

Final Evaluation Report of Ensuring the Consumer Voice in Coverage and Quality in Massachusetts

August 2010

This evaluation is being conducted by Carolyn Needleman, Ph.D. It began in 2007.

The Program Being Evaluated

This report describes a Robert Wood Johnson Foundation (RWJF) initiative titled “Ensuring the Consumer Voice in Coverage and Quality in Massachusetts,” which aims to ensure that consumers have an effective voice in efforts to achieve quality coverage and care as the details of implementing Massachusetts’s health reform are hammered out. RWJF supported the initiative with a three-year, \$1.5 million grant to a Boston-based consumer advocacy organization, Health Care For All (HCFA). Both the Foundation and the grantee organization saw Ensuring Consumer Voice (ECV) as a rare opportunity to combine an unusually fluid policy context with substantial funding support in order to learn more about building effective consumer voice in health system change, focusing on three areas: coverage, quality of care, and e-health.

About The Evaluation

An independent evaluator¹ contracted by the Foundation is assessing the project’s progress. Because the project itself is reactive to an unpredictable and rapidly shifting policy context, the evaluation’s design is by necessity formative, descriptive, and mainly qualitative. Its purpose is not to assess Massachusetts’ health reform as a policy approach, but rather to learn from HCFA’s efforts to engage consumers actively and strengthen consumer voice in health policy decision-making.

Evaluation Methods

The evaluation of ECV started May 1, 2007 and ran for three years, ending April 30, 2010. This summary is from the final

evaluation report that describes the project’s third year of operation, incorporating highlights of its first two years as well.

A plan for data gathering and analysis, described in more detail in the Year 1 report,² was worked out early in the project through discussions among the evaluator, RWJF officers, and the leadership and staff of HCFA as the grantee organization. Because of the initiative’s exploratory nature, the evaluation was cast as *formative research* – primarily qualitative, heavy on process description, and focused on extracting insights and strategies for consumer engagement that may be useful in other states or on a national level. Data came primarily from ongoing review of electronic and print documents, site visits, and hour-length monthly telephone interviews with approximately a dozen project staff and participating consumers. For analysis, information from all of these sources was first converted to narrative text in the form of content summaries. This text material was then combined and analyzed qualitatively to yield a description of project activities and a compilation of lessons learned.

Mirroring the timing of the initiative itself, the evaluation stretched across three years. During this time, three reports were produced: two *Interim Evaluation Reports* assessing the project’s first two years, and the present *Final Evaluation Report* summarizing its overall results. These reports are not intended to document every detail of HCFA’s multifaceted, fast-paced consumer advocacy work during the funding period. Instead, selected examples are used to explore the following main themes:

¹ The evaluator is Carolyn Needleman, Ph.D., a sociologist with over 30 years of involvement in public health and health policy research, professional education, and community-based advocacy practice. She is a Professor Emeritus on the faculty of Bryn Mawr College’s Graduate School of Social Work and Social Research and has headed numerous federal, state, and foundation-funded research projects and evaluation studies.

² The summary and complete Year 1 and 2 evaluation reports can be viewed at this Web address: <http://www.rwjf.org/pr/product.jsp?id=33719>.

- In each of ECV’s three focus areas, what kinds of consumer engagement activities and strategies have been used? What seem to be their strengths, challenges, and apparent results?
- If these activities and strategies changed over time, how did they change and why?
- What insights into consumer engagement have been gained, and what general lessons concerning consumer voice does the initiative’s experience imply for funders and health reform advocates?

Summary of Findings

The ECV initiative demonstrates that, with the right kind of support, consumers can play an extremely positive role in implementing the health reform goals of universal affordable coverage and quality improvement. Besides being the right thing to do in a democratic society, including a well-informed “consumer voice” in health reform implementation can be a very useful strategy for making sure that sweeping new health reform laws actually work as intended. Yet the experience of the ECV initiative also suggests that for consumers to participate in a constructive way, they need access to detailed policy information, help with indentifying entry points into the decision-making process, and support as they develop the needed skills and tools.

In Year 3, with the recession worsening and state revenues still declining, the task of holding past consumer gains became even more challenging as the state government sought ways of balancing the next fiscal year’s budget. HCFA and ACT!! (a HCFA coalition focused on health reform implementation) made three issues their top coverage priorities for the year, using methods honed during the project’s first two years to help consumers become better informed and make their opinions known to policy-makers. These three issues were: 1) restoring state funding for outreach and enrollment; 2) maintaining dental care as a covered benefit; and 3) protecting the coverage of vulnerable populations.

