

Tailoring Stakeholder Engagement for Study of Adults with Opioid-Treated Chronic Low Back Pain

Cindy A. Burzinski¹, Alice S. Yuroff¹, Gay R. Thomas³, Betty L. Kaiser³, Victoria G. Goodman-Strenski, Randall Coloni, Penney Cowan⁴, Christin Veasley⁵, Aleksandra E. Zgierska^{1,2}.

¹*University of Wisconsin-Madison, School of Medicine and Public Health, Department of Family Medicine and Community Health*

²*University of Wisconsin-Madison, School of Medicine and Public Health, Department of Population Health Sciences*

³*University of Wisconsin-Madison, School of Nursing, Wisconsin Network for Research Support (WINRS)*

⁴*American Chronic Pain Association*

⁵*Chronic Pain Research Alliance*

Chronic low back pain (CLBP) is often resistant to standard-of-care treatment and can result in the need for opioid medications. Strategies to Assist with Management of Pain (STAMP) Study is a five-year multi-site randomized clinical trial (RCT), involving University of Wisconsin-Madison, Brigham and Women's Hospital/Harvard University, and University of Utah sites. It will compare the effectiveness of mindfulness meditation (MM) and cognitive behavioral therapy (CBT) in 766 individuals with opioid-treated CLBP, followed for one year. To date, 360 participants have been enrolled. Reaching and engaging this clinical population is challenging, especially in the context of opioid-related stigma, public emphasis on "the opioid crisis," and local and national efforts to decrease the impact of opioids and opioid prescribing. This can promote fear, anxiety and stigmatization among many individuals with opioid-treated pain. Engaging multiple stakeholder groups from the study inception through its conduct is essential for effective recruitment, enrollment and retention of this complex STAMP Study population. We involved specialists in stakeholder engagement from the Wisconsin Network for Research Support (WINRS) to guide our approach to the selection of the study stakeholder members, assist with orientations for both the research team and stakeholder members, and provide ongoing consultation on effective stakeholder meeting agendas and engagement. Stakeholders provided input into STAMP study design. Two stakeholder groups inform the study on an ongoing basis: Patient/Family Advisory Committee (PFAC) and the Stakeholder Advisory Committee (SAC). The PFAC comprises individuals with a lived experience of opioid-treated CLBP; the SAC comprises four PFAC representatives, medical professionals, leaders of two pain patient advocacy groups and community organization representatives. Currently, in year 3 of the STAMP study, we identified several best practices for sustaining the engagement of multiple, specialized stakeholder groups: 1) An ongoing focus on rapport building both within the stakeholder groups, and between stakeholder and the research study team is essential to assure stakeholders have a clear, accurate understanding of their role as project advisors; 2) Provision of consistent feedback to stakeholders that demonstrates the unique value of their input and how it is being used by the study team to improve the project; 3) Creation of meaningful meeting agendas that invite stakeholder input on changeable issues/materials (e.g. providing feedback on recruitment materials, retention strategies and website development), avoiding excessive time spent on study updates or discussion of study materials that cannot be changed; 4) Tailoring meeting activities to match stakeholder group strengths (e.g. the PFAC is well-positioned to advise on issues surrounding stigma; SAC advisement has been effective on items related to data collection, tools and analysis). Effective, tailored engagement with our stakeholders has resulted in numerous study improvements, including revised STAMP study recruitment materials (brochure, letter, response card, phone scripts) and retention strategies, and qualitative interview scripts/questions.

Resources: "How stakeholders are making a difference" feedback template, sample PFAC and/or SAC agendas, recruitment brochure, response card, recruitment letter, phone screen voicemail script; in-depth qualitative interview.