Social Media and Pharmacovigilance

Institute of Medicine
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Social Media

• User-generated online content such as:
  – Blogs (self-published journalism)
  – Forums (online discussions)
  – Wikis (collectively edited knowledge stores)
  – Social networks such as:
    • Facebook
    • Twitter
    • LinkedIn
    • Patients Like Me
Social Media

• Anyone with an internet connection can create content.
• Content can be shared with, or recommended to, anyone else with an internet connection.
• In this environment, traditional hierarchies of authority and expertise do not always pertain.
Some Examples

patientslikeme

American Cancer Society Cancer Survivors Network
You’ve been there.
Now it’s time to Fight Back!
Take Action Now

e-patients.net
because health professionals can't do it alone
Accuracy & Privacy

• “Information posted on this site represents the experiences, opinions, and beliefs of the author; it may not be based on medical fact... Please note! CSN discussion boards are public forums open to search engines.”

ACS Cancer Survivors Network
http://csn.cancer.org/forum
Social Media and Pharma

The sector has been relatively slow to embrace social media for three reasons:

1. IP concerns
2. Regulation of DTC communications
3. Mandatory AER

i.e. “We don’t want to share, we’re not allowed to share, and if we do we’ll be swamped with FDA reports”
Social Media and AER

- 2008 Nielsen study – 0.2% of forum posts contained the 4 criteria which would trigger an AER.
- 2010 Patients Like Me study – 7% of forum posts contained all 4 criteria.

- Opportunity or threat?
- FDA regs. due December 2010.
Two Paths for Social Media & Pharmacovigilance

1. Social Media Monitoring
2. Online Community Management
Social Media Monitoring

• Massive ($$$) emerging industry.
• Monitoring any and all mentions of your brand, products and services in social media.
• Analytics re: sentiment, influence and ‘buzz’.
• Technologies to search, sort and select social media content from anywhere.
• Regulations re: privacy, IP and reporting are unclear.
SMM and Pharma

• Already happening for
  – Crisis management
  – Competitor research
• Efficacy reduced by DTC & AER regulations which prevent 2-way interactions.
• Industry concerns about the PR implications of monitoring / surveillance.
• Activist concerns about privacy.
Online Community Management

• Brand-sponsored online spaces for the discussion of products and services or
• Grassroots online spaces for the discussion of topics relevant to the brand’s interests.
• Both can be used for stakeholder research, both pre- and post-market.
PLM Epilepsy Community

“Last June, PatientsLikeMe and UCB announced this strategic partnership to build an online community for people living with epilepsy, which debuts today…

…To better understand the impact of medications that treat epilepsy in the real world, PatientsLikeMe and UCB are also taking the lead in implementing a drug safety program within this patient community. The program is designed to capture and report adverse events associated with approved UCB epilepsy therapies to the U.S. Food and Drug Administration (FDA).

Patients Like Me Press Release 1.26.10
The Future

• Both paths (SMM and OCM) likely to expand.
• SMM will become increasingly sophisticated.
• FDA/CDC need to invest heavily in SMM to keep up.
• Competition between pharma brands for the attention of online disease communities will increase.
• Healthcare professionals need to be educated about Pharma in OCM and to be more involved.