



# Health Activists And Social Media FDA Questions 1,2,3

Presented to the FDA's Public Hearing  
"Promotion of Food and Drug Administration-Regulated Medical  
Products Using the Internet and Social Media Tools"

November 12, 2009

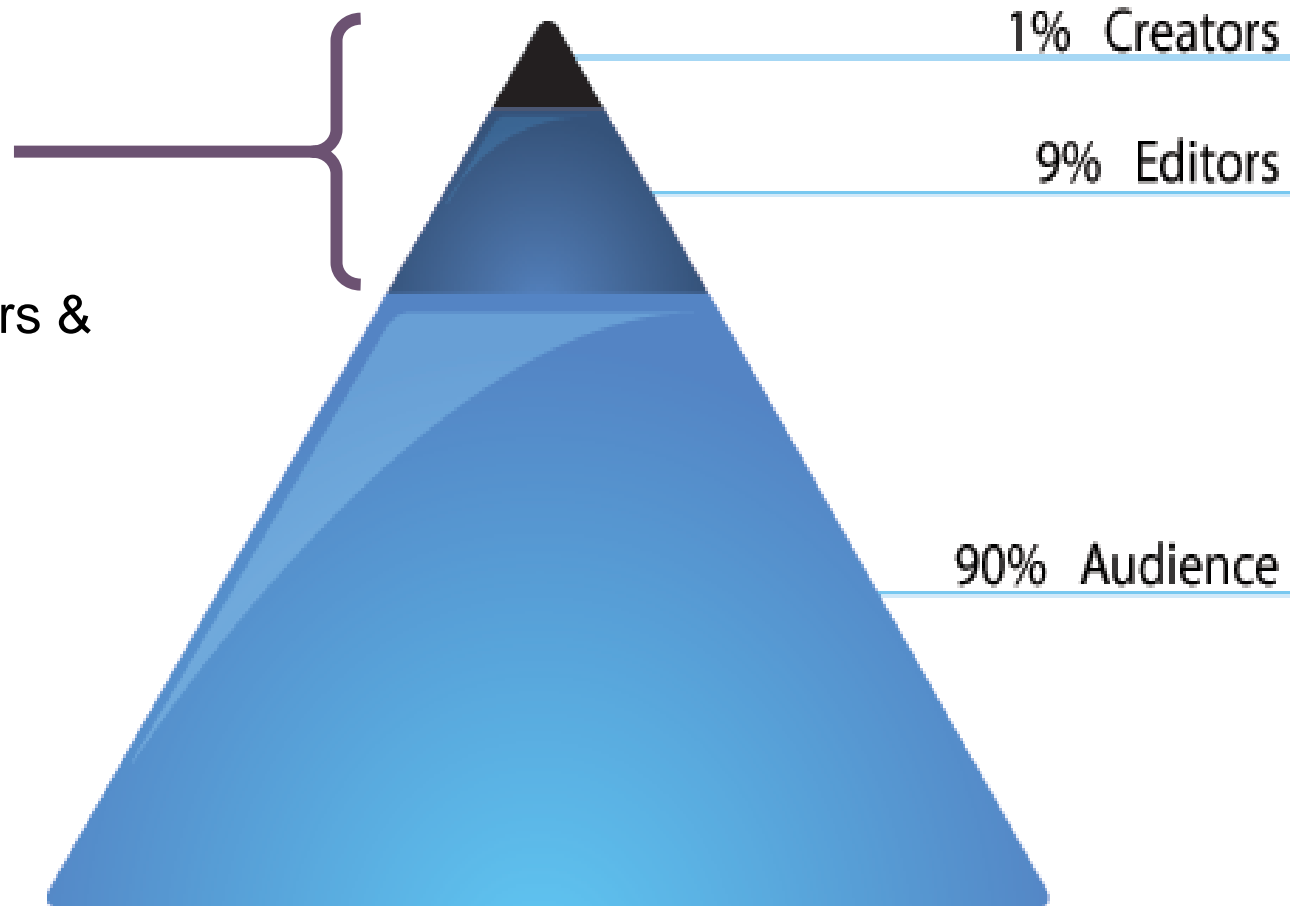
# WEGO Health Activists Are The New Opinion Leaders



