# Patient-Centered Consumer Health Social Network Websites: A Pilot Study of Quality of User-Generated Health Information

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## Abstract

*The quality of user-generated health information on consumer health social networking websites has not been studied. We collected a set of postings related to Diabetes Mellitus Type I from three such sites and classified them based on accuracy, error type, and clinical significance of error. We found 48% of postings contained medical content, and 54% of these were either incomplete or contained errors. About 85% of the incomplete and erroneous messages were potentially clinically significant.*

## Introduction

Although associated with support, consumer health social networking (CHSN) websites are increasingly significant sources of health information[1]. They have potential benefits, but may also compromise patient safety as a distribution platform for persuasive, personally tailored, but harmful *misinformation*. There is a mismatch between the sites patients visit and the ones researchers study. Patients seek and *generate* health information in a peer-to-peer fashion online while researchers of health information quality focus on professional health destination websites that *disseminate* information[2]. In response, we conducted a pilot study assessing the quality of user-generated information on CHSN websites.

## Methodology

We identified three CHSN sites (DailyStrength.org, RevolutionHealth.com, and CarePlace.com) and extracted a total of 50 user-generated postings related to Diabetes Mellitus Type I. This condition was chosen for the large body of clinical guidelines.

The two physician authors independently classified each posting as having medical content or not, then whether the medical content was accurate and complete, accurate and incomplete, or containing errors. Errors were classified as omissions (important information missing) or commissions (incorrect information). Inaccuracies and errors were classified based on clinical significance. The American Diabetes Association clinical guidelines were used as the reference standard.

## Results

Of the 50 user-contributed postings, 24 (48%) contained medical information, 13 (54%) of these were either incomplete *or* contained errors, and 11 (46%) could not be evaluated due to a lack of relevant guidelines (Table 1).

| Posts w/ Medical Content | Count | Percent |
|---|---|---|
| Accurate And Complete | 0 | 0% |
| Accurate But Incomplete | 6 | 25% |
| Error Of Omission | 3 | 12.5% |
| Error Of Commission | 4 | 16.7% |
| No Relevant Guidelines | 11 | 45.8% |
| **Total** | **24** | **100%** |

**Table 1.** Accuracy of posts with medical information

**Of the 13 incomplete or erroneous postings, 11 or 85% were potentially clinically significant.**

## Conclusion

We found very low quality user-contributed health information on three different CHSN sites. Half of all postings containing medical information were incomplete or contained errors. Of these, over 80% were potentially clinically significant.

Our next stage of research will characterize user-generated errors across more diseases, and explore health information quality improvement strategies consistent with social network processes.

## References

1. Landro L. "Social Networking Comes to Health Care." The Wall Street Journal [New York] 27 December 2006, D1+.
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