

Online Healthcare Communities

Exploring the Myths

Bob Brooks



bobb@wegohealth.com

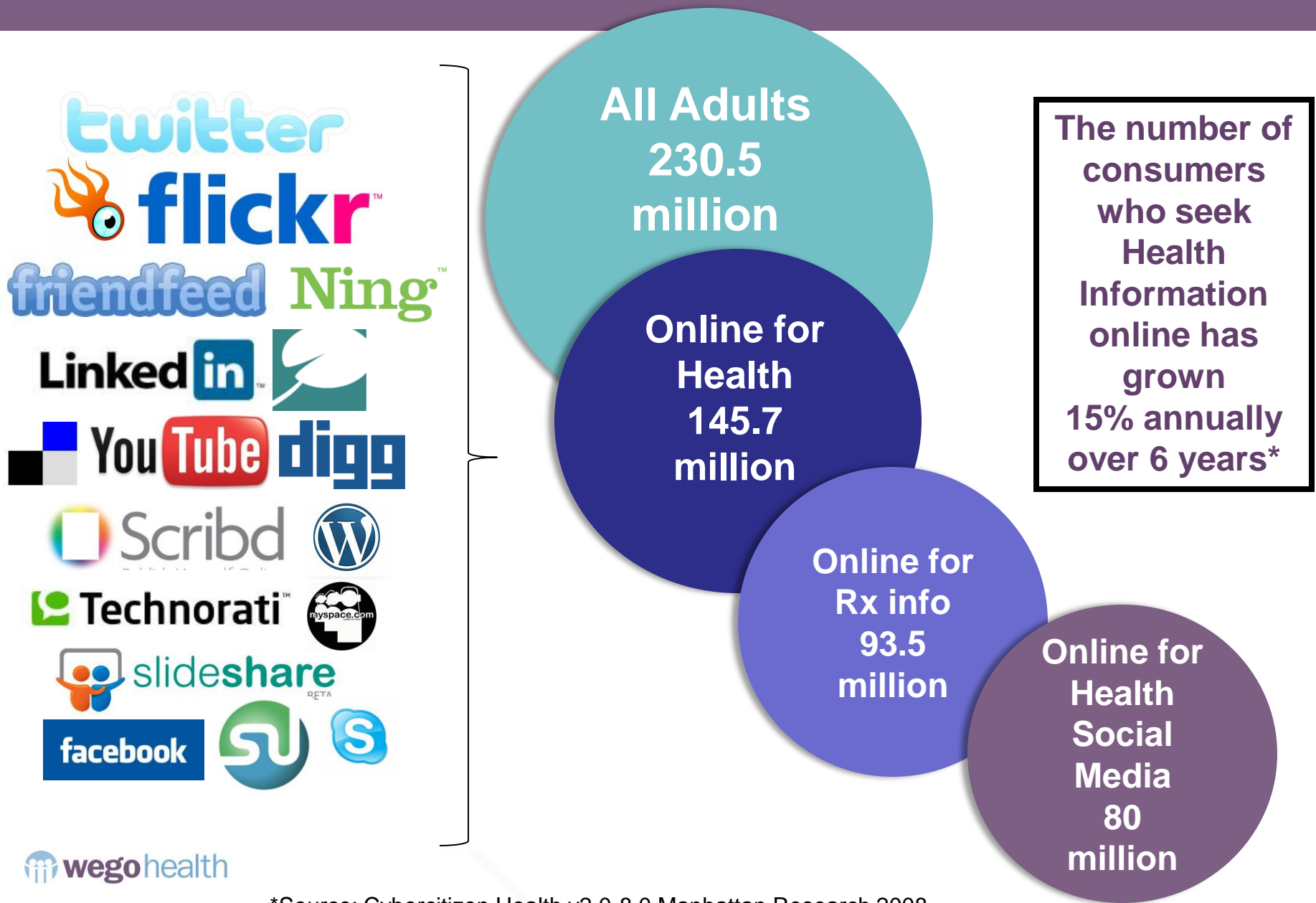


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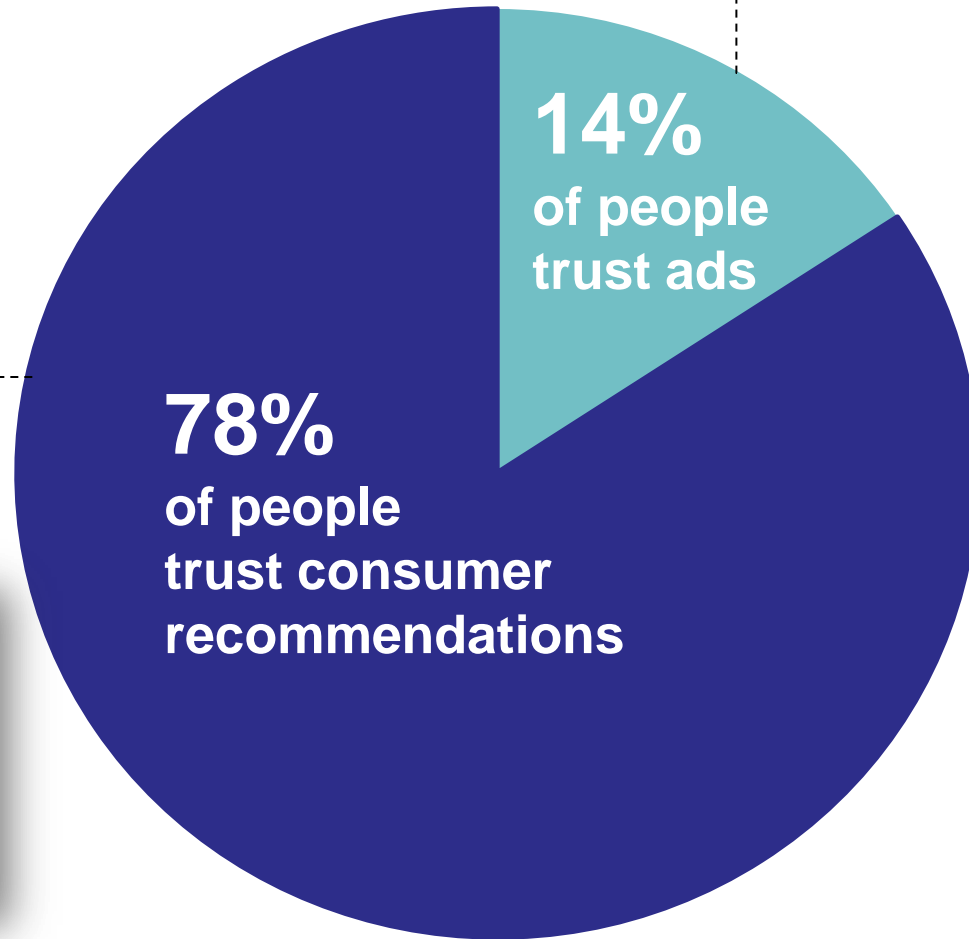
- **Industry Backdrop**
- **The FDA Survey – Health Activists**
- **The Big Myths:**
 - Online Influencer attitudes
 - Healthcare Companies participation
 - Adverse events reporting
 - Social Media and measurement
 - FDA and consumer perspectives

Consumers Seek Health Info Online



*Source: Cybercitizen Health v2.0-8.0 Manhattan Research 2008

Consumers Trust Consumers



September 29, 2008

YouTube Warning Letter



A Warning Letter was posted by CDER's DDMAC on Friday, September 26 that was sent to Shire Pharmaceuticals regarding a Web promotion and a YouTube video for Adderall XR. While normally Warning Letters are not featured here except in a quarterly roundup, this one has significance since it involves a foray into YouTube by a pharmaceutical company promoting a product. Again, the lesson here is that it is the message, not the medium, that trips the regulatory tripwire.



