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# Family Caregivers are Wired for Health

39% of U.S. adults provide care for a loved one, up from 30% in 2010, and many navigate health care with the help of technology

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# **Summary of Findings**

# 39% of U.S. adults are caregivers and many navigate health care with the help of technology

Four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30% in 2010. Caring for a loved one is an activity that cuts across most demographic groups, but is especially prevalent among adults ages 30 to 64, a group traditionally still in the workforce.

Caregivers are highly engaged in the pursuit of health information, support, care, and advice, both online and offline, and do many health-related activities at higher levels than non-caregivers.

# Caregivers and health activities

% of caregivers vs. non-caregivers who do the following health-related activities ...



**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults.

Indeed, being a caregiver is independently associated with key health-related activities. When controlling for age, income, education, ethnicity, and good overall health, caregivers are more likely than other adults to:

- Gather health information online, particularly about medical problems, treatments, and drugs.
- Gather health information offline, from clinicians, friends, family, and others who share the

same health condition.

- Go online specifically to try to figure out what condition they or someone else might have.
- Consult online reviews about drugs and other treatments.
- Track their own weight, diet, exercise routine, or other health indicator.
- Read online about someone else's personal health experience (which, in the case of caregivers, could be related to their own or their loved one's condition).
- Go online to find others with similar health concerns (again, there may be dual motivations to connect to find more information about handling caregiver stress, for example, or about their loved one's health challenges).

In a previous study by the Pew Research Center, 47% of U.S. adults say it is likely that, at some point in their life, they will be responsible for caring for an aging parent or another elderly family member.<sup>1</sup> Demographic patterns bear out this prediction: People ages 65 and older represented 12.4% of the U.S. population in the year 2000 but are expected to be 19% of the population by 2030.<sup>2</sup>

This survey finds that fully 75% of U.S. adults age 65 and older are living with a chronic condition such as high blood pressure, diabetes, or heart disease. Numerous studies have shown that the day to day management of these complex medical cases falls squarely on family members and friends who may not be trained.<sup>3</sup> But, as this study shows, caregivers are turning to every resource available to get the information and support they need.

## 39% of caregivers manage medications for a loved one; few use tech to do so

Thirty-nine percent of caregivers manage medications for a loved one, such as checking to be sure pills are taken properly or refilling prescriptions. Just 7% of caregivers use online or mobile tools, such as websites or apps, to do so.

<sup>&</sup>lt;sup>1</sup> "The Sandwich Generation," by Kim Parker and Eileen Patten. (Pew Research Center, January 2013). Available at: <u>http://www.pewsocialtrends.org/2013/01/30/the-sandwich-generation/</u>

<sup>&</sup>lt;sup>2</sup> Aging Statistics" (Administration on Aging, May 8, 2013). Available at: <u>http://www.aoa.gov/Aging\_Statistics/</u>

<sup>&</sup>lt;sup>3</sup> See, for example: "Home Alone: Family Caregivers Providing Complex Chronic Care," by Susan C. Reinhard, Carol Levine, and Sarah Samis. (AARP Public Public Policy Institute and the United Hospital Fund: October 2012). Available at: <u>http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html</u>

# Nine in ten caregivers own a cell phone and one-third have used it to gather health information

Eighty-seven percent of caregivers in the U.S. own a cell phone and, of those, 37% say they have used their phone to look for health or medical information online. This is a significantly higher than the rate of mobile health search among non-caregivers at the time of the survey: 84% of non-caregivers own a cell phone and 27% have used their phone to look online for health information.

### Most caregivers say the internet is helpful to them

When asked about the specific impact of the internet:

- 59% of caregivers with internet access say that <u>online resources have been helpful to their</u> <u>ability to provide care</u> and support for the person in their care.
- 52% of caregivers with internet access say that <u>online resources have been helpful to their</u> <u>ability to cope with the stress of being a caregiver</u>.

#### Who Are Caregivers?

Among all adults, the percent within each group who care for someone.



Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults. See Appendix for further details.

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## About this study

The results reported here come from a nationwide survey of 3,014 adults living in the United States. Telephone interviews were conducted by landline (1,808) and cell phone (1,206, including 624 without a landline phone). The survey was conducted by Princeton Survey Research Associates International. Interviews were done in English and Spanish by Princeton Data Source from August 7 to September 6, 2012. Statistical results are weighted to correct known demographic discrepancies. The margin of sampling error for the complete set of weighted data is ±2.4 percentage points. In this survey there are 1,171 respondents who are caregivers. Margin of error for results based on caregivers is ±4 percentage points.

The Pew Internet & American Life Project is an initiative of the Pew Research Center, a nonprofit "fact tank" that provides information on the issues, attitudes and trends shaping America and the world. The Project is nonpartisan and takes no position on policy issues. Support for the Project is provided by the Pew Charitable Trusts.

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# **Part One: Health Information Specialists**

# 39% of U.S. adults are caregivers

Bathing and dressing someone who needs help, driving to doctor appointments, sorting through paperwork, making sure this pill is taken with breakfast and that pill at bedtime—these hands-on, caregiving activities define the word "offline."

Yet, these days, caregivers are health information specialists. They have the safety, comfort, and even the life of a loved one in their hands. They are asked to perform a dizzying array of medical and personal tasks outside clinical settings and the stakes are very high.<sup>4</sup> Caregivers display what we at the Pew Research Center have identified as a core social impact of the internet: the ability to quickly gather information on a complex topic to make decisions.

This national survey by the Pew Research Center's Internet & American Life Project, supported by the California HealthCare Foundation, finds that caregivers are highly likely to gather advice from clinicians, family, friends, and peers; to track their own and their loved ones' health data; and to use the internet to research health conditions and treatments.

We find that being a caregiver is a special factor highly correlated with certain kinds of online information seeking. When controlling for age, income, education, ethnicity, and good overall health, caregivers are more likely than other internet users to:

- Gather health information online, particularly about medical problems, treatments, and drugs.
- Go online specifically to try to figure out what condition they or someone else might have.
- Consult online reviews about drugs and other treatments.
- Track their weight, diet, or exercise routine.
- Read online about someone else's personal health experience.
- Go online to find others with similar health concerns.

<sup>&</sup>lt;sup>4</sup> "Home Alone: Family Caregivers Providing Complex Chronic Care," by Susan C. Reinhard, Carol Levine, and Sarah Samis. (AARP Public Public Policy Institute and the United Hospital Fund: October 2012). Available at: <u>http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-</u> <u>chronic-care.html</u>

An aging population and a rise in the percentage of people living with chronic conditions means that the United States will need to increasingly rely on family caregivers to provide front-line health care. This study presents evidence about how caregivers currently gather, share, and create health information and support.

### Caring for both children and adults with significant health challenges

To measure the population of U.S. adults who provide care to loved ones with significant health issues, we asked a series of questions beginning with:

In the past 12 months, have you provided unpaid care to an adult relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

Some 36% of U.S. adults say they provided such unpaid care to an adult in the past year, up from 27% in 2010.

Those respondents were then asked:

Do you provide this type of care to just one adult, or do you care for more than one adult?

Two-thirds (66%) of that group say they care for one adult, which represents one-quarter of the U.S. population ages 18 and older. One-third (34%) of people who are helping an adult relative or friend say they care for more than one adult.

Half (47%) of those who care for adults say at least one is their parent or parent-in-law.

Separately, we asked:

In the past 12 months, have you provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term conditions, emotional or behavioral problems, or developmental problems, including mental retardation.

Eight percent of U.S. adults say the provided unpaid care to a child living with health challenges or disabilities, up from 5% in 2010.

In sum, 39% of U.S. adults are caregivers, up from 30% in 2010.<sup>5</sup> As the U.S. population ages and medical advances save and extend more lives, caregiving is likely to become a more common role than it has ever been before.

<sup>&</sup>lt;sup>5</sup> "Family Caregivers Online," by Susannah Fox and Joanna Brenner. (Pew Research Center: July 12, 2012). Available at: <u>http://www.pewinternet.org/Reports/2012/Caregivers-online.aspx</u>

### Who are caregivers?

Caregiving touches every segment of the population. Men and women are equally likely to be caregivers. People of all age groups provide care for loved ones, with a slightly higher percentage of those ages 30-64 saying they do so. Caregivers are more likely than other adults to be married and to be employed full time.

They are also more likely than non-caregivers to have gone through a recent health crisis or to have experienced a significant change in their physical health (including positive changes, such as quitting smoking). (See Appendix for detailed tables.)