Social Media Creators & Editors are

## Health Activists

On average, they create content for an audience of 10,000+ every month\*



Jakob Nielsen, *Participation Inequality*, 2006

\*Source: WEGO Health Activist Benchmark Survey 2008/9

# WEGO Health Activists Are Social Media Power Users

Ellen  
Audience of ~50,000 people per month



WEGO Health Activist



Featured blogger for Invisible Illness Week



Active member of Yahoo! Migraine Group



Featured in Headache Blog Carnival



Active member of care4dystonia.org



Active member of BioMedCentral



Active member of CafeMom



“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*

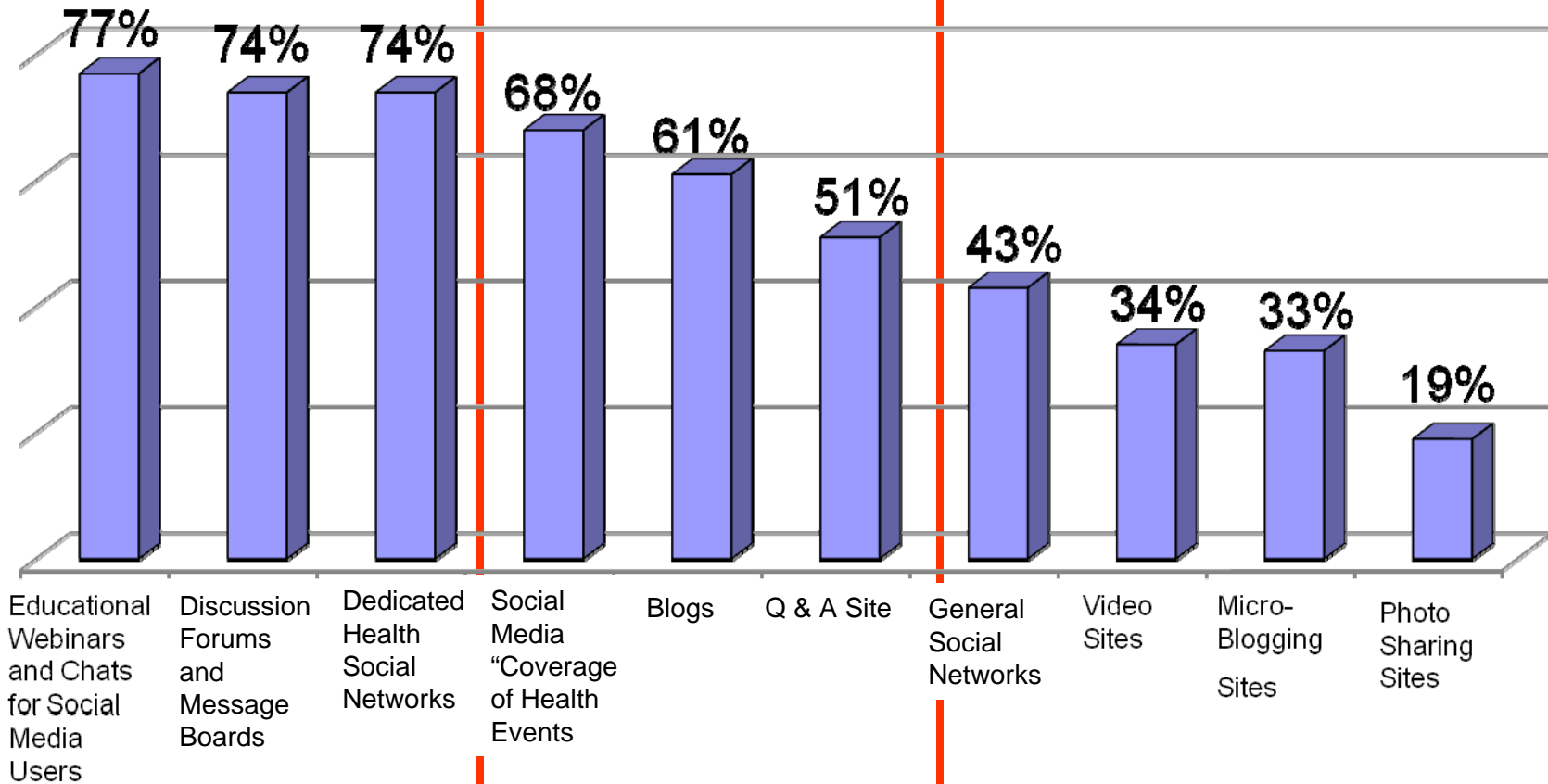
# Health Activist Perspective – Survey Results

