



Health Activists And Social Media

FDA Question 5: Adverse Event Reporting

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

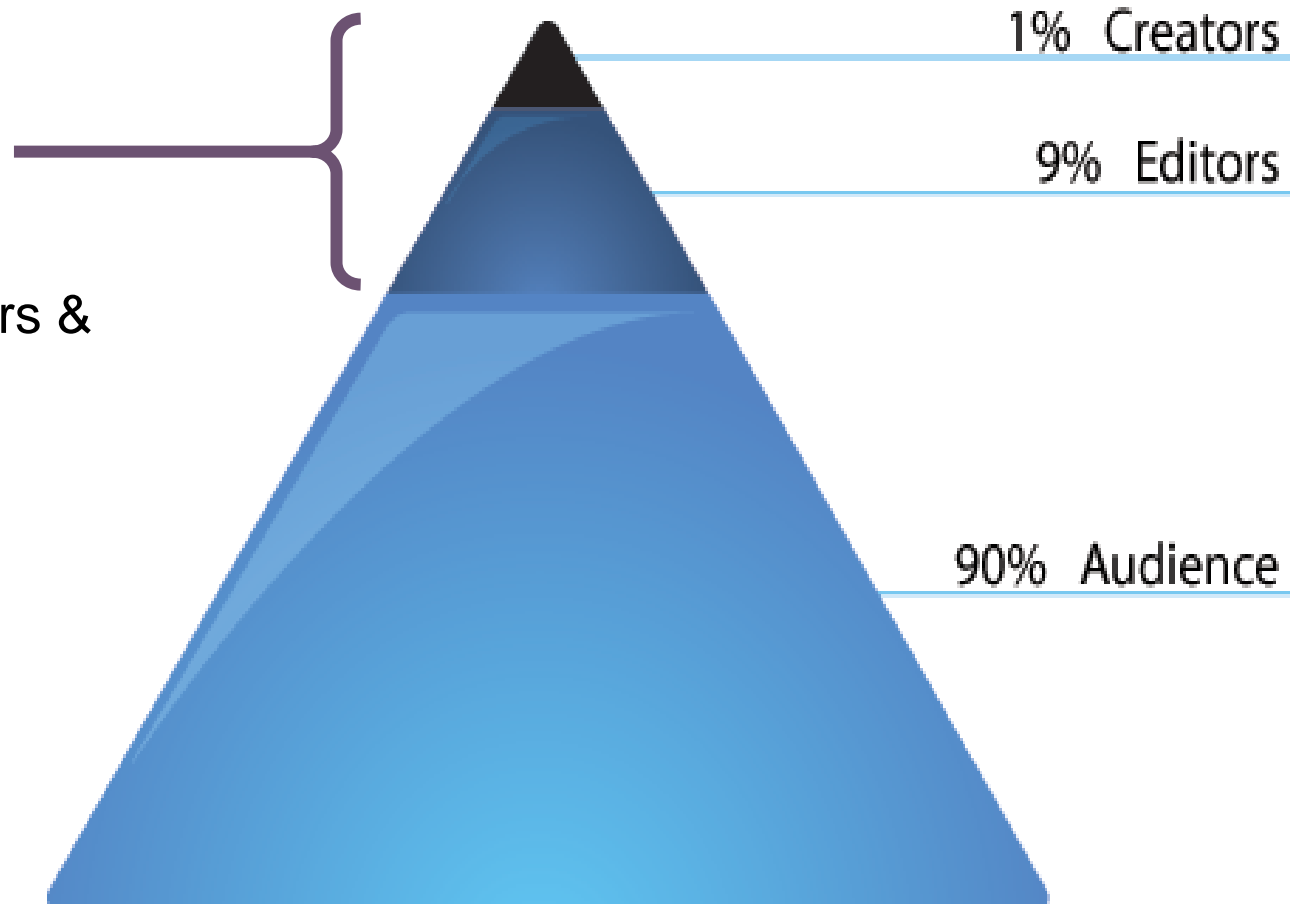
November 13, 2009

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: A Community Of Social Media Power Users

Ellen reaches ~50,000 people per month



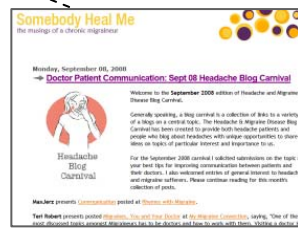
WEGO Health Pain Activist



Featured blogger for Invisible Illness Week
 • Linked to 15 sites with ~7,500 visitors



Active member of Yahoo! Migraine Group
 • 1,809 members



Featured in Headache Blog Carnival
 • Linked to 49 sites with ~20,000 visitors



Active member of care4dystonia.org
 • ~2,500 visitors



Active member of BioMedCentral
 • ~75,000 visitors



Active member of CafeMom
 • ~1.5M visitors



“As to the issue of how much (companies) can monitor misinformation or monitor what’s being said about their product... they can devote resources to have people whose job is to monitor the Internet, find out what’s being said, and see what the appropriate response is.

