



# Social Media Won't Wait: Health Activists Speak Out, Industry Speaks Up

Expanded and annotated report of the survey presentation delivered by WEGO Health and a panel of pharmaceutical executives at the April 2011 DTC National Conference

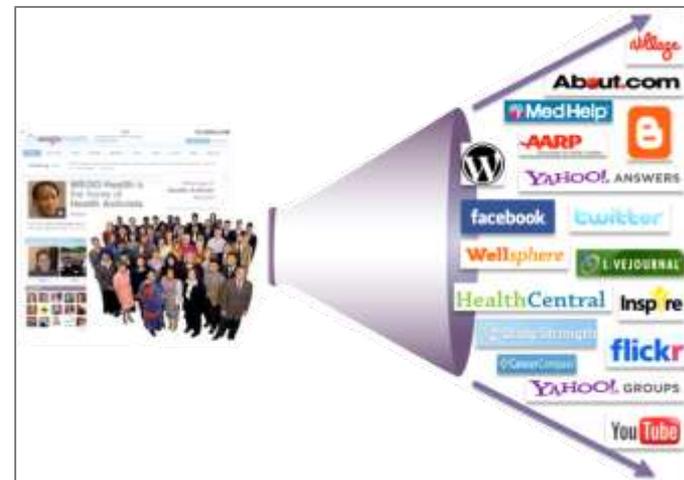


# About WEGO Health

WEGO Health is a different kind of social media company – our mission is to empower the top 10% of online health social media contributors to connect with each other and with healthcare companies. We call these passionate people [Health Activists](#) – they’re community leaders, bloggers, on Facebook, on Twitter, leading online forums, and usually “all of the above.”

**If online health communities are an unruly high school, then Health Activists are its dedicated teachers – and WEGO Health is the teacher’s lounge. We help leaders to come together, to learn from each other, and to go back to their classrooms better at their craft.**

Full-disclosure: WEGO Health funds its support for the Health Activist community through transparent, community-vetted [advertising and sponsorships from health companies](#): research, content development, education, events, conferences, distribution programs, ad networks and more. We believe a solid business model helps us to provide an enduring, self-sustaining home for Health Activists.



# About The Presenter



**Presenter:** Jack Barrette is CEO and founder of WEGO Health, the first online community to empower consumer Health Activists to help others through the health social web. WEGO Health's Activist Social Network is the trusted community liaison to pharmaceutical and health marketers, who engage the Activist Social Network through innovative sponsorships, industry advisory panels, collaborative content development, widget distribution and more.

Previously, Jack was Category Development Officer for Lifestyle, Health & Medicine at Yahoo!, where he was responsible for guiding Yahoo! strategy for healthcare consumers and the healthcare companies that market to them.

Jack is a frequent public speaker, blogger, twitterer ([@healthyjack](#)) and author.

# Survey Background & Methodology

## Methodology

Online survey of 223 vetted consumer Health Activists, conducted March 2011

## Background

The survey presented is an update to a survey developed with technical assistance from the FDA and presented at the November 2009 Social Media Hearings in Washington

This whitepaper:

- compares key data points from 2009 to 2011
- presents Health Activist's and pharmaceutical executive's reactions to the findings
- identifies strategic implications for Health Activists and healthcare companies



# WEGO Health Activists Have The Most At Stake In Social Media Regulations

Social Broadcasters &  
Mass Influencers are  
**Health Activists**

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

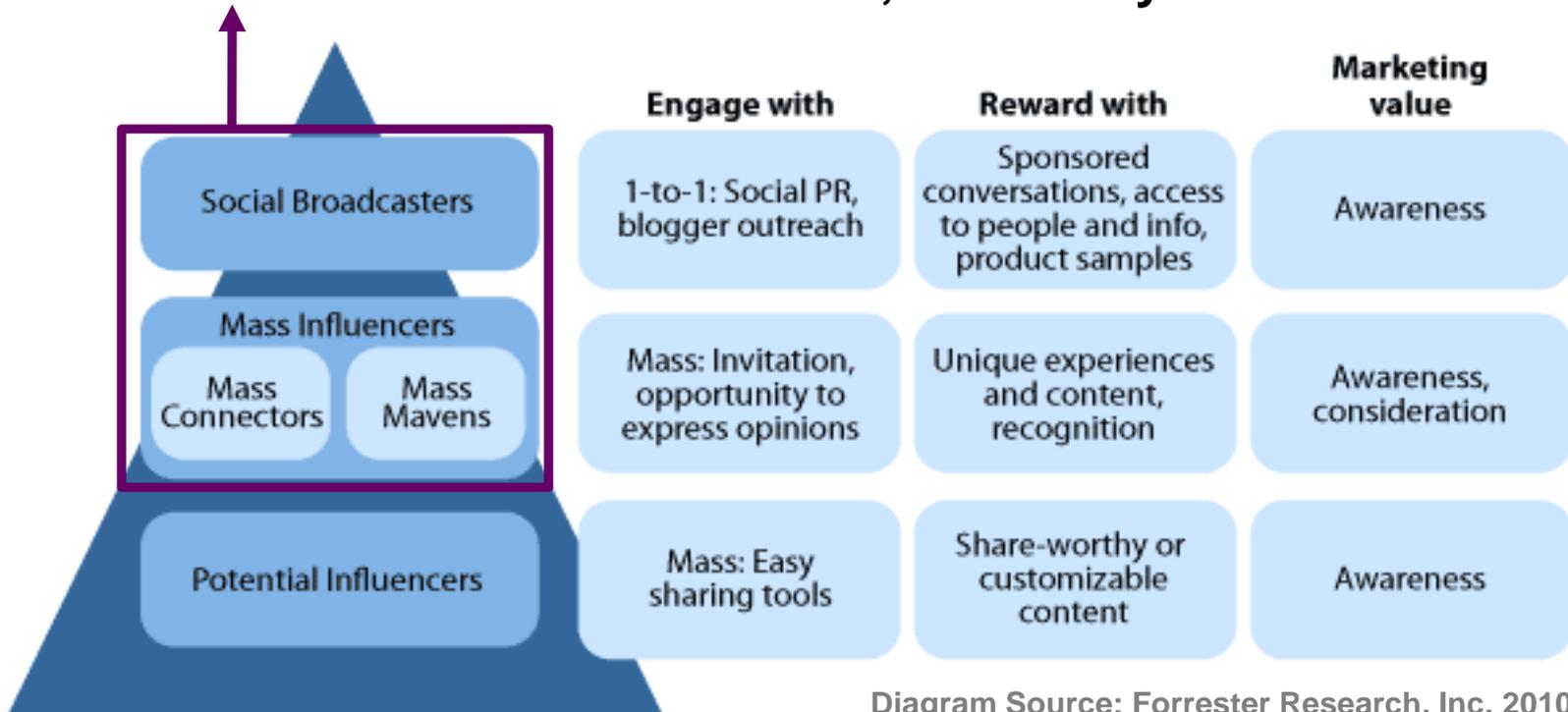
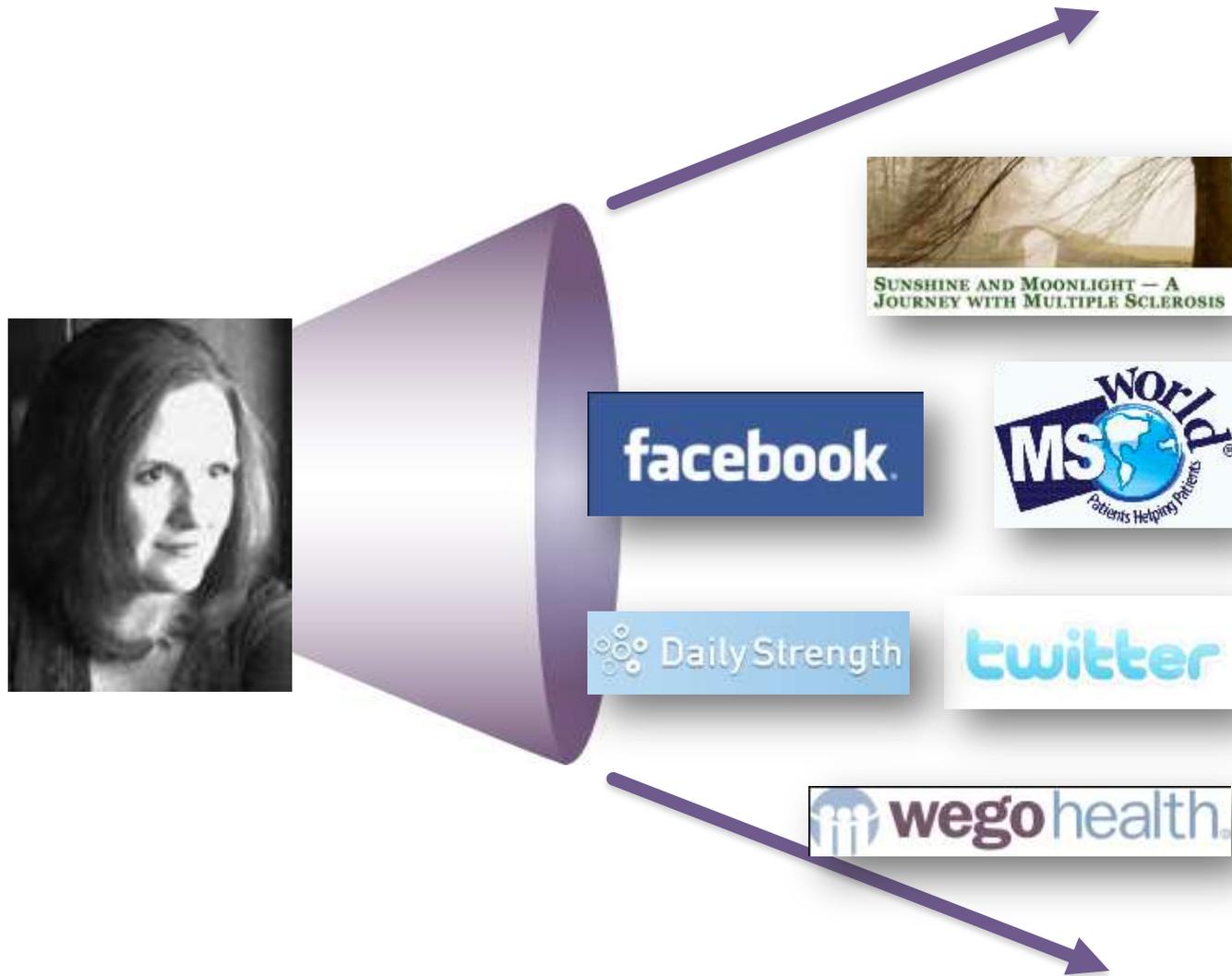