This finding dovetails with clinical studies showing that the stress associated with caregiving has an independent, negative effect on people's health.<sup>6</sup>

### Caregivers are wide-ranging online health information consumers

Fully 86% of caregivers have internet access, compared with 78% of non-caregivers. And 84% of caregivers with internet access say they went online within the past year to research health topics such as medical procedures, health insurance, and drug safety. By comparison, 64% of non-caregivers with internet access say they did online health research in the past 12 months.

For brevity's sake, we will refer to those who research health topics as "online health seekers." When calculated as a percentage of all U.S. adults, not just internet users, 72% of caregivers are online health seekers, compared with 50% of non-caregivers.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will go online to look for health information. Living in a higher income household and reporting a higher level of education also increases someone's likelihood to do health research online. Being age 40 or older decreases the probability that someone will do this type of research online.

We tested four topics and found that these patterns held for each one, that is, being a caregiver has an independent effect on someone's likelihood to look online for information about:

- A specific disease or medical problem
- A certain medical treatment or procedure
- Drug safety or recalls
- A drug they saw advertised

<sup>&</sup>lt;sup>6</sup> See, for example: "Caregiver Health" (Family Caregiver Alliance). Available at: <u>http://www.caregiver.org/caregiver/jsp/content\_node.jsp?nodeid=1822</u>

In other words, caregivers' appetite for certain kinds of online health information is related to their home health care role, independent of other demographic factors.

#### **Health topics**

The % of online caregivers vs. other internet users who have looked online for information about each of the following topics

Have you ever looked online for information about	Online caregivers (n=1,003)	Other internet users (n=1,389)
A specific disease or medical problem	71*	44
A certain medical treatment or procedure	57*	34
How to lose weight or how to control your weight	31*	23
Health insurance (private, Medicare or Medicaid)	31*	21
Food safety or recalls	25*	15
Drug safety or recalls	25*	10
Caring for an aging relative or friend	25*	7
A drug you saw advertised	23*	11
Medical test results	22*	10
How to reduce your health care costs	15*	8
Pregnancy and childbirth	14*	10
Any other health issue	28*	15
Yes to any of the above topics	84*	64

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on caregivers.

**Note:** Asterisks indicate statistical significance between caregivers and other internet users.

## Most caregivers say the internet has been helpful to them

When asked if online resources are helpful:

- 59% of caregivers with internet access say that <u>online resources have been helpful to their</u> <u>ability to provide care and support for the person in their care.</u>
- 52% of caregivers with internet access say that <u>online resources have been helpful to their</u> ability to cope with the stress of being a caregiver.

Younger caregivers are more likely than older ones to report that the internet has been helpful to their ability to provide care and support: 70% of caregivers ages 18-29 say that, compared with 51% of those ages 50-64 years old. Two-thirds of male caregivers say the internet has been helpful in this way,

compared with 55% of female caregivers.

Younger caregivers are also more likely than older ones to say the internet has been helpful in coping with related stress: 70% of caregivers ages 18-29 say that, compared with 43% of those ages 50-64 years old. There was no difference between men and women on this question, nor were there any other notable demographic differences.

### Eight in ten online health inquiries start at a search engine

When asked to think about the last time they searched online for health information, 79% of caregivers who are online health seekers say they started at a search engine such as Google, Bing, or Yahoo. Fourteen percent started at a site that specializes in health information, such as WebMD. Just 1% say they started at a more general site like Wikipedia and another 1% started at a social networking site like Facebook. There are no significant differences between caregivers and non-caregivers when it comes to starting an online health inquiry at a search engine, specialized health website, or other site.

Overall, this matches what we found in our first health survey more than a decade ago. Then, as now, eight in ten online health seekers are likely to start at a general search engine when looking online for health or medical information.

# Caregivers are likely to say their last health search was on behalf of someone else

Caring for others' information needs is a common activity among all internet users. Half of all health searches are conducted on behalf of someone else. This long-standing pattern, measured in our first health survey in the year 2000, is particularly pronounced among caregivers: 63% say their last search was at least in part on behalf of someone else, compared with 47% of non-caregiver online health seekers.

# Nearly half of all caregivers have gone online to try to figure out a possible health diagnosis

Fully 46% of caregivers say they have gone online specifically to try to figure out what medical condition they or someone else might have. By comparison, 28% of all non-caregivers say they have done so. Note that these results are based on all U.S. adults, not just on internet users.

## **Online diagnosis**

% of caregivers vs. non-caregivers who have looked online to diagnose a condition

		Caregivers (N =1,171)	Non-caregivers (N =1,843)	
	All	46%	28%	
а	Men	43	22	
b	Women	48	<b>34</b> <sup>a</sup>	
	Age			
а	18-29	58 <sup>cd</sup>	41 <sup>cd</sup>	
b	30-49	56 <sup>cd</sup>	33 <sup>cd</sup>	
С	50-64	35 <sup>d</sup>	<b>24</b> <sup>d</sup>	
d	65+	22	9	
	Race/ethnicity			
а	White, Non-Hispanic	46	31 <sup>bc</sup>	
b	Black, Non-Hispanic	46	18	
С	Hispanic	39	18	
	Annual household income			
а	Less than \$30,000/yr	37	18	
b	\$30,000-\$49,999	46	<b>31</b> <sup>a</sup>	
С	\$50,000-\$74,999	<b>49</b> <sup>a</sup>	<b>39</b> <sup>a</sup>	
d	\$75,000+	61 <sup>abc</sup>	<b>44</b> <sup>ab</sup>	
	Education level			
а	Less than high school/high school grad	34	14	
b	Some College	48 <sup>a</sup>	<b>36</b> <sup>a</sup>	
С	College +	<b>57</b> <sup>a</sup>	43 <sup>a</sup>	

**Source:** Pew Internet Health Survey, August 7 – September 6, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 for results based on caregivers.

**Note:** Percentages marked with a superscript letter (e.g., <sup>a</sup>) indicate a statistically significant difference between that row and the row designated by that superscript letter, among categories of each demographic characteristic (e.g. age). Differences between caregivers and non-caregivers are statistically significant for every demographic category except for one: annual household income of \$50,000-\$74,999.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver greatly increases the probability someone will go online for a diagnosis. Living in a higher income household, being college educated, and being white each have an independent effect, increasing the likelihood of someone going online to try to figure out a medical condition. Being age 40 or older decreases the likelihood.

## Medication management is a significant challenge for many caregivers

A 2012 study by the AARP Public Policy Institute and the United Hospital Fund reported that nearly half of caregivers perform complex medical and nursing care at home, such as managing multiple medications, preparing meals to adhere to a special diet, and attending to wounds.<sup>7</sup> Caregivers reported that these tasks are difficult and many would like to receive training, particularly for medication management since the result of making a mistake is so dire.

In order to build on those findings, we asked caregivers:

Do you manage medications for the people you help care for, such as checking to be sure they are taken properly or refilling prescriptions, or is this not something you do for them?

Thirty-nine percent of caregivers say yes, they manage medications. Women are more likely than men to say they manage a loved one's medications: 47% of female caregivers do so, compared with 38% of male caregivers. Caregivers age 30 and older are more likely than those between the ages of 18 to 29 to say they manage medications. There are no significant differences among education, income, or ethnic groups.

Of those who manage medications, 18% say they use online or mobile tools, such as websites or apps, to do so, which translates to 7% of all caregivers. College graduates are the most likely group to use technology to track medications. Otherwise, there are no significant differences among caregivers along age, income, or ethnic lines.

# Nine in ten caregivers own a cell phone and one-third have used it to gather health information

Eighty-seven percent of caregivers in the United States own a cell phone and, of those, 37% say they have used their phone to look for health or medical information online. This is significantly higher than the rate of mobile health search among non-caregivers at the time of the survey: 84% of non-caregivers own a cell phone and 27% have used their phone to look online for health information.

## Paywalls do not deter most caregivers; few actually pay

Thirty percent of caregivers who look online for health information say they have been asked to pay for access to some type of health information they wanted to see online, compared with 22% of non-caregivers who are online health seekers. Caregivers are tenacious: 89% of those who hit a pay wall say they tried to find the same information somewhere else; 9% gave up; 1% paid the fee. By comparison, 76% of non-caregivers who hit a paywall tried to find the information somewhere else; 19% gave up; 4% paid the fee.

