Making Healthcare Reform Matter to American Patients

Mark Zezza¹, Mario Nacinovich²

¹Vice President, The Lewin Group, New York, NY, USA
²Managing Partner, AXON Communications, Rye Brook, NY, USA

Keywords: ACA, Affordable Care Act, Healthcare communication, Healthcare reform, Patient-centered

Making Healthcare Reform Matter to American Patients

In October 2011, we discoursed about how conflicting messages and inadequate clarity in communications regarding the United States’ Affordable Care Act (ACA) caused major confusion among the American public and hindered progress on healthcare reform implementation.¹ Five years since President Obama signed the ACA into law on March 23, 2010, it would still be premature to draw definitive conclusions about its overall impact as some provisions are still being phased in (e.g., payment reductions to Medicare providers) and others have yet to be implemented (e.g., the tax on the most generous health insurance plans). However, with multiple constitutional challenges of the ACA now in the rearview mirror and an impending presidential campaign that will undoubtedly influence its impact, this is an opportune time to reassess how the law is currently perceived and how healthcare communication experts can assist in improving both messaging and implementation. We have deliberately focused on a specific subset of stakeholders—i.e., the patients—seeing pivotal opportunities available for them to be drivers of change.

The Majority of Americans Oppose the Current Form of the ACA

Healthcare reform remains a central political concern, ranking third in U.S. voters’ minds heading into last year’s congressional elections, which contributed to shifting the balance of power toward members of the Republican Party.² Given this outcome, and that the Republican party has focused on repealing facets of the law (if not the entirety) since its inception, it should not be a surprise that more Americans (47% as of July 2015) remain opposed to it than are for it.³

However, it may also be quite surprising that some disapproval reigns with the ACA having such substantial benefits for many lives. Perhaps most notably, subsidies are now available for millions of low-income Americans to acquire health insurance coverage and there is improved security of benefits for young adults and people with pre-existing conditions.⁴ Moreover, the US has experienced a prolonged period of increasingly low spending that many experts at least partially attribute to delivery and payment reform efforts accelerated by the ACA.

Why then are some people lukewarm toward the ACA? There are many reasons, such as the prolific messaging by ACA opponents: one report estimates nearly half a billion dollars has been spent on ACA-related advertising through early 2014, with 94% funding negative ads.⁵ Additionally, many Americans attribute all healthcare developments after March 23, 2010 to the ACA, including trends that started prior its inception. Among these pre-existing trends are the use of high deductible health plans or narrow network plans that may leave patients feeling like they are paying more for less coverage. Some citizens also feel that they have not benefited from the ACA, such as those who were not able to maintain their preferences and level of insurance coverage.
Perhaps the biggest reason for the tepid sentiments is that most Americans continue to perceive no meaningful personal impact from the ACA. In fact, many people, especially those from middle and high socioeconomic backgrounds, maintain the same insurance plan sans the ACA. It is also challenging for many to relate to the ballyhooed early ACA results from proponents, such as the reduction in the number of uninsured by six million people or that the ACA has been estimated to cost billions of dollars less than expected. While these numbers sound impressive, they are challenging for the average citizen to comprehend and do not convey personal impact.

The Ability of Patients to be Better Consumers may Determine Overall Impact of the ACA

Five years after the ACA, there still appears to be confusion about the many changes it has introduced in the US healthcare system. The many talking points on the ACA, which initially focused on budget impacts and more recently on the legality of the insurance expansion provisions, continue to undermine its potential effectiveness by shifting focus away from what really is the main problem for the US healthcare system—Americans still do not appear to get enough value in terms of improvements to patient health and satisfaction with care vs the amount of money being spent.

