

# Best Practices

## Developing Consumer Information

### Introduction

Individuals with TBI, SCI and burn injuries often experience life-long health problems that can be prevented or mitigated through appropriate self care and prevention. These individuals and their family members/caregivers need timely, concise and high-quality information about health and medical issues after discharge and throughout their lifetime in order to stay healthy and maximize quality of life.

### Trends impacting consumer information

- Shorter hospital stays require patients and family members to absorb a large amount of information quickly while in the hospital, and be proactive in finding health information once they are discharged.
- Health care professionals, specifically doctors and specialists, are less readily accessible to consumers once they are back to living in their communities. Therefore, consumers seek out other sources of health information such as the Internet.
- The Internet is becoming a commonly used source for health information. 74% of U.S. adults use the Internet, and 8 of 10 Internet users have looked for health information on-line. Increasingly, persons with disabilities are also using the Internet for health information (Pew Internet & American Life Project).

### Recommendations for content development

- *Balance problems and solutions* - Provide a balance of problems/issues and solutions.
- *Do it yourself solutions* - Provide practical and realistic solutions that consumers, family members and/or caregivers can do on their own, as well as those that require support from health professionals.
- *Everyone is unique* – Make sure the factsheet is not written as if all consumers have the same symptoms, outcomes and experiences related to their injury. Acknowledge that consumers have unique experiences recovering from their injuries, that not all information may apply to them, and that what does apply may change over time.
- *Get to the point* – Provide concise information that is useful to consumers. Avoid academic writing such as long introductions, extraneous information or unnecessary detail. Some consumers find long factsheets (more than 4 pages) intimidating or overwhelming to read.
- *Resources to learn more* – Provide resources such as books, websites and articles for consumers who want to learn more.
- *Use visuals* – When appropriate, use graphics/photos to present information more clearly and make the factsheets more engaging.

## Recommendations for content development (continued)

- *Use and define medical terms* – Using and defining medical terms helps consumers know what their doctors/health professionals are talking about and enables them to do further research on the topic.
- *Make content understandable to everyone* – Write for audiences with a range of reading levels. Specifically, avoid long sentences and paragraphs, define difficult words, use headings and labels that clearly describe content, and present information in bulleted lists when possible.
- *Use appropriate tone* –
  - Use encouraging rather than reprimanding language, as in “if you have a difficult time exercising daily, inconsistent exercise is better than no exercise at all”.
  - Use a personal tone, such as “you may feel” versus “a person feels”.
  - Avoid condescending statements, such as “reward the injured person if they behave appropriately”.

## Consumer Reviews to Ensure Understandability and Usefulness

The best way to determine if the information you develop is relevant, useful and understandable is to ask consumers.

- For each factsheet, interview 3-5 consumers who represent different circumstances or characteristics, such as time since injury, education level, race/ethnicity, gender, or age.
- Use guiding questions during interview to evaluate relevance, usefulness, and understandability of information (see Appendix – Guiding Questions).
- Modifications based on consumer interviews should be reviewed by content experts to ensure accuracy of information.

## Providing Information to Consumers

- *Provide information through different sources* – Provide information in web-based and printable formats via websites and in clinics. Provide factsheets to health care professionals and organizations that consumers rely on for health information.
- *Provide information that is accessible* – Make web-based and printable information accessible to persons with a broad range of disabilities such as vision, mobility and cognitive problems.
- *Timing is important* – Consumers are often overwhelmed with information during inpatient care and discharge. After they return home or during their first follow-up visit may be a more appropriate time to provide information. As one consumer expressed, “there is a point after you return home, that you stop being only taken care of and start taking control of your life again. This is when you need the information.”
- *Expand outreach* - Invest in reaching individuals who:
  - Are isolated geographically or socially or because of health problems (limited mobility, depression).
  - Have limited or no internet access – Individuals with less education, with lower income levels, from underrepresented ethnic/racial backgrounds and older (>65) are less likely to have access and use the internet.
  - Are less severely injured – Individuals who receive less follow-up care and contact with health professionals due to less severe injuries, but who still have health issues and need information.

## APPENDIX

## Guiding Questions - Consumer Factsheets

Thank you for participating in this interview. Your feedback is important to ensuring that this information is useful to injured individuals and their family members/caregivers.

1. What are your overall impressions of this factsheet?
2. What was most/least useful about this factsheet?
3. Did this factsheet cover all the important information? Was there too much information/too little information? What was missing?
4. Was all the information clear to you? Where there words that you did not understand?
5. Do you think the information in this factsheet will be clear to other people who have (SCI, TBI or burn injuries)?
6. When would have receiving this factsheet been most useful to you? (While in the hospital, when discharged, months/years after your injury)?
7. If you experienced this problem, did you find that any of the solutions described helped you? If so, which ones and how did they help?
8. Given all we have discussed, what do you think are the most important changes we should make to these factsheets to ensure they are useful to consumers?