7. We wanted to find out whether the drug

rankings were similar across the three sites. Spearman’s rank correlation coefficient (Spearman ρ) was calculated for each pair of sites. The Spearman ρ between the drug ranks for PatientsLikeMe and the other two sites were quite similar (0.33 for RateADrug and 0.20 for WebMD). However, the rank correlation between RateADrug and WebMD was -0.33, indicating an inverse correlation. All the correlations were not significant at the 0.05 level. Overall, it can be concluded that the drug ranking was not similar across the drug review sites.

We examined Table 7 more closely to identify cases where the drug ranking on one site was substantially different from the rankings on the other two sites. These “anomalous” ranks are bolded in Table 7. For example, Pioglitazone was ranked 4th on WebMD and PatientsLikeMe, but 9th (last) on RateADrug. We examined the qualitative reviews more closely to identify possible reasons for the anomalous rankings.

Table 6. Numerical rating assigned to qualitative ratings on PatientsLikeMe and RateADrug.

Social Media site	Original Qualitative Rating	Assigned Numerical Rating
PatientsLikeMe	Major	3
	Moderate	2
	Slight	1
	None	0
	Can't tell	0
RateADrug	Extremely	4
	Very	3
	Moderately	2
	Mildly	1
	Not at al	0

Table 7. Rankings of the nine drugs based on drug effectiveness ratings for each social media site

Disease	Drug Name	Rankings of the 9 drugs based on drug effectiveness ratings for each social media site		
		WebMD	PatientsLikeMe	RateADrug
Diabetes	Glyburide	5	5	3

	Metformin	9	8	6
	Pioglitazone	4	4	9
Asthma	Qvar	2	7	8
	Singulair	1	6	4
	Ventolin	6.5*	1	1
High Blood Pressure	Furosemide	6.5*	3	2
	Hydrochlorothiazide	8	9	5
	Spironolactone	3	2	7

*Ventolin and Furosemide have the same score for drug effectiveness ratings on WebMD. Hence, both are given the average ranking of 6.5.

The reasons for the anomalous rankings can be summarized as follows:

1. Small number of reviews
2. A higher proportion of reviewers in a particular site experiencing severe side effects
3. In WebMD, the aggregate ratings were inversely correlated with the number of reviews (i.e. drugs with more reviews tended to have lower aggregate ratings).

The substantially lower ranking for Pioglitazone on RateADrug was because there was only one review. The relatively high ranking for Hydrochlorothiazide in RateADrug was also because of the small number of reviews—12 reviews compared to 537 for WebMD and 127 for PatientsLikeMe. Similarly, Spironolactone had only 7 reviews on RateADrug, compared to 54 for WebMD and 30 for PatientsLikeMe.

However, this doesn't explain the high ranking for Qvar on WebMD, which had 47 reviews compared to 15 for PatientsLikeMe and 1 review for RateADrug. The reviews on RateADrug and PatientsLikeMe offered little information to explain the low ratings. In fact, the reviews on WebMD presented more types of side effects. It may just be chance that Qvar happened not to work well for the small number of reviewers on RateADrug and PatientsLikeMe.

The ranking for Ventolin in WebMD was much lower than for the other two drug review sites. This could be due to a higher percentage of reviewers on WebMD having a negative experience

with the drug. Out of the twelve reviews, five gave a rating of three or fewer stars (out of five stars) due to experiencing severe side effects such as severe rash and very bad cough, in addition to not seeing an improvement in their asthma condition. These ratings pulled down the overall rating even though a majority gave four or five star ratings. While some reviewers in RateADrug and PatientsLikeMe did mention experiencing some side effects after taking Ventolin, they appeared to be less severe and Ventolin did improve their asthma condition.

The same reason could apply to the relatively low ranking of Furosemide on WebMD. There was a larger percentage of users contributing a lower end rating for Furosemide in WebMD (27.7% rated two stars and below). The reviews on WebMD mentioned more serious and debilitating side effects such as leg cramps and even a case of hearing loss.

The generally lower ratings in WebMD made it easier for some drugs to obtain a high rank despite some amount of adverse reviews. Singulair was a case in point: despite a higher percentage of reviews in WebMD giving a lower end rating (17.4% rated two or fewer stars) than in PatientsLikeMe (14.6% rated “Slight”) and RateADrug (5% rated “Mildly”), Singulair still had the highest ranking in WebMD. As shown in Table 8, the average drug rating over all nine drugs was the lowest for WebMD.

