
Patient Protection and Affordable Care Act

Patient Advocate Perspectives

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A Tree Grows Strong in Honor of Cancer Survivors Everywhere

Planted in Kenya on the Masai Mara on October 17, 2005



Sources of Perspectives Shared

- Unscientific survey of ~10 patient advocates across several dimensions
 - Race/ethnicity
 - Age
 - Geographic Location
 - Income Levels
 - Community Conversations with
 - Family
 - Neighbors
 - Strangers
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Online Survey Questions

- What **benefits and changes** have you or your constituents/community experienced related to the ACA? What has **not changed**?
 - What **challenges** have they experienced related to the ACA?
 - Can you share any experiences related to the **ACA and clinical trial participation**?
 - Do you know of any **specific stories or experiences** that might be enlightening related to the impact of ACA on individuals and families related to prevention services, access to care and insurance (youth and those with pre-existing conditions), or other issues?
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Online Survey Questions

(continued)

- What are your thoughts or experiences related to **PCORI**, especially its role in changing patient access? Also, if you sit on a PCORI panel or have worked with PCORI in other ways, what is your perspective on the **role of advocates** in PCORI and of the type, number, and quality of applications submitted for funding? And, what would you **suggest to those interested in seeking PCORI funding**?
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Main Findings

- **No single patient perspective** on this or other issues—not a new concept
 - Lots of **misconceptions/ misunderstandings** (even about the name)
 - **Political/ideological component** to satisfaction or dissatisfaction with ACA
 - **Racial/ethnic component** to perceptions/findings
 - **Cost a major concern**
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**“I’m glad I don’t have that
Obamacare!”**

Areas of Greatest Interest or Concern

- Cost
 - Access to specific clinicians
 - Access to care
 - Acceptance of insurance carrier
 - Continuation of benefit to age 26
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Cost

- Mixed reactions
- Breakdown along broad income lines

“My health insurance cost DOUBLED in two years under ACA, and there is now no way to find a better rate. That is an awful record, and makes me seriously doubt the entire ACA thrust. Affordable? Not likely...I was a supporter, in principle, of the ACA. I now see it as a complete disaster.”

“...a name brand drug I take that's not a new drug has risen in cost from \$1200 / mo. to \$1700 / mo. It's a tier 5 and I hit the gap sooner. Benefit: closing gap, Con: raising cost of drug!”

Cost (continued)

“More options for health coverage especially for those that are previously uninsured. Better options for low and moderate income with expansion of Medicaid and introduction of Essential Plan in NY. However, there still are not a lot of doctors to choose from especially those that speak specific languages. Many doctors also do not take the Qualified Health Plan offered on the Marketplace limited network adequacy.”

“Even with tax credits, premiums are still expensive for many individuals and families.”

Cost (continued)

“One of our navigators, helped a family get insurance who was previously uninsured. They have a history of diabetes and are now able to seek needed medical care for the treatment of their condition.”

“This is the first time I’ve had insurance for a while. I like it. I don’t care what they say is bad about it. We can go to the doctor now.”

Patient-Centered Outcomes Institute (PCORI)

“As a member of the PCORI Patient Engagement Advisory Panel (PEAP), advocates were an integral part of drafting an engagement rubric, ..., which will help any person considering applying for PCORI funding.”

“For those interested in applying for PCORI funding, the PEAP has a very thorough rubric to help guide applicants, plus PCORI offers assistance to applicants in drafting applications. Applicants need to be aware of deadlines for applications, and that they are expected to perform according to their submission or possibly lose funding. Applications submitted are expected to include patient partners working with researchers...”

General Awareness of Provisions

- More awareness of challenges to “Obamacare” than of specific ACA provisions
 - Some state-specific brochures (e.g., California)
 - Public awareness campaigns insufficient
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Acknowledgments

- Everyone who completed any part of the grossly unscientific survey (No expletives are included in any comments.)
 - Bus and Metro riders (especially on the Orange line) who took the time to answer questions from a nosey stranger (that would be me)
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Greetings from Three Little
Advocates-in-Training

