

# Engaging Stakeholders and Patient Partners

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## KEYWORDS

• Patient engagement • Stakeholders • Patient-centered research • Co-learning

## KEY POINTS

- Engagement of patient stakeholders throughout preparation, execution, and translational stages of research can bridge the gap between researchers and stakeholders.
- Patient engagement facilitates (1) alignment of patient and research goals, (2) inclusion of patient-centered questions, (3) improvement of study design, and (4) effective communication of results.
- Successful relationships between researchers and stakeholders can be further developed through an iterative, cyclical process of (1) stakeholder initiation, (2) reciprocal relationships, (3) co-learning, and (4) assessment and feedback.
- Despite the recent progress in patient and stakeholder engagement, further work is needed to create systematic reporting methods to identify best practices for engagement.

## INTRODUCTION

Despite the natural involvement of patients in their own health care decisions, medical research has traditionally been performed by researchers independent of additional patient contribution beyond the designation of research subject. Detachment of patients from the traditional research process includes inherent drawbacks: (1) a disconnect between researchers' goals and patient values, (2) difficulty with study enrollment due to patient skepticism or unrecognized barriers, and (3) lack of dissemination of understandable and interpretable results to patients who benefit most.

Over the past several years, researchers have attempted to bridge this disconnect by developing innovative methods to involve patients and stakeholders in research projects. Three distinct stages of research engagement have been identified: (1) preparation, (2) execution, and (3) translation.<sup>1</sup> Preparation consists of identifying research questions to study, designing research, determining funding agendas, and identifying

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funding sources. Execution involves research conduct, patient enrollment, data collection, and analysis. Translation encompasses postanalysis activities, including dissemination and implementation. Although patient engagement is important in all 3 stages, researchers face different challenges, benefits, and outcomes at each stage. This article addresses the differences and similarities between stages, and how researchers can effectively engage patients and stakeholders throughout all stages. It focuses on the mechanisms, challenges, benefits, and future directions of patient and stakeholder engagement while providing examples of lessons learned from the body of evidence surrounding engagement. By drawing on recently published studies focused on patient engagement, successes and failures are discussed, as well as the benefits and challenges at each stage of the research process. Overlap between these stages creates common threads to promote successful engagement of patients and stakeholders throughout the research process.

### ***Defining Stakeholders***

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Before discussing the principles and stages of engagement, an understanding of the term stakeholder is required. As defined by Concannon and colleagues,<sup>2</sup> a stakeholder is “an individual or group who is responsible for or affected by health- and healthcare-related decisions that can be informed by research evidence.” This broad definition includes many groups with varying interests, goals, and possible conflicts of interest as described in the 7Ps framework to identify stakeholders in patient-centered outcomes research and comparative effectiveness research. The 7Ps stakeholder groups include patients and the public, providers, purchasers, payers, policy makers, product makers (ie, drug and device manufacturers), and principle investigators (ie, researchers and their funders).<sup>2</sup> In projects supported by the Patient-Centered Outcome Research Institute (PCORI), the following percentage of investigators reported interacting with the various stakeholder types: patients (88%), clinicians (89%), clinic or health system representatives (57%), patient or caregiver advocacy organizations (60%), caregivers (51%), subject matter experts (51%), training institution representatives (16%), policy makers (16%), payers (15%), life sciences industry representatives (5%), and purchasers (2%).<sup>3</sup> The wide variety of stakeholders allows for contribution from many different backgrounds, including those with distinct experiences with disease, different levels of understanding, and diverse goals. Based on the interests of these groups and how they interact with health care decisions, they may have different stakes or interests in particular research projects or stages of research. Bringing together various stakeholders during the research process allows the research team to create long-term relationships during which they can identify long-term shared goals and research outcomes.<sup>1</sup>

### ***Overarching Principles of Engagement***

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Effective engagement throughout research stages requires a healthy researcher-stakeholder relationship built on mutual respect. The PCORI describes engagement as the “meaningful involvement of patients, caregivers, clinicians, and other health-care stakeholders throughout the research process.” Engagement principles include reciprocal relationships, partnerships, and co-learning, as well as transparency, honesty, and trust.<sup>4,5</sup> In a recent systematic review, Shippee and colleagues<sup>1</sup> identified 202 studies pertaining to patient engagement in health and biomedical research. They distilled successful relationships between researchers and stakeholders into 4 related components of a cyclical, continuous process: (1) patient and service user initiation, (2) reciprocal relationships, (3) a co-learning process, and (4) reassessment and feedback. Patient and service user initiation was defined as the method by which

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