

# They Don't Care What You Say

## Why Patients Are Ignoring Us Online & How To Get Them To Listen

National Conference On Health Marketing & Media  
August 29, 2007



# Overview

Jimmy's Story

Why Jimmy's  
Story Is  
Relevant

Three Steps  
To Success



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Jimmy's Story

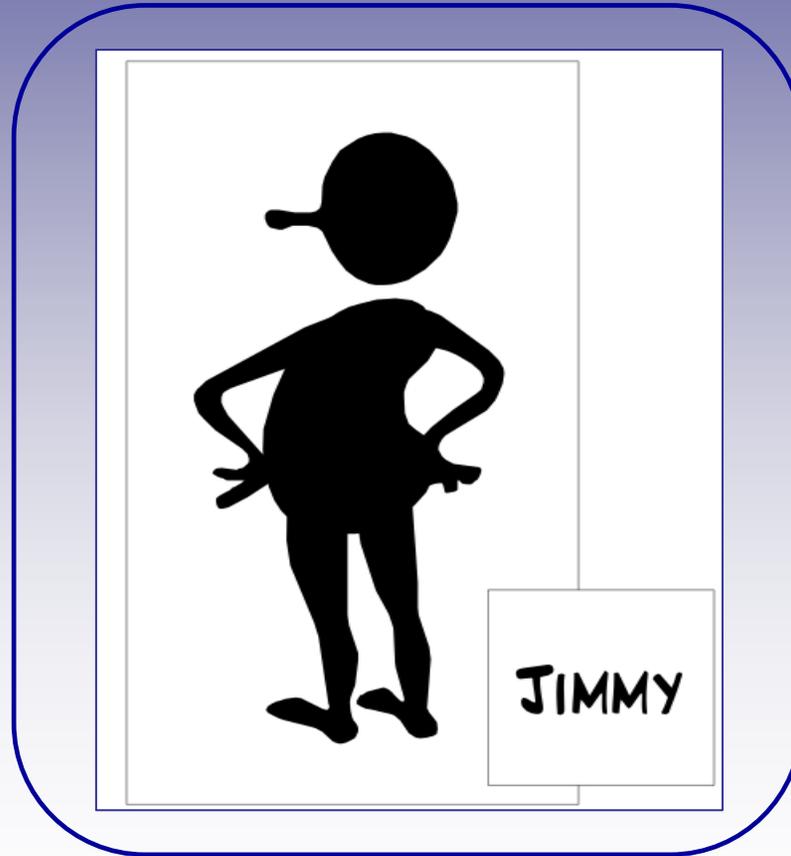
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# Jimmy's Story