A key question is whether it is important that the general public has a better understanding of the law and what is at stake. After all, most Americans still trust their healthcare practitioners, feel satisfied with their care, and invest a considerable amount of time and money seeking guidance to support their medical decisions. However, the ACA in many ways is relying on individuals to be better consumers of health care in order to help drive improvements in the health care system. For example, not only are all Americans being asked to obtain health insurance, but many of the insurance plan options in the exchanges involve narrow network and high-deductible plans. Ideally, patients would be able to feel confident they are choosing a plan that covers the best providers and services for them. However, even though data is now starting to be made available to comparatively “shop” for health plans, as well as hospitals, physicians, and other types of healthcare practitioners, it does not appear that consumers are really getting the information that matters to them or that they even know how to use that information. Research shows that patients are not making much use of the publically available data on provider and payer performance, and often make suboptimal health-related choices.

The ACA has also created new incentives and builds on existing wellness program policies to promote opportunities to support individuals in the pursuit of healthier lifestyles and overall healthier workplaces. The thought processes behind these plans being that by elevating the wellness of individuals, the population may be able to live healthier, and attain higher levels of personal performance while helping control healthcare spending—which ultimately needs to be better communicated and understood on how this will affect us moving forward.

The ACA also aims to get providers thinking about how to better engage patients in their own care. The law repeatedly includes requirements related to terms such as “patient-centered care,” “patient engagement,” and “patient satisfaction” in its provider performance reporting and payment provisions. However, it is not clear whether policy-makers or providers, let alone patients, really understand what these terms mean in practice.

Even if the ACA were ever to be repealed at some point in the future, many of these market trends toward greater consumer engagement and “patient-centered” reform efforts (which are certainly not limited to public programs) are likely to continue and expand. These efforts will be bolstered by information technology tools and the panoply of mobile apps that are improving the ability to capture, share, and decode health-related information.

Cultural Change Is a Critical First Step

To be effective in this new environment, patients will need to adjust how they engage in the healthcare system. This starts with decisions on which provider or insurance plan to choose, and includes how they interact with providers once at the doctor’s office, hospital or other health care setting, as well as how to manage one’s care when not in a provider setting, whether alone or with a family caregiver. One could imagine as an example a daughter using an app on her smartphone to identify the cardiac surgery mortality rates of the nearest hospitals to inform the decision of which hospital to use for her father, who is reporting heart attack type symptoms. The app might also inform the daughter what questions to ask and what information to be prepared to share once at the hospital. What information and how it is presented to the daughter will be critical in how useful it is to her. Moreover, the therapeutic plan after surgery should consider the lifestyle of the father—e.g., motor skills needed.
for work or hobbies—and follow-up processes should be in place for both the patient and provider to ensure the healthiest disease progression possible. Such planning involves conversations between patients and providers that can require time and communication skills that people are historically not used to having.

Operating in this new environment requires a cultural change that is difficult and cannot be simply mandated by laws. While patients still largely trust and rely upon their doctors, being more engaged will require the sometimes difficult and seemingly awkward activities such as questioning doctors’ recommendations, effort to do more research and to seek second opinions, and willingness to share more personal information. Healthcare communication experts are desperately needed to help smooth over this cultural transition, by educating patients on why it is important for them to take a more active role in managing their health and enabling them with tools to do so most effectively. Many of the barriers to improved patient engagement have been previously identified, but still require solutions to be polished, such as:

- **Facilitating conversations on patient needs.** Healthcare decision-making is difficult for many reasons, including the innate uncertainty involved in medicine and the high-stakes that can be involved. Also, understanding patient preferences, which are not always clear, should factor into decisions regarding when to perform more invasive therapies. Many clinicians remain ill-prepared to have these discussions with their patients and vice versa. Best practices are needed not only for clinician-patient communications, but also on how to include family caregivers in the discussion, particularly since their role is likely to become more prominent with the aging of the population.

- **Operationalizing what is actually important to patients.** Once patient preferences and needs are identified, the goal should be to figure out how to incorporate those needs into personalized patient care plans and how to track progress and define provider and patient responsibility on that progress.

