

Things for Investigators to know about using the Patient Activation Measure® (PAM®) Survey

- License effective date is August 4, 2017- August 4, 2018
- Contact Laura Robbins laura.robbins@unmc.edu for access to the PAM® survey, scoring materials, and REDCap usage.

Don't

- You shall not (a) copy or reproduce the PAM Materials or any part thereof and shall not disseminate, publish, or otherwise publicly display the PAM Materials or any part thereof, including but not limited to the PAM® survey (**except as is required to administer the PAM® survey to Participants**)
- Do not create derivative works or make alterations to the PAM Materials or any part thereof
- The PAM® survey should not be used to validate a similar assessment tool
- Do not reference or use the PAM Materials to advertise, promote, publicize or validate a proprietary measurement tool or intervention
- You cannot sublicense the PAM Materials
- Do not unlock, access, or attempt to access algorithms contained within the **PAM scoring tools** including : reverse engineer, reverse translate, decompile, disassemble or in any manner decode the PAM Materials or any part thereof, or any of the algorithms contained therein
- Do not alter, add, change, or remove from the PAM Materials any identification marks, including copyright or trademark notices without express written permission from Insignia

Publishing

- You must refer to the PAM Survey as the “**Patient Activation Measure®**” or the “**PAM® survey**,” and shall at all times refer to PAM as a “**measure of patient activation**” or “**measure of self-management**”
- Any results or findings from use of the PAM® survey shall at all times be referred to as results or findings of “patient activation” or “patient self-management.”

Consent

You are responsible for obtaining any consents from Participants that are necessary to allow the PAM Materials to be provided to Insignia and to share any data (including Usage and Outcome Data) with Insignia (**see Data Sharing**), and for maintaining Participant user access and authorization information in compliance with the Health Insurance Portability and Accountability Act of 1996, Public Law 104-191 (HIPAA).

Data Sharing

You must share with Insignia de-identified, individual level data related to the usage of the PAM Materials by Participants.

**(De-identified data for all participants from all time points should be sent to the CENTRIC Project Coordinator in an Excel file at the time of study completion. The data set should include variables from all CENTRIC required measures including demographics, EQ-5D-5L, PAM® survey, PROMIS 29 profile 2.0 and Self-Efficacy for Managing Chronic Disease 6-item Scale)*

You must report the exact number of Participants who received the PAM® survey during the license effective date to the CENTRIC Project coordinator Laura Robbins laura.robbins@unmc.edu no later than August 4, 2018.