### Health Care Callback Survey

Topline

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Princeton Survey Research Associates for the Pew Internet & American Life Project

Sample: n = 500 Internet users who go online for health care information (re-interview)

Interviewing dates: June 19 – August 6, 2001

Margin of error is plus or minus 4 percentage points for results based on the full sample

Note: All results presented in this survey are based on Internet users who go online for health or medical information.

#### [Q1 AND Q2c FOR SCREENING PURPOSES]

Pirst, do you ever go online to access the Internet or World Wide Web or to send and receive email?

% 100 Yes

-- No

-- Don't know/Refused

Q2 Please tell me if you ever do any of the following when you go online.

Do you ever ...

		YES, DO THIS	NO, HAVE NEVER DONE THIS	DON'T KNOW/ REFUSED
a.	Send or read email	98	2	0
b.	Check weather reports and forecasts	73	27	0
С.	Look for health or medical information online	100		

How often do you use the Internet to look for advice or information about health or health care — every day, several times a week, several times a month, every few months, or less often than that?

% 4 Every day

13 Several times a week

25 Several times a month

Every few months

15 Less often

0 Don't know/Refused

We're interested in the different things that might lead a person to look for health information online. Please tell me if each of the following has ever led YOU personally to look for health information online. (First/Next)... Is this something that has led you to look for health information online, or not?

		YES	NO	DON'T KNOW/ REFUSED
a.	Being diagnosed with a new health problem of your own	58	42	0
b.	Dealing with an ongoing medical condition, like diabetes or high blood pressure	47	53	0
C.	Someone you know being diagnosed with a medical condition	81	19	0
d.	Being a caregiver to someone else	38	62	*
e.	Deciding to change your diet or exercise habits	46	54	*
f.	Being prescribed a new medication or course of treatment	56	44	0
g.	Having unanswered questions after a doctor's visit	47	53	0
h.	Not having time to visit your physician	14	86	*
i.	Being unable to get a referral or an appointment with a specialist	8	92	*

- Overall, how much has getting health and medical information on the Internet improved the way you take care of your health a lot, some, only a little, or not at all?
  - % 10 A lot
    - 51 Some
    - 27 Only a little
    - 12 Not at all
    - 0 Don't know/Refused
- When you go online to look for information about health or health care, how often are you able to find the information you are looking for? Would you say...?
  - % 23 Always
    - Most of the time
    - 16 Only sometimes
    - 2 Hardly ever
    - 0 Never
    - \* Don't know/Refused

In general, how much of the health information you see on the Internet do you think you can believe – all or almost all of it, most of it, only some of it, or none at all?

- % 20 All or almost all
  - 52 Most
  - 27 Only some
  - 1 None at all
  - 1 Don't know/Refused
- Have you ever visited a health web site and thought that some of the information provided there was wrong or misleading?
  - % 28 Yes
    - 69 No
    - 3 Don't know/Refused
- We're interested in why people sometimes decide NOT to use health information they find online. Have you ever decided NOT to use information you found on an online web site because...

		YES	NO	DON'T KNOW/ REFUSED
a.	The site appeared sloppy or unprofessional	29	70	1
b.	You couldn't determine the source or author of the information	42	57	1
C.	You couldn't determine when the information was last updated	37	61	1
d.	The site was too commercial and seemed more concerned with selling products than providing accurate information	47	52	1
e.	The site lacked the endorsement of an independent organization you trust	30	69	2
f.	The information disagreed with your own doctor's advice	20	78	2
g.	The site contained other information you knew to be wrong	26	72	1

Now I'm going to read you a list of things people sometimes do when getting health care advice or information on the Internet. As I read each one, please tell me if this is something YOU personally have ever done. (First,) Have you ever used the internet to...?