Table 8. Average drug efficacy rating over all nine drugs for the three drug review sites.

	Average Drug Efficacy Rating Over All Nine Drugs	Average Rating Expressed as Percentage (%)
WebMD	3.44 (out of 5)	68.8
PatientsLikeMe	2.35 (out of 3)	78.3
RateADrug	2.88 (out of 4)	72.0

We checked whether there was a correlation between the ranking based on aggregate ratings and the ranking based on the number of reviews. This comparison was done only for WebMD and PatientsLikeMe as these sites listed the numbers of ratings used in the aggregate score. The Spearman ρ was -0.15 (p-value=0.71) for PatientsLikeMe, and -0.70 (p-value=0.04) for WebMD. The highly

negative correlation for WebMD (significant at the 0.05 level) indicates that drugs with a higher number of reviews tended to have lower ratings.

The relation between number of reviews and the aggregate rating probably depends on the characteristics of the reviewers and the ease of contributing a drug review. It is relatively easier to contribute a drug review on WebMD as reviewers do not need to create an account. They just fill in an online form, whereas reviewers on PatientsLikeMe have to create an account detailing their medical history and the drugs they are taking. WebMD probably attracts more one-time reviewers who are spurred by their negative experience with a drug, whereas the reviewers on PatientsLikeMe probably use the platform to manage and track their medical and drug history, with less focus on sharing their experience with the drugs. It is noted that PatientsLikeMe did not have any “anomalous” drug ratings in Table 7. It is important for users to be aware that the drug efficacy ratings can be affected by the number of reviews. Users should also take note of the different rating scales and qualitative labels used by the websites, which can affect the users’ rating decision in unknown ways.

We concede that it is not really appropriate to rank drugs across different diseases. Many factors can affect patients’ perception of efficacy (and hence ratings), including the severity of the disease and impact on quality of life, whether the disease is chronic, the side-effects of the drug, difficulty in undergoing the treatment, the patient’s mental state, etc. This exercise was carried out to obtain a rough indication of whether the drug efficacy rating was consistent across the drug review sites. The results suggest that the ratings must be interpreted with caution. Users should refer to the comments section of individual reviews to understand why the reviewer assigned a certain rating to the drug efficacy.

Here are the typical types of information that can be drawn from the unstructured comments:

- Whether a generic drug works as well as the brand name drug
- Comparison of drug efficacy with other similar drugs, or between new and old versions of the drug
- Patients’ physiological parameters (e.g., blood pressure or blood sugar readings) to illustrate drug efficacy or lack of

- Drug resistance or decrease in drug efficacy over the years reported by long-term users.

Even though generic drugs are expected to deliver the same efficacy as their brand name counterparts, the drug reviews indicated otherwise. Drug efficacy and side effects also vary across different generic versions of the drug. Drug manufacturers may change the formulation of a drug over time and long-term users of the drug may notice a drop in efficacy. The reviewer in Figure 7 noticed that new inhalers were not working as well as older ones. She had also sought confirmation from her pharmacist who had received similar feedback from other patients.

Condition: Asthma 3/14/2009 12:22:00 PM

Reviewer: 45-54 Female (Patient)

Effectiveness	★ ☆ ☆ ☆ ☆
Ease of Use	★ ★ ★ ★ ☆
Satisfaction	★ ☆ ☆ ☆ ☆

Comment:
 The new inhalers do not seem to work as well as the old ones. After talking to my pharmacist (been one for 20 years) he said many people have complained about the effectiveness of the new inhalers and I agree they don't work! My nebulizer works much better but can't exactly take it to my job to use.

6 people found this review helpful.
 Was this review helpful? [Yes](#) | [No](#) [Report This Post](#)

Figure 7. A review comparing old and new Ventolin inhalers.

Reviewers also tended to compare the efficacy of drugs when there was a new version of the drug (i.e. change in formulation), or when they were prescribed a replacement drug. Patients' drug prescription may be changed by their doctors due to side effects, unsatisfactory drug efficacy or the patients' financial constraint. The comparison of drug efficacy between similar drugs or between new and old versions helps to alert other users to alternative drugs if their current drug is not working well for them. At the same time, drug manufacturers can gather feedback on whether the new versions of the drugs are working as well on the patients.

