Executive Summary

HarrisInteractive

10,000 Patients Survey

Readable sample sizes for over 38 chronic conditions

Key Findings: The Study's Headlines

1. A huge sample shows that the chronically ill are a very diverse group

The 10,000 Patients Study, conducted online, has samples of more than 500 respondents for 18 disease states and sample of more than 20 respondents for 38 of the 41 disease states identified in this survey. These large samples allow us to *both* look at comparisons between people with different diseases, and to compare different types of people with the *same* condition. The findings reveal enormous variation between and *within* different disease states, and between and among other demographic groups.

Example 1: Non-compliance among patients is rampant, but varies dramatically

For pharmaceutical companies the good news is that over 90% of the chronically ill use prescription drugs. The bad news is that under half of those that do—only 43%—have taken them properly as prescribed by their doctor for the past 12 months. All the rest have in some way been non-compliant, and for some disease groups the story is far worse. Those with diabetes (50%) and hypertension (49%) report the highest levels of compliance, while those with back problems (36%), asthma (34%), depression (28%) or migraine (28%) are having the hardest time taking their drugs as prescribed.

Example 2: Different disease states cause different levels of satisfaction

Few people ever express dissatisfaction with the health services they have personally received. The chroni cally ill are no exceptions—only 13% of them are either somewhat or very dissatisfied. People with aller gies, diabetes and elevated cholesterol show similarly low levels of dissatisfaction. But the levels of dissat isfaction are much higher for some, especially those with gastro-intestinal complaints (22%) and back prob lems (24%).

Example 3: Large samples show that treatment patterns vary widely within disease states

These samples are so large that they can allow analysis within individual sub-groups. For instance, there is considerable variation in treatment within disease states. The analysis shows that black diabetics are much less likely to be under the care of a doctor than whites (57% versus 80%). Meanwhile, Hispanic diabetics are much less likely to be taking prescription medication (50% versus 79% for whites and 84% for blacks).

2. Insurance coverage is a big factor in drug use, especially for the elderly

Those people without drug coverage are far more likely to not fill a prescription or be in some way non-compli ant than those with some or full drug coverage. Seniors show the biggest discrepancy. Fifty-three percent (53%) of those over 65 without drug coverage have in some way reduced their drug use compared to only 30% of those with at least some coverage.

3. The Internet is used for health care by 50 million chronically ill Americans

The Internet is an important part of the life of the chronically ill online, with over 19% using it to look for health information often and only 13% saying they never do. People who are sicker use it most, although the online boomers use it far more than the online elderly. Significantly, fully 82% of those who use the Internet for health information think it has a positive impact on how they understand their health problems.

4. Commercial web players, not traditional health care stakeholders, are winning online

Commercial web sites—health pages or vertical portals ("vortals")—aimed at health care are far more popular with the chronically ill (and for that matter all Internet users) than sites provided by traditional health care stakeholders *of all and any type.*

5. E-Health: We're at the start of something big, not the end

Despite all the talk about consumerism and the growth of the Internet as a source of information for the chroni cally ill, relatively few numbers of the chronically ill have ever asked for a prescription drug by name. Similarly, few have complained to their health plan, asked about what their insurance covers, taken part in any type of on- or off-line support group, or used any software to manage their condition. Turbo-charging this type of aggressive consumerism is a huge opportunity—we are a long way from the medical *Quicken.*

Introduction: What is the 10,000 Patients Study? Why is it Different? Why Should You Care?

The 10,000 Patients Study is the first example of an entirely new type of healthcare research. Using the power of the Internet and the more than 1 million chronically ill cooperative respondents in Harris Interactive's 4 million strong panel, we have created a study that allows intensive analysis of a wide variety of issues concerning the chronically ill.

The Harris 10,000 Patients Study demonstrates the power of Internet research in three main ways.

a) It shows the power of the Internet as a research tool. In particular, the large sample sizes of hard-to-reach groups (like those with different disease states) allow analysis of small segments and micro-segments, and comparisons between them.
b) It demonstrates the attitudes and behavior of a large cross-section of the chronically ill with relevance to their choice of plan, provider and treatment, including prescription drugs.
c) It shows the extent of Internet use by the chronically ill, and its impact on their behavior and attitudes.

One of the most important aspects of this study is that, with a total of over 10,000 chronically ill respondents, we have very large samples for over 20 disease states (up to 4,000 in some cases and at least 500 for each) and between 20 and 500 for 18 more disease states. This study dramatically shows the power of large samples. These samples are so large that they enable cross-segmenting of different variables, such as age, insurance coverage, race, and co-morbidities. Up until now, conducting research which enabled these kinds of comparisons was so expensive that this type of segmentation was not done. The message from The 10,000 Patients Study is not only can this segmentation be done, but also that there is immense variation amongst the ill. So if you want to interact with this group, you need to segment them on many different axes.

Weighting and Formatting

In order to be representative to a larger universe almost all surveys need to be weighted. Because only 48% of American adults are Internet-users, and some types of adults are under-represented in a typical sample, Internet surveys require a different approach to weighting than phone-based surveys. (The details are too complex to be discussed here. A weighting table is included in the data file accompanying this report). In this report we have weighted the data in two different ways. The data for questions concerning general health care are weighted so that they represent the proportion of the chronically ill in the overall U.S. adult population. For the questions concerning online use by the chronically ill, we have weighted the data so that it is proportional to the number of the chronically ill who are online.

Study explanation: Overall impressions

This first major on-line study of the chronically ill suggests that, despite large variations on all kinds of issues among the entire chronically ill population, some groups appear considerably more savvy about their "Cyberchondria" than others. These groups are also more likely to be "acting up" within or even opting out of the traditional health care system.

The most interesting analyses revolve around the differences in the chronically ill by disease state, by age and gender, by frequency of interaction with the health care system, and by health status. The "patient" active online is more likely to be sicker, female, and aged 40-49. Patients with diseases that are typically harder for our conventional health system to "cure", such as back problems, menopausal problems, and depression, are likely to be least satisfied with their health services. The same patients are less likely to be compliant with their prescription drugs. Patients with heart disease or diabetes are more likely to be compliant, and more likely to be under a physician's care.

