



Testing Factsheets With Consumers

Purpose	This tool provides information on how to test the factsheets developed for Burn, Spinal Cord Injury (SCI), and Traumatic Brain Injury (TBI) survivors and their family and friends who may participate in their care. Obtaining feedback about how a patient or caregiver views, reacts to, and might use a factsheet is important and can help ensure that the information product is meeting the needs of those whom the Model System serves.
Format	This tool presents the goals, approaches, and tools needed when testing factsheets developed for Burn, SCI, and TBI survivors and the family and friends who may participate in the survivors' care.
Audience	This tool is designed primarily for researchers from the Model Systems that are funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The tool can be adapted by other NIDRR-funded grantees and the general public.
Resources	A research-based factsheet that is to be presented to Burn, SCI, and TBI survivors and their caregivers.

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Testing Factsheets: Do They Help Make Patient Decisions Easier?

Factsheets created for Burn, SCI, and TBI survivors and their caregivers are developed with specific goals in mind. Testing these information products with patients and family members ensures that the goals of each factsheet are being accomplished.

The goals of all factsheets are similar, although they may be accomplished differently for each unique topic. Factsheets created for Burn, SCI, and TBI survivors and their caregivers should

1. Be easy to read by individuals with intermediate literacy skills (6th-grade reading level and beyond)
2. Be easy for the reader to comprehend all the information in the factsheet
3. Answer questions and provide insights that readers find relevant and useful to their own individual situations
4. Enable conversation with clinicians and decisionmaking

Throughout the development process, evidence-based approaches to content selection, organization, word choice, phrasing, and visual support are applied to the factsheets. Yet the only way to confirm that these strategies have been applied correctly is to test the product, by having survivors and their caregivers provide their reactions and feedback.

Years of experience testing informational products has taught us important lessons about how best to solicit reactions and feedback that is most useful to improving the quality of the product.

This handout provides an example protocol that can be used for testing these materials with Burn, SCI, and TBI survivors and their families.

Overview of the Testing Protocol

The overarching goal of testing is to collect useful feedback that can increase the comprehension and usefulness of the factsheet's content, phrasing, and graphic presentation. Testing should not simply confirm the interest in the topic, but should assess that the majority of readers can understand and find use in the material.

To do so, the following protocol is recommended:

1. **ESTABLISH FOCUS:** The objective of this stage of the product test interview is to establish a clear focus for the participant in providing feedback. A key pitfall for many product tests is that participants are unclear about their role in testing the product, which can lead to a variety of limited or biased responses. It is important to emphasize that they understand that they are providing feedback about the product, not being tested on their own knowledge or ability to understand. It's okay for them to tell you that they don't understand the material.
2. **OBSERVE READING:** Participants should verbalize their thoughts and reactions to you as they read ("Think aloud."). Observers are looking for indications of difficulty in reading, unconscious positive and negative reactions to sections, and general patterns in consuming the material.

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3. **ASSESS UNDERSTANDING.** The best approach to confirming comprehension is to ask the participant to PARAPHRASE what they've read. Often, simply asking a participant, "Did you understand everything you read?" will NOT yield appropriate feedback. Many participants will answer "Yes," whether they understood the material or not, and may feel embarrassed to say that they didn't understand something.
4. **CONFIRM USEFULNESS.** After reading the materials, participants should express their intentions about how they will use the information to make health care decisions.
5. **GENERAL OPINIONS.** Participants should share their general opinions about the material and offer any suggestions for improvement or dissemination.

Each of the five tasks of product testing are critical to obtaining accurate feedback that can best revise and improve products for the majority of readers. The following guide provides instructions for each phase of a 1-HOUR product test, including a script for the interviewer to use throughout the product test. While following the script verbatim is not recommended, we suggest that you use the phrasing and order as much as possible.

PRODUCT TEST Protocol and Interview Guide

TOTAL TIME FOR TESTING: 60 Minutes
MATERIALS ON HAND: Color Printout of Draft Factsheet

Part 1: Establish Focus	5 minutes	00:00–05:00 minutes
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Once the participant has been greeted and seated for the test:

- a. **Purpose and Role:** "The Model Systems Knowledge Transfer Center has created a factsheet on [SUBJECT] to help patients and those who help to care for them better understand their choices. We ask people to review the sheets so that we can see whether they are easy to understand and are useful. To do this, we will ask you a set of questions about what you're reading. All we need from you are your honest thoughts and reactions as you read the sheet. We will use your reactions and the reactions of others to see what changes are needed to make the factsheet more useful for others."
- b. **Clarify and Reassure Protection:** "Please give us your honest feedback. There are no right or wrong answers. I did not write this factsheet and will not be offended by anything you say. My job is to collect all comments about the materials. If something is unclear or confusing to you, it's bound to be confusing to other people too. Nothing you say or do will have any impact on your relationship with this clinic or your care as a client. In fact, your name will never be associated with any feedback we give the creators of this factsheet from our time together."
- c. **Get Permission and Signed Consent:** If you are recording, be sure to inform the participant and seek permission prior to starting the recording. If there is a consent form to review and sign, this must be done before proceeding.