Diagram Source: Forrester Research, Inc. 2010

\*Data Source: WEGO Health Activist Benchmark Survey 2008 - 2011

WEGO Health is a social network specifically for Health Activists – that 3-4% of online health consumers who are social media power users, most passionate about helping others with health issues and about using social media technology for health.

# WEGO Health Activist Profile: Kim

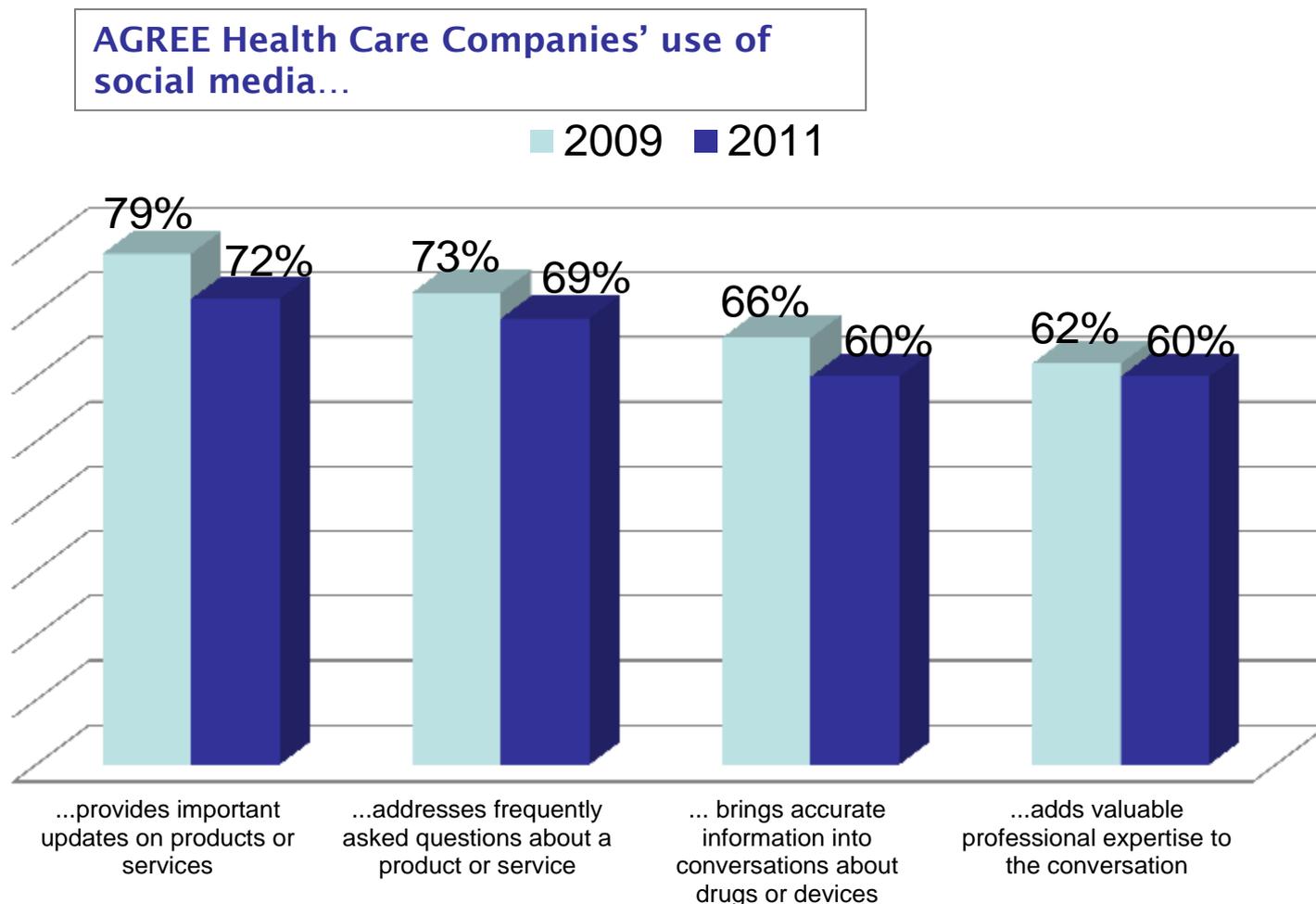


A good example is Kim, a Multiple Sclerosis Health Activist who's contributing to multiple health communities, on Facebook and Twitter, and writes a blog about her experience.