<sup>&</sup>lt;sup>7</sup> AARP Public Policy Institute and United Hospital Fund, 2012.

# **Part Two: Care and Conversation**

# Clinicians are a central resource for information or support during serious health episodes—and the care and conversation take place mostly offline

Many caregivers seem to leave no stone unturned when it comes to gathering health information, online or offline, in moments of calm or crisis. In order to capture a typical episode, we asked respondents to think about the last time they had a serious health issue and to whom they turned for help:

- 79% of all caregivers got information, care, or support from a doctor or other health care professional.
- 70% of caregivers got information or support from friends and family.
- 30% of caregivers got information or support from others who have the same health condition.

By comparison, non-caregivers are significantly less likely than caregivers to turn to each of these sources:

- 64% of all non-caregivers got information, care, or support from a doctor or other health care professional.
- 54% of non-caregivers got information or support from friends and family.
- 21% of non-caregivers got information or support from others who have the same health condition.

It is worth noting that caregivers are more likely than non-caregivers to tap all three sources both online and offline. For example, 28% of caregivers say they got online and offline advice and support from family and friends, compared with 14% of non-caregivers. Thirteen percent of caregivers were in contact with a clinician both online and offline, compared with 5% of non-caregivers. And 10% of caregivers obtained online and offline information and support from people who shared the same health condition, compared with 5% of non-caregivers.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability someone will get information from a health care professional, from friends and family, and from people who share the same health condition. In other words, there is a "caregiver effect" that extends to offline health information-gathering, too.

#### **Sources of Health Care Information**

Among all adults...

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issue, did you	Jou had a health get information, r support from	a doctor or other health care professional	friends and family.	others who have the same health condition.
Total Yes:	Caregivers	<b>79</b> %	<b>70</b> %	30%
	Non-Caregivers	64	54	21
Online	Caregivers Non-Caregivers	1	1 1	2 2
<b>S</b>	Caregivers	66	41	18
Offline	Non-Caregivers	58	38	14
Both Online	Caregivers	13	28	10
and Offline	Non-Caregivers	5	14	5
Not a Source	Caregivers	19	29	68
	Non-Caregivers	34	45	76

Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults.

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### Some seek counsel from fellow patients and caregivers

As noted above, 30% of caregivers sought information, care, or support from other people who share the same concerns during their last serious health episode. We have written about this phenomenon in detail in previous reports, such as "Peer-to-peer Health Care,"<sup>8</sup> and it is worth noting that caregivers are significantly more likely than non-caregivers to pursue this type of advice and support online.

<sup>&</sup>lt;sup>8</sup> "Peer-to-peer Health Care," by Susannah Fox. (Pew Research Center: Feb. 28, 2011). Available at: <u>http://www.pewinternet.org/Reports/2011/P2PHealthcare.aspx</u>

Indeed, caregivers are more likely than non-caregivers to engage in a range of online activities related to health:

#### The social life of health information

The % of online caregivers vs. other internet users who have interacted with their health online in the following ways

In the past 12 months, have you	Caregivers (n=1,003)	Non- caregivers (n=1,389)
Read or watched someone else's commentary or experience about health or medical issues online?	34*	20
Gone online to find others who might have health concerns similar to yours?	22*	11
Downloaded forms online or applied for health insurance online, including private insurance, Medicare, or Medicaid?	15*	9
Signed up to receive email updates or alerts about health or medical issues?	15*	7
Posted a health-related question online or shared your own personal health experience online in any way?	11*	6
Used the internet to do any of these	52*	33

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on caregivers.

Note: Asterisks indicate statistical significance between caregivers and non-caregivers.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will read others' commentary or experience about health or medical issues online. Being college-educated also increases someone's likelihood of taking in usergenerated health content, such as on a blog or in a video.

Of the 11% of caregivers who posted a health-related question or comment online:

- 45% say they posted comments or stories about personal health experiences
- 16% say they posted specific health questions
- 38% say they posted both

Fully 84% of caregivers who posted a comment, story, or question about their health say that they did so to reach a general audience of friends or other internet users. Eleven percent say they posted somewhere specifically to get feedback from a health professional. Two percent replied that they posted for both a general and a professional audience.

In addition, there is a "caregiver effect" when it comes to using the internet to find other people who share the same health concerns. When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will report going online to find peers. Education and ethnicity also play independent roles: being college educated or white also increase the likelihood that someone has gone online for this purpose. By contrast, being age 40 or older decreases the probability of going online to find others with the same health concerns.

## One in four online caregivers have consulted reviews of drugs or treatments

One area of online peer advice that continually confounds industry observers is the relative unpopularity of rankings and reviews of doctors, hospitals, and drugs. While 8 in 10 internet users say they have researched a general product or service online, only 2 in 10 internet users have looked up health care reviews.

Caregivers are potentially a ripe market for this type of service. They are more likely than non-caregivers to both read and write health care reviews, as shown in the table below.

Since caregivers' interest in drug information is particularly high, we tested the significance of the findings related to drug reviews. When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will consult online reviews of drugs or medical treatments. Being college educated or wealthier also increases the probability of this consumer-oriented behavior, while being age 40 and older decreases it.

#### **Health Care Reviews Online**

The percent of online caregivers vs. other internet users who have interacted with their health online in the following ways.

Have you ever	<b>Online Caregivers</b>	Other Internet Users
Consulted online reviews of particular drugs or medical treatments	24%	13%
Consulted online rankings or reviews of doctors or other providers	22	14
Consulted online rankings or reviews of hospitals or other medical facilities	19	10
Posted your experiences with a particular drug or medical treatment online	4	2
Posted a review online of a doctor	6	3
Posted a review online of a hospital	4	1
Have used the internet to do any of these	43	25

Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 3 percentage points for results based on internet users.

Note: All differences between online caregivers and other internet users are statistically significant.

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# **Part Three: Tracking for Health**

## Seven in ten caregivers track a health indicator for themselves

Fully 72% of caregivers track their own weight, diet, exercise routine, blood pressure, blood sugar, sleep patterns, headaches, or some other health indicator. By comparison, 63% of non-caregivers track some aspect of their health. When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will track a health indicator.

Education and age also play a role. Being college-educated increases someone's likelihood to track their weight, diet, or exercise routine. College-educated adults, however, are less likely to track other health indicators like blood pressure, blood sugar, sleep patterns, or headaches, possibly because they are less likely to be living with a chronic disease or other health condition. Being younger (between the ages of 18 and 39) is also independently associated with a lower likelihood to track other health indicators.

# One in three caregivers track health indicators or symptoms for their loved one

Thirty-one percent of caregivers keep track of their loved one's weight, diet, exercise routine, or other health indicators or symptoms. Female caregivers are more likely than their male counterparts to do so: 35% vs. 26%.

#### **Tracking health indicators**

*The % of caregivers vs. non-caregivers who track health indicators for themselves or others* 

Do you happen to track	Caregivers (n=1,171)	Non- caregivers (n=1,843)
Your own weight, diet or exercise routine?	64*	58
Any other health indicators or symptoms like blood pressure, blood sugar, sleep patterns, headcaches, or anything else?	39*	29
Any health indicators or symptoms for anyone besides yourself?	31	-
Any of the above	77*	63

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews =3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on caregivers.

**Note:** Asterisks indicate statistical significance between caregivers and non-caregivers.

## Tracking on paper, spreadsheet, mobile device—or just "in their heads"

When asked to think about how they track the health indicator they pay the most attention to, either for themselves or someone else, 44% of caregivers who track say they do so "in their heads," compared with 53% of non-caregivers who track.

Another 43% of caregivers who track say they use paper, like a notebook or journal, compared with 28% of non-caregivers who track.

Smaller groups say they use some form of technology to track their health data. Specifically:

- 8% of caregivers who track use a medical device, like a glucose meter
- 8% use an app or other tool on their mobile phone or device
- 6% use a computer program, like a spreadsheet
- 1% use a website or other online tool

There were no differences between caregivers and non-caregivers when it comes to the use of these types of technology.

# Caregivers are more likely than other trackers to share their notes with someone else

Fully 41% of caregiver-trackers say they share their tracking data with someone else, compared with 29% of non-caregivers who track.

