

The Case for a National Patient Library

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Perspective

- **Health services researchers put relatively little time, intellectual effort, or money into sophisticated communication of evidence-based information to patients and their families, and towards influencing the clinician/patient encounter.**
- **Manufacturers of medical products spend almost as much on advertising as on R & D, including billions on direct-to-consumer promotions.**
- **Hospitals and clinicians advertise to patients.**
- **Advocacy groups focus on communicating with patients.**
- **A National Patient Library of evidence-based information can help create a better balance in the information “available” to the public.**

Background

- **The Patient Protection and Affordable Care Act calls for “shared decision making” by patients and clinicians. See sections 931 and 936.**
- **The Act establishes the Patient Centered Outcomes Research Institute (PCORI). The National Patient Library could promote public awareness and the use of findings of PCORI’s independent research, and underscore the central role of public finance in conducting that research.**

What a library would deliver and to whom

- **Primary purpose—a repository and clearinghouse of evidence-based information designed for patients and their lay and professional caregivers.**
- **Other central purposes:**
 - **assess patients information needs and the degree to which they are met effectively.**
 - **serve as a center of innovation for health communication across the spectrum of media.**
 - **assess and disseminate evidence about the effects of patients' use of information on the use and cost of healthcare.**

Challenges and Opportunities

- **Meet patients' needs for trustworthy, accessible, and timely information.**
- **Achieving sufficient initial and sustainable funding.**
- **Ensuring that the public believes that the purpose of the National Patient Library is to serve them.**