As a patient you can choose the care that best fits your personal situation, but only if you have the right information to make a good decision. The purpose of this survey is to learn how seniors and their caregivers stay informed about their health – both general health information (such as tips for staying healthy), and how you look for answers to specific questions or information about health problems. Then we will know how to best reach you and other seniors with important information about health.

**Section 1: demographics and general health**

Your information is analyzed anonymously and cannot be used to identify individuals.

| Year of birth | __________ |
| Gender | M | F |
| Postcode (numbers only) | __________ |
| Highest education level | primary school | high school | vocational/housekeeping | associate's degree | bachelor | university/master |
| Country of birth | __________ |
| Marital status | married | divorced | widowed | cohabitating | single |
| Housing status | cohabitating (partner | friend | family) | living alone | nursing home |

Are you the primary caretaker for someone with a serious or chronic health condition?  
yes | no

In general, how is your health?  
very good | good | fair | bad | very bad

I can make an appointment for routine care (e.g. with my primary care doctor) as soon as I want  
strongly agree | agree | disagree | strongly disagree

Rating of all health care received in the last 12 months:  
1......2......3......4......5......6......7......8......9......10

unacceptable.....................average............................outstanding

**Section 2: API**

The questions for the Autonomy Preference Index were drawn from Simon et al., which were in turn based on Ende et al.

**Section 3: Sources of health information**

Health information is information about preventative care (such as vaccinations or good nutrition), specific conditions (such as diabetes or cancer), and medications or other forms of treatment. This section is about the ways you stay informed about your health.

How much of your health information do you get from each of the following sources:

| direct contact with a health professional | a lot | some | a little | none |
| pharmacy | a lot | some | a little | none |
| leaflets at the doctor's office (such as in the waiting room) | a lot | some | a little | none |
| telephone help line | a lot | some | a little | none |
| television | a lot | some | a little | none |
| radio | a lot | some | a little | none |
| newspapers | a lot | some | a little | none |
| magazines specifically about health | a lot | some | a little | none |
| other magazines | a lot | some | a little | none |
| friends /family | a lot | some | a little | none |
| church/religious group | a lot | some | a little | none |
| courses and lectures | a lot | some | a little | none |
| internet | a lot | some | a little | none |
| self-help/patient groups | a lot | some | a little | none |
| books/encyclopedias | a lot | some | a little | none |
Section 4: Searching for health information

People often have questions about health. This section is about searching for information beyond what your doctor provides to you. You may have asked a health professional for more information, or asked someone other than a doctor (such as family, friends, classes, or a patient support group). You may have searched on the internet, or looked for written information (such as in magazines or at the library). Please tell us if you have sought additional information, even if you didn’t find what you were looking for. Check all that apply.

In the last 12 months, I have sought health information:

- to decide whether I need to see a doctor: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- to prepare for an appointment: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- to look up information after an appointment: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]

I have sought health information about:

- specific symptoms, to find out what might be causing them: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- prognosis: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- treatment options: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- prescription drugs: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- side effects of treatment or medication: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]
- coping with a disease: no | yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]

Respondents commented that the phrasing of this question did not distinguish between “I don’t use this source because I don’t trust it” and “I don’t know if I trust this source, because I don’t use it.” The authors suggest adding a “not applicable” option to these questions.
A practical care information (e.g. bathing, first aid, etc.)

No | Yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]

R,D Nutrition/physical exercise

No | Yes [If yes, how?: asked a health professional | asked other people | on the internet | written materials ]

If I have a need for information, I prefer to (please choose 1 option):

I don’t search for health-related information
Ask a health professional
Search on the internet
Search using sources other than the internet (magazines, friends, etc.)

I often want more health information but don’t know where to find it strongly agree | agree | disagree | strongly disagree

I expect my doctor/health professionals to provide me with all of the information that I need. strongly agree | agree | disagree | strongly disagree

I have had difficulty finding health information in my primary language never | once | sometimes | often

Section 5: Consequences of health information seeking (Results previously published in [L])

1 Has the health-related information you found led to:

D deciding to see a doctor
never | once | sometimes | often

H deciding not to see a doctor
never | once | sometimes | often

D a conversation with a doctor about what I found
never | once | sometimes | often

I willingness to change diet/lifestyle habits
never | once | sometimes | often

I change of medicine without consulting a health professional
never | once | sometimes | often

I feelings of anxiety
never | once | sometimes | often

I feelings of reassurance or relief
never | once | sometimes | often

I suggestions/queries about a diagnosis
never | once | sometimes | often

H suggestions/queries about a treatment
never | once | sometimes | often

E more knowledge and understanding of a specific condition, disease or treatment
never | once | sometimes | often

N feeling more confused about a specific condition, disease, or treatment
never | once | sometimes | often

other/comment

[] Someone helped me with filling in this questionnaire

References


D1. modified from (D)

Questions in this study were derived from Baker L, Wagner TH, Singer S, et al. Use of the Internet and e-mail for health care information: results from a national survey. *JAMA* 2003;289:2400 –2406.


N. new