

# Information Needs Report 2009

## SCI and TBI Populations

### Background

Persons with spinal cord injuries (SCI) and traumatic brain injuries (TBI) need timely and high-quality information about health and medical issues after they leave the hospital and throughout their lifetime in order to reduce secondary conditions, stay healthy, and maximize quality of life. To determine the best approaches to delivering SCI/TBI-related information, it is important to understand the information needs of these populations.

MSKTC administered information needs surveys in 2007/08 to address the following questions:

- What are the preferred and currently used formats and sources of SCI/TBI related information?
- What topics do people with SCI/TBI need information on the most?
- How common is internet access among people with SCI/TBI and do they need assistance when accessing the internet?

### Summary of Results

Respondents from national convenience samples of SCI and TBI populations completed surveys to identify information needs and preferences for seeking information. Key findings include:

- Respondents from SCI and TBI populations most prefer to receive health information in person from their doctor or health care professional, followed by web pages or internet. The health care professional they most want to receive this information from is their doctor who is a SCI/TBI expert or rehabilitation specialist.
- Medical issues were most frequently ranked within the top three topics respondents needed information on over the past 6 months for both respondent groups.
- Respondents with TBI reported less access to and use of web pages and internet for getting health information than respondents with SCI. In addition, respondents with TBI reported needing assistance from another individual when using the internet more often than respondents with SCI.

Table 1. Demographics	TBI (n=365)	SCI (n=270)
Years since injury (mean +-SD)	9.9 +-9.5	12.4 +-10.1
Age (mean +-SD)	42.3 +-14.3	45.4 +- 14.3
Gender		
Male (n(%))	245(68%)	174(63%)
Female (n(%))	113(32%)	103(37%)

Table 2. Internet Access	% of TBI	% of SCI
With In Home Internet Access	65%	80%
Use assistive technology	7%	11%
Need assistance from another individual	22%	9%

## What are the preferred and currently used formats and sources of SCI/TBI related information?

- The most commonly top ranked (selected within the top three choices) current way SCI respondents received health information was by *web pages or internet*, while TBI respondents identified *in person from their doctor or health care professional* as their top ranked current way.
  - 59% of SCI respondents selected *web pages or internet*
  - 66% of TBI respondents selected *in person from their doctor or health care professional*
- The most commonly top ranked preferred way for both SCI and TBI respondents to receive health information was *in person from their doctor or health care professional*.
  - 55% of SCI respondents selected *in person from their doctor or health care professional*
  - 62% of TBI respondents selected *in person from their doctor or health care professional*
- SCI respondents rely on web pages or internet more heavily than TBI respondents for health information related to their condition.
  - 59% of SCI respondents selected *web pages or internet*
  - 40% of TBI respondents selected *web pages or internet*
- TBI respondents seldom use or prefer the following formats: *medical journals, newsletters received by email, books, magazines, by email from health care provider, and chat groups and listservs*.
- SCI respondents seldom use or prefer the following formats: *medical journals, by email from health care provider, and chat groups and listservs*.

(see Figures 1 & 2)

- 67% of TBI and 70% of SCI respondents prefer to receive health information related to their condition from *their doctor who is a TBI/SCI expert or rehabilitation specialists*, but only 51% of TBI and 50% of SCI respondents currently receive information from this source.
- The three top ranked current sources of health information for respondents with TBI were *their doctor who is a TBI expert or rehabilitation specialists*, (51%), *family doctors* (43%), and *other health care providers* (33%).
- The three top ranked current sources of health information for respondents with SCI were *their doctor who is a SCI expert or rehabilitation specialists* (50%), *SCI organizations/associations* (50%), and *family doctors* (45%).
- TBI respondents seldom use or prefer *physical therapists or nurse practitioners* as sources of health information.
- SCI respondents seldom use or prefer *other health care professionals, nurses practitioners, or occupational therapists* as sources of health information. The other health professionals category excludes the following health professionals listed on the survey: *doctor who is a TBI/SCI expert or rehabilitation specialists, family doctors, physical therapists, occupational therapists, and nurse practitioners*.

