

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

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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.

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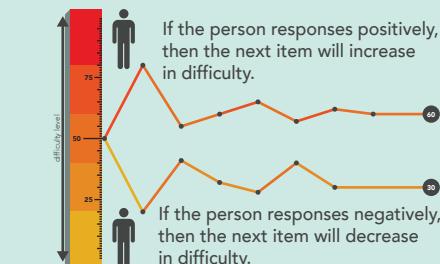
IV. SHORT FORMS

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

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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).



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V. RELIABLE, VALID, & RELEVANT

- 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.



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Tracking The Road Toward Recovery
How We Built The LIBRE Profile



This project is sponsored by NIDILRR grant number 90DP0055. 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.