The elderly are less likely to be using the Internet extensively and show some signs of being the group best integrated into the present system—judging by physician use and overall compliance. It is the college educated, higher income females who are looking to the Internet to help them deal with the system as it now stands—and to go around it.

Finally, the study indicates that those looking to interact with the chronically ill must not underestimate the huge amount of variation among them, and therefore must not misjudge the magnitude of the segmentation they must undertake.

How this report is structured

The sheer scale of this study means that we cannot hope to provide an exhaustive report with every sub-group documented. Instead we are providing three items:

a) this summary document which details some of the leading and most interesting findings;

b) a book of tables for all the questions, broken down with cross-tabs from 15 disease conditions and several demographic variables;
c) a data file of all 10,000 responses so that you can manipulate your own cross tabulations to compare micro-segments.

The remainder of this summary report looks at some of the most interesting findings from our analysis.

Section One: The Chronically Ill, Their Healthcare Services and Prescription Drugs

Illness, care patterns and satisfaction

The chronically ill respondents in this survey have a large number of chronic conditions. Although all 10,000 patients have at least one condition, the average respondent has 3.5 co-morbidities and 26% have 5 or more. Similarly, there is great variation in how those with different types of illnesses look after themselves or are looked after. Table 1 has a few examples.

For instance, while 54% of the chronically ill are under the care of a physician, people with hypertension are very likely to be under the care of a physician and taking a prescription medication (about three in four in both cases). Those with gynecological problems are much less likely, with only 16% of them taking a prescription drug and only 31% being under the care of a physician.

Table 1

Q.505 Which of the statements below describes your current situation?

		Condition		
Base:	All Respondents 10069 %	Seasonal Allergies 5322 %	Gynecological problems 1047 %	Hypertension 2020 %
I am under the care of a doctor	54	24	31	73
I take prescription medication on a regular basis	62	33	16	76
Do not receive any care or treatment	35	16	15	5

But it's not only between conditions that we see such variation, there is also considerable variation within them. Diabetics are a good example (Table 2). Non-white diabetics are much less likely to be under the care of a doctor than whites. (This does not appear to be because black diabetics are younger—even when adjusted by excluding those under 35, 80% of whites are under the care of a physician versus 57% of blacks). Hispanic diabetics are much less likely to be taking prescription medication (50% versus 79% for all) and much more likely to be using diet and exercise to control their condition (77% versus 51%). Conclusion—*Understanding ethnic and cultural differences in the way diseases are treated and the way the chronically ill behave within individual disease states is very important in its impact on health care and drug use.*

Table 2

Racial disparities in the care of diabetics

Q.505 Which of the statements below describes your current situation?

		Race		
Base:	All Diabetics 1126 %	White 934 %	Black 69 %	Hispanic 49 %
I am under the care of a doctor	75	80	57	54
I take prescription medication on a regular basis	79	79	84	50
I manage the condition with lifestyle habits (i.e. diet, exercise, stress management)	51	54	37	77

There are also some variations in levels of dissatisfaction with health care services. In general, whatever they think about the overall system, people tend to be satisfied with the health care services they have personally received. However, back in 1994, Harris started to detect increased levels of dissatisfaction (between 5% and 10% above average) among those in fair or poor health who were in managed care plans. That was a harbinger of things to come. In 1998, the result was the "backlash" against managed care. So the level of dissatisfaction is important. It is worth noting that while 13% of all chronically ill are either somewhat or very dissatisfied (Chart 1), the levels are much higher for those with gastrointestinal problems (22%) and back problems (24%), among others.

The chronically ill and prescription drugs

The 10,000 Patients Study includes a large number of questions about choices and attitudes concerning prescription drugs. There are many variations between and among different disease states which pharmaceutical companies will have to understand, if they are to use more direct-to-patient marketing successfully. Chart 2 demonstrates the several different stages along the "pharmaceutical value chain". Understanding patients' behavior at each link in the chain will allow better communication strategies and better results—leading to higher consumption of prescription pharmaceuticals. Getting the patient to ask for the drug, fill the prescription and take the drug are separate issues, all of which have a big impact on the product's bottom line. For example, Chart 3 shows that 28% of the chronically ill have asked their doctor for a specific brand name medication. However, only 23% of diabetics have done so, while those with depression (35%), gynecological problems (38%) or sinusitis (40%) are much more likely to do so. This might mean that there is more potential for direct-to-patient marketing to diabetics, or simply more acceptance of it from migraine sufferers, but in any event these differences need to be understood in a "one-to-one" future.

Chart 1
More intractable problems lead to less satisfaction with health services

Q.107 Overall, how satisfied are you with the health care services you have received in the past 12 months?

Those saying "somewhat" or "very dissatisfied"

Base: All respondents

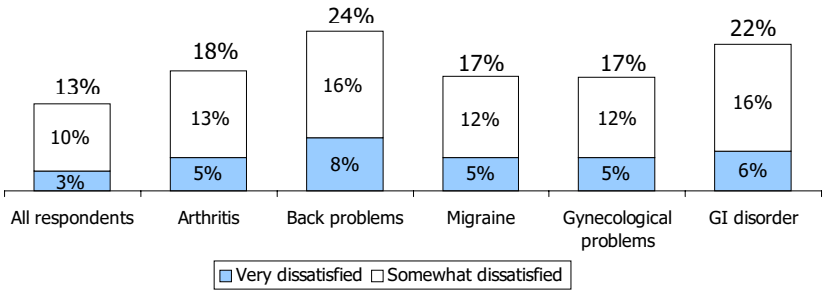


Chart 3
It's not just Claritin! Many patient groups show desire for brand-name drugs

Q. 305 In the past twelve months, have you asked the doctor to prescribe a specific brand name prescription drug, or not?