- Social media is an important tool for health communication, and Health Care Company participation provides value to the community
- But Health Care Companies have an obligation to the community to correct misinformation about their products, and to follow regulations
- Regulation of Health Care Companies in social media is challenging, and the FDA should work to tailor regulations to the practical realities of social media

Social media is an  
important tool for health  
communication

# How useful are each of these social media tools in helping people to understand important health issues?

## Very or Extremely Useful





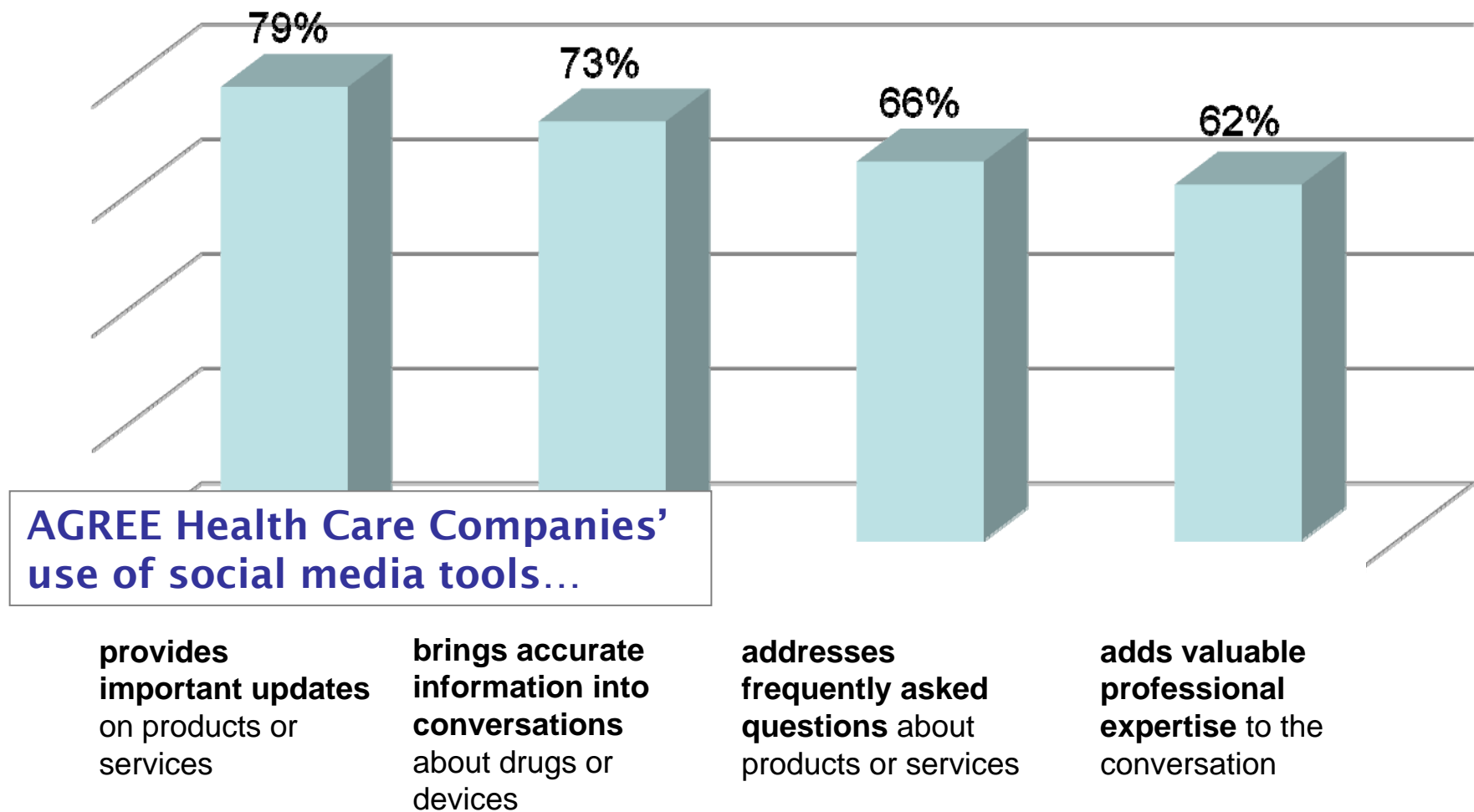
“It’s the people who seem to be the most interested in the topics and have done the most personal research and will tell personal stories...that’s what discussion forums are filled with... I think they’re wonderful, and you get such a variety of information...”

