# LIBRE Staff and Investigators

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
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<tbody>
<tr>
<td><strong>Principal Investigators</strong></td>
<td>Lewis E. Kazis, ScD</td>
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<td></td>
<td>Alan Jette, PhD</td>
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<td><strong>Clinical Leaders</strong></td>
<td>Amy Acton, BSN</td>
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<td>Colleen M. Ryan, MD</td>
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<td>Jeffrey C. Schneider, MD</td>
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<td><strong>Lead Data Analyst</strong></td>
<td>Gabriel Shapiro, MPH, PhD</td>
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<td><strong>Co-Investigators</strong></td>
<td>Austin F. Lee, PhD</td>
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<td>Pengsheng Ni, PhD</td>
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<td></td>
<td>Linda J. Resnick, PT, PhD</td>
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<td>Mary Slavin, PT, PhD</td>
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<td>Ronald Tompkins, MD, ScD</td>
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<td>Ross D. Zafonte, DO</td>
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<tr>
<td><strong>Staff</strong></td>
<td>Flor Amaya, MPH</td>
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<td>Emily Dore, MSW</td>
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<td></td>
<td>Molly Marino, MPH</td>
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<td>Laura Simko, BS</td>
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<td>Lily Sonis, MSW</td>
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LIBRE Clinical Advisory Board Members

- Arizona Burn Center, AZ
  - Kevin Foster, MD, MBA, FACS
- Brigham & Women's Hospital, MA
  - Bohdan Pomahač, MD
  - Indranil Sinha, MD
  - Nick Faoro, RN
- Harborview Medical Center, WA
  - Nicole Gibran, MD
  - Gretchen Carrougher, RN
- Hennepin County Medical Center, MN
  - Frederick Edorf, MD
- Maine Medical Center, ME
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- University of Texas Health Science Center, TX
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- University of Texas, Southwestern Medical Center, TX
  - Karen Kowalske, MD
  - Radha Holavanahalli, PhD
- University of Wisconsin School of Medicine and Public Health, WI
  - Lee Faucher, MD
- Weill Cornell Medical Center, NY
  - Abraham Houng, MD
Study Goals

• To develop a questionnaire that measures the social impact of a burn on an adult population
• To integrate the latest technology for constructing metrics that are reliable and valid using Computerized Adaptive Testing (CAT)
• To apply CATs to population based studies, clinical trials and patient feedback in real time during the clinic visit
• To track social participation of an individual over time
Significance

• Questions specifically designed to measure social interactions, work integration, and personal relationships are practically nonexistent for burn survivors

• Computerized adaptive testing (CAT) will be administered to burn survivors and scored to inform clinicians and patients
How a CAT works
Implications for Survivors

• Provide survivors and their families with information regarding recovery that is important for receiving needed support and care

• Enable survivors to better understand their recovery

• Enable survivors to better communicate needs to doctors and others
Clinical Implications

• Provide real-time feedback

• Screen for a wide range of issues affecting social participation

• Identify the needs of a population

• If we can measure it, we can optimize care
Study Timeline

- **Goal 1**
  - Create item pool: months 1-12
  - Field test the item pool: 13-24
  - Preliminary Psychometric Evaluation and Normative Study: 25-36
  - Pilot study: 37-48
  - Dissemination: 49-60

- *Study start date: October 1, 2013
- *Recruitment start date: October 1, 2014
Phase III: Preliminary psychometric evaluation and CAT Prototype Development

• IRT Analysis Generated 6 Domains for CAT Development
  1. Sexual Relationships
  2. Family and Friends
  3. Social Interactions
  4. Social Activities
  5. Work and Employment
  6. Romantic Relationships
LIBRE Profile

• Family & Friends (24 Items)
  • Person’s ability to interact with, fulfill social obligations, and achieve emotional satisfaction with family and friends
  • Example: Members of my family give me the support that I need.

• Social Interactions (25 Items)
  • Exchanges and contacts that a burn survivor experiences when engaging in various community activities that are important to them, and includes several items on relating with strangers
  • Example: I don't worry about other people's attitudes towards me.

• Social Activities (15 Items)
  • Burn survivor’s perceived difficulty with engaging in social and community events and obligations
  • Example: I avoid outdoor activities because of my burns.
LIBRE Profile

• **Work & Employment (19 Items)**
  • Satisfaction with one’s ability to complete work, and relationships with coworkers and supervisors
  • Example: Because of my burns, I am unable to finish many work tasks.

• **Romantic Relationships (28 Items)**
  • Emotional and physical aspects of these relationships, as well as communicating with a partner
  • Example: I have a partner who meets many of my emotional needs.

• **Sexual Relationships (15 Items)**
  • Engagement in and satisfaction with one’s current level and quality of sexual activity
  • Example: I avoid sexual contact because of my burns.
Future Work: Pilot Study

Phase IV: Pilot Study

• IRT Analysis Generated 6 Domains for CAT Development
• CAT Prototype has been developed
• Normative data has been received and is being processed
• Planning for the pilot study has begun
• Pilot study will include validity and reliability testing
CAT Prototype

Score Report:

<table>
<thead>
<tr>
<th>Scale</th>
<th>Score(SE)*</th>
<th>Scale</th>
<th>Score(SE)*</th>
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<tbody>
<tr>
<td>Family &amp; Friends</td>
<td>35.07(2.92)</td>
<td>Social Interactions</td>
<td>30.6(2.37)</td>
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<tr>
<td>Social Activities</td>
<td>41.75(2.95)</td>
<td>Work &amp; Employment</td>
<td>36.15(2.12)</td>
</tr>
<tr>
<td>Romantic Relationships</td>
<td>34.19(2.14)</td>
<td>Sexual Relationships</td>
<td>38.88(2.98)</td>
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*: T score (SE) (mean=50, SD=10 scale)
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• Contact Us:
  •  [libre@bu.edu](mailto:libre@bu.edu)
  •  1-844-255-9987