Cost of Drug

Information on cost of drug is conspicuously absent from authoritative websites. This is probably because the cost is dependent on many factors such as the drug manufacturer and sale location. The following types of information related to cost of drug could be found on the drug review sites:

- Cost of drug in relation to insurance coverage
- Information on drug subsidy programs
- Availability of generic drug forms.

Of the three drug review sites, only PatientsLikeMe had a structured component for cost of drug for the reviewers to indicate the price range of their drugs. The data for cost of drug was consolidated from all the reviews and used as a basis for comparing the cost of drugs. In general, the drugs for asthma seemed to be more expensive than the drugs for diabetes and hypertension, as a smaller percentage of reviewers stated that they paid less than \$25 monthly for the drugs. Also, there were noticeably more reviews (more than 10 reviews) commenting on the asthma drugs' high cost, especially for Qvar which did not have a generic form. On the other hand, there was no mention of the cost of drug for the three hypertension drugs. For the diabetes drugs, only one reviewer mentioned that Metformin was cheap.

Reviewers seldom stated the exact cost of drug in their qualitative reviews. In WebMD and RateADrug where there was no structured component for cost of drug, reviewers would have to either state the exact cost or use words like “cheap” or “expensive” to indicate the affordability of the drug. When reviewers state the exact cost of the drug, readers can assess the affordability of the drug or compare directly with the price they are paying. However, for cost information to be useful, it is important for reviewers to indicate their geographic location.

Cost of drug in relation to insurance coverage

The affordability of drugs to patients is closely related to the extent of their insurance coverage.

Reviewers may mention other financial problems such as no insurance coverage for certain drugs that are too expensive. The lack of insurance coverage may force the reviewer to switch to another drug

despite having positive experience with the previous drug. This is an especially significant issue for Qvar and Singulair (more than 10 of such reviews).

This type of information may be useful to doctors as they may need to consider their patients' insurance coverage when prescribing drugs to their patients. Moreover, insurance companies and health policy makers should look into such reviews and consider whether lack of insurance coverage for particular drugs is jeopardizing patients' health, leading to higher health costs in the long term.

Sharing information on drug subsidy programs

Sometimes reviewers share information on where to get financial assistance for drugs that are expensive. Such information can be useful for other patients who are unable to get insurance coverage for their treatment.

Cost of drug in relation to availability of generic drug form

Information on the cost of drug is also related to the availability of a generic form of the drug. As an example, before the generic forms for Singulair were approved by FDA on 3 August 2012, many reviews mentioning the cost of drug indicated that Singulair was effective but too expensive, and the reviewers expressed the hope for cheaper generic versions. After the generic forms were available, reviews mentioning drug cost mainly expressed dissatisfaction with the effectiveness of the generic versions and found them not cost effective overall.

Difficulty/Ease in Using the Drug

Reviews in drug review sites sometimes mentioned how difficult or easy it was for the reviewer to consume the drug. Such information is useful for drug manufacturers who can consider modifying the dosage forms to fit commonly prescribed dosages. The suggestions encountered in the user postings were mainly related to the pill forms of drugs (e.g., diabetes and hypertension drugs). Problems in consuming drugs in pill form included:

- Difficulty to swallow the pill due to large size
- Available pill dosage of the drug incompatible with their prescription

- Difficulty in remembering to take drugs on time if the drug requires multiple consumption per day.

It was also common to find reviewers stating that the available pill dosage of their drug was incompatible with their prescription. Some reviewers needed the drug in a smaller dose. One reviewer had to split his pill in half as his prescribed dosage was half of the available dosage form. Decreasing a drug's dosage to half seems to be a common practice when patients need to reduce the drug's side effects.

On the other hand, there were patients who were prescribed a higher dose than the available pill dosage. One reviewer was prescribed 15 mg of Glyburide per day. He had to take six of the 2.5 mg pills to fulfil his prescribed dosage, which he found hard to manage as he would lose a few of his pills.

Change in Prescription

While most of the drug reviews described the efficacy and side effects of a drug, some reviewers mentioned whether they were continuing with the drug or had stopped taking them. Reasons mentioned for the change in prescription included:

- Drug switching, i.e. change to a new drug or going back to a previous drug, and the reasons for this
- Discontinuing a drug, either on the doctor's direction or of the patient's accord.