While these events were unfolding in Year 3, the twin issues of national health reform and Massachusetts’ plans for reforming the state’s healthcare payment systems loomed ever larger in the background. Neither of these issues was

originally part of the ECV project, but both affected the ECV work indirectly as HCFA staff gave them more attention and ACT’s consumer members grew more involved with them. Year 3 ended with some of the ECV project’s key HCFA staff members temporarily redeployed to work on advocacy for national health reform in collaboration with HCFA’s sister organization Community Catalyst, in anticipation of Congressional action in March 2010. In addition, planning was underway to create a taskforce – possibly as a new ACT!! workgroup – to focus on how Massachusetts’s health reform program would mesh with national reforms, once those became law. On the issue of payment reform, a separate coalition (organized and staffed by HCFA and deliberately made up only of consumer advocacy organizations) was created during Year 3 to work on making sure that consumer voice plays a role in shaping the payment system changes now being considered in Massachusetts.

Descriptive findings from the initiative’s three focus areas include the following:

I. Consumer Engagement In Health Reform Implementation During Year 3

- HCFA and its consumer partners in the ACT!! coalition have achieved impressive success in the two areas initially defined as project objectives related to coverage – that is, “enrollment of newly eligible individuals and families into appropriate coverage,” and creation of “educational materials about Chapter 58 implementation for the public and policy-makers in Massachusetts and nationally.”
- Through the initiative’s efforts, consumers working with the project are now better equipped to engage with the details of health reform policy in an informed way, and the “consumer voice” has gained respect among state decision makers as a genuinely useful part of health reform implementation.
- While not always victorious, consumer voice has had a significant impact on policy decisions at both the legislative and administrative level. In addition, health reform implementation has been greatly smoothed by the HCFA HelpLine’s ability to gather information from

consumers, detect emerging problems quickly, and bring them to the attention of policy makers.

- The coverage component of the project has been forced to broaden out and take some unexpected turns, underscoring the complexity of health reform as a policy area and the need for consumer advocates to shift gears when necessary.

II. Consumer Engagement In Quality Care During Year 3

- Starting from scratch, a completely new and very effective channel for consumer voice has been created – the project’s Consumer Health Quality Council, made up entirely of consumers who care passionately about improving quality of care. Most of them have had direct experience with serious medical errors, which makes their public presentations particularly compelling. Through the ECV project, these ordinary people who had not previously worked on system change have become knowledgeable and confident consumer advocates, highly visible to state decision makers.
- HCFA and its consumer partners have been spectacularly successful in the three areas initially defined as project objectives related to quality – that is, constructing a “Massachusetts consumer-driven patient safety and improvement agenda,” producing “educational materials to teach consumers about quality improvements in Massachusetts,” and adding “a consumer voice in key Massachusetts quality councils and other fora.”
- The Council’s work has had a significant impact on both legislative and administrative decision-making. Consumer voice on quality issues has not only been strengthened; it has had real policy consequences.
- The Council originally focused sharply on patient safety, a very useful starting point for recruitment of volunteers. However, as the project funding period ended, the group’s agenda was beginning to address a wider range of consumer concerns about healthcare quality. As new quality-related policy issues arise (for example, shared decision-making and care transitions), their agenda will probably keep expanding.

III. Consumer Engagement In E-Health During Year 3

- Through the efforts of a professional hired to act as an e-health consumer advocate, HCFA was able to accomplish the specific objective originally set out in the project’s funding proposal – that is, to make “recommendations to ensure e-Health initiatives account for consumer interests.”
- In terms of increasing direct consumer voice (implied as a project objective, although not explicitly stated), the e-health component was relatively unsuccessful. However, much necessary groundwork for future consumer involvement did get put in place.
- HCFA leadership and staff were able to raise the visibility of consumer interests related to e-health in key policy planning bodies.
- As a result of the ECV activities, the idea is now better established among policy makers that e-health planning in Massachusetts will benefit from a connection with the consumer advocacy arena.

