



# TARGETING HARD-TO-REACH AUDIENCES FOR MARKETING AND DISEASE-EDUCATION PROGRAMS

by Justin Edge

Online communities enable a direct connection with low-prevalence disease sufferers and their caregivers

Until recently, pharmaceutical and device companies have focused most of their business intelligence efforts on understanding the needs of professional customers and influencers—doctors, technicians, nurses, and hospital administrators. But the past ten years have seen a surge in direct intelligence gathering among healthcare *consumers*, led primarily by prescription therapy marketers. The relaxation of Direct-to-Consumer (DTC) marketing restrictions in the 1990s set the stage for a surge in branded and unbranded advertising and promotional programs. Yet a basic challenge remains: How to efficiently reach low-incidence or hard-to-reach consumers who suffer from a particular condition or take a certain medication. (Lists of undiagnosed sufferers or lapsed

medicators are generally not available to researchers, planners and strategists.)

In fact, the costs associated with finding the right patient groups have increased, at a time when patients are less compliant than ever with their prescription therapies. Prescription therapy marketers are realizing that fixing the leaky bucket with educationally oriented Direct-to-Consumer and Direct-to-Patient programs might be preferable to filling up the bucket with new patients. And improving patient persistence rates with prescription therapies makes sense from a public health standpoint as well as a marketing ROI standpoint. It is against this backdrop that pharma players are exploring more efficient ways to communicate with and educate the healthcare consumer. But finding these patients (and, in some cases,

their caregivers) is proving difficult in an age of fragmented media, weakened physician-patient relationships, and increased skepticism of traditional prescription medicines.

The advent of the Internet is reshaping the options available to healthcare companies. Online communities of interest now act as magnets that attract consumers with similar interests, ailments, and needs. These communities offer the marketer and healthcare educator the opportunity to have a conversation with the most narrowly defined audiences, from sufferers of obscure conditions to lapsed medicators.

“Communities” of many types have been congregating around a shared interest in healthcare topics for many years. Age of Enlightenment anatomy lectures drew crowds of amateur enthusiasts as well as professionals, all focused on gleaning new insights or simply satisfying curiosity. Physician associations have organized around distinct specialties for more than over a hundred years. And patient advocacy groups predate the advent of the Internet by decades. These formal and informal communities have been defined by their very interest in a healthcare topic and their search for deeper learning about it.

Medical information seekers often have a motivation and determination in a different league to that of product enthusiasts, such as followers of Apple hardware or owners of iconic Leica cameras. Actors in healthcare communities are sometimes motivated by a high-stakes search for information that is the difference between life and death; the movie *Lorenzo’s Oil* tells the dramatic story

of parents’ hunt for a cure for their son’s adrenoleukodystrophy (ALD). At the other extreme are those with persistent but less-threatening conditions who are looking for new or alternative approaches to treatment.

Compared to product enthusiast groups, online healthcare communities focus less on a branded offering and more on unbranded, unbiased sources of information and tools that can benefit the community member in the offline world. (Think adult Gen X-ers researching glucose-monitoring options for their Type II diabetic parent rather than Gen Z-ers on mySpace complaining to their 967 “friends” about their iPod Nano.) In fact, the recent controversy over aggressive DTC promotion of prescription drugs has already prompted a growth in unbranded educational campaigns, as opposed to image-laden, branded advertising campaigns (see *Table 1*).

#### MARKETS TAP INTO ONLINE COMMUNITIES

Online consumer interest groups focused on healthcare have been with us for more than fifteen years. They often started out as a way for sufferers of chronic, progressive diseases to share information and support. These early chat rooms also provided a link to the outside world that bypassed the patient’s physical disability. It wasn’t long before healthcare marketers and researchers sought to tap into these communities—for example, by

- *Intercepting visitors with branded or unbranded messages* timed to influence consumers at a key moment in their decision making

**TABLE 1: TRAITS OF HEALTHCARE VS. CONSUMER-PRODUCT-FOCUSED COMMUNITIES ONLINE**

HEALTHCARE FOCUSED	PRODUCT FOCUSED
Attracts mainstreamers	Attracts innovators
Intended for family members as well as disease sufferers	Intended primarily for product users
Suspicious of brands	Open to brands
Episodic interest—when healthcare need presents	Ongoing interest

- *Engaging visitors/members with interactive tools that deepen the relationship, such as online health diaries*
- *Observing and extrapolating insights*—here the online community becomes a laboratory to understand the needs and motivations of patients and caregivers
- *Recruiting to clinical trials and commercial market research*—for example, inviting chronic, progressive multiple sclerosis sufferers to participate in an online survey or focus group

in-time opt-in entry points, and provide only general medical history.