## Executive Summary

- Social media is an important tool for health communication, and Health Care Company participation provides value to the community; Health Activists are growing impatient with non-participating companies.
- In particular, Health Care Companies have an obligation to the community to fight misinformation by contributing accurate content about their products, and to follow regulations.
- FDA guidance will encourage more and better communication, but those companies participating now are gaining Health Activist trust – and competitive advantage.

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



Despite an overwhelming commitment to objectivity, a strong majority of Health Activists continue to seek the expertise that companies bring to social media conversations – they want product knowledge experts to join them.

**3%** Of Health Activists did not want any company involvement in social media



An analysis of the comments from all Health Activist participants showed only 3% advocated that companies stay out of social media conversations.



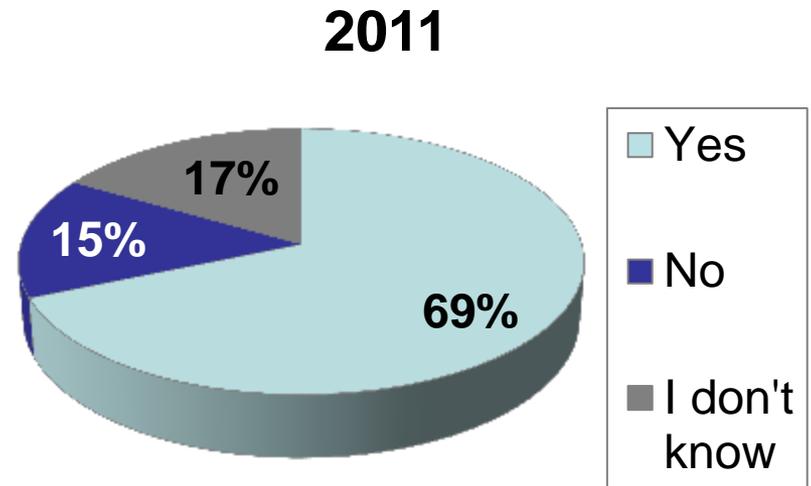
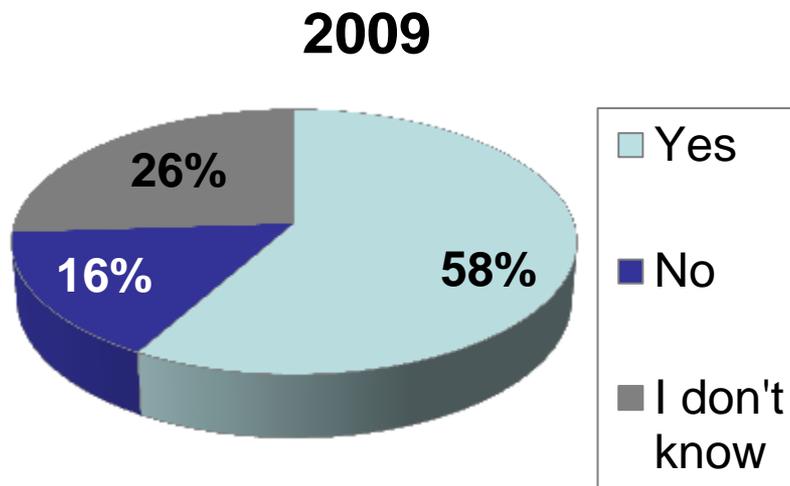
“Companies are largely missing from the supportive, real-life conversations going on in health discussion groups, on social networks, and such...

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*

**Strategic Implication: Health Activists should learn what regulatory barriers prevent company participation – and help advocate for new regulation**

# Are Health Care Companies using social media tools to engage with people online?

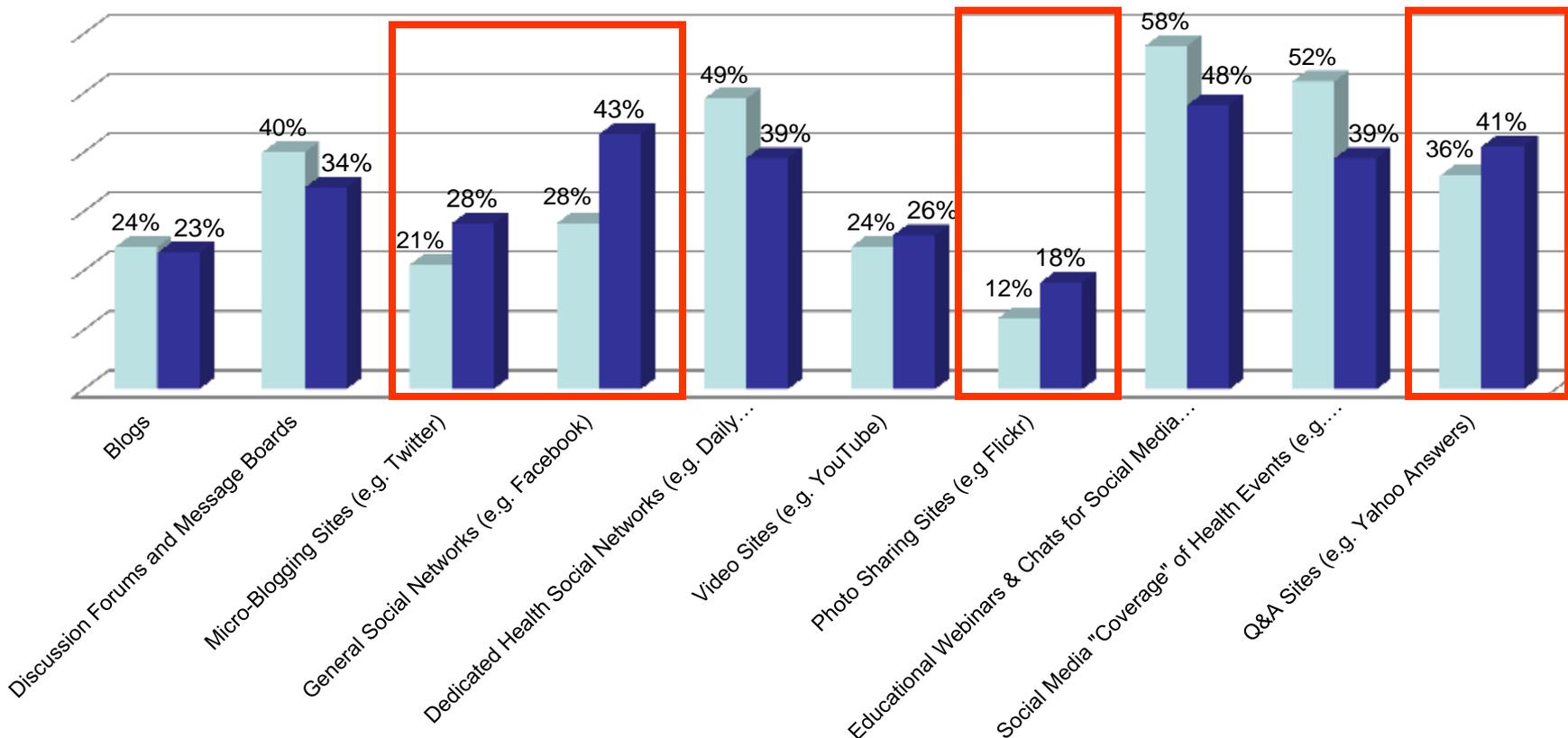


But while many companies remain on the social media sidelines, others are participating more actively now than in 2009. Despite a lack of FDA guidance, Health Activists see real growth in companies using social media tools.