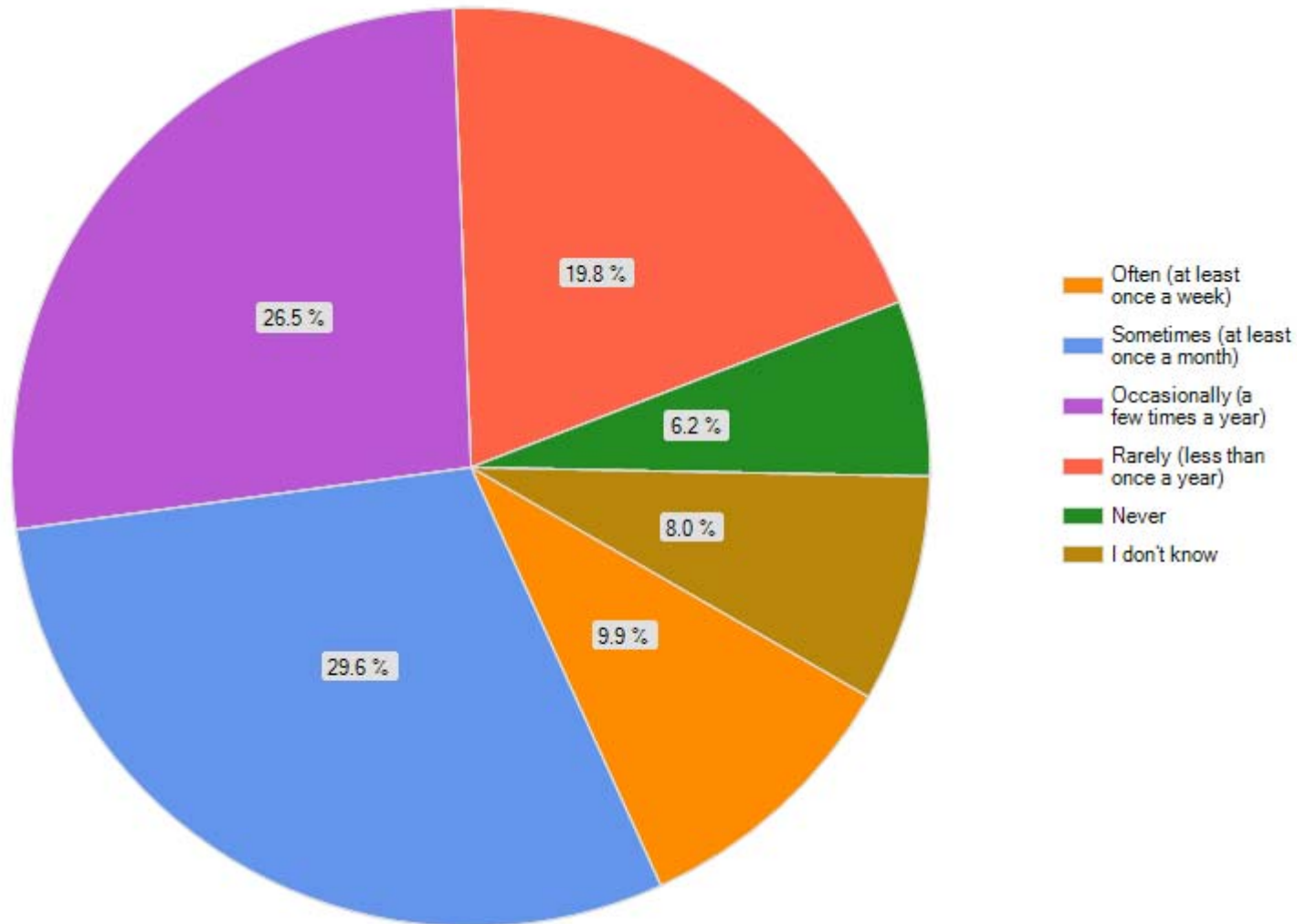
We’re not talking about you or me, we’re talking about companies that are big enough and wealthy enough to make sure that what’s out there is accurate.”