Those saying "have asked"

Base: All respondents

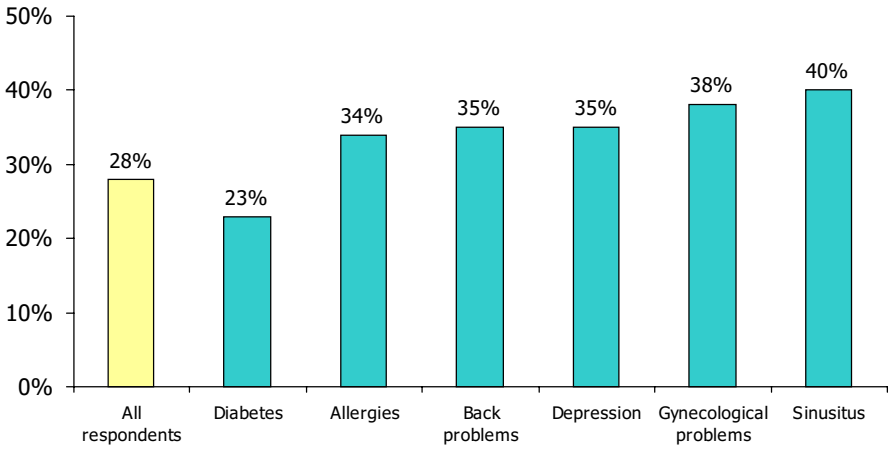
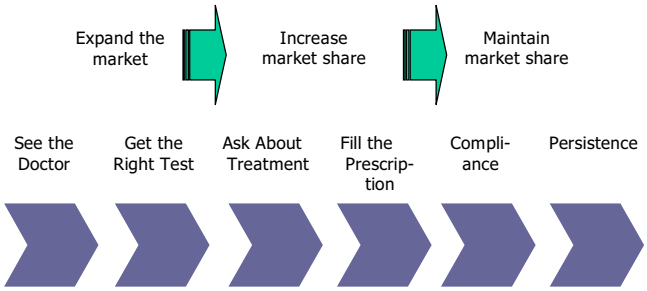


Chart 2
The Pharmaceutical Value Chain
Research can help pharmaceutical companies expand, increase and maintain market share



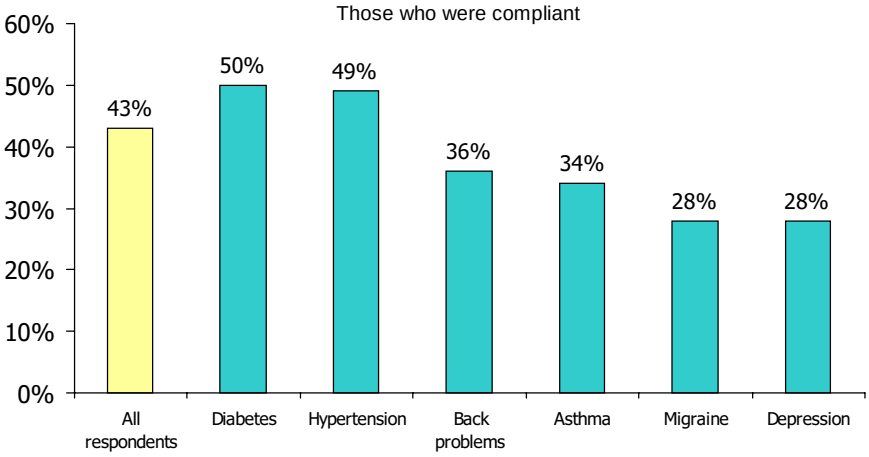
A 3% increase in sales at each step yields an overall increase in sales of nearly 20%

On the other hand, not filling a prescription, delaying filling one, taking a smaller dose than prescribed, taking it less often than prescribed, reducing the amount taken and/or stopping consumption of medication sooner than prescribed are all activities familiar to the chronically ill. Chart 4 shows that only 43% of the chronically ill have NOT "behaved badly," by making one or more of those "errors" in the past 12 months. However, when you look at who is behaving the "best", those with diabetes and hypertension (50% and 49% saying that they had done none of those things) were considerably more compliant than those with back problems, asthma, depression or migraine.

Chart 4
The good, the bad and the ugly

Q. 310 Those saying they had NOT engaged in at least one of a number of "non-compliant" behaviors which would have reduced their use of prescription drugs

Base: Used prescription drugs in past 12 months



One reason for this type of non-compliance may be out-of-pocket costs, another might be insurance coverage (or the lack of it). The current debate over Medicare drug coverage stems from complaints that the elderly without coverage are paying more out-of-pocket and in some cases going without needed medication because of high out-of-pocket costs. Tables 3 and 4 show an analysis combining data about out-of-pocket costs, insurance coverage, and compliance behaviors, all cut by age.

The analysis shows that in general the younger the chronically ill respondent, the more likely he or she is to reduce drug use from that prescribed for some reason. But the most interesting data, shown in Table 3, is that despite the rhetoric about seniors being unable to afford drugs, those over 65 with out-of-pocket drug costs in excess of $51 are only slightly more likely to reduce drug use than those with lower costs (36% versus 39%).

On the other hand, Table 4 shows that seniors are significantly affected by whether or not they have drug coverage. Fifty-three percent of those over 65 without any drug coverage have reduced their drug use, whereas only 30% of those with some coverage and 35% with full coverage have done so. *Conclusion: drug coverage (as opposed to out-of-pocket costs) is a key influence over seniors' use of prescription drugs, and their perception of whether it is possible to follow their prescriptions correctly.* Pharmaceutical companies interested in moving the debate in their favor and concerned about price controls also need to think of ways to connect drug coverage to greater ease of consumption.

On the other hand, drug switching for a variety of reasons is common amongst the chronically ill. For instance, while only 5% say they have switched drugs because they are concerned about becoming dependent on the medication they are taking, 10% of those

Table 3
Out-of-pocket costs don't impact the elderly's drug use too much . . .