**Jimmy: Just A Regular Guy Living Life**



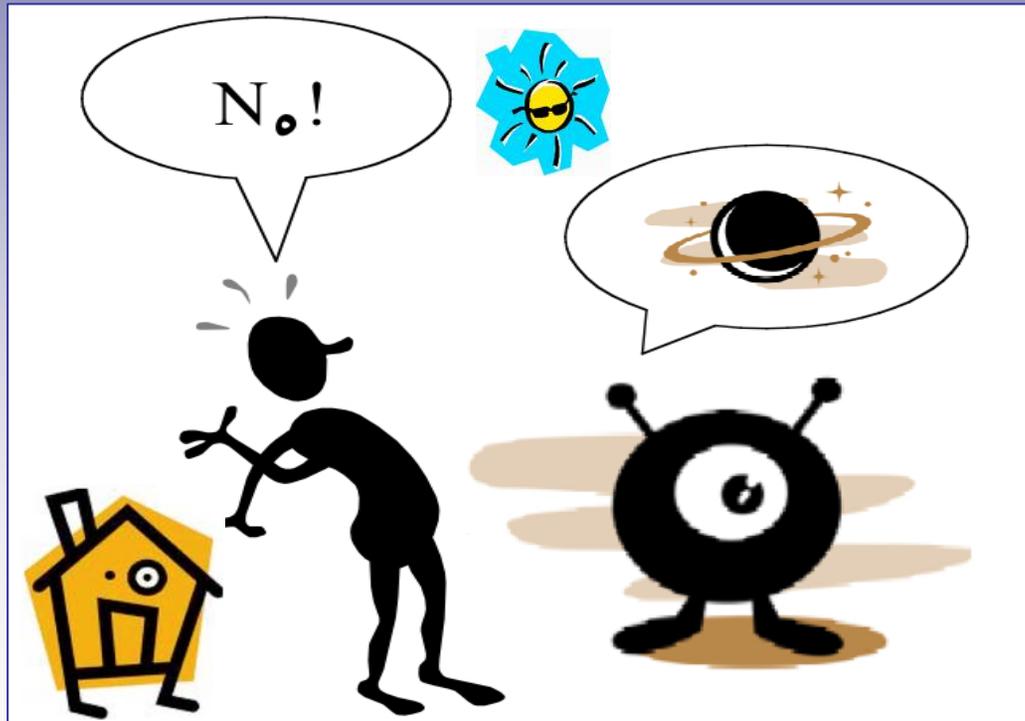
# Jimmy's Story

One Day Jimmy's World Changes Forever



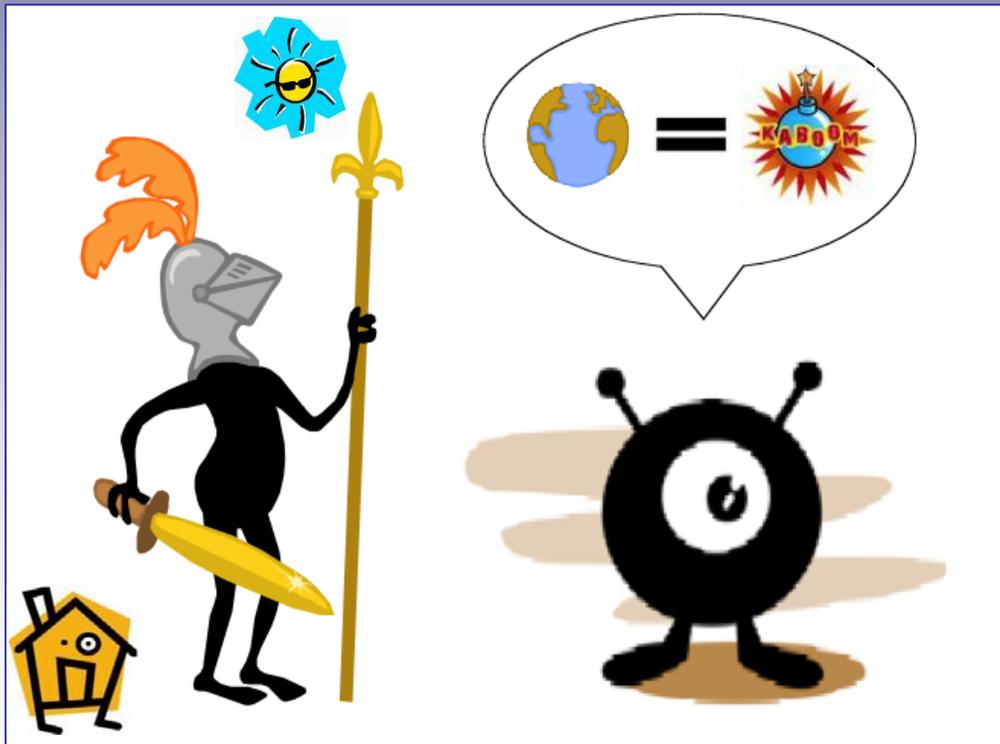
# Jimmy's Story

Earth's Alien Visitor: "Jimmy Come With Me."