Consider the case of the medical device manufacturer that wishes to interview patients who have had a defibrillator implanted to manage arrhythmias. Information privacy rules prevent the firm from accessing its patient registry for commercial market research. In the past, the manufacturer would have undertaken one or more of the following to recruit sufficient patients to conduct a valid and reliable survey:

### FINDING THE NEEDLE IN THE HAYSTACK

But when it comes to research that will guide marketing efforts, these online groups leave much to be desired. Problems of locating low-prevalence sufferers persist. It is still difficult to connect with sufferers or family members at the key point in a decision-making cycle—for example, right after the point of diagnosis. This is especially the case with access panels, which tend to rely on static data, collected at distant-

- Place ads in national and targeted publications, inviting potential respondents to register their interest in participating by dialing an 800 number or logging on to a Web site
- Recruit patients through physician offices by distributing flyers to a network of treaters
- Liaise with a patient advocacy group to mail its members or place an invitation

on the advocacy group's website or in its periodic newsletter

- Recruit the recruiter, where qualified patients are asked to reach out to friends and family members who may also fit the research protocol
- Identify concomitant conditions and likely demographics to screen among a more focused pool of potential candidates

Building a quorum of patients through these creative methods usually incurs significant up-front costs that can only be justified by conducting ongoing research with the captive and cooperative pool of respondents. One

### BUILDING A QUORUM OF PATIENTS THROUGH TRADITIONAL METHODS CAN ONLY BE JUSTIFIED BY CONDUCTING ONGOING RESEARCH

further cost of finding the needle in the haystack is the time required. These challenges are heightened for clinical research protocols that can be very restrictive—for example, HIV patients who have suffered virological failure on first- and second- line anti-retroviral therapy, or trauma-induced DIC (disseminated intravascular coagulation) patients who must be enrolled within forty-eight hours of admission, to test a new antiseptic drug. In these cases, it can take a year or more to reach an adequate number of enrollees for the trial.

One solution to these problems lies in online communities that are focused around distinct and very low-prevalence conditions

like hemophilia, sickle cell anemia, congestive heart failure, or Paget's disease. Knowledge Networks has developed a protocol for reaching survey-ready respondents who flow from online communities of interest. The stream of traffic to dedicated, disease-specific Web sites provides a source of sufferers and family/friends of sufferers that can be screened and qualified for study enrollment. We called these KnowledgeCommunities,<sup>™</sup> because they are formed out of a member's search for information and knowledge.

The quality-content Web sites essentially act as magnets for the healthcare information seeker. Reaching out to high-traffic clusters of these sufferers is a cost-efficient proposition that can be pulled off within a reasonable time frame. These communities offer the potential to get at patients and other interested parties who are often underrepresented in many healthcare research studies:

- the newly or soon-to-be diagnosed patient who has just started his or her information search
- the sufferer in an exurban or rural location who is not treated at a specialty center or at an academic medical facility in a major city
- the lapsed or naive treater who does not rely on his or her physician for treatment guidance (these are overlooked in studies that recruit via physician offices)
- family members of chronic sufferers, who can exert as much influence over the treatment decisions as the patient—for example, the spouse or adult child of a

Parkinson's Disease sufferer, the parents of a child with cerebral palsy, or the spouse of a stroke patient who has difficulty communicating

In addition to their ability to reach hard-to-find sufferers, panels derived from a genuine online community offer a quality of engagement and interaction that is lacking with older methods of enrollment and pure access panels. And, unlike some commercially available patient lists, there is no restriction around once-off use; patient perceptions and outcomes can be measured over time through repeated recontacts, yielding true measures of persistence, understanding of messages, and a track record of actions.