# How active are Health Care Companies in using these social media tools to engage with people online?

## Very or Extremely Active

■ 2009 ■ 2011



Health Activists see the growth in company participation mostly from increased use of Facebook and Twitter – with early signs of growth in Q&A sites and photo sharing as well. These trends align with overall growth in these platforms.



“Why Facebook? To go where people are natively (it's what we did with the HealthSeeker game, instead of developing it on our own TuDiabetes site, for example).

But the signal-to-noise ratio is a tricky element; so many people ‘broadcasting’ (putting company Facebook pages and people at the same level) that it's hard for people to tune in and sometimes easy to tune out.”

*-- Manny, Diabetes Activist*

**Strategic Implication: Health Activists and companies need to understand different types of Facebook presence – and find ways to stand out**

# Health Care Company Executive Comments\*

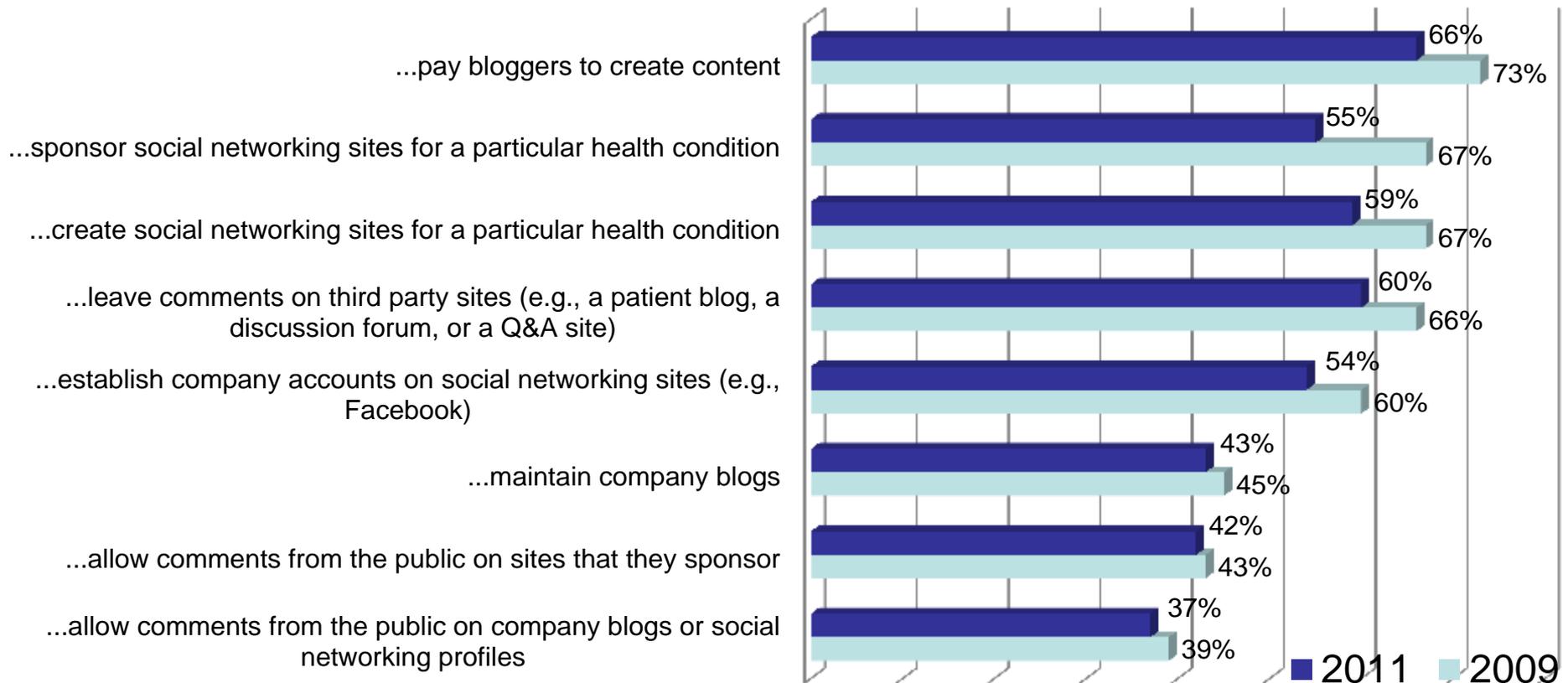
*“These numbers reflect the marketplace - more of us are moving into this space, more of us are doing pilots in social media, and that’s starting to show in the growth of Twitter followers of pharma companies, for example, and tweets from pharma. YouTube is also growing as more and more channels are sponsored by pharma companies - it’s more than doubled in terms of use.”*

**Strategic Implication: Companies investing in YouTube channels need to use other platforms to bring the social media audience to that content – reach out to Health Activists especially**