As an example, a reviewer reported that her doctor had switched her prescription from Metformin to Glumetza after using the former for 15 years. This switch was done after she developed lactose intolerance and bouts of diarrhoea. Such reviews could encourage other users to talk to their doctors on the possibility of trying an alternative drug and also provide suggestions on possible alternative drugs for other users who are experiencing the same side effects. Another reviewer halved his dosage of Metformin after experiencing side effects. He changed his dosage without his doctor's direction as he felt that his doctor did not pay sufficient attention to this problem.

Personal Advice and Encouragement

Some reviewers posted personal advice and words of encouragement for other patients. The following types of personal advice and encouragement were observed from the drug reviews:

- Giving advice on how to cope with side effects, based on the reviewer's personal experience
- Moderating negative comments from other reviewers, for example on the side effects of the drug
- Words of encouragement.

Most authoritative sites only provide information on the possible side effects of the drug and what precautions to take. There is a lack of information on the possible solutions to alleviate the drug's side effects. For example, a reviewer shared that taking Glyburide with a protein-rich meal helped to avoid the side effect of stomach pains and cramps.

Reviews reporting side effects can be quite negative in tone, which may discourage patients from taking the drug. Some reviewers contributed messages to moderate the tone and offer a balanced perspective. Figure 8 illustrates this.

While the social media sites studied here are drug review sites where many reviewers probably contribute a one-time post and there is little dialog or community as found in discussion forums or social networking sites such as Facebook groups, some reviewers would still include positive remarks or words of encouragement to encourage fellow patients. For example, reviewers may encourage other patients to tolerate the initial bout of side effects as the condition would get better based on their experience.

Condition: High Blood Pressure 12/5/2012 2:05:37 PM

Reviewer: Chuck, 65-74 Male on Treatment for 2 to less than 5 years (Patient)

Effectiveness	★ ★ ★ ★ ★
Ease of Use	★ ★ ★ ★ ★
Satisfaction	★ ★ ★ ★ ★

Comment:
 Don't pay attention to most of these reviews. Easy of use? What is easier than swallowing a tablet? Sulfa containing? Yes...read precautions and interactions. Dehydrated? You are supposed to loose fluids...drink water. Don't take drug when you don't want to be using the bathroom frequently (sleep time, etc) This is an old "tried and true" drug for treatment. It is certainly inexpensive ...so easy on the pocketbook. Talk with your pharmacist if you have questions because most physicians don't have the time to properly discuss medications.
[Hide Full Comment](#)


11 people found this review helpful.
 Was this review helpful? [Yes](#) | [No](#)  [Report This Post](#)

Figure 8. A reviewer moderating previous negative reviews of Hydrochlorothiazide.

Sentiment

In addition to factual information, the overall sentiment of the review (i.e. positive or negative) can leave a lasting impression on readers and influence their actions. It might be assumed that sentiment is correlated with drug efficacy. However, we observed from the reviews that the overall sentiment appeared to be related to the balance between drug efficacy and the severity of the side effects, and whether the side effects and inconveniences were worth tolerating. Here are some scenarios associated with positive and negative sentiments:

- Positive sentiment:
 - The drug improved the reviewer's condition and there were no or few side effects
 - The drug improved the reviewer's condition with some side effects but the reviewer was willing to tolerate the side effects for the sake of improving his or her condition
- Negative sentiment:
 - The drug improved the reviewer's condition but the side effects were deemed too serious and undermined the benefit of taking the drug
 - The drug did not improve the reviewer's condition.

Figure 9 is an example of a reviewer expressing negative sentiment towards a drug despite experiencing improvement in her condition after taking it. The reviewer described the side effects to be “worse than the illness”.

Condition: Type 2 Diabetes Mellitus 1/14/2013 11:09:37 AM

Reviewer: 45-54 Female on Treatment for 1 to 6 months (Patient)

Effectiveness	★ ★ ★ ☆ ☆
Ease of Use	★ ★ ☆ ☆ ☆
Satisfaction	★ ☆ ☆ ☆ ☆

Comment:
Muscle cramps, massive gastrointestinal upset. Who ever said this was the best drug for me to be taking was mad! The cure is worse than the illness! Apparently it will get easier the longer I take it. I've seen improvements but still can't leave the house at times :o(

8 people found this review helpful.
Was this review helpful? [Yes](#) | [No](#) [Report This Post](#)

Figure 9. Reviewer displayed negative sentiment to the drug due to side effects despite seeing improvement in her condition.