(see Figures 3 & 4)

Figure 1: Top Ranked Current and Preferred Ways to Receive TBI Information

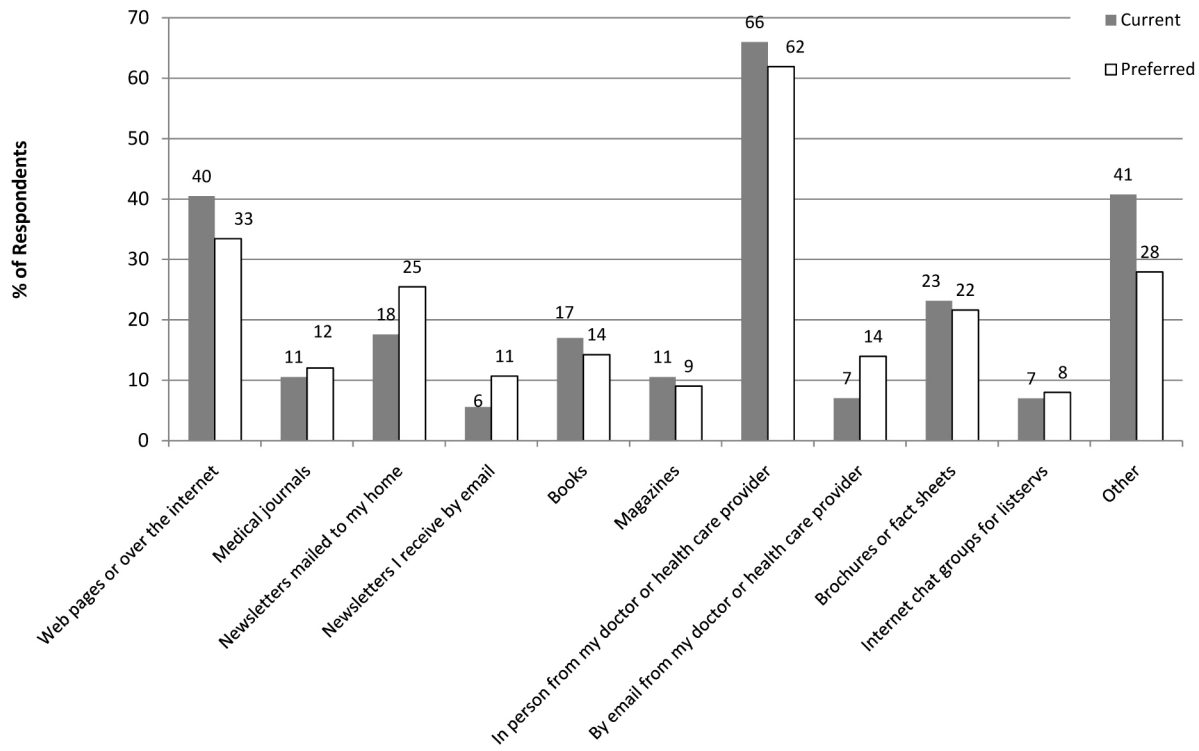