According to the FDA, there was both a webpage and a video promoting Adderall XR, both of which were said by the agency to overstate the efficacy of the product and citing the video for omitting important risk information. As well, the webpage was said to broaden Adderall XR's use beyond that approved by the FDA. There is a Warning Letter to suggest that the use of video to promote is a problem, merely the omission of information.

14 Drug Companies Cited for Misleading Google Ads

The FDA cited 14 drug companies for misleading advertising in sponsored ads among **Google** search results.

Those cited:

Biogen Idec, Sanofi Aventis, GlaxoSmithKline, Forest Laboratories, Cephalon, Bayer, Johnson & Johnson, Pfizer, Novartis, Genentech, Boehringer Ingelheim, Merck, Hoffman-LaRoche, and Eli Lilly.



FDA Demands Pharma Stops 'Misleading' Ads on Google, Yahoo

Letters to Major Marketers Say Advertised Drugs' Effectiveness Isn't Tied to Potential Risks in Search

By [Marissa Miley](#)

Published: [April 06, 2009](#)

FDA Internet Guidelines?

Good News

The FDA understands the issue.

[The guidelines] were written decades and decades ago... people weren't thinking about Twitter back then.

A lot of it revolves around the five questions we posed ... things like accountability, responsibility, ownership of the information and regulatory requirements.