CONCLUSION AND DISCUSSION

This study sought to identify the types of drug information provided on drug review sites compared to authoritative drug information websites. User reviews for nine drugs (three drugs for each of three chronic diseases—diabetes, hypertension and asthma) were downloaded from three drug review sites and compared to drug information on three authoritative websites.

The types of information found on authoritative drug information sites but rarely on drug review sites were storage recommendations, available forms of the drug, recommended time and method to consume drug, pharmacology, special population considerations (i.e. pediatric, geriatric and pregnant patients, and lactating mothers), contraindications and drug interactions. There were differences across the three authoritative sites in terms of depth and detail of information, how the content is structured, and presentation style.

Types of information common to both types of sites were purpose and uses of the drug, dosage, warnings/precautions, and side effects. However, drug review sites provide additional information. Whereas authoritative websites indicated recommended starting dosages and maximum daily dosage, drug review sites give a sense of the common drug dosages. Side effects reported on drug review sites are vividly described in context, with user assessment of severity based on discomfort, inconvenience and effect on their lives. Users also report side effects not found on authoritative sites.

Types of information found only on drug review sites were drug efficacy, cost of drug, difficulty in using the drug, comparison with other similar drugs and personal advice and encouragement. Drug efficacy ratings by users were found to be different across the three sites. In WebMD, drugs with more reviews tended to have lower aggregate ratings. Users make efficacy comparisons between generic and brand versions of the drug, between new and old versions, and with other similar drugs. Long term users may report on drug resistance or decrease in efficacy over the years. With reference to cost of the drugs, users alert readers to drug subsidy programs and generic forms of the drug.

It is clear that user postings on drug review sites contain several types of information that are useful to patients, caregivers, health professionals as well as drug manufacturers. Two kinds of information will be of particular interest to patients and caregivers—efficacy and side effects. Authoritative drug information websites do not provide an indication of how efficacious a drug is, and what the patient can expect. User postings can provide an indication of how fast a drug works and what kind of improvement the patient can expect. Some patients post actual physiological parameters such as blood pressure and blood glucose levels.

The sites also offer aggregated efficacy ratings by users that support comparison between alternative drugs. These have to be interpreted with care. Actual ratings can vary from site to site. In our opinion, ratings on websites such as PatientsLikeMe where users have to register and are expected to enter information about their health condition regularly maybe more trustworthy than sites that make it easy for users to post one review. The latter type of site is likely to be biased towards negative reviews, as unhappy users are more motivated to post reviews. Many factors can affect a user's

efficacy rating. Severity of side effects and their impact on daily life appear to have a substantial impact on efficacy ratings. So, lower efficacy ratings may reflect severe side effects that affect a small proportion of patients. It is important to review the unstructured comments to understand the reasons for low efficacy ratings. Also, sites with few postings for a particular drug and are not active may not provide reliable ratings.

User postings also sometimes compare the effects of different versions of a drug, especially between generic and brand versions. The comparisons are of course anecdotal and informal in nature, and may focus on the overt rather than internal clinical effects. Users may also contribute information about instances of drug resistance and decrease in efficacy with long-term use. This information may be provided in the context of the patient changing, reducing or discontinuing medication.

The user postings contain information about typical drug doses and their relation to treatment efficacy and management of drug side effects. Drug doses may be adjusted by the doctor or the patient without the doctor's knowledge in the hope of increasing efficacy or reducing side effects.

The above information is potentially useful to doctors, particularly with respect to new drugs or new versions of drugs that the doctor may not have experience with and do not have case information from the doctor's own patients. Pharmaceutical companies can also gather a sense of how well the drug is working directly from patients.

User postings also contain a lot of information about side effects. The lists of side effects on authoritative sites are dry and expressed in medical terminology. Side effects reported on social media are described in everyday language and in more detail, and therefore more understandable. They are also described vividly in the context of the patient's medical condition and daily life, and are easier to remember. The severity of side effects is assessed in terms of how tolerable they are and their impact on quality of life. Overt side effects, particular those that impact their daily lives, are more likely to be reported. Side effects that are internal and not overtly obvious may be under-reported.