--- *Bill, WEGO Health Activist*

**Strategic Implication: FDA and Health Care Companies must embrace social media to communicate effectively with consumers**

Health Care Company  
participation provides  
value to the community

# Does the use of social media by Health Care Companies help people to understand important health issues?





“I kind of see (company participation) as a little biased, but I do like it when you have a forum going on - and actual drug facts, what it’s used for, what the side effects are - when a company brings that into the picture, that’s excellent, either by providing links or listing everything right there...”

*--- David, WEGO Health Activist*

**Strategic Implication: Health Care  
Companies should participate in social  
media - IF they bring valuable information**

Health Care Companies have  
an obligation to correct  
misinformation about their  
products

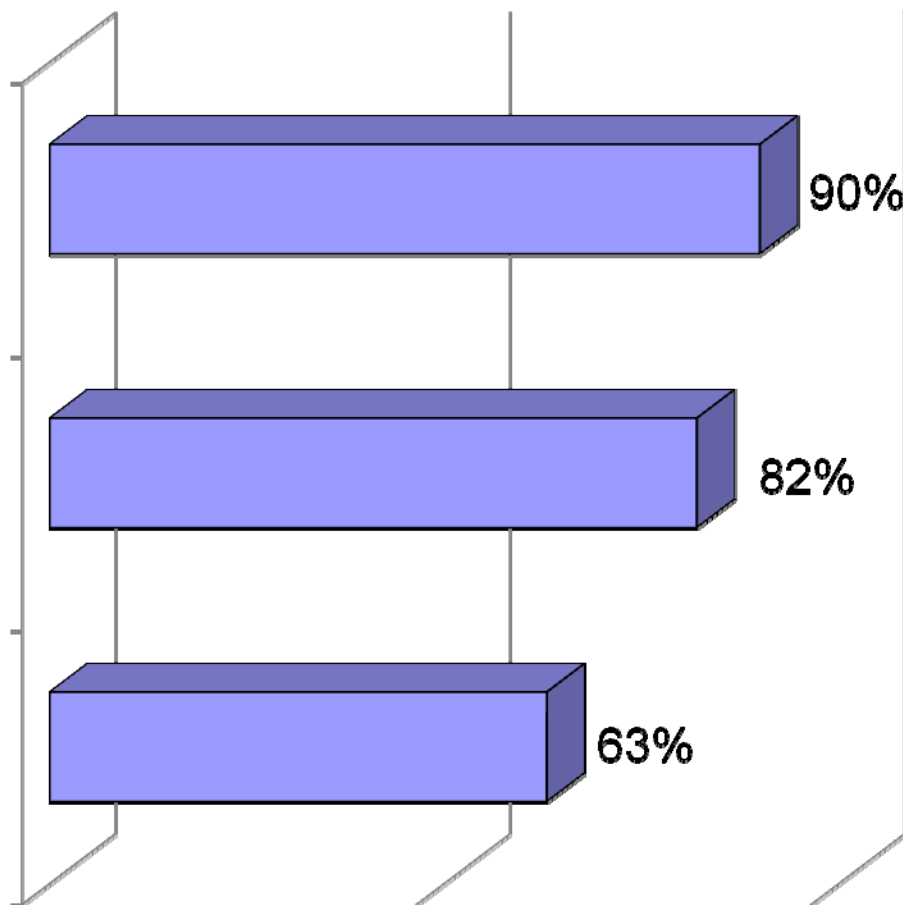
# How should Health Care Companies get involved in monitoring and correcting misconceptions or misinformation about their products on other Web sites beyond their control?