- **Setting expectations for “patient-centered” care.** Lip service is not enough for real change. A better understanding is needed for what patients and providers should expect when working in a “patient-centered” environment. As described in the example of the daughter and her father above, this includes protocols for decisions prior to going to a health care provider, while face to face with a provider, and after the visits. These protocols should encompass expectations related to the type of data that is available to support care decisions and how that data will be used for managing care. A process may be needed to define roles for the majority of time spent in life when the clinician and patient are not in the same room. This includes new methods of sharing data such as e-mail, as well as more work by patients to both prepare for doctor visits (e.g., knowing what questions to ask or identifying the best provider) and self-manage their care following visits.

- **Empowering patients.** Patients should feel confident that they can find and use information from various public reporting initiatives to improve their doctor and hospital choices. In particular, many insurers are making price data available to their members so that they can make more informed decisions on where to seek care. Eventually, more meaningful quality data needs to be incorporated in these tools. Such tools are starting with websites such as Hospital Compare. More work needs to be done to figure out how to best present the info so that it can be digested by non-clinicians. Communication experts and researchers should also look to fields such as behavioral economics and psychology to help inform the design of decision contexts in order to help ensure that making the optimal decision is as easy as possible. As an example, Peter Ubel and colleagues discuss how seemingly innocuous design decisions such as the labels used to categorize plans in health insurance exchanges or whether to present monthly versus weekly premium rates can have significant impacts on how people choose health plans. With more mature solutions to the cascade above and improvements in overall engagement, patients may have a clearer understanding of what their roles can be, the benefits of making those changes, and strategies for successfully achieving the benefits. Simply stated, better focus on patient needs and engagement can and should help shape future communications and the overall direction of healthcare reform.

Obviously, patients will not be able to drive change in the healthcare system on their own. Providers need to be more open to working with patients. Payers cannot simply push more accountability for health care costs on to patients (e.g., through high-deductible plans), but must also make tools available to patients so that they can feel comfortable knowing
that decisions to defer health care or to choose less expensive plans and providers will not harm their health. Governments cannot mandate cultural change, but they can facilitate through regulations the requisite exchange in information needed for consumers to become better shoppers. Provider, payers and government leaders also need to clarify what “patient-centric” means, as simply stating those terms in the design of new initiatives will not lead to any real or desired changes.

One thing is certain with health reform—changes are happening. By consumers becoming more engaged, they can help ensure that the changes are most directly aligned with what should always be the central health reform message and goal—improving patients’ health and satisfaction with care, while lowering the cost to patients.

Acknowledgements
The authors wish to thank Katrina Adano, Editorial Director at AXON Communications, for her editorial support in the preparation and submission of this manuscript.

Disclaimer statements
Contributors None.

Funding None.

Conflict-of-interest statement: The authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers’ bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

Ethics approval None.

References

Author information
Mark Zezza, PhD, is the Vice President, Federal Health and Human Services at The Lewin Group. In his preceding role he served as Assistant Vice President, Delivery System Reform and Cost Control at The Commonwealth Fund, where he worked on issues related to healthcare payment and delivery system reform. He received his PhD from the University of Maryland, Baltimore County in Public Policy. Mark is an esteemed member of this Journal’s Editorial Board.

Mario Nacinovich, MSc, is the Managing Partner at AXON Communications where he leads the healthcare practice in the United States. He provides strategic guidance to clients at pharmaceutical, biotechnology, diagnostic, and medical device companies, as well as to world-class medical universities, research institutes, and various leading non-profit organizations focused in healthcare. He received his MSc from Boston University in Healthcare Communications, where he is
also member of the adjunct faculty. He previously served as Editor-in-Chief of the Journal of Communication in Healthcare from 2008–2013, and continues to serve on the Journal’s editorial board as Editor Emeritus.

***

Inside Commentaries are authored by members of the editorial board of the Journal of Communication in Healthcare: Strategies, Media, and Engagement in Global Health on topics within the Journal’s scope and objectives, and only represent the opinion of the authors. This is an occasional section of the Journal, which only includes invited perspectives and short commentaries.