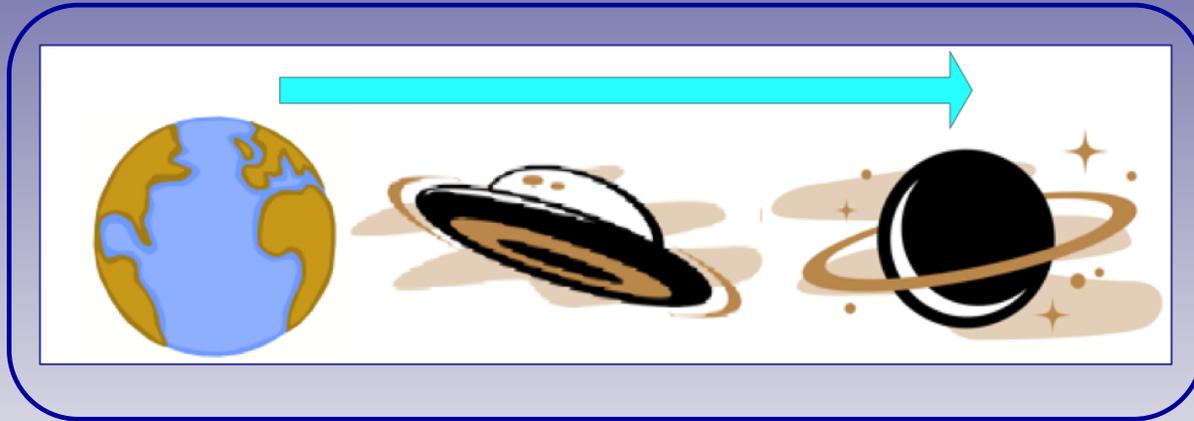
# Jimmy's Story

Earth's Alien Visitor: "Jimmy, Your Planet Is At Risk."



