PROJECT INFORMATION

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Developing a Process for Getting Patient and Caregiver Input on Clinical Practice Guidelines

Principal investigator

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Organization

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What was the project about?

Clinical practice guidelines help doctors decide on treatments to recommend for their patients. Guidelines are based on research that looks at the benefits and harms of different treatments. Patient and caregiver input can improve the usefulness of guidelines. But guideline developers often rely on the input of only a few patients and caregivers.

In this study, the research team created a process for getting feedback on guidelines from larger groups of patients and caregivers. This process is called the RAND/PPMD Patient-Centeredness Method, or RPM. The team tested RPM with guidelines for Duchenne muscular dystrophy, or DMD. DMD is a severe form of muscle loss that mostly affects young boys.

What did the research team do?

The research team recruited 24 patients and 71 caregivers from an online Duchenne Registry and assigned them by chance to one of two online panels. Ninety-one percent of panel members were white and 9 percent were other races. Also, 62 percent were women.

Each panel completed the same three-round process. In round one, panel members rated the importance and acceptability of 19 recommendations included in the DMD guidelines. Panel members explained each of their ratings and the factors that affected them.

In round two, panel members reviewed charts that compared their round one responses with those of the

full panel. The charts also showed whether the panel agreed on ratings. Panel members then discussed their feedback in a moderated online forum.

In round three, panel members could change their original ratings based on round two feedback and discussions.

The research team looked at

- How much panel member agreement on ratings changed between rounds one and three
- How similar the two panels' final ratings were
- How many recommendations were patient-centered, which the team defined as two panels rating a recommendation both important and acceptable

Patients, caregivers, doctors, and guideline developers gave feedback on the study.

What were the results?

Agreement. Between rounds one and three, panel member agreement on ratings increased from 95 percent to 100 percent.

Panel decision similarity. The panels reached the same decision on ratings for 89 percent of the recommendations.

Patient-centeredness. The research team deemed 12 of the 19 recommendations patient centered.

What were the limits of the project?

This study focused on one set of guidelines. Results may differ for other health problems. The research team tested RPM on finalized guidelines. Ideally, patients and caregivers would give input on draft guidelines. Then guideline developers could make changes based on their input.

Future research could test RPM on other guidelines. Studies could also look at how guidelines and their impact change when patients and caregivers are involved from the start.

How can people use the results?

Guideline developers can use the results when considering how to get input from large groups of patients and caregivers.

To learn more about this project, visit www.pcori.org/Khodyakov318.