Percentage that are reducing drug use in some way (Q.310)

	Age			
	18-34	35-49	50-64	65 +
Base: Used prescription drugs in past 12 months*	3082	3573	1814	297
	%	%	%	%
Out-of-pocket costs exceed $51 a month	76	73	55	**39**
Out-of-pocket costs less than $51 a month	67	62	46	**36**

** Note: Excludes respondents who did not answer one of the following questions: Q.310, 312, 315, 607*

Table 4
. . . . but lacking drug coverage does

Percentage that are reducing drug use in some way (Q.310)

	Age			
	18-34	35-49	50-64	65 +
Base: Used prescription drugs in past 12 months*	3059	3558	1818	303
	%	%	%	%
Insurance covers all pharmaceutical costs	66	61	38	**35**
Insurance covers some pharmaceutical costs	70	64	48	**30**
Insurance covers no pharmaceutical costs	72	76	61	**53**

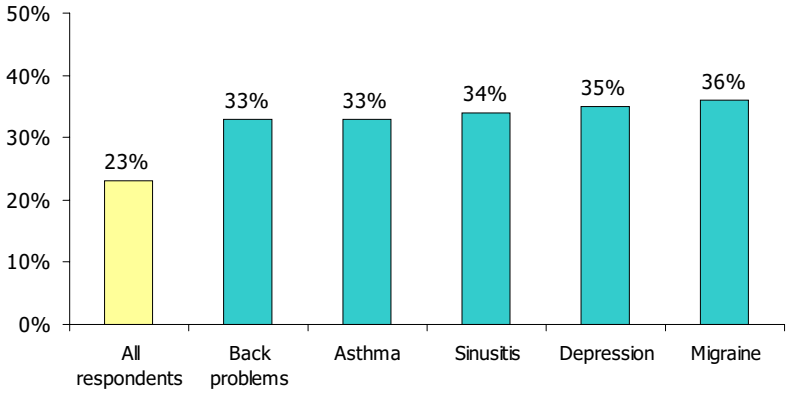
** Note: Excludes respondents who did not answer one of the following questions: Q.310, 312, 315, 607*

with depression have done so. Chart 5 shows that while 23% have switched drugs because they perceived the medication was ineffective, that proportion is much higher for those with back problems (33%), asthma (33%), sinusitis (34%), depression (35%), and migraine (36%).

Chart 5
Some disease states have ineffective drugs

Q. 311 Percentage saying in the past 12 months they had switched prescription drugs because the medication was not effective

Base: Used prescription drugs in past 12 months



Section Two: Internet Use By The Chronically Ill

The Growth of the "Cyberchondriacs"

The Harris Poll in July 1999 showed that over 48% of American adults were using the Internet. It is clearly the fastest growing technology in history. Like most other communication technologies, its evolution has been led more by those in search of entertainment, pornography and community than by those seeking information. However, information retrieval is an enormous part of the Internet, and so the industries that are information intensive, like financial services, now face most of their future online. What may be surprising is that health care is cited as an important reason to go online by a considerable number of Internet users. In June 1999 we estimated that number to be 72% of all adult American Internet users, or over 70 million people. Of the chronically ill, that proportion is even higher (Chart 6).

Who are the chronically ill "Cyberchondriacs"?

Eighty-seven percent (87%) of the chronically ill already online use the Internet to look for health information, with 19% doing so often, and 45% sometimes. Only two years ago your author (Matthew Holt) was quoted as saying that the Internet in health care was very, very important but only for a very small number of ill people. That statement was true then, but is not now. The chronically ill "Cyberchondriacs" are now a large group, accounting for 50 million Americans, or 87% of the 58 million chronically ill adults online in June 1999.

Chart 6
Almost all the online chronically ill are "Cyberchondriacs"

Q.200 How often do you look for information on-line about health topics

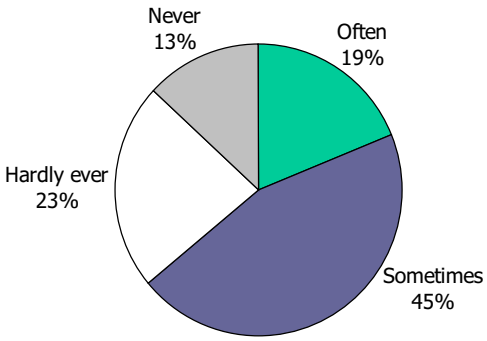


Chart 7
There are many hard-core users . . .

Q.200 How often do you look for information on-line about health topics
% responding "often"

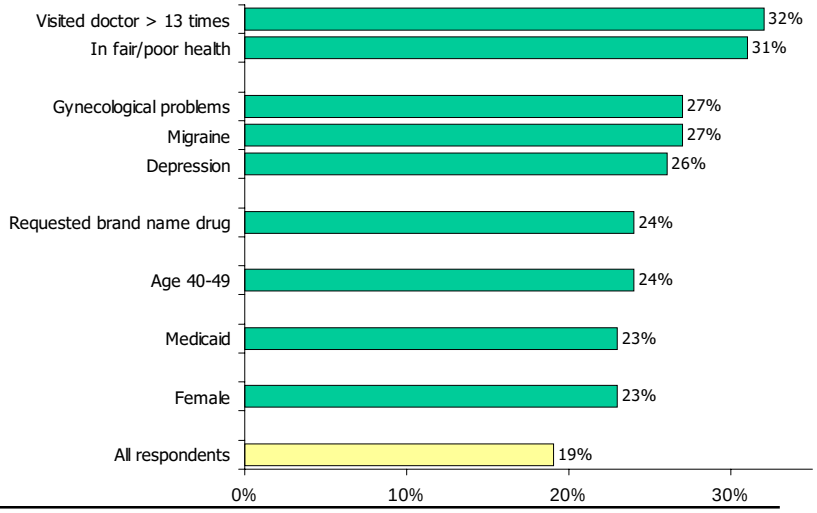


Chart 8
. . . but there are fewer active young, old and male "Cyberchondriacs"

Q.200 How often do you look for information on-line about health topics

% responding "often"