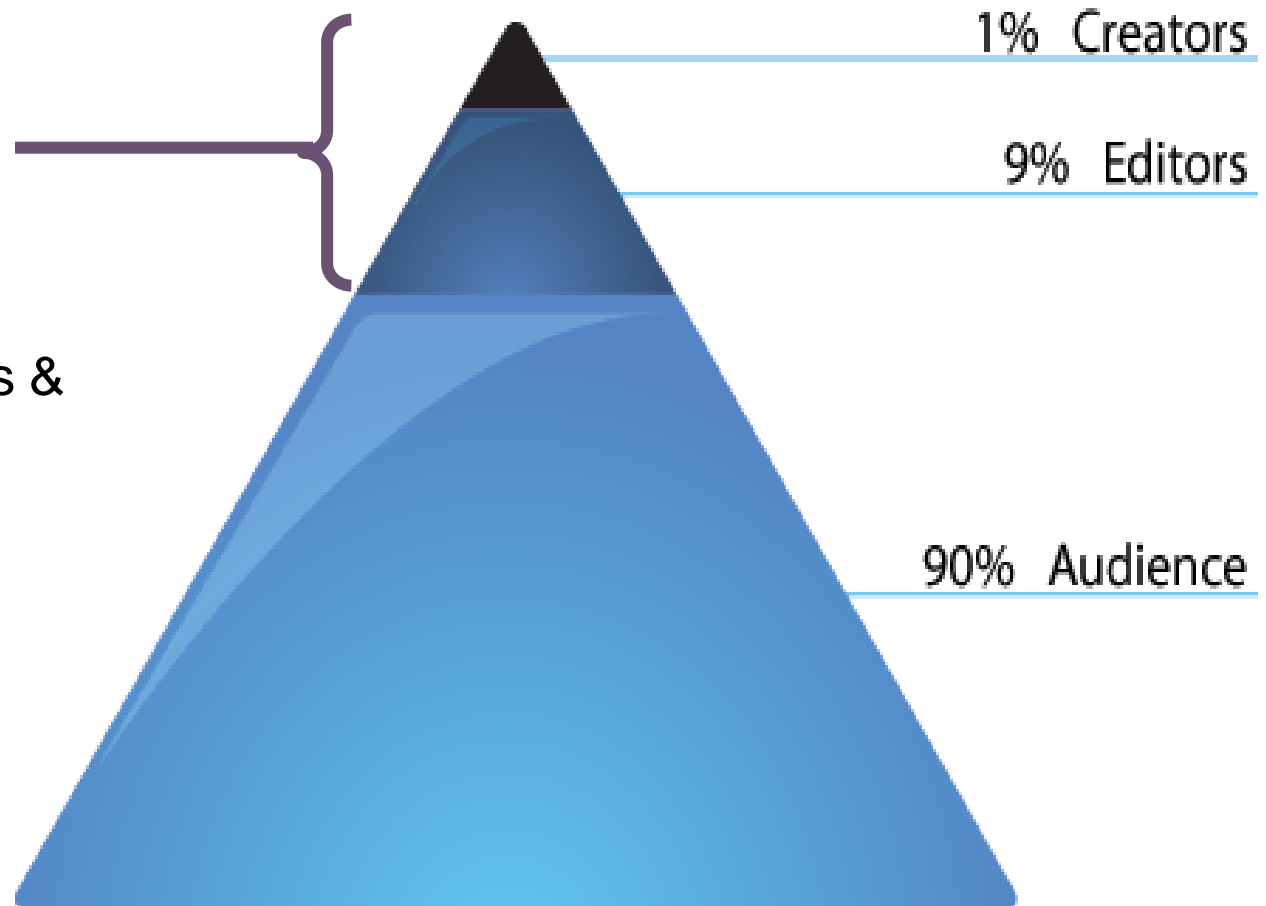
Dr. Jean-Ah Kang, Special Assistant to the Director in DDMAC

