Active Patient Engagement In Research

Paul Gionfriddo’s account (Sep 2012) of his son’s journey through the education and health systems is heartrending and provides important insight into the impact of health policy on patients and families. In his Narrative Matters essay, Gionfriddo explains how health systems missed opportunities to address his son’s serious mental illness and how the family’s hard-won insights were repeatedly dismissed.

His account also provides an example of how patient-centered research could have changed the care experience by generating information to improve timely diagnosis, optimize the match between treatment and individual, and enhance the evidence base for improving the mental health care system. Active engagement of patients in research is key to the patient-centered perspective and to generating new insights that supplement clinical experience and ultimately improve health services and policy.\(^1,2\)

By requiring active patient engagement in research that it funds, the Patient-Centered Outcomes Research Institute (PCORI) is working to generate actionable comparative information relevant to the health decisions that patients face. PCORI funding also requires attention to practical dissemination, with the goal of speeding the translation of research findings into practice.

Engaging patients in research and addressing ways to deliver study results quickly to those who need them represent a substantial difference from traditional clinical comparative effectiveness research. Patient-centeredness cannot solve all of the problems that Gionfriddo highlighted, but a patient-centered view, together with active research engagement, holds substantial promise for improving critical points along the patient journey.

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NOTES
1 Adams SA. Sourcing the crowd for health services improvement: the reflexive patient and “share-your-experience” websites. Soc Sci Med. 2011; 72(7):1069-76.