Figure 2: Top Ranked Current and Preferred Ways to Receive SCI Information

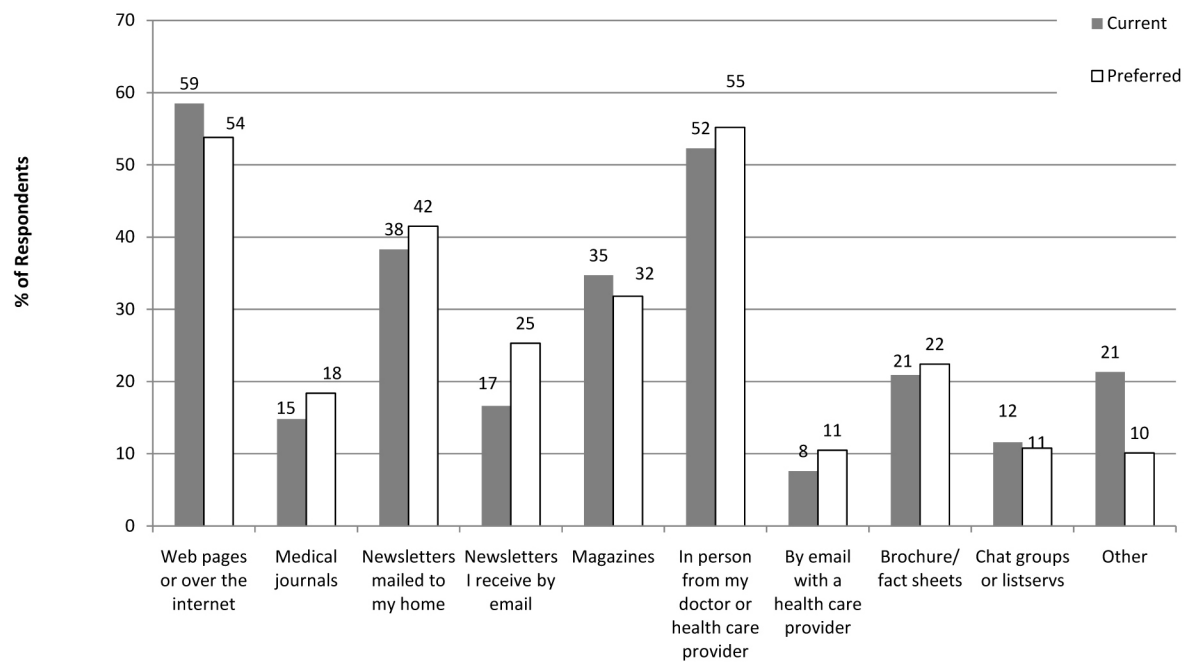