		YES, HAVE DONE THIS	NO, HAVE NOT DONE THIS	DON'T KNOW/ REFUSED
a.	Look for information about a particular illness or condition	93	7	*
b.	Look for information about a mental health issue like depression or anxiety	39	60	*
C.	Look for information about a particular doctor or hospital	32	68	0
d.	Look for information about alternative or experimental treatments or medicines	48	52	0
e.	Look for information about a sensitive health topic that is difficult to talk about	33	67	*
f.	Look for information or advice about nutrition, exercise, or weight control	65	35	0
g.	Look for information about prescription drugs	64	36	0
h.	Diagnose or treat a medical condition on your own, without consulting your doctor	18	82	0
i.	Gather information BEFORE visiting your doctor	55	45	0

- In general, when you look for health information online, is there a particular site you usually go to, or do you visit or browse different sites?
  - % 14 One favorite site
    - 86 Visit different sites
    - \* Don't know/Refused
- What is the name of this site?

# Based on those who use one favorite web site for online health information [N = 69]

- % 35 WebMD
  - 9 MayoClinic.com
  - 4 NIH.gov or National Institutes of Health or other "dot-gov" sites
  - 4 Intelihealth.com
  - 1 PubMed or Medline
  - 1 DrKoop.com
  - 33 Other
  - 12 Don't know/Refused

### Based on those who use one favorite web site for online health information [N = 69]

- % 25 Find it through an Internet search
  - Hear about it from a friend or family member
  - 3 Hear about it from a doctor or other health care provider
  - 25 See an advertisement for it
  - 12 Just come across it while surfing the Web
    - 7 Other
    - 3 Don't know/Refused

# What is the MAIN reason you usually look for health information at this particular site? [RECORDED UP TO 2 RESPONSES]

# Based on those who use one favorite web site for online health information [N = 69]

- % 30 The site is easy to use or navigate
  - 13 The site was recommended by friends or family
  - 6 The site was recommended by a doctor or other health care provider
  - 25 I trust the advice and information I get at this site
  - 14 The site has a lot of information about a particular health condition I'm interested in
  - 7 The site has certain features I like
  - 4 Other
  - 1 Don't know/Refused
- Q15 Have you ever looked into the privacy policy of this web site?

# Based on those who use one favorite web site for online health information [N = 69]

- % 19 Yes
  - 80 No
  - 1 Don't know/Refused
- Q16 Have you ever looked to see who provides the information on this site?

# Based on those who use one favorite web site for online health information [N=69]

- % 55 Yes
  - 42 No
  - 3 Don't know/Refused

O17 How often do you look to see when information on the site was last updated? Do you do this...

Based on those who use one favorite web site for online health information [N = 69]

6

- % 23 Every time you visit
  - 29 Sometimes
  - 19 Hardly ever
  - 26 Never
  - 3 Don't know/Refused
- About how many different web sites do you usually visit or browse when looking for health information?

Based on those who use more than one site for online health information [N = 429]

- % 47 Two or three
  - 31 Four or Five
  - 14 Six to Ten
  - 3 11 to 20
  - 3 More than 20
  - 2 Don't know/Refused
- How do you usually find or search for health-related web sites? Do you...

Based on those who use more than one site for online health information [N = 429]

- % 62 Use a search engine such as Google or Yahoo
  - 8 Go to a site that specializes in health information, like DrKoop.com or WebMD
  - Go to a more general site like MSN or the AOL homepage that contains information on all kinds of topics
  - 2 Other
  - 1 Don't know/Refused

420 How often do you look into the privacy policies of the health web sites you visit? Do you do this...

# Based on those who use more than one site for online health information [N = 429]

- % 6 Always
  - 11 Most of the time
  - 19 Only sometimes
  - 32 Hardly ever
  - 31 Never
  - 1 Don't know/Refused
- Q21 How often do you look to see who provides the information on the health web sites you visit? Do you do this...

### Based on those who use more than one site for online health information [N = 429]

- % 29 Always
  - 29 Most of the time
  - 23 Only sometimes
  - 12 Hardly ever
  - 7 Never
  - 0 Don't know/Refused
- How often do you look to see when the information on a health web site was last updated? Do you do this...