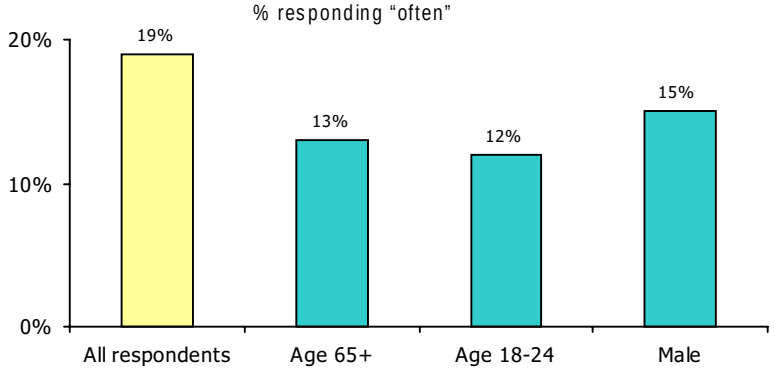


Chart 9
...and more of those groups never go online for heath information

Q.200 How often do you look for information on-line about health topics

% responding "never"

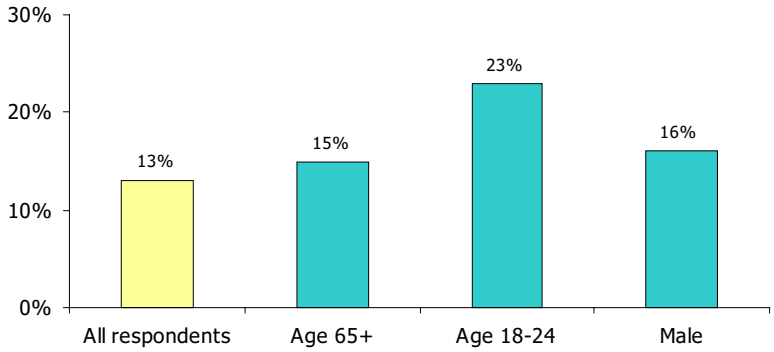
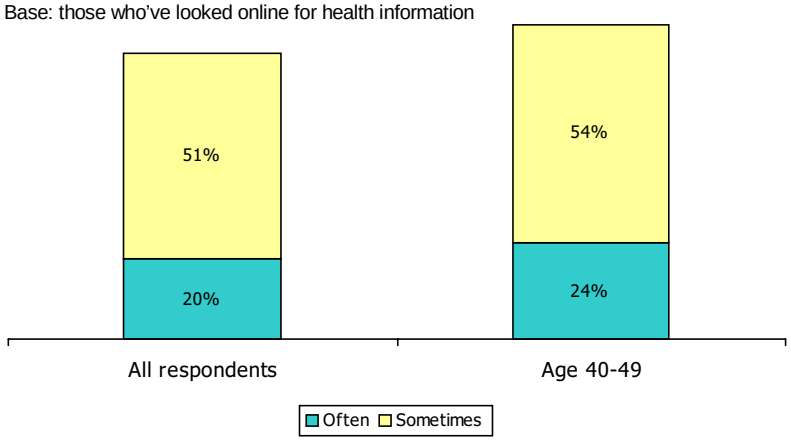


Chart 10
Most care about specific medical conditions . . .

Q.201 How often do you use the Internet to find information about specific medical conditions

% responding "often" or "sometimes"

Base: those who've looked online for health information



So who are the most intensive "Cyberchondriacs"? While overall 19% of the chronically ill online are likely to use the Internet for health information often, Chart 7 (on the previous page) shows that much higher proportions of those with depression, migraine, and gynecological problems do so. These are diseases that tend to be more common among women. This gives a major clue to the overall picture—*the Cyberchondriac is likely to be female. She is also more likely to be in only fair or poor health status, and a frequent user of the system* (judged by more than one physician visit each month).

Conversely, Charts 8 and 9 show that the young adults, the elderly, and males are less frequent users, and slightly more likely than average to have never gone online for health information.

However, those who *are* looking are in general seeking information about specific conditions (Chart 10) and 74% of them are looking for themselves. The most avid group is those aged 40-49 of whom nearly 4 in 5 have looked for condition-specific information.

Chart 11 shows the most frequent searchers, cut by disease state and health status. Again, those who are in fair or poor health status (35%) or make frequent physician visits (35%) are very active, as are those with migraine (27%), depression (27%) and gynecological problems (27%). However, those with arthritis (26%), gastrointestinal disorders (26%), back problems (26%) and sinusitis (26%) are also active information seekers. This analysis leads to a second conclusion—*someone with a health problem for which there may be no good quick fix is more likely to be an active Cyberchondriac.* Back problems and arthritis are good examples because often the medication for people with those conditions does not work well.

Who's capturing the market?

All this activity is being directed at an estimated 20,000 health care sites on the

Chart 11
. . . especially those in poor health or with a complex disease

Q.201 How often do you use the Internet to find information about specific medical conditions

% responding "often"

