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# Patient-Driven Research: Rich Opportunities and Real Risks

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### Abstract

**Summary:** Since the Internet's earliest days, patients have used online resources to share experiences, learn about diseases and treatments, and become advocates. A newer phenomenon has seen a growing number of online communities evolve into centers of patient-driven research (PDR)—especially for orphan diseases. Thanks to Health 2.0 capabilities, various models of PDR are being developed, usually involving methods of data collection and aggregation that can eclipse RCTs as meaningful evidence. A radical shift from the classical research model, this may result in accelerated findings and dissemination at a fraction of the cost of classic medical research.

While research projects conducted in a medical environment require supervision by IRBs (institutional review boards), no such limitation currently exists in PDR. This results in both greater immediacy and potentially harmful forms of bias in these research models. Acceptance of PDR as valid clinical research requires validated methodologies and tools, democratization of data, ethical oversight, and immediacy. Without these critical drivers, such research will continue to be marginalized and its benefits available only to the activated minority.

**Keywords:** Participatory medicine, orphan diseases, patient-driven research, patient empowerment

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### Online Communities as Centers of Research

Since the Internet's earliest days, patients have used online resources to share experiences, learn about diseases and treatments, and become advocates, all facilitated by the growth of disease-specific online communities. A number of these communities, used originally for information dissemination and support, have evolved into centers of patient-driven research (PDR)—especially for orphan diseases.

The Association of Online Cancer Resources ([ACOR](#)), an organization I co-founded with my wife 14 years ago, is just one of such information and support networks. Over 600,000 patients and caregivers have used one or more of its 163 public online communities. Starting years before the Institute of Medicine (IOM) published the seminal report *Crossing the Quality Chasm*,<sup>[1]</sup> they have contributed to a number of changes in models of care for patients suffering from rare and unusual diseases. These have been brought about by researching and sharing the latest scientific information and personal narratives of their conditions, by joining with others in public conversations, and, most remarkably, by organizing and developing new methodologies of data collection and aggregation—with the ultimate goal of guiding the research on their disease. Their efforts have also been instrumental in raising funds for scientific research and in policy making.

ACOR users, like so many other "e-patients," have helped forge the participatory medicine model, where an important component of the patient contribution is to balance what evidence-based medicine or conventional medical wisdom recommends with what is possible, desirable, and most acceptable for the individual patient. As Kent Bottles, MD, president of The Institute for Clinical Systems Improvement, explains, "Many of them have understood that the art of care is to determine how all the various actors—researchers, medical professionals, drug and medical device companies, payers, afflicted persons in general, themselves specifically,