Health Activists Are The New Opinion Leaders



Social Media Creators & Editors are:
Health Activists

**Source: WEGO Health Activist Benchmark Survey 2008 - 2010*



Jakob Nielsen, *Participation Inequality*, 2006

On average, they create content for an audience of
15,000+ every month*

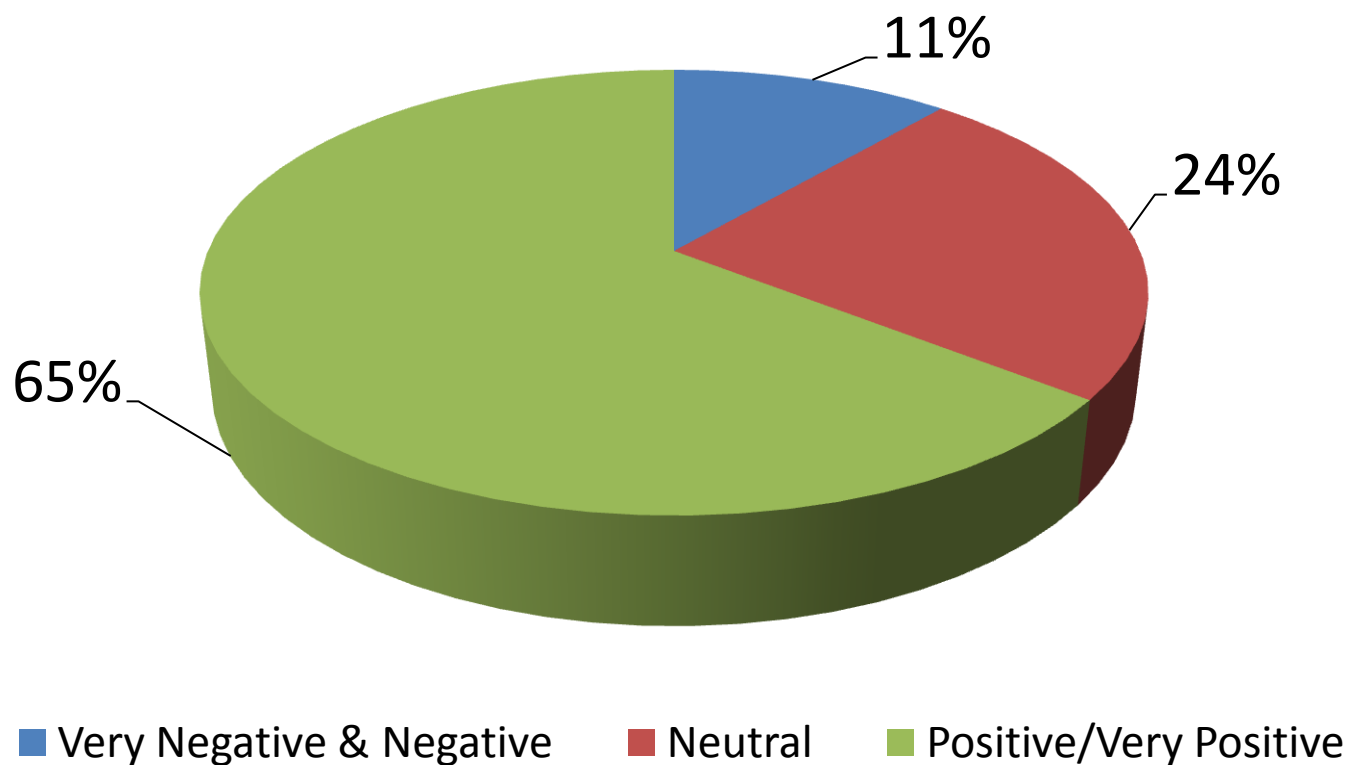
Concerns and Myths

Social Media is a Shark Tank – And Health Companies Are the Chum

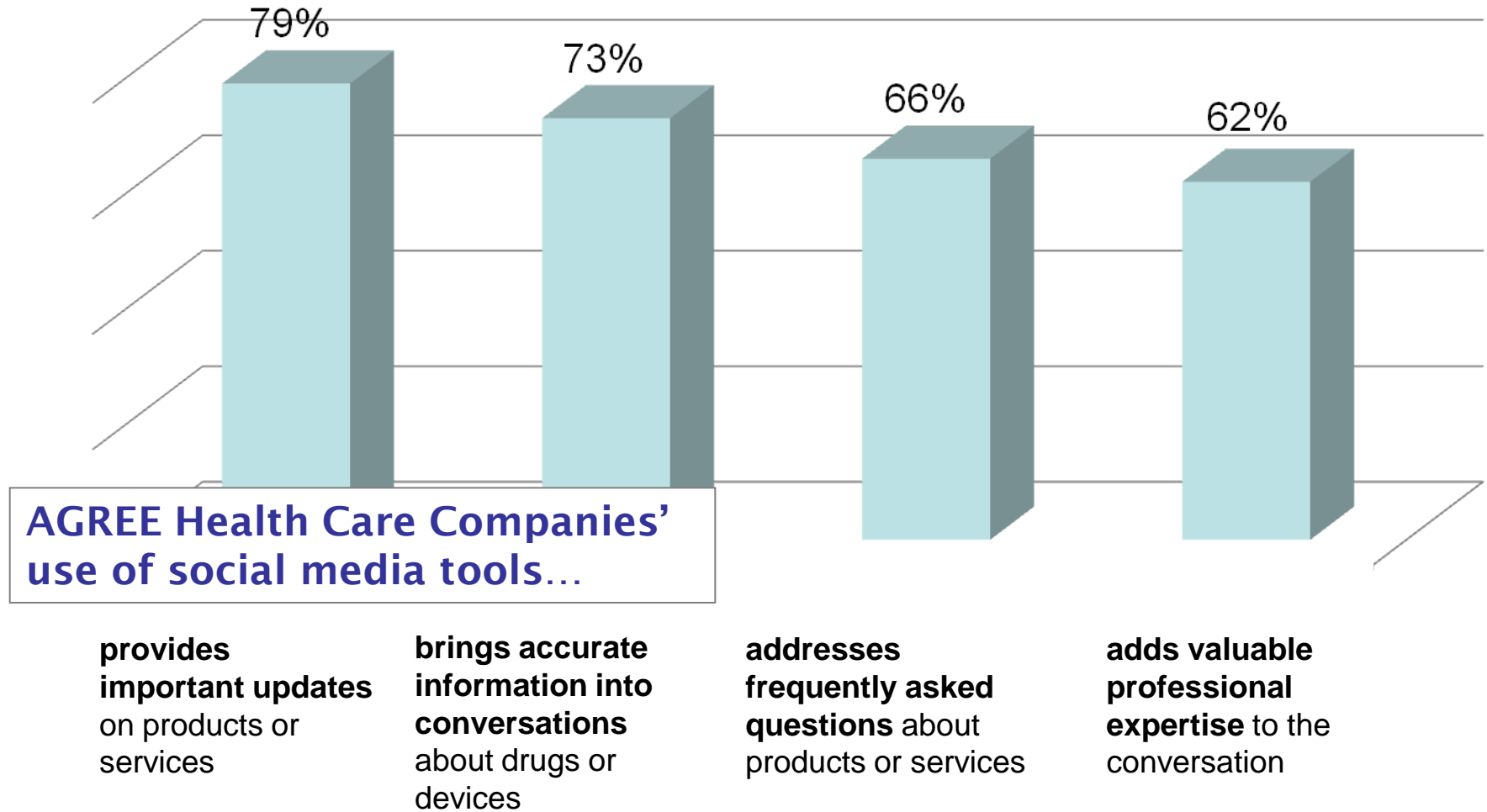


The Online Community May Be a Company's Safest Home

“In the online health communities in which you are active, what is the overall perception of the companies and products that treat this condition?”



Social Media Use Provides Valuable Information





“The Allergan corporation jumped on our Dystonia forum, it was surprising, because we were talking about Botox and marketing, basically complaining about it, and they came onto the site and left a comment about it, and it was good.

It made it seem like we aren't just yelling into the air, someone actually is paying attention to what we're saying and our concerns, and listening. And it seemed like they couldn't say much, but they said enough to say, 'we are listening to what you are saying, and we care.'”