Base: those who've looked online for health information

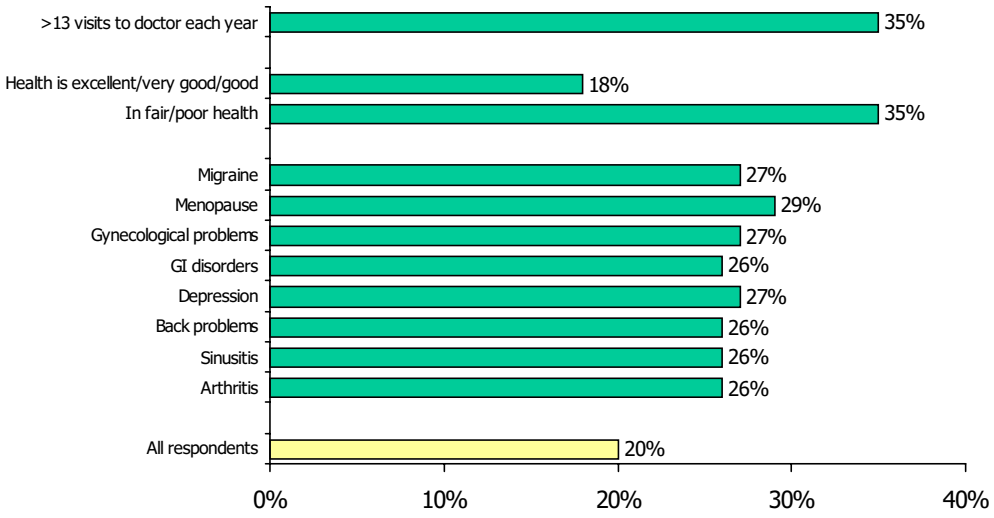
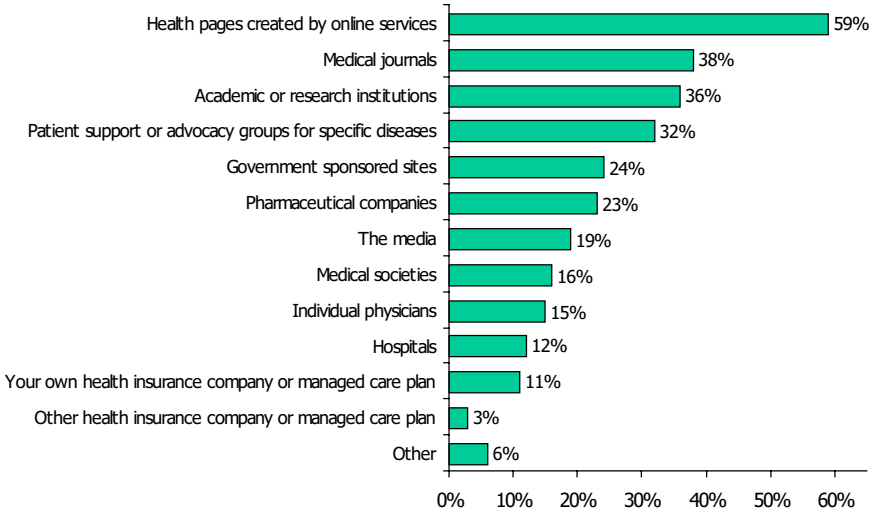


Chart 12
Which sources do they use? Health "vortals" are *Number One with a Bullet*

Q.203 Which of the following sources have you used to get health-related information off the Internet?

Base: those who've looked online for health information



Internet. While some of these sites are selling Viagra online, or dispensing *very* alternative therapies for all types of conditions, we have categorized them into several different types, based on who creates them. Chart 12 describes what types of sites are most popular.

"Number One with a Bullet" are health pages created by online services. These include the health channels on AOL, Excite and Yahoo, as well as the vertical portals such as drkoop.com, Americasdoctors, Intelihealth[1], Healthanswers, Mediconsult, Onhealth, etc. Over 59% of those who have gotten health information online have used these types of sites, whereas the next most popular categories, medical journals (38%) and academic and research institutions (36%) were visited by just over a third of those looking for health care information. The traditional stakeholders in health care, including pharmaceutical companies, medical societies, hospitals, physicians and health plans are also-rans among sites visited. Even when broken down by disease categories, only sites created by patient support or advocacy groups did slightly better amongst those with fair or poor health status (42% versus 32% overall). *Conclusion—the new media in health care is dominated by new players rather than by*

[1] *Intelihealth is owned by Johns Hopkins and Aetna US Healthcare. Along with the Mayo Clinic site (www.mayohealth.org), these are the only major consumer health sites created by "traditional" health care organizations.*

Table 5
Education matters for some types of web sites

Q.203 Which of the following sources have you used to get health-related information off the Internet? (You may choose more than one answer)

Base: Get health information from the Internet

		Education				
Base:	All 8998 %	Less than HS 166 %	HS 1377 %	Some College 4137 %	College Grad 2307 %	Grad School 965 %
Medical journals	38	29	33	38	43	47
Academic or research institutions	36	15	27	38	44	47
Patient support groups by education	32	21	27	35	35	37

established health care companies. Tentative conclusion—the lead these new players have and the capital behind them may make their online position unassailable, so traditional players will have to work with them rather than create their own online presence.

There is some variance in online Cyberchondriac behavior if you look by education level. Particularly, those with higher education levels are much more likely to use medical journals, academic and research institutions and patient support groups' sites (Table 5), as are those who are frequent physician-users and those in only fair/poor health (Table 6). But in general, the traditional players are late to the Internet party, and the Cyberchondriacs are mostly ignoring them.

So what difference does it make?

While a significant proportion of the chronically ill are using the Internet — which is becoming an important way to access them — a key question is: What impact is that having on their relationship with the health care system?

Table 6
Other distinctions matter for a few, too

Q.203 Which of the following sources have you used to get health-related information off the Internet? (You may choose more than one answer)

Base: Get health information from the Internet

Base:	All 8998 %	Fair/poor health 1729 %	>13 visits to doctor each year 1212 %
Medical journals	38	40	40
Academic or research institutions	36	36	46
Patient support groups	32	42	42

The Cyberchondriacs are information seekers. As such, the Internet is having a significant impact on how a large majority of them understands their own health condition — 41% say it has had a major impact and 41% a minor one (Chart 13).

A large majority say that it has helped them manage their health overall (71%). However, only small minorities say that it has had a major impact on either how they communicate with their physician or how they comply with treatments their physician recommends. Pluralities say that it has had no impact on these two issues.

Cyberchondriacs who feel that the Internet has had the biggest impact on understanding their own health are more aggressive in seeking their own treatments. This includes those who say they have paid more out of their own pocket for a specific test, treatment, physician or drug. This

Chart 13
Internet has big impact on understanding, less on provider interaction and compliance

Q.207 Overall, do you feel that the health related information you get from the Internet has had a major impact, minor impact, or no impact at all?

