

1

I. FRAMEWORK

- Until now, there has not been a tool to measure the social impact of burn injury. Burn survivors and medical/support team members were partners in this project from the beginning to the end.
- To start, we identified key areas of social participation affected by burn injury in three steps:
 1. Review of existing research
 2. Feedback from burn survivors and medical/support team members
 3. Focus groups with burn survivors and medical/support team members

2

II. ITEM DEVELOPMENT

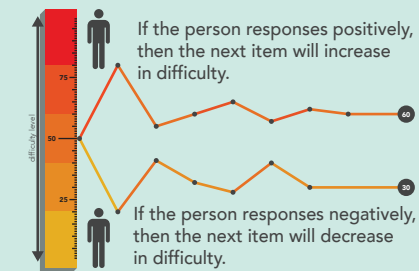
- We created items (questions) for the LIBRE Profile. We began with items from existing questionnaires that were related to social participation.
- Next, we held focus groups with burn survivors and medical/support team members. Based on their comments, we added additional items.
- Then, we interviewed burn survivors to make sure everyone understood the items in the same way. We reworded items that were confusing or unclear.
- This resulted in 192 items.

3

III. CALIBRATION AND CAT

- 601 burn survivors answered all the items. Then, we grouped items into 6 domains (categories):
 1. Relationships with family and friends
 2. Social interactions
 3. Social activities
 4. Work and employment
 5. Romantic relationships
 6. Sexual relationships
- We calibrated the items for each domain (put items in order of difficulty).

- Then, we built a Computerized Adaptive Test (CAT). The CAT uses a computer program to take each person's answers and select 5-10 items per domain for that person. The burn survivor gets a precise (exact) estimate of how they are doing without spending time on questions that are too easy or too hard.



4

IV. SHORT FORMS

- What if someone wants to use the LIBRE Profile somewhere without a computer? We created a different version called the LIBRE Profile short forms.

- We picked about 10 questions from each domain that give us as much information as possible about how the burn survivor is doing. This includes a mix of easy, medium, and hard questions.

- Scores from the short forms are nearly as precise as scores from the CAT. The short form lets people use the LIBRE Profile in places without a computer.

5

V. RELIABLE, VALID, & RELEVANT

- We did tests to ensure the LIBRE Profile is reliable (every time someone gives similar answers, it gives a similar score). Burn survivors took the short forms twice about a week apart, to make sure the scores stayed about the same.
- We also made sure the LIBRE Profile is valid (measures social participation accurately). We checked people's LIBRE Profile scores against their scores on questionnaires for similar topics. For example, we compared the LIBRE Profile Work & Employment domain to a different questionnaire about work.



Tracking The Road Toward Recovery

How We Built The LIBRE Profile



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Burn survivors, medical/support team members, and researchers were an important part of the whole project to make sure the tool is relevant and useful.