Figure 3: Top Ranked Current and Preferred Sources of TBI Information

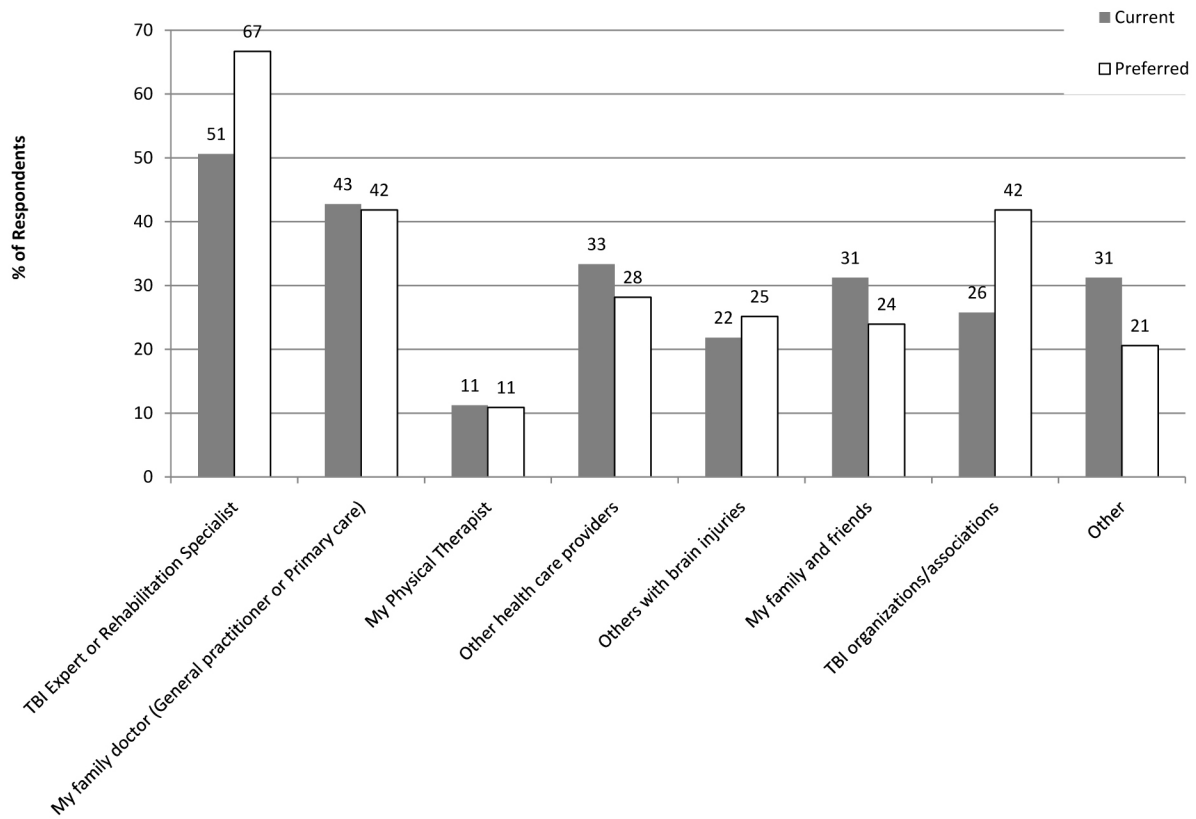
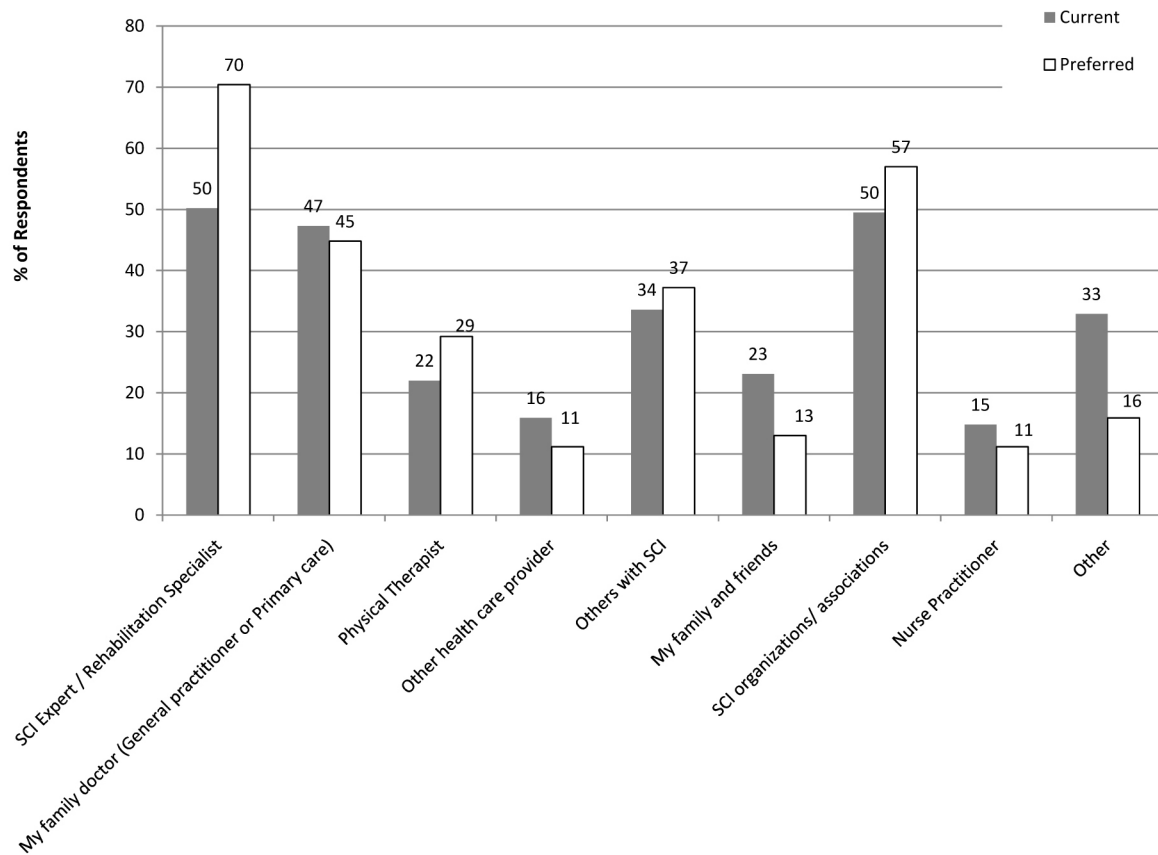