\* anonymous by request

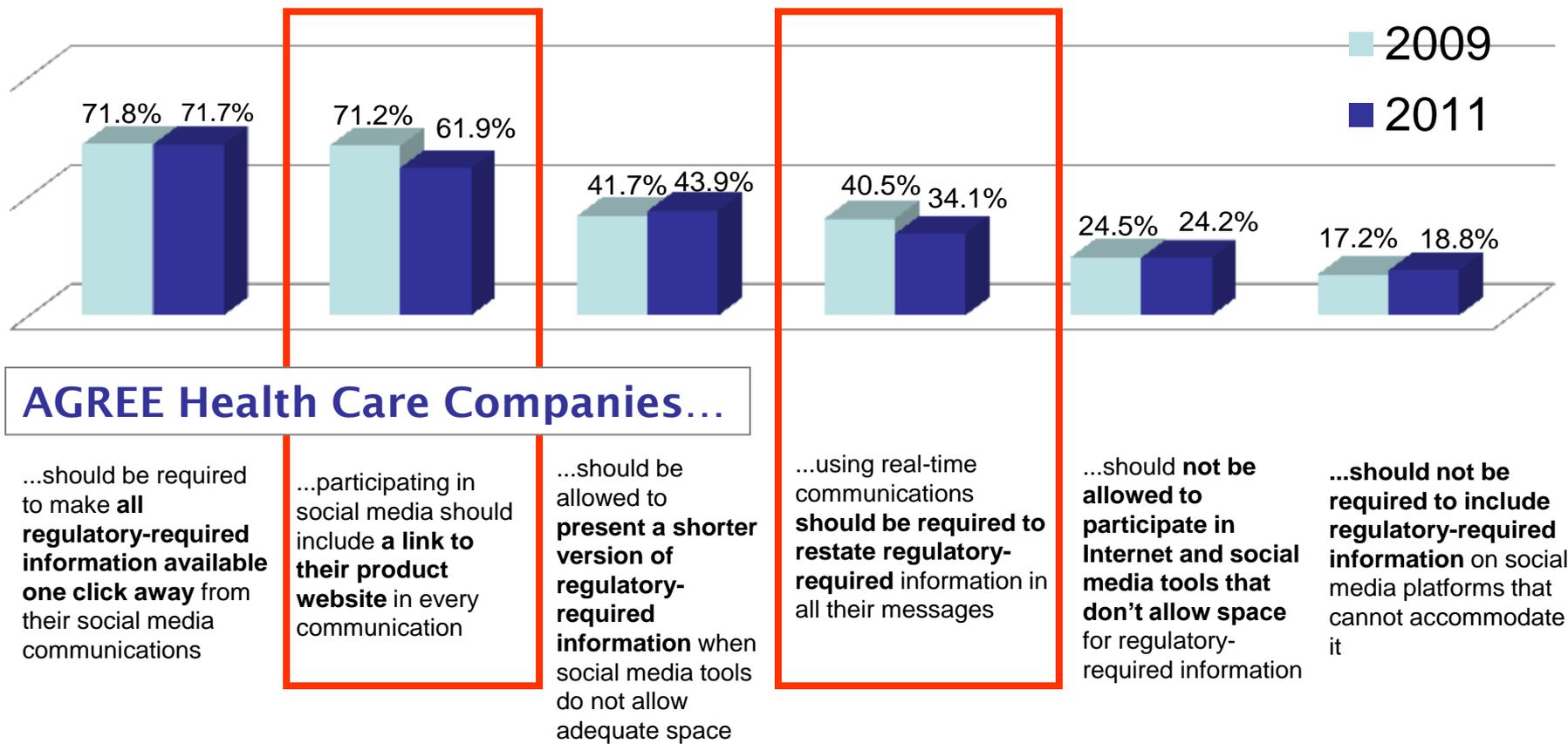
# When do you feel a Health Care Company's participation in Internet and social media technologies should be regulated?

## When Health Care Companies...



In both 2009 and 2011, the majority of Health Activists support regulation of companies' participation in social media - especially when they pay bloggers to create content, and sponsor social networking sites. But most striking is the declining Health Activist demand for regulation; 2011 results are lower than 2009 in every category studied.

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



A majority of Health Activists still agree that the best way for companies to make required info available is one click away (far left graph). But in the red boxes are changes from 2009 – with strongly fewer Health Activists preferring a link “in every communication,” or that companies restate required information “in all their messages.” In fact, this “fair balance fatigue” may explain a diminishing call for regulations.



“Companies can't be expected to be responsible for things which other social media participants say or do online. They can be responsible for their own actions online... make access to information easy - links, links, links.”

The Companies MUST NOT use the fear of FDA regulations to excuse their nonparticipation online. “

*--- Lisa, MS Health Activist*

**Strategic Implication: Health Activists should ask out loud in their communities for company participation – then recognize companies that respond**

# Health Care Company Executive Comments\*

*“I’m keenly aware of how desperate patients are for information. They’re really looking for other treatment options, understanding their disease, clinical trials, emotional support, financial support – for a pharma company to say “we don’t have a rule book yet, we can’t engage with you” is a sure way to lose any chance to have a relationship with that patient.*

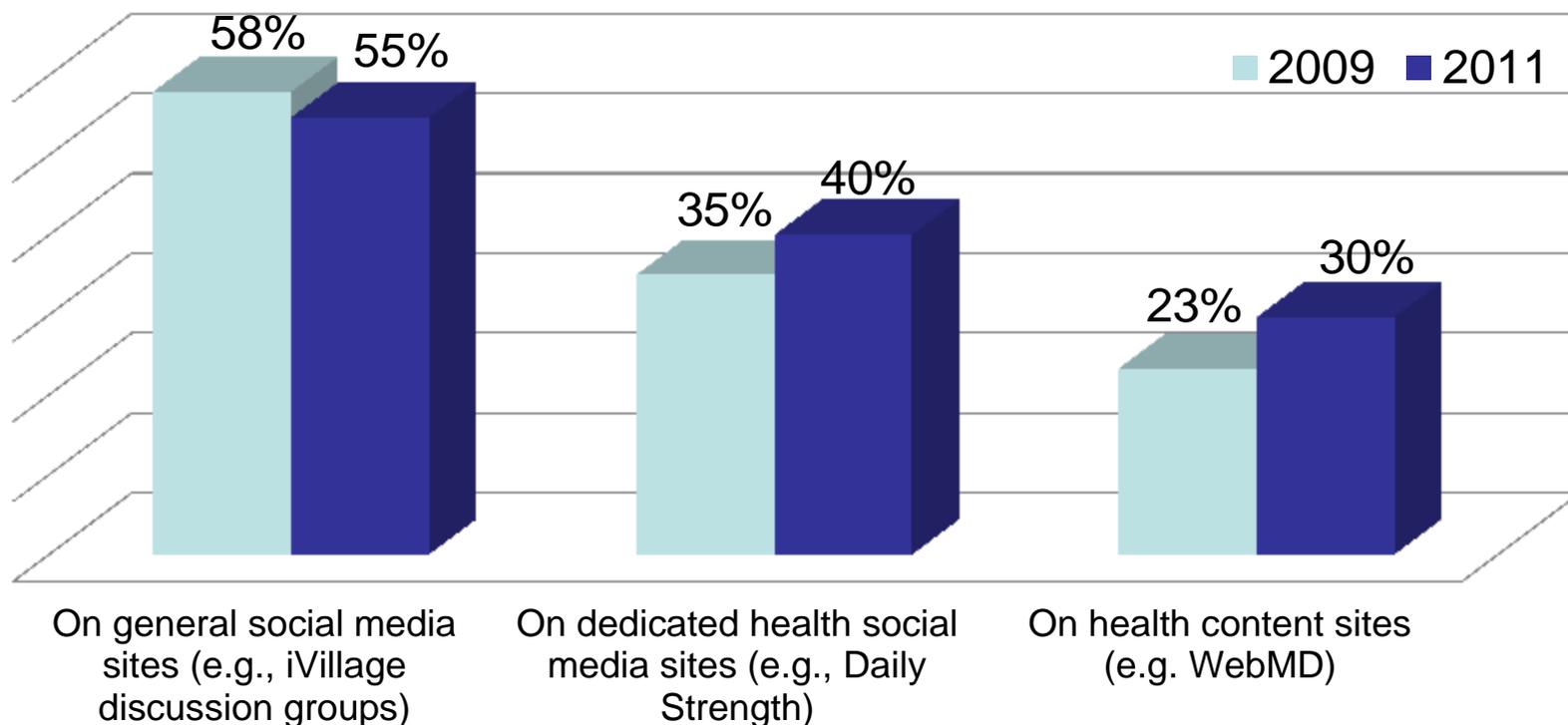
*But the truth is that we are engaging, we are taking steps to leverage some of these channels. There’s a long way to go, but we are moving the needle...we’re continuing to work with the FDA, our agency partners, folks like WEGO, anybody really that will help us give the patients that level of engagement they’re seeking that’s compliant, responsible, and ethical. Given time, we’ll get there.”*