Of those caregiver-trackers who share their notes:

- 56% share with a health or medical professional
- 17% share with a spouse/partner
- 14% share with another family member
- 8% share with a friend
- 10% share with their parent
- 6% share with their child
- 5% share with their sibling
- 1% share with members of a group, such as a church, community association, volunteer group, etc.
- 1% share with a personal trainer or health coach

• 5% share with someone else, not included in the above descriptions

These percentages are in line with non-caregivers' responses, with two exceptions: non-caregivers are more likely than caregivers to share notes with a spouse and less likely to share with a parent. We did not ask if the person that caregivers share the data with is, in fact, their care recipient.

### Caregivers are also likely to report tracking's impact

Among trackers, people actively caring for a loved one are more likely than others to say this activity has affected them:

- 52% of caregivers who track say it has affected their overall approach to maintaining their health or the health of someone they help care for, compared with 41% of non-caregiver trackers.
- 50% of caregivers who track say it has led them to ask a doctor new questions or to seek a second opinion, compared with 32% of non-caregiver trackers.
- 44% of caregivers who track say it has affected a decision about how to treat an illness or condition, compared with 26% of non-caregiver trackers.

Seven in ten caregivers who track (72%) agree with at least one of the three statements about the impact of health data tracking, compared with 56% of trackers who are not currently caring for a loved one.

# **Appendix**

#### **Demographics of caregivers**

Among all adults, the % within each group who care for someone.

		Caregivers
All a	adults ages 18+	39%
а	<b>Men</b> (n=1,337)	37
b	Women (n=1,677)	40
Rac	e/ethnicity	
а	White, Non-Hispanic (n=1,864)	39 <sup>°</sup>
b	Black, Non-Hispanic (n=497)	40 <sup>°</sup>
С	Hispanic (n=427)	32
Age		
а	<b>18-29</b> (n=478)	36
b	<b>30-49</b> (n=833)	42 <sup>d</sup>
С	<b>50-64</b> (n=814)	44 <sup>ad</sup>
d	<b>65+</b> (n=830)	30
Edu	cation attainment	
а	No high school diploma (n=269)	31
b	High school grad (n=830)	36
С	Some College (n=778)	44 <sup>ab</sup>
d	<b>College +</b> (n=1.115)	40 <sup>a</sup>
Ηοι	isehold income	
а	Less than \$30,000/yr (n=876)	36
b	<b>\$30,000-\$49,999</b> (n=523)	38
С	<b>\$50,000-\$74,999</b> (n=371)	46 <sup>a</sup>
d	<b>\$75,000+</b> (n=680)	43 <sup>a</sup>
Par	ent of minor	
а	Parent (n=785)	46 <sup>b</sup>
b	Non-parent (n=2,223)	36
Ηοι	isehold size	
а	1 adult (n=811)	32
b	2 adults (n=1,521)	40 <sup>a</sup>
С	3 or more adults (n=650)	<b>41</b> <sup>a</sup>

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults.

**Note:** Percentages marked with a superscript letter (e.g., <sup>a</sup>) indicate a statistically significant difference between that row and the row designated by that superscript letter, among categories of each demographic characteristic (e.g. age).

Caregivers are more likely than other adults to be married:

#### **Marital status**

Among all adults, % of caregivers and non-caregivers by marital status

	Caregivers (n=1,171)	Non-caregivers (n=1,843)
Married	53*	47
Living with a partner	8	9
Divorced	10	9
Separated	2	2
Widowed	5	7
Never been married	19	24*
Single (volunteered)	2	2

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on all adults.

Note: Asterisks indicate statistical significance between caregivers and non-caregivers.

Caregivers are more likely than other adults to be employed full time:

#### **Employment status**

Among all adults, % of caregivers and non-caregivers by employment status

	Caregivers (n=1,171)	Non-caregivers (n=1,843)
Full time	46*	40
Part time	14	11
Retired	15	20*
Not employed for pay	16	20*
Self/own business	2	2
Disabled	4	4
Student	1	1

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on caregivers.

Note: Asterisks indicate statistical significance between caregivers and non-caregivers.

Caregivers are as likely as non-caregivers to be living with a chronic condition. Caregivers are more likely than other adults to have gone through a recent health crisis or to have experienced a significant change in their physical health (including positive changes, such as quitting smoking).

### Personal health status

% of caregivers vs. non-caregivers who have experienced the following health issues

	Caregivers (n=1,171)	Non- caregivers (n=1,842)
Are you now living with any of the following health problems or conditions?		
High blood pressure	26	24
Asthma, bronchitis, emphysema, or other lung conditions	15	12
Diabetes or sugar diabetes	12	11
Heart disease, heart failure or heart attack	7	7
Cancer	4	3
Any other chronic health problem or condition not already mentioned	18	15
In the last 12 months, have you		
Personally faced a serious medical emergency or crisis?	14*	8
Experienced any significant change in your physical health, such as gaining or losing a lot of weight, becoming pregnant, or quitting smoking?	22*	16
Gone to the emergency room or been hospitalized unexpectedly	21*	14

**Source:** Pew Internet Health Tracking Survey, August 07 – September 06, 2012. Total number ("n") of interviews=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 4 percentage points for results based on caregivers. **Note:** Asterisks indicate statistical significance between caregivers and non-caregivers.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver is associated with a higher likelihood that someone will have had a serious medical emergency or been hospitalized in the past 12 months. If someone rates their health as excellent or reports a higher household income, the likelihood of a health emergency or hospitalization decreases.

When controlling for age, income, education, ethnicity, and good overall health, being a caregiver increases the probability that someone will have had a major health change. However, if someone is age 40 or older, white, living in a higher-income household, or report their health as excellent, they are less likely to report a recent health change.

# **Survey Questions**

# Health Tracking Survey 2012

Revised Topline 1

11/27/2012

Data for August 7–September 6, 2012

Princeton Survey Research Associates International for the Pew Research Center's Internet & American Life Project

Sample: n=3,014 national adults, age 18 and older, including 1,206 cell phone interviews Interviewing dates: 08.07.2012 - 09.06.2012

Margin of error is plus or minus 2 percentage points for results based on total [n=3,014] Margin of error is plus or minus 3 percentage points for results based on internet users [n=2,392] Margin of error is plus or minus 3 percentage points for results based on cell phone owners [n=2,581] Margin of error is plus or minus 3 percentage points for results based on online health seekers [n=1,741] Margin of error is plus or minus 4 percentage points for results based on caregivers [n=1,171]

Q1	Overall, how would you rate the quality of life for you and your family today? Would you
	say it is excellent, very good, good, fair or poor?

	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	don't know <sup>9</sup>	REFUSED
Current	17	26	32	19	5	*	*
April 2012 <sup>i</sup>	20	27	33	15	5	*	*
Feb 2012 <sup>ii</sup>	16	27	34	17	5	*	1
Dec 2011 <sup>III</sup>	17	26	34	17	5	*	1
August 2011 <sup>iv</sup>	17	26	33	17	6	*	*
May 2011 <sup>v</sup>	19	26	32	16	7	1	*
Sept 2010 <sup>vi</sup>	17	26	34	16	6	*	*
May 2010 <sup>vii</sup>	18	27	34	16	5	*	*
Sept 2009 <sup>viii</sup>	16	26	35	17	5	*	*
April 2009 <sup>ix</sup>	17	26	34	16	5	*	1
Dec 2008 <sup>x</sup>	15	26	34	19	5	*	1

<sup>&</sup>lt;sup>9</sup> For this question and many others throughout the topline, results for "Don't know" often reflect combined "Don't know" and "Refused" percentages. DK and REF are reported separately where available.

#### **INTUSE** Do you use the internet, at least occasionally?

EMLOCCDo you send or receive email, at least occasionally?