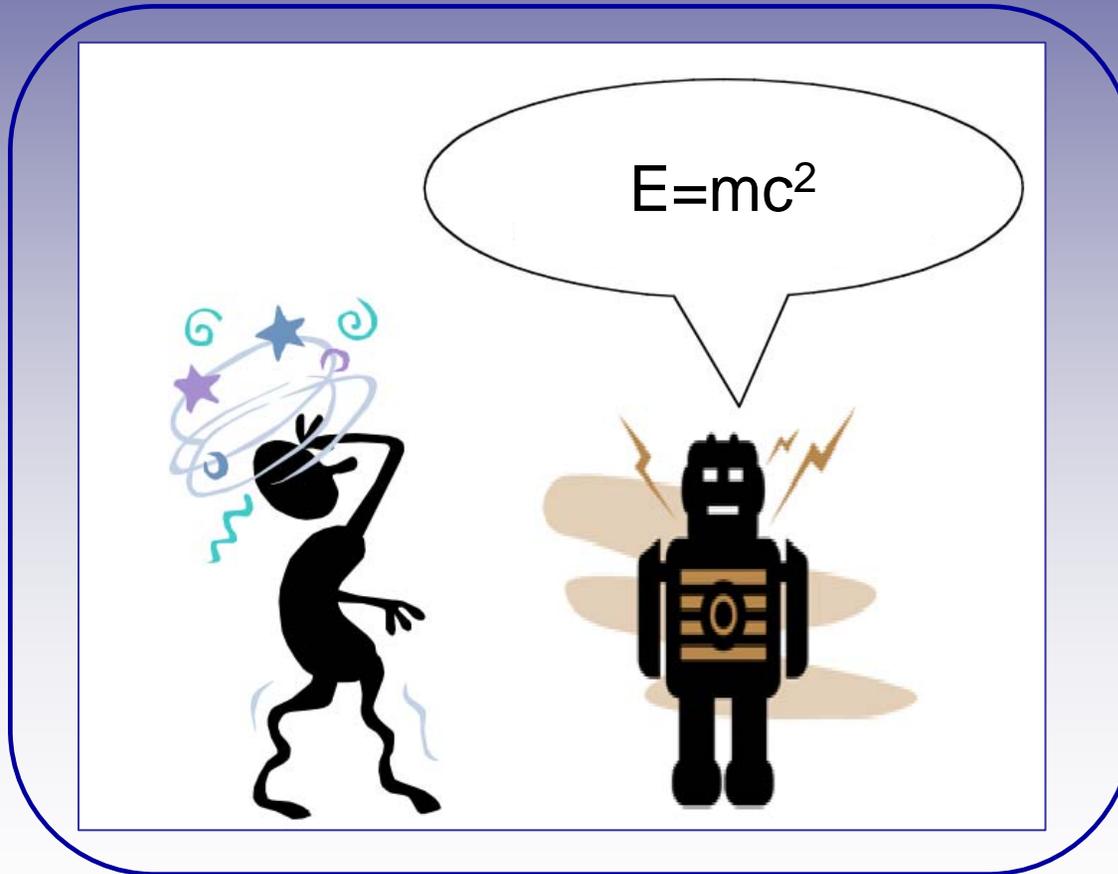
# Jimmy's Story

**Jimmy Bravely Travels Light Years From Earth**



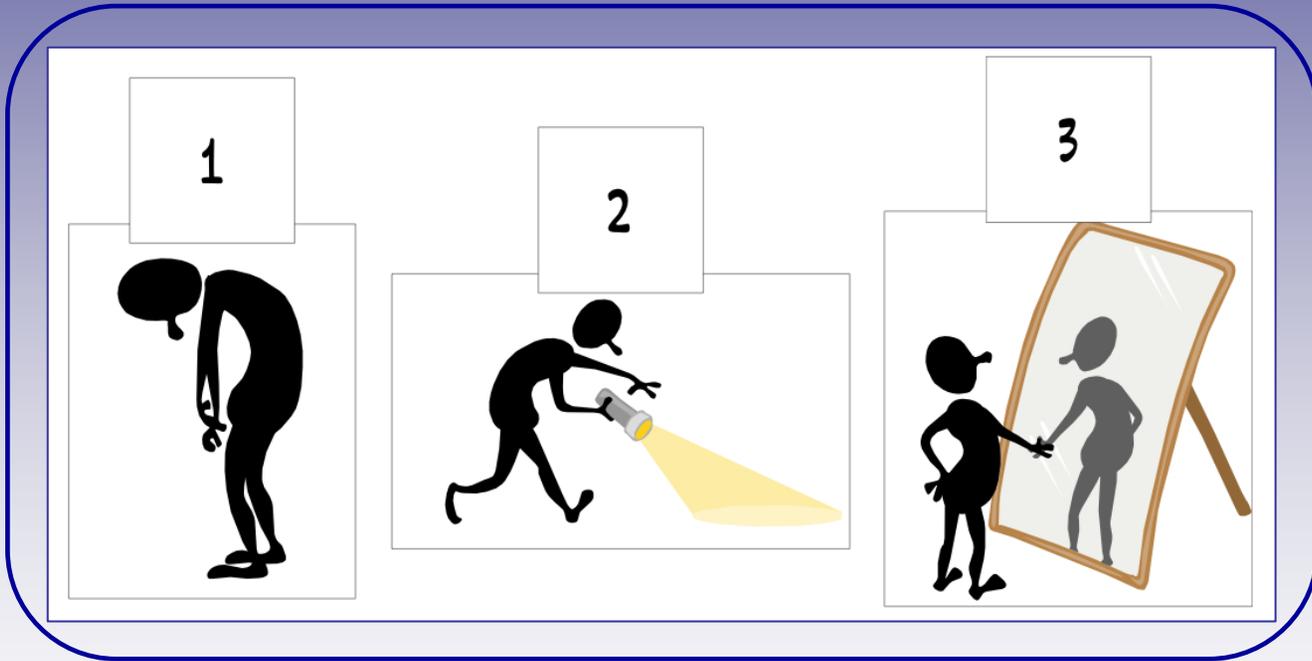
# Jimmy's Story

**But, Alien Biases & Assumptions Cause Big Problems**



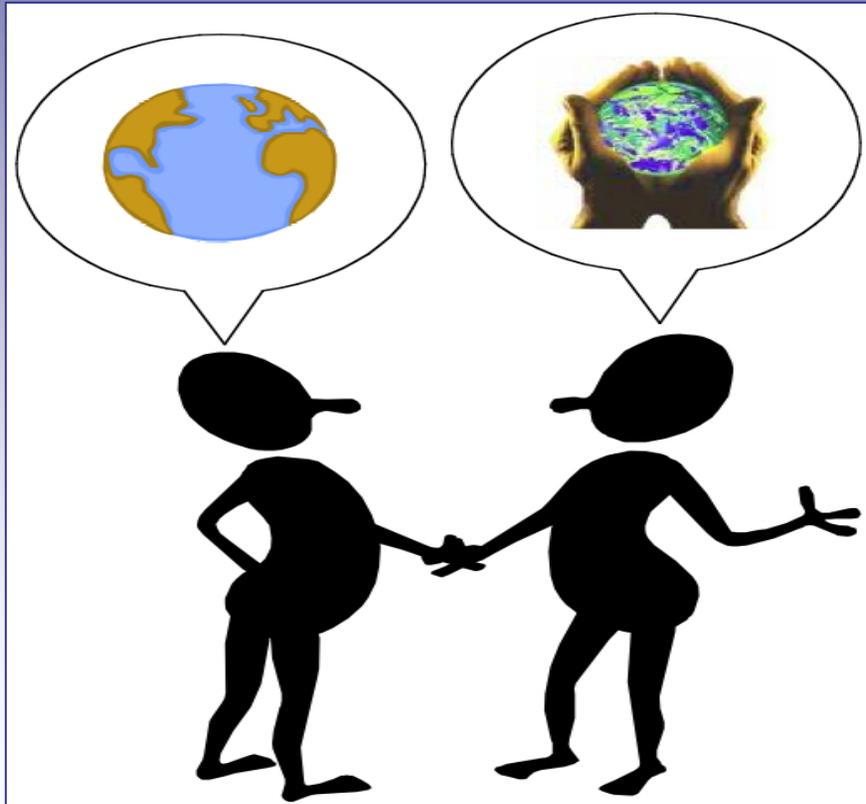
# Jimmy's Story

**Jimmy Is Distressed, But Soon Decides To Take