Base: those who've looked online for health information

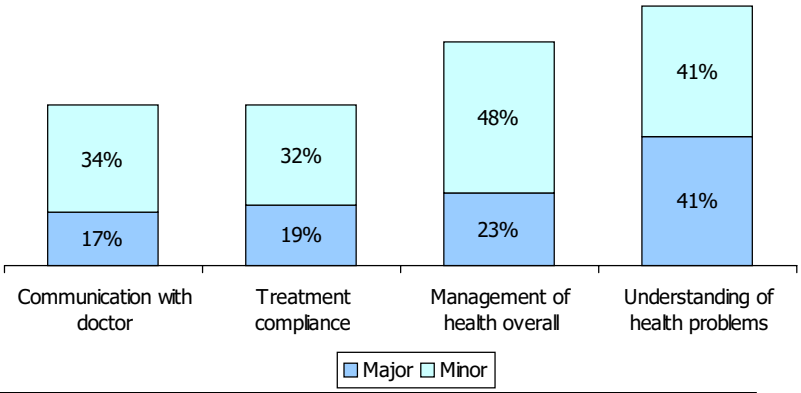


Chart 14
The more active (and usually female) patient reports better online understanding

Q.207D Overall, do you feel that the health related information you get from the Internet has had a major impact on the extent to which you understand any health problems you may have?

Base: those who've looked online for health information

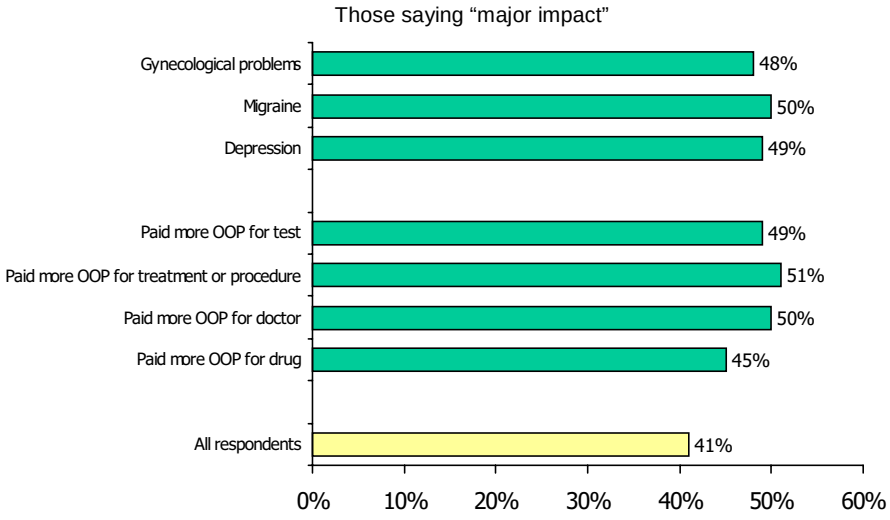


Chart 15
Almost no-one emails their doctors . . .

Q.208 Do you ever send e-mail messages to your doctor, or not?

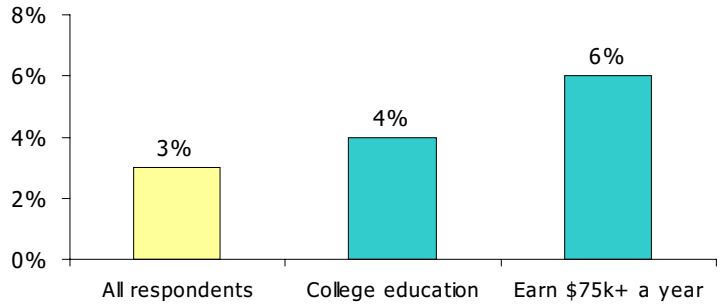
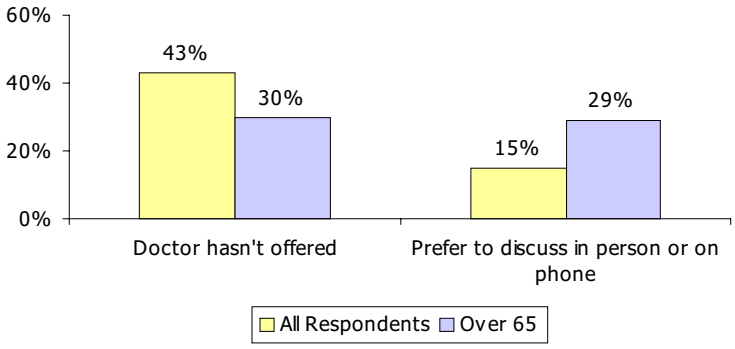


Chart 16
. . . because their doctors won't give out their address!

Q.209 Reasons for not emailing physician



is also true for those with migraine, depression and gynecological problems—diseases that are predominantly female (Chart 14).

Meanwhile, despite the extensive use of the Internet for both information retrieval and communication with other patients, the exchange of email between patients and their doctors is virtually non-existent (3%). Those who are using it are much more likely to be college educated and have annual household incomes in excess of $75,000 (Chart 15).

However, the major reason for not using email is that the physician hasn't offered it (43%), or the patient never thought of it (36%), rather than actually preferring an in-person or phone discussion. So when physicians do start offering email to their patients, they may find a great demand for it. However, the elderly — don't forget these are the elderly who are online already—are more likely (29% versus 15%) to want to discuss their issues with their physician in-person or over the phone (Chart 16).

Section Three: Attitudes To Health Care Services: The Agressive, Active Consumer Emerges

Chronically ill patients are increasingly becoming active consumers. Research for Harris' *Strategic Health Perspectives* project has characterized health care consumerization as being apparent in three locations: plan, provider and treatment. Table 7 shows that 33% of the chronically ill have paid more out-of-pocket for a drug; considerably fewer have done so for a treatment or test. However, the most interesting data indicates that most of the same groups who had been most dissatisfied with their services overall, have also been more likely to pay more out-of-

Table 7
Who has paid more for what?

Q.404 Below is a list of items related to how people spend money for health care services. Please indicate whether you have paid more out of your own pocket for the following health care services in the past twelve months. You may choose more than one answer.

