

## Sparking a Patient Activation Movement

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**B**y any measure, population health in the United States is dismal. In return for spending twice as much on health care as any other developed country, Americans shoulder a higher burden of disease, illness, and injury than their peers in other developed countries, and have the shortest life expectancy (National Research Council and IOM 2013). I cannot help but look at this paltry return on investment and wonder, do we have the wrong paradigm for health?

Traditionally, we worship our medical providers. We impart near mythological powers upon them, thinking that they will cure whatever ails us regardless of our personal choices. Health care is regarded as something that happens to us, rather than something over which we can take ownership. It is as though we are off to see the Wonderful Wizard of Wellness. But it is not that simple. Each day, we make myriad decisions related to sleep, diet, exercise, and stress management, among others, which collectively enhance or undermine our health. If we do not exhibit health-seeking behaviors and curiosity, providers' knowledge and experience only go so far. Without our contributions to wellness, there is just a man behind the curtain.

Here at the [Jewish Healthcare Foundation \(JHF\)](#), we believe that a great health care consumer awakening is upon us. We have entered the age of the activated patient—an informed, motivated consumer who consults digital health information and partners with providers to make decisions. They are not looking for quick fixes or medical wizardry.

Activated patients have the potential to transform our population health for the better, but they cannot accomplish that feat in isolation. There needs to be collective action—a patient activation movement—for a health revolution to take place. The Pittsburgh region has developed a playbook that funders across the country can use to ignite a social movement about pressing health problems in their communities.

### A PLAYBOOK FOR PATIENT ACTIVATION

Health breakthroughs do not necessarily happen in the physician's office. Communitywide efforts to bring forth positive social change—including HIV/AIDS activism, breast cancer awareness, and patient-focused end-of-life care—have dramatically improved population health, quality of life, and care outcomes. These whole-village efforts have catalyzed policy and cultural changes. In July JHF invited Pittsburgh's leading

voices from various backgrounds—medical providers, consumer advocates, policymakers, economists, and tech experts among them—to examine the DNA of past high-impact social health movements and then create their own strategies for consumer activation for six population health issues:

- becoming head of your health care team;
- building community housing options for frail seniors;
- coping with post-partum depression;
- increasing uptake of the cancer-preventing human papillomavirus (HPV) vaccine;
- managing the risk of developing breast or ovarian cancer; and
- promoting healthy eating habits, particularly among those at risk for heart disease or diabetes.

JHF considers these priority topics, not only in Pittsburgh but across the United States. We are already actively involved in developing solutions, from our [HPV Vaccination Initiative](#) to our [25-year commitment to seniors](#), to our [Center for Health Information Activation](#), which provides communication tools and skill-building for providers, consumers, and families, as well as guidance on finding and assessing health information, creative health apps, online communities, and other tools and services.

The July event, however, provided a multidisciplinary forum to identify critical elements of movements that galvanized large-scale behavior change and population health improvement. How did the leaders of these efforts build a coalition? Why did their message resonate with the general public or a targeted segment? How did they weather critics' scrutiny, sustain their momentum, and combat the status quo? Our strategy sessions yielded some key insights on addressing population-level health issues that require population-wide solutions:

- **The nature of the problem must be compelling.** For a community to take ownership of a health issue, they must know what is at stake. There has to be a sense of urgency—a credible message that if we do not do something today, it will matter. The community must also understand the value proposition: there is a clear payoff for their time investment.

- **The problem must be possible to solve.** Revolutions are born of hope, not despair. A community must rally around a vision of the ideal outcome, and the community should be framed as a source of strength in solving the problem.
- **Strong leadership is paramount.** Social movements that catch fire have authentic leaders who connect with the community. They often redefine the narrative, using personal experience and storytelling to upend prevailing opinions. These leaders *live* the problems that they seek to eradicate, or are in close contact with those who do.
- **Strategies should account for the diversity of stakeholders.** We were fortunate to have Alan Weil, Editor-in-Chief of *Health Affairs*, discuss how activated patients fit into the larger changes taking place in the U.S. health care system. He noted that longstanding barriers to patient engagement are crumbling. Medical education now places greater emphasis on communicating with patients and families, a profusion of health information helps consumers choose wisely, and payers are increasingly rewarding those who partner with patients to achieve quality outcomes (Weil 2015).