**INTMOB**Do you access the internet on a cell phone, tablet or other mobile handheld device, at least occasionally?<sup>10</sup>

	USES INTERNET	DOES NOT USE INTERNET
Current	81	19
August 2012 <sup>×i</sup>	85	15
April 2012	82	18
February 2012	80	20
December 2011	82	18
August 2011	78	22
May 2011	78	22
January 2011 <sup>xii</sup>	79	21
December 2010 <sup>xiii</sup>	77	23
November 2010 <sup>xiv</sup>	74	26
September 2010	74	26
May 2010	79	21
January 2010 <sup>xv</sup>	75	25
December 2009 <sup>xvi</sup>	74	26
September 2009	77	23
April 2009	79	21
December 2008	74	26
November 2008 <sup>xvii</sup>	74	26
August 2008 <sup>xviii</sup>	75	25
July 2008 <sup>xix</sup>	77	23
May 2008 <sup>xx</sup>	73	27
April 2008 <sup>xxi</sup>	73	27
January 2008 <sup>xxii</sup>	70	30
December 2007 <sup>xxiii</sup>	75	25
September 2007 <sup>xxiv</sup>	73	27
February 2007 <sup>xxv</sup>	71	29
December 2006 <sup>xxvi</sup>	70	30
November 2006 <sup>xxvii</sup>	68	32
August 2006 <sup>xxviii</sup>	70	30
April 2006 <sup>xxix</sup>	73	27
February 2006 <sup>xxx</sup>	73	27

<sup>&</sup>lt;sup>10</sup> The definition of an internet user varies from survey to survey. From January 2005 thru February 2012, an internet user is someone who uses the internet at least occasionally or sends/receives email at least occasionally (two-part definition with question wording "Do you use the internet, at least occasionally?" OR "Do you send or receive email, at least occasionally?"). Prior to January 2005, an internet user is someone who goes online to access the internet or to send and receive email (question wording "Do you ever go online to access the Internet or World Wide Web or to send and receive email?").

**SMPH** Some cell phones are called "smartphones" because of certain features they have. Is your cell phone a smartphone, such as an iPhone, Android, Blackberry or Windows phone, or are you not sure?<sup>11</sup>

Based on cell phone owners

%	current 53	Yes, smartphone	APRIL 2012 46	FEB 2012 45	MAY 2011 33
	40	No, not a smartphone	44	46	53
	6	Not sure/Don't know	10	8	14
	*	Refused	*	*	*
	[n=2,581]		[n=1,954]	[n=1,961]	[n=1,914]

**CELL1** Please tell me if you ever use your cell phone to do any of the following things. Do you ever use your cell phone to [INSERT ITEMS; ALWAYS ASK a-b FIRST in order; RANDOMIZE c-f]?<sup>12</sup>

		YES	NO	DON'T KNOW	REFUSED
a.	Send or receive email				
	Current [N=2,581]	50	50	*	0
	44		56	*	*
	April 2012 [N=1,954]	42	58	*	0
	August 2011 [N=1,948]	42	50		
	May 2011 [N=1,914]	38	62	0	*
	December 2010 [N=1,982]	38	62	*	*

Based on cell phone owners

CELL1 continued...

<sup>11</sup> Prior to the current survey, question wording was slightly different: "Some cell phones are called 'smartphones' because of certain features they have. Is your cell phone a smartphone or not, or are you not sure?"

<sup>12</sup> In May 2011, the question was asked of all Form B cell phone owners and Form A cell phone owners who said in CELL7 that they do more than make calls on their phone. The percentages shown here are based on all cell phone users, counting as "no" Form A cell phone owners who said in CELL7 they use their phones only for making calls. Prior to May 2011, question was asked of all cell phone owners. Prior to January 2010, question wording was "Please tell me if you ever use your cell phone or Blackberry or other device to do any of the following things. Do you ever use it to [INSERT ITEM]?" In January 2010, question wording was "Please tell me if you ever use your cell phone or Blackberry or other handheld device to do any of the following things. Do you ever use it to [INSERT ITEMS]?" For January 2010, December 2009, and September 2009, an answer category "Cell phone can't do this" was available as a volunteered option; "No" percentages for those trends reflect combined "No" and "Cell phone can't do this" results.

	_	YES	NO	DON'T KNOW	REFUSED
b.	Send or receive text messages				
	Current	80	20	*	0
	April 2012	79	21	*	*
	August 2011	76	24	*	*
	May 2011	73	27	0	0
	December 2010	74	26	*	*
	November 2010	71	28	*	0
	September 2010	74	26	*	0
	May 2010	72	28	0	0
	January 2010	69	31	*	0
	December 2009	68	32	*	0
	September 2009	65	35	*	0
	April 2009	65	35	*	0
	December 2007	58	42	0	
c.	Take a picture	82	18	*	*
	Current	82	18	0	0
	April 2012	73	27	*	0
	May 2011			*	*
	May 2010	76	24	T	
d.	Access the internet <sup>13</sup>				
	Current	56	44	0	0
	April 2012	53	46	*	*
	August 2011	48	52	*	0
	May 2011	44	56	0	0

<sup>&</sup>lt;sup>13</sup> In December 2007, item wording was "Access the internet for news, weather, sports, or other information"

.

	December 2010	42	58	*	*
	November 2010	39	61	*	*
	September 2010	39	61	*	0
e.	Look for health or medical information online <sup>14</sup>				
	Current	31	69	*	*
	April 2012	24	76	*	0
	September 2010	17	83	*	0
f.	Check your bank account balance or do any online banking <sup>15</sup>				
	Current	29	70	*	*
	April 2012	24	75	*	0
	May 2011	18	81	0	8

**Q2** Switching topics... In general, how would you rate your own health — excellent, good, only fair, or poor?

%	CURRENT	Excellent	SEPT 2010	DEC 2008	AUGUST 2006 33	DECEMBER 2002
	52	Good	49	51	47	48
	16	Only fair	16	14	14	12
	4	Poor	5	5	4	4
	*	Don't know	*	*	1	1
	*	Refused	*	*		

<sup>&</sup>lt;sup>14</sup> In April 2012, question was asked of cell phone owners who use the internet or email on their cell phone or download apps to their cell phone [N=953]; results are re-percentaged on all cell phone owners. In September 2010, question was a standalone question with the following question wording: "Do you ever use your cell phone to look up health or medical information?"

<sup>&</sup>lt;sup>15</sup> In April 2012, question was asked of Form A cell phone owners who use the internet or email on their cell phone or download apps to their cell phone [N=953]; results are re-percentaged on all Form A cell phone owners.

**Q3** Are you now living with any of the following health problems or conditions? First, [INSERT ITEM; RANDOMIZE a-e; ITEM f ALWAYS LAST]? And what about... [INSERT ITEM]? [IF NECESSARY: Are you now living with [INSERT ITEM]?]

		YES	NO	DON'T KNOW	REFUSED
a.	Diabetes or sugar diabetes				
	Current	11	88	*	*
	September 2010	11	89	*	*
	December 2008	10	90	*	1
b.	High blood pressure				
	Current	25	74	1	*
	September 2010	24	75	1	*
	December 2008	23	76	1	1
C.	Asthma, bronchitis, emphysema, or other lung conditions				
	Current	13	86	*	*
	September 2010	12	88	*	*
	December 2008	12	87	*	1
d.	Heart disease, heart failure or heart attack				
	Current	7	92	*	*
	September 2010	6	94	*	*
	December 2008	7	92	1	1
e.	Cancer				
	Current	3	96	*	*
	September 2010	2	97	*	*
	December 2008	3	96	1	1
f.	Any other chronic health problem or condition I haven't already mentioned				
	Current	16	83	*	*
	September 2010	17	82	*	1

#### **Q4** In the last 12 months, have you personally...[INSERT ITEMS IN ORDER]?

		YES	NO	DON'T KNOW	REFUSED
a.	Faced a serious medical emergency or crisis <sup>16</sup>				
	Current	11	89	*	*
	September 2010	12	88	*	*
b.	Gone to the emergency room or been hospitalized unexpectedly				
	Current	17	83	*	*
c.	Experienced any significant change in your physical health, such as gaining or losing a lot of weight, becoming pregnant, or quitting smoking <sup>17</sup>				
	Current	18	81	*	*
	September 2010	17	83	*	*

**qs** Thinking about the LAST time you had a serious health issue or experienced any significant change in your physical health... Did you get information, care or support from... [INSERT ITEM; RANDOMIZE]? [IF YES AND INTERNET USER: Did you interact with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline?]<sup>18</sup>

		YES, ONLINE	YES, OFFLINE	YES, BOTH	NO, NOT A SOURCE	DON'T KNOW	REFUSED
a.	A doctor or other health care professional						
	Current	1	61	8	28	1	1

<sup>&</sup>lt;sup>16</sup> In September 2010, question was asked as a standalone question. For December 2008 and earlier, trend question wording was: "And in the last 12 months, have you or has someone close to you faced a serious medical emergency or crisis?"

<sup>&</sup>lt;sup>17</sup> In September 2010, question was asked as a standalone question with the following question wording: "And in the last 12 months, have you experienced any other significant change in your physical health, such as gaining or losing a lot of weight, becoming pregnant, or quitting smoking?"