## AGREE Health Care Companies...

...should get involved in monitoring and correcting misconceptions or misinformation when the information may be harmful to people using the product

...should get involved in monitoring and correcting misconceptions or misinformation whenever the Health Care Company feels it has product information that may be helpful to the community

...should get involved in monitoring and correcting misconceptions or misinformation about their product anywhere on the Internet





“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*

**Strategic Implication: Health Activists welcome fully transparent corrections by companies – and trust companies who make the effort**

Online content ...can be altered from its original state by people who don't work for the company

**64%**

Agree Health Care Companies should be responsible for policing any unauthorized versions of their content

**60%**

Agree Health Care Companies cannot reasonably keep up with the monitoring of all mentions of their content

“Online content created by Health Care Companies, and regulated by the FDA, can be altered from its original state by people who don't work for the company. This unauthorized, altered content can be posted or distributed. Indicate your perspective.”



“It’s paradoxical, really. It’s a good thing if (companies) could do it, but I can’t imagine how they could be everywhere. It’s sort of unreasonable.

I would tell them to hire people for that purpose. It’s important, it’s just important.”

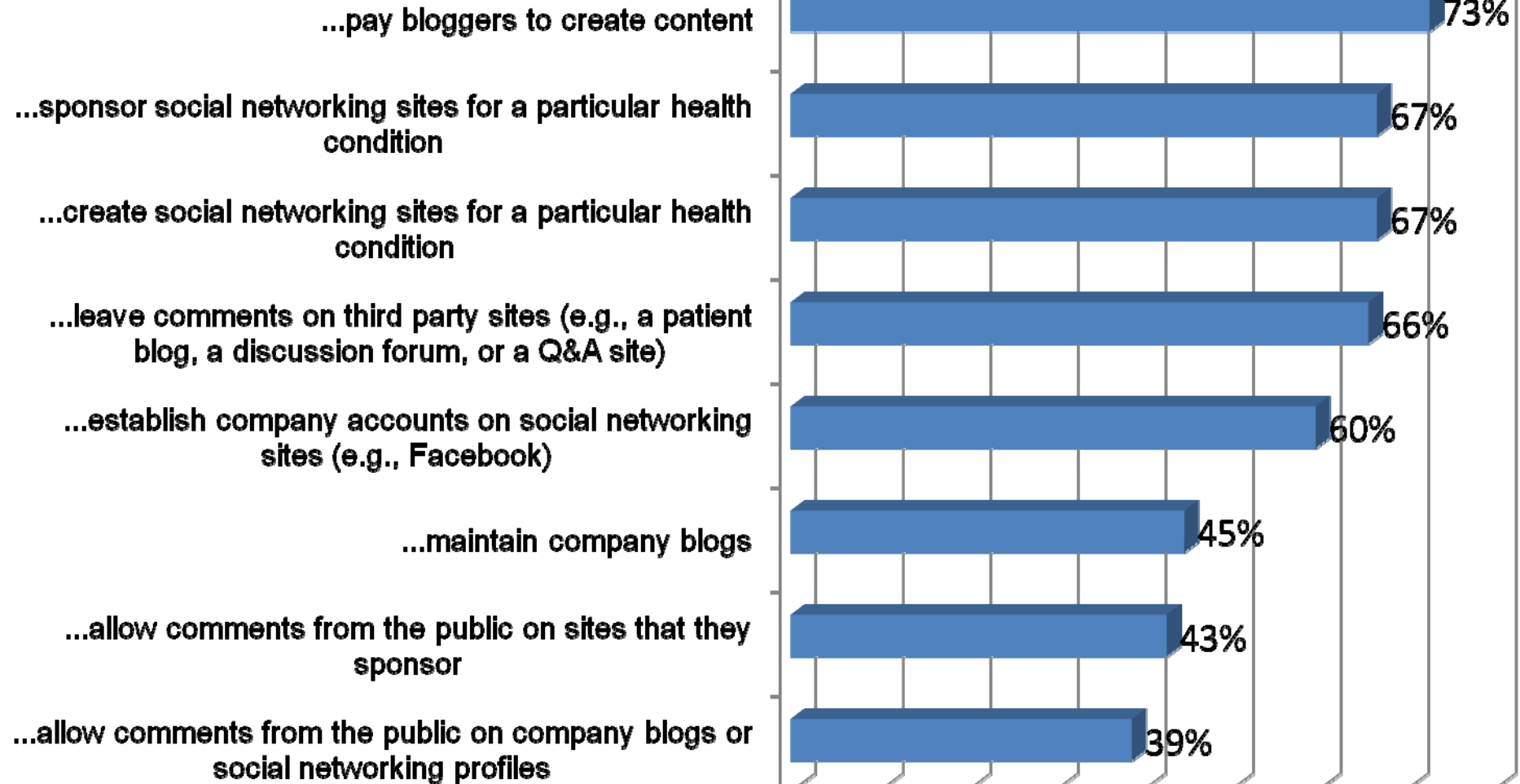
--- *Debra, WEGO Health Activist*

**Strategic Implication: Health Care Companies must monitor proactively, while FDA – and Health Activists – need to define “best effort”**

Health Care Companies have  
an obligation to follow  
regulations

# When do you feel a Health Care Company's participation in Internet and social media technologies should be regulated?

## When Health Care Companies...





“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...