# Based on those who use more than one site for online health information [N = 429]

- % 27 Always
  - 28 Most of the time
  - 20 Only sometimes
  - 11 Hardly ever
  - 14 Never
  - 0 Don't know/Refused

- When was the LAST time you went online to look for advice or information about health or health care today, within the last week, in the last month, in the last six months, or before that?
  - % 4 Today
    - 22 In the last week
    - 37 In the last month
    - 32 In the last six months
    - 5 Before that
    - 1 Don't know/Refused
- Q24 Did you go online from HOME, from WORK, or from someplace else?
  - % 80 From home
    - 16 From work
    - 4 From someplace else
    - \* Don't know/Refused
- Were you looking for health information for yourself, for your spouse or partner, for a child, for a parent, for another relative, or for someone else?
  - % 47 Yourself
    - 10 Your spouse or partner
    - 10 Child
    - 9 Parent
    - 10 Another relative
    - 1 Someone else
    - 8 Friend or Co-worker (VOL)
    - 2 Patient or Client (VOL)
    - 2 Research (VOL)
    - 1 Don't know/Refused
- What TYPE of information were you looking for the last time you went online for health information? Were you looking for...
  - % 62 Information about a specific illness or condition
    - 14 Information about a specific doctor, hospital, or medicine
    - 10 Information about a specific surgical or diagnostic procedure
    - 14 Information about fitness, nutrition, or general wellness
    - 10 Basic health care news
    - 1 Other
    - \* Don't know/Refused

### Based on those who got information about a particular illness [N = 312]

- % 12 Cancer
  - 6 Diabetes
  - 5 Heart condition
  - 4 Arthritis
  - 3 Mental health
  - 3 Digestive condition
  - 2 Skin condition
  - 2 Kidney condition
  - 2 Lung condition
  - 2 Alzheimer's
  - 2 Osteoporosis
  - 1 Blood condition
  - 42 Other
  - 4 Don't know/Don't remember/Don't know the name
  - 10 Refused/No answer

### Where you mainly looking for information about...? [RECORDED UP TO 2 RESPONSES]

### Based on those who got information about a particular illness [N = 312]

- % 40 SYMPTOMS that might be related to certain health conditions
  - 50 What MEDICATIONS or TREATMENTS are available to treat a particular illness
  - 21 What HAPPENS to people who have a specific illness or medical condition
  - What happens to people who receive a certain type of TREATMENT or MEDICATION
  - 2 Research
  - 1 General information
  - 2 All of the above
  - 1 Other
  - 2 Don't know/Refused
- O29 Still thinking about the LAST time you went online to look for health information... How did you begin your search? Did you start...
  - % 55 At a search engine such as Google or Yahoo
    - 15 At a site that specializes in health information, like DrKoop.com or WebMD
    - At a more general site like MSN or the AOL homepage that contains information on all kinds of topics
    - \* Doctor/Health Insurance
    - 1 Surfing/Knew where to go
    - 1 Newspaper/Advertisement
    - 0 Other
    - 2 Don't know/Refused

Q30	When you	got vour sea	arch results.	how did	vou decide	what web	site to v	visit first?	Did you.	
200	Willell you	Sot Jour so	arcir resures,	mon ara	you accide	Willat WCO	DILC LO	vibit illibt.	Dia you.	• •

#### Based on those who began with a search engine like Google or Yahoo [N = 277]

10

- % 45 Start at the top of the search results list and work your way down
  - Read the explanation of each web site and choose the one that best fit what you were looking for
  - 12 Click on a site whose name and sponsor you recognized
  - \* Other
  - 2 Don't know/Refused
- O31 Did you find the information you were looking for at this first web page, or did you have to go on to other web sites to find the information you needed?

# Based on those who did not use a search engine to look for health information [N=203]

- % 53 Found info on this site
  - Went to other sites
  - 10 Don't know/Refused
- Overall, about how many web sites did you visit during your last search for health information online? ...
  - % 17 One
    - 43 Two to Three
    - 22 Four to Five
    - 11 Six to Ten
    - 3 11 to 20
    - 2 More than 20
    - 1 Don't know/Refused
- And altogether, about how much time did you spend online during your last search for health information? ...
  - % 12 Less than 15 minutes
    - 27 More than 15 minutes but less than half an hour
    - 35 Between half an hour and an hour
    - 19 One to two hours
    - 7 More than 2 hours
    - 0 Don't know/Refused

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% 14 Yes

86 No

0 Don't know/Refused

#### Who did you get advice from? [RECORDED UP TO 2 RESPONSES]

### Based on those who got advice before they began their search [N = 71]

- % 38 Friends
  - 38 Family members
  - A health care provider, such as a doctor or nurse
  - 8 Other
  - 0 Don't know/Refused
- O36 Did you follow this advice when you went online to look for health information, or did you mostly find information on your own?