Figure 4: Top Ranked Current and Preferred Sources of SCI Information



## What topics do people with SCI/TBI need information on the most?

- Respondents were asked to select the top three topics that they needed information on the most in the past 6 months. *Medical issues* related to SCI/TBI were most frequently top ranked (selected within top three). The second most frequently top ranked topic for both groups was *fitness/ health promotion/nutrition*.
- *Social relations/ maintaining relationships with others, employment, and psychological issues* were ranked within the top three more often for the TBI than SCI respondents.
- SCI respondents ranked *equipment or assistive technology* as a top ranked topic more often than did TBI respondents.
- *SCI Cure* was selected more often (29%) within top three than *TBI Cure* (15%).

Table 3. Top Ranked Topics	TBI	SCI
	% of respondents	
Medical issues related to SCI/TBI	62	65
Fitness/ health promotion/nutrition	27	29
Social relations/ maintaining relationships with others	26	7
Employment	26	9
Financial issues/ health insurance/ disability benefits	25	22
Improving my level of physical function	25	29
Psychological issues (e.g., depression, anxiety)	21	7
Long term prognosis or forecast	18	-
TBI/SCI Cure	15	29
Legal issues/ disability rights	9	11
Sexual function/ fertility	8	13
New experimental treatments	7	-
Housing	5	11
Personal care assistants or providers	4	12
Equipment or assistive technology	3	25
Home modifications	3	12

## Recommendations for meeting information needs of SCI and TBI populations

1. More research is needed to understand why receiving information in-person from a health care provider, specifically from a doctor who is an expert or rehabilitation specialist is preferred to other sources. Is it because this source is deemed most trusted? Is it the in-person nature of interacting with an expert or rehabilitation specialist or would on-line interaction be as preferred?
2. Develop strategies to improve access to information provided by experts or rehabilitation specialists:
  - a. Identify barriers consumers experience when trying to receive information from this source.
  - b. If appropriate, create access via email and web-based knowledge base for those individuals who do not have ready access to their SCI/TBI rehabilitation specialist. The web-based knowledge base should be designed to answer or direct individuals to resources in response to specific questions, including medical/health related questions, employment and financial questions.
3. More research is needed to understand what constitutes a trusted web-based source of information in order to design web-based materials that will be useful to individuals with TBI and SCI.
4. Ensure evidence-based consumer information is available on high priority (top-ranked by 25%+ of samples) topics for each population.
  - a. TBI topics: Medical issues related to TBI (i.e. fatigue), fitness/ health promotion/nutrition, social relations/ maintaining relationships with others, employment, financial issues/ health insurance/ disability benefits, and improving my level of physical function.
  - b. SCI topics: Medical issues related to SCI, fitness/ health promotion/nutrition, improving my level of physical function, SCI Cure, and equipment or assistive technology.
5. More research is needed to identify effective alternative avenues (such as mail and telephone) to disseminate information to individuals with TBI due to the low (65%) rate of in-home access to the internet.
6. 22% of the individuals with TBI required assistance to access the internet. More research is needed to identify (1) who provides this assistance (2) what type of assistance is provided and (3) in what ways this assistance influences how and what type of information is sought.
7. Family doctors ranked high as an information source for both individuals with TBI and with SCI. More research is needed to identify effective and useful methods to disseminate TBI and SCI clinically relevant research to family practitioners.

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