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- d. **Instruct:** “You should have been sent a draft of the factsheet. You can print it to read it or view it on your computer screen as we talk. Let me know when you have it in front of you. (*Wait, if needed, until the participant has the sheet in front of him or her.*) I would like to ask you to ‘think out loud’ as you read this—in other words, share the thoughts and reactions you have to the information as you read it out loud. For example, you may have to read a sentence twice to make sense of it. In that case, you might say out loud, ‘Huh? I don’t get that. Let me read it again.’ Or you may see something that helps you understand, and may say, ‘Oh, I get it. That makes sense.’ You might also have an immediate reaction to something, such as ‘I would never do that,’ and should say so out loud. Do you understand what I am asking you to do?”
- e. **Focus:** “We are especially interested in understanding how you might use this information when making decisions about your own care or improving your life. I’d like you to focus on that aspect when reviewing this sheet. In other words, I’d like you to think about how the information on this sheet is or is not useful to you, and why. For example, something you read may be ‘good to know’ but is not information that you would or believe that you could act on. It will be very helpful to hear about what you read that you feel you could act upon, and what is just ‘good to know.’ Do you have any questions before we begin?”

Part 2: Observe Reading

10–15 minutes

05:00–20:00 minutes

- a. Confirm that the participant has the document in front of him or her. Ask if the participant is viewing a printed document or viewing it on the screen. If the document is printed, ask if the document is printed in color or in black-and-white (this can help understand some comments later).
- b. Ask the participant where his or her eyes went to when he or she first looked at the document, by asking: “What’s the first thing you read when you looked at this document? What caught your attention first?”
- c. If the participant is not vocalizing responses, gently remind him or her to share his or her thoughts out loud. Some examples of what to say include: “Remember to tell me your thoughts and reactions as you’re looking at the handout.” “What are you thinking as you read that section?” “I see your face is making an expression as you read that section. Can you tell me what you’re thinking or feeling?”
- d. Keep asking the participant where he or she is reading next, especially during pauses while the participant is reading. Be sure to ask where he or she is “going” on the document—is he or she following the order of the page, or skipping around? Is the participant drawn to the text boxes, or the main text?

Note:

- Where the participant took a long time to read a section, or appeared to “hover” over a section
- Where the participant skipped a section
- Where the participant went back to a section later
- What section the participant was reading, if the participant changes mood or tone in response

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Part 3: Confirmed Comprehension

15 minutes

20:00–35:00 minutes

Check overall comprehension of materials. After the participant has finished reading the sheet, ask: “Now that you’ve read the entire thing, can you tell me, in your own words, what did this factsheet tell you? What are you taking away in general from what you’ve read?”

- Do NOT indicate a judgment of whether the response is correct or incorrect, or attempt to correct the participant’s comprehension. Note the participant’s response and probe for additional detail. If at the end of the session you want to clarify and educate, you may, but do NOT do so at this point.
- It is important to avoid responses like “Good!” or “That’s right.” Simply respond by saying “Thank you.”

Continue through the major sections of the piece and ask the participant to say in his or her own words what he or she thinks the section is trying to say. It is especially important to test sections where the participant showed signs of reading difficulty or change in mood during observation. “Can you read this section again and tell me, in your own words, what you think the authors are trying to say?”

Record in your notes where confirmation is confirmed or inaccurate. You may want to probe a paraphrased message in more detail, where the participant may understand but have difficulty verbalizing his or her understanding. The interviewer should continue asking questions until he or she has a strong sense of the participant’s thinking process, or the participant is showing signs of fatigue or irritation.

Part 4: Confirmed Utility

15 minutes

35:00–50:00 minutes

Thank the participant for providing his or her understanding of the information on the sheet, and remind him or her again that there is no right or wrong answer. “Now I’d like to ask you about what this information makes you think or want to do. Let’s start with the overall factsheet. After reading this, what decisions, if any, does this fact sheet help you make for yourself (or your loved one) about this issue?”

Probe:

- Ask for concrete statements of action. Paraphrase the response, being sure not to change the meaning of the response, but asking the participant to confirm your understanding of the action he or she would most likely take. For example, “I hear you saying that after reading this, you would decide to _____. Did I understand that correctly?”
- If a participant struggles to share a definitive action, you may want to ask, “How might you use this information? What could knowing this do for you?”