The cornerstone of patient activation, Weil noted, is demanding a health care system that is designed to account for our differences. There is no generic “health care consumer.” We possess a spectrum of assumptions, knowledge, and experiences that influence our ability and motivation to engage with the health care system. Just as Apple crafts products with user experience in mind, so must we create messages that are diverse, personalized, and iterative.

## ENGAGED CONSUMERS, HEALTHIER COMMUNITIES

Why does patient activation matter? Because it is quickly becoming the new norm, and patients who are engaged in their care achieve better health outcomes at a lower cost. Ninety-three percent of consumers surveyed by the Altarum Institute either want to make joint health care decisions with their doctor, or be completely in charge of their treatment (Lynch et al. 2012). A majority of consumers recently surveyed by PricewaterhouseCoopers (2015) track their weight, blood pressure, and caloric intake each month. That level of engagement has serious social and economic benefits.

A recent study in *Health Affairs*, for example, found that primary care patients with higher scores on the Patient Activation Measure scale (a tool used to assess consumer health characteristics, including confidence, knowledge, goal orientation, and health-seeking behaviors) fare better than more passive patients in a variety of health indicators (Greene et al. 2015).

Activated patients are more likely to maintain a healthy weight, avoid tobacco products, and report fewer symptoms associated with depression. The 32,000 patients tracked during the two-year study took advantage of preventive health

services and screenings more often, and spent fewer days in the hospital and emergency department. Those who maintained the highest levels of patient activation had projected costs that were 31 percent lower than those of the most passive patients. When consumers take control of their health, communities prosper (Greene et al. 2015).

## #WECANDOBETTER

Our patient activation event was just the beginning. Several of the campaigns that our stakeholders developed, including a [social media video](#) to protect more kids and young adults from HPV-related cancers, will soon roll out. The event will be a spring board for community action to tackle the six health topics examined and will guide our future grantmaking efforts, such as recent awards directed toward adolescent health, as well as community health workers who will help seniors remain independent.

Our next challenge? Harnessing the passion, creativity, rapid-fire problem solving, and sense of interdependence displayed in Pittsburgh and spreading it across the country. We are prepared to help others confront their vexing population health problems with our patient activation playbook. There is no Wonderful Wizard of Wellness. But a community working together toward better health? That is magical.

## SOURCES

Jessica Greene, et. al. “When Patient Activation Levels Change, Health Outcomes and Costs Change, Too.” *Health Affairs*. 34, no. 3 (2015): 431-437.

Lynch, Wendy, Brad Smith, and Michael Slover. *Altarum Institute Survey of Consumer Health Care Opinions*. Fall 2012. [http://altarum.org/sites/default/files/uploaded-related-files/cchc\\_Altarum%20Inst%20Survey%20of%20Consumer%20Health%20Care%20Opinions%20-%20Fall%202012%20FINAL%20V2.pdf](http://altarum.org/sites/default/files/uploaded-related-files/cchc_Altarum%20Inst%20Survey%20of%20Consumer%20Health%20Care%20Opinions%20-%20Fall%202012%20FINAL%20V2.pdf).

PricewaterhouseCoopers. *Personal Health Management: The Rise of the Empowered Health Consumer*. April 2015. [http://www.pwc.com/en\\_US/us/advisory/customer/publications/assets/pwc-personal-health-management\\_-final.pdf](http://www.pwc.com/en_US/us/advisory/customer/publications/assets/pwc-personal-health-management_-final.pdf).

National Research Council and Institute of Medicine. *U.S. Health in International Perspective: Shorter Lives, Poorer Health*. Washington, DC: National Academies Press, 2013.

Weil, Alan. *Health Affairs*. “Redesigning Health Care for Activated Patients.” Pittsburgh Regional Health Initiative YouTube video, 27:39. Published July 16, 2015. <https://www.youtube.com/watch?v=fmUwKKOiMhI>.

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