



Finding a Collaborative Pathway to Broad Consumer Engagement on Healthcare Affordability

For several years, polling data and related qualitative research has shown that healthcare affordability is a top-of-mind consumer concern.¹ Moreover, data also show that consumers don't believe their personal actions are capable of fixing the affordability problem, nor is the market likely to address the issue—they believe there must be some government oversight.²

Currently, few pathways exist for frustrated consumers to advocate for state and federal action on healthcare affordability issues. The overwhelming reader response to the *New York Times* series entitled *Paying Till It Hurts*³ suggests that consumers and patients are looking for these pathways.

This report summarizes a discussion of consumer advocates held on Sept. 11, 2017, in Washington D.C. With the group was former *New York Times* reporter Elisabeth Rosenthal, who authored the *Paying Till It Hurts* series, to provide detail on what she heard from readers. The group brainstormed on how to work collaboratively to provide ways for frustrated consumers and dissatisfied patients to effectively band together and demand marketplace change to make healthcare more affordable and higher quality.

Time is Right

The group agreed that the time is right to foster a consumer movement on healthcare affordability. Consumers are frustrated and worried about high healthcare costs. Elisabeth Rosenthal administers a Facebook group with more than 9,000 members. The most common question among group members is how they can take action to make a change. Consumers are ready to be engaged but advocacy groups need to do more to create resources and guidance that meets the needs of these consumers.

Approaches to Increase Consumer Engagement

The experts discussed the most important things consumers need to become more engaged, including: find other likeminded people; learn how healthcare got this way; take personal actions that keep them safer, healthier and reduce costs when they get care; and take public actions so no one has to encounter poor quality, unnecessary care or overpriced healthcare.

The group agreed that the greatest success would be realized if we provide many different levels of engagement, reflecting the diversity of people seeking to make a change. Some people are comfortable taking a public action, such as attending a protest or writing a letter to the editor, while others want to become more informed so they can take private action to protect themselves from overpaying or potential harm when receiving healthcare services. The group agreed that there needs to be an "on ramp," or incremental set of actions that start small and escalate for those that want to be more active and vocal.

Find Other Like-Minded People

Consumers don't want to feel as if they are acting alone. They want to be able to find other people who feel the same way or have similar experiences with the healthcare system. While they are willing to take actions on this issue, they want to do so as part of larger, organized group so their actions have a greater chance of being effective.⁴

The group discussed ways to help consumers band together to achieve their goals. A few themes emerged:

Reach people where they are: The group agreed that it is important to go to people where they are (such as by attending NAACP and AARP meetings). We need to tap into the connections that people already have and leverage

List of Attendees

We are extremely grateful to the experts who took the time to attend our convening. We hope that this effort leads to additional collaboration and progress towards increasing consumer engagement on healthcare affordability.

Chuck Bell

Consumer Reports

Rhett Buttle

Public Private Strategies

Vincent DeMarco

Maryland Healthcare for All Coalition

Stephanie Glover

National Partnership for Women and Families

Erin Hemlin

Young Invincibles

Ann Hwang

Community Catalyst

Margarida Jorge

Healthcare for America Now

Steven Knievel

Public Citizen

Claire McAndrew

Families USA

Anne Pfrimmer

SEIU

Leni Preston

Consumer Health First (MD)

Carol Regan

Community Catalyst

Elisabeth Rosenthal

Kaiser Health News

The following Altarum and Healthcare Value Hub staff also participated in the brainstorming session: Erin Butto, Amanda Hunt, Shyloe Jones, Sunita Krishnan, Tad Lee and Lynn Quincy. On the phone were Beth Beaudin-Seiler, Chris Duke and Christine Stanik.

trusted voices. To help those who have not already participated with such organizations, we can tap into new groups that are emerging, such as Do the Most Good in Maryland.

Leverage social media: One participant discussed the concept of a “Match.com” for activated consumers, a safe relay system that would make it easier for consumers to find other like-minded individuals. Facebook is also a potential solution. As noted above, the Paying Till It Hurts Facebook group has more than 9,000 members who want to know what they can do and whether others have had similar experiences or can offer advice.

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Create shared knowledge: Consumers want to find people that have similar experiences. For example, it is not always easy to see when price gouging is occurring. It can be obvious with prescriptions, but not with lab fees and other procedures. This holds back the masses from coming to public judgment.

Learn How Healthcare Got this Way

Consumers want to feel they have the information needed to make wise decisions. However, our healthcare system is complicated and, for many, foundational understanding may be missing. Put another way, health system literacy is very low.