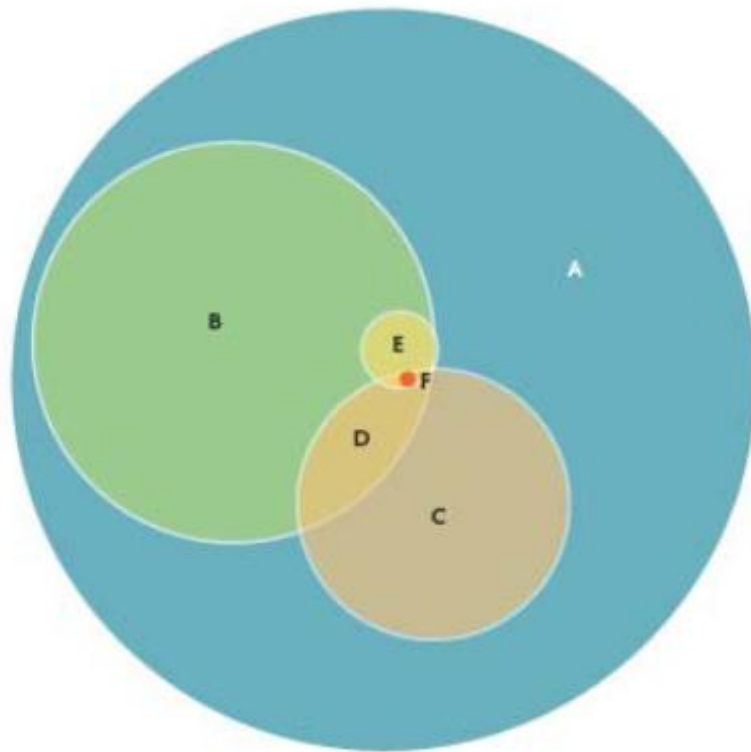
--- Jennifer, WEGO Health Activist

Adverse Event Reporting

If given an open forum, patients
will post waves of reportable
“adverse events”

1 in 500 posts actually contain all the information required for an adverse event report.

A small fraction of social media posts contain reportable AEs.



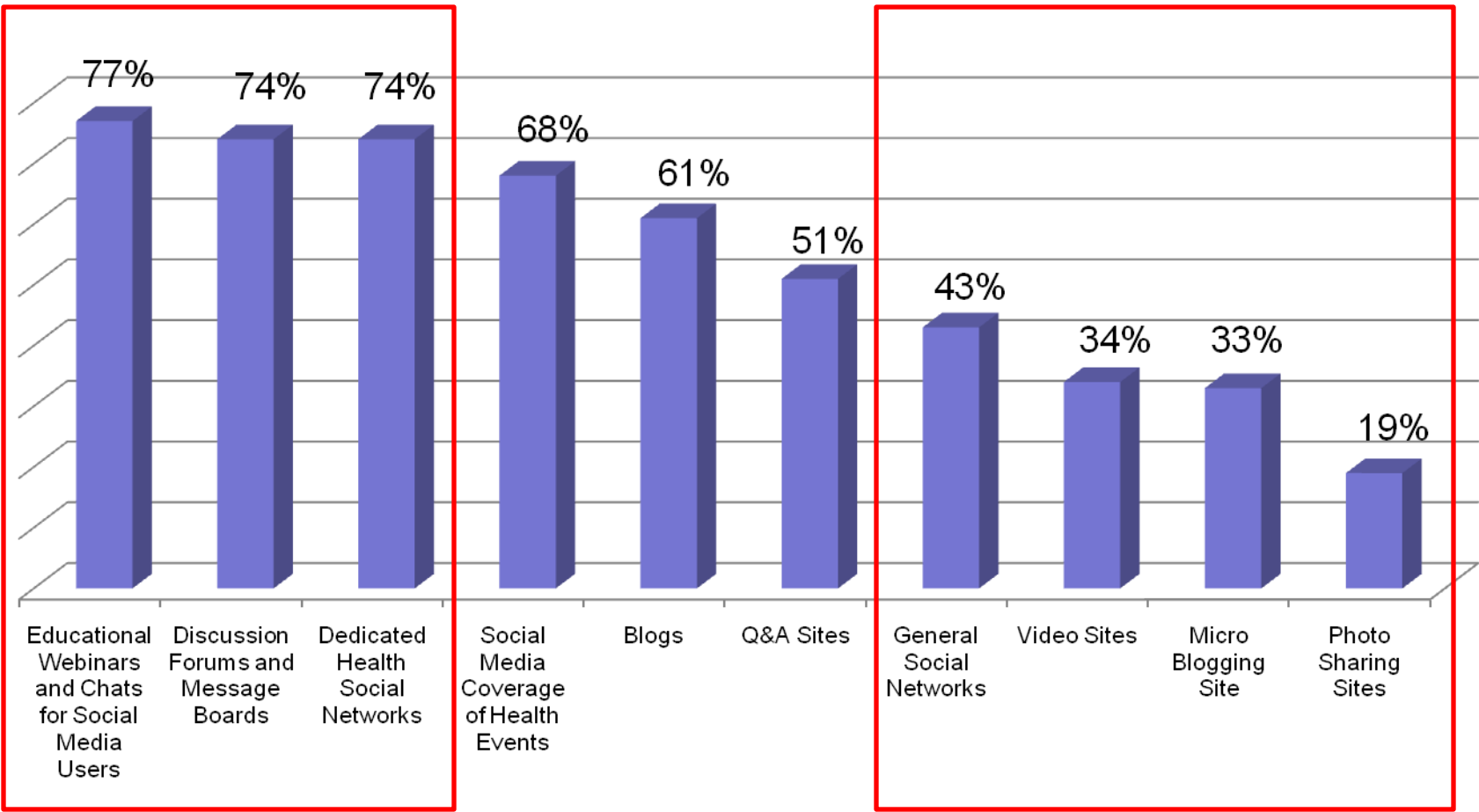
- A 494 messages mention an identifiable patient
- B 100 messages mention a specific medication
- C 56 messages mention an identifiable reporter
- D 14 messages both mention a specific medication and an identifiable reporter
- E 4 messages mention an adverse experience and include an identifiable patient and a specific medication
- F 1 message also included an identifiable report