**Strategic Implication: Companies should find ways to tell online community leaders about their efforts to participate in social media**

\* anonymous by request

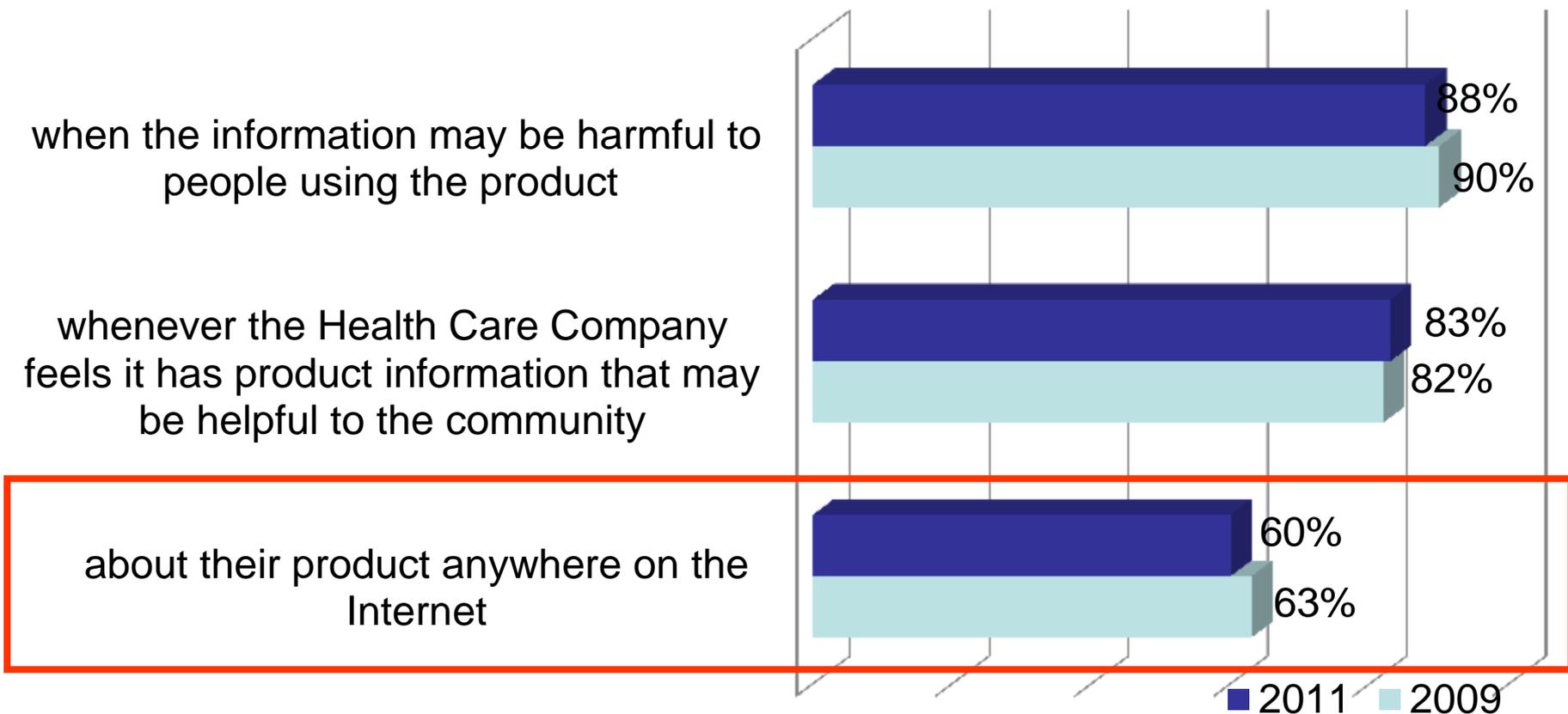
# Health Activists Need Companies' Help To Fight Misinformation

Somewhat or Completely Agree “there are many misconceptions, and a great deal of misinformation, about Health Care Companies' products”



Despite their best efforts as responsible consumer leaders, Health Activists report growing misinformation in health sites – likely attributable to overall explosive growth in health social media.

# Health Activists Agree Health Care Companies Should Get Involved In Monitoring and Correcting Misconceptions or Misinformation...



And Health Activists expect that companies will be vigilant brand stewards, making proactive effort to counter inaccurate information about their products. That demand extends beyond company pages to a hope that companies will seek and correct misconceptions or misinformation about their product “anywhere on the internet.”

## Most Health Activists Acknowledge The Monitoring Challenge

In 2009:

**60%**

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

In 2011:

**56%**

At the same time that Health Activists are demanding that companies police their products online, they recognize the inherent challenges. In fact, current monitoring technologies are incomplete at best, and both companies and Health Activists are waiting for FDA guidance to define monitoring “best effort” in some way.



“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 Activists - who expect companies to make corrections and to add accurate product information to social conversations – should post positive support for these contributions when companies make them**

# Health Care Company Executive Comments\*

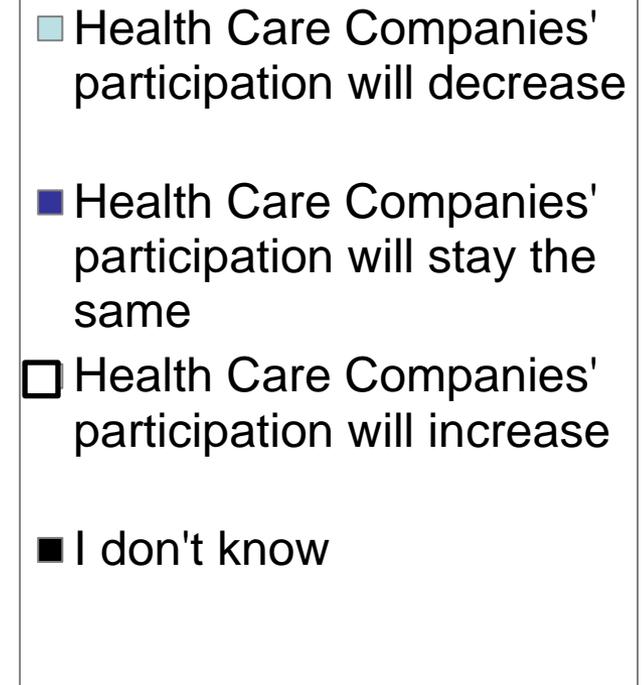
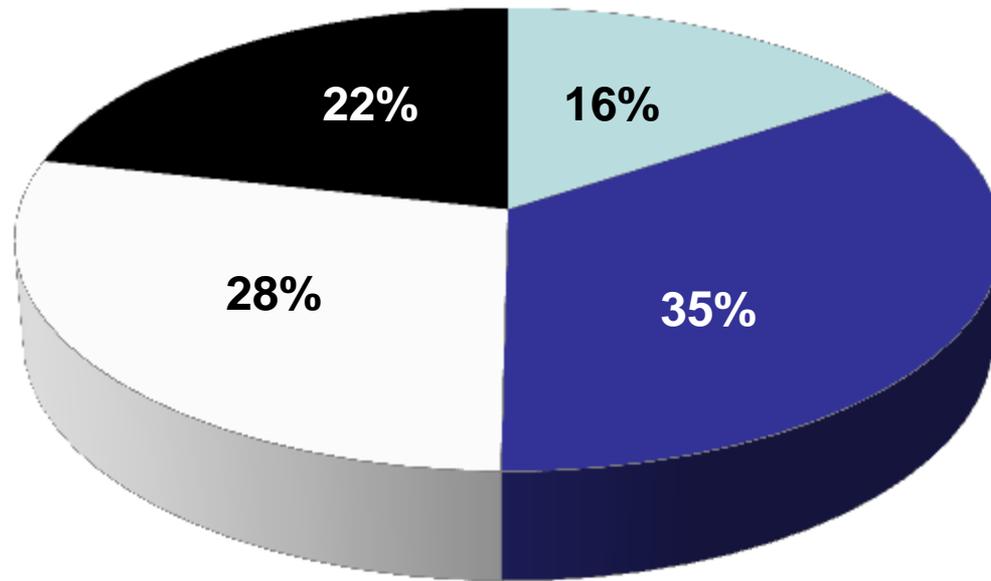
“As a marketer, the request we’re hearing is really reasonable. [Health Activists] understand it’s more difficult for us. Is this a promotional issue, proactive, reactive, branded, unbranded, commercial? Clinical development? All of those things have different implications and obligations for us in how we monitor and react to our content. On top of that, we haven’t been told what rules we’ll be judged by.