Lessons Learned

Healthcare consumers seeking an effective voice in policy gain enormously by partnering with an experienced advocacy organization, and the advocacy organization gains as well. Such a partnership puts consumers on a more equal footing with other healthcare stakeholders, by linking them with advocacy resources that are hard to develop from scratch – professional expertise, research and policy analysis, detailed familiarity with the state’s policy-making procedures, and the kind of entrée afforded by having policy-relevant relationships and organizational alliances already in place. In turn, by tapping more fully into direct consumer voice, the advocacy organization enhances its credibility gains information, and gets a useful reality check on its own assumptions about consumer concerns.

As a focus for consumer voice, expanding coverage is a starting point rather than an end goal. As the ECV initiative shows, a strong consumer voice can help keep the focus on the right goal. Consumer testimony and support through ACT!! and the Consumer Health Quality Council helped keep policy-makers constantly aware that the test

of Massachusetts' health reform is not the state's nominal coverage rate or a budget balanced through cuts in covered benefits. Rather, the test is whether – in the eyes of consumers and consumer advocates – health reform succeeds in bringing about “real change for real people.”³

Consumer engagement requires enormous amounts of what might be called “invisible work.” Both ACT!! and the Consumer Health Quality Council were supported not only with HCFA's more obvious advocacy resources, but also with a great deal of informal under-the-radar activity by HCFA staff. Invisible work seems to have been essential to the project's success, judging from the fact that problems temporarily arose in the occasional instances where it was neglected.

Familiarizing consumers with a range of stakeholder perspectives is complicated and time consuming, but very useful for increasing the sophistication of consumer voice. By testing ideas in discussions that include diverse perspectives, rather than emphasizing one particular point of view, consumers are more likely to appreciate complexities in health reform policy and to advocate for policy measures that are practical, politically viable, and less likely to backfire in unexpected ways. While sometimes unsettling and extremely time-consuming to manage, such idea exchange ultimately promotes more realistic and credible consumer voice.

Formal ground rules help greatly in keeping consumer-based advocacy coalitions focused on system change. A group lacking this kind of compass can easily spin off into unproductive activity and internal competition, and it becomes harder to get back on course without some written document to cut through infighting. For example, one very helpful tool for managing disagreement within ACT!! was a set of written principles that member organizations agree to honor when they join the Steering Committee, listing expectations such as “no side deals” (avoid secret deals with other members) and “no surprises” (give advance warning if you're going to oppose another member's position publicly). These principles could be invoked when needed, and they got the group through some potentially awkward moments without sacrificing mutual trust.

Consumer engagement in health reform policy requires active outreach; unfortunately, the tools for outreach are often underfunded. To develop an effective voice in health reform policy, consumers first have to believe that they can realistically make a difference and that their healthcare concerns do actually have policy solutions. Considerable effort may be needed to make this case; in effect, potential consumer volunteers need to be courted. For example, in addition to providing consumer assistance and supplying policy makers with a summarized picture of emerging implementation problems, the HCFA HelpLine's counselors were able to identify individual consumers who might volunteer their time or contribute vivid personal stories. However, to secure these consumers' active involvement, a great deal of additional HCFA staff time was needed as a follow-up.

The need for consumer voice in health reform has no clear end point. It's generally recognized that in a major policy change, legislation is only the beginning of a lengthy process; the actual de facto policy emerges over time, often over many years, through the legislation's implementation. For this reason, consumer advocacy of course needs to go beyond legislation and also focus on implementation. However, implementation of health reform is itself a multi-level process, starting with a new law's broad brush strokes; leading down through the administrative minutia of developing definitions and detailed regulations, followed by “sub-regulatory” guidance documents that spell out exactly who must do what; and then branching out into issues of regulatory compliance and enforcement – all reinforced by continuous efforts to inform the public, keep on top of how health reform is actually affecting consumers, and at all stages alert policy makers to unanticipated problems. As this project demonstrates, even state budgeting decisions and state tax policies can become crucial to health reform implementation. To make matters even more complicated, many important administrative decisions don't stay put after they are made once; they get revisited and perhaps revised (as in the case of the Massachusetts Health Connector's affordability schedule, which is periodically renegotiated.) Thus, supporting consumer voice in health reform policy needs to be recognized as a long-term commitment.

³ “Real change for real people” is part of HCFA's logo, and serves as a guiding principle and reminder that getting legislation passed is not in itself the be-all and end-all of consumer advocacy.