This information is useful in alerting readers to conditions that are possibly side effects of their medication, which might otherwise take them longer to realize. Readers can also learn of coping strategies to deal with the side effects. Doctors can learn about how particular side effects can affect

patients' daily lives, issues encountered by patients, and patient behavior that affects their recovery. They can also counsel their patients on coping strategies.

In addition, users also reported a variety of side effects that were not stated on authoritative sites. While most of the instances of "new" side effects were isolated cases, there were a few side effects that had a noticeable number of reviewers reporting. For example, twelve reviewers complained of swelling and eight reviewers complained of low potassium levels after taking Hydrochlorothiazide. Pharmaceutical companies and government regulatory bodies can monitor the side effects reported on social media sites to see if there is a trend of new side effects surfacing that were not previously known from clinical trials.

User postings also contain information about practical issues such as cost and affordability, and issues in consuming the medication and following the treatment. Readers are alerted to cheaper generic versions, subsidy programs and alternative sources of the drug. Doctors and pharmaceutical companies are alerted to affordability issues and lack of insurance coverage for the drugs. Pharmaceutical companies can learn about problems patients are having with pill size, inconvenient pill dosage and taking the drug multiple times a day.

This study has analyzed the kinds of drug information on consumer drug review sites that are potentially useful to patients and caregivers. Consumer-contributed information is of course anecdotal, informal, incomplete in unknown ways, and biased to the reviewers' contexts and situations. The information is not of the same stature as the results of randomized controlled trials, the gold standard of evidence-based medicine. Nevertheless, consumer drug reviews provide useful leads, alerts and ideas that a patient can follow up with his or her physician or pharmacist, and about which the patient can search for more information in authoritative sources. Some advice in these reviews, such as everyday coping strategies, may be safe for the patient or caregiver to explore. However, more studies are needed to investigate how useful the different types of information and advice are for different types of diseases and patients.

There is a danger of disinformation and misinformation on unmoderated consumer review sites. On an active site, blatant disinformation may be caught and flagged by other users. Esquivel, Meric-Bernstam and Bernstam (2006) studied the accuracy of posts on an online breast cancer

mailing list, and the self-correction of inaccurate information on the list. They found a very small proportion (0.22%) of false or misleading statements, most of which were corrected by other users within an average of four and half hours. They cautioned, however, that their results may not generalize to other online forums. It is not known under what conditions false or misleading information will be corrected promptly by other users in a health social media site. Moreover, as Boulos (2012) pointed out, a patient might read the inaccurate post and make health decisions based on it before the information is corrected by the community, or might miss the posted correction.

The results of this study confirm the results of Hughes and Cohen's (2011) study of two psychotropic drugs. They had found that although commercial health portals provide concise and comprehensive lists of drug effects, consumers may not find the information meaningful because of lack of context. They noted that consumer reviews "provide abundant concrete descriptions and situational examples of how specific effects may manifest in various combinations and to varying degrees." However, their study was focused on side effect information. We have sought to map out more comprehensively the various types of information that can be expected in drug reviews.

Chuang and Yang (2012) focused on the different types of "nurturant support" expressed in an online community. This is not the focus of this study. It would be interesting to find out whether the pattern of nurturant support in consumer drug review sites is similar to the pattern that Chuang and Yang found for an alcoholism discussion forum. As drug review sites are not social networking sites, we expect a smaller proportion of nurturant support compared to informational support. Nevertheless, the reviewers were clearly motivated to support other patients with advice and words of encouragement. As can be expected, expressions of positive and negative sentiments are common in the review postings, but it is not clear whether these provide emotional support to other patients.

The results of this study are limited to common chronic diseases where patients can live a relatively normal life. The results may not be applicable to debilitating diseases, acute diseases and terminal diseases. The types of drug information identified here can provide a framework for studies of other diseases and drugs. The most common types of information found on drug review sites are drug efficacy and side effects information. In-depth studies can be carried out on these two types of information.

Studies can also be conducted from the user point of view to understand how they determine which review is useful and the types of information deemed as more useful, and the number of reviews users need to read to get sufficient information. Hughes and Cohen (2011) had found that reading the latest 20 reviews was sufficient to obtain a fair estimate of the relative frequencies of the common side effects.

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