### Based on those who got advice before they began their search [N = 71]

- % 49 Followed others' advice
  - 41 Found information on own
  - 10 Both/Combination of above (VOL)
  - 0 Don't know/Refused
- At any point during your online search, did you communicate with...?

		YES	NO	KNOW/ REFUSED
a.	The webmaster of a particular health web site	3	96	1
b.	Members of an online support group	3	97	0
C.	An online health care professional, like a doctor or nurse	3	97	0

DON'T

- Which of the following best describes how your online search for health information ended...
  - % 78 You found most or all of the information you were looking for
    - 6 You couldn't find the information you were looking for and gave up
    - 14 You just ran out of time and had to stop looking
    - 1 Other
    - Don't know/Refused

We'd like to know a little more about the health information you found online... Did this information come from a web site you were already familiar with or had used in the past, or did it come from a web site you had never heard of before?

#### Based on those who found information they were looking for [N = 391]

- % 51 Site familiar with
  - 44 Site never heard of before
  - 3 Both (VOL)
  - 2 Don't know/Refused
- Q40 Did the health information you found online have a MAJOR impact on your own health care routine or the way you care for someone lese, a MINOR impact, or no impact at all?

### Based on those who found information they were looking for [N = 391]

- % 16 Major impact
  - 52 Minor impact
  - 31 No impact at all
  - 1 Don't know/Refused
- In which of the following ways, if any, did the information you found online affect your own health care routine or the way you care for someone else? (First,) did the information you found online...?

#### Based on those who found information they were looking for [N = 391]

	_	YES	NO	DON'T KNOW/ REFUSED
a.	Affect a decision about how to treat an illness or condition	44	56	*
b.	Change your overall approach to maintaining your health or the health of someone you help take care of	34	65	*
C.	Change the way you cope with a chronic condition or manage pain	25	74	1
d.	Affect a decision about whether to see a doctor	17	83	1
e.	Lead you to ask a doctor new questions, or to get a second opinion from another doctor	38	62	0
f.	Change the way you think about diet, exercise, and stress	30	69	1

Did the health information you found online mostly AGREE WITH what you already thought or knew, or did it mostly DISAGREE with what you already thought?

#### Based on those who found information they were looking for [N = 391]

- % 89 Mostly agreed
  - 4 Mostly disagreed
  - 7 Both equally/Neither (VOL)
  - 1 Don't know/Refused
- Odd you learn anything NEW from the information you found online, or didn't you learn anything new?

### Based on those who found information they were looking for [N = 391]

- % 81 Yes, learned something new
  - 19 No, did not
  - \* Don't know/Refused
- Did the web sites you visited provide mostly the SAME information, or did you find DIFFERENT information at different web sites?

# Based on those who visited multiple web sites and found the information they were looking for [N = 318]

- % 67 Provided same information
  - 30 Provided different information
  - 3 Don't know/Refused
- Did the fact that they provided mostly the same information give you more confidence in these web sites, or not? If YES: Did it give you a LOT more confidence, or only a LITTLE more?

### Based on those who visited multiple web sites that provided mostly the same information [N = 214]

- % 49 Yes, a lot more confidence
  - 38 Yes, a little more confidence
  - 11 No
  - 2 Don't know/Refused

Did the fact that they provided different information give you less confidence in these web sites, or not? If YES: Did it give you a LOT less confidence, or only a LITTLE less?

# Based on those who visited multiple web sites that provided mostly different information [N = 96]

- % 6 Yes, a lot less confidence
  - 17 Yes, a little less confidence
  - 76 No
  - 1 Don't know/Refused
- Did you later talk too a doctor or other health care professional about the information you found online, or didn't you happen to do this?