Participants noted that most consumers may not be interested in the policy details, but they want a basis for taking action. The group agreed that we need to find the sweet spot that encourages foundational understanding of our affordability problems. As one participant put it, “to be successful we must build the deliberative capacity of the American people.” This could be done by creating new resources and by providing in-person opportunities to foster increased understanding. One key to success might be to ensure that consumers can “see themselves in the story”—the approach of Elisabeth Rosenthal’s Paying Till It Hurts series. As another pointed out, we have to make it

“We need to build an on ramp for people. There is a big leap from people writing a letter or posting a comment on social media to talking to 10 people they know or don’t know.”

relevant to those that have not yet had adverse experiences with the health system.

The group discussed tested, easy-to-digest background materials that could perhaps be used in community group or house party setting.⁵ The group described house parties as a powerful tool to engage consumers and build capacity among them, and suggested that having house parties loosely organized around a local hospital could be a good way to attract and assemble attendees.

Another expert suggested providing interested consumers with a skills toolkit, including information such as how to write letter to editor and how to get an in-district meeting with a member of congress. Further, we need to distill proposed legislation to help people understand how the bill would impact them.

However, the group agreed that we live in a day and age where we need to reach people in the moment, when they are accessing the health system and thinking about healthcare—such as when they are just leaving the hospital. While leveraging house parties and other community groups are a useful component of an engagement strategy, it may not reach those who have never been engaged before. Consumers are angry and we need to provide a way for those who are both well-versed in activism, as well as those that are newly activated. The group discussed creating an app for activism, whereby consumers could take actions and learn about additional actions they could take.

The group also discussed the concept of a patient bill of rights so consumers would better understand their legal rights as well as new protections they might want to ask for.

Taking Personal Actions

The group discussed personal actions that consumers can take to promote incremental steps towards healthcare affordability. Building upon a list provided in the

Rosenthal book, *An American Sickness*, Lynn Quincy, Healthcare Value Hub director, showed the group a prototype list of questions and actions consumers can take while accessing the healthcare system (see box below).

List of Personal Actions to Take

- Ask: How much will this test/surgery/exam cost?
- Ask: Where will this test/surgery/exam be performed?
- Ask: Are there cheaper alternatives that are equally good, or nearly so?
- Ask: Who else will be involved in my treatment? Will I be getting a separate bill from another provider.
- During your hospital stay: decline a private a room; refuse unnecessary equipment; keep a log of what happens; employ a patient safety checklist
- When you get your bill: ask for itemization; appeal; negotiate; seek out a billing advocate, if necessary.

Several in the group expressed skepticism that the average consumer would engage in this way. One participant noted that she had tried many of the steps when getting treatment and it delayed getting the care she needed. The group agreed that these steps might be more appropriate for more seasoned advocates, but not a typical consumer. But at least one participant felt that providers should be able to answer these types of questions in a timely way for consumers.

To create a system that is easier to navigate, one expert suggested that we need to ask consumers to take actions that aren’t too intimidating. The group agreed that it is important to create opportunities for consumers to be successful in their actions, or they will lose faith in their ability to effect change.

However, this doesn’t solve the larger problem of consumers not having access to concrete information about how to raise issues with providers or other

stakeholders, and the correct contacts with which to raise issues. One expert noted that the group should look at harnessing the data and create a forum for consumer complaints, e.g., to the state insurance regulator. The group discussed a decision tree that would assist in navigating the large number of potential avenues for raising complaints.

Ultimately, it was agreed that this area is ripe for research, and we need to learn more about small actions that consumers can successfully take that will help them in the short and immediate term, such as calling insurers for billing complaints, asking for generic drugs, etc.

Take Public Actions

The group transitioned to discussing public actions that consumer can take so no one has to encounter poor quality, unnecessary care or overpriced healthcare.

As one participant put it *“I don’t have to crowdsource what a loaf of bread costs, why should I have to crowdsource my knee X-ray?”*⁶

Standard actions include sharing one’s story, signing a petition, writing a letter to the editor, advocating for or against a particular piece of legislation. But a key shortcoming for healthcare affordability work was the shortage (but not absence) of meaningful, consumer-friendly and evidence-based legislative proposals to rally around. Several participants liked the idea of compiling the state efforts to address high drug prices. The Healthcare Value Hub is a source of policy ideas that could meet this need. Further, it was noted that non-legislative actions might work best in some states.

The concept of creating a resource for people to share stories was proposed, such as *Healthcareforall.com/hearmystory* in Maryland. Enabling people to share their stories could be empowering and can serve other public action goals, such as supporting media coverage of the issue and testimony.

The public actions that consumers can take could fit into an overall advocacy strategy, for example as outlined by Maryland Healthcare for All. The group developed a six-step plan that has been used to successfully pass legislation address health system issues in Maryland:

- Develop an evidence-based solution
- Poll public to test support for the issue
- Build a coalition
- Use the media
- Make it an election issue
- Take it to legislature

Participants noted it is important to test messaging around legislation that will appeal to both red and blue states.

Participants suggested this would have to be a sustained, long-term movement. In order to build long-term support for change, one expert suggested that consumers need to create messaging plans and actions that can be used repeatedly to create demand for change over time.