Concerns and Myths

Social Media = **facebook**

Health Activists Want Engagement and Education

Very or Extremely Useful





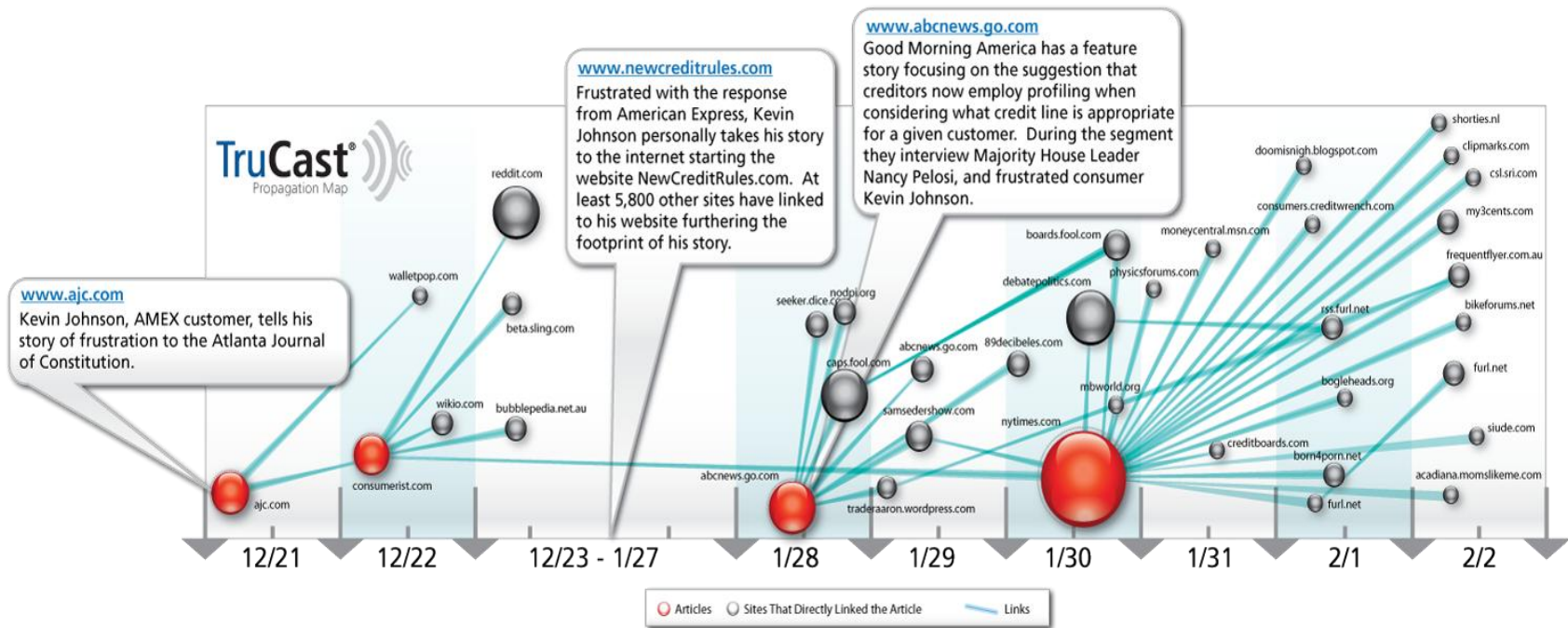
“Companies are largely missing from the supportive, real-life conversations going on in health discussion groups, on social networks, and such...

I’ve been at this long enough to know they have regulations that get in the way, but everyone would benefit if (companies) could be at the table with us...”

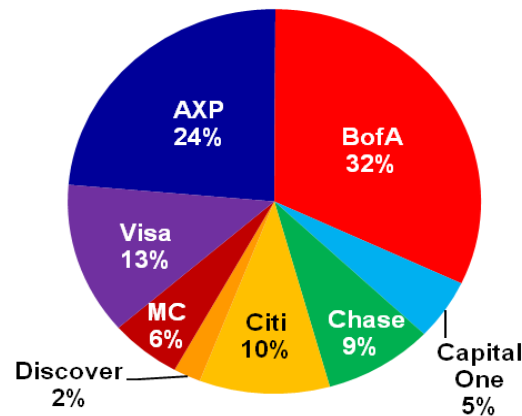
--- *Ellen, WEGO Health Activist*

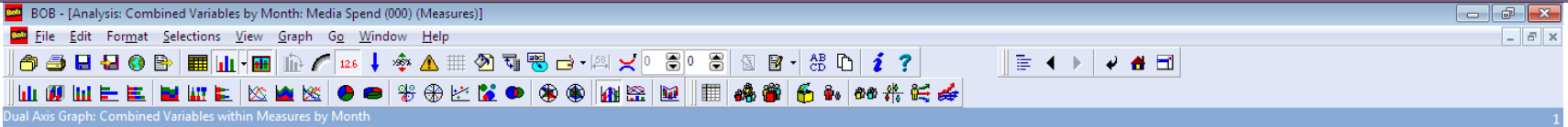
Measurement?