<sup>&</sup>lt;sup>18</sup> September 2010 question wording was slightly different: "Thinking about the LAST time you had a health issue, did you get information, care or support from... [INSERT; RANDOMIZE]? [IF YES AND INTERNET USER: Did you interact with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline?]"

	September 2010	1	66	4	29	*	*
b.	Friends and family						
	Current	1	39	20	39	*	1
	September 2010	1	42	12	44	1	*
c.	Others who have the same health condition						
	Current	2	15	7	73	1	1
	September 2010	1	16	4	77	2	*

[READ TO ALL:] On another topic...

**CARE2** In the past 12 months, have you provided UNPAID care to an adult relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

[IF R ASKS IF GIVING MONEY COUNTS, ASK:] Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things?

	CURRENT		SEPT 2010
%	36	Yes	27
	64	No	72
	*	Don't know	*
	*	Refused	*

**CARE3** Do you provide this type of care to just one adult, or do you care for more than one adult?

Based on those who provide unpaid care to adults

	CURRENT		SEPT 2010
%	66	One adult only	66
	34	Provide care to multiple adults	33
	*	Don't know	*
	*	Refused	*
	[n=1,085]		[n=790]

- **CARE4** [ASK IF PROVIDE UNPAID CARE TO ONE ADULT:] Is this person your parent or your mother-in-law or father-in-law, or not?<sup>19</sup>
- **CARE5** [ASK IF PROVIDE UNPAID CARE TO MULTIPLE ADULTS, DON'T KNOW OR REFUSED:] Are any of the adults you care for your parent or your mother-in-law or father-in-law, or not?<sup>20</sup>

Based on those who provide unpaid care to adults

%	CURRENT 47 53 *	Yes, parent or mother-in-law/father-in-law No, not a parent or mother-in-law/father-in-law Don't know	SEPT 2010 38 62 *
	*	Refused	*
	[n=1,085]		[n=790]

**CARE6** In the past 12 months, have you provided UNPAID care to any CHILD under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term conditions, emotional or behavioral problems, or developmental problems, including mental retardation.

	CURRENT		SEPT 2010
%	8	Yes	5
	92	No	94
	*	Don't know	*
	*	Refused	*

<sup>&</sup>lt;sup>19</sup> September 2010 question wording was slightly different: "Is this person a parent of yours, or not?"

<sup>&</sup>lt;sup>20</sup> September 2010 question wording was slightly different: "Are any of the adults you care for a parent of yours, or not?"

**CARE7** Do you manage medications for the people you help care for, such as checking to be sure they are taken properly or refilling prescriptions, or is this not something you do for them?

Based on all caregivers [N=1,171]

%	CURRENT 39 61 *	Yes, manage medications No, not something R does for them Don't know		
	0	Refused		

**CARE8** When managing their medication, do you use any online or mobile tools, such as websites or apps, to research or keep track of medications?

Based on caregivers who manage medications [N=468]

	CURRENT	
%	18	Yes
	82	No
	0	Don't know
	*	Refused

**CARE9a** Overall, would you say the internet has been HELPFUL or NOT HELPFUL in your ability to provide care and support for the person you are taking care of?

Based on caregivers who are also internet users [N=1,003]

	CURRENT	
%	59	Helpful
	36	Not helpful
	3	Don't know
	2	Refused

# **CARE9b** And overall, has the internet been HELPFUL or NOT HELPFUL in your ability to cope with the stress of being a caregiver?

Based on caregivers who are also internet users [N=1,003]

	CURRENT	
%	52	Helpful
	43	Not helpful
	3	Don't know
	3	Refused

**Q6** Now, we'd like to know if you've looked for information ONLINE about certain health or medical issues, either for yourself or someone else. Specifically, in the last 12 months, have you looked online for information about... [INSERT FIRST ITEM; ASK a-b FIRST IN ORDER THEN RANDOMIZE c-k; ITEM L ALWAYS LAST]? In the last 12 months, have you looked online for information about... [INSERT NEXT ITEM]?<sup>21</sup>

		YES, HAVE DONE THIS	NO, HAVE NOT DONE THIS	DON'T KNOW	REFUSED
a.	A specific disease or medical problem Current	55	44	*	*
b.	A certain medical treatment or procedure				
	Current	43	56	*	*
c.	Health insurance, including private insurance, Medicare or Medicaid Current	25	75	*	*
d.	Pregnancy and childbirth				
	Current	12	88	0	*
e.	Food safety or recalls				
	Current	19	80	*	*

Based on all internet users [N=2,392]

<sup>&</sup>lt;sup>21</sup> Prior to the current survey, question wording was: "Now, we'd like to ask if you've looked for information ONLINE about certain health or medical issues. Specifically, have you ever looked online for... [INSERT ITEM]?" List of items may vary from survey to survey. The phrase "in the last 12 months" was added in the 2012 survey.
f.	Drug safety or recalls				
	Current	16	84	*	*
g.	Medical test results				
	Current	15	85	*	*
h.	How to lose weight or how to control your weight				
	Current	27	73	*	*
i.	How to reduce your health care costs				
	Current	11	89	*	*
j.	Caring for an aging relative or friend				
	Current	14	86	*	*
k.	A drug you saw advertised				
	Current	16	84	*	*
I.	Any other health issue				
	Current	20	79	*	*
	Total yes to any item above	72			
	Total no to all items	28			

**Q7** Thinking about the LAST time you went online for health or medical information... Did you go online to look for information related to YOUR OWN health or medical situation or SOMEONE ELSE'S health or medical situation?

%	CURRENT 39 39	Own Someone else's	sept 2010 36 48	DEC 2008 41 43	AUGUST 2006 36 48	DEC 2002 37 49
	15	Both (VOL.)	11	9	8	8
	3	Don't know	4	4	8	7
	3	Refused	2	2		
	[n=1,741]		[n=1,655]	[n=1,356]	[n=1,594]	[n=1,017]

Based on online health seekers

**Q8** Still thinking about the LAST time you went online to look for health information... How did you begin looking? Did you start... [READ 1-4 IN ORDER]

Based on online health seekers [N=1,741]

	CURRENT	
%	77	At a search engine such as Google, Bing or Yahoo
	13	At a site that specializes in health information, like WebMD
	2	At a more general site like Wikipedia, that contains information on all kinds of topics, OR
	1	At a social network site like Facebook?
	3	(VOL.) Other (SPECIFY)
	2	(VOL.) Don't know
	2	(VOL.) Refused

There is no Question Q9.

**Q10** When looking for health information online, have you ever been asked to PAY for access to something you wanted to see on the internet?

Based on online health seekers [N=1,741]

	CURRENT	
%	26	Yes
	73	No
	1	Don't know
	*	Refused

**Q11** The last time you were asked to PAY to access health content online, what did you do? Did you... [READ 1-3; READ CATEGORIES IN REVERSE ORDER FOR HALF THE SAMPLE]

Based on online health seekers who have been asked to pay for health content online [N=456]

	CURRENT	
%	2	Pay for access
	83	Try to find the same information somewhere else
	13	Give up
	1	(VOL.) Other
	*	(VOL.) Don't know
	*	(VOL.) Refused

**Q12** Have you ever gone online specifically to try to figure out what medical condition you or someone else might have?

Based on online health seekers [N=1,741]

% 59 Yes 40 No \* Don't know \* Refused

**Q13** Did the information you found online lead you to think that this was a condition that needed the attention of a doctor or other medical professional, or that it was something you could take care of at home?

Based on online health seekers who have gone online to figure out what medical condition they or someone else might have [N=1,003]

	CURRENT	
%	46	Needed attention of doctor
	38	Could take care of at home
	11	Both/in-between (VOL.)
	4	Don't know
	1	Refused

### Q14 Did you happen to talk with a medical professional about what you found online?

Based on online health seekers who have gone online to figure out what medical condition they or someone else might have [N=1,003]

	CURRENT	
%	53	Yes
	46	No
	1	Don't know
	1	Refused

**Q15** Did a medical professional confirm what you thought the condition was with a medical diagnosis, did they offer a different medical opinion or diagnosis, or did you not visit a doctor or other medical professional for a diagnosis?

Based on online health seekers who have gone online to figure out what medical condition they or someone else might have [N=1,003]

	CURRENT	
%	41	Yes, confirmed
	18	No, did not confirm/offered different diagnosis
	35	Did not visit a doctor or medical professional for a diagnosis
	2	Confirmed part but not all of R's diagnosis (VOL.)
	1	Medical professional was unable to diagnose (VOL.)
	1	Don't know
	1	Refused

**Q16** Apart from looking for information online, there are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of online health-related activities you may or may not have done in the last 12 months. Just tell me if you happened to do each one, or not. (First,) in the last 12 months, have you... [INSERT ITEM; RANDOMIZE]? In the last 12 months, have you....[INSERT ITEM]?