Record:

- Note areas where utility is clearly identified and where it is not—the comments are more “That’s interesting,” than “Given what this says, I think I would want to...”
- Note specific perceived utilities of information per section.
- Note any connection between areas of inaccurate comprehension and limited utility per section.

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Part 5: General Opinion

8 minutes

50:00–58:00 minutes

Finish the test by collecting participant opinions about the materials.

1. What words would you use to describe this factsheet to someone else?
2. Was there information that you felt was missing from this factsheet? Is there anything you wanted it to tell you more about that it did not?
3. Do you think the information in this factsheet will be helpful to other people who have [*SCI, TBI, or burn injuries*]? Why or why not?
4. When would getting this factsheet have been most useful to you (e.g., while in the hospital, when discharged, months/years after your injury)?
5. If you experienced this problem, did you find that any of the options described helped you? If so, which ones and how did they help?
6. 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 yourself and others?

Closing

2 minutes

58:00–60:00 minutes

Thank the participant again for his or her feedback and remind him or her that it will be used to improve the product.

Ask the participant if he or she has any questions about the project or the materials. If you feel it appropriate, you might want to correct any inaccurate interpretations of the material, particularly if the miscomprehension could lead to potentially harmful decisions or actions.

Complete whatever paperwork is necessary to provide the participant with his or her incentive award.

Processing the Notes from the Product Test

To best use the feedback from participants, it will be important to systematically organize the feedback in ways that help you see what changes should be made in the product. Here are several suggestions:

1. You may want to reorganize your notes from the test into comments per section of the factsheet. In other words, your test results would show all issues of comprehension, utility, and opinion per participant in one place per section of the factsheet, so that you have all comments on each section in one place. See the next page for an example of a product test report.
2. Be clear to use or paraphrase the participant's thoughts and not your interpretation of the participant's thoughts. Avoid using any adjectives that were not expressed directly by the participant. For example, the participant's statement "I don't think knowing this would help anyone very much," should not be recorded as "Participant found that information useless." The best way to avoid observer bias is to ask after recording a note, "How do I know that?" The best answer is "Because that's what he or she did/said/confirmed when I asked."

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3. As tempting as it may be, do not interpret any comment individually as a directive to make a change in the product. Even something as clear as “Participant couldn’t understand anything in this section,” may not necessarily translate to “Rewrite this section.” Decisions about revision can be made after looking across participant responses, and there may be more than one aspect of revision needed to increase comprehension or utility. You may feel that an individual comment has good merit to create a change in the document, but it should be considered in light of the overall collection of reactions.

The Revision Process

Once notes are collected, they will be reviewed by the MSKTC staff and original authors. A revision plan will be agreed upon and executed.

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SAMPLE PRODUCT TESTING NOTES REPORT (2 out of 5 participants recorded)

Participant	Title/purpose	What to know	Understanding your body	Why problem	Options—meds	Options procedures	General comments
1 M 58	Expectation matched title. Didn't read the sidebar. Thought the topic very important.	Read quickly. Said "uh-huh" after each bullet. Surprised to see surgery option. Wanted more info/didn't connect section as overview.	Responded positively to the graphic. Could not pronounce terms with guide. Thought good to know but didn't know how to use info.	Read twice, stuck in second paragraph. Comprehension problems; didn't understand "sacral micturition center." "This is good to know, but what do I do about it?"	Read section quickly. High comprehension. Struggled understanding the medication names or what they meant. Wanted brand names. Wanted more info on which one was best or which one had side effects.	Read section quickly. Could not paraphrase the section. Strong mood change at surgery. "I hope I don't need that." Confirmed that section made him uncomfortable. Wanted to know what he could do to avoid this.	Most helpful at hospital. Need to clarify if procedures are only if med doesn't work or is needed anyway. Thought it could make some people depressed because there are few good options. Had difficulty feeling comfortable discussing topic.
2 F 36	Expected more about what she could do, not what doctors would do. Thought topic was important; was hoping for something like this.	Skipped and went to section below. Saw as an overview. "I like the summary, it makes it easy to talk to my doctor."	Graphic "too small" to see well. Read slowly and nodded. "This is good. It explains a lot." Would use to understand where things were happening in her body and what terms doctors use.	Paraphrased accurately. "I guess this is telling me why they need to do these things to fix it." Didn't want pronunciation guide.	Read section twice. Difficulty understanding what medicines would do. Wanted cost of medicines. Not clear how to choose medicine. "Won't my doctor just pick one that's best for me?"	Read slowly. Paraphrased accurately. Unclear what choice she had in the decision; "I guess they tell me if I need this, but would I ever say no?"	Most helpful later—too much to think about right after injury. Thought it better for explaining to family what was happening and why. Didn't see how it would help decisions.
3							
4							
5							