Action**



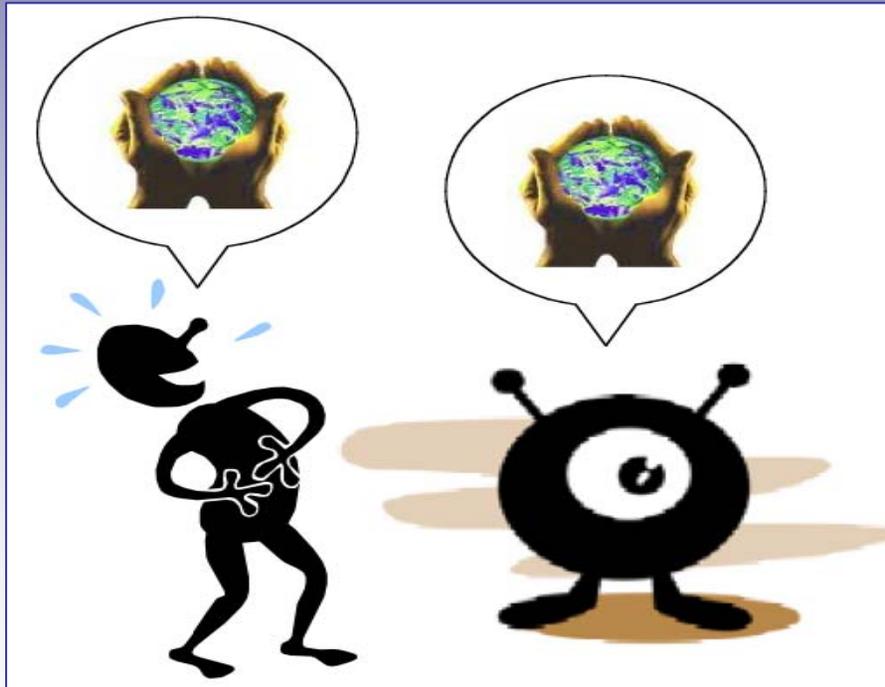
# Jimmy's Story

## Jimmy & Another Human Find A Solution



# Jimmy's Story

**Jimmy: "I've Done It! I've Saved Earth!"**



# Jimmy's Story

**Jimmy Returns A Happy & Changed Man**



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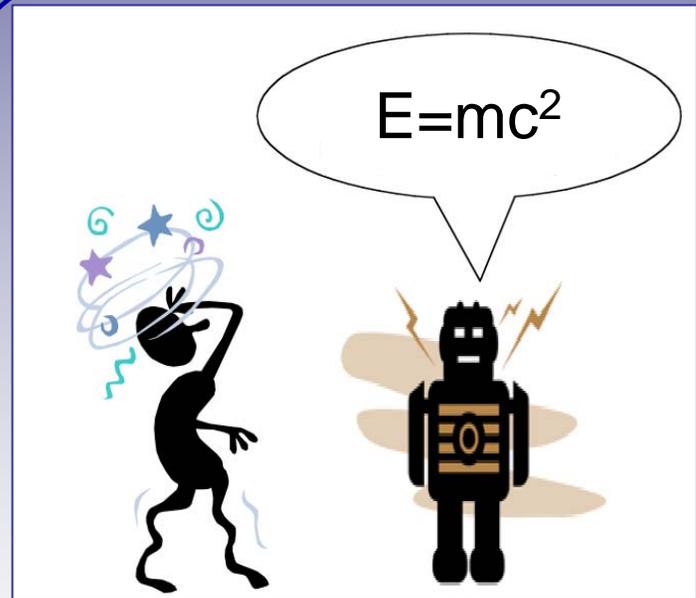