--- Megan, WEGO Health Activist

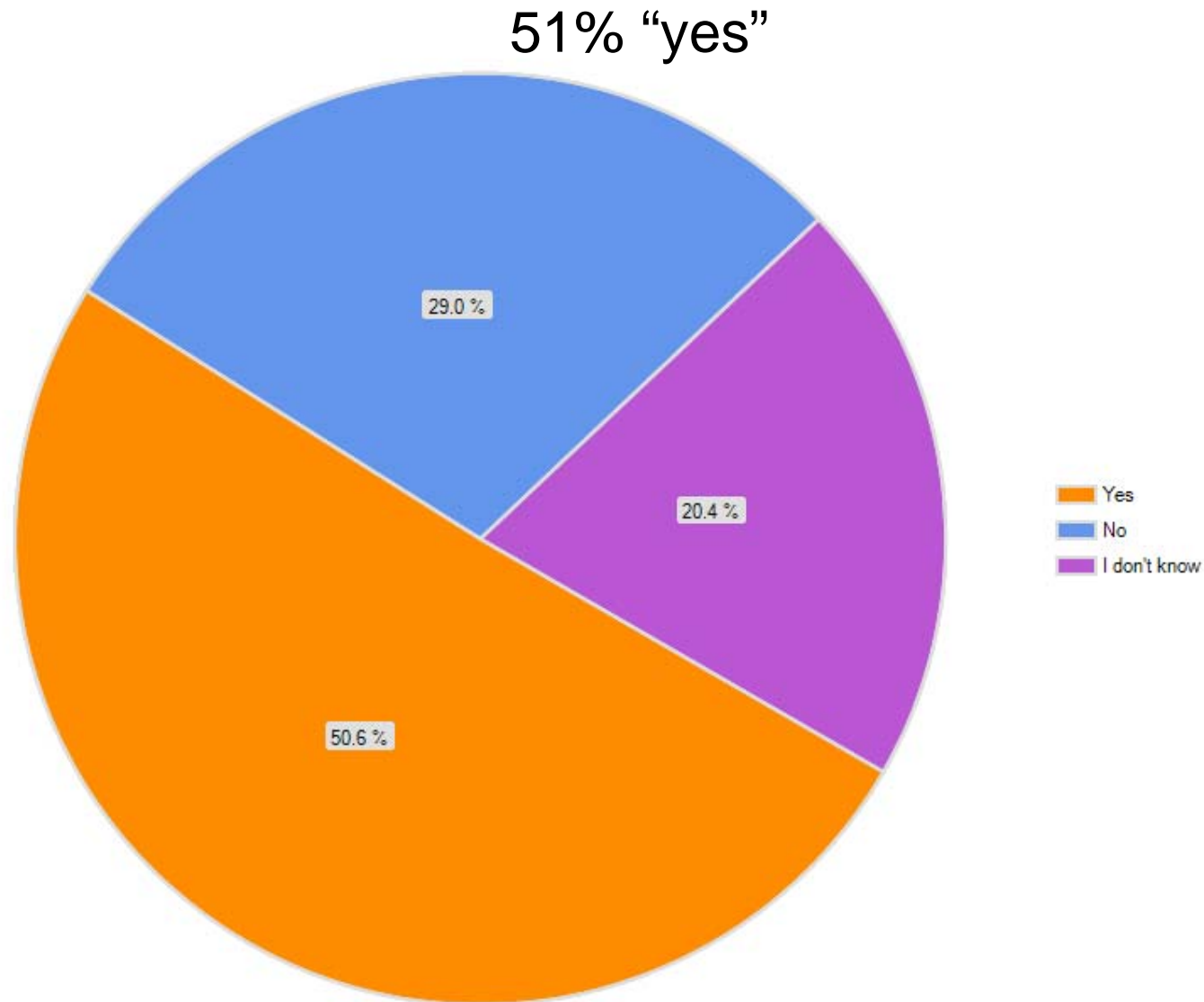
From *WEGO Health Activist Social Media Survey, October 2009, 162 participants*

Keeping in mind the 4 elements that must be present...how often do you feel you see reportable adverse events online?

36% “sometimes” or “often”



Do you feel Health Care Companies should actively monitor online conversations to seek possible adverse events?



If a Health Care Company cannot identify the “patient” describing an adverse event online, what should the company do?

