Collaborating with patient partners to model clinical care pathways for major depressive disorder: mixing evidence and experience

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BACKGROUND:
Working with patient partners to design and develop simulation models is encouraged but not common, and no guidelines currently exist for patient involvement in modeling.

CURRENT FOCUS:
We’re presenting the steps we took to form an effective partnership with patients to create the SiMMDep Model in the hopes that it will encourage other teams to partner with patients in healthcare modeling endeavors.

RECOMMENDATIONS BASED ON EXPERIENCE:
1. Patient partners should be meaningfully included in modeling projects to increase credibility in the model and its outcomes.
2. Embrace the “uncertainty” stage – this is where rapport is built and expectations are clarified as everyone has an opportunity to be heard.

IMPLICATIONS:
Patient partner engagement in modeling increases the democracy of scientific decision-making, leading to more robust models and relevant directions for future research.

“What is intense validation in having one’s experiences heard and knowing lessons learned from those experiences will be passed on and shared with other researchers.”

- Pharmacogenomics for Depression Study Patient Partners