# Why Jimmy's Story Is Relevant

## Poor Health Literacy Limits Understanding

**“Most health information is written at levels the average adult cannot understand.”\***

\*New York City Literacy Assistance Center



# Why Jimmy's Story Is Relevant

## Are Our Biases & Assumptions Negatively Impacting Health Content?

**Developers of a migraine patient education tool assumed:**

- **Patients want formal medical information**
- **Non-physician migraine sufferers lack knowledge**

DE Forsythe. *Medical Anthropology Quarterly*  
December 1996, Vol. 10, No. 4, pp. 551-574



# Why Jimmy's Story Is Relevant

## Are Our Biases & Assumptions Negatively Impacting Health Content?

### Interviews revealed migraine sufferers:

- Wanted informal and/or specific knowledge
- Sought to apply medical information to their lives
- Had a secret, unaddressed fear:  
“Do I have a stroke or brain tumor?”

DE Forsythe. *Medical Anthropology Quarterly*  
December 1996, Vol. 10, No. 4, pp. 551-574



# Why Jimmy's Story Is Relevant

## Some Patients Are Reacting By Skipping Official Online Content

**According to research conducted by Pamela Briggs of the UK's Northumbria University:**

- **Government Websites are being rejected because they contain generic or irrelevant content**
- **People favor online sources featuring personal stories they can relate to**

Bodies Online - Information and Advice Seeking in the Health and Fitness Domain,

Briggs P, 2007, United Kingdom Economic and Social Research Council



# Why Jimmy's Story Is Relevant

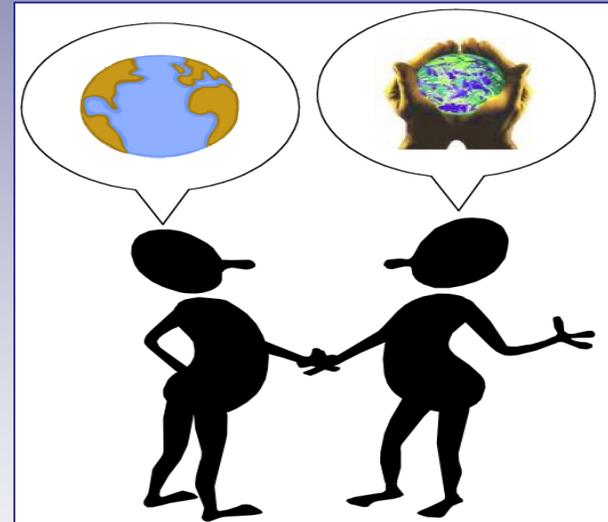
## Patients/Consumers Are Flocking To Unofficial Online Sources

Search Term: Lexapro (Prescription Or OTC Drugs)	
Website	% Of Overall Traffic Going To Website*
www.lexapro.com	50.58%
www.drugs.com	12.13%
www.healthsquare.com	5.77%
www.crazymeds.org	5.36%
www.rxlist.com	5.02%

Search Term: Bipolar Disorder (Mental Health)	
Website	% Of Overall Traffic Going To Website*
www.nlmh.nih.gov	14.86%
bipolar.about.com	12.42%
www.seroquel.com	8.26%
www.wikipedia.org	7.17%
www.bipolar.com	6.21%

Source: Hitwise (www.hitwise.com)  
Timeframe: Four weeks ending January 13, 2007  
\*Among Internet users typing in search term



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# Three Steps To Success

## Improving Our Relevance By Engaging Patients On Their Own Terms

### Step I: Engage

- Pre-test & engage in ongoing dialogue
- Build online platforms to facilitate meaningful patient engagement



# Example Of Success

## HHS Flu Pandemic Blog



The screenshot shows the header of the "Pandemic Flu Leadership Blog" from the U.S. Department of Health and Human Services, dated May 22 - June 27. The header features the HHS logo and the title in white text on a blue background. Below the header, the main content area has a light blue background with a subtle pattern. It begins with a "Welcome" section followed by a paragraph of text. A "Closing Thoughts" section is introduced with a blue underlined heading, accompanied by a small portrait of Michael O. Leavitt and his name below it.