#### BUILDING A BETTER ONLINE COMMUNITY

Knowledge Networks' partnership with morefocus group has identified a few preconditions for engaging healthcare community members for high-quality research:

- Members should not be baited into participation by offering irrelevant incentives such as a free iPod. This simply attracts skewed respondents who will tell you what they think you want to hear.
- Multiple opt-ins ensure a permission-based system for enrollment that will not run afoul of any ethical guidelines.
- The invitation to participate in certain types of research should only be issued to members of certain types of healthcare communities. This principle is based on mutual engagement—engage the community member on the topic that he

or she is interested in. For example, there is little benefit in asking osteoporosis community members to consider taking an unrelated survey about flu vaccines, whereas there is merit in asking these osteoporosis community members about their views of calcium supplements.

Once these audiences can be located, marketers wish to unlock the power of patient-level data that can track progress against business and health-outcomes goals. This appetite for reliable patient-centric information mirrors consumer initiatives in a variety of other industries. Applications include

- Understanding patient motivations for switching and drug holidays
- Quantification and validation of forecast assumptions for a low-prevalence audience (too often this is achieved through qualitative methods or gut feelings)
- Testing branded and unbranded product messages against a unique subset of sufferers who seek out information
- Pulsing the viewpoints of “networked” patients after adverse events

#### CASE STUDY: DIABETES

Through its work on Knowledge Communities™, Knowledge Networks has found that the profile of these healthcare community members is slightly different from that of mainstream disease sufferers, but is not as different as online product enthusiasts compared to offline product users.

**TABLE 2: SOURCES OF DIABETES INFORMATION, OTHER THAN DOCTOR**

	KNOWLEDGE COMMUNITIES™	ONLINE PATIENT PANELS
Diabetes-related magazine	47%	33%
Web site of a diabetes-management mfr.	47%	38%
Family/friends	17%	27%
Diabetes educator	22%	19%
800 # of diabetes-management product mfr.	1%	8%
Educational course/formal training	10%	11%
Nonprofit organization	11%	9%
A governmental agency	5%	6%
Other source	15%	8%
I have not looked for information in P3M	21%	33%

*Q. "Besides visiting a doctor, where have you looked for information regarding diabetes in the last 3 months?"*

**TABLE 3: DEMOGRAPHIC PROFILE OF COMMUNITY VS. PANEL MEMBERS**

	KNOWLEDGE COMMUNITIES™	ONLINE PATIENT PANELS
Age 18–49	29%	27%
Age 50+	71%	73%
Male	49%	44%
Female	51%	56%
White	71%	72%
Ethnic	29%	28%
Insulin users	21%	21%
Non-insulin users	79%	79%
Median income	\$36,000	\$36,500
Married	64%	62%
Not married	36%	38%
Mean # in household	2.5 KIDS	2.4 KIDS
Kids in household	20%	19%

A KnowledgeCommunities™ offering was created for Type II diabetics and compared to other research Knowledge Networks has conducted using its own representative patient panels and volunteer panels.

In general, Type II diabetics recruited from online communities of interest are more likely than the mainstream to proactively search for information. Only one in five of these community members has not looked for diabetes information in the months prior to the survey, compared to one in three of the mainstream diabetic respondents.

The KnowledgeCommunities™ members are also more likely to use proactive tools like magazines and online information sources, whereas the mainstream diabetics relied more on passive sources like friends and family members (see Table 2).

The differences between the two groups are restricted to information searching and consumption. They share similar demographic characteristics (see Table 3).

Symptomatology is also fairly similar between these two groups of diabetics, although the mainstreamers suffer slightly more from some related conditions than the Knowledge Communities™ members (see Table 4).

