Study of Methods for Assessing Research Topic Elicitation and pRioritization (SMARTER)

A PLAIN LANGUAGE SUMMARY OF

"Study of Methods for Assessing Research Topic Elicitation and pRioritization (SMARTER): Study Protocol to Compare Qualitative Research Methods and Advance Patient Engagement in Research" by Danielle Lavallee, Bryan Comstock, Mary Scott, Andrew Avins, David Nerenz, Todd Edwards, Donald Patrick, Sarah Lawrence, Zoya Bauer, Anjali Truitt, and Jerry Jarvik. Published in JMIR Research Protocols, 2017.

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What is this study about?

When planning medical research, there are uncertainties about which topics are most important to patients to study. Patients have historically not been involved in setting research agendas, or in the selection of issues to investigate. However, input needs to come from those who live with the medical condition under study. Sometimes it is hard to find large groups of patients to ask for their input, even though low back pain is a relatively common medical condition. This research study aims to explore ways to involve patients with low back pain in setting research agendas. This project compares three different activities to obtain patient input – online crowd-voting, in-person focus groups, and mailed surveys – and explores the advantages and disadvantages of each method including the patients' view of their experience participating in each activity. This summary presents the design of the study, also known as the study protocol.

How will this research be done?

Two phases are planned to gather information on research priorities from people with low back pain. In the **first phase**, the study team invites two groups of people with low back pain to complete a survey to provide input on which research topics they think are most relevant to them to study. The two groups of people include:

(a) People who participate in a patient registry called BOLD (Back-pain Outcomes using Longitudinal Data). These participants come from two different healthcare centers in California and Michigan. All are at least 65 years old and have been diagnosed with low back pain.

(b) People from across the United States aged 18 and older who are signed up online through the Amazon Mechanical Turk (MTurk) platform to assist with a variety of tasks, including survey research. The survey will only be sent to those who experience low back pain as indicated by a screening questionnaire.

All of the participants will complete a survey where they will rank a list of research topics in order of priority to them, and pick the five topics that they think are most important. They can also suggest other research topics not on the list.

In the **second phase**, we will invite the participants from the BOLD registry who agree to participate in additional activities to complete one of following three priority-setting activities:

1) Focus groups: The participants selected for focus groups will meet and discuss face-to-face in groups of up to 10 people at a time. In these group discussions, the participants will generate research ideas and review the research topics rated during the first phase surveys.

2) Mailed surveys: Each selected participant will be mailed the written topic list from the first phase. They will be asked to rate each topic's importance on a five-point scale (1 for "not at all important" to 5 for "extremely important"). Then, after all of the ratings from the group are compiled, the participants will review the new rank-ordered topic list and have a chance to make changes to their ratings if they choose. This method of reaching consensus on a ranked list is called a Delphi panel.

3) Crowd-voting: The participants selected for crowd-voting will participate in an online discussion board over a one-month period, where they will brainstorm, discuss, and vote on research topics.

To compare the above three methods of collecting input, the list of research priorities obtained from the participants and their ranking will be studied. Participants will be asked to complete an additional survey about their experience with the activities, including how satisfied they were with the way they were asked to provide input, how effective they think the process was, and whether the discussions with other participants changed any of their research priorities. Upon answering these questions, 10 participants from each activity will be interviewed by phone to provide more in-depth feedback.

How will the results of this study be used?

We plan to invite 3,500 participants to complete the Phase 1 survey, and up to 250 participants to complete the Phase 2 activities. The results from this study will help us understand which research topics are most important to people with low back pain, especially for older adults. The results from Phase 2 will also help us identify the best ways to involve patients in research. Ultimately, findings from this study will aid doctors and researchers to identify the most relevant and important research topics that matter most to patients, and the best ways to get them.