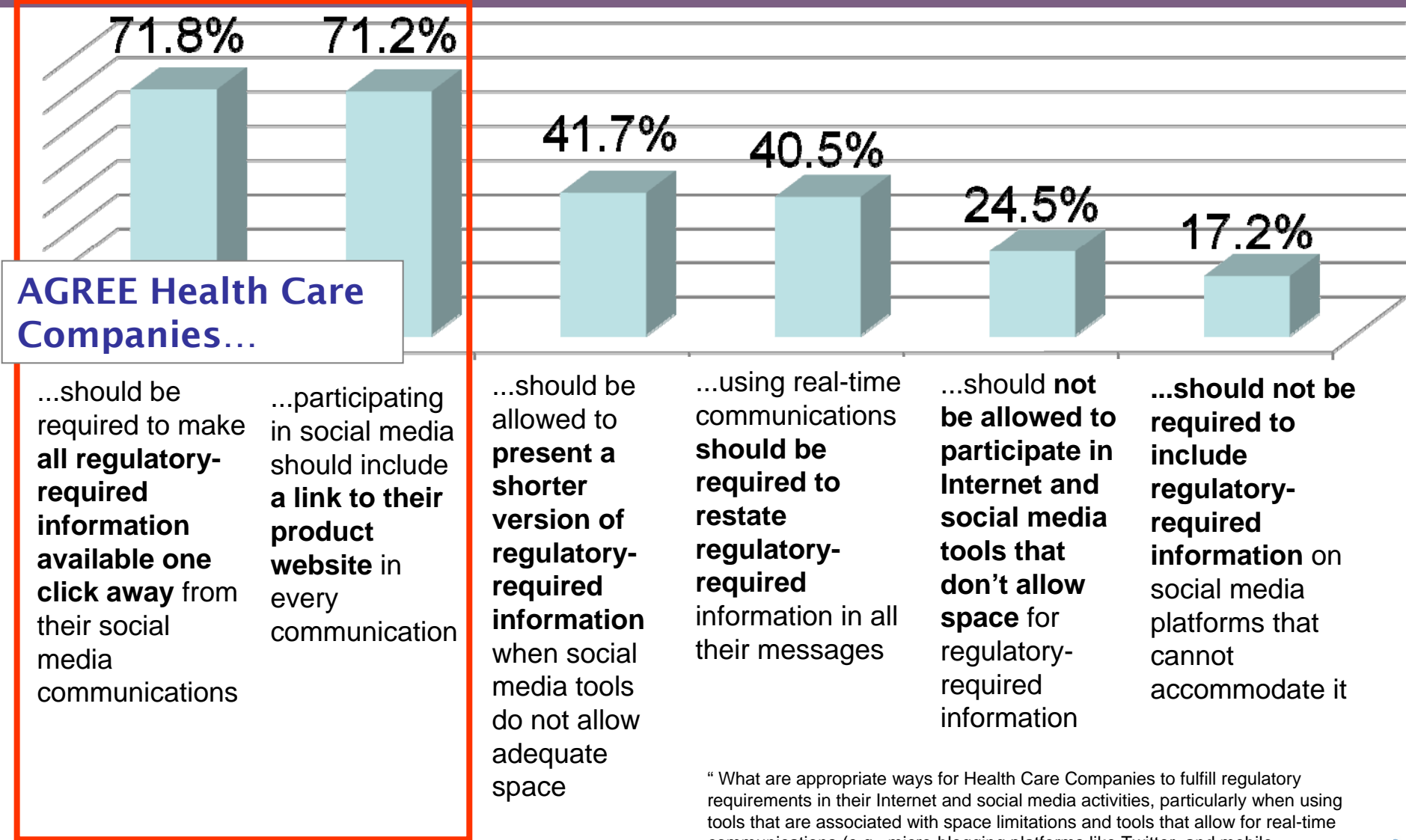
I think we need to balance that conversation with the negative perception of Health Care Companies . They should have their opportunity to present their side as well, we should have a real dialogue.”

--- *Lauren, WEGO Health Activist*

**Strategic Implication: Health Activists want regulation – but not at the expense of Health Care Companies’ participation**

Regulation of Health  
Care Companies in social  
media is challenging, and  
the FDA should work to  
tailor regulations to the  
practical realities of  
social media

# 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)?”



“On Hulu(.com), they do the Yaz commercial. So they do the one-click away link, and they do the regulation thing in the end of the video.

I don't want to watch the last two minutes of this video with all the side effects to Yaz. But if you click anywhere on the screen it takes you to the Yaz website, it's more information than if you talk to your doctor about it. It's very thorough, I guess all within the FDA guidelines, and they're covering everything you could probably think of from that video...”

*--- Jennifer, WEGO Health Activist*

**Strategic Implication: Health Activists support fair balance – if it's presented in a way that's tailored to the online experience**

# 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**



“It’s not like somebody has the upper hand, as it is in the case of TV advertising, where only companies with lots and lots of money get their voice heard on TV...people don’t have to have money and that kind of influence to be able to become a voice that is listened to in social media and the online world.

Which means there are a lot more voices and things are going to get debated, which hasn’t been the case in the kinds of media that the FDA is used to.”

*--- Megan, WEGO Health Activist*

**Strategic Implication: Let’s work together – FDA, Health Care Companies and Health Activists – to develop guidance that works for us all**



For a full review and analysis of the  
WEGO Health Activist Social Media Survey:

[www.wegohealth.com/socialmediasurvey](http://www.wegohealth.com/socialmediasurvey)

[info@wegohealth.com](mailto:info@wegohealth.com)