In order to move forward on these issues, the group agreed that there should be consensus around a few high-profile policy issues, such as pharmaceutical price gouging or surprise medical billing. As next steps, the group could map who is already doing work in the space and how we can leverage them. Additionally, they suggested creating model legislation to facilitate legislative action.

Create an Online Resource

The expert group once again returned to the concept of an online resource to serve as an entry point for consumers, that could also collect stories and list local opportunities to engage and distribute information.

The concept of posting hospital bills to simultaneously stir up anger and promote action and also act as a learning opportunity (by explaining how to read a hospital bill) was proposed as a step in the “on ramp.” This solution, beyond having a cathartic effect for consumers, would also reach providers who, ideally, might think twice about their charges if they knew that they could be publicly scrutinized.

An additional component of the online resource that the group discussed is creating a review system, similar to Yelp. The experts liked this idea, as creating a Yelp for healthcare consumers could also serve the purpose of the “Match.com” concept that was raised early in the

“To create a true national movement, we need to create visibility at the local level.”

discussion. Local organizations who are advocating for consumer causes could use Yelp to connect with people in their community and build their case.

Partnering with Community Change Agents

In order to promote forward momentum on the consumer movement, participants agreed that communities need groups that are working on behalf of dissatisfied consumers.

One expert mentioned that many states have cost commissions.⁷ Creating a typology of different cost commissions and providing consumers with this information would create expectations that there are watchdogs who are dedicated to the cause. This information could live on the larger online resource that has been proposed.

Other key partners are state-level healthcare advocates. These groups are active and tuned in to the local stakeholder and political landscape. National advocacy groups also often partner with state advocates to affect change.

The possibility of creating a national call center or website to help consumers navigate the health system was also proposed, as it could create a central point of contact for people, but this idea was dismissed by other members in the room because other states have tried to do this and the range of potential questions was so broad that it would be difficult to manage at a national level.

Opportunities for Research

Participants cited the need to do some definitional work: what do we mean by affordable healthcare? Affordable to whom?

The concept of polling and leveraging surveys was also discussed. The group strongly felt the need to leverage the “patient army” to show that these issues are voting issues.

However, we need more consumer-facing research to understand what it would take for people to take action, for example, by writing a letter to the editor. We need to ask people, “What is the primary issue that moves you? Is it your insurance premium, doctors who won’t take your insurance?” Once we understand what concerns people the most, we can provide them with actions that they can take. And we need to learn the phrases that are accurately understood by consumers on these issues, as well as the types of messaging that would move consumers into action.

Further, the group agreed that this conversation needs to extend “beyond the beltway.” To create a true national movement, we need to create visibility at the local level. One expert suggested convening annual panels across the country about healthcare value issues, to reach the parts of the country where there isn’t currently any discussion about this issue.

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Conclusion and Next Steps

The expert group agreed that we have an opportunity to organize and then mobilize consumers around healthcare cost and affordability issues. The time is ripe to do so and creating visible consumer demand for change is integral to system reform.

Creating an on-ramp that provides different levels of engagement is essential for all consumers, not just those who are seasoned activists. We need to develop a menu of actions that can provide both short- and long-term victories for consumers.

Further, we need to create a central “hub” to consolidate information and provide an online venue for consumers to connect and voice their concerns. It can also serve as a library of resources to educate consumers about cost and affordability issues. These resources will need to be maintained and enhanced over time to create the kind of movement that leads to change.

Notes

1. Healthcare Costs Top U.S. Families' Financial Concerns, Gallup (April 27, 2016). <http://www.gallup.com/poll/191126/healthcare-costs-top-families-financial-concerns.aspx>
2. *Engaging Consumers on Healthcare Cost and Quality Issues*, Consumers Union (2014).
3. “Paying Till It Hurts” drew an unprecedented numbers of readers—more than 10,000—who shared their individual experiences in response to the series. Further, a 9,000-member Facebook group has come together to share their stories.
4. Consumers Union (2014).
5. As a model, see the Great Decisions discussion guides by the Foreign Policy Association. http://www.fpa.org/great_decisions/
6. Examples of crowdsourcing site include State of Health by KQED in San Francisco. <http://ww2.kqed.org/stateofhealth/2014/06/23/share-your-bill-make-health-costs-transparent-in-california/> and *Clear Health Costs* at www.clearhealthcosts.com
7. *State Agencies with Broad Health System Oversight: An Environmental Scan*, Healthcare Value Hub, forthcoming October 2017. The brief discusses the various roles these entities play and how they are beneficial to consumers and healthcare value.

We are grateful to Erin Butto for drafting this report.



ABOUT THIS SERIES

The Healthcare Value Hub takes a careful look at the evidence and consults with experts in order to clarify for advocates, media and policymakers the important cost drivers and the promising policy solutions. Hub Research Briefs, Easy Explainers, infographics and other products are available at our website.

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