		YES	NO	DON'T KNOW	REFUSED
a.	Signed up to receive email updates or alerts about health or medical issues				
	Current internet users [N=2,392]	11	89	*	*
b.	Read or watched someone else's commentary or personal experience about health or medical issues online				
	Current internet users	26	74	*	*
c.	Gone online to find others who might have health concerns similar to yours				
	Current internet users	16	84	*	*
d.	Downloaded forms online or applied for health insurance online, including private insurance, Medicare, or Medicaid				
	Current internet users	12	88	*	0

**Q17** Still thinking just about the last 12 months, have you posted a health-related question online or shared your own personal health experience online in any way?

Based on all internet users [N=2,392]



**Q18** And what was it that you posted or shared online? Was it a specific QUESTION about your health, a COMMENT or STORY about your personal health experience, or BOTH a question and a comment?

Based on internet users who have posted about a health topic or shared a health experience online [N=173]

CURRENT

%

- 19 Specific health question
  - 40 Comments/Stories about personal health experiences
  - 38 Both
  - 2 Neither/Something else (VOL.)
  - 1 Don't know
  - 0 Refused
- **Q19** And the LAST time you posted or shared health material online, did you post it somewhere specifically to get feedback from a health professional, or did you post it somewhere it would be read by a more general audience of friends or other internet users?

Based on internet users who have posted about a health topic or shared a health experience online [N=173]

%	CURRENT 11 78 4 5	Health professional More general audience Both (VOL.) Neither/Something else (VOL.)
	5	Neither/Something else (VOL.)
	1	Don't know

0 Refused

**Q20** Thinking again about health-related activities you may or may not do online, have you... [INSERT ITEM; RANDOMIZE]? (Next,) have you...[INSERT ITEM]?<sup>22</sup>

		YES	NO	DON'T KNOW	REFUSED
a.	Consulted online rankings or reviews of doctors or other providers <sup>23</sup>				
	Current internet users [N=2,392]	17	83	*	*
	Sept 2010 internet users [N=2,065]	16	84	0	*
b.	Consulted online rankings or reviews of hospitals or other medical facilities <sup>24</sup>				
	Current internet users	14	86	*	0
	Sept 2010 internet users	15	85	0	*
c.	Consulted online reviews of particular drugs or medical treatments				
	Current internet users	18	82	1	*
	Sept 2010 internet users	24	76	*	*
d.	Posted a review online of a doctor				
	Current internet users	4	96	0	0
	Sept 2010 internet users	4	95	0	*
e.	Posted a review online of a hospital				
	Current internet users	3	97	*	*
	Sept 2010 internet users	3	97	0	*
f.	Posted your experiences with a particular drug or medical treatment online				
	Current internet users	3	97	*	0

<sup>&</sup>lt;sup>22</sup> Current question was asked of all internet users. September 2010 trend question was also asked of all internet users, with items asked in rotated order. December 2008 trend question was asked of online health seekers, with the following question wording: "There are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of things you may or may not have ever done online related to health and medical issues. Just tell me if you happened to do each one, or not. Have you... [INSERT ITEM; ROTATE]?"

 <sup>&</sup>lt;sup>23</sup> December 2008 trend item wording was "Consulted rankings or reviews online of doctors or other providers"
 <sup>24</sup> December 2008 trend item wording was "Consulted rankings or reviews online of hospitals or other medical facilities"

Sept 2010 internet users	4	96	0	*

[READ TO CELL PHONE OWNERS:] Now thinking about how you might use your cell phone to help manage your health...

**Q21** Do you receive any TEXT updates or alerts about health or medical issues, such as from your doctors or pharmacists?

Based on cell phone owners who text message [N=1,896]



**Q22** On your cell phone, do you happen to have any software applications or "apps" that help you track or manage your health, or not?

Based on cell phone owners

	CURRENT		SEPT 2010
%	11	Yes	9
	88	No	90
	1	Don't know	1
	*	Refused	*
	[n=2,581]		[n=2,485]

**Q23** What kind of health apps do you currently have on your phone? [IF NECESSARY, CLARIFY: What health issue or topic do your apps deal with?] [DO NOT READ; PRECODED OPEN-END]

Based on those who have health apps on their cell phone [N=254]

%	CURRENT 38	Exercise, fitness, pedometer or heart rate monitoring (includes specific types of exercise like running, ab workouts, yoga, etc.)
	31	Diet, food, calorie counter
	12	Weight
	7	Period or menstrual cycle
	5	Blood pressure
	4	WebMD
	3	Pregnancy
	2	Blood sugar or diabetes
	2	Medication management (tracking, alerts, etc.)
	*	Mood
	*	Sleep
	14	Other (SPECIFY)
	6	Don't know
	*	Refused

Note: Total may exceed 100% due to multiple responses.

**Q24** Now thinking about your health overall... Do you currently keep track of your own weight, diet, or exercise routine, or is this not something you currently do?

	CURRENT	
%	60	Yes, keep track
	39	No, not something R currently does
	*	Don't know

\* Refused

**Q25** How about any other health indicators or symptoms? Do you happen to track your own blood pressure, blood sugar, sleep patterns, headaches, or any other indicator?

**CARE10** Turning again to the UNPAID care you provide to family, friends or others... Do you happen to keep track of any health indicators or symptoms for any of the people you care for?

Based on all caregivers [N=1,171]

	CURRENT	
%	31	Yes
	69	No
	*	Don't know
	*	Refused

**Q26** Thinking about the health indicator you pay the MOST attention to, either for yourself or someone else, how do you keep track of changes? Do you use... [READ 1-6]

Based on those who track a health indicator for themselves or others [N=2,183]

	CURRENT	
%	34	Paper, like a notebook or journal
	5	A computer program, like a spreadsheet
	1	A website or other online tool
	7	An app or other tool on your phone or mobile device
	8	A medical device, like a glucose meter
	49	Or do you keep track just in your head?
	2	(VOL.) Other (SPECIFY)
	2	(VOL.) Don't know
	1	(VOL.) Refused

Note: Total may exceed 100% due to multiple responses.

**Q27** How often do you update your records or notes about this health indicator? Do you do this on a regular basis, or only when something comes up or changes?

Based on those who track a health indicator for themselves or others [N=2,183]

	CURRENT	
%	46	Regular basis
	49	Only when something comes up or changes
	2	Don't know
	2	Refused

## **Q27a** Do you update this information... [READ 1-6]

Based on those who track a health indicator for themselves or others on a regular basis [N=1,053]

%	CURRENT 13	Several times a day
	23	About once a day
	15	3-5 days a week
	23	1-2 days a week
	16	Once or twice a month
	9	Less than once a month
	1	(VOL.) Don't know
	1	(VOL.) Refused

**Q28** Do you share these health tracking records or notes with anyone, either online or offline?

Based on those who track a health indicator for themselves or others [N=2,183]

%	CURRENT 34 65 *	Yes No Don't know
	*	Refused

# **Q29** Who do you share this information with? [PRECODED OPEN-END]

Based on those who share health tracking records or notes with others [N=761]

	CURRENT	
%	52	Health or medical professional (includes doctor, nurse, therapist, physician's assistant)
	22	Respondent's spouse/partner
	11	Other Family member/Family relationship
	8	Friend
	7	Respondent's parent
	7	Respondent's child
	5	Respondent's brother/sister/sibling
	1	Member of Group: Church, community association, volunteer group
	*	Personal trainer or health coach
	5	Other (SPECIFY)
	*	Don't know

0 Refused

Note: Total may exceed 100% due to multiple responses.

# **Q30** In which of the following ways, if any, has tracking this health indicator affected your own health care routine or the way you care for someone else? (First,) has it... [INSERT ITEM; RANDOMIZE]?

Based on those who track a health indicator for themselves or others [N=2,183]

		YES	NO	DON'T KNOW	REFUSED
a.	Affected a decision about how to treat an illness or condition	34	64	2	1
b.	Changed your overall approach to maintaining your health or the health of someone you help take care of	46	53	1	1
c.	Led you to ask a doctor new questions, or to get a second opinion from another doctor	40	59	*	1

[READ TO ALL:] A few last questions for statistical purposes only...

