RWJF Awards Grant to PatientsLikeMe to Develop New Measures for Healthcare Performance

**Release Date:**
Tuesday, December 8, 2015 8:00 am EST

**Terms:**

**Dateline City:**
CAMBRIDGE, Mass.

*Patient Network to Work with the National Quality Forum to Ensure Patients Drive Healthcare Value*

CAMBRIDGE, Mass.--(BUSINESS WIRE)--PatientsLikeMe has been awarded a $900,000 grant from the Robert Wood Johnson Foundation (RWJF) to help jumpstart changes that will amplify the patient voice in the measurement of healthcare performance.

A portion of the grant funds a collaboration between PatientsLikeMe and the National Quality Forum (NQF) to develop, test and facilitate the broader use of patient-reported outcome measures (PROMs) to assess patient-reported health status. While PROMs have been used in clinical research, they are rarely used in routine clinical care to assess provider performance. In such settings, performance is primarily assessed by what was done to the patient (using process measures) and what happened to the patient (using clinical outcome measures), but not always by what may be most important to the patient.

The grant comes as value-based purchasing is gaining ground in both the public and private sectors, with the Centers for Medicare & Medicaid Services (CMS) setting aggressive targets for linking performance related to quality, value and patient-centered care to payment. “Measuring what is relevant, useful and actionable for patients has never been more important,” said PatientsLikeMe Co-founder and President Ben Heywood. “This initiative will help quantify the patient experience at the clinical level, so that real patient outcomes can start to prompt changes in behavior, help tailor care, and improve reimbursement. With it, we’ll start to move the whole system toward more patient-centered care.”

NQF is a not-for-profit, nonpartisan, multi-stakeholder, membership-based organization that works to help advance improvements in healthcare. It evaluates, endorses, and selects measures of quality, safety and cost for accountability. The collaboration with PatientsLikeMe is one of several that are part of NQF’s new Measure Incubator, an innovative effort that holds the potential to facilitate measure development and testing more efficiently through collaboration and partnership.

NQF’s Chief Scientific Officer, Helen Burstin, MD, MPH, sees the collaboration with PatientsLikeMe as the answer to an urgent need for new measures that can improve health and healthcare outcomes.

“We have an abundance of clinical measures, but we need to better incorporate the voice of the patient into performance measurement,” said Dr. Burstin. “We must be able to accurately measure and understand the patient’s day-to-day experience living with pain and fatigue as well as how they are functioning with routine activities to get the full picture. PatientsLikeMe’s inherent focus on patients will move us closer to having the patient voice be the driver and definer of health care value.”

Creating measures that matter to patients became easier in 2013 when RWJF gave PatientsLikeMe a grant to create the Open Research Exchange (ORE), an open-participation platform that allows researchers to connect with PatientsLikeMe’s 380,000 members to create, test and validate new measures. The collaboration with NQF will initially use the ORE platform to ask patients to prioritize measures, then PatientsLikeMe will develop and test them. This process will ensure that when implemented in clinical care settings, the measures broadly show a patient population’s progress and reflect health outcomes that are important to patients that can then be used to assess an organization’s performance and ultimately to determine reimbursement.

**About Patient-Reported Outcomes Tools & Performance Measures**

Patient-reported outcomes (PROs) are defined as any report of the status of a patient’s (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else. Various tools such as questionnaires, scales, or single-item measures that enable researchers, administrators, clinicians and others to assess patient-reported health status for physical, mental, and social well-being are referred to as PRO measures (PROMs). PROMs have been commonly used in clinical research because they are based on patient input, and can help ensure that the treatments developed actually help people feel better and improve symptoms or function. Their application in the clinical care setting is limited, but growing interest among various stakeholders is moving PROMs into more routine use for performance measurement. An example of this is the widely used Patient Health Questionnaire 9 (PHQ-9) that screens and monitors the severity of depression. In a clinical setting, PROMs can help monitor patient progress over time at the individual and population level and support shared decision making. A PRO performance measure (PRO-PM) is based on aggregated patient-reported data and is used to assess quality of care for accountable entities, such as hospitals, physician practices or accountable care organizations (ACOs). NQF endorses PRO-
PMs for purposes of performance improvement and accountability.

**About the NQF and the NQF Incubator**
The National Quality Forum leads national collaboration to improve health and healthcare quality through measurement. The NQF Measure Incubator initiative aims to help organizations developing needed, meaningful measures do so more efficiently. The NQF Measure Incubator will connect groups interested in particular measure concepts with experts who can develop measures and provide data and/or financial and technical resources to facilitate measure development. Having continuous access to data to test and adjust measures can reduce the time to develop a measure. The Measure Incubator also holds promise to reduce the time and expense of real-world testing. Learn more at [www.qualityforum.org](http://www.qualityforum.org).

**About PatientsLikeMe**
PatientsLikeMe is a patient network that improves lives and a real-time research platform that advances medicine. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers, and nonprofits develop more effective products, services, and care. With more than 380,000 members, PatientsLikeMe is a trusted source for real-world disease information and a clinically robust resource that has published more than 70 research studies. Visit us at [www.patientslikeme.com](http://www.patientslikeme.com) or follow us via our [blog](http://www.patientslikeme.com/blog), [Twitter](http://www.twitter.com/patientslikeme) or [Facebook](http://www.facebook.com/patientslikeme).

**About the Robert Wood Johnson Foundation**
For more than 40 years the Robert Wood Johnson Foundation has worked to improve health and health care. We are striving to build a national Culture of Health that will enable all to live longer, healthier lives now and for generations to come. For more information, visit [www.rwjf.org](http://www.rwjf.org). Follow the Foundation on Twitter at [www.rwjf.org/twitter](http://www.rwjf.org/twitter) or on Facebook at [www.rwjf.org/facebook](http://www.rwjf.org/facebook).

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