I’d say to [Health Activists] that we are trying, but it’s going to take time for us to get involved to the level that she expects. The first thing that we can do is to learn how to engage in ways that are not risky. I can’t tell you if [AstraZeneca’s Twitter chat] #rxsaves was successful, I don’t know if AZ can tell you, but I can tell you [AstraZeneca] is much more prepared to have conversations with their customers.”

**Strategic Implication: Some companies are gaining community trust – and competitive advantage – by working closely with internal teams to execute “safe” social media engagement**

\* anonymous by request

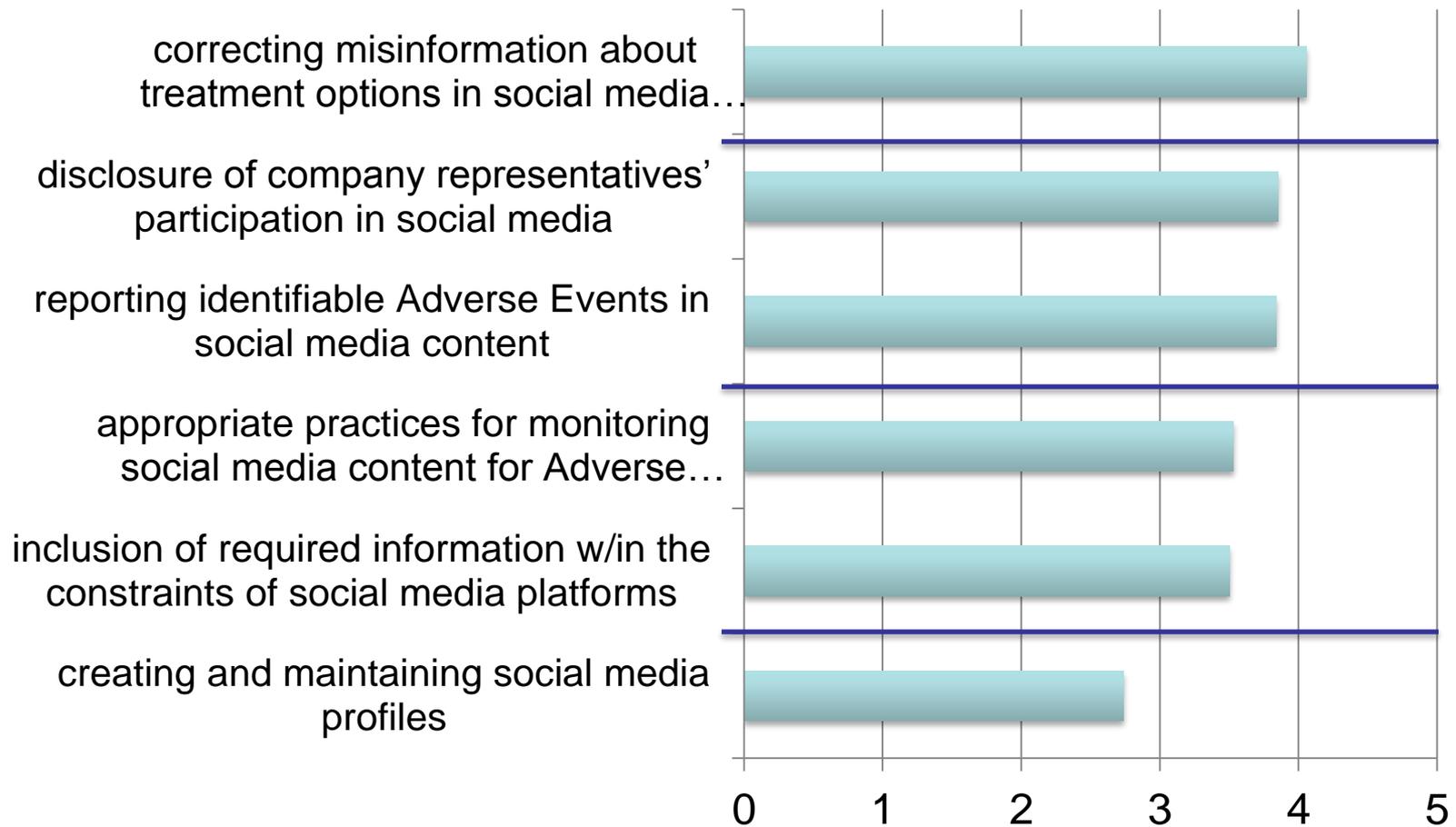
# What impact do you believe new FDA guidance will have on Health Care Companies' participation in social media?



**63% “increase or stay the same”**

While Health Activists have asked for company participation, and for regulation, most of these social media opinion leaders also believe that new FDA guidance will have no effect, or will increase, companies' participation in social media. Health Activists know that companies are over-regulating themselves in the absence of FDA guidance.

# Rate the importance of specific FDA guidance to your online health communities



In their rank ordering of the proposed FDA guidance components, Health Activists have begun calling for FDA to drive company correction of “misinformation about treatment options” – demanding that companies bring their superior resources to bear. At the same time, community leaders insist that companies disclose that participation.



“2009 and 2011 are wildly different in terms of what we thought participation could be - it literally changes every day. The FDA is trying to put a fence around something that is expanding exponentially.

Some companies like AstraZeneca are starting to branch out, and I don't see what they're doing as something that the FDA is ever going to wind back in.”

*---Alicia, Breast Cancer Activist*

**Strategic Implication: Health Activists should support companies who make an effort to engage them in the absence of FDA guidance – while offering comment to the FDA process**

# Health Care Company Executive Comments\*

“We’re willing to police ourselves, but we need the FDA guidance to help us get in deeper to social media. Without the guidance, we’re going to continue to stand on the side of the dance floor, we’re never going to get in the middle there. Just because FDA isn’t going to reel us back in, doesn’t mean they can’t help guide us to go further.

There is a lot of misinformation out there. We need Health Activists to help us: if you see bad info, help us, let us know! We aren’t going to just keep standing on the sidelines when we hear from you.”