Concerns and Myths: Measurement



Monthly Share of Voice

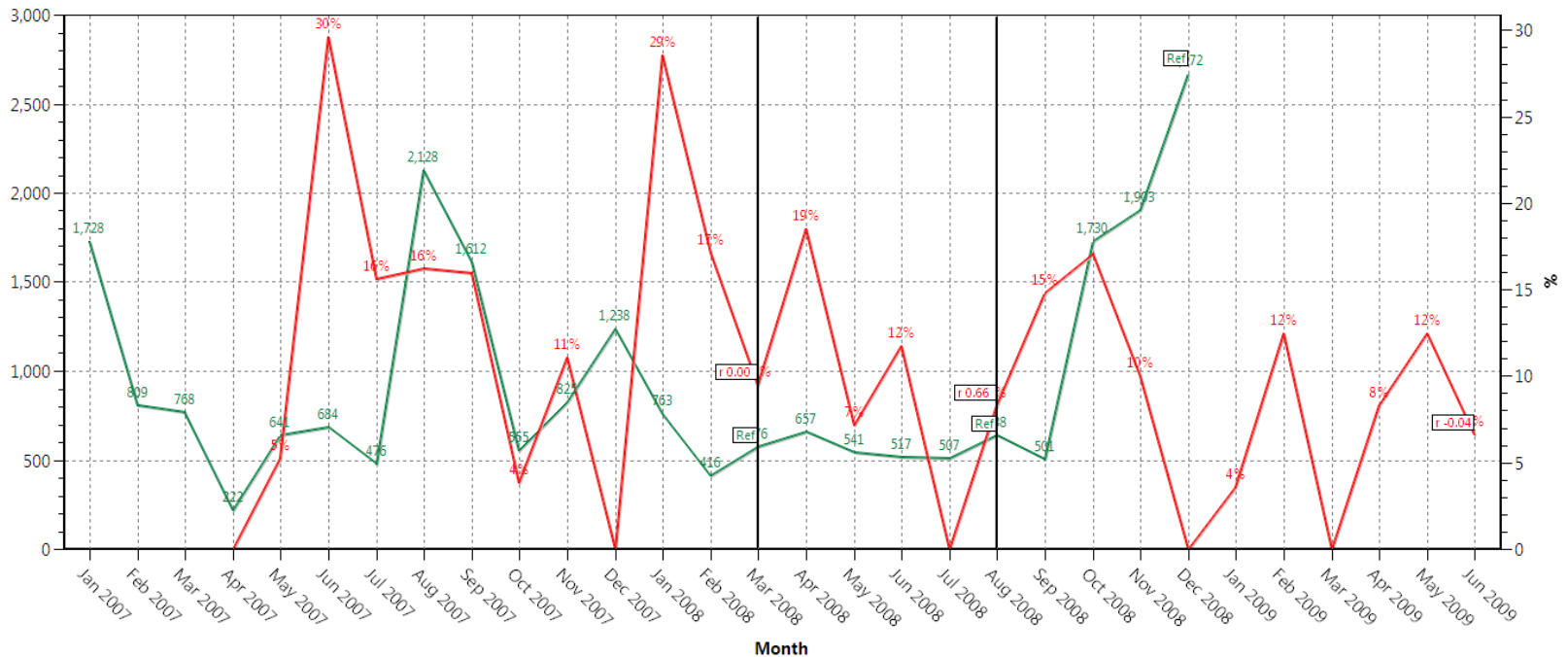




Combined Variables within Measures by Month

AMEX - Visible Technologies (2009), Credit Card Brands Media Spend, Credit Card Brands Share of Voice, Credit Card Tracker

Combined Variables
 Media Spend (000):Media Spend: — American Express
 Counts:Sentiment of Post: — Positive