48%

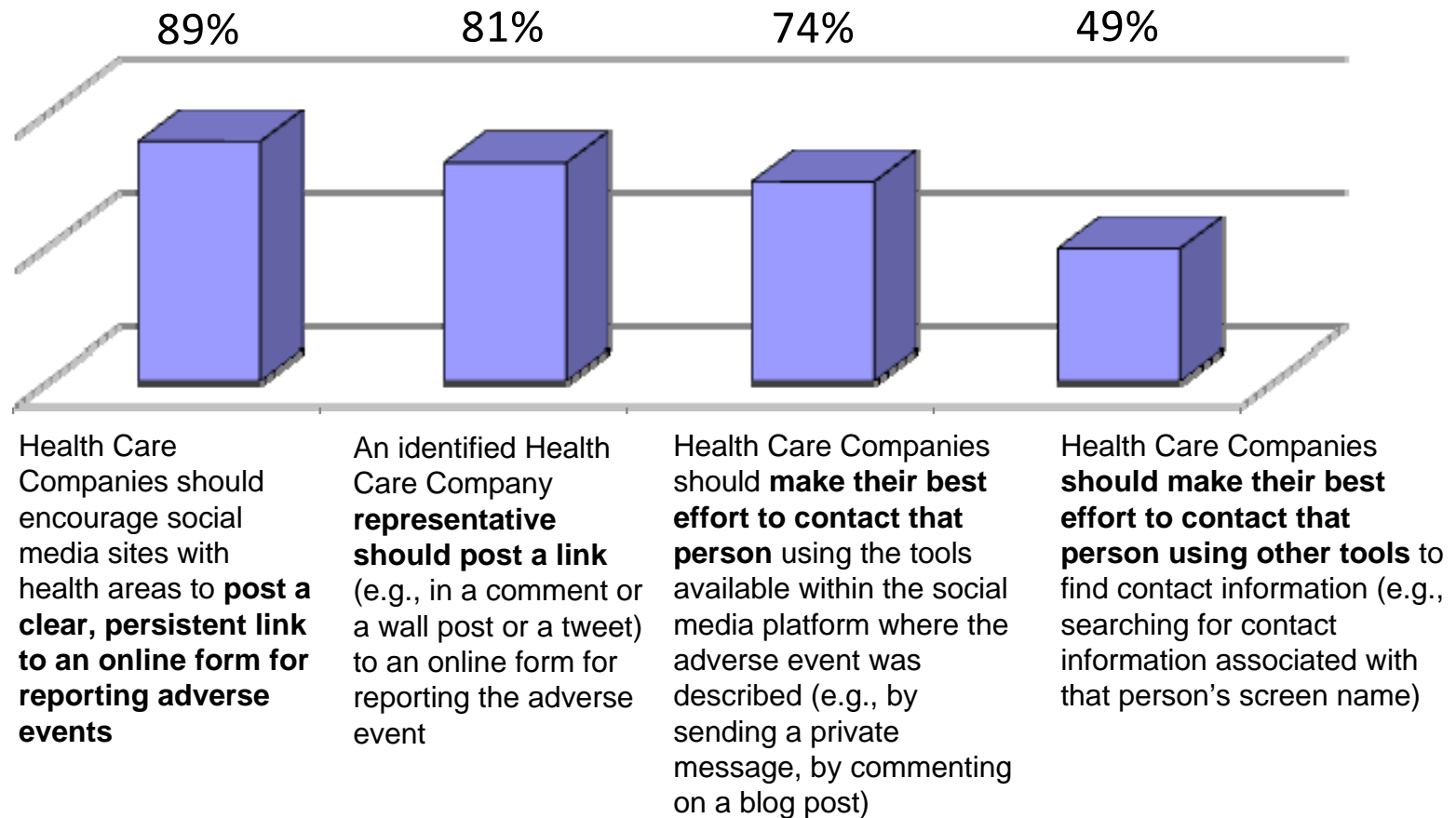
AGREE: Health Care Companies should respect that person’s anonymity and no report should be required

47%

DISAGREE: Health Care Companies should make every available effort to contact that person, using all available avenues to find contact information (e.g., querying ISPs to request the person’s email address)

If a Health Care Company cannot identify the “patient” describing an adverse event online, what should the company do?

Somewhat or Completely Agree





“Contacting them thru the same platform they posted the info on is one thing, but starting to Google search them, trying to track down their contact information...people could feel very violated, especially since people use screen names online to protect their anonymity...”

--- Lauren, WEGO Health Activist

Strategic Implication: Health Activists expect vigilance on adverse events – but within the boundaries of online convention, and not at the expense of privacy



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

www.wegohealth.com/socialmediasurvey

info@wegohealth.com