 **Pandemic Flu Leadership Blog**  
May 22 - June 27

**Welcome**

On June 13, 2007, Michael O. Leavitt, Secretary, U.S. Department of Health and Human Services, convened a Leadership Forum on pandemic preparedness, which brought together influential leaders from the business, faith-based, civic and health care sectors to discuss how to convince and help Americans prepare for a possible influenza pandemic. The Department hosted this short-term blog to expand the conversation leading up to and following the Leadership Forum. While comments are no longer enabled, the wealth of insight from this open dialogue will remain available online as part of the Department's ongoing effort to help Americans prepare.

 **Closing Thoughts**

As we close the HHS Pandemic Flu blog, I want thank all of you for participating. The passion of respondents was a happy surprise to me. I have come to understand there is an army of well trained and motivated people who understand this issue and the need for a sustained concentrated effort.

Posted by  
**Michael O. Leavitt**

# Three Steps To Success

## Improving Our Relevance By Engaging Patients On Their Own Terms

### Step II: Incorporate

- Build alliances with expert patients
- Highlight patient content on official sources



# Example Of Success

## Web MD

The screenshot displays the WebMD homepage with several key sections:

- TOP 12 health topics:** A list of 12 topics categorized by gender (MEN, WOMEN, CHILDREN). Topics include HPV Vaccine, Dehydration, Depression, Western Diet, Caffeine, Cervical Cancer, TMJ, West Nile Virus, Rosacea, Menopause, Pregnancy Calendar, and OCD.
- Latest Headlines:** A news section featuring a headline about "Kids' High Blood Pressure Often Missed" with a sub-headline and a "Read Full Article" link. It also includes "News" and "Trends" sub-sections with various health-related articles.
- People Are Talking:** A section for user-generated content, including "Blogs" (e.g., "Health insurance should be the right of all individuals."), "Message Boards" (e.g., "Out of control ADHD child!"), and "Ask The Experts" (e.g., "Are hypersomnia and narcolepsy the same thing?").
- Interactive Check-Ups:** Promotional boxes for an "Arthritis Quiz" and a "Metabolism Calculator".
- Advertisements:** Promotional banners for Vicks VapoDrops, Hand Sanitizer, and WebMD services like "get started on WebMD" and "Simple Tips for Better Health".

A callout box labeled "Patient-Generated Content" points to the "Blogs" and "Message Boards" sections, highlighting user-generated text.

# Three Steps To Success

## Improving Our Relevance By Engaging Patients On Their Own Terms

### Phase III: Support

- Help patients develop health info seeking skills
- Train providers to work with patients using peer-developed content



# Example Of Success

## NHS Expert Patient Program

**Expert Patients Programme**

Home | Site Feedback | Contact Us | Jobs | Search this site [ ] Go

**Home**

About Expert Patients

What is an Expert Patient?

Views from patients and professionals

Long-term health conditions

Get involved

Find Courses

Supporting Parents Programme

Looking After Me - course for carers

News and events

### What is an Expert Patient?

Expert patients are people living with a long-term health condition, who are able to take more control over their health by understanding and managing their conditions, leading to an improved quality of life.

### Benefits of becoming an Expert Patient

Expert patients...

- Feel confident and in control of their lives
- Aim to manage their condition and its treatment in partnership with health care professionals
- Communicate effectively with professionals and are willing to share responsibility on treatment
- Are realistic about the impact of their disease on themselves and their family
- Use their skills and knowledge to lead full lives.

### Become an Expert Patient

Take control of your condition by becoming an Expert Patient. Find ways to control your

**Latest news headlines**

[Read the latest news...](#)

**Links**

- [Long-term Medical Conditions Alliance](#)
- [Stanford Patient Education Research Center](#)
- [NHS Direct](#)

**Your comments**

We will be expanding the site over the coming months. We welcome your [contributions, stories and comments](#).

# How To Contact Me

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