**INS1** Now I would like to ask you about any health insurance you CURRENTLY have that helps pay for the cost of health care. I'm going to read a list of a few types of health insurance, and I'd like you to tell me which of these you have, if any. (First,) are you now PERSONALLY covered by [INSERT ITEMS IN ORDER]?

[IF RESPONDENT NOT SURE WHICH INSURANCE IS INCLUDED: Please think about insurance plans that cover the costs of doctor and hospital bills IN GENERAL, and NOT those that cover ONLY dental or eye care or the costs of caring for specific diseases.]

[IF RESPONDENTS TRY TO TELL TYPE THEY HAVE INSTEAD OF GOING THROUGH THE LIST: I'm sorry but I have to ask about each type of insurance for the survey. Just tell me 'no' if you don't have this type.]

	YES	NO	DON'T KNOW	REFUSED
<ul> <li>Private health insurance offered through an employer or union [IF "NO": This could be insurance through a current job, a former job, your job or someone else's job.]</li> </ul>	51	47	1	1
<ul> <li>A private health insurance plan that you bought yourself</li> </ul>	17	82	1	1
<ul> <li>Medicaid, [IF STATE CALIFORNIA: Medi-Cal], or some other type of state medical assistance for low-income people</li> </ul>	14	85	1	*
<ul> <li>Medicare, the government program that pays health care bills for people over age 65 and for some disabled people</li> </ul>	21	78	1	*
Item E: Based on those who are not insured through				
private health insurance, Medicaid, or Medicare [N=526]				
e. Health insurance through ANY other source, including military or veteran's coverage	12	87	*	1

**INS2** Medicare is health insurance coverage most people receive when they turn 65 and are eligible for Social Security. This includes different kinds of health plans offered THROUGH the Medicare program — like the plans called H-M-Os. Are you now covered by Medicare or by ANY Medicare plan?

Based on those age 65 and older who are not covered by Medicare [N=82]

% 38 Yes, covered 56 No, not covered 3 Don't know 3 Refused **INS3** Does this mean you personally have NO health insurance now that would cover your doctor or hospital bills?

Based on those who are not covered by any health insurance or are undesignated [N=450]

	CURRENT	
%	91	I do NOT have health insurance
	7	I HAVE some kind of health insurance
	1	Don't know
	-	
	2	Refused

### SUMMARY OF INSURANCE STATUS (BASED ON INS1, INS2, INS3)

	CURRENT	
%	82	Insured
	18	Not insured

The remaining demographic questions are not reported in this topline.

# **Methods**

The 2012 Health Survey, sponsored by the Pew Research Center and the California HealthCare Foundation, obtained telephone interviews with a nationally representative sample of 3,014 adults living in the United States. Telephone interviews were conducted by landline (1,808) and cell phone (1,206, including 624 without a landline phone). The survey was conducted by Princeton Survey Research Associates International. Interviews were done in English and Spanish by Princeton Data Source from August 7 to September 6, 2012. Statistical results are weighted to correct known demographic discrepancies. The margin of sampling error for the complete set of weighted data is ±2.4 percentage points.

Details about design and data collection procedures, as well as survey results, can be found at:

http://www.pewinternet.org/Shared-Content/Data-Sets/2012/September-2012--Health-Tracking-(prelim).aspx

<sup>iii</sup> December 2011 trends based on the Gates Reading Habits Survey 2011, conducted November 16–December 21, 2011 among those age **16 or older** [n=2,986 people age 16+, including an oversample of 317 e-Reader only owners, 300 tablet computer only owners and 119 e-Reader/tablet computer owners].

<sup>iv</sup> August 2011 trends based on the August Tracking Survey 2011, conducted July 25 – August 26, 2011 [n=2,260, including 916 cell phone interviews].

<sup>v</sup> May 2011 trends based on the Spring Tracking Survey 2011, conducted April 26 – May 22, 2011 [N=2,277, including 755 cell phone interviews].

<sup>vi</sup> September 2010 trends based on the September Health Tracking Survey 2010, conducted August 9 – September 13, 2010 [N=3,001, including 1,000 cell phone interviews].

<sup>vii</sup> May 2010 trends based on the Spring Change Assessment 2010 survey, conducted April 29 – May 30, 2010 [N=2,252, including 744 cell phone interviews].

<sup>viii</sup> September 2009 trends based on the September Tracking 2009 survey, conducted August 18 – September 14, 2009 [N=2,253, including 560 cell phone interviews].

<sup>ix</sup> April 2009 trends based on the Spring 2009 Tracking survey, conducted March 26-April 19, 2009 [N=2,253, including 561 cell phone interviews].

<sup>x</sup> December 2008 trends based on the Fall Tracking survey, conducted November 19-December 20, 2008 [N=2,253, including 502 cell phone interviews]. Trends do not include California oversample.

<sup>xi</sup> August 2012 trends based on the Civic Engagement Tracking Survey 2012, conducted July 16–August 7, 2012 [N=2,253, including 900 cell phone interviews].

<sup>xii</sup> January 2011 trends based on the Pew Internet Project/Project for Excellence in Journalism/Knight Foundation "Local News survey," conducted January 12-25, 2011 [N=2,251, including 750 cell phone interviews].

<sup>xiii</sup> December 2010 trends based on the Social Side of the Internet survey, conducted November 23–December 21, 2010 [N=2,303, including 748 cell phone interviews].

x<sup>iv</sup> November 2010 trends based on the Post-Election Tracking Survey 2010, conducted November 3-24, 2010 [N=2,257, including 755 cell phone interviews].

<sup>&</sup>lt;sup>i</sup> April 2012 trends based on the Spring Tracking Survey 2012, conducted March 15–April 3, 2012 [N=2,254, including 903 cell phone interviews].

<sup>&</sup>lt;sup>ii</sup> February 2012 trends based on the Winter Tracking Survey 2012, conducted January 20–February 19, 2012 [N=2,253, including 901 cell phone interviews].

<sup>xv</sup> January 2010 trends based on the Online News survey, conducted December 28, 2009 – January 19, 2010 [N=2,259, including 562 cell phone interviews].

<sup>xvi</sup> December 2009 trends based on the Fall Tracking "E-Government" survey, conducted November 30 – December 27, 2009 [N=2,258, including 565 cell phone interviews].

<sup>xvii</sup> November 2008 trends based on the Post-Election 2008 Tracking survey, conducted November 20-December 4, 2008 [N=2,254].

xviii August 2008 trends based on the August Tracking 2008 survey, conducted August 12-31, 2008 [N=2,251].

xix July 2008 trends based on the Personal Networks and Community survey, conducted July 9-August 10, 2008 [N=2,512, including 505 cell phone interviews]

<sup>xx</sup> May 2008 trends based on the Spring Tracking 2008 survey, conducted April 8-May 11, 2008 [N=2,251].

<sup>xxi</sup> April 2008 trends based on the Networked Workers survey, conducted March 27-April 14, 2008. Most questions were asked only of full- or part-time workers [N=1,000], but trend results shown here reflect the total sample [N=2,134].

 $^{xxii}$  January 2008 trends based on the Networked Families survey, conducted December 13, 2007-January 13, 2008 [N=2,252].

<sup>xxiii</sup> December 2007 trends based on the Annual Gadgets survey, conducted October 24-December 2, 2007 [N=2,054, including 500 cell phone interviews].

<sup>xxiv</sup> September 2007 trends based on the Consumer Choice survey, conducted August 3-September 5, 2007 [N=2,400, oversample of 129 cell phone interviews].

<sup>xxv</sup> February 2007 trends based on daily tracking survey conducted February 15-March 7, 2007 [N=2,200].

<sup>xxvi</sup> December 2006 trends based on daily tracking survey, conducted November 30 - December 30, 2006 [N=2,373].

<sup>xxvii</sup> November 2006 trends based on Post-Election tracking survey, conducted Nov. 8-Dec. 4, 2006 [N=2,562]. This includes an RDD sample [N=2,362] and a cell phone only sample [N=200]. Results reflect combined samples, where applicable.

xxviii August 2006 trends based on daily tracking survey, conducted August 1-31, 2006 [N=2,928].

xix April 2006 trends based on the Annual Gadgets survey, conducted Feb. 15-Apr. 6, 2006 [N=4,001].

<sup>XXX</sup> February 2006 trends based on the Exploratorium Survey, conducted Jan. 9-Feb. 6, 2006 [N=2,000].