

Funder: Patient Centered Outcomes Research Institute (PCORI)

Project Name: Concept Mapping as a Scalable Method for Identifying Patient-Important Outcomes

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Project Dates (3 years): 1/1/16-12/31/18

Project Overview: Patients are often minimally engaged about their priorities or needs when seeking medical care, leading to treatment plans that may not be optimally designed to meet their needs. For example, patients might care more about their ability to participate in family events, while clinicians or investigators may be more interested in preventing hard medical outcomes and avoiding hospital readmissions. One-on-one interviews and focus groups are most often used to engage patients. While these methods provide valuable information, they are often time-consuming and may leave the final process of analyzing data and identifying outcomes in the hands of researchers instead of patients. **Thus, patient-centered researchers would benefit from development of additional methods for identifying individual patient-important outcomes.**

We suggest that concept mapping, a method for participant engagement commonly used in non-healthcare research settings, may be one such efficient and effective method. Concept Mapping is a group process that takes place over multiple sessions in which participants 1) brainstorm ideas, 2) organize ideas and 3) analyze ideas to generate a final list of “outcome clusters.” In this proposal, we propose to test the application of concept mapping as compared to one-on-one interviews as a comprehensive and efficient method of identifying patient-important outcomes for use in research.

Our specific aims are:

- 1) To engage patients to identify their own patient-important outcomes for managing their chronic conditions through one-on-one interviews and concept mapping groups;
- 2) To compare the comprehensiveness of concept mapping to one-on-one interviews for identifying patient-important outcomes and
- 3) To compare the efficiency of concept mapping to one-on-one interviews for identifying patient-important outcomes.

Findings from this work will improve patient-centered outcomes research methods by providing researchers with information about standardized scalable methods to identify patient-important outcomes for use in research studies, so that individual patients are able to select outcomes that are most useful to them.

Position Needed: Research Coordinator

The Research Coordinator will have the following responsibilities:

- Work with project investigators to design and oversee the patient recruitment and enrollment
- Oversee analysis of 90-120 interviews, including development of codebook, training of coding team, and actual coding an analysis (to be performed with NVivo)
- Assist in ensuring and documenting adherence to project milestones, including monitoring of patient identification, recruitment, and enrollment, and timely communication with the co-PIs regarding accrual of case subjects and any deviations from the projected timeline
- Provide daily oversight and as-needed trainings in research protocols and qualitative for the research assistant and PAKSAB members who are working as part of the research team
- Perform data collection (perform interviews, participate in conduction of concept mapping sessions) along with other members of the research team
- Ensure secure management of all data – including data cleaning activities, investigate data omissions, and ensure subject confidentiality.
- Other administrative duties may include: participation in weekly research team meetings; electronic back-up storage of operations research models as they are progressively formulated; and assistance as needed for the maintenance of Institutional Review Board communications, contract agreements, and expense files.
- Other tasks as needed

Skills required: qualitative interview analysis expertise (codebook development, approaches to coding, node summarizing), NVivo, project management experience, Masters required

The Research Coordinator will have informal daily contact with the co-PIs on an individual, face-to-face basis to discuss the project's general progress and offer strategic advice. The Research Coordinator will be paid at the institutional salary that is consistent with the salaries at TJU.