**Strategic Implication: Companies can bolster their monitoring effectiveness – and their relationship with Health Activists – by welcoming their help in correcting misinformation**

\* anonymous by request

# What advice do Health Activists have for Health Care Companies participating in social media?

An analysis of over 200 free-text Health Activist answers to this question yielded 4 key themes

# What advice would you give to Health Care Companies?

1

Use your knowledge and facts to help the community have a more accurate conversation



“I believe there are ways for consumers and companies to work together to increase proper use and reporting of products, and to increase health benefits for everybody.”

While Health Activists are primarily asking companies to add their resources to the daily conversations about their products – that request is turning to a somewhat frustrated demand. Companies who support accurate discourse through careful participation will be rewarded disproportionately at this time.

# What advice would you give to Health Care Companies?

## 2

Put patients first –  
don't sell, educate



**“Educate consumers on conditions  
without having to interject  
promotional materials.  
Consumers are smarter than you  
think.”**

While community leaders do not welcome communications consisting solely of promotional messaging, Health Activists are not requiring that all company participation be unbranded. Educational messaging about a brand – about mechanism of action, for example – is more than appropriate.

# What advice would you give to Health Care Companies?

## 3

Be transparent and follow the rules – you're joining late, but welcome



“Think of all the positives that can come of this, for the patients you benefit, not just for yourselves. **And remember the benefits outweigh any perceived negatives.**”

If Health Activists did form a policy committee, their first policy would require unwavering transparency from company participation on their communities. Anyone working for or with a company is welcome if they announce their affiliation, and remind other community members. Best practice: the Novartis #IWorkAtNovartis tag on all tweets.

# What advice would you give to Health Care Companies?

## 4

Be genuine, be real



“To be honest, attempt to correct disinformation, **be proud of (your) participation, show how (you) can help.**”

And while transparency may be a policy, “keep it real” is practical advice from Health Activists to companies. Do: use a person (not a logo) to engage, like Johnson & Johnson’s Marc Monseau. Don’t: create fake personas to act like real people, and don’t prohibit company participants from sharing their personalities.

# Health Care Company Executive Comments\*

“It’s striking that over 50% of organizations don’t have social programs. If you’re a consumer marketer, and you can’t participate in social because your company doesn’t have guidance, you’re marketing with one hand tied behind your back.

At my company social policies were a grassroots project, we met for over a year for guiding principles, standard operating procedures, to feel comfortable participating in social. They did eventually get approved.

Today, because we created these internal guidelines and got executive support, we can engage with bloggers, have Facebook pages, we can engage with Health Activists. For the 50% of you who don’t have social programs, it’s worth the effort to get your organization involved so that you can participate in the future..”

**Strategic Implication: Companies creating their own social media policies are gaining competitive advantage**

\* anonymous by request

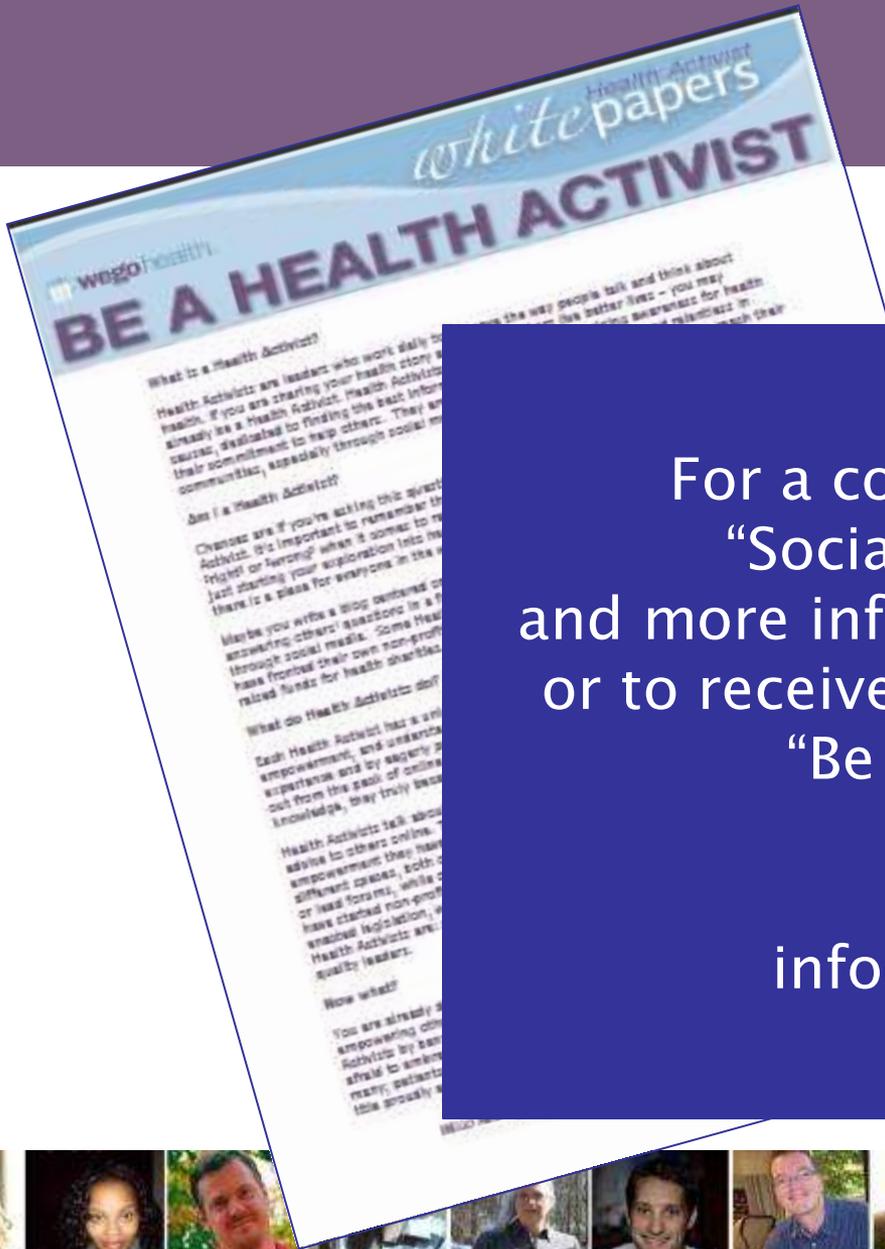


“Social media are used by patients to learn about their health concerns from peers because there is a higher level of trust in a patient to patient discussion. Health Activists fill a need and have become a very large part of e-patient and healthcare 2.0 network.

Health care companies who learn to leverage these relationships will have the greatest success in participating in a meaningful and successful way via social media. When it comes to my health, I don't want to join a discussion with someone who is trying to sell or sway me especially with respect to my health. I want to discuss these issues with a peer who happens to also be diagnosed with the same disease.

It may be difficult for health care companies to tap into this unique relationship but the health care companies who find a way will see the reward of a happy and loyal patient consumer.”

*-- Jenna, Ankylosing Spondylitis Health Activist : The Feeding Edge, Art Apple a Day*



For a copy of this whitepaper  
“Social Media Won’t Wait”  
and more information about this survey  
or to receive a copy of our whitepaper  
“Be A Health Activist”  
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