Patient attitudes toward their diabetes and their treater explain the more proactive information-seeking behavior that is found in online community members. KnowledgeCommunities™ respondents are more skeptical of their physicians' approaches to treating their diabetes and overall seem less satisfied with their physician relationship (see Table 2). They also rely less on their faith and their families to manage their diabetes,

	KNOWLEDGE COMMUNITIES™	ONLINE PATIENT PANELS
Blurred vision	39%	42%
Numbness of feet	31%	39%
Chest pain	20%	25%
Kidney problems	8%	8%
Stroke	4%	12%
Heart attack	4%	15%
Foot ulcers	2%	3%

perhaps explaining why they turn to online communities as a means of filling the information and coping gap (see Table 5 on the following page).

#### CASE STUDY: HIV/AIDS

KnowledgeCommunities™ was used to assist a pharmaceutical company that had developed a new treatment specifically targeted at HIV patients who had experienced virological failure with early-line therapies. The company wished to gain some survey insights and boost Phase II clinical trial enrollment within a very tight schedule.

**TABLE 5: ATTITUDES TOWARD DIABETES CARE (% AGREEMENT)**

	KNOWLEDGE COMMUNITIES™	ONLINE PATIENT PANELS
It is important to manage my diabetes	97%	96%
Current treatment allows me to control my diabetes	87%	89%
My doctor explains things in a way I can understand	86%	91%
My doctor is respectful of my preferences and needs	79%	89%
Confident my doctor knows best way to treat my diabetes	71%	91%
My doctor takes time with me; I don't feel rushed	74%	85%
My family is very interested in helping me care for my diabetes	67%	73%
I am confident that I know the best way to treat my diabetes	65%	68%
My nurse educator explains things in a way I can understand	70%	61%
My faith is very important to caring for my diabetes	53%	65%
I rely on my family to help care for my diabetes	32%	41%
I feel like my doctor for diabetes is not aware of new medical research	28%	26%
I feel like my diabetes nurse educator is not aware of new medical research on diabetes	23%	22%

*Q. "Please indicate how much you agree or disagree with each of the following statements?"*

The goal was to recruit and survey 200 HIV-positive patients with a ten-minute survey critical for an effective clinical trial retention program. These respondents would then be screened for future trial participation. The fast-moving process—taking less than a month—unfolded as follows:

- Web site content development, design, production, and publication was achieved within a week.
- The scripting, coding, and field engagement survey was completed in one day; this provided newsworthy content, which was pushed out to newspapers, TV,

magazine, and online content suppliers, thus driving more traffic to the website.

- Other “calls to action” and placement of the articles on related sites and in newsletters followed.

This process quickly generated more than 1,100 site visitors that yielded more than 240 completed surveys and 145 clinical trial registrations—compared to a client expectation of forty registrations—underscoring the high levels of engagement survey respondents have with the topic of interest.

#### PART ENTHUSIAST, PART MAINSTREAM

Online communities of interest offer healthcare researchers, consultants, and planners an unprecedented opportunity to conduct a dialogue with low-prevalence groups. This can be achieved within reasonable time frames and budgets, compared to the hybrid methods that existed for recruiting these subgroups in an offline world.

The community members are far more likely to be avid healthcare information seekers, but they are similar to mainstream disease sufferers in many other respects. Because of this, they should complement rather than replace other sources that more effectively embrace older, sicker, non-compliant, offline disease sufferers. Within this constraint, however, communities of interest are ideal for evaluating new therapies and programs among an information-literate subgroup of disease sufferers. ▀

#### KEY CHALLENGES IN PATIENT/ CAREGIVER RESEARCH

- Difficulty of accessing low-incidence patient populations due to low prevalence of many diseases (<1% inc).
- Challenge of encouraging existing volunteer patient panels cannot yield a quorum of low incidence sufferers
- Frequent defaults to qualitative methods because insufficient survey-ready respondents are available to support quantitative insights.
- Increasing problems (expense and time intensiveness) of traditional approaches to blended “snowball” samples – for example, recruiting patients through doctor’s offices, treatment centers, one-off uses of online and print ads, and partnering with patient advocacy groups.

*Justin Edge is Senior Vice President and Senior Managing Director at Knowledge Networks, where he also serves on the Executive Staff and is one of the leaders of the pharma/healthcare practice. He can be reached at [judge@knowledgenetworks.com](mailto:judge@knowledgenetworks.com).*