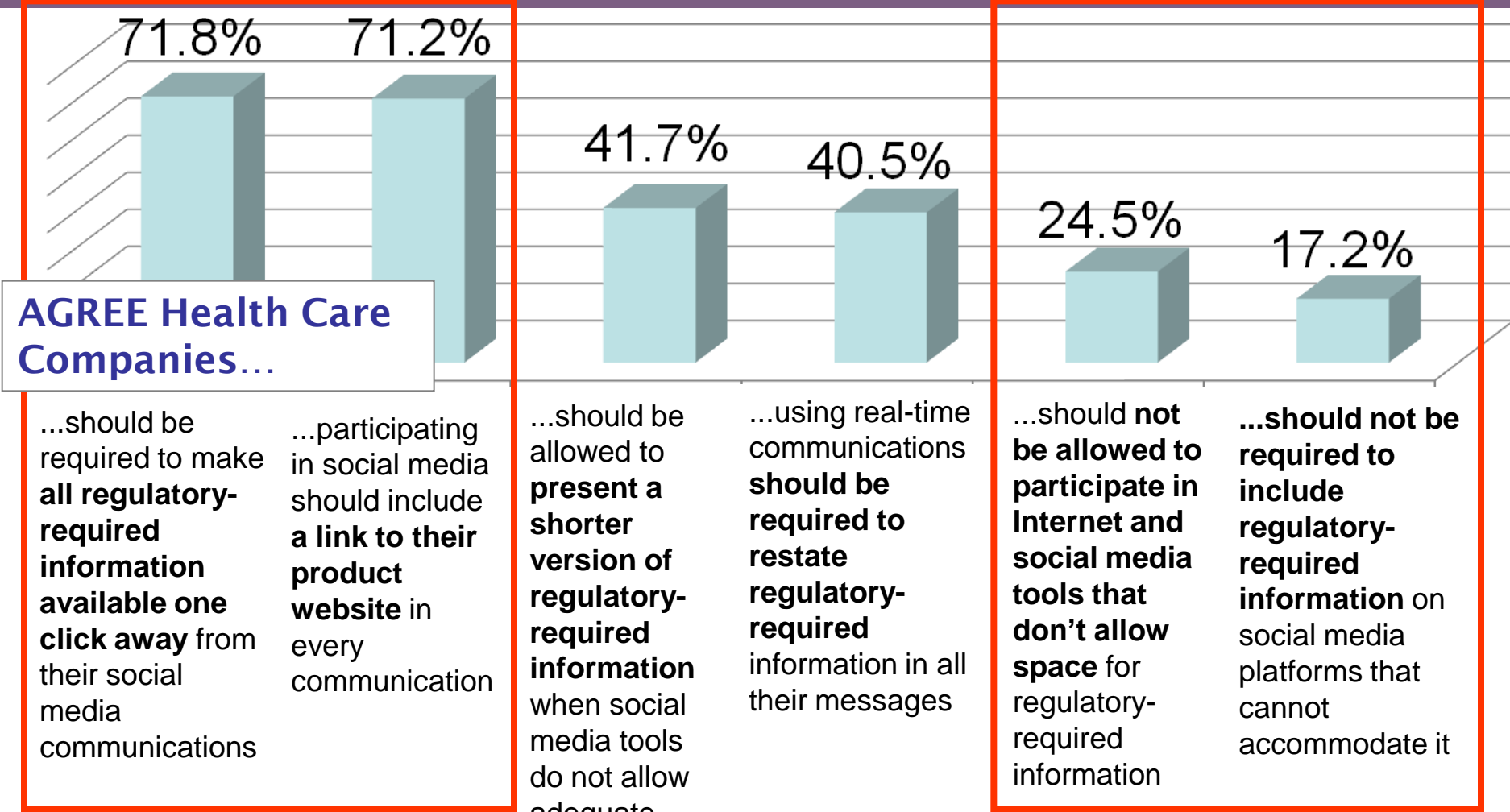


Autobase Off

INTEGRATED METRICS – SOCIAL & TRADITIONAL RESEARCH

Consumers Are Unaware of The FDA Regulations and Registrations of Health Care Companies

What are appropriate ways for Health Care Companies to fulfill regulatory requirements in their Internet and social media activities...?



AGREE Health Care Companies...

...should be required to make **all regulatory-required information available one click away** from their social media communications

...participating in social media should include **a link to their product website** in every communication

...should be allowed to **present a shorter version of regulatory-required information** when social media tools do not allow adequate space

...using real-time communications **should be required to restate regulatory-required information** in all their messages

...should **not be allowed to participate in Internet and social media tools that don't allow space** for regulatory-required information

...should **not be required to include regulatory-required information** on social media platforms that cannot accommodate it

“ What are appropriate ways for Health Care Companies to fulfill regulatory requirements in their Internet and social media activities, particularly when using tools that are associated with space limitations and tools that allow for real-time communications (e.g., micro-blogging platforms like Twitter, and mobile technology)?”

How do you feel about regulation of Health Care Companies' participation in Internet and social media?

74%

Agree regulation of Health Care Companies' participation in Internet and social media **needs to be tailored** to the unique attributes of the Internet and social media

64%

Agree open Internet and social media conversation between Health Care Companies and people online is valuable, and **regulations should not prevent those open conversations**

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Pharma values

- ⊗ Risk averse
- ⊗ Heavily regulated
- ⊗ Closed, security-focused
- ⊗ Controlled access to data
- ⊗ Authoritative, heavily filtered
- ⊗ Remote voice
- ⊗ Long lead times
- ⊗ IP closely guarded
- ⊗ Marketing-dependent

Social media values

- ⊗ Risk taking
- ⊗ Open to all
- ⊗ Transparent
- ⊗ Sharing culture
- ⊗ Wisdom of crowd
- ⊗ Personal voice
- ⊗ Rapid deployment
- ⊗ Open source
- ⊗ Marketing-suspicious

Hat tip to Len Starnes, Head of Digital Marketing, Bayer Schering Pharma



“Health Care Companies have the most direct information about their own studies that they’ve conducted and their products, and we’ll lose that whole side of the conversation...

I think we need to balance that conversation with the negative perception of Health Care Companies . They should have their opportunity to present their side as well, we should have a real dialogue.”

--- *Lauren, WEGO Health Activist*

Bob Brooks
Vice President, WEGO Health
bobb@wegohealth.com
617.649.1506

Twitter.com/wegohealth
www.wegohealth.com