		Medical Condition					
Base:	All 1006 9 %	Arthritis 2271 %	Sinusitis 1498 %	Diabetes 1126 %	Depress-ion 2634 %	Back Problems 1848 %	GI Disorder 1609 %
Prescription	33	41	43	44	41	39	42
Treatment	16	22	24	20	18	24	22
Medical test	18	22	22	18	19	21	21
Medical equipment	6	9	9	15	8	8	8
Doctor	14	16	19	13	18	21	18
Hospital	7	7	8	7	9	8	9

pocket for prescription drugs, including those with arthritis (41%), back problems (39%) and gastrointestinal disorders (42%). Diabetics (44%) and those with sinusitis (43%) have also been more likely to pay out-of-pocket for prescription drugs. Those with back problems are particularly likely to pay more to see a different doctor (21% versus 14% overall). We know from years of survey data that high out-of-pocket costs are a key driver of consumer dissatisfaction with health care services—something pharmaceutical companies need to bear in mind as they move towards a "consumer" future.

Another feature of aggressive consumers is their likelihood to take actions about (and usually against) their health plans. Table 8 shows that large numbers of the chronically ill have asked for information about what services their plans will pay for (38%) or even called or written with a complaint (20%). This activity is much more likely from those who are in "heavy" managed care plans (50% and 30%) as compared to "lite" managed care (39% and 18%) or fee-for-service (21% and 12%) plans.

Table 8
Actions taken in regard to health plans

Q.406 The list below describes actions people sometimes take with regard to their health plans. In the past two years have you done any of the following things? You may choose more than one answer.

Base: Insured

		Extent of Managed Care Restrictions		
Base:	All 8778 %	FFS 1457 %	Lite MC 4069 %	Heavy MC 3157 %
Asked for information	38	21	39	50
Complained	20	12	18	30
Requested information about how to stay	6	4	5	8

Self care and the search for "community" with other patients has been a major trend over the last decade. Small but significant percentages of the chronically ill population have been involved in physical "support groups" (11%), reading or posting to newsgroups and bulletin boards (25%), or subscribing to listservs or email lists (14%). However, a much larger percentage (61%) have not been involved in any type of support or community activity (Table 9). (Don't forget that these data represent the *online* chronically ill population). Some numbers of those with different diseases who are involved in using the various types of on and off-line support groups are much higher—29% of diabetics have been to

Table 9
Self-support and "community" actions taken by disease state
(among the online population)

Q.552 Have you ever done the following?

		Medical Condition				
Base:	All 10069 %	Diabetes 1126 %	Depression 2634 %	Arthritis 2271 %	Back Problems 1848 %	Migraine 1881 %
Attended a patient support meeting in person	11	29	21	17	15	15
Read or posted messages on a news group or bulletin board	25	35	33	30	29	32
Participated in forum or chat session	6	7	11	8	10	8
Subscribed to a list-serve or e-mail that focuses on health care	14	18	21	18	19	19
Used some kind of computer software to help track or manage you or your family's health	6	13	7	8	7	6
None of the above	**61**	43	47	55	56	52

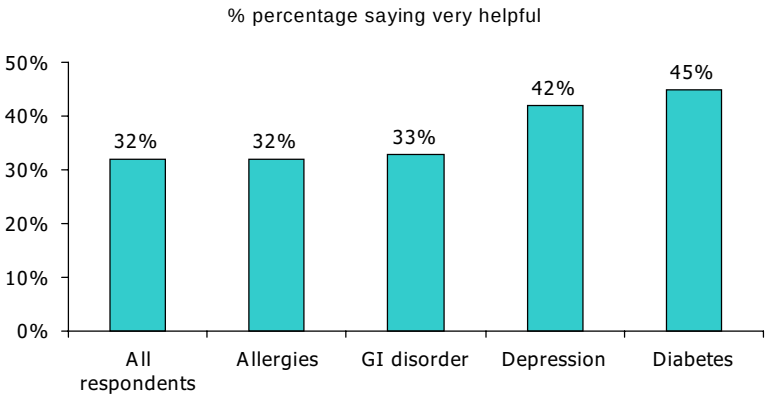
an in-person support group, 35% have used a newsgroup, and 13% have used some type of software to manage their condition. Similar, but not as large, percentages of those with arthritis, depression, back problems and migraine are also taking part in these activities.

However, there is a significant demand for software to help patients manage their condition. Although only 6% of the chronically ill are using that type of software, 26% of those not using it think that it would be very helpful for managing their overall health. Thirty-two percent (32%) think that it would be very helpful if that software allowed them to transmit personal health information to their physician over the Internet. Chart 17 shows that people with depression and diabetes are particularly interested in that capability.

Chart 17
A pent-up demand for supported self-care and communicating the results to physicians

Base: Have not used software to manage disease

Q. 554 If computer software were available that helped you transmit health information to your doctor via the Internet, how helpful would that be to you for managing your health overall



We know from the health services research literature that sick people who are involved in different types of support networks both have better health outcomes and are more satisfied with their health services. We also know that the chronically ill who manage their disease properly, whether on their own or in conjunction with organized support systems, can maintain good health status and avoid adverse acute events. This study shows that over 64% of the online chronically ill are using the Internet at least sometimes to get health information, but that comparatively few are using offline or on-line support mechanisms, such as support groups or management software. *Conclusion—there is an untapped market for the provision of both disease management software and ready access to support groups for the chronically ill on the Internet. As more chronically ill patients come online this market will grow.*

Conclusion

The Internet, and its use by consumers, has been the biggest change in health care in the last five years, and most of that change has come about in the last two years. The 10,000 Patients Study is the first survey to use the Internet as a research tool to create such a large and detailed sample of the chronically ill, but it will not be the last. We conclude with two simple messages:

1. The power of the Internet as a research tool—not to mention the increased consumerization of the patient which the Internet is helping to promote—shows that the chronically ill can no longer be approached as an undifferentiated group, looked at only by disease state or health status. The 10,000 Patients Study demonstrates enormous variation between and within disease states, ethnicities and a whole host of other demographic variables. These differences are evident even before we start to look at traditional marketing differentials as they apply to health care, such as awareness of different pharmaceutical products, health plans or hospitals. Anyone treating or marketing to the chronically ill had better become very familiar with that reality very quickly.

2. The Internet has already changed the way patients understand their conditions. But we are just scratching the surface of the Internet's ability to impact the health care utilization, behavior and outcomes of the chronically ill. No one involved in health care can afford *not* to concentrate on this phenomenon in the months and years to come.

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