### Based on those who found information they were looking for [N = 391]

- % 37 Talked to a doctor/nurse/medical professional
  - 63 Didn't talk to
  - 1 Don't know/Refused
- When you talked with a doctor or other health care professional, how interested were they in hearing about the information you found online? Were they...?

### Based on those who talked to a doctor about the information they got online [N = 143]

- % 31 Very interested
  - 48 Somewhat interested
  - 10 Not too interested
  - 3 Not at all interested
  - 8 Don't know/Refused
- Q49 Did the doctor or other health care professional you talked with mostly AGREE or DISAGREE with the information you found online?

# Based on those who talked to a doctor about the information they got online [N = 143]

- % 82 Agreed
  - 4 Disagreed
  - 8 Both/Neither (VOL)
  - 6 Don't know/Refused

15

What is the MAIN reason you didn't later talk with a doctor or other health care professional about the information you found online?

### Based on those who did not talk to a doctor about the information they got online [N = 245]

- % 43 It wasn't a health issue that required a visit or phone call with a doctor
  - 12 You didn't think the information was worth mentioning
  - 2 You forgot to bring it up
  - 2 You didn't think your doctor would listen to you
  - 2 It was too difficult to talk about
  - 17 Information was for someone else
  - 8 Wanted to see if information agreed with doctor (VOL)
  - 4 Research (VOL)
  - 7 No time/Haven't been back to doctor (VOL)
  - 3 Don't know/Refused
- Overall, would you say it was EASY or DIFFICULT to find online the health information you were looking for? Was it VERY (easy/difficult) or only SOMEWHAT (easy/difficult)?

#### Based on those who found information they were looking for [N = 391]

- % 61 Very easy
  - 33 Somewhat easy
  - \* Very difficult
  - 5 Somewhat difficult
  - 1 Both/Neither (VOL)
  - Don't know/Refused
- Do you currently have any health-related web sites "bookmarked" or saved as a "favorite place" so you can go back to them on a regular basis?
  - % 29 Yes
    - 70 No
    - 1 Don't know/Refused
- Have you ever set up a personal profile at a favorite health web site, or customized a health web site so you receive only the information you're most interested in?
  - % 8 Yes
    - 92 No
    - \* Don't know/Refused

Q54		Have you ever participated in an online support group or e-mail list for people concerned about a particular health or medical issue?				
	%	9 91 *	Yes No Don't know/Refused			
Q55		e you ev lical upo	ver signed up for an electronic newsletter that e-mails the latest health news or lates?			
	%	19 81 1	Yes No Don't know/Refused			
Q56			re you or has anyone you know been SERIOUSLY HARMED by following vice or health information you found on the Internet?			
	%	2 98 *	Yes No Don't know/Refused			
Q57			r has anyone you know been SIGNIFICANTLY HELPED by following medical ealth information you found on the Internet?			
	%	32	Yes			

16

Q54

65

4

No

Don't know/Refused

#### Methodology

This report is based on the findings of a survey of Americans about their use of the Internet. The results in this report are based on data from telephone interviews conducted by Princeton Survey Research Associates between June 9, 2001 and August 6, 2001, among a sample of 500 Internet users, 18 and older, who have ever gone online to look for health or medical information. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is plus or minus 4 percentage points. In addition to sampling error, question wording and practical difficulties in conducting telephone surveys may introduce some error or bias into the findings of opinion polls.

Interviews for this survey were completed from a pre-screened sample of Internet users who in past surveys identified themselves as Internet health information seekers. Once the household was reached, interviewers asked to speak with the individual who had recently completed a telephone survey. Once the targeted person was on the phone, they were asked a few screening questions to make sure that they had ever gone online to look for health or medical information.

At least 10 attempts were made to complete an interview at every household in the sample. The calls were staggered over times of day and days of the week to maximize the chances of making contact with a potential respondent. Interview refusals were re-contacted at least once in order to try again to complete an interview. The final response rate for the callback portion of this survey is 54%.